

Participation for Aotearoa New Zealand Children after
Traumatic Brain Injury: An Integrated Approach

Margaret A. Jones

2014

A thesis submitted to the Auckland University of Technology in
fulfilment of the requirements for the degree of Doctor of
Philosophy

Primary Supervisor: Professor Clare Hocking

Abstract

Children's participation is essential to their development and health. Although children who sustain a traumatic brain injury (TBI) are at risk of limitations to their participation, there is only a small body of research informing us about their participation. This research shows variability in study findings, reflecting limitations in study designs, differences in assessment instruments, and contextual factors, such as policy towards inclusion, and service availability.

The present study was conducted to learn more about Aotearoa New Zealand children's participation after TBI. It was guided by Dewey's pragmatist philosophy, which emphasizes the continuity of people with their context. The study was conducted in three phases.

Phase One used case study methodology to understand what was important about the children's participation, and the facilitators and the barriers to their participation. The notion of Shared Occupation was found to be central, involving Fit, Connection, and Pattern across people, their occupations, the physical context, and time. The children's participation was characterized by Misfit of participation demands, fragile or broken Connections, and by confined, irregular, and imbalanced Patterns. However people showed varying levels of Participation Skills in the areas of Driving, Leading, Including others, and Performing Shared Occupations, and used these to promote the children's participation.

In Phase Two, a narrative review of community-focused intervention approaches to facilitating children's participation was undertaken. Its purpose was to name, describe, and compare current approaches, to evaluate the strategies used in those approaches against important aspects of participation identified in the case studies, and to evaluate the evidence for the effectiveness of the approaches. Systematic methods were applied to retrieve, screen, and critically appraise articles. Systematic comparison identified fifteen strategies and five overall intervention approaches. Three of the approaches had some evidence for their implementation with children with TBI, and one approach had good evidence. A need for multiple strategies was indicated. The findings from the case studies and the review were used to develop a draft, occupation-focused resource, with strategies to mobilize and enskill people in the children's social communities to facilitate their participation.

Phase Three aimed to further develop the resource. A pragmatic action research methodology was employed. Seventeen participants from different stake-holder groups

took part in a workshop. Analysis revealed themes that were collectively interpreted with a metaphor of Ta Kupenga, or Net-making. Information was also generated about additional content for the resource, its format, and its dissemination. The themes and ideas from the analysis were incorporated into the draft resource.

The study has implications for provision of rehabilitation. The concept of Participation Skills was identified, as was the importance of those skills in facilitating the children's participation. There is a need for rehabilitation to address participation in context at the point where people use those skills in Shared Occupation. Attention should be paid to the Fit between children's preferences and abilities and the context of their participation, the Connections they experience through participation, and the Patterns of their participation. The study has generated a resource which meets these criteria. Further research to pilot the resource is recommended.

Table of Contents

Abstract	i
Table of Contents	iii
List of Figures	x
List of Tables.....	xi
List of Appendices	xiii
Attestation of Authorship.....	xvi
Acknowledgements	xvii
Intellectual Property Rights	xix
Chapter One	1
Introduction.....	1
Coming to the Topic: Practice Uncertainty.....	2
Outline of the Study	3
The Concept of Participation	3
Definition and Mechanisms of TBI in Children.....	5
Children’s vulnerability to TBI.	6
Classification of TBI.	7
Implications of TBI for Children’s Participation	7
Physical, cognitive, and affective concerns and implications for participation.	7
Developmental concerns for participation.....	9
Long term concerns for children’s participation.	9
The Importance of Participation for Children: Educational and Developmental Theory.....	10
The Importance of Participation for Children: Research	11
The Context of the Study	12
Aotearoa New Zealand legislation and policy, and participation.....	12
Provision of rehabilitation in the context of Aotearoa New Zealand.	13
The incidence and costs of childhood TBI in the context of Aotearoa New Zealand.	15

Research into childhood TBI in the context of Aotearoa New Zealand.....	16
Overview of the Thesis	16
Summary	19
Chapter Two.....	20
Understandings Guiding Practice and Inquiry: Dewey’s Pragmatist Philosophy.....	20
Background	21
Ambiguity.....	24
Evolutionary Naturalism	25
Connection and Continuity	26
Change.....	28
Transaction	29
Inquiry	30
Learning	30
Democracy	31
Summary	32
Chapter Three.....	33
Review of the Literature: Participation for Children after TBI.....	33
Purpose of the Review and Definition of Terms.....	33
Search Strategy.....	33
Focusing the Review	34
Sequence of the Review	35
Participation Limitations for Children with Disabilities	36
Quantitative Studies of Participation Changes for Children Following Brain Injury	
.....	40
Behavioral changes.....	40
Social changes.	45
Participation changes measured with instruments aligning with the ICF.	46
Participation Changes for Children from a Qualitative Perspective	53
The Social Context of Children’s Participation following Brain Injury	55
The social context of children’s participation: Family.....	55
The social context of children’s participation: Other children.	59
The social context of children’s participation: Teachers	60
The social context of children’s participation: Service delivery.	61

Summary	65
Chapter Four	68
Research Phase One: Case Studies: Methodology and Methods	68
Developing the Research Questions.....	68
The Methodology	70
Choice of methodology: Case study.....	70
Studies using case study methodology to research children’s participation. .	73
Approaches to case study methodology.	73
Type of case study used: Instrumental.	74
Concepts of quality in case study methodology: Validity and generalization.	74
The Research Methods	76
Ethical approval.....	76
Gaining insight into my pre-suppositions.....	76
Definition of the case.....	76
Conceptual structure of the case.....	77
Case selection.	79
Access to participants.	80
Informed consent.	81
Data gathering plan.....	82
Data collection.....	82
Participant confidentiality.....	86
Data analysis for individual cases.	87
Individual case study reports.	97
Data analysis across cases.	98
Features and strategies that support validity and generalization.	101
Summary	103
Chapter Five	104
Research Phase One: Case Study Findings: Individual Case Study Reports.....	104
Sequence in which the Findings are Presented	104
Overview of Case Studies One to Six	105
Selection of Case Six for Inclusion in the Body of the Thesis.....	109
Contents and Sequence of Case Study Reports.....	109

Case Study Six: Ash.....	110
Summary	137
Chapter Six.....	138
Research Phase One: Case Study Findings: Cross-Case Assertions.....	138
Sequence in which Cross-Case Assertions are Presented	138
The Categories Informing Cross-Case Assertions, and their Relationships	139
Introduction to Cross Case Assertions	139
The Research Questions and Cross Case Assertions	141
Research Question One: What are the aspects of participation that are important to Aotearoa New Zealand children who have had a clinically significant TBI?	141
Research Question Two: What are the facilitators and barriers to successful participation for Aotearoa New Zealand children who have had a clinically significant TBI?	152
Limitations of the Case Studies.....	154
Discussion and Summary	156
Chapter Seven	162
Study Phase Two: A Review of Community-Focused Interventions to Facilitate Participation for Children with TBI: Methodology and Methods.....	162
Review Methodology	164
Review Methods.....	165
Purposes and questions.....	165
Definitions of terms in questions.....	166
Inclusion and exclusion criteria.....	167
Searching for data.....	167
Search terms.....	168
Screening.....	169
Extraction of data.....	171
Analysis of data.....	172
Summary	180
Chapter Eight	181
Study Phase Two: A Review of Community-Focused Interventions to Facilitate Participation for Children with TBI: The Findings.....	181

Results of the Literature Search and Screening Process	183
Addressing Questions One, Two, and Three: Description of Community-Focused Intervention Approaches.....	184
Summary of the five intervention approaches in Tables 8.1–8.5: Overall consideration of evidence, outcomes, applicability, and viability.....	198
Addressing Question Four: Description of Strategies Used in the Intervention Approaches	200
Addressing Question Five: The Relationships between the Strategies and Important Aspects of Participation	213
Limitations of the Review	216
Discussion and Implications for Addressing Children’s Participation	216
Chapter Nine	220
Study Phase Three: Modeling of a Community-Focused Resource to Facilitate Participation for Children with TBI: Methodology and Methods.....	220
Development of the Resource	221
Genesis of the Study to Generate Feedback on the Draft Resource.....	225
The Philosophical and Practice Understandings Guiding the Study.....	227
Connection of theoretical and practical knowledge.	227
Commitment to democracy.	227
Learning.....	228
Research Aim and Question.....	229
Methodology	229
Pragmatic action research.....	230
Research Methods	233
Participants.	233
Recruitment.	235
Ethical considerations.....	242
Cultural support.	242
Facilitators.	243
Venue.....	244
Workshop process.	244
Focus groups.....	247
Data analysis.....	253
Summary	260

Chapter Ten.....	261
Study Phase Three: Modeling of a Community Focused Resource to Facilitate Participation for Children with TBI: The Findings.....	261
Recruitment Results	262
Overall participant numbers.	264
Participant Details	265
Study Findings	267
Overview of the metaphor Ta Kupenga: Net-making.	267
Ta Kupenga: Net-making: Participants' experiences of the children's participation.....	269
Implications of experiential themes for the resource.....	276
Ta Kupenga: Net-making: Ideas expressed by participants for content, format and dissemination.	279
Reflection on Validity and Quality of the Findings	284
In what ways did outcomes emerge during the study?.....	285
What outcomes of longer-term consequence emerged?.....	286
How did the study focus on practical concerns?	287
What is the significance of the outcomes?	288
How was the democratic involvement of participants supported?.....	288
How did the study support diversity of perspectives?.....	290
Fit with the Case Study Findings and Contribution to the Literature	292
Summary	295
Chapter Eleven.....	296
Discussion of the Study as a Whole.....	296
Summary of the Study.....	297
Situating the Findings with Existing Literature	298
Research about children's participation after TBI.....	298
Social networks.	298
Participation skills.	300
Situating the Findings with Theoretical Understandings	301
The World Health Organization definition of participation.	301
Social change: Dewey's pragmatist philosophy.....	302
Social change: Activity theory.	303

Limitations and Strengths of the Study	304
Implications of the Study Findings for Rehabilitation	306
Service delivery.	306
Assessment.	307
Intervention.....	309
Informing Legislation and Policy.....	310
Further Research	311
Reflection on Terminology	313
Conclusion.....	313
References	315
Glossary of Aotearoa New Zealand Māori Terminology (Te Reo).....	372
Glossary of Terminology	375
Appendix 9.1: Draft Resource for Workshop	379
Appendix 9.18: Modified Draft Resource: Response to Feedback.....	416

List of Figures

Figure 1.1: Contents and Sequence of Chapter One	2
Figure 2.1: Contents and Sequence of Chapter Two	21
Figure 3.1: Contents and Sequence of Chapter Three	36
Figure 4.1: Contents and Sequence of Chapter Four	68
Figure 4.2: Common Assumptions & Characteristics of Case Study Methodology	72
Figure 4.3: Continuum of Case Study Designs	74
Figure 4.4: Example of Mapping Analysis: Case Two.....	94
Figure 4.5: Steps in the Process Used for Cross-Case Analysis	99
Figure 5.1: Contents and Sequence of Chapter Five	104
Figure 6.1: Contents and Sequence of Chapter Six	138
Figure 6.2: Conceptual Model of Relationships amongst Categories Informing Cross-Case Assertions.....	139
Figure 7.1: Contents and Sequence of Chapter Seven	163
Figure 8.1: Contents and Sequence of Chapter Eight	182
Figure 8.2: Flowchart of the Literature Search	183
Figure 9.1: Contents and Sequence of Chapter Nine	221
Figure 9.2: Planned Process for Recruiting Whānau/Parents, Carers, and Community Support People	239
Figure 10.1: Contents and Sequence of Chapter Ten	262
Figure 11.1: Sequence and Contents of Chapter Eleven	296

List of Tables

Table 4.1: Features of Case Study Methodology Aligning with Dewey’s Pragmatist Philosophy and Relevant to Answering the Research Questions.....	71
Table 4.2: Conceptual Structure: Matrix to Guide Data Collection for Case Studies.....	78
Table 4.3: Features and Strategies Supporting Validity and Generalization.....	102
Table 5.1: Overview of Cases One to Six.....	106
Table 6.1: List of Cross-case Assertions Relating to Research Questions One and Two.....	140
Table 7.1: Search Terms used for Literature Review.....	169
Table 8.1: Description of Community-Focused Intervention Approach 1: Structuring Shared Occupation.....	186
Table 8.2: Description of Community-Focused Intervention Approach 2: Creating Opportunities to Experience Occupation with Others.....	188
Table 8.3: Description of Community-Focused Intervention Approach 3: Developing Supportive Friendships.....	190
Table 8.4: Description of Community-Focused Intervention Approach 4: Fostering Inclusive Communities.....	192
Table 8.5: Description of Community-Focused Intervention Approach 5: Rehabilitation Service Provision Models and Modalities for Participation.....	196
Table 8.6: Summary of the Five Intervention Approaches described in Tables 8.1–8.5.....	199
Table 8.7: Strategies Identified from the Articles, Grouped according to Therapeutic Considerations.....	201
Table 8.8: Features of Strategies Identified from the Articles: Therapeutic Grouping One: Promoting Client Perspectives.....	202
Table 8.9: Features of Strategies Identified from the Articles: Therapeutic Grouping Two: Making Shared Occupation Available.....	205
Table 8.10: Features of Strategies Identified from the Articles: Therapeutic Grouping Three: Addressing Fit between a Child’s Needs and Abilities, Occupation, and Context.....	207
Table 8.11: Features of Strategies Identified from the Articles: Therapeutic Grouping Four: Addressing Disability-related Support Needs.....	210

Table 8.12: Potential of Strategies from Articles to Address Important Aspects of Participation identified in Case Studies.....	214
Table 9.1: Integrated Strategies Used in the Resource, and the Important Aspects of Participation from the Case studies and Strategies from the Review they Incorporated.....	223
Table 9.2: Workshop Process.....	247
Table 10.1: Responses from Whānau/Parents Recruited through Hospital Locality.....	262
Table 10.2: Responses from Whānau/Parents Recruited through Inpatient Rehabilitation Locality.....	263
Table 10.3: Responses from Teaching, Rehabilitation & Community Support Staff.....	263
Table 10.4: Total Numbers Participating in Study by Stakeholder Group.....	264
Table 10.5: Demographic Details of Whānau/Parent Participants.....	265
Table 10.6: Demographic Details of Professional Participants.....	266

List of Appendices

Appendices in Body of Work¹

Appendix 9.1:	Draft Resource for Workshop.....	379
Appendix 9.18:	Modified Draft Resource: Response to Feedback.....	416

Appendices on Disc One

Appendix 4.1:	Table of Case Study Methodology Assumptions and Characteristics
Appendix 4.2a:	Northern Y Regional Ethics Approval January 2007
Appendix 4.2b:	AUTEC Ethics Approval March 2007
Appendix 4.2c:	ACC Ethics Approval February 2009
Appendix 4.2d:	Northern Y Ethics Committee Approval Amendments November 2007
Appendix 4.2e:	Northern Y Ethics Committee Approval Amendments December 2008
Appendix 4.3:	Pre-suppositions Interview
Appendix 4.4:	Definitions of Terms in Issue Statements
Appendix 4.5a:	Information Sheet Parent February 2008
Appendix 4.5b:	Information Sheet Child February 2008
Appendix 4.5c:	Information Sheet Teacher July 2007
Appendix 4.6a:	Consent Form Parent February 2008
Appendix 4.6b:	Consent Form Child July 2007
Appendix 4.6c:	Consent Form Teacher July 2007
Appendix 4.6d:	Proxy Consent Form July 2007
Appendix 4.7:	Data Gathering Plan and Protocol
Appendix 4.8:	Demographic Questionnaire
Appendix 4.9a:	Semi-structured Interview Guide Parents
Appendix 4.9b:	Semi-structured Interview Guide Teacher
Appendix 4.9c:	Semi-structured Interview Guide Children
Appendix 4.10:	Observation Guide
Appendix 4.11:	Case Study One Anna Draft Report

¹ Appendices are numbered according to the chapter to which they are first mentioned, and in the order they are discussed in the text in that chapter. For example, Appendix 4.1 indicates the appendix is first mentioned in Chapter Four and is the first appendix discussed in that chapter. Appendix 7.3 indicates the appendix is first mentioned in Chapter Seven, and is the third appendix discussed in that chapter.

- Appendix 4.12: Approaches to Data Analysis for Individual Case Studies
- Appendix 4.13: Mapping Analysis Cases Three and Six
- Appendix 4.14: Cross-case Analysis Worksheets 2-6
-
- Appendix 5.1: Case Study Report 1 Anna
- Appendix 5.2: Case Study Report 2 Tish
- Appendix 5.3: Case Study Report 3 Anton
- Appendix 5.4: Case Study Report 4 Dana
- Appendix 5.5: Case Study Report 5 Bob
- Appendix 5.6: Case Study Report 6 Ash
-
- Appendix 7.1: School Grades and Ages Table
- Appendix 7.2: Data Extraction Table
- Appendix 7.3: Example of Qualitative Appraisal
- Appendix 7.4: Example of Quantitative Appraisal
-
- Appendix 8.1: Frequency of Strategy Use Across Five Intervention Approaches
-
- Appendix 9.1: Draft Resource for Workshop
- Appendix 9.2: Ethical Approval District Health Board April 2010
- Appendix 9.3: Ethical Approval District Health Board Māori Research Review March 2010
- Appendix 9.4: Northern Y Regional Ethics Committee Approval April 2010
- Appendix 9.5: Advertisement
- Appendix 9.6a: Reply Form Whānau-Parent
- Appendix 9.6b: Reply Form Professional-Community Support
- Appendix 9.7: Recruitment Table
- Appendix 9.8: Whānau-Parent Information Sheet
- Appendix 9.9: Professional Community Support Information Sheet
- Appendix 9.10: Correspondence with ACC Ethics
- Appendix 9.11: Ethics Approval Rehabilitation Service Recruitment February 2010
- Appendix 9.12: Whānau-Parent Consent Form
- Appendix 9.13: Professional-Community Support Consent Form
- Appendix 9.14: Facilitator Guidelines

- Appendix 9.15: Resource-Presentation for Workshop
- Appendix 9.16: Workshop Question Guide
- Appendix 9.17a: Cognitive Maps Whānau-Parents
- Appendix 9.17b: Cognitive Maps Pacifica Parents
- Appendix 9.17c: Cognitive Maps Professionals
- Appendix 9.17d: Cognitive Maps 1 and 2 Final
- Appendix 9.18: Modified Draft Resource: Response to Feedback
- Appendix 9.19: Scanned Receipt for Copyright to use Photo

Attestation of Authorship

“I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.”

A handwritten signature in dark ink, appearing to read "Margaret A. Jones". The signature is written in a cursive style with a large, stylized initial 'M'.

24/11/14

Acknowledgements

In undertaking this research, I would like to acknowledge those who have shared in the process alongside me. First and foremost, I would like to thank the study participants who shared their time and understandings. Their experiences and wisdom were generously given in order that the study might make a difference to others whose lives are connected with children who sustain a traumatic brain injury. Their stories have been an inspiration to me throughout the study. I am indebted too to the referring organizations and individuals within those organizations who supported recruitment and data collection for the project.

I wish to thank my supervisors. Clare and Kath, I could not have done this without the benefit of your wisdom, your critical comment, and your editing skills. Thank you for all the encouragement, and practical assistance.

I extend a special thank you to Whāea Louise Elia. I am humbled by your generosity in supporting me throughout my study. I have loved our trips together, your coaching, the chocolate biscuits. Thank you for sharing your very special knowledge and Te Reo Māori.

Carla, I would like to say thank you for all your assistance with the graphics and figures. Your reliability, attention to detail and your patience throughout all the changes has been a wonderful support. Shoba, I valued your support and friendship. Your quick turn-around with transcribing and proof-reading was much appreciated. I am also indebted to Drew, who has been a wonderful source of knowledge, and who always provides librarian support with interest and enthusiasm.

Thank you to my family and friends. Stuart, thank for your patience, and all the times you help out, picking up the jobs around home and on the farm so that I can get my writing done. Thank you for grounding me, for being there.

To John and Normand, my unofficial third and fourth supervisors, I have appreciated your frequent and enthusiastic monitoring of my progress. And thank you to my colleagues: I am grateful for your caring, your encouragement, and humor.

I wish to acknowledge the generous financial support provided by the Health Research Council of New Zealand through the Disability Research Placement Programme. This included reimbursement of fees, a stipend of \$25,000:00 per annum for 3 years, \$10,00:00 for research expenses, and \$2,000:00 for mentoring. I also appreciate the practical and financial support provided by AUT University. This has included support with tuition fees and writing retreats,

To the late Mark Ylvisaker. You provided me with the theoretical understandings to guide my practice in this area, and the inspiration to undertake this work.

The study has received ethical approval from the Northern Y Regional Ethics Committee (NTY/06/12/134- 01/07; NTY/10/01/003-04-10); Auckland University of Technology Ethics Committee (07/24- 03/07); ACC Research Ethics Committee (AUT #152-05/07, 02/09); Auckland District Health Board Māori Research Review Committee- (03-10); Auckland District Health Board Research Review Committee (A+4683-04/10); Nga Kai Tataki Māori Research Review Committee- (02-10); and the Waitemata District Health Board- (02/10).

Intellectual Property Rights

Except for the purposes of fair reviewing no part of the draft resources “FIT & CONNECT: A KitSet to Help Children Participate after Traumatic Brain Injury”; and “Ta Kupenga: Net-Making: A KitSet to Help Children Participate after Traumatic Brain Injury” may be reproduced or transmitted in any form or by any means, electronic or mechanical, including photocopying, recording or any information storage and retrieval system, without permission in writing from the author.

Chapter One

Introduction

“Such happiness as life is capable of comes from the full participation of all our powers in the endeavor to wrest from each changing situation of experience its own full and unique meaning” (Dewey, 1930/1998, p. 25). Children’s participation in community life is fundamental to their well-being and development. Through participation, children share in culturally meaningful activities, come to understand themselves and their changing world, learn to communicate with others, realize their aspirations, and foster their health (Rodger & Ziviani, 2006).

For some children however, participation is interrupted by events that affect them and their environment, bringing both immediate and future concerns. A traumatic brain injury is an event which often holds lifelong consequences for children, their families, and for the communities in which they live. From the distress of an accident, children move with their families through the upheavals of hospitalization, and on to the challenges of a return to community participation and adjustment to the changes that have taken place.

This chapter introduces a study that was undertaken to understand Aotearoa² New Zealand children’s participation after traumatic brain injury (TBI). The discussion begins by explaining the practice situation that led to the study. The philosophical framework that guided the study is introduced, and the three phases of the study are outlined for readers. Next, the focus of the study is discussed. This includes an introduction to the concept of participation. The term TBI is defined, and is explained in terms of the mechanisms involved, children’s vulnerability, and the classification of injury severity. Discussion then moves on to justify the study, highlighting the implications of TBI for children’s participation, and the importance of participation for their function and development. Following from this, the study is situated for readers, with an explanation of the incidence and costs of TBI, and the rehabilitation context in Aotearoa New Zealand. The chapter concludes with an overview of the remainder of the thesis. The content and sequence of the discussion is shown in Figure 1.1.

² Aotearoa is the Māori name for New Zealand. The Glossary contains definitions for Māori words and phrases used in this thesis.

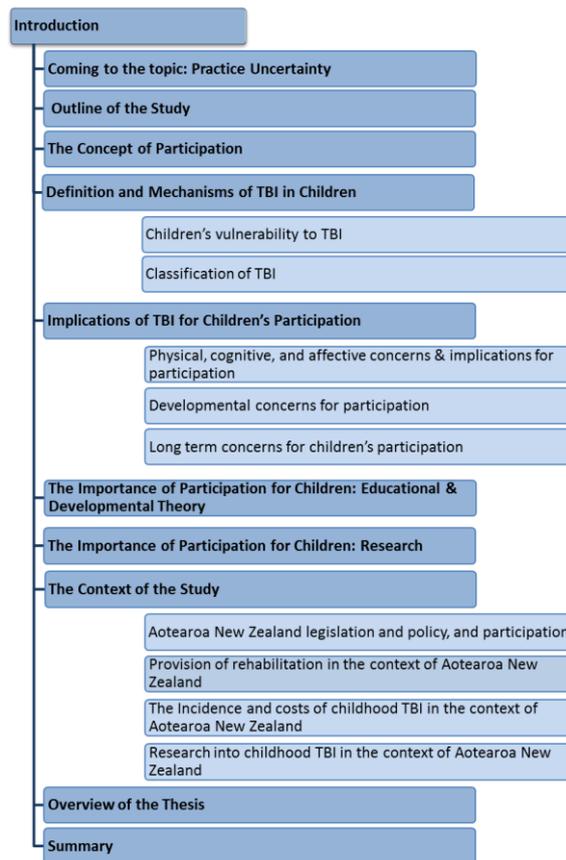


Figure 1.1: Contents and Sequence of Chapter One

Coming to the Topic: Practice Uncertainty

A concern with children's participation after TBI arose from my occupational therapy practice in a pediatric rehabilitation setting. I had noticed that despite rehabilitation aiming to enhance their occupational performance, children continued to have difficulty taking part in activities long after they returned to their communities. As an occupational therapist, I believed that participation was essential to health. However, I did not know if children and families shared those beliefs, with parents often expressing a greater desire to remediate their children's visible impairments, such as mobility limitations, than address participation. I was unsure what people understood by the term participation, or what was important about participation for this group of children. I felt uncertain about the things that were contributing to the participation difficulties I observed for children, let alone knowing the most appropriate way to go about assessing or addressing those difficulties.

Outline of the Study

This study responded to my practice concerns. It was guided by the pragmatist philosophy of John Dewey, which portrays humans as one with and continuous with the world. In this way, as the world changes and evolves so too do humans change and learn. Dewey believed education to be essential to equip us to meet the challenges we encounter as we go about our daily activities with the changing world. Concerned with the practical outcomes of knowing, Dewey saw inquiry and learning as experiential, involving action with the world over time, and argued that they should be regarded as connected with, and not apart from the real world. Underpinning Dewey's philosophical perspective was a moral belief in building a democratic society that enabled mutual exchange of experiences amongst people from diverse walks of life, this enhancing people's learning and providing the foundations for social change (Scott Johnston, 2006).

Holding to this philosophy, and maintaining the concept of participation central, inquiry proceeded in three phases. In the first phase, six case studies were undertaken to understand the aspects of participation that are important to Aotearoa New Zealand children after a moderate to severe TBI, and the facilitators and barriers to their participation. To address this aim, this first phase sought the perspectives of the different stakeholders involved with each case, and sought information about participation as it occurred in context and as it had changed over time.

The second phase of the study was prompted by concerns for the children's participation found in Phase One. Identifying the need for a practical response to these concerns, a review of the literature was undertaken to explore the strengths and limitations of community-focused intervention approaches for facilitating children's participation. The review used systematic principles, but adopted both an interpretive and a quantitative descriptive approach in analyzing the data.

In the third phase of the study, drawing from findings of the case studies and the systematic review, a draft resource was developed, with strategies that could be used by stakeholders to facilitate the children's participation. Incorporating principles of action research, a workshop was held with key stakeholders to generate feedback on the draft resource, and ideas for its dissemination.

The Concept of Participation

Dewey's pragmatist philosophy embraces participation and argues its centrality to people's lives (1930/1998). In more recent times too, the World Health Organization

(WHO) has prompted our awareness of the importance of participation. The International Classification of Functioning, Disability and Health (ICF) (WHO, 2001; 2007) identifies participation as part of an interactive process contributing to people's health. The process includes components such as body functions and structures, health conditions, activity, environmental factors, and personal factors. The ICF defines participation as "a person's involvement in a life situation", whereby participation embodies a "societal perspective of functioning" (WHO, 2001, p. 213). Participation influences a person's body structures and functions, but is also influenced by those structures and functions. The environment is essential to this process, and is considered in terms of the way it can either facilitate or present barriers to a person's participation. Using the ICF, people's participation is qualified according to a) performance, considering "what the person does in his or her current environment", or "the lived experience of people' in the actual context in which they live", and b) capacity, which is "an individual's ability to execute a task or an action" (WHO, 2001, p. 15).

Whilst the importance of participation is now widely acknowledged, the WHO's view of participation (2001) has been criticized for its lack of clarity (W. J. Coster & Khetani, 2007; G. Maxwell, Alves, & Granlund, 2012; Piškur et al., 2013), with confusion over the definition hampering the practical application of the construct in research and practice. Critique has also highlighted the importance of taking into account people's experience of their participation, and their autonomy, aspects not encompassed by the WHO definition (Hemmingsson & Jonsson, 2005; Ueda & Okawa, 2003). Addressing these concerns, emergent evidence is building a case for implementing a subjective qualifier for participation (Granlund et al., 2012; G. Maxwell, Augustine, & Granlund, 2012). Meanwhile, others have endeavored to unravel some of the confusion around the term social participation, indicating that this term includes participation as a consumer, participation in social activities, and societal involvement (Piškur et al., 2013), although this discussion perhaps raises more questions than are answered.

Researchers have also aimed to shed light on the important aspects of participation. According to Hoogsteen and Woodgate (2010), for children with disabilities, these have included taking "part in something or with someone," feelings of "inclusion," "control", and striving towards "a goal or enhanced quality of life" (p. 325). Others have reported that sharing activities with others, and experiencing fun, success and independence, are essential to the meaning of participation for children with

disabilities (Heah, Case, McGuire, & Law, 2007). Research with adults indicates similar concepts, but suggests challenges in attempting to identify hard and fast rules about the meanings people attribute to the term (Hammel et al., 2008). Perhaps recognizing this variability, Law (2002) adopted a more general and dynamic view of participation when she proposed that it was represented by transactions between people, their environments, and their occupations, this view aligning with Dewey's philosophical stance (Dewey & Bentley, 1949a).

In Aotearoa New Zealand, for Māori people, health beliefs that differ from Western views have implications for practitioner understandings as to what is important about participation. One widely recognized Māori perspective of health is the “whare tapa whā” (four-sided house) model (Durie, 1998, p. 68). From this perspective, health includes four essential aspects, including taha wairua (spiritual), taha hinengaro (mental), taha tinana (physical), and taha whānau (extended family). Underpinning the whare tapa whā model is an understanding of integration, where there is connection between the different aspects of people and their contexts. Although the whare tapa whā model does not use the word participation, the notion of taha whānau arguably reflects a participatory understanding of health, seen as belonging and connectedness with family and the wider community across time (Durie, 1998; Ministry of Health: Manatū Hauora, 2013). This contrasts with the separation between different parts of the person, and the individualism often seen in Western views of health (Durie, 1998).

On commencing this study, participation was defined as meaningful and satisfactory involvement in a life situation, and was seen as encompassing a “societal perspective of functioning” (WHO, 2001, p. 213). This definition was in accordance with the WHO definition, but also recognized that children and those involved with them may have unique views about their participation as it occurs in context (Hemmingsson & Jonsson, 2005; Hoogsteen & Woodgate, 2010; Ueda & Okawa, 2003).

Definition and Mechanisms of TBI in Children

My own concerns about participation arose when providing rehabilitation services with children who had sustained TBI. The ICF suggests that participation will be in part influenced by a person's body structures and functions (WHO, 2001). The nature of TBI in children is therefore discussed next.

From a medical perspective, TBI may be defined as damage to a person's brain due to external physical force(s) (New Zealand Guidelines Group, 2006). This

differentiates it from the broader term acquired brain injury (ABI), which also includes diagnoses such as stroke, or encephalitis (Brain Injury Association of America, n.d.). Traumatic injuries to the brain structures vary in nature and severity. There may be direct trauma to a person's brain through open head injury, which involves skull fracture, where brain tissue is damaged by an object or by skull fragments. In contrast, closed head injury occurs when the brain moves forcibly around inside the intact skull (for example, when the head is shaken backwards and forwards through a car collision) (Appleton, 2006). Such injuries are thought to result in varied deformation of brain tissue, tensile strain on neurons, and torsional strain on vascular structures (Margulies & Coats, 2010). Lesions may be focal, involving damage that is localized to a particular area, while diffuse brain lesions involve widespread damage to structures. In practice, many injuries include both focal and diffuse lesions. While these types of injury are considered to be primary injuries to brain tissue, damage from secondary injuries also ensues. Disruption to oxygen perfusion may take place with bleeding and oedema in the brain. Additionally, if areas of the brain controlling heart-rate, breathing and/or blood pressure are affected by injury, oxygen supply is further disrupted (Appleton, 2006; H. S. Levin, 2003; Vavilala et al., 2006).

Children's vulnerability to TBI.

Animal studies suggest that on a number of fronts, children are more vulnerable to both primary and secondary effects of TBI than their adult counterparts. Differences include biomechanical factors such as thinner skull in children, incomplete fusion of cranial sutures, large head size relative to body size and neck muscle strength, greater ratio of cranium to facial size, and forehead protrusion (V. Anderson, Catroppa, Morse, Haritou, & Rosenfeld, 2005; Catroppa & Anderson, 2010; Pinto, Poretti, Meoded, Tekes, & Huisman, 2012). Additional concerns for children arise from neurobiological factors such as higher brain water content, decreased extent of myelination, different levels of cerebral blood flow, and unique responses to excitotoxic neurotransmitters (V. Anderson, Spencer-Smith, & Wood, 2011; Giza, Griesbach, & Hovda, 2005; W. L. Maxwell, 2012; Pinto et al., 2012; Prins, Giza, & Hovda, 2010). It is possible the effects of these factors are modified to some extent by increased neuroplasticity in childhood, where the brain has ability to transfer functions from injured tissue to intact areas, although research supporting this view is limited. Whilst information about the effect of an injury on a child's brain structures cannot inform us immediately about participation,

the severity of the effects on those structures does have a bearing on children's outcomes (V. Anderson, Spencer-Smith, et al., 2011).

Classification of TBI.

The severity of a TBI may be classified according to the depth of coma, the duration of post-traumatic amnesia (PTA), and/or with the use of imaging such as computed tomography. Such methods classify injuries as mild, mild complicated, moderate or severe, and the classifications subsequently assist in predicting outcomes (Carney & Schoenbrodt, 1994; Fernando, Eaton, Faulkner, Moodley, & Setchell, 2002; McDonald et al., 1994; New Zealand Guidelines Group, 2006; F. P. Rivara et al., 2011; Siegert & Levack, 2005; Teasdale & Jennett, 1974; Thickpenney-Davis, Ogden, & Fernando, 2005). The present study was concerned with children who had sustained a moderate to severe TBI, greater injury severity being consistently associated with worse outcomes (V. Anderson, Spencer-Smith, et al., 2011).

Implications of TBI for Children's Participation

Moderate and severe TBIs typically have a negative impact on children's body functions and activity performance (V. Anderson, Le Brocque, et al., 2012; V. A. Anderson, Catroppa, Haritou, Morse, & Rosenfeld, 2005; Catroppa, Anderson, Morse, Haritou, & Rosenfeld, 2008; G. C. Fay et al., 1994; T. B. Fay et al., 2009; F. P. Rivara et al., 2011; F. P. Rivara et al., 2012; H. G. Taylor, 2010; H. G. Taylor et al., 2002), suggesting a likelihood of poor outcomes for their participation (WHO, 2001). Physical, cognitive, and affective functions are commonly disrupted, with consequences for children's development and longer term outcomes.

Physical, cognitive, and affective concerns and implications for participation.

Although many children experience some initial recovery of their physical skills (Dumas & Carey, 2002; Haley, Dumas, Rabin, & Ni, 2003; Russell, Krouse, Karas Lane, Leger, & Robson, 1998; Wilkening, 1997), residual high-level sensori-motor impairments are likely (Åhlander, Persson, & Emanuelson, 2013; Katz-Leurer, Rotem, Lewitus, Keren, & Meyer, 2008; Russell et al., 1998). Impairments in balance, motor speed, or coordination make it more difficult for children to engage in movement based activities with peers (Hawley, Ward, Magnay, & Long, 2002). Health issues such as seizure activity, fatigue, sleep disturbances, photosensitivity, decreased tolerance of noise, and headache are also common symptoms following TBI (Hawley et al., 2002; S.

R. Hooper et al., 2004; Matsumoto et al., 2013; Renström, Söderman, Domellöf, & Emanuelson, 2012; Stores & Stores, 2013; Tham et al., 2013), and may directly limit the time and quality of children's attendance at school and day-to-day participation.

Children's receptive and expressive communication skills are often affected by a TBI. Communication losses especially constrain children's ability to interact with family, teachers, and friends (Hay & Moran, 2005; Sullivan & Riccio, 2010; Vu, Babikian, & Asarnow, 2011; Ylvisaker & Feeney, 2007). Less obvious impairments in cognitive skills also present (V. Anderson & Yeates, 2010; Carney & Schoenbrodt, 1994). Whilst some return of function may continue for several years (V. Anderson, Catroppa, Godfrey, & Rosenfeld, 2012; V. Anderson et al., 2005; Chadwick, Rutter, Brown, Shaffer, & Traub, 1981; T. B. Fay et al., 2009; Van Heugten et al., 2006), particularly so for older children with more severe injuries, there is much evidence as to the presence of impairments relative to peers, across a range of cognitive functions, and in terms of performance in academic activities (S. W. Anderson, Barrash, Bechara, & Tranel, 2006; V. Anderson & Catroppa, 2005; V. Anderson et al., 2005; Catroppa & Anderson, 1999; Catroppa et al., 2008; Catroppa, Anderson, Muscara, et al., 2009; Ewing-Cobbs, Levin, & Fletcher, 1998; Gorman, Barnes, Swank, Prasad, & Ewing-Cobbs, 2012; H. G. Taylor, 2010; H. G. Taylor et al., 2002; Van Heugten et al., 2006; Vu et al., 2011). The frontal areas of the brain are particularly vulnerable to injury in children (Beauchamp et al., 2011; Hudspeth & Pribram, 1990; Hughes, 2011; Kolb & Gibb, 2010; Kriel, Krach, & Panser, 1990; Nadebaum, Anderson, & Catroppa, 2007; Pinto et al., 2012; Ylvisaker & Feeney, 1998). In more severe injuries (Nadebaum et al., 2007) damage to the frontal structures is thought to be responsible for deficits in flexibility of thought, task initiation and planning, speed of thought, attention span and problem solving. Such functions underpin task performance in context (Ylvisaker & Feeney, 1998), and are particularly likely to bear an effect on participation.

The frontal areas of the brain also play a role in regulating social behavior and emotions (Ylvisaker, 2006; Ylvisaker & Feeney, 1998). For these functions, a significant number of children with TBI demonstrate impulsiveness, disinhibition, agitation, or irritability which are likely to negatively affect their interactions with siblings and peers, particularly if such behaviors do not resolve with increasing maturity (J. P. Gerring et al., 2009; Hawley, 2004; Li & Liu, 2013; Prigatano, Fulton, & Wethe, 2010; Yeates et al., 2001; Ylvisaker, Szekeres, & Feeney, 1998). Although the emotional impact of TBI is not widely discussed, there is recognition, and some

evidence, that this contributes further to stress and changes in behavior (Hawley, 2012; Mather, Tate, & Hannan, 2003; Sherwin & O'Shanick, 1998, 2000). Alongside such concerns, children have been found to have an increased incidence of psychiatric disturbances following TBI, including anxiety and mood disorders (Harvey, Brewin, Jones, & Kopelman, 2003; Levi, Drotar, Yeates, & Taylor, 1999; Luis & Mittenberg, 2002; Max, Arndt, et al., 1998; O'Connor et al., 2012; Yeates et al., 2012; Yeates et al., 2001).

Developmental concerns for participation.

It was previously believed that children made a much better recovery from brain injury than adults (Dennis, 2010). However, it is now known that TBI holds particularly serious developmental consequences for children, posing on-going concerns for their ability to participate successfully in the community. In contrast to children with congenital health conditions, children with TBI have a history of developmental progress which is interrupted traumatically and often permanently. While many children make encouraging gains early in their rehabilitation, and while there can be some return of function over many years, developmental progress typically slows. Delays in skill attainment relative to other children become apparent in certain areas, and these delays then increase over time, with children potentially finding it harder to take part in activities alongside their peers (V. Anderson, Catroppa, et al., 2012; V. Anderson et al., 2005; T. B. Fay et al., 2009; Van Heugten et al., 2006).

Building evidence points to these incremental delays being more marked for children who are severely injured (V. Anderson et al., 2005), and for younger children injured at critical stages in their skill development (V. Anderson & Catroppa, 2005; V. Anderson, Catroppa, Morse, Haritou, & Rosenfeld, 2000; V. Anderson et al., 2005; V. Anderson, Le Brocque, et al., 2012; V. Anderson, Spencer-Smith, et al., 2011; Crowe, Catroppa, Babl, & Anderson, 2013; Ewing-Cobbs et al., 1998; Lah, Epps, Levick, & Parry, 2011; H. S. Levin, 2003). Recent evidence suggests that middle childhood is a time of particular concern (Crowe, Catroppa, Babl, Rosenfeld, & Anderson, 2012).

Long term concerns for children's participation.

Although some children experience a smooth transition to adulthood after TBI (V. Anderson, Brown, & Newitt, 2010; Emanuelson, Von Wendt, Beckung, & Hagberg, 1998; Klonoff, Clark, & Klonoff, 1993), international studies generally flag continuation of difficulties through into adult life. Adult survivors of childhood TBI

report poor social integration, feelings of difference, being misunderstood or disliked, and difficulties with interpersonal relationships (Backhouse & Rodger, 1999; Brenner et al., 2007; Burleigh, Farber, & Gillard, 1998; Emanuelson et al., 1998; Kao & Stuijbergen, 2004; Muscara, Catroppa, Eren, & Anderson, 2009). Vocational concerns, and a need for ongoing assistance with daily activities, contribute to long-term reliance on families and rehabilitation services (V. Anderson, Brown, Newitt, & Hoile, 2009, 2011; Backhouse & Rodger, 1999; Brenner et al., 2007; Emanuelson et al., 1998; Jonsson, Horneman, & Emanuelson, 2004; Van Heugten et al., 2006; Wongvatunyu & Porter, 2005).

The Importance of Participation for Children: Educational and Developmental Theory

Concerns for children's participation after TBI sit alongside theory that promotes participation as an essential influence on learning, development, and health. John Dewey's philosophy emphasized the importance of activity and participation to enable children's development and citizenship. For Dewey, children have a need to be directly involved in a variety of activities, both in and out of school, in order for learning and development to occur. "Only by direct active participation in the transactions of living does any one become familiarly acquainted with other human beings and with 'things' which make up the world" (Dewey, 1948/2005, pp. 4-5). Children's participation in the social context of schools was particularly highlighted by Dewey for the role it plays in enabling their ongoing contribution to democratic society. "Apart from participation in social life, the school has no moral end nor aim" (Dewey, 1909/1998, p. 247).

The developmental psychologist, Vygotsky also held that children's developmental changes were facilitated through participation in physical and social situations. Vygotsky had a particular interest in understanding the development of children with learning difficulties such as brain injury. He argued that children's engagement in shared activity with peers and adults, their use of culturally relevant physical objects such as toys when involved in play, and the language that is used during those interactions, molds their responses to increasingly complex challenges, and the way they think and develop in an ongoing way (Glick, 2004; Holzman, 2009; Miller, 2002).

The Importance of Participation for Children: Research

Supporting such theoretical understandings, an increasing body of research attests to the role children's participation plays in different aspects of their development and health. Earlier research provided evidence for relationships between children's participation in play and their development of movement skills (Adolph, Bertenthal, Boker, Goldfield, & Gibson, 1997; Mulligan, Specker, Buckley, O'Connor, & Ho, 1998; Pellegrini & Smith, 1998; Wachs, 1990), language abilities (Elardo, Bradley, & Caldwell, 1977; Hammer & Weiss, 2000; Hart & Risley, 1995; Wells, 1981), and social competence (E. P. Fisher, 1992; Pate, Dowda, & Ross, 1990; Pellegrini, 1987; P. K. Smith & Boulton, 1990). Around this time, research also related the amount of time children participated in school, homework and reading activities to achievement in various areas of the curriculum (R. A. Anderson, Wilson, & Fielding, 1988; Fuligni & Stevenson, 1995; Keith & Page, 1985; Leone & Richards, 1989; Paschal, Weinstein, & Wahlberg, 1984).

More recently, there has been a focus on the importance of children's participation in regular physical activity for promoting physical health, movement skills, and fitness (Carrel, Clark, Peterson, Eickhoff, & Allen, 2007; Donaldson & Ronan, 2006; A. Fisher et al., 2005; Valois, Zullig, Huebner, & Drane, 2004; Wake & Reeves, 2012). Participation in clubs has been found in several countries to have a particularly strong association with health, including dimensions such as health complaints, smoking, drinking, diet, and physical activity (Zambon et al., 2010). However studies which look at computer and television viewing give a mixed picture. Although they suggest benefits in terms of development of visual processing and computer literacy skills, this occurs alongside obesity risk, isolation, depression, and increased aggression (Marshall, Biddle, Gorely, Cameron, & Murdey, 2004; Subrahmanyam, Kraut, Greenfield, & Gross, 2000; Wake & Reeves, 2012).

In light of theoretical understandings and research about the benefits of participation, it is possible children with TBI may face double concerns for their health and development. Not only do they experience loss of skills and delays relative to their peers as a direct result of the injury, but it is possible that inadequate participation in community activities may further restrict their recovery and progress.

The Context of the Study

Aotearoa New Zealand legislation and policy, and participation.

Countering concerns over children's participation after a TBI, a requirement to support children's participation is embedded into several areas of Aotearoa New Zealand legislation and policy. Often however, the term is used in documents in a generalized manner, with little or no definition to clarify its application. Te Tiriti o Waitangi (The Treaty of Waitangi) is Aotearoa New Zealand's founding document (Orange, 2004). Although its texts and its translations do not specifically use the term participation (State Services Commission, 2005), in 1988, the Royal Commission on Social Policy identified principles of Partnership, Participation, and Protection in response to a need to support understanding of the intent and application of the Treaty (Durie, 1998; Kingi, 2006). The principle of Participation is interconnected with the other two principles. In connection with health, the principle of Participation addresses "the obligation to ensure that Māori are able to participate in the delivery of health services" (Kingi, 2006, p. 11). There is debate over the presence of the principles of Partnership, Participation, and Protection in the Māori and European versions of the treaty, and over the merits of those principles (Durie, 1998). However, they remain enmeshed across a wide range of Aotearoa New Zealand government legislation and service policy today.

The Aotearoa New Zealand Disability Strategy also acknowledges participation when it articulates an objective "to enable disabled children and youth to lead full and active lives." This includes facilitating "their active participation in the community" (Ministry of Health, 2001, p. 13). The strategy does not specify what activities this goal might entail. However, a framework developed to review progress towards the objectives articulates a vision of "a society that highly values our lives and continually advances ... full participation" (p. 10). A range of outcomes that will support this vision of participation are proposed to include citizenship, access to health and education, a choice of employment and income, housing, transport and recreation, relationships, and feeling valued (The Office for Disability Issues, 2007).

In schools, the New Zealand Curriculum similarly has a vision for young people to be "actively involved", which includes participating across different life areas (Ministry of Education: Te Tāhuhu o te Mātauranga, 2007, p. 7). The curriculum incorporates a value of "community and participation for the common good" (p. 10). A core competency within the curriculum regarding students' community involvement is

called “participating and contributing” (p. 13). It includes contribution to groups, social interactions, and supporting others’ contributions. In this context, participation is seen as instilling awareness of belonging in children, building their confidence, recognizing each other’s rights and responsibilities, and developing their skills to protect and enhance social and physical environments.

Importantly, a concern with participation is inherent to some, although not all of the Accident Compensation Act 2001 (Parliamentary Counsel Office/Te Tari Tohutohu Pāremata, 2013). This legislation provides for state-funded rehabilitation for injuries Aotearoa New Zealand children might acquire in an accident, such as a TBI. The context of rehabilitation service provision provided within the scope of this act is discussed next.

Provision of rehabilitation in the context of Aotearoa New Zealand.

After a child sustains a moderate to severe TBI, there is generally a need for hospitalization, and then for inpatient and/or community based rehabilitation (Appleton, 2006; Appleton, Furlong, & Baldwin, 2006). Internationally, not all children have their medical costs met by insurance (Families USA, 2006b; S. R. Hooper et al., 2004; Tilford et al., 2005), and their access to hospital services, education support services, consultation, rehabilitation provision and curriculum content varies significantly according to jurisdiction. Many children receive insufficient or no services after discharge from hospital (Glang et al., 2008; Prigatano & Gray, 2008).

In contrast, in Aotearoa New Zealand, rehabilitation costs for injuries children acquire in accidents are met through the Accident Compensation Corporation (ACC), a crown entity (ACC, 2013). This funding stream is different than that provided for children who acquire a brain injury as a result of infection or stroke (Independent Living Service and Tiaho Trust, 2013). Under the provision of the principal Accident Compensation Act 2001, ACC administers a state funded scheme that provides 24 hour no fault accident insurance cover for Aotearoa New Zealand citizens, residents, and temporary visitors (Parliamentary Counsel Office/Te Tari Tohutohu Pāremata, 2013). When injuries occur, the *purpose* of the Act is stated as ensuring that “the Corporation’s primary focus should be on rehabilitation, with the goal of achieving an appropriate quality of life through the provision of entitlements that restores to the maximum practicable extent a claimant’s health, independence, and participation” (Parliamentary Counsel Office/Te Tari Tohutohu Pāremata, 2013, p. 20). Hence, one of the Act’s intentions is to address a claimant’s participation. Although participation is not defined,

this creates opportunity for addressing the various aspects of participation that are important to individuals.

Hospitalization costs incurred after a child has a TBI are bulk-funded by ACC through district health boards (New Zealand Guidelines Group, 2006). Certain education costs such as equipment needs in school, specialist teacher assistance, and some therapist consultation in the classroom are also bulk-funded by ACC through the Ministry of Education Special Education initiative (New Zealand Ministry of Education, 2013). Additional rehabilitation is provided on the basis of individually assessed needs. Under the Accident Compensation Act 2001, rehabilitation, including physical and cognitive rehabilitation, vocational rehabilitation, and social rehabilitation, is defined as “a process of active change and support” and has a specific goal of restoring participation. (Parliamentary Counsel Office/Te Tari Tohutohu Pāremata, 2013, p. 35). Through the *definition of rehabilitation* therefore, the Act further situates participation as a key outcome.

Social rehabilitation includes, according to assessed need, provision of aids and appliances, attendant care, child care, education support, home help, modifications to the home, training, and transport. The purpose of social rehabilitation is “to assist in restoring a claimant’s independence to the maximum extent practicable” (Parliamentary Counsel Office/Te Tari Tohutohu Pāremata, 2013, p. 95). Whilst participation is an intent of the Act, and is named as a rehabilitation outcome, in the context of social rehabilitation it is not specified as an outcome. It is uncertain how this anomaly affects delivery of social rehabilitation services and children’s participation.

Nonetheless, delivery of rehabilitation services in Aotearoa New Zealand is informed by international literature and trends (New Zealand Guidelines Group, 2006). In line with the development of the ICF (WHO, 2001, 2007), international publications have increasingly emphasized the need to consider outcomes in terms of involvement in community activities (Kendall, Buys, & Lerner, 2000; G. King et al., 2002; Mitchell, 1999; D. Wade, 2003; D. T. Wade, 2001; Ylvisaker et al., 2005; Ylvisaker & Feeney, 1998). Authors highlight a need for rehabilitation services to develop and implement assessments and interventions that are directly focussed towards clients’ participation in their own environments. This is particularly relevant for individuals who have had a TBI, where it has been shown that de-contextualised assessments of some cognitive functions do not adequately reflect function in real-life tasks, and where interventions directed at cognitive impairments do not necessarily generalize to improvements in task

performance in the real-life environment (Silver, 2000; Ylvisaker et al., 2005; Ylvisaker & Feeney, 2007; Ylvisaker & Feeney, 1998; Ylvisaker, Hanks, & Johnson-Greene, 2002).

Although the ACC scheme is available to meet children's rehabilitation needs after TBI, and although the scheme arguably has an intention to address participation, clinical experience suggests there may be some inconsistencies in obtaining services across population groups and geographic areas. Inequalities in access to rehabilitation may be particularly prevalent for Māori. Concerns have been expressed by Māori over difficulties with completing required paperwork, slow time-frames for service provision, communication, and levels of comfort with non-Māori rehabilitation providers (Jansen, Bacal, & Crengle, 2008).

The incidence and costs of childhood TBI in the context of Aotearoa New Zealand.

For children, the provision of rehabilitation services represents a long-term commitment. The population in Aotearoa New Zealand is relatively small, approaching 4.5 million people (Statistics New Zealand: Tatauranga Aotearoa, n.d.), and the numbers of children sustaining TBI are relatively low. However the cost to the community over a child's lifetime is likely to be disproportionately large.

A comprehensive, epidemiological study has recently been conducted by Feigin and colleagues (2013). The Brain Injury Outcomes New Zealand In the Community (BIONIC) study was conducted in a large urban/rural area in Aotearoa New Zealand, and captured information from multiple sources about the incidence of new TBIs for all ages between 2010 and 2011. A total of 1369 new cases of TBI were reported, with an incidence of 790 cases per 100,000 person years. It was found that TBI was most frequent in the 0-4 and 15-34 years age bands. Children of these ages reflected particularly high incidences of mild TBI ($n = 378$), although seven moderate to severe TBIs were also reported. There was a significantly greater incidence of TBI for males than females, and for Māori people than for those of other ethnicities. Moreover, the study suggests the Aotearoa New Zealand incidence of TBI is much greater than that reported internationally, although such claims should be interpreted with some caution, given variability between data collection strategies and classification systems used. Whilst recognizing that the figures only represent one year and one area, they raise some concerns for the long-term impact of children's TBI in Aotearoa New Zealand.

Statistics from the ACC Claims Management: Information, Analysis and Reporting department adds weight to these concerns. In 2012, there were 1314 existing claimants aged 0-19 years with severe or moderate to severe traumatic brain injury (personal communication, December 23, 2013). In the same year, a further 36 children in that age bracket sustained a severe or a moderate to severe traumatic brain injury. That year, the total social rehabilitation costs for those claimants were \$105,474,000. However, the projected costs are more concerning. From 1st July 2013, for each claimant who sustained a moderate to severe brain injury when they were aged 0-19 years, the average projected lifetime cost of social rehabilitation is estimated as \$13.8 million, while for those whose injury was severe, the estimated cost is \$22.1 million.

Research into childhood TBI in the context of Aotearoa New Zealand.

Although service provision for children after TBI would seem to be more readily available in Aotearoa New Zealand than in other countries, and despite the costs of that rehabilitation, few studies of outcomes for children with TBI have been conducted. Even fewer of these studies involve children who are Māori (Elder, 2012). Studies that have involved children have concerned themselves with injuries sustained (Bruce, Schut, & Sutton, 1984), or with impairments in areas such as language, behavior problems, and neuropsychological sequelae (Leatham & Body, 1997; C. Moran & Gillon, 2004). One study of outcomes for children with skull fractures excluded children with neurological pathology (Marsh & Whitehead, 2005). Other studies have limited their sample to children with mild injuries only (McKinlay, Grace, Horwood, Fergusson, & MacFarlane, 2010). One Aotearoa New Zealand study looked at psychosocial outcomes, and included both children and adults with severe TBI, but the children's ages are not stated: data for those children were analyzed as part of the overall data-set (Kersel, Marsh, Havill, & Sleigh, 2001a, 2001b). No studies were found that addressed children's participation.

Overview of the Thesis

Given this lack of information, and driven by my practice concerns, the implications of TBI for children's involvement in daily life, the importance of their involvement, and legislation and policy which seemingly required their involvement, this study was undertaken in the first instance to understand Aotearoa New Zealand children's participation after TBI. Subsequent phases of the studies took steps towards addressing participation difficulties.

This first chapter has set the scene of the study for readers. It has explained the practice concerns that prompted the study. It has introduced the philosophical perspective of John Dewey, which drove a need to understand participation in context, the points of view of the diverse stakeholders involved, and a concern with practical outcomes. The content and process of the study has been outlined, and the key area of focus, participation for children after TBI has been defined. The study has been justified in light of the implications of TBI for children's participation, and the importance of participation for children's development and health. The Aotearoa New Zealand context of the study has been described, with reference to legislation, policy, provision of rehabilitation, demographics, and research. The remainder of the chapters in the thesis go on to explain the three phases of the study in detail.

Chapter Two explains the influences that led to my interest in John Dewey's pragmatist philosophy, and explains the relevance of this philosophy to understanding children's participation. It sets out the aspects of the philosophy that guided the research process for all three phases of the study.

In Chapter Three, the body of literature that provides information about children's participation after TBI is described and critically reviewed. The content of the review is informed by Dewey's pragmatist philosophy. The review summarizes key understandings from literature about participation for children with disabilities then focuses on what is known about participation for children with TBI. The context of children's participation after TBI is explored. Gaps in the literature are highlighted.

Next, in Chapter Four, the methodology and design of the first, case study phase of the research, is described. This phase aimed to understand the children's participation, and the facilitators and barriers to their participation. The case study methodology used in the study is explained and justified in relation to Dewey's philosophical perspective and the research question. The different aspects of the design of the study are detailed, including the study's conceptual structure, case definition and selection, ethical considerations, and data collection. Explanation is provided of the analytic process used for individual cases and in the cross-case analysis. Rationales are provided for decisions made at different points in the research process. The chapter closes in considering the validity of the study.

Chapters Five and Six present the Case Study findings. Chapter Five presents a summary of the six case studies, and presents the full findings of one of the case studies. The report from Case Study Six was chosen for the breadth of information it provides

across different stakeholder perspectives and contexts, and for the depth to which it illustrates the phenomenon of the children's participation. The remaining case study reports are appended on Disc One. Chapter Six presents the findings of the cross-case analysis, which drew together information from all six cases and developed assertions about children's participation after TBI in Aotearoa New Zealand.

Phase Two of the study, in which a literature review was undertaken to identify approaches to addressing children's participation is discussed in Chapters Seven and Eight. The methodology chosen for the review, and the methods employed in gathering and analyzing information for the review are outlined in Chapter Seven. Chapter Eight presents the findings of the review.

Phase Three of the study is presented in Chapters Nine and Ten. A resource for facilitating the children's participation that was developed from information gathered in the first and second phases of the study is appended in the body of the thesis. The methodology and design of the study which was implemented to gather feedback about the resource is outlined in Chapter Nine. This includes information about the action research methodology that guided the inquiry. The methods used to recruit key stakeholders to the project as co-researchers, gather data in the context of a workshop, and the process of analyzing that data are outlined. Chapter Ten presents the findings from this phase of the study. It outlines the modifications that were made to the resource, and ideas that were generated for its dissemination.

Chapter Eleven draws together the overall findings of the study and situates them in relation to extant literature. A summary of the key findings from the three phases is provided. The contribution of the findings to the body of knowledge is discussed, and the implications of those findings for rehabilitation of children who sustain a TBI and for policy are explored. The limitations of the study are acknowledged, and weighed against the strengths of the information generated. Recommendations for further research are outlined. The thesis concludes with a brief reflection.

Throughout the chapters, to support brevity, apart from the resource which was developed, appendices are located on Disc One. Where reference is made to appendices on Disc One, they are numbered according to the relevant chapter number and the sequence in which they are discussed within that chapter.

Reflecting the Aotearoa New Zealand context of the study, some information is expressed using terms from the Aotearoa New Zealand Māori language, Te Reo, as this

language best captured the meaning. When Te Reo is used, explanation is given in English, and terms are also defined in a glossary. A second glossary includes definitions of terms used in explaining the philosophical understandings in Chapter Two and terminology relating to research methods. In line with the stylistic preferences of the Publication Manual of the American Psychological Association (2010), American English spelling is used throughout the thesis.

Summary

This study has set out to understand Aotearoa New Zealand children's participation after TBI. Guided by Dewey's pragmatist philosophy, it seeks understanding from the perspectives of the different stakeholders involved, and to generate information about the children's participation as it occurs in context and as it has changed over time. A concern with practical outcomes of inquiry has driven the development of a resource which provides a foundation for addressing some of the issues around participation that face children and their whānau/families. The next chapter discusses the philosophical underpinnings of the study, and introduces the notions within that philosophy that shaped the inquiry.

Chapter Two

Understandings Guiding Practice and Inquiry: Dewey's Pragmatist Philosophy

The philosophy of a profession encompasses the “beliefs, ideas, and knowledge which underpin its practice” (Hagedorn, 1992, p. 272). As health professionals, our practice is supported when we are aware of the things we value, our understandings about reality, and how we come to know things. Such insights help us explain our practice, sensitize us to the reasons underpinning our decisions and actions, prompt our regard for others' viewpoints, and provide a basis for dialogue (Breines, 1990; Cody, 2006). When undertaking a study about practice issues, our philosophical understandings will influence the questions we ask, the ways we go about answering them, and our interpretation of the answers. By articulating the philosophical understandings underlying practice inquiries, our assumptions, and thereby the reasons for our decisions, are more transparent to others who wish to evaluate, learn from, and use the information (Cresswell & Plano Clark, 2007; Crotty, 1998; Dewey & Bentley, 1949c).

The previous chapter introduced a practice issue, involving uncertainty over children's participation after TBI in the Aotearoa New Zealand context. It explained the concept of participation, what was involved with children's TBI, the risks to their participation, and its importance to their development and health. A study was proposed to understand more about children's participation after TBI. I brought to the study a perception that participation is about people being occupied with their world. By locating this perception within a philosophical perspective, I was able to frame the way I understand people in relation to the world, and how, as people, we come to know our world. This provided a basis for teasing out why it might be necessary to understand children's participation, the things that would be important to consider about their participation, and the methods I should use to inquire into their participation.

This chapter explains the process by which I came to John Dewey's pragmatist philosophy, and how, by gaining deeper understanding of its tenets, I came to resolve some ambiguities that I found with my initial readings of Dewey's work. I summarize the evolutionary and naturalistic aspects of his philosophy that depict humans with their world. The chapter then examines the ideas within John Dewey's philosophy that stood out to me as key to conceptualizing children's participation. These include the notions of connection and continuity, change, transaction, learning, and democracy. The ways in

which Dewey's philosophy guided my practice inquiry and helped shape a resource to address participation difficulties will be described in the relevant methodology sections of this thesis. Definitions of the terminology used are contained in the Glossary. The contents and sequence of the chapter are shown in Figure 2.1.

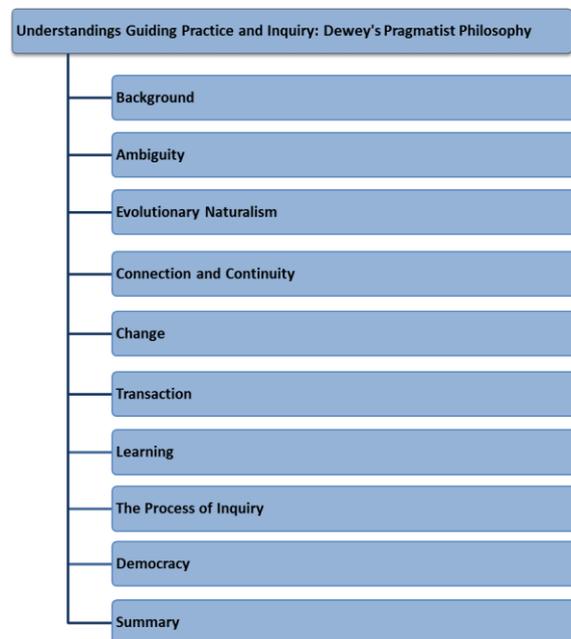


Figure 2.1: Contents and Sequence of Chapter Two

Background

In my occupational therapy practice, I am aware of the way in which the understandings of my profession have evolved over time, variously embracing both reductionistic, mechanistic and impairment-focused views of people and their occupations, and holistic, meaning-focused perspectives (Carlson & Clark, 1991; B. Hooper & Wood, 2002; Kielhofner, 1992). I believe myself fortunate to be informed by both. I draw on biomedical, neuropsychological, and sociological understandings, alongside my understandings about the importance of participation in occupation for people's health. I value and use the science underpinning surgical, medical and innovative, environmental technology to support positive outcomes for children, but believe that outcomes are equally influenced by contexts, experiences, and the meaning things hold for people. As rehabilitation unfolds, this diversity of understandings enables me to discern the range of things that might be influencing a child's occupations, and supports assessment and intervention for occupational issues at the levels of body structures and functions, occupational performance, or the environment. I

appreciate the way numerical indicators can convey to funding bodies that rehabilitation is making a difference, but equally take heed of the words and signs children and whānau/families use to express to me their goals and the changes they perceive. Although I notice some commonalities between the clients I work with, I am also struck by unique perspectives and singular experiences that are expressed to me. In reflecting on this array of information, my focus is on bringing about change, on enabling children to “do things” that are important to them, and making it possible for them to participate in the day-to-day occupations that are part of, and recognized by, the community in which they live.

When undertaking my studies, I felt the need to be honest with myself and others, in explaining that I believed it was possible to sometimes think in a reductionistic, objective manner about phenomena relating to occupation, but also to embrace meanings and experiences as a way of making sense of the occupational world. My original research proposal had suggested a mixed methods study. Although this plan changed over the course of my studies, in searching for answers to explain and draw together my juxtaposed views of phenomena, I turned once again to literature I had obtained when exploring mixed methods research. Researchers using mixed methods have faced similar dilemmas in explaining the paradigmatic underpinnings of research that deliberately involves both quantitative and qualitative information.

Mixed methods literature proposes that an interweaving of paradigmatic understandings is increasingly common in social science practice and research (Maxcy, 2003), where a blend of qualitative and quantitative data is a practical response to multifaceted issues and real-life questions (Greene & Caracelli, 2003). A pragmatist view of the world and knowledge offers a means of conceptualizing and validating linkages between structuralist and naturalistic forms of inquiry. Moreover, by purposefully mixing research methods to generate diverse types of knowledge, it is argued that our understanding of phenomena, and the utility of data is enhanced (Greene & Caracelli, 2003). Although pragmatism has been well recognized since the latter part of the 19th century, with different leaders adopting some varying points of view (Cherryholmes, 1992), John Dewey (1859-1952) is cited as contributing extensively over his long working life to our understanding of the philosophical tradition (Maxcy, 2003).

As I began to explore Dewey’s writings, I felt they resonated with my own understandings, immediately reflecting a concern for people to be occupied and engaged with their worlds. With further reading, my understandings of people as being one with

their world through occupation became more refined. Literature that informed me about the historical context in which Dewey worked portrayed a community that was also increasingly aware of the importance of occupation for people's health and development, and one which was proactive in providing disadvantaged groups with opportunities to participate in occupations that held meaning for them (Addams, 1912, 1935/2004; Baum, 2002; Breines, 1990; Dalton, 2002; A. Meyer, 1922/1977; Schwartz, 2009).

While in his position as Professor and Chair of the Department of Philosophy at the University of Chicago, and through his involvement with Hull House, a settlement house which was established to address social inequities faced by European immigrants and factory workers in Chicago, Dewey associated with several who contributed to the beginnings of the occupational therapy profession. Amongst Dewey's colleagues and companions at that time was Adolf Meyer, a psychiatrist, who, with his wife, Mary Potter Brooks Meyer, advocated for the health benefits of habituating a healthy daily routine for patients with mental illness, and for ensuring such patients had opportunity to participate in meaningful work and leisure occupations (Breines, 1990; Kielhofner, 1992; A. Meyer, 1922/1977; Schwartz, 2009). Another of Dewey's contemporaries, Jane Addams, social worker, Nobel Peace Prize recipient, and co-founder of Hull House, recorded her experiences from that period. She described her many discussions with Dr Dewey about the ways in which occupation could support immigrants to adjust to the changes in their new country (Addams, 1912). Also present in the community at that time were Jessie Luther, a pioneer occupational therapist and advocate for the value of arts and crafts in people's lives, who went to work at Hull House in 1901 (Canadian Association of Occupational Therapists, n.d.); and Julia Lathrop, a close friend of Jane Addams, who went on to provide training and classes at Hull House in the use of occupations with those with psychiatric disorders (Addams, 1935/2004).

In recent times, occupational science literature has continued to raise awareness of the contribution that can be made by Dewey's pragmatist philosophy to our understandings, drawing from it to look critically at the ways in which we conceptualize occupation, and using certain concepts to point to ways in which we can further our knowledge in supporting people's well-being (Breines, 1990; Cutchin, 2004, 2007; Dickie, Cutchin, & Humphry, 2006; B. Hooper & Wood, 2002; Ikiugu & Schultz, 2006). As with these authors, Dewey's philosophical method has helped map my world

view, explaining and informing my own understandings, as well as guiding my path through the different phases of my study.

Ambiguity

While I identified with Dewey's pragmatist perspective, initially, the pathway he pointed to seemed unclear. The mixed methodology texts I had referred to either failed to specify the ways in which Dewey's philosophy could direct both quantitative and qualitative inquiry (Cresswell & Plano Clark, 2007), presenting what seemed to me to be an "anything goes" approach, or subscribed to an instrumentalist view of Dewey's inquiry methods (Maxcy, 2003). An instrumentalist view seemed to circumscribe what I had understood to be Dewey's explicit valuing of science and his frequent use of scientific examples alongside an experiential view of the world, but lacked explanation of how this was possible. For some time I remained baffled as to how Dewey was able to advocate for a scientific method of inquiry, involving experimentation, concepts of cause and effect, reductionism, and a spectator view of knowledge, when his writings were also concerned with meaning, experience, holism, commonsense knowing, and intuitive, aesthetic understandings.

Careful reading was required to come to grips with the context of phrases used by Dewey, to avoid misinterpretation of his position. Reflecting his long life span, Dewey's writings are extensive and his discussion can sometimes be convoluted. Further confusion arose with differences between Dewey's earlier and re-written works, the re-writing undertaken in response to criticism and shifts in his own views over time (1925/1981). Little light was shed by divergent views in the surrounding literature, summarized by James Scott Johnston (2006), which argued that Dewey followed either one or the other of these seemingly contradictory positions.

Scott Johnson's (2006) work provided a way forward however, in drawing together and endeavoring to answer the debate surrounding Dewey's writings. As with Maxcy (2003), Scott Johnson situated the two positions adopted by Dewey in an instrumental, inquiry-based context, but, importantly, drew attention to the moral context surrounding inquiry. He proposed that for Dewey, inquiry was a tool which was used to investigate and address problems that humans encountered as they acted with their world. The form of inquiry was not only modeled and shaped by the problem and the context in which it arose, but also by the uses to which the information would be put to benefit human-kind. Attempts by various authors to identify either a positivist or a naturalistic model of inquiry in Dewey's writings therefore lack purpose, when Dewey

was rather envisioning inquiry as being flexible, situation specific, and as conducted with an overall aim of supporting democratic ideals, learning, and community growth and well-being.

Evolutionary Naturalism

Although I agreed with Scott Johnson's (2006) position, my initial, fragmented readings continued to raise some questions about the seeming juxtaposition of science and meaning in Dewey's writings. How was it possible for individuals to sometimes distance themselves from their world, and to search for overarching laws of cause and effect (albeit with the aim of serving ideals for a better community for all), while still living in a world that they believe is inseparable from meaning and experience? These questions were solved as I read more widely, building a better picture of a whole. While providing some answers, Scott Johnson neglected to discuss Dewey's evolutionary, naturalistic conception of humans and human thought (Hickman & Alexander, 1998), which provides another important foundation-stone in understanding the connection between science and meaning.

Building from Darwin's theory of evolution, Dewey saw humans as beings who, whilst inseparable from a meaning-laden, natural world, developed thought mechanisms which enabled them to momentarily set themselves apart from a situation in order to achieve certain purposes. In a similar vein, Dewey recognized the human ability to temporarily distinguish and focus on an isolated aspect of a situation or object in thought, or to momentarily see subject and object as separate entities. These skills, when integrated with other abilities, enable humans to respond to unusual situations, reflect symbolically, and consider possible outcomes, aiding development of adaptive and functional solutions (Dalton, 2002). Dewey and his co-author, Arthur Bentley stated this assumption:

Our position is simply that since man as an organism has evolved among other organisms in an evolution called 'natural,' we are willing under hypothesis to treat all of his behaviors, including his most advanced knowings, as activities not of himself alone, nor even as primarily his, but as processes of the full situation of organism–environment. (Dewey & Bentley, 1949a, p. 104)

People's everyday activities and scientific inquiry are proposed to be practical occupations in which humans frequently use abstract thought, temporarily distancing themselves from the day-to-day world (Dewey, 1949). This ability to think of one's

world in the abstract, and its implications is aptly illustrated in Dewey's second edition of *Experience and Nature*.

To distinguish in reflection the physical and to hold it in temporary detachment is to be set upon the road that conducts to tools and technologies, to construction of mechanisms, to the arts that ensue in the wake of the sciences. That these constructions make possible a better regulation of the affairs of primary experience is evident.... Along with this added ability in regulation goes enriched meaning and value in things, clarification, increased depth and continuity. (Dewey, 1925/1981, p. 20)

Dewey's point of view not only provides grounding for understanding the difficulties that many children experience after a TBI, but also opens an avenue to address those difficulties. When a child's natural capacity for reflection and insight into situations involving his or her actions or those of others is impaired, the ability to inquire into, learn from, and respond adaptively to challenges is limited. However, Dewey's position also recognizes connections between a child and a context where technology can be developed and used to ameliorate these limitations, thereby supporting participation and progress.

Connection and Continuity

Although Dewey acknowledged humans' natural ability to see themselves as separate from a situation in thought, he warned against a tendency to see this disconnection as the way things really stand in the world. "The problem is then to get together again what has been sundered- which is as if the king's men started with the fragments of the egg and tried to construct the whole egg out of them" (Dewey, 1925/1981, p. 19). He advocated for us to begin with, and refer reflective understandings back to, the test of real world issues in order to support growth and change. When this circularity is disregarded

the result is a picture of a world of things indifferent to human interests because it is wholly apart from experience. It is more than merely isolated, for it is set in opposition. Hence when it is viewed as fixed and final in itself, it is a source of oppression to the heart and paralysis to imagination. (Dewey, 1925/1981, p. 20)

In line with his evolutionary naturalism, notions of connection and continuity are present throughout Dewey's writings, providing a strong background for his other ideas about the world and how we come to know it. Dewey consistently depicts people,

their activities, their thinking, and their experiences as continuous with all aspects of the environment through time and space. Although people may focus on a static snapshot of time when they are thinking or acting, we are urged by Dewey to always look to our past, our present, and our future. Through reflection, history is able to inform our present, may be seen in a new light, and also provides a guide to future possibilities.

We cannot lay hold of the new, we cannot even keep it before our minds, much less understand it, save by the use of ideas and knowledge we already possess. But just because the new is new, it is not a mere repetition of something already had and mastered. The old takes on new color and meaning in being employed to grasp and interpret the new. (Dewey, 1925/1981, p. 3)

Likewise, whilst we may see ourselves as apart from our physical environment, in reality it is continuous with us. The elements in the environment are also present in us. Air, water, plant matter, and animal matter become part of our bodies by dint of our living and are necessary to our living, doing, and thought. Our body is essential for our mind to function in thought. Our thoughts, our various activities, our experiences do not arise from nowhere, but grow as we participate with others and our physical world.

Experience is of as well as in nature... 'Experience' denotes the planted field, the sowed seeds, the reaped harvests, the changes of night and day, spring and autumn, wet and dry, heat and cold, that are observed, feared, longed for; it also denotes the one who plants and reaps, who works and rejoices, hopes, fears, plans, invokes magic or chemistry to aid him, who is downcast or triumphant. It... recognizes in its primary integrity no division between act and material, subject and object, but contains them both in an unanalyzed totality. (Dewey, 1925/1981, p. 18)

For children, a TBI has the potential to weaken or sever these connections with their world. Their ability to move, to participate in, and experience the world may be impaired. Tertiary care settings often distance them from their home and community contexts. Meaningful occupations in which they previously participated may no longer be possible, and the continuity between past experiences and the present and future takes a dramatic shift. Recognizing the place of connection and continuity in bringing about growth and realizing future possibilities should surely underpin rehabilitation service delivery. Programs should aim to re-build and strengthen those connections.

Change

Linking with these notions of continuity and connection, themes of change are also present in Dewey's writings. Humans with their world are seen as continuously evolving. Through their connections with other things, some aspects of the world change slowly. In other situations, change processes occur very rapidly, leading to uncertainty. "We live in a world which is an impressive and irresistible mixture of sufficiencies, tight completenesses, order, recurrences which make possible prediction and control, and singularities, ambiguities, uncertain possibilities, processes going on to consequences as yet indeterminate" (Dewey, 1925/1981, p. 47). Dewey went on to explain:

... in truth, anything which can exist at any place and at any time occurs subject to tests imposed on it by surroundings, which are only in part compatible and reinforcing....The stablest thing we can speak of is not free from conditions set to it by other things. (1925/1981, p. 63)

We are however reminded by Dewey of the practical implications of change; "This fact is nothing at which to repine and nothing at which to gloat over. It is something to be noted and used" (1925/1981, p. 63). What is important is the rate of change, and how we can use changes, or act to bring about change, through an understanding of connecting events. Even while changes may occur suddenly after a traumatic event for a child, our world also opens up the possibility of bringing about further change.

Even though people often act habitually (Dewey, 1922/2007), the changing world presents obstacles to activities and well-being. As part of this world, humans also have the natural capacity to lead change and resolve issues through the processes of mindful inquiry and action.

The mind is within the world as a part of the latter's own ongoing process. It is marked off as mind by the fact that wherever it is found, changes take place in a directed way, so that a movement in a definite one-way sense—from the doubtful and confused to the clear, resolved, and settled takes place. From knowing as an outside beholding to knowing as an active participant in the drama of an on-moving world. (Dewey, 1929/1988, p. 232)

Transaction

An important notion that derives from Dewey's conceptualisation of a connected and continuous, but changing world is that of transaction. Mentioned in other earlier texts, transaction is discussed by Dewey in greatest depth in his final publication, which was undertaken with Arthur Bentley (Dewey & Bentley, 1949c). In this text, transaction is the term used to describe the inquiry-based need for full observation and exploration of the two-way changes as they occur when people act in connection with their context. "Transaction" is differentiated from the term "interaction," where entities are viewed as separate and one entity may be seen as affecting another only in a single moment of time (Dewey & Bentley, 1949a). "There is no such thing as an interaction that is merely a one way movement" (Dewey, 1939/1988, p. 110). The changes that come about with events such as a brain injury are always connected with other aspects of the world. Dewey's philosophy reminds us that it is necessary to consider how these changes might also affect and change others who participate along with a child in their world. Dewey explained the concept of transaction as follows:

... human life itself, both severally and collectively, consists of transactions in which human beings partake together with non-human beings, so that without this togetherness of human and non-human partakers we could not even stay alive, to say nothing of accomplishing anything. From birth to death every human being is a Party, so that neither he nor anything done or suffered can possibly be understood when it is separated from the fact of participation in an extensive body of transactions—to which a given human being may contribute and which he modifies, but only in virtue of being a partaker in them. (1949, p. 271)

For humans, the ability to communicate using symbolic information plays a central role in this exchange process. Communication enables people to share in each other's experiences, and to make connections with past, present, and future, supporting cooperation and changes in understandings. Whilst children's communication may be impaired after a TBI, this notion suggests that the exchange of information that occurs through communication and participation in shared occupation will play an essential role in helping adjustment to changes and understandings about how to contribute together. "The heart of language is communication; the establishment of cooperation in an activity in which there are partners, and in which the activity of each is modified and regulated by partnership" (Dewey, 1925/1981, p. 141).

Inquiry

Transactions are at the heart of Dewey's conceptualization of inquiry. He defined inquiry as "the controlled or directed transformation of an indeterminate situation into one that is so determinate in its constituent distinctions and relations as to convert the elements of the original situation into a unified whole" (Dewey, 1938/2008b, p. 108). The process of inquiry changes and evolves over time, and is seen as making change both to the inquirer and the situation. Dewey did not argue for a particular type of inquiry, instead proposing that it is an activity undertaken by humans to overcome barriers they encounter. Rather, the pattern of inquiry people adopt is guided by their knowledge about the relative effectiveness of previous types of inquiries used for gaining particular results.

Although scientific inquiry addresses different types of problems, and uses some different tools, it is seen as involving a similar pattern to that used in the common-sense inquiries carried out by people as they go about their day to day occupations. The pattern of inquiry proposed by Dewey is "progressive" (1938/2008b, p. 113) and cyclical, and involves:

- An "indeterminate situation" ((Dewey, 1938/2008b, p. 109), which is a situation that provokes doubt or uncertainty as to how to progress;
- Identifying that the situation is problematic, that it requires an inquiry in order that it may be addressed, and establishing the characteristics of the problem;
- Determining a solution to the problem. This includes a movement back and forth between observation of the facts of the situation that can be taken as settled and, correspondingly, generating ideas about possible solutions;
- Using reasoning as to what will happen if particular solutions are implemented, and which of these is more relevant;
- Execution of a particular solution and observations as to the outcomes.

Learning

The process of transaction is also essential to learning. "Only by direct active participation in the transactions of living does anyone become familiarly acquainted with other human beings and with 'things' that make up the world" (Dewey, 1925/1981, p. 272). Consistent with Dewey's recognition of continuity over time, learning is processual; that is, learning is the catalyst for further activity and inquiry, leading to further learning. Limiting children's opportunities to transact with their environment is therefore a barrier to ongoing learning and development. "Narrowing of the medium is

the direct source of all unnecessary impoverishment in human living” (Dewey, 1949, p. 272).

Although Dewey was a strong advocate of occupation-focused learning, in conjunction with this he also emphasized the physical and social environment, stressing the importance of learning activities having practical meaning for children, through connection with interests and experiences that derive from their community.

An experience is always what it is because of a transaction taking place between an individual and what, at the time, constitutes his environment, whether the latter consists of persons with whom he is talking about some topic or event, the subject talked about being also part of the situation; or the toys with which he is playing; the book he is reading (in which his enviroing conditions at the time may be England or ancient Greece or an imaginary region); or the materials of an experiment he is performing. The environment, in other words, is whatever conditions interact with personal needs, desires, purposes, and capacities to create the experience which is had. (Dewey, 1938/2008a, p. 25)

When children engage in and experience meaningful activities and meet challenges during those activities, there is a shift in their understandings as well as in the learning context. Environments and activities that are of interest to the children, the changes they see they can bring about in the environment, and positive experiences with that environment, support children to engage in ongoing learning—they learn how to learn (Dewey, 1938/2008a).

Democracy

Democracy was viewed by Dewey as a context which can maximize learning, as it enables participation, free exchange of information, and changes in understanding. It is defined in his philosophy as “a way of life controlled by a working faith in the possibilities of human nature” (Dewey, 1939/1998, p. 341). Dewey was unapologetic for his beliefs. In his writings, democracy is not merely a political ideal, but is seen as a way of living and acting. A democratic community recognizes the potential of all its members. Individuals within that community have a responsibility to act in supporting all to reach their potential. Democratic beliefs are “insincere” if

in our daily walk and conversation, we are moved by racial, color or other class prejudice; indeed by anything save a generous belief in their possibilities as human beings, a belief which brings with it the need for

providing conditions which will enable these capacities to reach fulfilment.

(Dewey, 1939/1998, p. 341)

Dewey therefore anchored democracy firmly with notions of shared activity, experience, open communication, and transaction. In this way, learning and growth are made possible. A community which welcomes diversity, and which facilitates free exchange of experiences and ideas, including those of the more vulnerable, is necessary to the well-being of all of its members.

To cooperate by giving differences a chance to show themselves because of the belief that the expression of difference is not only a right of the other persons but is a means of enriching one's own life-experience, is inherent in the democratic personal way of life. (Dewey, 1939/1998, p. 342)

Summary

This chapter has outlined the pragmatist philosophical understandings that informed my practice inquiry into Aotearoa New Zealand children's participation after TBI. The path by which I came to Dewey's philosophy and my resolution of ambiguities found during early readings of the philosophy have been described. Key aspects of John Dewey's pragmatist philosophy that gave direction to the study have been explained. The next chapter reviews the extant literature about participation for children after TBI. Guided by Dewey's argument that humans should be considered in continuity with a changing world, the review does not limit itself to information about the children, but also draws on literature that contributes knowledge about the contexts with which they participate, and changes that occur.

Chapter Three

Review of the Literature: Participation for Children after TBI

The previous chapter explained the aspects of John Dewey's pragmatist philosophical understandings that resonated with my understandings about the study. Dewey recognized the contribution made by prior knowledge to people's understandings about problematic situations, such as the practice issue I faced. However, he also warned of the need to treat such information thoughtfully.

While the direct use of objects, factual and conceptual, which have been determined in the course of resolving prior problematic situations is of indispensable practical value in the conduct of further inquiries, such objects are not exempt in new inquiries from need for reexamination and reconstitution. (Dewey, 1938/2008b, p. 143)

Therefore, before undertaking the study, prior knowledge was sought and critically considered. This helped to clarify my understandings about the situation facing children with TBI when they come to participate with their communities. The information confirmed the need for the study, and identified some key points to be addressed by the study. Over the course of the study, the information in the review was added to and refined. This chapter describes that review.

Purpose of the Review and Definition of Terms

The present chapter critically reviews the literature to describe what is currently known about participation for Aotearoa New Zealand children after a TBI, and what is known of the facilitators and barriers to their participation. As described in Chapter One, for the purposes of this review, participation was defined as meaningful and satisfactory involvement in a life situation, and was seen as encompassing a "societal perspective of functioning" (WHO, 2001, p. 213).

Search Strategy

The search for literature began early when the study proposal was first developed in 2007, and was structured along two broad avenues. Firstly, literature was sought about participation for children with disabilities. Although this identified some general themes, most of the literature involved children with physical disabilities, and could not fully illuminate the participation of children with TBI, many of whom experience significant cognitive and behavioral difficulties (Ylvisaker, 1998) which may affect participation.

Secondly, literature was sought about children with brain injury. The broader term *brain injury* was deliberately employed. Although the types and locations of traumatic damage to children's brain structures have some unique features (Margulies & Coats, 2010; Prins et al., 2010), and the Aotearoa New Zealand rehabilitation service provision context differs for such injuries, it was reasoned that the review, which was focused on participation, would still be usefully informed by studies that also involved children with brain injuries from non-traumatic causes. Much of the literature obtained this way was directed at the effect of the injury on children's body functions (WHO, 2001), such as intelligence, attention, memory, or executive function. However studies were located that contributed some information about children's participation from a behavioral perspective, and a small number of studies were found about participation as defined by the ICF. Manual searches of references listed in articles further added to the information obtained.

In 2012, as the study drew to completion, the literature was updated using searches that were more focused. At this point, literature addressing activities and participation of children with brain injury was specifically sought. Guided by the ICF definition of participation, which indicates its socially situated nature (WHO, 2001), this literature was supplemented with studies exploring social outcomes for children.

Dewey's philosophical perspective prompted the need to recognize and attend to the connection and continuity between people and context (Dewey, 1925/1981). Responding to this, and noting concerns raised in earlier literature about social barriers to children's participation, a final search was undertaken for literature that described the experiences of parents, siblings, educators, and peers after a child sustains a brain injury.

Focusing the Review

Given the large amount of literature retrieved, further focus was required. The review therefore emphasizes primary and secondary research articles. Where research articles were retrieved that addressed a broad range of outcomes for children, information was only used that was relevant to participation in activities rather than the changes in children's body functions. The focus was likewise kept on participation in community settings as opposed to hospital and rehabilitation settings.

Discussion was restricted to studies involving children or adolescents, recognizing that information about adolescent populations may help inform understandings about children, but that adult populations are likely to reflect different

participation issues (WHO, 2007). Studies involving both adults and children which fail to tease out child-specific issues were excluded from the review. Because the present research was focused on children with moderate to severe TBI, literature that only involved children with mild brain injury was also excluded.

Studies of interventions that are intended to generate changes in participation are discussed here in general terms only, as these studies were systematically reviewed in Phase Two of the study. That review is reported in Chapters Seven and Eight. Few studies investigate participation outcomes for Aotearoa New Zealand children who sustain brain injuries, therefore discussion is informed for the most part by the international literature.

Sequence of the Review

The tools people use when they seek information about an indeterminate situation are interconnected with the conditions, goals, and outcomes of their inquiry (Dewey, 1949/2008, 1938/2008b). Therefore, as a means of supporting a logical progression of ideas, discussion in this review is guided by the various areas of focus, and the methodologies and instruments adopted by researchers. The review commences with key findings about participation for children with disabilities. This sets the scene for the review by highlighting a number of key concerns, some of which are reflected in studies of children with TBI.

Next the focus turns to studies which used quantitative means to investigate children's participation outcomes after a brain injury. Outcomes are considered from behavioral, social, then participation perspectives. Influences on children's participation are outlined, and comparisons are made with the participation of children with other conditions.

At this point, a summary of qualitative research is presented, which draws together and adds to some of the other understandings, by describing the participation experiences of the children and young people. Literature is then introduced which provides contextual information about those with whom children participate after their injury, including their family, peers, educators, and rehabilitation service providers. The review concludes with a summary of the state of knowledge with regards to children's participation after TBI, drawing attention to gaps in that knowledge. The content and sequence of the topics addressed in the chapter are illustrated in Figure 3.1.

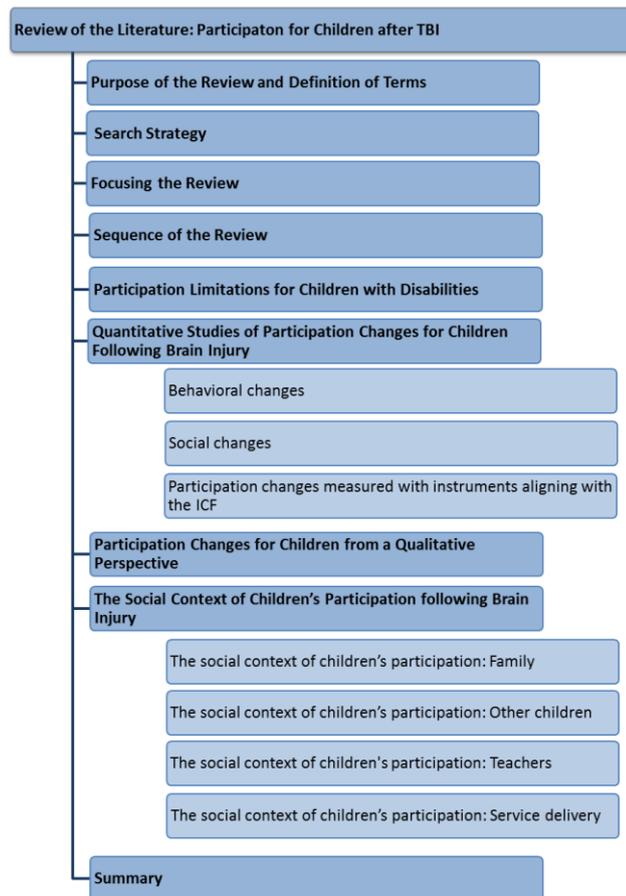


Figure 3.1: Contents and Sequence of Chapter Three

Participation Limitations for Children with Disabilities

A body of research which has investigated participation for children with a range of disabilities informs us that those children participate less frequently, in a narrower range of activities and contexts, and with fewer people than their typically developing peers (G. Bedell et al., 2013; Bendixen, Senesac, Lott, & Vandenborne, 2012; Calley et al., 2012; W. Coster et al., 2011; W. Coster et al., 2013; Engel-Yeger, Jarus, Anaby, & Law, 2009; Hilton, Crouch, & Israel, 2008; M. Law et al., 2013; Poulsen, Ziviani, Cuskelly, & Smith, 2007; Schenker, Coster, & Parush, 2005). Internationally, although involvement in activities alongside peers stands out consistently as being important to children with disabilities, social aspects of their participation are often compromised (G. Bedell et al., 2013; Bendixen et al., 2012; W. Coster et al., 2013; Engel-Yeger et al., 2009; Heah et al., 2007; Hilton et al., 2008; Kramer, Olsen, Mermelstein, Balcells, & Liljenquist, 2012; Liptak, Kennedy, & Dosa, 2011; Missiuna, Moll, King, King, & Law, 2007; O'Brien, Bergeron, Duprey, Olver, & Onge, 2009; Pereira, la Cour, Jonsson, & Hemmingsson, 2010; Pitt & Curtin, 2004;

Poon, 2011; Poulsen et al., 2007; Raghavendra, Olsson, Sampson, McInerney, & Connell, 2012; Shikako-Thomas, Majnemer, Law, & Lach, 2008; Shikako-Thomas et al., 2013). Participation in physical recreation such as sports, and unstructured play activities outside the home is typically problematic for children with disabilities (G. Bedell et al., 2013; Bendixen et al., 2012; Calley et al., 2012; Hilton et al., 2008; Magalhães, Cardoso, & Missiuna, 2011; Majnemer et al., 2009; Missiuna et al., 2007; Poulsen et al., 2007; Shikako-Thomas et al., 2008; Simmeonsson, Carlson, Huntington, Sturtz McMillen, & Lytle Brent, 2001). In line with such findings, studies have suggested that these children have somewhat better levels of participation in solitary, less active recreational activities in the home setting (Engel-Yeger et al., 2009; Harding et al., 2009; Hilton et al., 2008; Imms, Reilly, Carlin, & Dodd, 2009; M. Law et al., 2013; Majnemer et al., 2009; Shikako-Thomas et al., 2008). Concerningly, at school, at home, and in the community, for those activities in which children with disabilities do participate, their level of involvement appears to be significantly less than that of their non-disabled peers (G. Bedell et al., 2013; W. Coster et al., 2013; M. Law et al., 2013). Of note, in the period of time spanned by this body of research, little appears to have changed; participation limitations that were reported earlier (Egilson & Traustadottir, 2009; Eriksson, Welander, & Granlund, 2007; Schenker et al., 2005; Simmeonsson et al., 2001) still appear to be the case today (G. Bedell et al., 2013; W. Coster et al., 2013; M. Law et al., 2013). Although parents do not necessarily seek more frequent participation for their children (G. M. Bedell, Khetani, Cousins, Coster, & Law, 2011), recent study findings reflect a situation that remains less than adequate, with parents frequently reporting a desire for change (G. Bedell et al., 2013; W. Coster et al., 2013; M. Law et al., 2013).

Some exceptions to these patterns have been identified (Hammal, 2004; Michelsen et al., 2009), thought to result from variability in the extent to which different countries act to include people with disabilities into society (Anaby et al., 2013). Nonetheless, an Aotearoa New Zealand study based on government census statistics is consistent with findings of participation limitations, reporting that almost 70% of children with physical disabilities encountered problems taking part at school, including participation in areas such as physical education, school excursions and camps, playground interactions, and friendships (P. Clark & MacArthur, 2008).

One general point that emerges from literature is the presence of age and gender differences. The gap between levels of participation for children with disabilities and

their peers appears greater for older children in some studies (Bendixen et al., 2012; Heah et al., 2007; Hilton et al., 2008; M. Law et al., 2006; M Law, Petrenchik, King, & Hurley, 2007; Missiuna et al., 2007). Older children with disabilities do not demonstrate the increases in social activities experienced by their non-disabled peers, and show less enjoyment of those activities (G. King, Law, Hurley, Petrenchik, & Schwellnus, 2010). Further, younger children with disabilities have been found to have more intense participation than their older counterparts, (Bendixen et al., 2012; Palisano et al., 2011; Shikako-Thomas et al., 2008), particularly in active physical activities (Bendixen et al., 2012; Majnemer et al., 2009; Michelsen et al., 2009). While boys have significantly greater enjoyment and involvement in physical activities, girls show more enjoyment and involvement in social, skill-based and self-improvement activities (G. King et al., 2010; G. A. King et al., 2007; M. Law et al., 2006; Majnemer et al., 2009; Michelsen et al., 2009; Shikako-Thomas et al., 2008; Shikako-Thomas et al., 2013).

As might be expected, children's levels of impairment and their functional performance affect their participation (Beckung & Hagberg, 2002; Bult, Verschuren, Jongmans, Lindeman, & Ketelaar, 2011; Egilson & Hemmingsson, 2009; R. Forsyth, Colver, Alvanides, Woolley, & Lowe, 2007; Hammal, 2004; Heah et al., 2007; Hilton et al., 2008; Imms et al., 2009; G. King et al., 2006; G. King et al., 2003; Lawlor, Mihaylov, Welsh, Jarvis, & Colver, 2006; Majnemer et al., 2009; Mandich, Polatajko, & Rodger, 2003; Michelsen et al., 2009; Missiuna et al., 2007; Mulcahey et al., 2010; Oates, Bebbington, Bourke, Girdler, & Leonard, 2011; Palisano et al., 2011; Pereira et al., 2010; Poulsen et al., 2007; Shikako-Thomas et al., 2008; Shikako-Thomas et al., 2013; Simmeonsson et al., 2001). Beyond their performance however, children's perceptions as to their competence (G. A. King et al., 2007), their preferences, and their perceptions of their environment, are also essential to acknowledge when gaining a picture of their participation (Eriksson, 2005; Harding et al., 2009; Heah et al., 2007; Hemmingsson, Borell, & Gustavsson, 2003; Imms et al., 2009; G. King et al., 2006; G. King et al., 2003; Majnemer et al., 2009; Palisano et al., 2011; Pereira et al., 2010).

In addition to factors intrinsic to the children, and aligning with the theoretical assumptions of the ICF (WHO, 2001), the environment also influences their participation by presenting a range of barriers and supports, although it is uncertain whether these operate directly, or indirectly (Anaby et al., 2014; G. King et al., 2006). The physical environment often poses barriers to participation in terms of accessibility and availability of occupations (Anaby et al., 2014; G. Bedell et al., 2013; Colver et al.,

2012; W. Coster et al., 2013; Egilson & Traustadottir, 2009; Heah et al., 2007; Imms, 2008; G. King et al., 2006; Pereira et al., 2010; Piškur et al., 2012; Pitt & Curtin, 2004; Shikako-Thomas et al., 2008; Simmeonsson et al., 2001; von Benzon, 2010), as are tasks which present unreasonable levels of challenge (G. Bedell et al., 2013; W. Coster et al., 2013; Imms, 2008; G. King et al., 2006; M. Law et al., 2013). Of significance however, some studies note that it is people's willingness to make changes that mediates the effects of physical and occupational barriers (Anaby et al., 2013; Imms, 2008; M. Law et al., 1999), with the social environment consistently identified as a key influence (Anaby et al., 2013; G. Bedell et al., 2013; Colver et al., 2012; Egilson & Hemmingsson, 2009; Egilson & Traustadottir, 2009; R. Forsyth et al., 2007; Harding et al., 2009; Kramer et al., 2012; M. Law et al., 1999; Lawlor et al., 2006; Mihaylov, Jarvis, Colver, & Beresford, 2004; Missiuna et al., 2007; Palisano et al., 2011; Pereira et al., 2010; Pitt & Curtin, 2004; Shikako-Thomas et al., 2008; von Benzon, 2010). In particular, the family social environment exerts influence through factors such as provision of support, family cohesiveness, financial pressures, and the extent of wider family involvement in activities (Anaby et al., 2013; W. Coster et al., 2013; Heah et al., 2007; G. King et al., 2003; G. A. King et al., 2007; M. Law et al., 2006; Liptak et al., 2011; Oates et al., 2011; Palisano et al., 2011; Shikako-Thomas et al., 2008). Of relevance to the present study where rehabilitation is perhaps more readily available, families have frequently identified policies as a barrier to participation, with concomitant concerns over access to quality resources and services (Anaby et al., 2013; G. Bedell et al., 2013; Colver et al., 2012; W. Coster et al., 2013; R. Forsyth et al., 2007; Harding et al., 2009; Kramer et al., 2012; M. Law et al., 2013; M. Law et al., 1999; Mihaylov et al., 2004; O'Brien et al., 2009; Pitt & Curtin, 2004; Raghavendra et al., 2012; von Benzon, 2010).

Although this body of literature points to some general trends, the majority of both earlier and recent studies of participation for children with disabilities have focused on populations of children with movement disorders. A large study in Canada recently identified differences in participation according to the types of impairments experienced by children with neurodevelopmental conditions (Mâsse, Miller, Shen, Schiariti, & Roxborough, 2013). Similar effects have been reported by others with respect to the type and level of function experienced by children (Anaby et al., 2014; G. Bedell, 2009; M. Law et al., 2004). As noted by Anaby et al. (2013), studies of participation for children with physical disabilities may lack applicability to those with conditions

involving difficulty with cognition, communication, and behavior; problems often identified for children who have a TBI (V. Anderson, Spencer-Smith, et al., 2011; Egilson & Hemmingsson, 2009; Haley, Dumas, Rabin, & Ni, 2003; Mâsse et al., 2013; Russell et al., 1998; Yeates et al., 2004; Ylvisaker, 1998). Discussion in the present review therefore turns next to the smaller body of literature that is focused on participation for children with brain injury.

Studies that inform us about participation for this group have been undertaken using both quantitative and qualitative methodologies. Overall, measures used in quantitative studies are robust, and some concerns for behavioral aspects of the children's participation are highlighted. However the ability to draw conclusions across studies is also hampered by variability in findings. Such differences reflect heterogeneity in the way participation measures have been operationalized, limitations in sample sizes, short time-frames for follow-up, and failure to account for the effects of pre-injury function, or contextual factors. Although qualitative studies provide a more detailed picture of the children's participation, these are few in number, and most of these have focused on adolescents, limiting the understandings about participation for those who are younger. Such studies have seldom gathered data directly from the children's perspectives. Studies using quantitative methodologies are discussed first.

Quantitative Studies of Participation Changes for Children Following Brain Injury

A number of studies have used quantitative methods to evaluate changes to children's participation. The measures used are generally robust. However there is variability in the way measurements of participation are operationalized. Limitations also result in a number of studies from small sample sizes, and short time-frames for follow-up. Variability in findings complicates the conclusions that can be drawn.

Behavioral changes.

Many studies carried out with children with brain injury emphasize neurobehavioral outcomes, and function in self-cares, motor function, communication, and academic activities. Notwithstanding a focus on performance of activities rather than "involvement in a life situation" (WHO, 2007, p. 229), some of these studies provide initial insights into how children's participation might change after their injury.

A number of studies carried out in the United States and Australia have employed the Vineland Adaptive Behavior Scales (VABS; Sparrow, Balla, & Cicchetti,

1984) to assess children after TBI (V. Anderson & Catroppa, 2005; V. Anderson, Le Brocque, et al., 2012; V. A. Anderson et al., 2005; Arroyos-Jurado, Paulsen, Merrell, Lindgren, & Max, 2000; Arsanow, Satz, Light, Lewis, & Neumann, 1991; Catroppa et al., 2008; T. B. Fay et al., 2009; Fletcher, Ewing-Cobbs, Miner, Levin, & Eisenberg, 1990; Max, Koele, et al., 1998; Micklewright, King, O'Toole, Henrich, & Floyd, 2012; H. G. Taylor et al., 1999; H. G. Taylor et al., 2002; Yeates et al., 1997). The VABS define adaptive behavior as “performance of the daily activities required for personal and social sufficiency” (p. 6). The focus is on a child’s “typical performance, not ability” (p. 6) from the perspective of the parent(s) and/or teacher. Given these definitions, the scales have some congruence with the notion of participation contained in the ICF (G. Bedell & Coster, 2008; WHO, 2001). Using the VABS, a child’s level of function is determined by comparing their performance with age-normed data (p. 6). Evidence for the validity and reliability of the scales is outlined in the manual (Sparrow et al., 1984), and their wide application in multiple studies involving children with TBI suggests they are sensitive to changes in adaptive function for this group.

Studies using the VABS are characterized by differences in their objectives, populations, time-frames, and controls, and in the variables addressed (V. Anderson & Catroppa, 2005). In spite of this variation, it is typically found that children with TBI have deficits relative to pre-injury function and/or controls in areas such as (a) receptive, expressive and written communication; (b) personal, domestic and community living skills; (c) socialization with others and use of play/leisure time; and (d) total adaptive behavior (Sparrow et al., 1984). Painting a somewhat brighter picture however, T. B. Fay et al. (2009) queried whether typical methods of data analysis, which establish statistical significance on the basis of “mean differences between groups” (p. 272), accurately capture variability observed across different children, an acknowledged feature of TBI (V. Anderson, Spencer-Smith, et al., 2011; Ylvisaker, Shaughnessy, & Greathouse, 2002). Instead, by exploring the changing patterns of impairments in individual children, this group found that 48 to 67% of children with severe injuries experienced no impairments in any domain, including adaptive functioning.

Nonetheless, more severe injuries are typically related to lower adaptive function (V. Anderson & Catroppa, 2005; V. Anderson, Le Brocque, et al., 2012; V. A. Anderson et al., 2005; Arroyos-Jurado et al., 2000; Arsanow et al., 1991; Catroppa et al., 2008; T. B. Fay et al., 2009; Fletcher et al., 1990; Max, Koele, et al., 1998; H. G.

Taylor et al., 1999; H. G. Taylor et al., 2002; Yeates et al., 1997), this finding aligning with studies of children with general disabilities which have identified that levels of impairment influence participation. Of note, the recent study by V. Anderson et al. (2012) found that injury severity was only related to the socialization domain of the VABS. Particular concerns over the impact of a brain injury on social aspects of children's participation are apparent in other literature (Bohnert, Parker, & Warschausky, 1997; G. C. Fay et al., 1994; Hawley et al., 2002; Hermans, Winkens, Te Winkel-Witlox, & van Iperen, 2012; Jaffe, Polissar, Fay, & Liao, 1995; Prigatano & Gray, 2008; Prigatano & Gray, 2007; Prigatano & Gupta, 2006; Sharp, Bye, Llewellyn, & Cusick, 2006; Vilela, Phillips, & Minnes, 2008; Yeates et al., 2004). It may be that Anderson et al.'s (2012) result simply reflects the short-term (6 month) follow-up used, given that time since injury has also been shown to influence adaptive behavior, with longer time-frames post-injury showing deteriorating adaptive function (V. Anderson & Catroppa, 2005; V. A. Anderson et al., 2005; Catroppa et al., 2008; Fletcher et al., 1990).

Apart from Max et al.'s (1998) study, which involved a small sample ($n = 45$), studies of adaptive behavior for children with brain injury have not shown significant effects exerted by impairments in functions such as intelligence, cognitive abilities, or academic performance. This is inconsistent with study findings for children with other disabilities, but possibly reflects the focus of the wider literature on children with physical disabilities, or perhaps the use of different assessment instruments. However the studies do tell us that participation outcomes as measured by the VABS are not only influenced by injury severity and time since injury, but by a combination of other factors such as pre-injury function (V. Anderson & Catroppa, 2005; V. Anderson, Le Brocque, et al., 2012; Arroyos-Jurado et al., 2000; Catroppa et al., 2008; T. B. Fay et al., 2009; H. G. Taylor et al., 2002), age at injury (V. Anderson, Le Brocque, et al., 2012; Yeates et al., 1997), ethnicity (Yeates et al., 1997), and, aligning with the wider pediatric disability literature, the family context (V. Anderson, Le Brocque, et al., 2012; T. B. Fay et al., 2009; Yeates et al., 1997).

However the influence of family factors, measured according to socio-economic status, family function, and burden or stress, on children's adaptive behavior is by no means clearly established. Two recent Australian studies (V. Anderson, Le Brocque, et al., 2012; Catroppa et al., 2008), and a study in the United States (T. B. Fay et al., 2009) failed to find any significant relationship between family factors and adaptive function.

In fact, rather than exerting a direct influence on adaptive behavior, the family environment is thought to mediate the influence of child factors (e.g. pre-injury function, injury severity, and age) to differentially affect outcomes at different time-points (Nadebaum et al., 2007; Yeates, Taylor, Walz, Stancin, & Wade, 2010).

Another assessment that generates information about behavioral aspects of children's participation, the Child Behavior Checklist (CBCL; Achenbach, 1991), has also been used in a number of studies of children with TBI (V. Anderson, Le Brocque, et al., 2012; Arsanow et al., 1991; G. C. Fay et al., 1994; T. Fay & Barker-Collo, 2003; T. B. Fay et al., 2009; Fletcher et al., 1990; Max, Koele, et al., 1998; J. B. Rivara et al., 1993; J. B. Rivara et al., 1994; Sokol et al., 1996; H. G. Taylor et al., 1999; H. G. Taylor et al., 2001; H. G. Taylor et al., 2002; S. L. Wade, Taylor, et al., 2006; Yeates et al., 1997), including one study conducted in Aotearoa New Zealand (T. Fay & Barker-Collo, 2003). Like the VABS, the CBCL uses normative data. However, it has some different areas of focus, drawing on parent and/or teacher reports of children's problems with behavioral regulation, as well as their involvement and competence in activities across the life areas of sports, leisure, community groups, chores, friendships, and academic subjects (G. Bedell & Coster, 2008). Unfortunately, it is often difficult to draw conclusions about specific concerns for children's participation in studies using the CBCL, due to the lack of detail about scores within the different areas of life, and an emphasis on behavioral concerns rather than involvement in activities. Additionally, some have criticized the CBCL for a lack of sensitivity to subtle changes in behavioral well-being (J. B. Rivara et al., 1994). In general, increased severity of injury is found to be associated with more severe behavior problems, which would seem likely to impact on participation.

One study (G. C. Fay et al., 1994) which used the CBCL does indicate significantly more parent anxiety over children's school performance, socialization, social competence, and behavior after brain injury, highlighting concerns for social aspects of participation. These findings were endorsed by Prigatano and Gray's later (2007) qualitative analysis of parent responses to CBCL categories, which similarly flagged parents' worries over their children's academic performance, angry or apathetic behaviors, and social integration. Of interest, a single study using the CBCL reported that children with severe injuries had significantly less involvement in athletic and recreational activities than children with mild or moderate injuries, indicative of possible reductions in leisure participation with peers (Fletcher et al., 1990).

As with studies using the VABS, family context has been considered in some of the studies using the CBCL, with adverse pre-injury and post-injury family function, and post-injury family stress predicting poor academic performance and behavioral difficulties (Max, Koele, et al., 1998; J. B. Rivara et al., 1993; J. B. Rivara et al., 1994; H. G. Taylor et al., 2001; Yeates et al., 1997). Corresponding with findings about the influence of family function and stress, post-injury progress in academic performance and socialization were also worse for children in families with socioeconomic disadvantage (Max, Koele, et al., 1998; H. G. Taylor et al., 2002).

It should be recognized that studies which use measures of behavior such as the VABS and the CBCL typically exclude children with a history of developmental delays, and behavioral or psychiatric disturbances, therefore the findings may be less applicable to those children should they sustain a brain injury (e. g. McKinlay, McLellan, & Daffue, 2012). Collectively, what such studies do highlight is the need to recognize the effects of different variables such as injury severity, time since injury, pre-injury function, family context, and ethnicity when undertaking research into children's participation outcomes (J. P. Gerring & Wade, 2012; H. G. Taylor et al., 2002; Yeates et al., 1997).

Another consideration when using the VABS and the CBCL is that aspects of the physical and social environment which might influence participation (e.g. peer attitudes, physical access, or provision of rehabilitation services) are not considered unless additional measures are implemented by the researcher. Furthermore, because the VABS and the CBCL were developed to quantify actual task performance relative to normative data (Achenbach, 1991; Sparrow et al., 1984), little understanding is gained through these studies of qualitative and social aspects of children's participation as it occurs in context. For example, a child might perform written tasks very poorly in the classroom, but the child and his or her parents may still be satisfied, and the child actively involved and learning with other students in a group task by helping color a chart and contributing verbally.

Moving away from the behavioral view of participation promoted by the VABS and the CBCL, another group of studies have specifically addressed social outcomes for children after brain injury, exploring concepts such as socialization, integration, and friendships. Whilst more research is required in order to adequately understand the issues (Rosema, Crowe, & Anderson, 2012), the studies addressing these social aspects

of children's recovery do provide some further information about the societal dimensions of children's participation, and are overviewed next.

Social changes.

Studies which address social difficulties for children after TBI indicate that these aspects of their participation are likely to be affected (Hermans et al., 2012). Using the socialization scale of the VABS, Yeates et al. (2004) found 109 school-age children with TBI had worse socialization outcomes than children with orthopedic injuries alone, these difficulties persisting at least 4 years post injury. More severe injuries were associated with worse social function, and this relationship was further influenced by the family socioeconomic status and function. Socialization was also significantly predicted by children's pragmatic language and executive function. Although the influence of the family environment was taken into account, the influence of other social contexts such as teachers or peers in children's lives was not addressed in the study.

Similar findings have been obtained in relation to children's social integration (Prigatano & Gray, 2008), with parent ratings of social integration for 80 children with TBI lower than the ratings for controls, and correlating significantly with severity of injury. Social integration also correlated modestly with a pre-injury history of special education services, and with numbers of friends (Prigatano & Gray, 2008). Further to this, children injured at a younger age appear likely to have worse social integration in early adulthood than those injured in late adolescence (Donders & Warschausky, 2007).

Friendships have been nominated as a concern for children in some outcomes studies (Hawley et al., 2002; Jaffe et al., 1995). In 1997, Bohnert, Parker, and Warschausky investigated several aspects of friendship with 22 children with TBI and their parents, using matched control data from previous data sets. Children with brain injury were most concerned about social aspects of their participation, whilst parents were more concerned about their children's health. Neither was concerned about participation in sports. Encouragingly, no differences were found between the children and control data for friendship numbers, duration, contacts, or for more qualitative aspects of friendship such as companionship. This was a small sample however ($n = 22$), and as current age does not appear to have been entered into this analysis, it is unclear whether concerns were resulting from the injuries, or whether they instead reflected the levels of children's social development.

In contrast, the more recent study by Prigitano and Gupta (2006) drew on data relating to friendships from the CBCL, and from parent report, finding that children with more severe injuries have fewer close friends in the initial 12–18 months following injury than those with milder or orthopedic injuries. Unfortunately the findings of this study are also confounded, in this case by failure to gather data about pre-morbid friendships. In addition, the objective of the study to determine the presence of a dose-response relationship between TBI severity and friend numbers limits the extent of information that might have been generated about more qualitative aspects of friendship. It is possible, for example, that children are less concerned by numbers of friends, and more concerned by the quality of friendships, or activities that they are involved in together.

Congruent with studies which identify concerns for behavioral aspects of children's participation after brain injury, the findings from these studies of children's social outcomes do suggest similar problems. At this stage however, the degree to which such findings can be trusted is limited by gaps in study designs, small samples, and the small number of studies conducted. Furthermore, because the data lacks information about the context of activities in which social interactions and friendships occur, the ability of such studies to fully inform our understandings about participation is again limited.

Several more recent quantitative studies have specifically investigated children's participation after TBI, using instruments that align more closely with the wider WHO (2001) definition of participation. Given their explicit focus on participation, these studies are considered next in more depth.

Participation changes measured with instruments aligning with the ICF.

The Children's Assessment of Participation and Enjoyment (CAPE; G. King et al., 2004; G. A. King et al., 2007) has recently been used to investigate participation changes in a Canadian cohort of children with ABI. The intensity, diversity, and enjoyment of their out-of-school activities over the first 12 months after recommencing school was measured (Anaby, Law, Hanna, & Dematteo, 2012; M. Law, Anaby, Dematteo, & Hanna, 2011). In Law et al.'s first exploratory study (2011) with the group, their out-of-school participation was found to have less intensity and diversity across recreational, active physical, self-improvement, and skill based activity types than a control group of peers without disabilities ($p < 0.001$), although the effect size

was analyzed as small to moderate only. An exception was the area of social activities, in which children with brain injury had similar levels of intensity to their peers. This may be explained by the type of activities the CAPE defines as social, which are more sedentary in nature, and perhaps more suited to children with increased fatigue after a brain injury. Types of activities participated in were similar for both groups however, emphasizing social and recreational activities, and are in line with trends identified in studies of children with other conditions (Engel-Yeger et al., 2009; Harding et al., 2009; Majnemer et al., 2009). Reasons underlying the similarity between the groups have not been identified, although, as suggested by Anaby and colleagues (2012) in their later publication, these indoor activities may have reflected weather patterns over the assessment period.

Surprisingly, at this early stage of recovery, activity patterns identified for children with brain injury were unrelated to the severity of their injuries (M. Law et al., 2011). However, the later publication by this group (Anaby et al., 2012) differed, finding injury severity differentially predicted shifts in participation intensity over time for recreational, physical, and social types of activity. Diversity of participation in skill-based areas was predicted by family function, whilst family income affected shifts in participation intensity for the area of recreation.

Although the intent of these studies was exploratory and descriptive, several limitations detract from the credibility and utility of these findings, co-incidentally highlighting some of the challenges posed by research in this area. Firstly, because the authors do not specify the pre-injury participation status of the children (V. Anderson, Le Brocque, et al., 2012; Catroppa et al., 2008; Swaine, 2012), it is difficult to conclude how much of the difference was a direct result of the injury (J. P. Gerring & Wade, 2012). This may have explained the low to moderate effect size. Secondly, there were very low numbers of children with moderate and severe injuries (only 35 out of 135 for the injury group), perhaps explaining the discrepancy between the studies in relation to injury severity, and between the 2011 study and other research, which typically shows injury severity is one of the main variables affecting outcome (V. Anderson & Catroppa, 2005; V. Anderson, Le Brocque, et al., 2012; V. A. Anderson et al., 2005; Arroyos-Jurado et al., 2000; Arsanow et al., 1991; Catroppa et al., 2008; G. C. Fay et al., 1994; T. B. Fay et al., 2009; Fletcher et al., 1990; Max, Koele, et al., 1998; J. B. Rivara et al., 1993; J. B. Rivara et al., 1994; Yeates et al., 1997). Third, the baseline for commencing assessments was time of starting school. Although 80% of children

attended school immediately after discharge, duration of hospital stay ranged from 1–89 days, therefore variability in the time since injury and natural recovery may have influenced the findings. Finally, although the length of hospital stay was addressed in the analysis, intervention in the community was not, which, given concerns over the impact of service-availability on participation in this same country (M. Law et al., 1999), is also a potential source of bias and equally limits the generalizability of the study.

Description of participation outcomes for children with brain injury has also been furnished by Bedell in the United States, who has been proactive in developing instruments to evaluate children's participation in rehabilitation and community settings. Initially the Clinical Performance Measure for Paediatric Brain Injury, which subsequently became the Pediatric Functioning after Brain Injury (FABI) Scales (Smith, Haley, & Coster, 2005), was developed for assessing outcomes during in-patient rehabilitation (G. M. Bedell, Haley, Coster, & Smith, 2002a). The prototype of this instrument was applied retrospectively across eight sites to investigate whether children were ready to cope with participation at the point of discharge (G. M. Bedell, Haley, Coster, & Smith, 2002b). Although limitations in this study should be recognized, such as its retrospective nature and failure to ascertain rater-reliability across sites, results showed only 3–27% of the children were considered by rehabilitation team members to have adequate levels of performance to support participation at discharge. The importance of social aspects of participation is highlighted by the finding that children's social behaviors prior to discharge explained 74% of the variance in participation readiness scores.

Later, another assessment was developed called the Child and Adolescent Scale of Participation (CASP; G. M. Bedell, 2004; G. M. Bedell & Dumas, 2004). The scale addresses participation across contexts of home, school, and community, with parents rating on a 4-point scale the degree to which their children participate in activities compared to their same age peers. Studies conducted as part of the process of establishing the psychometric properties of the scale provide some information about children's participation after ABI, but also highlight some of the complexities associated with researching participation for this population. Findings of these studies are treated cautiously in the following discussion, as it is reported that changes were later made to some of the scales associated with the CASP (G. M. Bedell, 2004).

The CASP was completed in the first instance by parents of 60 children with ABIs. The children were aged 3–21 years, and were between 0.39–6.72 years post-discharge from an inpatient rehabilitation center in the United States (G. M. Bedell, 2004; G. M. Bedell & Dumas, 2004). Data were also gathered about child-related and environmental factors using the Pediatric Evaluation of Disability Inventory (PEDI; Haley, Coster, Ludlow, Haliwanger, & Andrellow, 1992) and two further measures developed by Bedell, the Child and Adolescent Factors Inventory (CAFI) and the Child and Adolescent Scale of Environment (G. M. Bedell, 2004). Children's participation in routines, social play, and structured events such as sport was rated as lower compared to others of the same age (G. M. Bedell & Dumas, 2004), findings that have some congruence with the patterns identified in children with other conditions (G. Bedell et al., 2013; W. Coster et al., 2011; Engel-Yeger et al., 2009; Hilton et al., 2008).

Also echoing the findings of studies of children with other conditions (G. Bedell et al., 2013; Colver et al., 2012; R. Forsyth et al., 2007; Kramer et al., 2012; M. Law et al., 1999; M Law et al., 2007; Lawlor et al., 2006; Mihaylov et al., 2004; Missiuna et al., 2007; O'Brien et al., 2009; Pereira et al., 2010; Pitt & Curtin, 2004; Raghavendra et al., 2012; Shikako-Thomas et al., 2008), parents in Bedell and Dumas's (2004) study identified lack of information, services, and support, and others' attitudes at school and in the community, as some of the main environmental problems, these contexts contrasting with the more supportive home environment (G. M. Bedell & Dumas, 2004). More recent discharge was associated with lower levels of participation and higher levels of service. Moreover, service levels were significantly and negatively associated with participation – that is, those who had more service had less participation, likely reflecting that those with more severe injuries (and who were therefore receiving more services) had more difficulty with participation. Supporting this assumption, children's cognitive-behavioral, social, and self-care function, and length of inpatient rehabilitation, were highly correlated with participation scores (G. M. Bedell & Dumas, 2004). Although age related differences in participation were found, with older children participating more than younger children, it is unclear if this reflected different levels of difficulty within the CASP items (G. M. Bedell, 2004). Fitting with recent findings by Jarus et al. (2010) for children without disability, gender was not related to levels of participation. Race and ethnicity were also unrelated to levels of participation, at variance with findings in Yeates et al.'s earlier, larger study of

children with TBI (1997); this discrepancy potentially reflected differences in the sample used by Bedell and Dumas.

As acknowledged by the authors (2004), the small sample size and the recruitment of participants from only one setting limits the external validity of the study. A lack of information about injury severity adds a further constraint, albeit this gap perhaps reflected challenges in establishing injury severity across the different diagnostic categories included in the study. Although the PEDI and the CAFI provided some indication of children's functional abilities, there has been criticism of the PEDI for a lack of responsiveness to differences in function (Thomas-Stonell, Johnson, Rumney, Wright, & Oddson, 2006).

Resembling limitations in the studies by Anaby et al. (2012) and Law et al. (2011), children's pre-injury levels of participation are not reported either, another variable that may impact the validity of the findings (J. P. Gerring & Wade, 2012; Parkin, Maas, & Rodger, 1996; J. B. Rivara et al., 1994). Some additional concerns are raised in connection with the CASP scale itself. As acknowledged by Galvin, Froude, and McAleer (2010), reliance on parents' perceptions of *other* children's function (against whom parents rate their own child), and on parental knowledge of their child's participation at school (a problem previously identified by Leathem and Body in 1997), may have introduced discrepancies in reporting amongst parents, reducing the reliability of the scale. Likewise, there is a possibility parents were rating their child's *performance* rather than their *involvement*, potentially prompted when they are required to compare their child's participation to that of others (G. Bedell, 2009).

Concerns over relying solely on parent ratings of children's participation were raised with the more recent development of a youth report version of the CASP. A study of this instrument which compared youths' ratings of their own participation to their parents' proxy ratings, found the youths' self-report ratings were significantly higher (McDougall, Bedell, & Wright, 2013). Such findings suggest the benefits of gathering information from different sources to gain a comprehensive picture of participation.

Further validation was later completed on the parent-report CASP instrument with a much larger sample ($n = 313$) from across the United States, Canada, Australia, and Israel, including children with brain injuries, other conditions, and children with no disabilities (G. Bedell, 2009). Although this was a heterogeneous population, the study is discussed in this section, as 56% of the sample comprised children with brain injuries. Heterogeneity was also evident in children's ages, which ranged from 3–22 years, and

(for children with brain injury) in the time since injury, which ranged from 4 months to 21 years. Additionally there was no analysis of race or ethnicity factors due to missing data, and neither are details provided of injury severity, these issues limiting the conclusions which can be drawn with respect to sub-groups of this sample. Nevertheless, the study reported statistically significant differences in the levels of participation between children with and without disabilities. No significant differences were found for children with brain injuries when compared to children with other disabilities, or between children of different ages. The latter finding is at odds with others who, using a different measure, have found developmental variance in participation (M. Law et al., 2006). As with the earlier study (G. M. Bedell & Dumas, 2004), Bedell (2009) found negative correlations between CASP scores and children's impairments in function, and between CASP scores and environmental factors; lower levels of participation related to higher levels of impairment and greater environmental barriers.

The CASP has since been adopted for use in a much larger prospective cohort study over a 3-year time frame in the United States (F. P. Rivara et al., 2011; F. P. Rivara et al., 2012). Children with TBI ($n = 729$ assessed at 3, 12, and 24 months, and $n = 769$ assessed at 36 months), were compared with children who had sustained upper-limb trauma (F. P. Rivara et al., 2012). Despite the limitations of the CASP instrument, findings from Rivara et al.'s studies are relatively robust due to the large sample, inclusion of pre-injury data (albeit this derived from parent/carer recall after the injury), and control of socio-demographic variables including gender, ethnicity, funding source, family income, and parent/carer education status. Severity of injury was identified using Glasgow Coma Scale (GCS) scores (Teasdale & Jennett, 1974), and missing medical data was treated by imputing calculated data. Results show the arm injury control group returned to their pre-injury function as measured by the CASP at 3 months, and children with mild injuries also improved, maintaining and increasing their participation scores. In contrast, participation for children with moderate or severe TBI remained significantly lower than their pre-injury levels at 3, 12, 24, and 36 months, with small improvements at 12 and 24 months only, but no further improvement at 36 months. Data were not obtained regarding service provision, a fact acknowledged by the author, therefore it cannot be known whether intervention for these children was ineffective or whether there was simply a lack of services after discharge.

Results are less conclusive for two smaller Australian studies which also used the CASP. First, the participation of 20 children aged 5–15 years, with moderate to severe ABI (as established by the GCS, Teasdale & Jennett, 1974) was described by Galvin, Froude, and McAleer (2010). It is not stated whether the study involved a subset of the sample used in Bedell's (2009) study, or drew from a different cohort. All children were attending mainstream schools, and time since injury ranged from 4 months to 7 years. Along the lines of Bedell's own studies (G. M. Bedell, 2004; G. M. Bedell & Dumas, 2004), child-related and environmental factors were measured, but there is no information provided about pre-injury function or ethnicity. Between 25 and 75% of children were identified by parents as participating less than their peers across the range of CASP items. Consistent with the results obtained by Bedell and Dumas (2004), children were most restricted in the community and at school for structured and social activities. Contact sports were typically stated as very restricted. Modest negative correlations were found between children's impairments and environmental barriers, and participation. Cognitive and behavioral concerns were commonly reported as a problem limiting participation, but attitudes of others were less often noted as a limitation. Support from education personnel, provision of additional time to complete tasks, and time for rest were stated as being helpful. In contrast to the findings by Rivara's team (2012), no relationship was found between time since injury and participation.

The second study in Australia (Foo, Galvin, & Olsen, 2012) using the CASP explored the relationship between children's performance at discharge in self-care, mobility, and communication tasks as measured by the PEDI (Haley et al., 1992), and their later participation in the community. This study complements that conducted by G. M. Bedell et al. (2002) which explored children's readiness to participate at discharge, but design limitations constrain the credibility of Foo et al.'s findings. The sample ($n = 28$) was very diverse, with ages ranging from 5–19 years, and time since discharge ranging from 2½ months to 7 years. Although analysis found age did not impact on the correlations between participation and performance, time since discharge was not entered into the analysis. Given the small sample size, this potentially influenced the internal validity of the study, and also the degree to which information can be generalized to any one group from the findings. As with the studies by Bedell (G. Bedell, 2009; G. M. Bedell, 2004; G. M. Bedell & Dumas, 2004), the severity of children's injuries was not recorded, impacting on the external validity of the study.

Neither was data obtained relating to ethnicity, pre-injury function or environmental factors, although data relating to service provision is reported. Ceiling effects were reported in this study for both the CASP and the PEDI, although the extent of this problem in clinical terms is unclear due to a lack of information about injury severity.

Supporting results of the study by Bedell and Dumas (2004), a significant negative relationship was found between levels of service and participation. However, in contrast with the data obtained from rehabilitation teams in Bedell's study (2002), no relationship was found between children's performance in functional tasks at discharge and their participation scores. The authors conjecture that the absence of correlation may reflect a lack of sensitivity in the PEDI or the CASP (Foo et al., 2012). However, the contribution of the small sample size and possible confounders also need to be considered. Another possibility is that skills to perform tasks measured by the PEDI are different to those required to participate in activities in community settings.

Some of the themes identified above are discussed in a narrative review of research into children's participation outcomes (van Tol, Gorter, Dematteo, & Meester-Delver, 2011). The review is not emphasized in this chapter, as literature relevant to the topic and resultant themes have already been discussed, including additional literature. In line with the present discussion however, the review concluded that there was some evidence that children who sustain an ABI are likely to have reduced levels of participation up to 1½ years following discharge from hospital or in-patient rehabilitation.

Participation Changes for Children from a Qualitative Perspective

A small number of qualitative studies convey information about children's experiences of participation after TBI, and point to some important aspects of participation that are not captured by studies using quantitative methodologies. Most of these qualitative studies are with adolescents, and it is uncertain how well such findings can transfer to younger age groups who may prefer different activities, and who may have fewer teachers and less pressure for academic achievement at school.

Only one study involved younger children (Roscigno, Swanson, Vavilala, & Solchany, 2011). Information was gathered directly from 39 children and young people aged 8 to 20 years who were between 4 months and 3 years post injury, yielding insights into their perspectives and experiences. As with quantitative studies, children's responses were found to reflect their developmental level prior to their injuries, the severity of their injuries and the time that had passed since the injury. The children and

young people expressed how difficult and effortful activities had become, and how others' understandings and actions were central to their inclusion. Suggesting an alternative explanation for negative correlations found between service provision and participation (G. M. Bedell & Dumas, 2004; Foo et al., 2012), students felt therapy activities could interfere with time for participation with friends, or refused services fearing attention might be drawn to their disability, a worry also identified by Gauvin-Lepage and Lefebvre (2010). With the loss of friendships, increased time was spent with family (Rosignano et al., 2011).

Other qualitative studies involved adolescents, and reflect various perspectives of participation, including those of the teenagers themselves, as well as those of their parents, their siblings, and professionals. Time away from school and a graded return over time are described, including contact with friends and staff (Gauvin-Lepage & Lefebvre, 2010; Robson, Ziviani, & Spina, 2005; Sharp et al., 2006). This time of transition back to participation could be stressful however, and students were impatient to move to full-time attendance to maintain friendships and to avoid missing too much schoolwork (Mealings & Douglas, 2010; Sharp et al., 2006; G. H. S. Singer & Nixon, 1996). Adaptations to support activity performance at school included fewer subjects, modified assignments, and substitute activities, albeit staff sometimes lacked the desire, time, or knowledge to implement such strategies (Todis, Glang, & Fabry, 1997). In spite of this, support gained from family, friends, neighbors, and teacher aides was an important facilitator of participation (Chleboun & Hux, 2011; Mealings & Douglas, 2010; Sharp et al., 2006). Building on the notion of support, Mealings and Douglas (2010) and Todis, et al. (1997) both identified that it is the way in which the support is delivered that makes a difference to participation, whereby positive relationships with teaching and support staff, involvement in decision-making, and support that promotes independence where possible, means better acceptance of assistance by students.

Sometimes obvious physical or communication disabilities were present for students, with the need to feel part of a peer group and not be singled out a common concern (Gauvin-Lepage & Lefebvre, 2010; Mealings & Douglas, 2010; Sharp et al., 2006). Nevertheless, fears of lost friendships all too often became a reality (Chleboun & Hux, 2011; Gauvin-Lepage & Lefebvre, 2010; Rosignano et al., 2011; Sharp et al., 2006). Fitting with quantitative findings regarding the relevance of pre-injury function (V. Anderson & Catroppa, 2005; V. Anderson, Le Brocque, et al., 2012; Arroyos-Jurado et al., 2000; Catroppa et al., 2008; T. B. Fay et al., 2009), Gauvin-Lepage and

Lefebvre's (2010) study revealed that positive family social experiences prior to the accident were an intervening factor in the teenagers' participation later on in recovery.

The Social Context of Children's Participation following Brain Injury

The mediating effect exerted by the social context on children's participation is a consistent theme in pediatric TBI literature, with studies showing the influences of family factors, service availability, and people's knowledge and attitudes on aspects of participation (V. Anderson, Le Brocque, et al., 2012; G. M. Bedell & Dumas, 2004; Chleboun & Hux, 2011; T. B. Fay et al., 2009; Galvin et al., 2010; Gauvin-Lepage & Lefebvre, 2010; Max, Koele, et al., 1998; Mealings & Douglas, 2010; J. B. Rivara et al., 1993; J. B. Rivara et al., 1994; Roscigno et al., 2011; Sharp et al., 2006; H. G. Taylor et al., 2001; H. G. Taylor et al., 2002; Todis et al., 1997; Woods, Catroppa, Barnett, & Anderson, 2011; Yeates et al., 2004; Yeates et al., 1997). However the emphasis of such research has been directed towards the implications of such factors for injured individuals. Although this is undoubtedly important information, less attention has been paid to describing the wider social context in which a child's participation occurs after a brain injury, or to exploring others' experiences of that participation. Dewey reminded us that participation of an individual is inseparable from, and at one with, the context with which they participate, such that the context is equally a part of the participation and undergoes changes through that participation (Dewey, 1949; Dewey & Bentley, 1949a). Exploration of the available literature about the social context of the children's participation may fruitfully provide insights into some of the reasons others respond the way they do, as well as generating further details about the children's own participation. This social context is described next, beginning with the context of the family.

The social context of children's participation: Family.

After a child has a TBI, he or she participates first and foremost with his or her family. Research into children's participation outcomes reveals that following the accident, they are likely to spend greater periods of time at home (Chleboun & Hux, 2011; Gauvin-Lepage & Lefebvre, 2010; Hawley et al., 2002; S. R. Hooper et al., 2004; Mealings & Douglas, 2010; Robson et al., 2005; Roscigno et al., 2011).

In seminal work, Muriel Lezac (1986) proposed that in the time following a child's injury, families undergo a series of adjustments. These include stages of happiness, confusion and anxiety, discouragement, guilt and sadness, depression, then mourning, with these feelings eventually resolving through either detachment, or by re-

interpretation of the relationship. Lezac's theory suggests that with support, these adjustments are also a time of learning, providing a basis for more positive interactions with the injured family member. Later publications support the relevance of this theory, with families described as moving through a raft of responses such as gratitude, guilt, grief and loss, and adjustment (A. Clark, Stedmon, & Margison, 2008; Collings, 2007; G. C. Fay et al., 1994; Gauvin-Lepage & Lefebvre, 2010; J. B. Rivara et al., 1993; J. B. Rivara et al., 1994; Robson et al., 2005; Roscigno & Swanson, 2011), although experiences are likely to vary according to ethnicity (Yeates et al., 2002) and parent gender (Robson et al., 2005). It also appears that parents are likely to experience distress, increased levels of stress, psychological symptomatology, and feelings of burden after a child's brain injury (V. A. Anderson et al., 2005; A. Clark et al., 2008; Foster & Carlson-Green, 1993; Hawley, Ward, Magnay, & Long, 2003; Hermans et al., 2012; Kao & Stuifbergen, 2004; Micklewright et al., 2012; Prigatano & Gray, 2007; Roscigno & Swanson, 2011; Stancin, Wade, Walz, Yeates, & Taylor, 2010; S. L. Wade, Taylor, Drotar, Stancin, & Yeates, 1998; S. L. Wade, Taylor, et al., 2006).

Some studies of parents' responses lend support for a transactional view (Dewey & Bentley, 1949a) of children's participation in the family context. Pointing to the presence of two-way interactions, increased levels of stress and burden in parents are associated with worse behavior in children. Worse behavior is then associated with increased levels of stress and burden for parents, these interactions mediated by injury severity, pre-injury behavior, and time since injury (V. A. Anderson et al., 2005; Keenan, Runyan, & Nocera, 2006; J. B. Rivara et al., 1993; J. B. Rivara et al., 1994; Robson et al., 2005; H. G. Taylor et al., 2001). Parents of children who sustain a severe TBI are thought to be particularly vulnerable to negative exchanges, with critical and conflicting parent-child interactions predicting 40% of the variance in levels of stress and difficulties with family functioning (S. L. Wade et al., 2003). Most recently, it appears the strategies parents use to manage their children's behavior also play a role in this relationship, with a sector of parents who adopt authoritarian approaches to behavior management reporting higher levels of distress (Micklewright et al., 2012; S. L. Wade et al., 2011; Woods et al., 2011; Yeates et al., 2010).

However, rather than any single factor, such as behavior, triggering parental stress, stressors appear to be cumulative, with some stressors operating indirectly (Hawley et al., 2003; Josie et al., 2008). From an occupational perspective, literature suggests that parents are undertaking increased levels of responsibility for daily

activities for their children (G. M. Bedell, Cohn, & Dumas, 2005; Carson, 1993; Johansen, 2002; M. Jones, Hocking, & Wright-St Clair, 2010; Micklewright et al., 2012; Roscigno & Swanson, 2011), obtaining support and advocating for their child (Roscigno & Swanson, 2011), managing their own relationships (Foster & Carlson-Green, 1993; Robson et al., 2005; Roscigno & Swanson, 2011), and endeavoring to meet the needs of siblings who are adjusting to the accident (Robson et al., 2005; Roscigno & Swanson, 2011). It appears that the demands of meeting the needs of other family members do not begin to present as a stressor until approximately 6 months after the accident, when the injured child has progressed through the acute stages and is moving towards community participation (V. A. Anderson et al., 2005).

Changes to family routines are often described (G. M. Bedell et al., 2005; Foster & Carlson-Green, 1993; M. Jones et al., 2010). Responding to the trauma of the accident, parents are initially fearful, keeping to a close-knit family circle, and attempting to protect their child from further injury or failure at tasks (G. M. Bedell et al., 2005; A. Clark et al., 2008; Foster & Carlson-Green, 1993; Gauvin-Lepage & Lefebvre, 2010; M. Jones et al., 2010; Robson et al., 2005; Roscigno & Swanson, 2011). Although little time is left at this point for parent or family leisure activities (Hawley et al., 2003), and despite many parents expressing a lack of information on how to meet their injured children's needs (G. M. Bedell & Dumas, 2004; A. Clark et al., 2008; Hawley, 2003; Hawley et al., 2002, 2003; Hermans et al., 2012; Marks, Sliwinski, & Gordon, 1993; Roscigno & Swanson, 2011; Waaland, Burns, & Cockrell, 1993), they make active efforts to enable the children to participate in the community (G. M. Bedell et al., 2005; Johansen, 2002; M. Jones et al., 2010; Sharp et al., 2006).

Literature further highlights parents' active involvement in children's medical appointments, rehabilitation programs and education settings (Braga, Da Paz Junior, & Ylvisaker, 2005; A. Clark et al., 2008; Foster & Carlson-Green, 1993; Robson et al., 2005; Sharp et al., 2006; S. L. Wade, Oberjohn, Burkhardt, & Greenberg, 2009; S. L. Wade, Wolfe, Maines Brown, & Pestian, 2005). Whilst parents may take time off or leave paid employment to care for their child and to oversee arrangements for the return to school (Hawley et al., 2003; Sharp et al., 2006), financial concerns are common, and are associated with increased stress levels and worse outcomes for families (Hawley et al., 2003; Keenan et al., 2006; G. H. S. Singer, 1996; G. H. S. Singer & Nixon, 1996; S. L. Wade, Taylor, et al., 2006).

For some families, coping has been associated with stronger family relationships, problem solving, and social support. However, indicators are that the stressors can result in a negative spiral, and that these mediating factors may fall off over time. Outside the immediate family, although family and friends may equally be a source of support, others' negative responses to a child's injury can further aggravate a stressful situation (Chleboun & Hux, 2011; A. Clark et al., 2008; Hawley et al., 2002; M. Jones et al., 2010; Robson et al., 2005; Roscigno & Swanson, 2011; Stancin et al., 2010; S. L. Wade et al., 1998; S. L. Wade, Taylor, et al., 2006). Qualitative research has found that, over time, links with others in the community tend to drop away, and that families keep more to themselves in response to others' lack of understanding, and the demands of caring for their children (Chleboun & Hux, 2011; G. H. S. Singer & Nixon, 1996).

Literature draws attention to changes for siblings of injured children. In the acute phase after an accident, siblings show signs of fear, trauma, and stress (Foster & Carlson-Green, 1993; Hawley et al., 2002; Johnson, 1995; Robson et al., 2005). Without support networks they can experience feelings of separation while parents are tending to an injured brother or sister (Robson et al., 2005; Sambuco, Brookes, & Lah, 2008; G. H. S. Singer, 1996).

Beyond this time, findings are mixed as to changes in sibling behavior (Sambuco et al., 2008). On a positive note, most find the behavior of siblings of children with brain injury is little different to that of siblings of orthopedic-injury controls, normative data, or class-mates (McMahon, Noll, Michaud, & Johnson, 2001; Sambuco, Brookes, Catroppa, & Lah, 2012; Sambuco et al., 2008; Swift et al., 2003). On the other hand, an Aotearoa New Zealand study using the CBCL identified higher levels of internalizing behavior in siblings (T. Fay & Barker-Collo, 2003). Siblings have also been found to experience lower self esteem (Sambuco et al., 2012), and McMahon et al. (2001) found a relationship between injured children's function, and siblings' self-concept and depressive symptoms. Mediating such concerns however, correlations have been identified between sibling behavior and their knowledge about brain injury, their awareness of social supports, and, more often, the behavior of the injured child (T. Fay & Barker-Collo, 2003; Sambuco et al., 2012; Sambuco et al., 2008; Swift et al., 2003).

A picture is painted of siblings who take on increased responsibilities after a brother or sister's accident, including contributing more to household chores, increased effort in school and work, supporting the emotional well-being of other family

members, and assisting and protecting the injured child (Chleboun & Hux, 2011; Gill & Wells, 2000; Sambuco et al., 2008; G. H. S. Singer & Nixon, 1996). One study found that for siblings of mixed gender, interactions after one sibling sustained a brain injury were more negative than those of controls (Swift et al., 2003). However another study suggests more variability, whereby if injured and non-injured siblings continued to share activities together, their relationship was close. Conversely, where the behavior of the injured child disrupted joint activities, sibling relationships were distanced (Gill & Wells, 2000).

The social context of children's participation: Other children.

Although a limited number of studies discuss sibling's responses to a brother or sister sustaining a brain injury and changes in their participation relationships, fewer studies have explored the responses of peers. Other children are described variously as responding differently to the child after the accident or not acting any differently, being curious as to what happened, protective, refusing to communicate or play, teasing, bullying, or helpful and accepting (G. M. Bedell et al., 2005; Mealings & Douglas, 2010; Roscigno et al., 2011; Sharp et al., 2006; J. Singer, 1997).

Only one study has specifically examined children's attitudes towards peers who sustain a brain injury (Crothers, Linden, & Kennedy, 2007). Conclusions in this study are limited by the use of a vignette to elicit children's attitudes, which may vary in a real-life situation (Roberts & Lindsell, 1998), and failure to control for variables such as prior experience or knowledge levels. However findings align with studies of children with different conditions, in that female students were more open than males to being friends with a peer who had a brain injury, and male students at secondary school were more willing to be friends than males at primary school (S. M. King, Rosenbaum, Armstrong, & Milner, 1989; Laws & Kelly, 2005; Nowicki, 2006; Tripp, French, & Sherrill, 1995). Whilst this suggests attitudes might be more accepting by females, and by more children in secondary school, the study is not able to inform us as to student's day-to-day actions towards a peer with a brain injury. Additionally, given the possibility of cultural differences in children's attitudes (Longoria & Marini, 2006; Wong, 2008), the findings may vary with an Aotearoa New Zealand population.

Although it seems knowledge may support more positive attitudes, only one study that investigated pupils' knowledge about TBI was identified, and this study was carried out in Aotearoa New Zealand (Leatham & Body, 1998). Findings showed teenagers had some basic understanding into the causes and consequences of TBI, but

more so for mild injury. Those who had personally experienced a brain injury showed higher levels of understanding. Leatham and Body surmised that knowledge may have been supported by the introduction of legislation requiring helmets to be worn by cyclists. Understandings have possibly changed since 1998 with media promoting awareness of brain injury, but the findings suggest peers may have little knowledge on which to base insight into a class-mate's experience of brain injury, and to support their interactions.

The social context of children's participation: Teachers.

Despite calls to adequately educate teachers about TBI (Glang, Todis, Sublette, Eagan Brown, & Vaccaro, 2010), and despite the central role teachers play in students' participation at school (Parkin et al., 1996), there is scarce research into their perspectives on having children with TBI participate in their class. Those studies which have gathered data from teachers using the CBCL (G. C. Fay et al., 1994; Max, Koele, et al., 1998; J. B. Rivara et al., 1993; J. B. Rivara et al., 1996; J. B. Rivara et al., 1994; H. G. Taylor et al., 1999; H. G. Taylor et al., 2002) are largely concerned with the level of children's involvement in activities, or behavior, and pay less attention to teachers' experiences of involving a child with a TBI in classroom activities, and their responses to those experiences.

The few available studies involving teachers of children with brain injury would seem to support the call to educate the educators. In the United Kingdom, one study questioned 67 teachers of students with TBI, and found that 31% of those teachers were not even aware they had students with TBI in their class. This knowledge gap appeared to arise when information was not passed on with changes of class (Hawley, Ward, Magnay, & Mychalkiw, 2004). A similar difficulty is flagged in qualitative studies. Where children make a good physical recovery and do not exhibit behavior problems, remaining cognitive, communication, and learning problems are likely to be hidden if information is not shared with educators (Foster & Carlson-Green, 1993; Gauvin-Lepage & Lefebvre, 2010; Sharp et al., 2006; Todis et al., 1997).

Earlier studies found teachers' knowledge of brain injury was often inaccurate, especially around recovery processes, learning, memory, and behavior (Farmer & Johnson-Gerard, 1997), and that few teachers had received training about brain injury (Mohr & Bullock, 2005; Todis et al., 1997). In Mohr and Bullock's study, teachers obtained information as they needed, with most stating they would value consultation with a specialist in the area. Inadequate information impedes collaboration across

teaching staff and settings, creating inconsistencies in the demands placed on injured students. Other qualitative studies confirm teachers' lack of understanding, but also report responses such as prejudice, fear of litigation when an injury had occurred at school, and singling an injured child out from others in class (G. M. Bedell et al., 2005; Mealings & Douglas, 2010; Roscigno et al., 2011; Sharp et al., 2006; Todis et al., 1997). Unfortunately, there are some indications that therapists, who might be one useful source of knowledge, similarly feel ill-prepared to advise on appropriate strategies for these children (P. Jones, Drummond, & Vella, 2007; Todis et al., 1997).

The situation with regards to teacher knowledge of brain injury appears to have changed little. Most recently, in the United Kingdom, Linden, Braiden, and Miller (2013) surveyed 388 teachers, discovering that a high proportion lacked knowledge about issues such as the likelihood of after-effects following loss of consciousness, or whether children with head injury might experience difficulties with anger management.

Strategies used by teachers to support participation and achievement include establishing liaison people and communication systems between different stake-holders, gathering information about interventions used in the rehabilitation setting, adjusting students' time-tables, and involving the family. Most teachers feel that these strategies, the use of empathy, and assessments they implemented with other students with disabilities are also adequate for students with TBI (Mohr & Bullock, 2005; Todis et al., 1997). However this is at odds with rehabilitation literature which argues for structured and individualized processes to support successful school re-entry (Mohr & Bullock, 2005; Ylvisaker, Shaughnessy, et al., 2002).

The social context of children's participation: Service delivery.

Although there is a general understanding that children and their families will benefit from participation in rehabilitation after a TBI (Agnihotri et al., 2012; V. Anderson, Spencer-Smith, et al., 2011; V. A. Anderson et al., 2005; T. J. Feeney & Ylvisaker, 2003; Glang, Todis, Cooley, Wells, & Voss, 1997; Patrick, Patrick, & Duncan, 2006; Robson et al., 2005; Vilela et al., 2008; S. L. Wade, Oberjohn, et al., 2009; S. L. Wade et al., 2005), most studies of children's outcomes fail to evaluate the influence of any services children receive (e.g. Arroyos-Jurado et al., 2000; F. P. Rivara et al., 2012). While some studies do make reference to inadequate service provision (G. M. Bedell & Dumas, 2004; A. Clark et al., 2008; DeMatteo et al., 2008; Galvin et al., 2010; Hawley, 2003; Hawley et al., 2002; Hawley et al., 2004; Morgan & Skeat, 2011; Robson et al., 2005; Roscigno & Swanson, 2011; Waaland et al., 1993), there is also

reference to parent satisfaction with services (Glang et al., 2008; Robson et al., 2005; Vilela et al., 2008), making it difficult to obtain any generalized understandings, and suggesting variability.

Funding differences contribute to variation in service provision, with some children's needs met through private insurance, some through publicly funded rehabilitation schemes, and others through different schemes within the education sector (Glang et al., 2008; G. H. S. Singer & Nixon, 1996; Slomine et al., 2006; Vilela et al., 2008). One study in the United Kingdom found that only 7.6% of a group of children received any rehabilitation, this frequently physiotherapy, and that only 12.2% received a full rehabilitation program (Hawley et al., 2002). In the United States, Bedell and Dumas (2004) reported that 25% of children did not have any rehabilitation services, but 73% were accessing specialist education services. However another study from the United States reported that one third of their sample of 56 children received neither formal education services nor informal adaptations (Glang et al., 2008); this concern was also reflected in Prigatano and Gray's study (2008), where only 25% of severely injured children received education services. More positively, in Foo et al.'s (2012) study in Australia, 21 out of the 28 children in the sample were receiving services, although the types of service are not specified. This contrasts with another study, which involved Australia, Aotearoa New Zealand, the United Kingdom, and Ireland, stating (disappointingly) that only 12% of children were referred for speech and language therapy (Morgan & Skeat, 2011), even though language difficulties are common for this group (Ylvisaker, Szekeres, & Haarbauer-Krupa, 1998).

Management of transitions between settings (Glang et al., 2008; Hawley et al., 2004; New Zealand Guidelines Group, 2006), families' insurance status (Families USA, 2006a; Slomine et al., 2006), poorly resourced services (Slomine et al., 2006; Todis et al., 1997), and failure to meet diagnostic criteria qualifying children for state funded services (V. Anderson, Le Brocque, et al., 2012), are also raised as issues impacting on service uptake. In fact, some families express a preference to cope themselves rather than face uncertainty about services (A. Clark et al., 2008). Although unmet needs have been identified in the areas of information provision, medical services, and interventions for social integration (G. M. Bedell & Dumas, 2004; Hawley, 2003; Hawley et al., 2002; Marks et al., 1993; Vilela et al., 2008), two studies in the United States found that most families did not see a need for education and health services for their children after a brain injury (Gfroerer, Wade, & Wu, 2008; Slomine et al., 2006). For those families

who did see a need, most had these needs met, although gaps were identified in the areas of interventions to address behavioral needs. Likewise, Glang et al. (2008) found most parents were satisfied with the informal supports implemented by teachers, many expressing relief their children did not require formal intervention. A study in Canada reported readily available and satisfactory services for families through both public and insurance funding, but found most preferred not to access the services (Vilela et al., 2008), perhaps reflecting concerns raised in other literature regarding the impact of rehabilitation services on schoolwork and peer relationships (Gauvin-Lepage & Lefebvre, 2010; Roscigno et al., 2011; Sharp et al., 2006; Todis et al., 1997; Vilela et al., 2008; Ylvisaker, Shaughnessy, et al., 2002).

Literature suggests that Aotearoa New Zealand children who sustain a TBI are likely to be relatively well served. A consumer survey including both adult and pediatric clients by McNaughton (as cited in New Zealand Guidelines Group, 2006) found that 60% of people were satisfied, although others suggest that services for Māori and Pacific children may be less appropriate to their needs (Elder, 2012; Faleafa, 2009). The New Zealand Evidence-based Practice Guideline for TBI (2006) described a sequence of service provision, with clients and their families participating in rehabilitation in the hospital setting, through to participation in-patient rehabilitation, then in community-based (residential) rehabilitation. Available services reported in this resource include speech language therapy, physiotherapy, occupational therapy, nursing, social work, school liaison, and psychology, although it is noted that remote or rural areas may be less well served by some disciplines.

Children may also be involved with rehabilitation services through the education sector (New Zealand Guidelines Group, 2006). Although no literature was found describing delivery of this option for children with TBI, a Ministry of Education report (P. Clark, MacArthur, McDonald, Simmons Carlsson, & Caswell, 2007) described a child attending a special needs unit attached to a primary school following a stroke, indicating extensive amounts of time participating in rehabilitation. During her school hours, she participated in four sessions of speech language therapy per week and two occupational therapy sessions (one of these combined with physiotherapy). These included individual and group sessions. Her school week also involved attendance at hydrotherapy and horse-riding for children with disabilities.

Although diverse intervention approaches for children with brain injury are described in the literature (Agnihotri et al., 2012; Braga et al., 2005; Byard, Fine, &

Reed, 2011; Catroppa, Anderson, & Muscara, 2009; Chen, Heinemann, Bode, Granger, & Mallinson, 2004; Dise-Lewis, Calvery, & Lewis, 2002; T. Feeney & Ylvisaker, 2006; T. J. Feeney & Ylvisaker, 2003; T. J. Feeney & Ylvisaker, 2008; Gardner, Bird, Maguire, Carreiro, & Abenaim, 2003; Glang, Tyler, Pearson, Todis, & Morvant, 2004; Gray et al., 2011; P. Jones et al., 2007; Mallay, 2002; Marcantuono & Prigatano, 2008; McDougall et al., 2006; Mealings & Douglas, 2010; New Zealand Guidelines Group, 2006; S. L. Wade, Walz, Carey, & Williams, 2009; S. L. Wade et al., 2005; Woods, Catroppa, Giallo, Matthews, & Anderson, 2012; Ylvisaker, Shaughnessy, et al., 2002), evidence for the effectiveness of these approaches in facilitating participation is limited. Most studies focus on outcomes such as the acceptability of the service, neurobehavior, child adjustment, movement, performance of self-care activities, engagement in rehabilitation, family function, or education of school personnel (Braga et al., 2005; Catroppa, Anderson, & Muscara, 2009; Chen et al., 2004; Glang et al., 2004; Mallay, 2002; Marcantuono & Prigatano, 2008; S. L. Wade, Walz, et al., 2009; S. L. Wade et al., 2005; Woods et al., 2012). An exception however is a study which found that children enrolled in a community outreach program scored significantly better for activities and total competence on the CBCL than a control group which received a standard intervention (McDougall et al., 2006).

Studies and descriptions of programs adopting contextualized use of positive behavior supports provide some evidence for the use of these approaches in promoting participation, with one group of studies in particular adopting a robust single-subject reversal design (T. Feeney & Ylvisaker, 2006; T. J. Feeney & Ylvisaker, 2003; T. J. Feeney & Ylvisaker, 2008). Alongside data showing decreased frequency and intensity of challenging behavior, qualitative reports of this approach point to positive interactions with families, teachers, and peers, and improvements in academic performance and independent living skills (Byard et al., 2011; T. Feeney & Ylvisaker, 2006; T. J. Feeney & Ylvisaker, 2003; T. J. Feeney & Ylvisaker, 2008; Gardner et al., 2003).

A very small number of intervention studies have specifically targeted participation. Agnihotri et al. (2012) used focus groups, the CAPE (G. King et al., 2004), and the Canadian Occupational Performance Measure (M. Law et al., 1994) to evaluate the effects of a theatre-skills training program for two adolescents. Findings were mixed, but suggested positive experiences, varying increases in activity intensity between participants for different activity types, and improvements in performance and

satisfaction, although time with friends may have been compromised over the duration of the intervention. Given the small sample and lack of control however, the influence of confounders cannot be excluded.

Two other studies described an intervention directed at mobilizing peers to improve social networks (Glang et al., 1997; Sowers, Glang, Voss, & Cooley, 1996). Although improvements occurred in the number of friendships and activities students shared with peers (Sowers et al., 1996), and in numbers of social contacts and involvement in school life (Glang et al., 1997), informal reports suggested these improvements were not maintained (Glang et al., 1997).

Summary

This review aimed to describe the participation of Aotearoa New Zealand children after TBI, and to describe the facilitators and barriers to their participation. Participation was defined as meaningful and satisfactory involvement in a life situation, and was seen as encompassing a “societal perspective of functioning” (WHO, 2001, p. 213). Although the wider disability literature about children’s participation identified some overall themes, it was unclear how well these might apply to children with TBI. Literature was therefore sourced which addressed children’s participation after brain injury from behavioral and social perspectives, or which was directly based on the ICF definition of participation (WHO, 2001). This was supplemented with information about the social contexts in which children participate. Few relevant Aotearoa New Zealand studies were found. The review indicates that after a child’s brain injury, participation is likely to undergo change, and, aligning with studies of children with physical disabilities, to become problematic. However, the review also found variability in outcomes, this reflecting the interplay of varying historical, temporal, and injury-related factors, and socio-cultural contexts. The ability of the studies to usefully inform us about children’s participation was frequently limited by small sample sizes, short time-frames for follow-up, lack of measurement of pre-morbid function and contextual factors. Qualitative studies have seldom involved younger children, and infrequently obtain information directly from the children.

Multiple international studies have evaluated behavioral aspects of children’s participation after brain injury. Although the majority of these studies pointed to performance deficits across a range of activities, recent evidence based on different data analysis techniques raises the possibility that many children carry out activities with no problems. Studies of children’s behavior consistently showed that activity performance

is affected by several intrinsic variables. These include pre-injury performance, injury severity, time since injury, and ethnicity. Whilst some of these studies align with the wider pediatric disability literature in informing us that family context also influences children's behaviors, information is not provided about the other social contexts in which activities occur. Very few studies were found that reported the children's perspectives.

Another small group of studies have focused efforts on measuring children's social outcomes. As with children with other disabilities, limitations to social aspects of participation are indicated, with reduced socialization, social integration, and friendship numbers reported. In these studies however, social outcomes are measured apart from the context of activities in which social interactions typically occur.

A limited number of studies have evaluated children's participation after TBI using instruments founded on the ICF definition of participation. Although reduced participation was discovered, findings are variously constrained by small, heterogenous samples, failure to take into account the variables identified in behavior-focused studies, and failure to address the influence of the service provision context.

Qualitative studies depict the children's participation as involving increased time in home-based and rehabilitation activities, missed schoolwork, lost friendships, and feeling singled out. Participation is hampered by others' negative attitudes, but is facilitated by family involvement in community activities prior to the injury, family and community support, promotion of independence, and involvement in decision-making.

Meanwhile, the family context of children's participation is one undergoing adjustment. Parents struggle with inadequate information, multiple demands on their time, and financial challenges. Siblings also experience stress and change, with shifts from playmate to support roles, although interactions are eased by shared activities. At a time when families most need support, many of their support systems are not maintained.

On the basis of the limited available information, peer reactions appear to vary. Classmates may be curious, protective, avoidant, bullying, or accepting. More information is available about teachers, this generally indicating a lack of understanding about brain injury, poor communication of information at times of transition, and for some, concerns over possible litigation or disruption to others' learning.

The context of service delivery is characterized by differences across study settings, and inconsistencies within studies, with findings of inadequate service

provision sitting side-by-side with reports of available services but families and children who are wary of accessing them. Only limited information exists as to the effectiveness of interventions in addressing children's participation outcomes, and less still as to service delivery in Aotearoa New Zealand.

In conclusion, the literature supports the need for further study. Despite variability in outcomes, the literature raises concerns for children's participation after TBI, particularly so for the social aspects of that participation. However existing studies of behavior and of social function provide a partial picture only, and the validity of quantitative studies focusing on participation as defined by the ICF is constrained by small, diverse samples and inadequate control of extraneous variables. Little is known of the children's perspectives. Recent literature has not addressed these gaps in the knowledge. In light of findings identifying the influences of culture, ethnicity, and service availability on participation, it is not clear whether such findings can be generalized to Aotearoa New Zealand, where services may be more available.

A study was therefore proposed to understand more about Aotearoa New Zealand children's participation after TBI, and the facilitators and barriers to their participation. Literature in this review suggests that the study methodology and design needed to seek a holistic picture of the children's participation, and that it should acknowledge and explore variability and change. Literature pointed to the importance of capturing information about multiple variables and different contexts. Information was particularly needed about the social dimensions of participation. It indicated the perspectives of the children should be gained, and also the experiences of others with whom they participate in order to support a comprehensive view of any concerns, and of the influences involved. The ways I went about addressing these aspects are discussed in the next chapter, which describes the methodology and design of the study.

Chapter Four

Research Phase One: Case Studies: Methodology and Methods

The review of the literature in the previous chapter identified gaps in knowledge regarding children's participation after a TBI. Diversity across findings and contexts was highlighted, raising questions as to the applicability of existing knowledge to the Aotearoa New Zealand setting. This chapter describes the research methodology and methods used in a study undertaken to understand participation for Aotearoa New Zealand children after TBI. The sequence of the chapter contents are outlined in Figure 4.1.

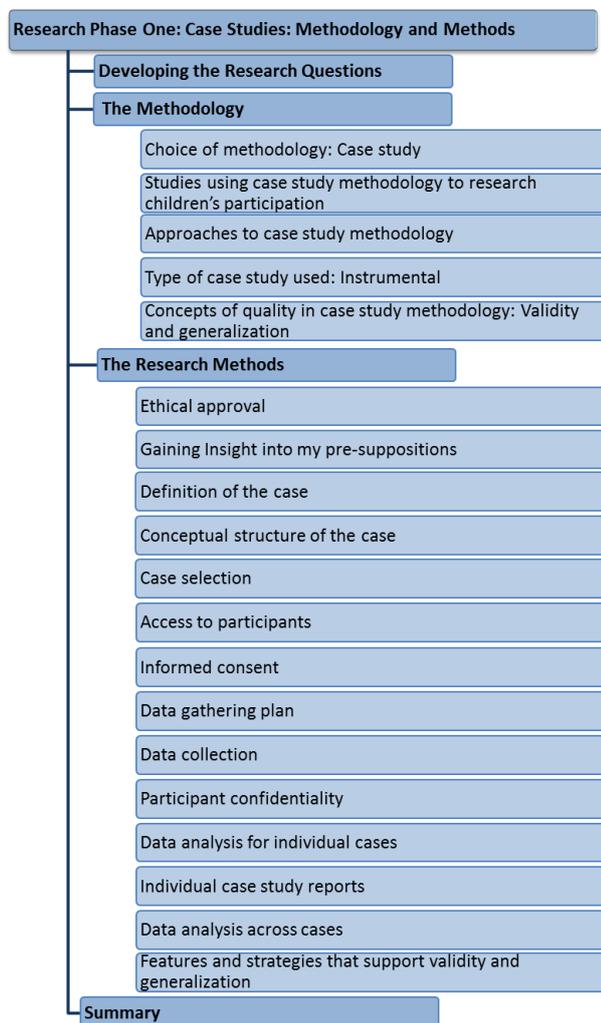


Figure 4.1: Contents and Sequence of Chapter Four

Developing the Research Questions

When facing uncertainty, Dewey argued that inquiry processes should first clarify whether the characteristics of a situation are problematic or not, and “search out

the *constituents* of a given situation, which, as constituents, are settled” (Dewey, 1938/2008b, p. 112). Reflecting the need to clarify the situation in relation to the children’s participation in the Aotearoa New Zealand situation, the research questions were open in nature. This was in order to generate information about any problems and identify important constituents of the situation. Drawing from the literature discussed in Chapters One and Three, the following constituents of the situation were taken as settled when developing the questions:

- Participation may be defined from both objective and subjective viewpoints.
- After a TBI, children’s participation changes.
- The quality of the children’s participation varies.
- Multiple variables and contexts are involved, and influence participation. In this way, the perspectives of the children and other key stakeholders are essential to understanding their participation.

The questions that were developed were therefore as follows:

1. What are the aspects of participation that are important to Aotearoa New Zealand children who have had a clinically significant TBI, and
2. What are the facilitators and barriers to their successful participation from
 - a. the children’s perspective
 - b. the whānau/parents’ perspective³
 - c. the teachers’ perspective
 - d. the perspective of rehabilitation providers, and
 - e. my observational perspective (within the family, school, and/or community settings)?

Participation was defined as “meaningful and satisfactory involvement in a life situation” (Hemmingsson & Jonsson, 2005; Ueda & Okawa, 2003; WHO, 2001). In research question one, the word “to” is used to indicate the things that children and others believed to be significant in relation to the children’s participation experiences.

³ The Māori translation of whānau is “extended family” or “family group” (Moorfield, n.d.). The term “whānau” is used in the thesis in acknowledgement of the central role of extended family in a child’s life in Māori culture (Walker, 2006). The alternative term “parents” shown here is not a translation of whānau, but is applied in the thesis with reference for non-Māori families, who may see a child’s parents as the key people in their life.

The Methodology

Choice of methodology: Case study.

My choice of methodology was guided first by my philosophical understandings, which assumed that the motive, means, and meaning of children's participation would be closely connected with the context of their participation, including those people with whom they participate (Dewey, 1938/2008b). It was further assumed that the children, other participants, and other aspects of the environment, would change through the participation. I believed people's experiences of these changes would prompt and guide future actions. A methodology was needed that could furnish information about participation experiences as they were entwined with their context, not apart from context. The methodology also needed capacity to attend to changes over time.

Inquiry, from Dewey's perspective, is one of many natural human occupations, and is evolutionary in nature:

We know that some methods of inquiry are better than others, in just the same way in which we know that some methods of surgery, farming, road-making, navigating or what-not are better than others. It does not follow in any of these cases that the "better" methods are ideally perfect ... They are the methods which experience up to the present time shows to be the best methods available for achieving certain results. (1938/2008, p. 108)

In line with Dewey's perspective, the choice of methodology for this study was also guided by reasoning about how to best address the research questions. These were concerned with (a) aspects of the children's participation that were important, and (b) different stakeholders' perspectives about things in the environment that influenced the children's participation. Therefore the methodology needed to generate understandings about the aspects of participation that different people saw as important, and about their perceptions of what these things meant. Information was needed about a range of environments, and about various aspects of those environments. The practical concern with facilitators and barriers to participation meant that the methodology needed to attend to both common and unique experiences, given that both might provide useful clues about participation difficulties and solutions.

A case study methodology was selected as being best suited for addressing the above concerns. Yin (2009) defined case study as an "empirical inquiry" which "investigates a contemporary phenomenon in depth and within its real-life context"

particularly in circumstances where “the boundaries between phenomenon and context are not clearly evident” (p. 18). It involves in-depth investigation of a case to yield understandings and/or explanations about the phenomenon or issue. A case may be an event, an episode, a program, an activity, an individual, a social group in their context, or an institution. Although case studies are often considered to be qualitative, they may aggregate the occurrences of phenomena to support understanding, and sometimes include quantitative data (Stake, 1995, 2005, 2006; Yin, 2003b, 2009). Table 4.1 displays the features of case study methodology I identified as aligning with Dewey’s philosophical viewpoint, and as being relevant to the research questions (C. Adelman, Jenkins, & Kemmis, 1980; Cresswell, 2007; George & Bennett, 2005; J. Gerring, 2007; Hammersley & Gomm, 2000; D. Harper, 1992; Merriam, 1998; Platt, 1992b; Simons, 2009; Stake, 1995, 2005; White, 1992; Yin, 2003b).

Table 4.1: Features of Case Study Methodology Aligning with Dewey’s Pragmatist Philosophy and Relevant to Answering the Research Questions

Theoretical Assumptions of Case Study Methodology	Characteristics
Focus on the complexities of real life	Case study methodology is concerned with generating rich information about an instance of a particular and complex phenomenon or issue as it occurs/occurred in day to day social life
Valuing of context and experience	At least a part of, if not all, of data collection takes place vicariously, with the case in its natural environment.
Capacity to address temporal change	The study may focus on the case at a single point in time, either in history or the present, or it may be followed over time
Valuing of experience	The real-life experiences of key stake-holders in the case are seen as integral to the phenomenon. Knowledge of these experiences is essential to arriving at understandings and/or explanation
Concern with particularities as well as commonalities	Although valuing single instances, the methodology is also able to aggregate information about aspects common to multiple cases

Case studies have been considered by some to function as precursors to more comprehensive and rigorous research projects (Platt, 1988, 1992a). However, for the present project, exploration was seen as essential (Dewey, 1938/2008b). It was seen that case study methodology would generate valuable understandings that would hold merit in their own right.

Others have held that the term *case study* refers not to a methodology, but to a choice about the focus of the study (a case), and the technique used to gather information (Hesse-Biber & Leavy, 2011). In contrast with this view, I concur with Cresswell (2007) and Taylor (2013a), who referred to case study as a methodology. Taylor (2013b) defined qualitative research methodologies according to the “sets of theoretical assumptions, which underlie the choice of data collection and analysis methods and processes” (p. 3). She posited that the theoretical assumptions of case study methodology align with the broad understandings which underpin qualitative research (Taylor, 2013a). My own reading suggests that the theoretical assumptions of case study methodology go further than this, reflecting common beliefs about the connectedness of people and their contexts and human capacity for experiential learning; that there are multiple ways of knowing; that knowledge can be both general and unique in nature; and that the nature and value of knowledge is relative to the situation in which it arises and in which it is used (C. Adelman et al., 1980; Merriam, 1998; Simons, 2009; Stake, 2005; B. Taylor, 2013a; Yin, 2009) (refer to Appendix 4.1 for examples from texts illustrating these theoretical assumptions). I further found that the theoretical assumptions in case study methodology give rise to shared characteristics, including the area of focus, intent, strategies and processes used, and output. I developed Figure 4.2 to display the common assumptions and characteristics of case study methodology. The assumptions are outer-most, and the characteristics are in the circles.

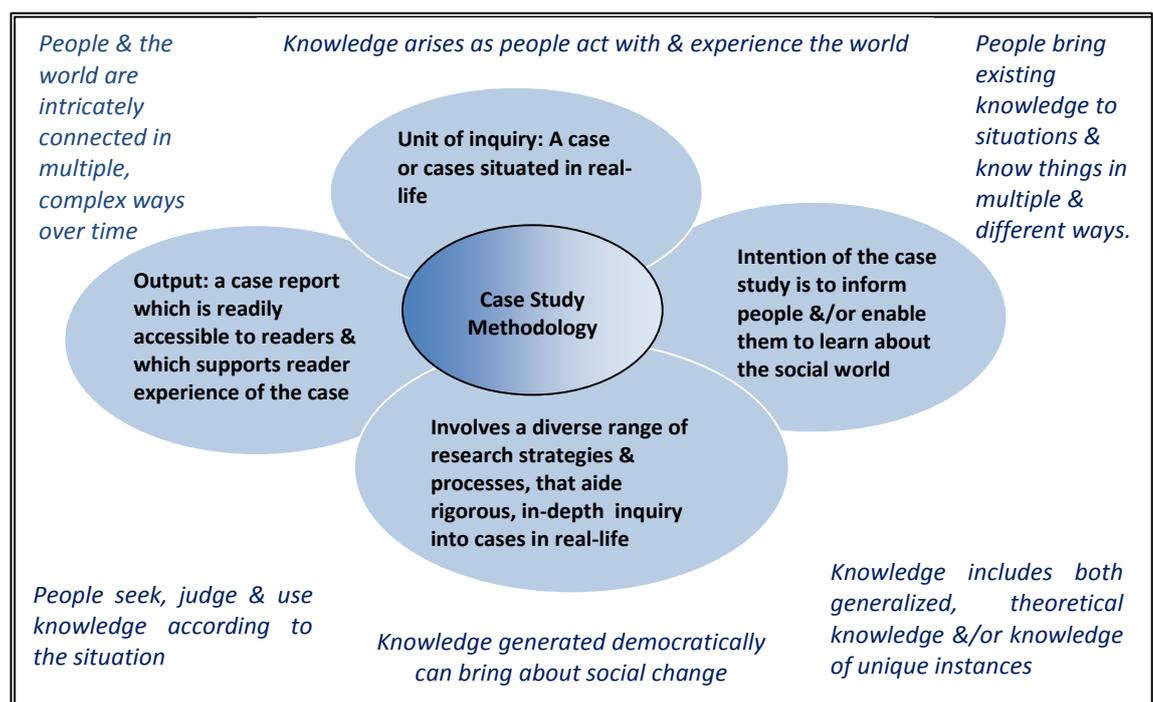


Figure 4.2: Common Assumptions & Characteristics of Case Study Methodology

Studies using case study methodology to research children's participation.

Despite the apparent utility of case study methodology for answering the research questions, at the time of commencing this research, case studies had not been used to investigate children's participation after TBI. Since then, one case study from the United States has been published about long term adjustments amongst the support networks of children with TBI (Chleboun & Hux, 2011). Although the two child participants were 15 years old, this study proved to be a rich source of information about the social aspects of the young people's participation, and of social changes that took place over time. It conveyed information from the perspectives of the young people and different members of their support networks, providing further rationale for adopting case study methodology for the present study.

Approaches to case study methodology.

Two broad approaches have been put forward in case study methodology. Authors such as Gerring (2007) and Yin (2003a, 2003b, 2009) emphasized the application of case study methodology in theory building, and to support the discovery of cause and effect relationships. In this way, case studies contribute to generalizations that readers can apply across multiple contexts.

In contrast, the interpretive case study approach developed by Robert Stake (Stake, 1995, 2005, 2006) emphasized the meaning of events and experiences situated in real life settings and time. From this perspective, although deeper understandings of phenomena are sought, the approach guides inquiry into both unique and shared meanings, and supports readers to judge how well they might apply information to their own contexts. Stake's approach was adopted as fitting best with the project's research questions.

The selection of Stake's approach also held practical advantages. Stake (1995, 2006) has particular expertise in implementing case studies with children, their families and teachers, aligning with the focus of this study. His approach has flexibility, addressing either single or multiple case-study designs. For less experienced researchers, Stake (1995, 2006) described the implementation of case study methodology in detail, and provided examples of education-based case studies to support understanding. There was some description of the process of analyzing data for individual cases, and step-by-step description of the process for multiple cases. In

addition, practical resources are available on a web-site to support development and implementation of the case study protocol (Stake, 1995, 2006).

Type of case study used: Instrumental.

Case studies may be classified according to their purpose, including exploratory, descriptive, explanatory, or evaluative studies (Merriam, 2009; Stake, 1995, 2006; Yin, 2009), with these different applications eliciting design variations. As illustrated in Figure 4.3, Stake (1995, 2006) further proposed that case studies can be considered as being intrinsic, instrumental, or multiple in their design, according to the number of cases involved and the need to generalize information. Although it was acknowledged for the present project that each case would be unique, the focus was supporting application of the information to other, similar contexts, therefore an instrumental case study was proposed.

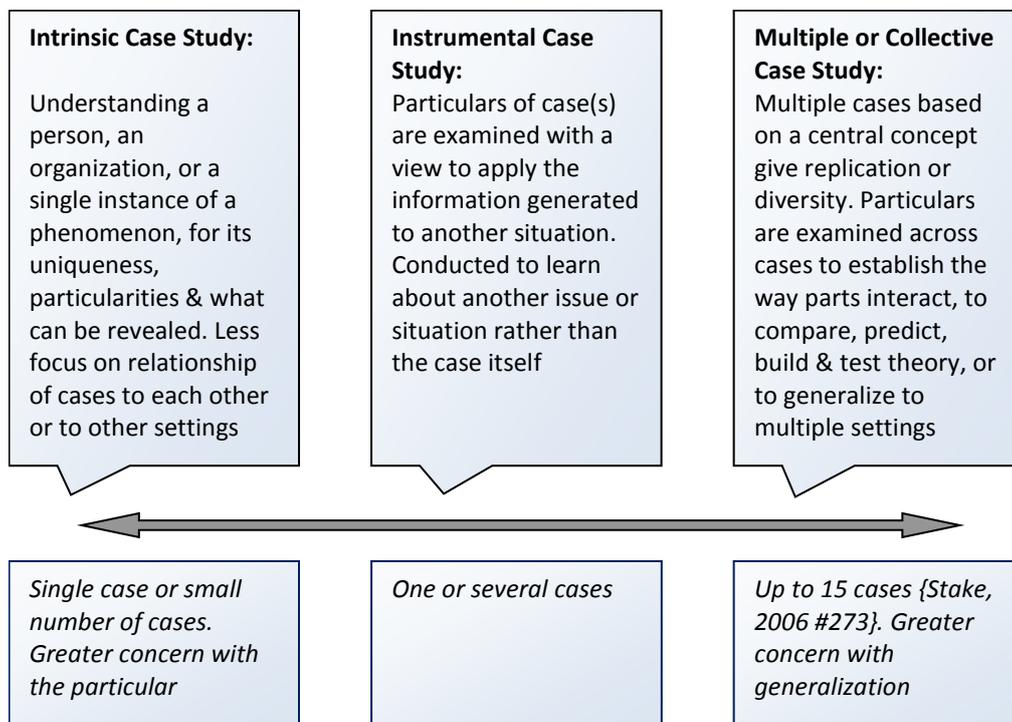


Figure 4.3: Continuum of Case Study Designs (Stake, 1995, 2006)

Concepts of quality in case study methodology: Validity and generalization.

As with other methodologies, case study researchers recognize a responsibility to provide accounts that are valid and which may have application beyond the research project. The terms “validity” and “generalization” are often associated with positivist and post-positivist approaches to research (Guba & Lincoln, 1989; Hesse-Biber &

Leavy, 2011; Simons, 2009; Stake, 1995). In case study literature however the terms remain in common use for conveying the “quality and adequacy of findings” (Simons, 2009, p. 127).

Stake (1995) articulated validity for case studies as being about the accurate representation of the case for readers. He challenged case study researchers to implement all stages of the research process thoughtfully and with rigor, and provided strategies to support validity. However, Stake took the notion of validity for case studies beyond this, and argued the need for case study to provide a sound basis for readers’ experiential learning and future action. “The value of interpretations vary—relative to their credibility and utility” (Stake, 1995, p. 102). Dewey similarly captured this position when he spoke of the connection between coming to know through experience, and the truth of that knowing in terms of its application. “If we see that knowing is not the act of an outside spectator but of a participator inside the natural and social scene, then the true object of knowledge resides in the consequences of directed action” (Dewey, 1929/1988, p. 157).

For Stake, the notion of validity then is bound together with the ability of the case study to bring about generalization of the knowledge. Unlike the concept of transferability of knowledge, which has come to be traditionally associated with qualitative social science research (Guba & Lincoln, 1989), Stake recognized two, related types of generalization that are involved with case study research. Firstly, “naturalistic generalizations” (Stake, 2005, p. 85) are tacit understandings that derive from direct or “vicarious” experience of the case, and which add to and modify earlier understandings that might be held about the world. Secondly, “propositional” or “explicated” generalizations are theoretical assumptions gained by other, didactic means, such as taught concepts, or factual knowledge from a text-book (Stake, 2005, p. 85). Stake reflected that the two types of generalization are not entirely separate: “one set of generalizations through two doors” (Stake, 2005, p. 85). This claim is on the basis that the internal understandings gained through experience translate towards more formal, propositional understandings when communicating them, and reflecting and acting on them in relation to other situations.

My study was guided by Stake’s conceptualizations of validity and generalization. The methods used in the study are discussed next. Aspects of the methods and strategies I employed that supported validity and generalization are described in Table 4.3 later in this chapter.

The Research Methods

Ethical approval.

Prior to beginning the study, ethical approval was gained from the Northern Y Regional Ethics Committee, New Zealand, and the Auckland University of Technology Ethics Committee. Approval was also gained from the ACC Ethics Committee to obtain material from the participants' case files. Refer to Appendices 4.2a to 4.2e for copies of the Ethics Approvals.

Gaining insight into my pre-suppositions.

Going into the study, I saw that my own beliefs would form one of the constituents of the situations I encountered (Dewey, 1938/2008b). My practice, philosophical, and theoretical understandings have been discussed in Chapters One and Two. However, qualitative research encourages researchers to use strategies that enhance their awareness of their own understandings and suppositions about phenomena (Corbin & Strauss, 2008; Dey, 2007; Holton, 2007; Munhall, 2007; Stake, 1995). Therefore, before proceeding with the study, to gain further insight into my beliefs, I arranged an interview with a practice colleague. The interview was recorded, and then repeated listening and reflection were undertaken. The process helped to sensitize me to my own views, and provided a basis for discerning the ways in which those views influenced the issues I was concerned about, the questions asked, the data sought, and my analysis of that data. My reflections from the interview process are summarized and explained in the table in Appendix 4.3 on Disc One.

Definition of the case.

There are multiple definitions of what is understood by the term "case", and Stake did not adopt any one definition. However, he did state that a case is "a specific, a complex, functioning thing." He referred to the case having "working parts", and explained that it is a "system" (1995, p. 2). Stake also described cases as having boundaries, although it is likely that these boundaries are defined by researchers to manage the scope of studies (L. M. Smith, 1978). He offered examples of a case being a person, or a group of people in a particular place, or a program (Stake, 1995). For this study, the case was understood as an Aotearoa New Zealand child with TBI, and stakeholders who were concerned about and involved with that child, such as family, teachers, and rehabilitation providers. A case also included the child's local community, and rehabilitation legislation and policies as enacted in rehabilitation report formats.

Conceptual structure of the case.

Case studies are supported by a conceptual structure that clarifies the context and helps to define the boundaries of the case. The conceptual structure also identifies data sources, guides the questions asked of the different data sources, and can be drawn on to support the analysis. Stake (1995) built the case study conceptual structure around issue statements or issue questions. Some texts refer to these as “foreshadowed” issues or problems (Malinowski, 1922; Simons, 2009; L. M. Smith, 1978), indicating their role in laying open existing viewpoints, and delineating the situation driving the study. Although issue statements are laid out before beginning the study, there is an understanding that as the case study progresses they are open to re-definition. Based on my prior knowledge and understandings and the review of literature described in Chapter Three, and framed by the research questions, the following issue statements were identified for this case study:

1. For Aotearoa New Zealand children aged 9–12 years who are in the chronic stages following clinically significant TBI, the consequences of impairments to body functions and structures will manifest in changes to participation.
2. The children’s participation will be perceived by the children themselves and by key stakeholders to be changed and restricted relative to their previous performance and to that of their peers.
3. Physical, social, cultural, and institutional aspects of different participation environments will be perceived during observations, by the children, and by key stakeholders to be facilitators or to be barriers to the children’s participation.

To provide boundaries for the case, the different terms within the issue statements were defined. The definitions of terms in the issue statements are shown in Appendix 4.4.

Derived from the issue statements and their definitions, a matrix, displayed in Table 4.2 was developed to guide data collection. The top row of the matrix lists the issue statement numbers. Below these are the topics that were developed to generate information relating to the issue statements. The left column lists the data sources within cases that were identified as being able to contribute information to answer the topical questions. Ticks indicate a match between the information sought and the relevant data source. Items in italics are those added later as understandings of the issues evolved. The matrix pinpointed where information was triangulated across different components, and ensured there were not any gaps in what was proposed.

<i>Issue Statements</i>	1	3	1	2	2	2	2	1, 2, 3	3	3	3
TOPICS: Information sought.	Age at injury, severity, type, time since injury	The injury- Family attributes- location, structure, ethnicity, roles	Child attributes- age, gender, health, genetic inheritance, body functions and structures affected	Naming & describing the current participation- life situation, activity involved, changes, restrictions	Temporal aspects of current participation- when, how long, how frequently, changes, restrictions	Current (actual) participation- perceived meaning & satisfaction. Changes	Needed/desired participation	Description of life situation /envt in which participation takes place. Home, school, community x physical, social, cultural, institutional <i>Changes</i> .	Observed features of environment that facilitate/ limit participation & action/modality	Perceived things that are facilitators to participation- <i>How do they facilitate?</i>	Perceived things that are barriers to participation- <i>How do they limit?</i>
DATA SOURCE & PERSPECTIVES											
Child Perspective				✓	✓	✓	✓	✓ <i>Changes</i>		✓	✓
Parent Perspective				✓	✓	✓	✓	✓ <i>Changes</i>		✓	✓
Teacher Perspective				✓	✓	✓	✓	✓ <i>Changes</i>		✓	✓
Observed by Researcher			✓	✓	✓	✓ Satisfaction		✓	✓	✓ <i>How</i>	✓ <i>How</i>
Artifacts- child photographs				✓		✓		✓			
Parent Report		✓	✓					✓			
Rehabilitation Provider File	✓		✓								
Demographic Questionnaire	✓	✓	✓		✓						
Document Analysis - ACC File- <i>reflects interpretation & implementation of policy & legislation.</i>			✓	✓	✓	✓	✓	✓	✓	✓	✓

Table 4.2: Conceptual Structure: Matrix to Guide Data Collection for Case Studies Note: *Issue Statements*: 1: For Aotearoa New Zealand children aged 9-12 years in the chronic stages following clinically significant TBI, the consequences of impairments to body structures & functions will manifest in changes to participation.2: The children’s participation will be perceived by the children & key stakeholders to be changed & restricted relative to their previous performance & to that of their peers. 3: Physical, social, cultural, & institutional aspects of different participation environments will be perceived during observations, by the children, & by key stakeholders to be facilitators or to be barriers to the children’s participation.

Case selection.

Cases were not sought on the basis of them being *typical*, or for their ability to represent the issue and thus provide generalizability. Stake (1995) pointed out the learning that can be acquired from the atypical case, or cases where features are contrasting. Hence, participants were sought who could provide information that would maximize the understandings that could be gained.

Up to five cases were initially proposed for the study. It was thought this number would allow for in-depth exploration of the issues, but would support the instrumental nature of the study. This number was also thought realistic given the time frames available. Stake (2006) suggested that at least four cases are needed for a multi-case study, but that more than 15 cases will limit the depth of understanding that can be obtained due to the amount of data. As it happened, a sixth family who met the inclusion criteria heard about the study through word of mouth, and approached me to ask if they might be involved. Given that this case had potential to add to the diversity of perspectives, ethical approval was obtained to increase the number of cases to six. A summary of the six cases is available in Chapter Five, Table 5.1.

A specific age group was selected as it has been shown that children's participation varies with age (G. King et al., 2010; G. A. King et al., 2007; M. Law et al., 2006; Palisano et al., 2011). It was proposed that cases would center on children aged 9-12 years because involvement in wider community activities becomes increasingly important at this age (Hoffnung, Hoffnung, Seifert, Burton Smith, & Hine, 2010). This age was also targeted in consideration of the ethical concerns relating to children's level of cognitive and moral development for giving informed consent. It has been shown that by the age of 9 years, children are less likely to make choices because they think they must obey adults to avoid punishment, and are beginning to consider issues of trust, care, and loyalty as a basis for making decisions (Kohlberg, 1976). It was surmised that adolescents may face a range of different participation issues, and their participation would be better addressed in a separate study.

Inclusion criteria. Whānau/parent(s) and children were invited to participate if children: were 9-12 years old; had sustained a moderate to severe TBI (defined below); had been discharged at least 6 months previously from hospital or inpatient rehabilitation following a TBI (to support adequate experience of participation after the TBI); were living in the community with their whānau/ parent(s); whānau/ parent(s) were able to understand and express issues and ideas in conversational English; children

were not currently receiving therapy or assessments from me or my place of work to avoid risk of coercion.

Exclusion criteria. There were no exclusion criteria. While the children's basic cognitive abilities were identified by referrers to assist description of body functions affected by the injury, children were not excluded from the study on the basis of communication skills.

Determination of the clinical significance of a child's injury as moderate or severe was defined by GCS score (Teasdale & Jennett, 1974). Although reservations have been expressed as to the ability of the GCS to establish injury severity for children (Adelson, 2010; Fletcher, Ewing-Cobbs, & Francis, 1995; Ghaffarpasand, Razmkon, & Dehghankhalili, 2013; Green, 2011; Lieh-Lai et al., 1992), it was adopted for the study as this was the modality commonly used and reported by the hospitals in the acute stages. It eventuated that two of the child participants were injured when very young, and their scores were not available. These two cases were included in the study on the basis that their injuries were consistently described in records as moderate or severe, and that they were experiencing ongoing difficulties subsequent to the injury.

Access to participants.

Recruitment for a case study is complicated by the potential involvement of a number of participants in different roles and/or from different contexts within each case. The process for this study commenced by engaging rehabilitation providers to approach, by telephone, those whānau/parents of children on their case-load who met the inclusion criteria. Whānau/parents ascertained their child's willingness. If families expressed interest in participating in the study, their names were passed on to me to contact. Whānau/parents who consented to take part then provided contact details for other important participants, such as teaching staff or rehabilitation case managers, and nominated important activities which should be observed. In this way, participants played a part in shaping the case and immediately began identifying what was important about the children's participation.

Recruitment onto the study proceeded very slowly. At first only one rehabilitation provider was approached. Due to low numbers however, ethical approval was gained to approach a further two providers, this eventually yielding enough cases for the study.

Informed consent.

I provided potential participating whānau/parents with an information sheet (refer to Appendix 4.5a), explained the study verbally, and gave them an opportunity to ask questions. Because the children potentially had less ability to understand the implications of the study due to their injuries, they had the study explained to them by their parents. I provided them with a simplified information sheet (Appendix 4.5b), and explained the study on a second occasion during my initial visit.

Although participants needed to understand and express ideas in English, interpreters and cultural support people were available as needed. For Māori participants, a *kanohi ki te kanohi* (face-to-face) approach was arranged to explain the study under the guidance of the District Health Board Whāea (mother) or Kaumātua (elder). Māori cultural support was obtained with recruitment and data collection for three whānau, and one whānau declined cultural support. Interpreter support was obtained during recruitment for one family.

I contacted a total of seven families, and, as described above, one family approached me. Of the seven families I contacted, one declined to participate on the basis of too many commitments. A child in another family declined to participate on the basis that he no longer wished to have contact with rehabilitation specialists, and preferred to focus on attending school and community activities.

Teaching staff who were nominated by the whānau/parent(s) were contacted at the school after consultation with the school principal. They were provided with an information sheet (Appendix 4.5c), and were given opportunity to consider taking part in an interview and/or having observations made of classroom sessions. Where data collection identified further participants who could usefully provide information (e.g. extended family members, family friends, education specialists), they were similarly approached.

Signed informed consent⁴ was sought from whānau/parent(s), the child, and teaching staff. Copies of the blank consent forms are attached in Appendices 4.6a-4.6d. Although proxy consent was sought for the children, this was in addition to seeking their signed informed consent directly, respecting their active role in the project (Atwool, n.d.). Literature suggests that whilst children this age may need some additional explanation, they have some skill in judging what will be required of them (Hill, 2005). All but one of the children on the study signed the consent form

⁴ Refer to the Glossary for explanation of the differences between consent, assent, and proxy consent.

themselves, with that one child's motor impairment leading to them indicating their assent with gesture and sound. As explained above, one child declined to take part, suggesting that he showed understanding of what was required and was not coerced.

Specific consent was sought from the whānau/parent(s), and the child for me to 1) access the child's clinical records at the rehabilitation provider, and 2) request photocopies of the documents from the child's ACC case-files. Participants were able to initiate contact with me or give consent at any point until 12 weeks after receiving the written information.

Data gathering plan.

Before commencing data collection for a case study, it is recommended that a data gathering plan is developed to ensure that the study runs smoothly (Stake, 1995; Yin, 2009). The plan for this study (refer to Appendix 4.7) detailed the conceptual structure, ethical approvals, recruitment processes, participant contact details, researcher and participant safety procedures, equipment, and the sequencing of interviews and observations. It included the topical information questions that had been developed, the interview and observation guides, and a copy of the demographic questionnaire. As recommended, a tentative report outline was also developed, but, perhaps reflecting researcher inexperience, proved inadequate for capturing what needed to be conveyed, and was abandoned with the write up of the first case study. A new reporting structure was developed and utilized.⁵

Data collection.

As is typical in case study designs (Merriam, 1998, 2009; Stake, 1995; Yin, 2003b, 2009, 2014), and to adequately address the data needs and contexts indicated by the conceptual structure table (refer to Table 4.2), a variety of data collection sources were used. This promoted diversity of information, and supported the exploratory nature of the study. It strengthened the study findings by allowing for triangulation⁶ of information. The data sources included a brief demographic questionnaire, interviews, observations, photographs taken by the children of artifacts representing important occupations, and document review. Due to the number of data-collection sources, time-points, and settings for each case, data was gathered for one case at a time.

A total of 33 interviews with 34 people were conducted across the cases (ranging from 4 to 8 interviews per case, with each interview lasting from 30-75

⁵ The second reporting structure is used in the case study reports that are presented in Chapter Five.

⁶ Refer to the Glossary for explanation of triangulation.

minutes). A total of 25 observation sessions were conducted (ranging from 2 to 6 observations per case, with each session lasting from 30-90 minutes). Twenty five rehabilitation documents were read and analyzed. Additional time was spent reading children's case files at the rehabilitation providers to capture key injury and demographic details. Data collection for the six cases was conducted over two and a half years, the time-frames reflecting recruitment delays, and researcher illness which necessitated an extended leave of absence from the study. Participant details and data collection sources for each case are contained in the individual case study reports in Chapter Five, and on Disc One in Appendix 5.1.

To facilitate adults and children to feel relaxed and able to engage in the data collection process, I responded to their routines and needs, and, as far as possible, arranged sessions at times and places that people nominated. This flexible approach also fitted around child care arrangements, and allowed for observational data to be captured about participation in activities that whānau/parents and teachers felt were important. A number of the whānau/parent interviews, and home or community-based observations were therefore carried out in the early evening and weekends. The duration of interviews with children was carefully monitored, and interviews were stopped if children showed signs of fatigue, such as changes in attention or communication (Boylan, Linden, & Alderdice, 2009). Most whānau/parent interviews took place in people's homes, and most teacher interviews took place at school. However, one parent requested an interview in his work setting, and one teacher requested an interview to be held at my place of employment. Although most whānau/parents chose to be interviewed without their children present, three preferred their child to be directly involved in the interview. Three of the interviews involved two parents/grandparents together.

Data were gathered over several time-limited episodes rather than single, whole days, which helped capture a variety of activities and some of the changes that took place over time. Although a strict data collection schedule was initially proposed, this proved unrealistic, given school events, holidays, and participant commitments. Therefore a more flexible approach was adopted while remaining within the time limits approved by the ethics committees.

After children and their families consented to take part in the study, brief demographic details were gathered verbally, guided by a questionnaire (Appendix 4.8). At this point, participants were invited to nominate a pseudonym that would be used in

the case study report to support anonymity. Some participants elected for me to allocate their pseudonyms. Children's injury details were obtained from Locality Provider clinical records, and photocopies were requested of the children's most recent assessment reports, rehabilitation plans, and current education plan (if any) from children's ACC Case Files.

Semi-structured interviews were held with adults and children in the home and school contexts, broadly seeking information according to interview guides. The guides contained topical questions devised from the case study conceptual structure (Table 4.2), and are contained in Appendices 4.9a to 4.9c. Although interview guides were used, discussion was also flexible, responding to relevant topics raised by participants. For example, in Case Study One, during the interview with Anna's mother Jan, she unexpectedly described how other girls excluded Anna from party invitations. During a pause later in the interview, I asked "*You talked about her being excluded, do you feel that happens at school?*" (Case Study One, Anna, Mother Interview, p. 18). Interviews were recorded using a digital audio-recorder, and were then transcribed by a transcriptionist, who had signed a confidentiality agreement. I checked transcriptions against audio-recordings, and corrections were made as needed.

For all but one who had a more severe physical disability, children were provided with a camera in a session prior to their interviews, and were encouraged to move around their home environment, taking photographs of objects and activities they felt were significant, and explaining these things to me. At a second session with each child, hard copies of the photographs were included into a poster-making activity, during which questions were asked around the content of the poster, and as prompted by the interview guide. The photography session activity served several purposes:

- The session facilitated the children to establish rapport with me preparatory to their interviews (Bowden, 1995; Boylan et al., 2009; Lloyd, Gatherer, & Kalsy, 2006; Mawson, 2013).
- Artifacts and photographs are often used as a source of data in case studies (Yin, 2014). In line with the conceptual structure (Table 4.2), data were generated about activities and objects in the environment that children saw as important to their participation.
- Clinical experience and research literature (Boylan et al., 2009; Catroppa et al., 2008; Chapman et al., 2001; Hay & Moran, 2005; Nadebaum et al., 2007; Roscigno et al., 2011) suggested the children would be likely to experience difficulties with

information processing and communication, and this was found to be the case. However, at interview, the photographs supported the children to understand questions and to express their ideas (Boylan et al., 2009; Lloyd et al., 2006). The activity of incorporating the photographs onto posters during interviews prompted their attention and memory (Boylan et al., 2009; Lloyd et al., 2006).

- Through taking a lead on the design of their posters, children helped drive the content of their interview (Curtin & Murtagh, 2007; Mawson, 2013).

Before inclusion onto the posters, photographs were edited to ensure they did not include any identifying details (e.g. people, car registrations, names on certificates). Participants were provided with copies of their transcribed interviews, and were given opportunity to change details if they wished, although none requested changes.

Observations of children's involvement in daily activities were conducted at home, at school, and in other relevant community settings (e.g. sports). It has been found that observations are a useful means of assessing interactions, providing different information to that reported by parents (S. L. Wade et al., 2003). Therefore, it was judged that observations would not only provide information about the physical context of participation, but would provide supplemental information about the social context. As with the interviews, the data collected during observations were defined by observation guidelines (Refer to Appendix 4.10 for the observation guide), which contained topical questions deriving from the case study conceptual structure (Table 4.2). Videos were not made during observations, due to a concern this would overly influence interactions, and the risk of recording data about others who had not consented to be involved in the project (e.g. video material of siblings or classmates). Instead, during participant observations, brief notes were made about children's interactions and activities, and descriptions were written about the context. The notes and descriptions were re-written as more detailed narratives shortly after completing the observations. The short time delay helped prevent memory lapse, and provided some opportunity for reflection on what had been observed, these reflections being incorporated into the narratives.

Stake (1995) explained the need for researchers to identify their personal involvement with the case. During observations at home, I interacted with the family as seemed natural, to minimize their feelings of being observed. However I limited my degree of involvement during observations in the classroom, to avoid drawing attention to the participant or affecting his or her interactions with classmates. Two teachers

chose to introduce me to their classes, but observation notes show that for the most part, the children and their classmates did not pay undue attention to my presence.

As data collection progressed, specific information was often sought during interviews and observations to clarify or add to themes that had been identified with previous participants and cases. Case study texts typically refer to this as progressive focusing (Parlett & Hamilton, 1972/1976; Simons, 2009; Stake, 1995, 2005). For example, when gathering data for Case Five, observations unexpectedly suggested Bob (the child with TBI) sometimes took the lead when interacting with a particular child sitting beside him in class. It was unclear whether this seating arrangement was coincidental or deliberate. In earlier cases, some teachers had mentioned changing children's groupings in the classrooms to encourage children to get to know each other. At interview, his teacher was therefore asked "*Have you thought much about Bob's buddy, who he's sitting with?*" She responded "*I'm just trying to think if we've shifted desks since you were in.... The person he's with at the moment is quite outgoing.... which seems to help Bob to participate because he's kind of pushed in to it a little bit more.... I shift them around quite often anyway.... regardless of whether it's working or not*" (Case Study Five, Teacher 2 Interview, p. 1).

Participant confidentiality.

The issue of participant confidentiality has not been considered in any depth in existing case study texts, but was found to be significant in the present study. Strategies to support participant confidentiality were identified in the ethics application, including secure storage, access limited to me and my supervisors, and the use of code-names. However, I found that the multiple points of reference increased the likelihood that a case could be identified by a person external to that case but familiar with the field (e.g. a case manager or a rehabilitation provider). Moreover, within each case, there was a risk to individuals of having sensitive information such as criticism of another participant inadvertently revealed to that other participant, should they obtain a copy of the case study report. To address this, where criticism was voiced, the information was excluded if it was considered to pose any risk to participant safety. Identifying details were also altered, but this needed to be balanced with preserving essential information and maintaining the overall character of the case. As far as possible however, demographic details that would have little impact on others' interpretation of the case were changed, including one or more of the following for each case: gender, age, family details, school details, injury details, location, and time-frames. Pseudonyms were used

for all participants, and the cases were numbered in a different order to that in which they were undertaken. Individual participants were provided with a report about the study cross-case findings only.

Data analysis for individual cases.

Consistent with the use of Stake's (1995) case study methodology, the analysis needed to remain open to new understandings. It needed to delve into and explore the phenomenon. However the findings also needed to provide a useful basis for later studies which were more focused. An analysis of individual cases was performed first to gain depth of understanding. This was followed by a cross case analysis to gain insights into common themes.

Although Stake's (2006) text, *Multiple Case Study Analysis* provides a detailed description of the process to follow when performing a cross-case analysis, his earlier (1995) text, *The Art of Case Study Research* does not provide a specific process, instead relating general suggestions to the underlying interpretive theoretical framework, and giving guidance and examples. Stake suggested that the type of data analysis used in a case study needs to be one that is effective for the researcher, and should draw on their "experience and reflection" (1995, p. 77). He proposed that the situation of the case study as intrinsic or instrumental (refer to Figure 4.3) will also help determine the best analytic strategies for meeting the study objectives (Stake, 1995, 2006).

A number of points were systematically considered when selecting an analytic approach for the individual case studies:

- As discussed in Chapter Two, given a philosophical understanding of continuity between people and the contexts with which they participate, the analysis needed to attend to, maintain, and convey this continuity. It was desirable that it could simultaneously consider participants' participation contexts with the context of data collection (Dewey, 1925/1981).
- Also discussed in Chapter Two, reflecting a concern for people's democratic involvement (Dewey, 1916, 1939/1998), the individual voices of participants needed to be captured in the analysis, in order that their perceptions and experiences might be conveyed in the reports. This was particularly important for participants such as the children, whose perspectives had potential to be overlooked where they were not readily expressed, a point noted in my review of existing literature in Chapter Three.

- The analysis needed to generate answers to the research questions. As shown in Figure 4.3, the case studies were instrumental in nature. Therefore the analysis needed to provide depth (to understand what was important), to attend to particulars (e.g. where single instances of a facilitator may be of practical use), and convey commonalities seen across different data sources (Stake, 1995).
- At a practical level, the analysis needed to address diverse data, including that gathered from interviews and observations, rehabilitation documents, and the photographs on children's posters.
- Given significant amounts of data generated for each case, analysis needed to consider the time frames available for the study.
- Readers should be able to comprehend the analytic decisions that were made, and consider the validity of those decisions (Stake, 1995).
- It was necessary to generate material in a form which was accessible and practical for readers such as busy whānau/ families, rehabilitation providers, and teaching staff (Simons, 2009; Stake, 1995; Yin, 2009).

Refining the analysis approach. Initially, methods were applied for Case One, that were in keeping with the guidance and examples for case studies provided by Stake (1995). Strategies to support the process included repeated reading of the data, reflection, directly interpreting individual instances in the transcripts which provided answers to the questions or which gave information about context, and aggregating instances. Patterns, and repetition of patterns in particular conditions were sought in the data. Sections of text were incorporated into a draft report, which was narrative in style and included personal description of experiences and context. This approach proved problematic because it did not clearly tease out the key findings from the case that answered the research questions, and the overly long description failed to satisfy the criteria for reader accessibility. For a sample of the draft report generated using this approach, refer to Disc One, Appendix 4.11.

The difficulties stimulated a re-think of how the analysis for Case One might be improved. Merriam (2009) provided a detailed outline of the process of analyzing qualitative data, and stated this process is appropriate to use with case studies. Responding to Merriam's guidance, this process was applied to the data for Case One as follows:

1. In open coding, interview transcripts, observation narratives, and documents were re-read, and notations were made in the margins beside any sections of data that

provided answers to the research questions. Sometimes a notation referred to a single word or short phrase, and sometimes to a paragraph of text. Sections of text were given a name, or code that reflected what they conveyed about participation. I began noting frequently occurring codes on a diagram on a whiteboard, this aiding recognition of codes in subsequent data and supporting me to think of the relationships of codes to one another.

2. Next, coded items of data were cut apart into segments and grouped with other similar codes. Codes contributing to similar ideas were merged and named as categories. This process was iterative, with new codes compared with earlier codes, some categories subsumed as subcategories, some categories being re-named, and some coded material being re-categorized. A tentative list of the categories and subcategories was made. The list was revised as the process progressed.
3. Lastly using re-iterations of the diagram and list, and comparing the different properties of each category by inspecting the coded data segments, conclusions were drawn about the properties of each category, and about the ways the categories related to each other. Details of the categories and illustrative examples were written into the case study report. Descriptive data about the participants and contexts were later extracted from the data and added.

Illustrating this process, the following excerpt is present in the interview I completed with Anna's mother. "*I've been hounding her [Anna] just to take a sweatshirt. 'I'm not taking a sweatshirt, I don't need it Mum!' ... and you end up in a semi-argument trying to say 'well just put it in your bag,' 'it makes my bag too heavy' "*" (Case Study One, Mother Interview, p. 4). I made the following notations on the transcript: "*Telling her*" [referring to Jan's statements], "*Her viewpoint/judgement about what she needs*", and "*choices*" [referring to Anna's reported responses]. The paragraph was initially coded as "*Child Directing Activity*"⁷. It was compared with other codes such as Resistance/Refusal, Preferences, and Having Aims, and Having a Say. These codes were all merged into a category called Having a Say, as this name used Jan's words, and collectively captured the meaning of all those codes in relation to an important aspect of Anna's participation. Next, I began to notice on my diagrams that along with Having a Say, other categories such as Satisfaction, Having Help, and Grinding to a Halt (fatigue) all influenced Anna's experience of her participation. These categories were therefore identified as subcategories of a broader category, which was

⁷ Categories deriving from the data are written as names beginning with an upper-case letter.

called Experience and noted on the list. It was identified amongst the codes that other people's Understandings were often incongruent with what Anna wanted when she was Having a Say; this participation situation was called Misfit.

Despite this process facilitating individual case analysis, and the writing of the first case study report, it was decided the approach also had limitations in terms of application to the remaining case studies. I was concerned at the amount of time taken, and the amount of data that would be involved for each case. Additionally, although I used color-coding, the different data sources and differences between them tended to be lost in the categorization process, rather than being preserved and acknowledged. I also felt the process did not adequately integrate context during the analytic process, due to the fragmentation of the data (J. A. Maxwell & Miller, 2008).

At this point, I stopped and took stock of the different analytic approaches available. Appendix 4.12 displays the table I developed to record details of this review. I also re-visited Dewey's philosophical understandings, this prompting consideration of the value of mapping. Although Dewey did not apply maps in the analysis of data, he often referred to maps metaphorically to illustrate the way people's theoretical understandings are developed, and the way that such understandings serve to assist others who tread the same path.

Without the more or less accidental and devious paths traced by the explorer there would be no facts which could be utilized in the making of the complete and related chart.... the map, a summary, an arranged and orderly view of previous experiences, serves as a guide to future experience.... Through the map every new traveler may get for his own journey the benefits of the results of others' explorations. (1902, pp. 19-21)

It was clear that a mapping strategy (Northcott, 1996) would be well suited for analyzing the case study data for the following reasons:

- The completed maps would provide a record of coding decisions.
- The use of visual diagrams had earlier proved particularly helpful for engaging with and reflecting on the data.
- Maps would lend flexibility for working with the diverse data sources in each case.
- Data could be integrated with contextual elements throughout the analysis.
- Work by Daley (1996) suggested that maps from different data sources could be compared with each other.

Some mapping strategies described in the literature moved analysis towards aggregation of data to build theory (Clarke, 2005), while others were used for gathering rather than analyzing data (Wheeldon & Faubert, 2009). None of the existing mapping strategies had been applied with a case study methodology. The intuitive, cognitive mapping strategy outlined by Northcott (1996) held promise, but relied on audio data. Building on Northcott's work, a modified mapping strategy was applied with Case Two, and was refined with subsequent cases. Given that Case One had been completed, and had generated answers to the research questions, it was decided not to re-analyze that case. The process used to map and analyze the data for Cases Two to Six is described next. The process is illustrated with excerpts from the data to support reader understanding. The excerpts largely derive from Case Two, Tish⁸ to maintain continuity for the reader.

Application of mapping strategy to analyze Cases Two to Six. The mapping strategy was applied one case at a time. First, data in the interview transcripts, written observation narratives, and rehabilitation documents were read methodically. The child's poster (apart from Case Three) was inspected for understandings that it could contribute. Notations were made as to possible meanings inherent to chunks of data, and what was happening. Names which conveyed the content of each data chunk were allocated, these being derived from the data itself where possible, or its suggested meaning. Data were considered in chunks rather than word by word to ensure the meaning was interpreted in context. However, where an individual word or short phrase seemed significant, it was noted, and its meaning considered in relation to the context of what was being said. For example, in Tish's case study, his parents explained that he was always first out of the school gate in the afternoon. His stepmother was asked "*maybe the teacher lets him out first?*" but she responded "*No, I doubt it. She treats him just like everyone else...She doesn't want to spoil him or anything*" (Case Study Two, Parent Interview, pp. 48-49). The chunk of data was tentatively coded on the transcript as 'Pace' noting that his parents were talking about Tish's speed, but after reflection, was re-coded as 'Being Treated the Same', considering that the data also indicated not singling a child out, or not indulging them.

The coded information for each participant or data source was mapped freely by hand onto individual sheets of semi-transparent paper (the reason for which will become apparent below), using different colors to reflect each source. A copy of the map from

⁸ Tish is the pseudonym chosen by the child.

the interview with whānau for Tish's case study is in Figure 4.4 on page 94 in the body of the thesis⁹. The maps for Tish were my first attempt at this process. I gained increasing confidence and skill as the mapping progressed through the cases. For further reference, the maps for Case-Six, which were completed last, can be seen on Disc One, Appendix 4.13. Brief direct quotes and their page numbers were incorporated onto the maps to help capture the features of codes and to provide an audit trail. As discussed by Stake (1995), this process was intuitive, but systematically responded to the codes interpreted from the data. Codes that had similar qualities were situated adjacent to each other, suggesting possible categories, and where codes seemed to be related to each other, arrows were drawn. For instance, Tish's father talked about his son's resistance to getting back into his school routines after the holidays, saying "*I won't pamper it [him]. You know we won't pamper it*" (Case Study Two, Parent Interview, p. 86). This was coded as "Won't Pamper", with a note that it may reflect not giving special treatment, and was situated next to the "Being Treated the Same" code. Data about the context were not seen as separate, but were coded onto the map along with information about participants, to preserve the notion of a whole, continuous system.

With each new data source in a case, a new map was begun, semi-visible below earlier maps (hence the value in using semi-transparent paper). Efforts were made with these new data sources to remain open to new understandings. However, if, after reflection, codes were clearly in line with those from earlier data sources, they were placed in a similar position on the new map. Illustrating this, it was noticed that Tish, his teacher, his teacher aide, and my observations all discussed the importance of him being treated by adults and his peers in the same way as other children. The codes were also all situated next to things people *did* to help him fit in and be part of things, such as "Keeping an Eye on Him", Welcoming", and "Seeking and Giving Help". This pattern was noted, and the group of codes across data sources was collectively called "Inclusive Actions" because this term best conveyed the intent and results of things people did.

The conceptual framework that was developed at the start of the project shaped the questions that were asked of participants, but was not referred to in the process of analyzing the data. Similarly, the analysis was not driven by any particular theoretical concepts. However it was not possible to completely divorce myself from an occupational perspective. Therefore the codes and categories that were interpreted, such as the understandings about the centrality of Shared Occupation, and the importance of

⁹ To support confidentiality, some parts of the map have been obscured.

People, Place, Occupation, and Time, show alignment with themes often present in occupational therapy literature.

In time, based on the maps for Cases Two and Three, and supported by the use of successive diagrams developed to test ideas and aid reflection, a conceptual model was derived that captured the patterns in the data, and which conveyed the important aspects of participation described by the participants in the context of the case. The diagramming, and the resultant conceptual model also supported insight into the way categories related to each other, and helped identify subcategories. The conceptual model for Case Six, Ash, can be seen in that Case Study report on page 117, and is also used to support understanding of the cross-case assertions on page 139.

The central category of Shared Occupation is placed at the center of the model, because it emerged strongly through all the case studies, and was a reference point for the other things people talked about¹⁰. Central, twisting, colored lines are used to represent the way children's participation was intertwined with those around them. The double-ended arrows indicate how people made sense of the children's participation experiences by looking not only to the past, but also forward towards future participation. The arrows also indicate the degree to which the children's participation changed, and was able to change. Throughout all the case studies, the central category of Shared Occupation comprised four important aspects: the People involved; the Place where the participation occurred; the Occupation(s) involved; and Temporal aspects of the participation. The degree to which there was a Fit between each of the four aspects, the qualities of the Connections made with each of the four aspects, and qualities of the Patterns created influence the experience of participation. These categories and subcategories which form the model are explained in more depth and illustrated in Chapters Five and Six, which report, respectively, the findings for the individual case studies and for the cross case analysis.

The conceptual model varied with subsequent cases in terms of the subcategories associated with the four categories of People, Place, Occupation, and Time, reflecting the different situations. Although there was variance, the core ideas held true for the remaining cases. For example, in Case One, Anna, the previous analytic process (Merriam, 2009) had identified that where there was a Fit between her abilities and characteristics of the People, Place, Activity, and Time, this positively influenced her feelings of Being A Part Of things. Conversely, where there was Misfit, she experienced feelings of Being Apart from things.

¹⁰ The terms "Occupation" and "Shared Occupation" are defined in the Glossary.

For Case Two, Tish, repeated mappings gave rise to slightly different interpretations. Here, feelings of Connection with other People, Places, Occupations, and Times were important, such as the Connections created and strengthened between whānau, fishing occupations, the beach and holidays noted by Tish's father. "*We went up in ... oh, Queen's Birthday [weekend].... Stayed in the caravan.... He [Tish] likes to go up there, because we go fishing, we got to the beach ... on the sand. Just surf-cast. Kahawai [a type of fish], yeah, seven. Man that was a buzz for him ... Oh yeah, Granddad just loved him*" (Case Study Two, Parent Interview, pp. 35-37). Problematic participation was characterized by a variation on this category, Broken Connections. Although the category of Fit can be seen in some of the maps for Tish, for this and subsequent cases it was interpreted as being part of the Connection category, because where there was Fit, Connection seemed to be present.

As data analysis moved on, my written reflections pointed to continued "niggles" as to whether the notion of Fit was in fact a separate category to that of Connection. On 07-09-12, my diary notation reads "*I was clear about Fit- it is about a match between things....I am less clear about Connection. Does it include Fit? What is Connection about? Engaging, Experience, Memory: Knowing. What's important about Connection? The quality of the Connection. On checking the maps, I see Connection can be tentative, stretched, deep, strong, continuous, broken, fragmented. Why is it important? It may be the basis for knowing how to share occupations.*" Subsequently, the maps for all the cases were re-checked for the notion of Fit, and it was re-interpreted as a category in its own right, providing an alternative explanation for some instances of problematic participation.

The mapping process generated understandings about the aspects of participation that were important to a case, and some of these pointed to facilitators and barriers. However, an overall interpretation of the facilitators and barriers to participation was sought. This was framed by Dewey's writings about the things that drive human inquiry, where he makes reference to problematic situations encountered, and the solutions that people determine to resolve those situations (Dewey, 1938/2008b). The interpretation was again generated using a mapping process.

For this second phase of analysis, each map was scrutinized, seeking words that a) conveyed problems, and b) indicated things that had been of use in overcoming those problems. Retaining the same colors as those in the original maps, the two groupings of words were mapped opposite each other into a single new map, this new map

integrating the ideas sourced from all the other maps for that case. Where the ideas from one data source replicated or fitted with those from another data source, they were aligned above or below each other. When this process was complete, each group of words was considered for the ideas it was conveying, and given a name, testing different names until they adequately conveyed the sense of the data. Finally, words were used to capture the overall meanings inherent to all the things that were problematic to the participation, and the solutions that were used to address problems.

Consultation with a cultural support person, Whāea Louise Elia, was obtained during data analysis for the cases involving children who identified as Māori. Support was provided with the use of Te Reo Māori, or Māori language. Interpretations were checked, and the case studies were reviewed. Feedback was provided to support insights and understandings of participants' experiences from a Māori perspective. The information in the case study reports was adjusted to reflect this feedback. For example, in Case Study Six; Ash, I had interpreted the teacher's actions towards the group of children during prayers as Directing, seeing that they supported Ash's involvement. Whāea Louise explained that such actions assisted the other children to learn about and respect differences, or rerekētanga. This information was recorded on page 16 of Ash's case study.

Individual case study reports.

Presenting case study findings is an important part of case study methodology and design. A report format may be informed by the original conceptual framework, but will also reflect the new discoveries and assertions that developed in the course of the study. Reports can include any combination of narrative, direct quotations, diagrams, and quantitative data. They should provide vicarious experience of the case; therefore the audience must be kept in mind when developing the format (Stake, 1995; Yin, 2003b, 2009).

In writing reports for each of the case studies, the need to convey meaning concisely was balanced against the desire to provide readers with depth of experience. The core information in the reports needed to be accessible and meaningful. I anticipated that readers would be busy whānau/parents, educationalists, or rehabilitation providers, so where possible, visual media such as photographs, and diagrams were incorporated. To support the reader's direct experience of cases, wherever possible, descriptions of categories and relationships drew on excerpts from the transcripts to communicate findings in the words of the participants. Following Stake's (1995) advice,

where different interpretations were considered, these are included to enable readers to reflect on possible alternative explanations. Several iterations of the reports were made, refining the presentation and diagram formats for clarity.

A brief overview of all the cases and the individual case study report for Case Six are presented in Chapter Five. For brevity, the individual case study reports for Cases One, Two, Three, Four, and Five are presented on Disc One in Appendix 5.1.

Data analysis across cases.

When all six individual cases had been analyzed, and individual case study reports written, a cross case analysis was undertaken. Whilst the individual cases gave valuable insights into unique instances in context, it was anticipated that a cross-case analysis would contribute useful, overarching understandings, or assertions, in relation to the research questions (Dewey, 1938/2008b; Stake, 2006). Stake (2006) was clear that such assertions fall short of proof of a single truth, and that they remain open to other interpretations. However, they are grounded in the data, and give “logical persuasion” as to their credibility (p. 41). In this way, the understandings in assertions provide some foundation for action.

Stake explained the means of undertaking a cross case analysis in his text on *Multiple Case Study Analysis* (2006). The strategies, worksheets, and processes he offered, and their application in the present study, are described next in Figure 4.4. For reader reference, examples of the completed worksheets are contained in Appendix 4.14. In line with Stake’s use of terminology, the original research questions are referred to here as Themes. Worksheet 1 is not discussed here, as it is a resource made available for organizing data collection rather than analysis. It was not used in this study, as the Conceptual Structure table I developed (refer to Table 4.2) made it redundant.

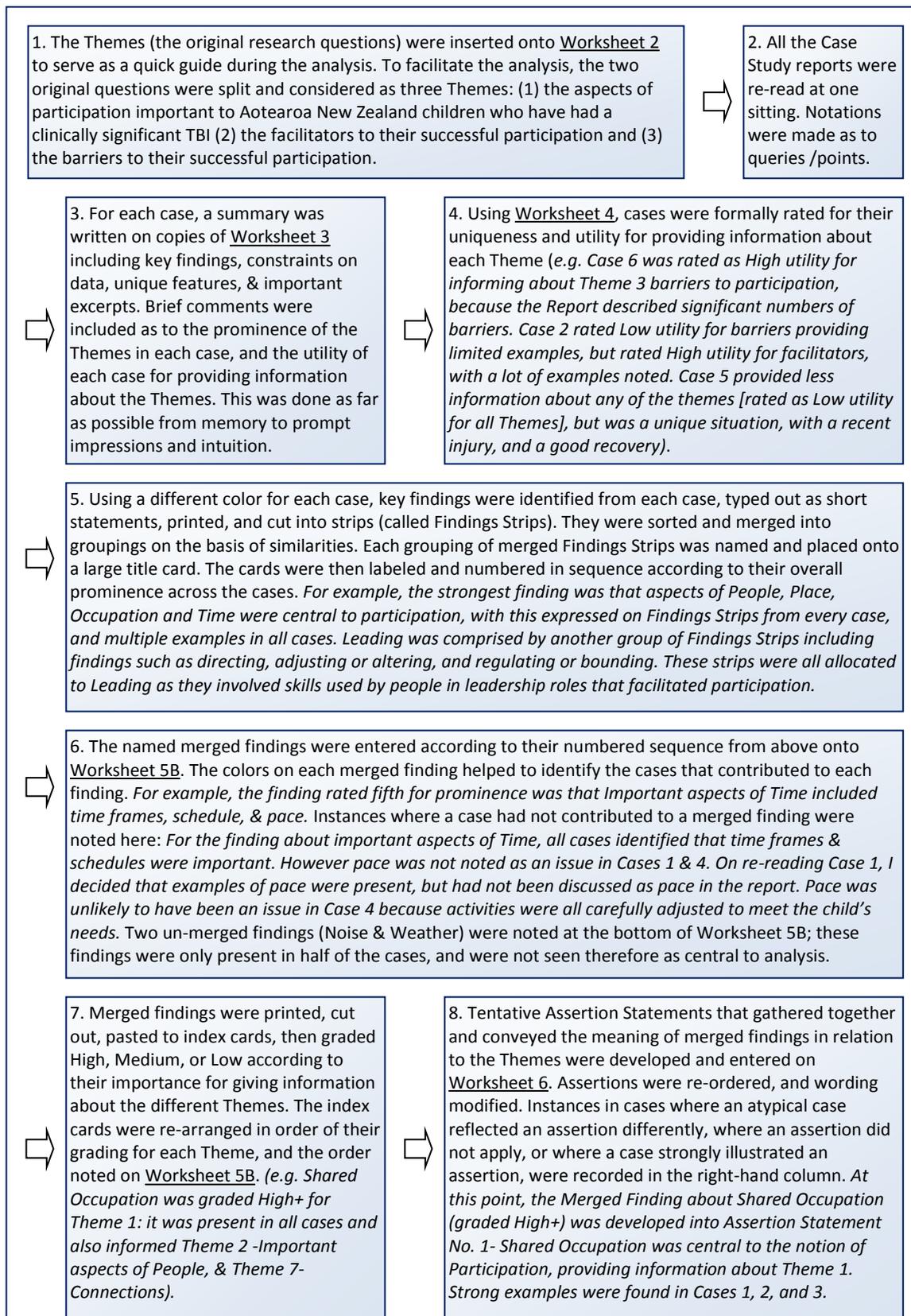


Figure 4.5: Steps in the Process Used for Cross-Case Analysis (Stake, 2006). Worksheet 2= The Themes (p. 43). Worksheet 3=Analyst's Notes While Reading a Case Report (p. 45). Worksheet 4=Ratings of Expected Utility of Each Case for Each Theme (p. 49). Worksheet 5B=Matrix for Generating Theme-Based Assertions from Merged Findings Rated Important (p. 59). Worksheet 6=Multicase Assertions for the Final Report (p. 73). At the point of Box 6 above, Stake offered three choices or Tracks for the analysis, reflecting different degrees of focus on the individuality of cases versus generalization. For this study, Track Two was used, to recognize the individual variation between cases, but still generate overall understandings that applied across cases. Boxes 6 to 9 describe the process of implementing Track Two.

Challenges posed by aspects of the cross case analysis. Some aspects of the cross case analysis were more difficult than others. The reasons for this are considered next, and strategies employed to overcome the difficulties are described. The Steps referred to are those outlined in Figure 4.4 above.

Firstly, it was noted that Stake (2006) offered guidance on the basis that the individual case studies may well have been conducted by different researchers or teams. As this was not the situation with the present study, some of the processes were supported by my familiarity with the data. Equally, this meant that care needed to be taken to look at the cases afresh, and to avoid prejudging the analysis.

In Step 4, rating the case studies in terms of their utility for providing information about the Themes (Stake, 2006) was difficult, as it seemed that all cases had generated information about the Themes. Nonetheless the step was attempted, and, as the process progressed, it became apparent that some of the cases indeed contributed more understandings about some questions than others. For example, when writing up the cross-case assertions, Case Four, Dana, contributed much useful information about the barriers to participation, but little about the facilitators. In contrast, Case Five, Bob, contributed less information about the facilitators and barriers to participation than other cases.

Identifying the key findings from the cases (Stake, 2006) in Step 5 was assisted by the maps and conceptual model that had been generated earlier within each of the individual cases, although careful reading was also required to look at the cases afresh. As it eventuated, some important new understandings began to emerge around this time. One instance of gaining new insights into the data occurred when I noted that a group of subcategories which had been depicted on individual case diagrams under the heading "People," tended to fall into four distinct groupings of skills people used when they did things to promote participation; Driving, Leading, Including, and Performing. At this point, the notion of participation skills was added to the conceptual model. A blue spiraling line was also added to the model, to illustrate the changes that took place in people's participation skills in the context of Shared Occupation. The altered conceptual model can be seen in Figure 6.2, page 139, where it is used to illustrate the assertions which were developed out of the cross-case analysis.

The process used for Step 6, entering the merged findings onto Worksheet 5B, varied slightly from that in Stake's text (2006). Stake suggested noting the number of times a case contributes to a merged finding. Although there was variability across

cases, it was evident in the maps that almost all cases had contributed strongly and multiple times to each of the key findings identified for the cross-case analysis. It is possible that this reflected the fact that the case studies had all been completed by the single researcher, resulting in some congruity across cases. Further, the reporting style used in the case studies was different to that used by Stake; to support clarity of the answers to the research questions, and accessibility for readers, the reports had a greater emphasis on explaining and illustrating themes as opposed to writing longer, narrative accounts. Therefore, rather than enumerating the number of occurrences each case study made to a finding, it was found to be more useful to highlight instances where a case had not contributed to a merged finding.

The process of Step 7, grading the merged findings according to their importance for answering each research question (Stake, 2006), was difficult: the findings about things that were important also seemed to provide information about facilitators and barriers. In response, most of the findings were classified as highly important for Research Question One. The remaining two findings, which characterized the problematic aspects of participation, and solutions to those problems, respectively were related to Research Questions Two and Three about facilitators and barriers. Once this process was completed, it was found it had prompted thinking about the most important aspects of participation that could be used to promote change.

The Assertions that were developed out of the Cross Case analysis were written up, and are discussed in Chapter Six. They are supported and illustrated with excerpts drawn from the original raw data.

Features and strategies that support validity and generalization.

As discussed in the methodology section of this chapter, case study researchers are concerned with the validity of their findings. They further see validity as foundational to enabling readers to experience and learn, or take on propositional knowledge from the case, supporting them to judge and apply that knowledge in other situations. Towards this end, in the present study, a number of features and strategies help readers to validate and generalize the findings. In line with Dewey's rejection of "ideal" forms of knowledge (Dewey, 1938/2008b), and arguments by Barbour (2001) and Simons (2009), it is recognized that such strategies do not guarantee the truth of an account, but rather that they provide support, and that their value should be considered within the overall context of the study. The features and strategies are discussed in Table 4.3.

Table 4.3: Features and Strategies Supporting Validity and Generalization

Feature or Strategy	Explanation and Examples
Information about the researcher and her views (Stake, 1995)	Information about me and my theoretical understandings are provided in Chapters One and Two, and in the understandings recorded from the pre-suppositions interview in Appendix 4.3. This allows readers to perceive my position in relation to the data, and to weigh up for themselves the value of the interpretation and assertions generated.
Detailed and clear description of methodology (Yin, 2003b, 2009)	The reader can judge the logic of the study design, and its appropriateness for answering the research questions. Clear articulation of the study's conceptual framework shows the rationale for topical information sought, and the data sources used in the case studies. Decisions undertaken at different stages in the research processes are transparent for readers.
Cultural support (Health Research Council of New Zealand, 2010; National Ethics Advisory Committee, 2012b)	For this study, there was a requirement to undertake the study in accordance with the Treaty of Waitangi, including principles of partnership, participation, and protection. In this way, the research can support quality research that promotes health for Māori, and adequately informs policy and practice. Cultural support facilitated recruitment of participants of Māori heritage. Relationships were able to be forged with those participants that aided communication. Observations and interpretations were checked with the cultural support person, and adjusted as needed to best convey participant perspectives.
Reflection (Simons, 2009; Stake, 1995)	Reflection is frequently mentioned in case study texts, but the use of reflective journals and memos is not an overt part of the research process. Nonetheless I kept a reflective journal for this study. A reflective approach was enacted by being responsive to new avenues for data collection, and by adapting the study design thoughtfully when problems such as recruitment difficulties arose. My individual responses were captured in the diary. Reflection supported interpretations, and provided a record of alternative explanations considered and analytical decisions made. It supported my awareness of my perceptions and decisions. <u>DIARY EXAMPLE: 09-04-08 Case Study One:</u> Reflections on School Observations: <i>Independence vs interdependence. As a society, do we nurture and influence and enculturate our children to be independent, to the point that "interdependence" would be a foreign notion? In the classroom I see children all working along on their own pieces of work. Achievement is individual. They have groups going, but only earn points for their group for their individual behavior, not collective collaboration/co-operation. I need to check though, if there are group projects happening</i> ". In Case Study One "Interdependence" was later interpreted as "Being a Part of". In Case Study Two, similar concepts were eventually interpreted as Connection.
Audit trail (Houghton, Casey, Shaw, & Murphy, 2013)	Decisions about adjustment to the research design were recorded so that readers may judge the rationale underpinning those decisions. <u>EXAMPLE Case Study One:</u> It was initially planned to interview only one teacher at children's schools. After completing observations at school and interviewing Anna's teacher, reflection on the data suggested that adjunctive teaching staff, such as teacher-aides or special education staff were likely to have longer experience of working with the children than the teachers. On discussion with supervisors, a decision was made to gain ethics permission (05/02/08) to recruit additional teaching staff to the study.
Triangulation (Houghton et al., 2013; Simons, 2009; Stake, 1995, 2005)	Multiple participant perspectives, and multiple data collection methods help to confirm the findings, but also provide breadth of information and insights into differences between cases.
Prolonged engagement (Houghton et al., 2013)	I engaged with the six case studies over 2 ½ years. Data collection involved 33 interviews, each 30-75 minutes long, and 24 observations sessions, each 30-90 minutes long. Further time was spent reading and analyzing case notes.
Analytic decisions were mapped	Readers may view the maps and cross-reference the information to the raw data. The validity of descriptions, relationships, and interpretations can be considered by readers.
Iterative processes, such	Decisions and interpretations were questioned in the light of new data, experiences,

as progressive focusing (Simons, 2009; Stake, 1995; Yin, 2009)	emergent understandings, and existing theory. I looked back as well as forward, and changes and refinements to the conceptual framework, plan, or interpretations were made where indicated.
Peer debriefing (Houghton et al., 2013)	<p><u>EXAMPLE Case Study One:</u> A page of further Topical Questions were recorded for the interview with Jan (mother) subsequent to observations and interview with Anna (child). The page reflects on previous data gathered, and indicates the emergence of future understandings about Changeability. Here, Anna is noted as having “<i>fluctuating function</i>” (later interpreted as “<i>changeable</i>”), with a prompt to ask more about it. There is also a note to ask how Anna’s friend’s mother “<i>learned how to help</i>” - Learning was later identified as an important theme in the cross-case assertions.</p> <p>Coding decisions and interpretations were checked with a supervisor. In some instances this prompted alternative interpretations, in others it confirmed the interpretations made.</p> <p><u>EXAMPLE Case Study One:</u> The categories interpreted and diagrammed were regularly reviewed by and discussed with a supervisor. A query was made over the category of Time, which seemed to be about the duration and timing of activities. After discussion, and testing the fit of options, the category of time was re-interpreted as including both “<i>Time Frames</i>” and “<i>Routines</i>”.</p>
Member checking (Houghton et al., 2013; Stake, 1995)	Transcripts were made available to participants for checking. Participants were provided with a copy of the cross-case analysis report. No changes were requested by participants, suggesting accounts were acceptable to them.
Reports employ straightforward language, diagrams. Raw data illustrates interpreted and alternative explanations. Participants and contexts are clearly described.	Case study reports employ straightforward language and diagrams to support reader accessibility. Raw data and alternative explanations assist readers to reflect on the validity and value of interpretations, and to consider other possible perspectives. Description and illustrative excerpts are provided about the participants, the context for the research, and the context of data collection. This provides a background for interpretations, and supports readers to learn and generalize the information to their existing understandings and to other situations.

Summary

This chapter has described the case study methodology and the methods used to explore Aotearoa New Zealand children’s participation after TBI. Rationales have been provided for the decisions made at the different stages of the research process, and actions are illustrated with excerpts from the case studies. Chapter Five provides one of the individual case study reports from this study. The remaining case study reports are appended on Disc One, Appendices 5.1-5.5. Chapter Six reports on the findings of the cross-case analysis.

Chapter Five

Research Phase One: Case Study Findings: Individual Case Study Reports

The previous chapter outlined the case study methodology and the methods used to answer the following questions: From the perspectives of the children¹¹, their whānau/parents, teachers, and rehabilitation providers, and from an observational perspective

1. what are the aspects of participation that are important to Aotearoa New Zealand children who have had a clinically significant TBI, and
2. what are the facilitators and barriers to their successful participation?

Six case studies were undertaken. This chapter presents the findings of the six case studies.

Sequence in which the Findings are Presented

The content and sequence of this chapter are outlined in Figure 5.1 below. First, a brief overview is provided of the six cases. Next, one of the individual case study reports is presented in full: Case Study Six: Ash. In keeping with the confines of PhD presentation requirements, only one case is presented in full in the body of the thesis. The rationale and process for selecting this case for inclusion is outlined. Details of the remaining individual case study reports are presented on Disc One, Appendices 5.1-5.6. The cross-case assertions that were developed out of the six cases are reported in Chapter Six. For participant confidentiality, demographic details have been changed, and some names have been excluded.



Figure 5.1: Contents and Sequence of Chapter Five.

¹¹ The term “children” used in this chapter, refers to children with TBI, unless otherwise specified.

Overview of Case Studies One to Six

Table 5.1 provides an overview of the six cases. It is intended to provide a reference point for the individual case discussed in this chapter, and for the cross-case assertions and illustrative excerpts reported in Chapter Six.

Table 5.1: Overview of Cases One to Six

Note: y. = years; m. = months; GCS = Glasgow Coma Scale (Teasdale & Jennett, 1974); PTA = Duration of Post Traumatic Amnesia; TBI = traumatic brain injury; PT = physiotherapy; OT = occupational therapy; SLT = speech language therapy; AMs = mornings; PMs = afternoons. For explanation of the School Years in Aotearoa New Zealand, refer to Disc One, Appendix 7.1, School Grades and Ages Table.

Case One: Anna

Female. **Age:** 10 y. **Age at Injury:** 1 y 2 m. **Time Since Injury:** 8 y 10 m.

Injury Details: Frontal contusions, diffuse axonal injury, fronto-parietal fracture

GCS and PTA scale not available. Rehabilitation reports classify TBI as severe. Has hemiplegia. Vision, speech, and learning difficulties.

Treatment and rehabilitation: Hospitalized 22 days. In-patient rehabilitation 6½ months. Regular surgery and rehabilitation to address orthopedic issues secondary to TBI. Currently receives PT, OT, SLT.

Community: Growing semi-rural township.

Culture: New Zealand European.

Family: Lives with mother and younger brother.

School: Attends full time in Year 5/6 class at local primary school. Moving to intermediate school.

Anna's participation: Anna occasionally plays ball games with her class at school, but is not able to play weekend sports. She was asked what was important about playing soccer. *"Then well like I can be in like a team"* (Child Interview, p. 168).

Case Two: Tish

Male. **Age:** 11 y. **Age at Injury:** 9 y. **Time Since Injury:** 2 y.

Injury Details: GCS 8/15. In a coma 3 days. Learning difficulties.

Treatment and rehabilitation: Hospitalized 4 weeks then discharged home. Currently receives OT and SLT.

Community: Small rural township.

Culture: New Zealand Māori.

Family: Lives with father, stepmother, older brother, and two stepsisters. Visits mother in holidays.

School: Attends full time in Year 7 class at local primary school.

Tish's participation: Tish is in the school kapa haka group. He is hoping to be able to play rugby again. Meanwhile he enjoys using his playstation. *"My bestest game would be Getting Up Under Pressure...It's got this fella in it. He shoots and fights and runs around and does missions and all that. He goes in to wars...Not in a gang, he's just got mates walking around with him. Oh, he's got this house ...that becomes his place where he is, chills out. And he's got heaps of mates in there"* (Child Interview, pp. 40-41).

Case Three: Anton

Male. **Age:** 11 y. **Age at Injury:** 6 y. **Time Since Injury:** 5 y.

Injury Details: GCS 3/15. Seizures, ataxic movement. Requires a high level of support with communication, behavior, safety, and daily activities.

Treatment and rehabilitation: Hospitalized 4 weeks. In-patient rehabilitation 11 months. Currently receives PT at school.

Community: Semi-rural outskirts of city.

Culture: New Zealand European.

Family: Lives with father, mother, younger brother.

School: Attends full time in Year 7 in a special needs class across the city.

Anton's participation: Anton has a carefully structured program of activities with teachers and other students who have special needs in his class. He enjoys going to scouts and swimming after school, but is often unwell after seizures. He was observed at his holiday program. *"A teacher aide holds out a basket of plastic toys. Anton starts picking out toys, but is prompted, 'Choose. You can't throw them on the floor' ... Anton picks out one small colored toy and is taken back over to the black couch where he sits down with his toy in his hand in front of the TV.... He rests down on the couch... staring fixedly at the plastic wheel with a small colored object inside it. He looks momentarily at the TV, then returns to staring at his toy"* (Observations, Holiday Program, pp. 3-4).

Case Four: Dana

Female. **Age:** 10 y. **Age at Injury:** 8 y 9m. **Time Since Injury:** 1 y.

Injury Details: GCS 5/15. PTA 21 days. Experiences fatigue, cognitive difficulties.

Treatment and rehabilitation: Hospitalized 3 weeks. In-patient rehabilitation 10 days. Currently receives OT and SLT.

Community: City suburb.

Culture: New Zealand Māori.

Family: Lives with mother, mother's cousin, and younger sister.

School: Attends 5 AMs and 3 PMs in Year 5 in a nearby primary school.

Dana's participation: Previously active in swimming, hockey, netball and cricket. She is learning to swim again at school. *"She wasn't even allowed to go out at lunchtime. She'd be in a computer suite in the library.... When she ran on concrete and she thought [X] might find out she was really worried... she knows [X] has the power to say 'that's it, not this, not that'"* (Interview, p. 18).

Case Five: Bob

Male. **Age:** 12 ½ y. **Age at Injury:** 10 y 8m. **Time Since Injury:** 1 y 10 m.

Injury Details: GCS 5/15. PTA 9 weeks. Experiences fatigue, and difficulties with memory and speed of information processing.

Treatment and rehabilitation: Hospitalized 4 weeks. In-patient rehabilitation 12 weeks. No longer receiving therapy.

Community: Semi-urban seaside community.

Culture: New Zealand European.

Family: Lives with mother, father, and younger brother.

School: Attends full time in Year 7 at local primary school.

Bob's participation: Previously active in swimming, rugby, hockey, athletics, marathons, cycling, and skateboarding. Swimming, running, and cycling again. *"[The pediatrician] she says 'oh nah, he won't be playing [rugby] again'. And he was quite upset at that. And then when we went to [another pediatrician] the guy says 'absolutely not' and he broke down in tears and started crying and he says 'but all I ever wanted to do is be an All Black' and that was quite hard"* (Father, Family Interview, p. 59).

Case Six: Ash

Male. **Age:** 9 y. **Age at Injury:** 2 y 6m. **Time Since Injury:** 6 y 6 m.

Injury Details: Fronto-parietal skull fracture, cerebral contusions, petechial hemorrhages, a L) subarachnoid hemorrhage, diffuse axonal injury, shearing injury to basal ganglia. GCS and PTA scale not available. Rehabilitation report classifies TBI as moderate. Has hearing difficulty, experiences fatigue, and behavioral disturbances if stressed. Learning difficulties. Needs prompting with self-care tasks.

Treatment and rehabilitation: Not currently receiving therapy.

Community: City suburb.

Culture: New Zealand Māori.

Family: Lives alternate weeks between mother and father.

School: Attends 4 days/week in Year 4 at local primary school.

Ash's participation: Ash enjoys swimming, watching movies, and playing with his father's dog. He has begun learning to play drums, and takes part in kapa haka. *"The children come and sit on the mat again when the writing time is over. Ash is sitting very much on the edge of the group... I don't think he is listening. Other children are talking to each other, but do not talk to him. He is not contributing to the discussion"* (Observations, Room 5 Morning, p. 1).

Selection of Case Six for Inclusion in the Body of the Thesis

This section presents the full case study report for Case Six, Ash. Whilst similar themes relating to participation were seen across all cases, no single case could be considered as typical. In deliberating which case to present in full in the body of the thesis, I reflected on the cases that might best reveal the perspectives underlying the cross-case assertions; the breadth of understanding that was generated by the different perspectives involved in each case; and the depth of understanding each case provided about the children's participation. The decision was also guided by the processes used in the cross-case analysis, where there was systematic consideration of factors for each case, including constraints on the data gathered, unique features, the prominence of the themes, and the ability of the case to provide information about the themes (Stake, 2006). In weighing up these factors, Case Study Six best met these criteria. This case also illustrated the complexities associated with longer-term participation issues.

Contents and Sequence of Case Study Reports

The case study reports include the following information:

- An introduction to the child at the center of the case. The posters developed by the children are shown, the exception being Anton who was not able to participate in an interview;
- The second page of each case study lists the contents. It provides keys to the abbreviations used to identify data sources for illustrative cited excerpts and to the colors used to signify different participation contexts;
- The participants and other data sources which informed each case study;
- A time line of key events for the children following their injuries, apart from Case One due to this child's young age at injury. Dates given on the time line refer to the month/year of events;
- The occupations¹² in which children had recently participated at the time of data collection;
- The conceptual model illustrating the important aspects of the children's participation that was developed during the mapping process for the individual cases. The categories within the model were able to be applied across all cases, and are also

¹² The word "occupation" is used throughout the case studies and cross-case assertions in preference to the term "activity" as it was felt to better convey the idea that the meaning of the activity was important. The term "occupation" is defined in the Glossary.

referred to in the next chapter which outlines the cross-case assertions. However, the subcategories varied according to cases.

- For each case, the categories and subcategories which form the diagram are explained and illustrated with excerpts from the data in subsequent pages. Page numbers provided in the citations for illustrative excerpts refer to the page number in the relevant interview transcript, observation narrative, or rehabilitation report. Alternative interpretations that were considered for some of the categories and subcategories are presented in text-boxes.
- Each case concludes with an overall characterization of the participation problems faced, and the solutions that were being used to address these problems.

Case Study Six is presented next.

Case Study Six: Ash

Ash is 9 years old. His mother Jessica is Samoan, and his father Piri is New Zealand Māori. He lives with his mother Jessica in a home with another family in Clearwater. A number of families who serve in the armed forces live in this suburb, their children attending the same pre-school, then going on to school and college together.

Piri still serves in the army, but now lives across town. He has been separated from Jessica since Ash's babyhood, but he cares for Ash every second weekend. Last year, Jessica left the army, and spent 8 months in another area of the country completing her training as a nurse. Ash lived with Piri during that time. Jessica now works shifts.

Ash sustained a moderate TBI in a pedestrian versus car accident when he was 2 ½ years old. His injuries included a fronto-parietal skull fracture, cerebral contusions, petechial hemorrhages, a left subarachnoid hemorrhage, a diffuse axonal injury, and a shearing injury to his basal ganglia. Ash has a significant hearing impairment,

experiences fatigue, and has behavioral disturbances when stressed. He is independently mobile, but has subtle balance difficulties, and has difficulty with activities requiring fine manipulation. He requires prompting to complete self-care tasks.

He attends a Year 4 class at Clearwater Primary School 4 days/week. Ongoing community-based rehabilitation services were only discontinued a year ago, although a recent review has recommended further involvement of an occupational therapist and a psychologist.

Ash loves swimming, watching movies, and playing with his father's dog, Dino. He is a skilled drummer, has fun performing parts from favourite movies, and takes part in kapa haka performances with his school. Last year he was in the school mini-ball team, and has also tried playing T-Ball. For the holidays he often flies down to the South Island to spend time with his uncle and cousins.

Whānau

"They are like a huge support network... Yeah, all his connections" (Jessica, MI, p. 1)

All it takes is a Tennis Ball

"On the last Christmas here, all his cousins, hundreds of them.... They've got heaps of stuff to do. They're all stand offish at first, sussing each other out but then they, all it takes is a tennis ball or something and away they go" (Piri, FI, p. 15).

On the Edge

"The children come and sit on the mat again when the writing time is over. Ash is sitting very much on the edge of the group. Again, I don't think he is listening. Other children are talking to each other, but do not talk to him. He is not contributing to the discussion" (Obs R5, p. 12).



Case Six: Ash

Contents of Case Study Six

<ul style="list-style-type: none"> • Introduction to Ash. The poster Ash made about his occupations..... • Contents of the case study. Key to the abbreviations used to identify quotations..... • Display of participants & data sources in the case study. Quotations provide information about the data..... sources & Ash • Timeline of key events since Ash's accident..... • Ash's recent occupations. Quotations illustrate some of the occupations..... • Diagram: What was important about Ash's participation • Discussion: Important aspects of Ash's participation: The concepts in the diagram are explained & illustrated • Qualifying the problematic situation..... • Determining solutions..... 	Page 1 2 3 5 6 7 11 26 28	Key to Colors for Participation <div style="display: flex; align-items: center; margin-bottom: 5px;"> <div style="border: 1px solid green; width: 20px; height: 10px; margin-right: 5px;"></div> Green Family </div> <div style="display: flex; align-items: center; margin-bottom: 5px;"> <div style="border: 1px solid yellow; width: 20px; height: 10px; margin-right: 5px;"></div> Yellow Community </div> <div style="display: flex; align-items: center; margin-bottom: 5px;"> <div style="border: 1px solid blue; width: 20px; height: 10px; margin-right: 5px;"></div> Blue School </div> <div style="display: flex; align-items: center;"> <div style="border: 1px solid pink; width: 20px; height: 10px; margin-right: 5px;"></div> Pink Rehabilitation (medical) </div>
---	--	--

Key: Abbreviations used in citations of data sources for Ash's case study			
R	Researcher	SFI	Special Education Needs Coordinator(SENCO)/Family Friend Interview
MI	Mother Interview (Jessica)	Obs CWS KH	Observations - Clearwater School Kapa Haka practice
FI	Father Interview (Piri)	Obs Rm5 MonAM	Observations – Room 5, Monday morning session
CHI 1	Child Interview – poster-making (Ash)	Obs Rm5 FriAM	Observations – Room 5, Friday morning session
CHI 2	Child Interview re drums (Ash)	Obs Rm5CT	Observations – Room 5, Circle Time
CHI 3	Child Interview re play (Ash)	Obs Rm5R	Observations - Room 5, Reading
GMI	Grandmother Interview (Annie, Nana 1)	Rehab SNA	Rehabilitation Document: Support Needs Assessment report
GFI	Grandfather (Puru) & Step-Grandmother Interview (Nana 2)	Rehab IEP 09	Rehabilitation Document: Individual Education Plan 2009
TI	Teacher Interview (Brenda)	Rehab IEP 10	Rehabilitation Document Individual Education Plan 2010
TAI	Teacher Aide Interview (Sylvie)	Rehab ESAR	Rehabilitation Document: Education Support Assessment report

NB: Demographic details, including dates & the gender of some participants have been altered throughout the case study to support participant confidentiality

Contents & Key to Abbreviations & Colors

Jessica: Ash's Mother

"I guess, for us the main, important thing was him to mainstream ... I just wanted him to mainstream.... Yeah & just progress through.... He's in group reading now, & that's huge, for him. It's normally been withdrawn, one on one. But he's at the level of like four other kids. So that's an achievement in itself for him. So just keep him on track, just keep channelling into the reading.... How he fits into the scheme ... Yeah, how he fits into the scheme of things"(MI p. 3).

Piri: Ash's Father

"I think it was me that wouldn't let him do it. Because you know he'd jump in the shower & I'd think geez what if he went straight to hot & got burned.... Even Jess said that to me, she said 'man you've got to let him do some things'. Like even ride the bike. I was saying 'You should ride on the inside ... What if he falls over ... What if somebody picks him up?' Far! Yeah, but even my mates, go 'Far bro, you've got to let him just go man'" (FI, p. 11).

"That's one thing I want for him too, is to get him ... teach him little bits, but more into his culture.... Learning the ways of when you go onto marae you know ... I make him learn you know, get up there & get in there & do the dishes you know, make sure you take your hat off when you go somewhere ... just respect, values.... he's been to a few funerals, & he's still a bit scared about it.... Thinking back when I was young then, I was scared too. I never growl him you know, I just go 'oh well, don't worry, just go around & give everyone a kiss & you know, a hongi [nose rub]"(Piri). "I get shy" (Ash). (FI, p. 14).

Ash

What I'm Good At: "Playing with my dog, running. Drawing. And, um, climbing trees. Playing football (ripper). Listening and writing" (Ash, Ch13, p. 10).

"You didn't like the video of your drums?" (R).... "I, I don't like it.... It's because, I get little bit ... I got, got shy & I, forgot my drum sound" (Ash, Ch11, p. 14).

Annie, Nana 1

"We play on the Wii. Been to the craft shop. Just something to do so that he's not just in front of the t.v.... Well he says he's allowed to because he's resting. I said 'yeah, but is he allowed to watch it?' ... Well that must be part of his um, rehab.... And um, swimming. We're spending a lot of time.... All my kids love the water.... Yeah we were raised on you know, anything to do with the sea" (Nana, GMI, pp. 5-6).

"I did kapa haka. Rimu [cousin] did kapa haka. Wiremu [cousin] did kapa haka" (Ash). "Yeah at school, & then as he gets older ... he can go in & join a club. But that's good. That's really good. Good for him & mixing & learning the reo [Maori language]. And it's physical. You know especially for the boys. The haka and all that" (Nana, GMI, p. 23).

Puru & Nana 2

"I guess I'm a little bit protective of him too at times you know. Is he going to be alright down there [visiting a neighbor]? Are they going to treat him alright?"(Puru, GF1, p. 13)

Brenda: Ash's Teacher, Clearwater School, 2010

"Last year's teacher seemed to pull him out quite a bit ... Whereas this year we really tried to pull that back in and try and tighten that right up ... try and work, operate in a classroom ... make him realize that there are boundaries there and he's got to try and conform. So sort of to pull that back quite a bit" (TI, p. 1).

Sylvie: Ash's Teacher Aide, Clearwater School, 2010

"You see I think he sees himself, he is a part of the class ... At the beginning of the year he would just get up and wander away.... Now he'll sit on the mat, and he'll listen and he knows that he's doing what everyone else is doing ... he doesn't wander off.... I think it's really important ... not to focus so much that he's got a head injury, even though you're aware that he has and he is different" (TAI, p. 3).

Katrina: SENCO, Clearwater School, and Family Friend

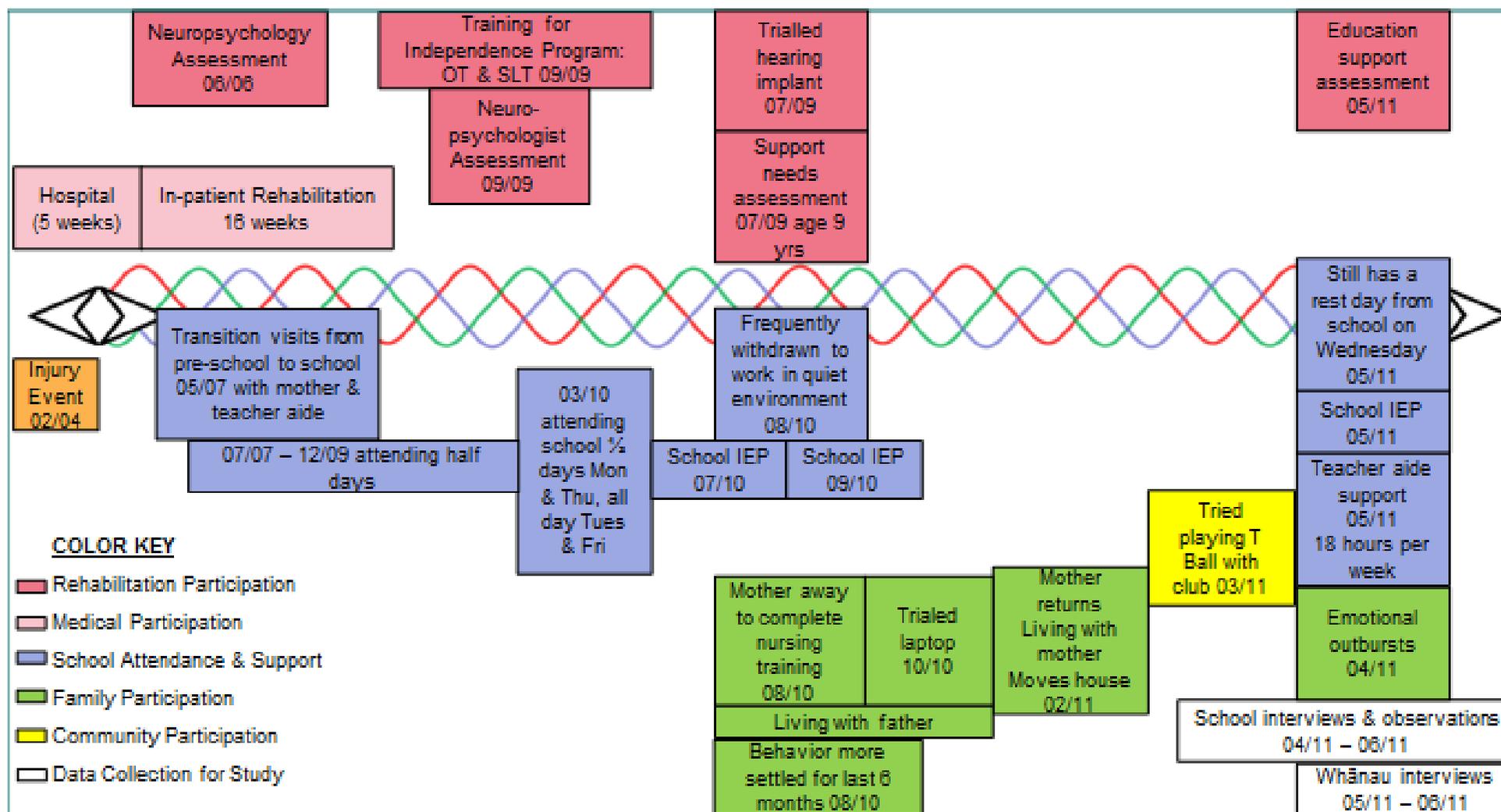
"When he first started school he was heavily reliant on his teacher aide ... the transition period into school was, slow, and he was heavily supported.... and then probably, 18 months he was only having half days ... because he couldn't handle his fatigue.... Through the years his level of concentration and his time at school has extended" (SFI, p. 2).

Observations Clearwater School: Year 5 Room 2 Classroom Visits and Kapa Haka Practice

"This is going to be class collaborative problem solving [about how playground games can be changed to be safer]. The children have to work in small groups.... tricky with so little room. Ash's group chooses rugby to change. The noise levels are really high, and each of the children in Ash's group are shouting different ideas over the top of each other.... One girl comes up with a good idea, then Ash promptly comes up with another idea, to hug the other person instead of doing a tackle. This is a really appropriate idea- Ash has obviously understood the goal of the discussion.... Unfortunately his idea is put down by another boy in the group, and when Ash attempts to defend his idea he is shouted down. The other boy moves back from the group and starts writing his own ideas down on the paper. Nobody has listened to the girl's idea" (Obs Rm5CT, p. 3).

Rehabilitation Reports

"... he is working at an academic level that is well below that of his class mates. He is removed from class for reading recovery with RTLB [Resource Teacher for Learning and Behavior]. Small group work is encouraged by his teacher aide to facilitate social skill development and modeling of appropriate behaviors. Ash currently has teacher aide support for 18 hours a week" (Rehab SNA, p. 7).

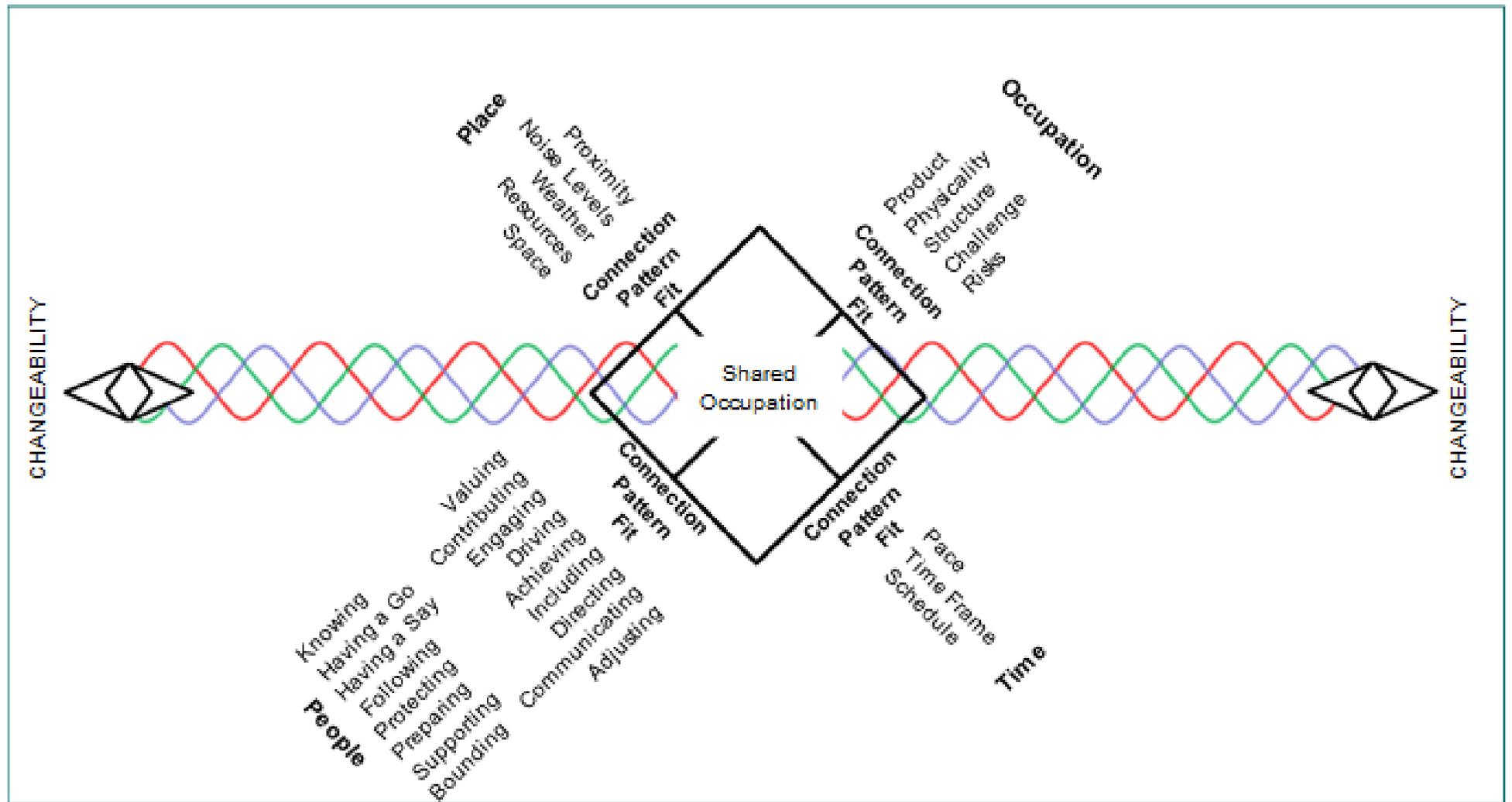


Time Frames for Key Events & Changes for Ash since Injury

Occupations with Whānau	Getting ready for school, being picked up from school, traveling home with father, having a shower, having dinner at the table, boxing training with father, play with same-age peer after boxing, going for runs, shopping with dad or nana, helping Puru in the garden, helping Puru feed the animals and collect eggs, fishing with Puru, attending tangis (funerals), unveilings, & reunions at marae, sleeping at the marae, helping in the kitchen at the marae, playing Wii tennis with dad or nana, skateboarding with nana, swimming at the pool with nana, watching uncle's new baby with nana, going to Waka Ama, camping up north, going to the beach, going eeling, swimming at the beach, playing ball or cards with cousins at family parties, learning waiata, playing and drawing with cousins in garage, travelling to and staying with whānau in Christchurch, jumping on the trampoline with Rimu or neighbor's child, watching TV, riding bike around the school with mum, watching movies, X Box games, coloring pictures, boy things in the back garden with Mike (owner of flat) – hardware store, putting up a basketball hoop, painting, play date with a friend (recent), reading books, fantasy stories on CD, climbing tree
Occupations with pets	Feeding the dog (Blue), walking Blue, running on the grass with Blue, wrestling with Blue, swimming with Blue, sleeping with Blue, petting the cat

Physical Education	Cross country training, jump jam fitness circuit, class gym lessons
Extra-curricular Occupations	Miniball, t-ball, basketball, going to individual drum lesson, playing drums at assembly, kapa haka: includes karakia (prayer), introduction, and learning waiata
Class Occupations	Roll call, planning for school camp, listening to story with Sylvie (teacher aide), class discussions on the mat, playing cards with a peer when other children at bible study, circle time, buddy reading with younger peer, learning spelling with a peer, maths games with Sylvie, maths with teacher & a peer, dictating stories to teacher aide, publishing stories with peer, testing (e.g. science knowledge), going to library for quiet-time, reading a book on couch in corner of classroom, going for a walk with Sylvie, listening to stories on the CD with a peer & Sylvie, card games & reading with supplementary learning support (SLS) teacher
Playground	Rugby ripper, playing on the field, walking around the playground, tackle ball

Ash's Recent Occupations



What was Important about Ash's Participation?

Changeable Participation Over Time with Others

The twisted strand in the diagram represents the way Ash's participation was intertwined with other participants, & the way this participation evolved over time. Multiple short-term changes meant travel, and temporary shifts in and out of different caregiving and living situations for Ash. Changes occurred at weekends, holidays and in response to his parent's work and study demands. People moved in and out of his life, with changes of teachers, support people, and rehabilitation staff. *"His team ... like his case workers and his support OTs and um physios and things like that have changed, numerous times over the years.... We'll just get notification that so and so case worker has finished on Ash's case and now our point of contact [at ACC] is someone else.... we've given him a term to settle into school and settle into home because his mum's come back from college"* (Katrina, SFI, p. 4).

Arrows point two ways, indicating participants looked to the past, but were also concerned for the future. The accident triggered a violent change in the course of Ash's life and that of his whānau. It changed life plans for Puru, Ash's grandfather. *"I worry about him, I worry about his future. I had plans for him when he was a little fella. And it all got chopped to bits"* (Puru, GFI, p. 13).

Changeability also refers to the ease with which aspects of Ash's participation could change, including change in people, time, place, and occupation. Some occupations such as classroom testing situations were not designed to be changed, and Ash was precluded from participating. He had a long-standing pattern of non-participation in

class occupations. Frequent disappearances from the classroom and withdrawal from activities suggested he had come to see himself as apart from the class. Observations of classmates also suggested they saw him as apart from them. *"The children come and sit on the mat. Ash sits on his own over on the couch reading his book. The children take no notice, seem unconcerned. They seem to accept that he is there, but doesn't always take part in what they are doing"* (Obs Rm5 FriAM, p. 6). This pattern of non-participation was proving hard to change, although by clarifying boundaries and expectations, there had been some gradual increases in his presence in class activities.

What was important about Ash's Participation?

Shared Occupation

Occupations that were shared with other participants were central to Ash's participation.

The occupations Ash shared with whānau were a rich source of participation experiences. *"Specially fishing.... Cause my, Puru, my granddad took me fishing the other day.... I caught, a little hammer head shark.... It was about, as big as my hand.... I threw it back in the water.... It was alive. And it was going rah, rah.... Yeah my granddad got a snapper"* (Ash, Ch1, p. 7). However, extending participation experiences out from whānau was also seen as essential to his wellbeing.

"There's a word called support. There's a word called encouragement.... There's times when support can be, is a really good thing, there's time when it can be a bad thing, in as much as when that support is not there, what happens? And then there's the other side, of encouragement, extending themselves and what have you. So that if the support should fail, you know they're halfway to standing up, and moving on anyway.... They've just got to have another avenue for themselves.... And the wider scope is people, outside the family unit" (Nana 2, GFI, p. 13).

Ash shared occupations with others directly, and also indirectly, such as sharing his experiences verbally and in writing. Another aspect of shared occupation emerged in this case study, where occupations and skills for those occupations were shared through inheritance and also practically amongst whānau members. *"He loves music. He'll get that,*

probably, oh you know, we're all into music, I used to DJ. My brother is in one of the, a well-known band, [not named to support confidentiality]. Ash likes reggae, he likes drums.... Oh he's been hearing it all his life you know" (Piri, FI, p. 13).

What was important about Ash's Participation?

Connections

Ash was continuously connected with, and part of a loving extended family, both living and ancestral, and with the land; his whakapapa. *"My grandmother [Ash's great-grandmother] ... Yes, she's [buried] in A., right around the coast. My brother, myself and my brother, and these are all first cousins. And we were all brought up together in the same house.... My nan brought them up because the mums were, in the city. They come to the city to work. And those are my, mum, and her sisters, and the burial site is just up over here.... That's W's son Rimu. This one here's Ash. Piri, Tai, and Tamati, the one down in Christchurch ... Tai's boy ... "* (Annie, sharing family photos with me, GMI, pp. 1-2).

Connections were further woven with others in particular places and times through shared occupation, expressed as being "with," "in there," "ties into," "close to," "joining in" or "getting on," "part of," and "fitting into." This same depth of connection was absent from rehabilitation documents, which instead spoke of "interacting", "influence," "contacts", "working with", and "remaining on task". At school, connection with teaching staff was often described by them and rehabilitation providers as "one-on-one".

Relationship was not only with others & place, but also with occupations. His mother described Ash as being "into" or "drawn to" physical and musical occupations. Ash would deeply engage in a shared occupation, shown through his focus, listening, watching, and effort.

Sharing in occupations with others meant connections could be linked through to other people, occupations, places, and times. *"Swimming! ...*

He's a fish, yeah. Yeah definitely and I think a lot of that was because he did a lot of the swimming therapy [during inpatient rehabilitation] as well, so it just stemmed from that" (Jessica, MI, p. 8).

Connections between whānau contexts, and rehabilitation and school were sometimes lacking, where people in one setting were not easily able to communicate information about shared occupations with others in another setting. Ash himself had limited ability to share occupation experiences vicariously across settings. Jessica, who hadn't been aware of Ash's behavior problems when participating in class, discussed ways she could be more involved. *"He's got cross country on Tuesday I think ... and he doesn't want to do it. And I'm like, 'well if I'm not working I'll come and run it with you'. He was quite excited about that, so. Hopefully I'm not working ... Think I'm working a night shift"* (Jessica). *"Is it quite a good thing for you to be at school?" (R). "Probably for him, because around here all the mums are at school. And involved. But I'm never, been, involved within you know all those things.... I get to what I can ... But around here most of the mums can go to, all the soccer mums can go to all the school stuff"* (Jessica, MI, p. 9).

Outside of school, whānau provided opportunities to share in occupations with children of a range of ages, although Ash tended to connect more easily with younger children, and also had a close connection through play with Blue, his father's dog. *"A lot of the time Ash relates to, kids that are a little bit younger than himself.... He gets on good with babies. You know like a lot of kids wouldn't bother but he does.... he just likes younger kids"* (Puru, GF1, p. 2).

What was important about Ash's Participation?

Pattern

At school, there was a pattern of Ash's occupations being apart from other children, sharing instead with adults, or one-on-one with another child with a disability. *"He is removed from class for reading recovery.... Ash is frequently withdrawn from class to a quieter environment with his teacher aide during writing tasks to increase his concentration"* (RehabSNA, pp. 7-8). In classroom activities, when he was not working one-on-one with an adult, he often removed himself from occupations in which other children were sharing. In the playground he did not easily share in occupations with his peers. *"If you watch him at morning tea when everyone's sitting down in their little groups eating, he is aimlessly walking around.... And at morning tea and lunchtimes, he basically wanders around the playground. Just walks from group to group"* (Brenda, T1, p. 6).

Ash's patterns of participation at school were detailed, and closely monitored through rehabilitation assessments and at his IEPs. *"Currently: Ash participates well for half the gymnastics session as he is in drums for the first half. Ash is generally participating well in daily fitness. Ash is often eating some or all of his food before school starts. Strategies: Ash is to join Room 2 for the first half of their session immediately after Room 3's gymnastics. To only eat at morning tea and lunch eating times. Ash will try coming on Wednesdays from 9:00-11:25 AM."* (Rehab IEP, p. 2). Whilst patterns at school were more regular, outside of school, changes in funding, care arrangements, home setting, and in his parent's work meant frequent shifts in the pattern of participation. *"Because obviously we're going to deal with things differently, and he copes with being bounced [between people &*

places], but I mean that's another coping thing that he has to deal with as well" (Jessica, M1 p.4).

Fit

The degree to which Ash's abilities & actions were congruent with aspects of other participants, place, occupation & time involved in a shared occupation.

People's words and actions often picked Ash out from shared occupations in class, differentiating him from others who shared in the occupations, and emphasizing his misfit. Ash himself was increasingly aware of his difference. *"He's beginning to realize that he's not up to the level as other children"* (Jessica, M1, p. 2). *"Ash is sitting on a chair for a class discussion. The other children are all sitting cross-legged on the floor. Alan also attempts to sit on a chair. He is asked to get off the chair. He objects. 'It's not fair'. The staff member explains sharply that it is fair. 'Do you have something wrong with your brain?' 'No'. 'Well get off'"* (Obs Rm5 MonAM, p. 2).

What was important about Ash's Participation?

Knowing: understandings about each other's abilities and preferences, how to involve each other, places where participation was situated, and about the occupation.

"He knows what to do when we're inside a marae, when the whaikōrero (formal speech) is going, he knows you just don't get up and walk straight out, things like that" (Annie, Nana 1, GMI, p. 21).

Changes occurred in the context of shared occupation over time, and involved learning. Knowing in rehabilitation documents, was concerned with Ash's learning of curriculum content, and social skills.

Whānau and teachers were more confident about Ash's participation where others knew him.

"So yeah, I said, 'well if he goes down there [to stay at a different uncle's place], can you [Jessica] go with him? I don't want him to go down there by himself, you know because, well he doesn't really, know them'. Oh he does, but... he might do something that might, get, a bit hoha [firesome] with them, and they won't know how to handle it" (Piri, FI, p. 9).

With direction from adults, and with frequent chances to share with Ash in play, his cousins began to acquire skills at participating with him. *"It's not as though he's left out at any stage.... Through the years I've explained to them too that you know, you've got to include Ash in these things. He might be a bit slower, and they realize that.... they used to tease him a bit. I used to have to sit down and say 'hey listen, you know*

Ash's been through a bit of trauma in his life, you've got to look after him, take care, and, include him in your games and stuff like that ... have a bit of patience with him'. And they, start to realize that.... they're sort of starting to cotton on now" (Puru, GFI, p. 7).

Valuing: participants' enjoyment or like of, interest in, and preferences for a shared occupation. Participation was facilitated where an occupation was highly valued. Ash valued physical occupations, and occupations which were achievable for him.

"He likes his x-box" (Puru, GFI, p. 2).

"He's good at basketball, he loves shooting the hoops. He does great voices, he loves talking like an Aussie [Australian]. He is so funny. He would be great on stage" (Sylvie, TAI, p. 10).

Having a Go: attempting a shared occupation.

"He'll give things a go, like he really enjoys, things within the school curriculum, um, athletics, gymnastics, um, cross country not so much, but um swimming, all of the PE subjects. Um gymnastics he really thrives on that because he likes to challenge himself".

Although Ash more readily had a go at physical occupations, fear of failure or of appearing different often hampered him from having a go. *"Difficulty spelling words, and appeals for help before attempting to apply strategies to have a go himself"* (Rehab IEP 10, p. 3).

Important Aspects of Ash's Participation: People

Contributing: giving actions or ideas, or carrying out a role in shared occupation(s). Ash enjoyed having a role in class, and was responsible for taking down the chairs in the morning. He could listen, but found it hard to contribute to group activities unless in a one-to-one situation with a peer who also had a disability. His teacher felt his ideas contributed little, and his answers in class discussion were often incorrect. During a class problem-solving session, he was observed to contribute useful ideas, but they were not acknowledged by his peers.

"They had to brainstorm in the groups as many different disasters they could.... He's very passive. He's part of that group but he's actually not contributing anything (Brenda, TI, p.6).... He just listened, he didn't, contribute anything. He doesn't contribute anything that's particularly relevant"(p.9)

Having a Say: expressing preferences or making a choice about a shared occupation. Opportunities were given in class for children to choose activities, although Ash's vote (along with others in the minority) might be over-ridden. Ash often voiced a request in relation to his preferences, although his requests were often refused. For many occupations, Ash did not have a choice, and where this was out-of-line with his preference, he became upset. Much of the time, he was seen to express his preference by refusal to participate or by withdrawing from shared occupation. At home he was increasingly arguing his preference or point of view. His new teacher aide was learning to encourage him to express his thoughts with some positive results.

"I did push him a little bit, but in the end he did this amazing work like he, finished it, a sentence independently ... and I was like 'wow'. I've worked him out a bit more in the last week. But I says to him the other day, instead of getting really aggressive and angry , and sort of yelling at me, I said 'I can't read your mind. So you need to tell me, you know 'Sylvie, I'm finding this hard, I don't get it, whatever'. And we can explain it in a different way or try something else, but just going off, and he's just got to learn to channel it in a different way. And he's aware of it now" (Sylvie, TAI, p. 3).

Engaging: focusing on and exerting effort in a shared occupation. Ash found it hard to engage in many classroom occupations and was described as "needing constant checking and prompting" to "remain on task" (Rehab SNA, p. 22). He typically engaged in short bursts, although on occasion would over-engage, and become upset when moved onto another occupation. His engagement was expressed through listening, watching, concentrating, and persevering. When he was not well engaged he was described as unsettled or restless.

"It's interesting with the drums.... the level of concentration that he had, showed and he responded just so quickly to an instruction ... This child [Ash] was very receptive, absolutely quiet, very settled, and just totally focused. And this guy was introducing something new, and Ash watched it, he concentrated, and he tried so hard to master it" (Brenda, TI, p.11).

Important Aspects of Ash's Participation: People

Following: using similar actions to those used by other participants in a shared occupation. Following facilitated Ash to take part in occupations alongside his peers. "Teaming him" with another child helped him to follow the actions required for an occupation. Although Ash disliked doing things differently, he did not often follow his peers, setting himself apart from them. Following became problematic where Ash followed the actions of other children with behavior difficulties.

"He gravitates towards children with behavior issues and he'll mimic their behaviors, or learning" (Katrina, SFI, p. 8).

"This morning we had, volleyball and he didn't want to participate. But I don't think he actually understood what was going on. And when we teamed him up with somebody and he felt confident and secure, he joined in.... He had removed himself from the group. He had his back to the group.... I said well hang on, look around, everybody else is still doing it. And he just got up and joined in again" (Sylvie, TAI, p. 4).

Driving: Pressing towards participation in a shared occupation. This involved having a vision for the participation, looking for participation opportunities and "channelling" Ash into that occupation using words and actions (MI, pp. 2, 3). Ash's participation was largely driven by others, but on occasion he drove his own participation, particularly with whānau: "He makes sure that he's in there, you know" (Annie, Nana 1, GMI, p. 12). At other times he refused to be driven: "He'll go 'nah', or 'not!'" (Sylvie, TAI, p. 3). There was a concern over his continued part-time school attendance, and people had begun to drive him towards full time participation.

"I try and promote Ash maybe, mixing, mixing with other kids outside the family.... Just have those other outlets you know what I mean? Like on my side, with my nephews, it opens a whole new door for him (Nana2, GFI, p. 7).

Protecting: acting to ensure another participant's safety and well-being. Ash's whānau frequently expressed their need to protect him. This can be interpreted as a sense of kaitiakitanga, or stewardship towards Ash, but also shows their aroha (love) for their tamariki (children). Protecting was directed at ensuring both physical and emotional safety. It included tūpato or caution, safeguarding Ash in occupations that were seen as involving risk, watching out for him, and responding when he was unsafe. Piri recognized that he was sometimes over-protective of Ash, preventing him from participating. When Ash's classmates were concerned about his unsafe behavior, they stayed away from him and informed an adult.

"[Jessica] needs to 'keep an eye on him' in most situations as he is not aware of dangers and is unable to project ahead in a 'what if' scenario. Jessica reported he has poor traffic safety awareness and she would not let him cross a street without adult supervision" (Rehab SNA, p. 17).

Important Aspects of Ash's Participation: People

Achieving: performing a shared occupation to a satisfactory level. Ash was sometimes dissatisfied with his performance. In general he required support to achieve at classroom occupations, but gained pleasure from achieving without support. He enjoyed it when others recognized and shared in his achievement. Concrete rewards such as recordings, sticker charts or points, and products of the occupation meant he could share his achievement with others.

"He was typing up his writing on the computer. I showed him how... I can type like 60 words per minute and then all of a sudden of course that back-fired. 'I'm not doing it because I can't type fast'. I said 'mate, that took me 15 years to learn that!' ... he sort of looked at me and he was back into it... I said 'I'll just leave you there and let you get on with it' and he was fine ... I walked off to get something ... And he was really good. Like really good. Very pleased with himself and he said to me 'I'm being really good, I might get a certificate in assembly'. He wants the praise, he want the glory for it all. Which is fair enough" (Sylvie, TAI, p. 6).

Preparing: Readyng a person for participation in a shared occupation. Preparing included cues given to alert a person to and inform them about an occupation, teaching skills, and practice runs to ensure familiarity.

"They go down to the park for the actual cross country- another training for it. So they've asked if I'll take him down I think next week on my own and just ... walk the course so he understands exactly what the course is and how far it is" (Sylvie, TAI, p. 8).

Including: actions towards another participant that facilitate them to be involved in a shared occupation. Actions reported and observed to be used by children and adults included, Notiding, Greeting, Introducing, Inviting, Touching, Listening, Asking, Explaining, Sharing resources, Turn-taking, Reciprocating, and Encouraging. Ash himself often used inclusive actions, and his skills were recognised by his whānau. In class and in the playground, Ash's peers were seldom observed to use inclusive actions towards him. Reports of inclusive actions used by others were seldom evident in interviews with education personnel or in rehabilitation documents.

"The coach [at boxing] is real good ... it's not focused on ah, beating everyone up type of thing, but ah, fitness, friendships too. The coach is real good, he makes everybody go around, shake everybody's hand. Like when we first got there, everybody would come around in a circle and shake our hands and introduce ourselves" (Piri, FI, p. 5).

*"How are you doing at basketball?" (R) "I don't play any more" (Ash).
"Do you think you might go back to it [basketball]?" (R) "Nah" (Ash).
"What don't you like about it?" (R) "Well, cause it my cousin Kevin, he never passes the ball ... But when I have the ball he passes, he passes it to me". "You mean when you have the ball you pass it to him?" "Yeah, but he never passes it to me" (Ash, Ch1, p. 3).*

Important Aspects of Ash's Participation: People

Supporting: helping another participant to contribute their skills in a shared occupation.

Ash was initially "heavily supported" when he began school (Katrina, SFI, p. 2). His teacher described this as "guiding" and "scaffolding" (p. 1). Although the amount of help had reduced, he was still provided with high levels of support to take part in most curriculum activities. His teacher aide was learning that at times it was better to "be quiet" and "let him get on with it" (Sylvie, TAI, p. 8). At home, there had been some reductions in the support he needed to take part in household occupations.

"The [classmates] know that a teacher aide is there to work with him but then there are various teacher aides in the school helping other children for various needs or groups of children. So I think the whole school culture around getting that support, accessing support of the teacher aide, or not being able to do a set task, is very accepting.... The teacher aide helps to simplify the task and to act as a sounding board for him to complete the tasks and to um, manage his learning. And to not, not waste his learning time. Keep him on track and on task because concentration is an issue with him" (Katrina, SFI, p. 3).

Ash's support was generally provided by adults, and this was accepted by children who held back from providing support themselves. On one occasion however, another child was directed to support Ash with his publishing on the computer. She showed skill in the way she provided support, facilitating Ash to carry out work on his own where he was able. *"Mary works patiently with him, standing at his side, responding*

gently to errors, reading the words out for him, and spelling the letters for most words. She waits patiently while Ash finds letters and the space bar. Sometimes, but not very often, she points to a letter on the keyboard. More often, she helps Ash with backspacing if he has made an error.... Ash looks often to his book, and consults Mary for help, but speaks little, concentrating on the task" (Obs Rm5 MonAM, p. 11).

Directing: establishing actions and processes for involvement in a shared occupation. Occupations were directed verbally, by modeling, and through written instructions.

"The teachers cue the children with abrupt, clear commands to line up properly, and some are prompted to take off sweatshirts and place them at the side of the room. After a little while, Katrina prompts Ash quietly, and he brings me a chair. The session begins with a karakia (prayer). The teacher speaks to the children in Te Reo, encouraging them to repeat words and phrases back. The karakia is written on the whiteboard and the children practice the words. Now they bow their heads, and say the karakia together. Next the children are instructed to sit in a big circle.... When it is Ash's turn [to say his name], he is unable to speak.... The teacher speaks respectfully for him, then requests paki [clapping]". (Obs CWS KH, pp. 2-4)

Alternative Interpretation

At kapa haka, the teachers words and actions towards Ash and the other children were helping them to learn about honoring differences or rerekētanga.

Important Aspects of Ash's Participation: People

Bounding: Regulating performance, temporal and spatial boundaries, and people's involvement in a shared occupation. Boundaries were typically established for shared occupations in Room 5, although the boundaries were not always respected. The boundaries of occupations in which Ash did participate were made obvious to him to support his participation. People also recognised the importance of enforcing boundaries consistently in order for Ash to respect them. However, boundaries were also placed right around multiple occupations perceived to be unsafe for Ash, barring his involvement. Ash found it hard to cope where temporal and spatial boundaries were placed on shared occupations.

"Dad only lets him spend about an hour on it [x-box] a day" (Piri, FI, p. 12).

"He'll say to us 'oh can we go and work outside' and I ... said 'no, no, you've got your workspace here, you'll work in the classroom with us" (Brenda, TI, p. 2).

"Rough sports, he's not really allowed to get too physical" (Annie, Nana 1, GMI, p. 14).

"When there is laughing [at children who are unable to introduce themselves], teachers rebuke them firmly, requiring respectful behavior" (Obs CWS KH, p. 4).

Adjusting: Changing an occupation. Some occupations were more flexible, and could be more readily changed than others.

"Ash needs curriculum modification, even within his group tasks" (Rehab ESAR, p. 3).

Ash's teacher adjusted the way the science test was delivered to Ash. *"Brenda shows Ash a colorful diagram depicting the stages of the water cycle, and explain what it is about, prompting Ash as she goes to talk about what he knows. Ash shows some understanding, 'the water all runs up into the clouds'. Ash is given the diagram, and goes off to sit at his desk. He is told he can use the diagram to help, but that he has to write about what happens"* (Obs Rm5 MonAM, pp. 10-11).

Important Aspects of Ash's Participation: People

Proximity: the location of people to each other, to resources, and to an occupation. Ash's habitual sitting places were at a distance from groups of other children in the classroom. When he was distant from an occupation or group however, he found it harder to see and hear. In contrast, he often worked in close proximity to adults in a one on one situation, and when unsure, he placed himself in close proximity to an adult.

Close proximity of people's workplaces, homes, and school settings facilitated participation: Less time was spent in travel, and it became easier for adults and children to share in occupation together. Many of Ash's whānau lived some distance away from each other and from their tūrangawaewae (place where one belongs through kinship and whakapapa or genealogy). This necessitated increased travel, although this was an occupation shared.

"I don't like the look of him sitting in the corridor which is where he would like to be. He likes to sit on the floor with his back to the wall by my door so he can hear us.... he'll usually sit behind my white board. Or ... he likes to sit right in front of me, right at the back on the periphery, but he's swinging the door or he's not actually focused... what I try and get him to do is come and sit right next, in front of me" (Brenda, T1, p. 3).

"Which marae do you go to?" (R). "Just my home ones ... down L. coast. Dad's one which is in M, X, and my mum's which is ah, north, A. But my main one is on P. because that's where I was born, that's where his ah afterbirth is buried.... He was up there [north] not long ago, we were up there just after Christmas. So we went all the way, we went all

the way from P. [far south], we drove all the way up to the north in one day. Fourteen hours" (Piri, F1, p. 14).

Noise Levels: Ash found it hard to participate in environments that had high noise levels. Higher noise levels occurred in environments that were very crowded, but also in environments that were large and prone to echo-effects. Some of Ash's responses to noise levels may have reflected his hearing difficulties. Room 5 was an older classroom, and was crowded with the number of people in it. It is possible Ash found the acoustics in the library facilitated his hearing, as well as his concentration, although this reduced his proximity to peers.

"I have to do [maths] with him in a different room, generally it's in the library, it's a lot quieter. Because maths we get quite noisy sometimes they're doing group things, yeah so it can get noisy" (Sylvia, TAI, p. 7).

Weather: Changes in the weather prompted shifts in the types and locations of shared occupations in which children engaged.

"I took him skateboarding.... Like in the summer, it depends on the weather" (Annie, Nana 1, GMI, p. 4).

Important Aspects of Ash's Participation: Place

Resources: things in an environment that afford opportunities for occupation or which facilitate shared occupation. Rehabilitation funding and education-based funding were a resource that facilitated Ash's involvement in curriculum occupations through provision of support and specialists. However this resource equally meant that Ash shared in occupations with adults more than his peers.

Communication resources were often mentioned in the case study, including diverse modalities such as phone and email. For Ash himself, rehabilitation funding provided technical resources that were intended to facilitate his communication, such as sound systems and a lap-top. However Ash found the sound system uncomfortable, and felt the lap top singled him out, preferring simple resources such as the writing books used by his peers, recorded stories, drawing and coloring materials, and photographs.

Simple resources were also used to good effect to facilitate engagement in maths activities, including the use of fingers, or bunched straws. Whānau were aware of the way simple resources such as balls or simple tools facilitated participation amongst cousins. In particular, Ash's nana and his father valued natural resources such as the sea, water, and sand for facilitating participation amongst children.

"[Ash] plays with the kids, plays hard out. Playing, running around.... cause there's always a rugby ball around.... It's just so much for the kids to do, and because we've got the sea just down the road.... they've got the sand hill.... they go down on cardboard eh?" (Annie, Nana 1, GMI, p. 7).

Space: the open-ness of an environment. Crowded spaces were a barrier to participation, with high levels of noise and activity. In contrast, environments with very open spaces supported engagement in physical, shared occupations.

"They've got the whole run of the place virtually you know ... they're not confined to here ... all their toys are out in the garage out there ... we've only got one acre, but um, as you can see we've got all the market gardens around us, there's no neighbors apart from over there and way up in the hills, so kids can make as much noise as they like" (Puru, GFI, p. 2).

Important Aspects of Ash's Participation: Place

Product: objects or tangible outcomes of shared occupation. There was little mention of the products of Ash's occupations by adults who were interviewed. However the products of Ash's shared occupation were very important to him, and were obvious in his own interviews. Objects resulting from a shared occupation supported him to share the experience of that occupation with others.

"How did you feel when you had to go and play [the drums] at assembly?" (R) "Kind of stage fright ... my mum was proud, my step-mum and, my little cousin, oh my little brother um ... he watches the DVD all the time ... he watches it every day after school" (Ash, Ch12, p. 2)

Physicality: levels of somatosensory experience associated with a shared occupation. Physicality resulted from occupations involving heightened levels of movement or touch. Ash enjoyed engaging in occupations with high levels of physicality, but was aware of safety risks associated with some of those occupations.

"What do you do with Blue [father's dog]?" (R) "I tackle him. And I play with him and. Um, I have this control thing and it makes him go crazy. And he goes rahhh! And I play wrestling with him. And I, play tug of war with the sock! And he bites my toes. And also he bites my fingers" (Ash, Ch11, p. 10).

Structure: the actions and steps involved in a shared occupation. Occupations which had a simple structure facilitated Ash's involvement. When he learned the structure of one occupation, it helped him with understanding the structure of others.

"Format of follow-up task is the same, but has variety" (Rehab IEP 10, p. 3).

"Ash requires task to be broken down into component steps and he completes one step at a time" (Rehab SNA, p. 14).

"The more intricate games, card games, I mean it's harder for him. If it's a real straight-forward, basic sort of game ... he can be alright" (Nana 2, GFI, p. 4).

Important Aspects of Ash's Participation: Occupation

Challenge: the degree to which an occupation drew on the abilities of those who shared in it. Ash was avoidant of occupations which he perceived were too challenging or which "extended him" too far (TI, p.2). Occupations provided challenge to participants at an individual, one-on-one, or team level. Ash had little participation in team-based challenges, but did participate in individual and one-on-one challenges.

"Learning Strategies: Set 'personal best' target. Ash is working on improving his own personal performance ... working with another student with the same ability which generates a competitive edge to the lesson" (Rehab IEP 10, pp. 3-4).

"I said tennis ... that seems to be a thing that he wants to do, individual ... that's his achievement, but he still does need that team-work" (Jessica, MI, p. 11).

Risks: the dangers associated with a shared occupation. Dangers derived from the social and physical environment, and with the objects involved in an occupation. These presented risks when they became part of a shared occupation.

"I don't let him ride his bike around my area eh.... There's a lot of hoons driving up and down you know. I think Jessica lets him, oh you know, go to the school on his bike, but it's a different area. It's safe. I don't tend to, yeah, let him ride around on his bike in my area" (Piri, FI, p. 6).

"We haven't got a trampoline at my house ... I don't like those because I saw a program about them man, and most injuries with kids these days is from a trampoline, spinal injuries, back, nah, that's the last thing we need ... Oh he doesn't ride his bike at my house without a helmet. Or his skateboard. Yeah, well a skateboard's just as bad I think" (Piri, FI, p. 13).

Important Aspects of Ash's Participation: Occupation

Pace: the speed at which a shared occupation was performed. The pace at which Ash performed in a shared occupation varied, from slow through to very quick. When he was given small, achievable chunks of work, he completed them very quickly. *"Probably seven to eight words is what we try & go for & then that really helps him. He just gets it down really quickly. He seems to fill up the gaps really quickly"* (Brenda, T1, p. 2).

At other times, he went too quickly, making errors. *"Ash confuses his answers sometimes- it feels more due to impulse responses. When he is prompted to slow down & think carefully he is able to correct himself"* (Obs Rm5 MonAM, p. 6).

Time Frame: the duration or point in time at which a shared occupation occurred. Ash's tendency to over-engage or under-engage meant that time frames of his occupations were also variable. Sometimes, he would keep at a shared occupation he was enjoying for inappropriately long time frames. *"He's a water rat. He'll just stay in the water- even if it's winter he'll jump in. He'll stay in there all day. Like Christmas, we were down at my girlfriend's family, & he was in, him & the dog, & all the family were going 'Far, look at that boy & that dog down there', all day from about 7 in the morning till it started going dark"* (Piri, F1, p. 6). Other times Ash responded best with short bursts of a shared occupation. His specialist teacher recognized this, & structured her lesson with *"activities that were short in duration"* (Obs, Rm5 FriAM p. 2).

Some time frames fitted with Ash's capacities better than others. He

began his days very early with his father. This meant that his days were long, & he was often tired by the end of his school week.

Important Aspects of Ash's Participation: Time

Schedule: the arrangement of shared occupations over time. Schedules that were very regular were called “structured” by education & rehabilitation personnel. Ash’s schedules at school were highly regular, & detailed as to the times at which various shared occupations occurred. The exception was Friday, which was unstructured. In contrast, schedules at home were less regular over the time of a week, & less structured, with Ash spending time with different people out of school.

“We’re so busy, we’ve got this little window ... on Friday we’ve got children going to choir, he’s at kapa haka, so we’ve got these little windows of half an hour to do the spelling and then the basic facts tests and maths testing” (Brenda, T1, p. 3).

Schedules at home & at school were both very busy. This meant little time for whānau to spend with Ash at school to support his participation. When Ash became over-wrought, he needed time in his schedule to be alone & calm down.

“My hours have been pretty good so far with the school being able to do the week abouts. But yeah, I think he’s, he felt it this week, with me, um, working and he really wanted to ... come home, but he’s not coming home until Sunday night he’s staying with Piri until Sunday night because I’m doing day-shifts, and I’m working until Saturday” (Jessica, M1, p. 8).

Important Aspects of Ash’s Participation: Time

Dis-integrated: Ash's future was "chopped to bits" when the accident happened. Now, 6 ½ years later, Ash's ability to participate would begin to fray, then he would suddenly "go to bits", or have a "melt-down".

Misfitting: Others repeatedly highlighted the differences between Ash and his peers, labeling his abilities as at a lower level or inferior. Ash had become very aware of his difference. He saw himself as standing apart from the others. Fearing failure, and aware of people's eyes on him, comparing him to others, he often pulled away from group activities with his peers.

Unsettled: The patterns of Ash's participation were confused, and were characterized by continually shifting connections as he spent time with different family members in different places at different times, or "wandered aimlessly" around the playground, moving from place to place.

Resistant: In the face of unsettled patterns, Ash often resisted change or avoided new experiences. He found it hard to move from one situation to another, grieving when he left whānau, becoming angry when needing to stop an activity, or dawdling on his way between different classes and breaks.

Fragmented: When Ash did participate, it was typically for short bursts only. Although he had some good skills, it was often only for some aspects of an occupation. Likewise, he could carry out the actions for a shared occupation, or could interact with another in that occupation, but found it hard to do both at once.

Split: There were divisions between the different contexts with which Ash participated. Ash participated with his mother, with his father, or with extended family scattered around the country, and he participated at school, but these contexts were detached from each other, and Ash found it hard to make the connections and share information across settings. There were sometimes rules for one place, and rules for another.

One-on-One: Ash's connections tended to be with single people. He did not have siblings. He participated with one parent, or another, but not at the same time. At school, he participated one-on-one with a teacher, and sometimes one-on-one with another child, but avoided participation with a bigger group.

Imbalance: Ash spent more time with female adults, with younger children, and with girls. He spent limited time with male peers.

Uncertain: People were uncertain about Ash's future. Many, new to participating with him, were uncertain of what to expect. Ash was unsure of himself and his abilities. In unfamiliar situations, he lacked confidence, and was unclear about what to do. He was unsure of how to join in with a group.

Stretched: Many of those who shared in occupations with Ash were stretched in multiple directions. Ash's parents and teacher struggled to meet the multiple demands on their time. Jessica and Piri were often torn between spending time with Ash and workplace commitments.

Qualifying the Problematic Situation:
Longstanding Disconnection, Irregular Patterns

"The teacher aide [last year]...., she seemed to pull him out quite a bit when he was unfocused, or he'd lost his concentration, or things were too hard.... So I was a little bit apprehensive, because he used to look at me from a distance.... You know he enjoys adult companionship.... But when it comes to the structure of sitting down and settling down to routine and sticking to routine ... he finds it difficult. And knowing when to let him have the leeway, and just call it quits, or when we ... push him a bit harder, that's the fine line that I find that is hard because he ... just switches off.... He actually went to bits after you left. He had a meltdown.... I don't work with him enough, you know my teacher aide looks after him in that respect. In writing ... he's just a little thing all of his own, because the others can all write, form an idea, and put it on paper. Whereas he has the ideas, but they're all jumbled up" (Brenda, TI, p. 1).

Qualifying the Problematic Situation:
Longstanding Disconnection, Irregular Patterns

Continuity: Although connections were lacking in some areas of his life, and although Ash grieved at being physically distanced from whānau, there was always the presence of a strand connecting him to them, continuity with living and ancestral family. This thread sustained him and gave security and surety in times of uncertainty. Further continuity was provided by people in the community who remained part of his life over long periods of time.

Aggregated: By ensuring Ash shared occupation as one of a team, he was seen as a part of the whole, rather than apart.

Cottoning On: As people shared occupations with Ash, through trial and error, and working it out, people gradually "cottoned on" to him and how to participate with him. They came to know the fine line between what was comfortable for him, and how far he could be taken beyond that.

Simplified: Simple occupations meant certainty. People found that steps of more complex shared occupations that were performed one part at a time also facilitated Ash's participation.

Over and over: Certainty increased with familiarity. Patterns of shared occupation that were repeated multiple times increased Ash's confidence and that of those around him, as they learned how to participate together.

Securing: Tightening up routines for occupations, pulling loose ends in, and providing clear boundaries helped certainty when Ash was feeling unsure.

Gradual Transitions: Changes that were eased in slowly assisted Ash to learn new participation routines.

Interweaving Support: Support which was interwoven amongst participants worked as a scaffold, providing resilience. It freed up others when they were stretched. Ash's parents both had support networks through whānau and friends.

"We're typical grandparents, like when they need us we're here... we all work in" (Nana 2, p. 1).... "We try and involve him in most things we do" (Puru). "He is always ... involved with his cousins. They're all very, very close ... He feels comfortable, he interacts with them really, really, really well and you're talking from say 3, through to 12 ... because they're family, he's grown up with them, it doesn't matter about the age there ... when he's with his own relations, his whānau there isn't that [feeling uncomfortable] at all... They're treated, they're treated as a whole ... because they're all treated the same.... I try to promote Ash maybe mixing with other kids outside the family. I just think it is important for Ash to just spread his wings a little bit further. Just have those other outlets" (Nana 2, p. 6-7).

Determining Solutions:

Learning to Share Occupation: Extending Connections from a Secure Base, Establishing Patterns

Summary

This chapter has provided an overview of the six case studies which were undertaken. A full case study report has been presented for one of the cases, with the remaining reports included on Disc One.

As discussed in Chapter Four, following development of the individual case study reports, a cross-case analysis was performed across all six cases. This generated overarching understandings, or assertions which pertained to the research questions (Stake, 2006). The next chapter presents the assertions that were developed through that analysis.

Chapter Six

Research Phase One: Case Study Findings: Cross-Case Assertions

After the individual case study reports were completed, a cross case analysis was undertaken. Drawing from all six of the case studies, and following Stake (2006), 12 assertions were identified which articulated the combined key findings in relation to the research questions. This chapter presents the assertions. Readers may wish to make reference to the Overview of Case Studies One to Six (Table 5.1, pp. 106-108) in the previous chapter.

Sequence in which Cross-Case Assertions are Presented

The contents and sequence of this chapter are outlined in Figure 6.1. First the chapter introduces the reader to the cross-case assertions using a diagram that displays the concepts in the assertions and their relationships. The 12 assertions are then presented in numbered order. They are illustrated using excerpts from all six cases. The chapter concludes with a brief discussion about the relationship of the case study findings to the material incorporated in the literature review. It draws on the deeper and more extensive findings in the individual case studies, as well as the findings of the cross-case analysis.

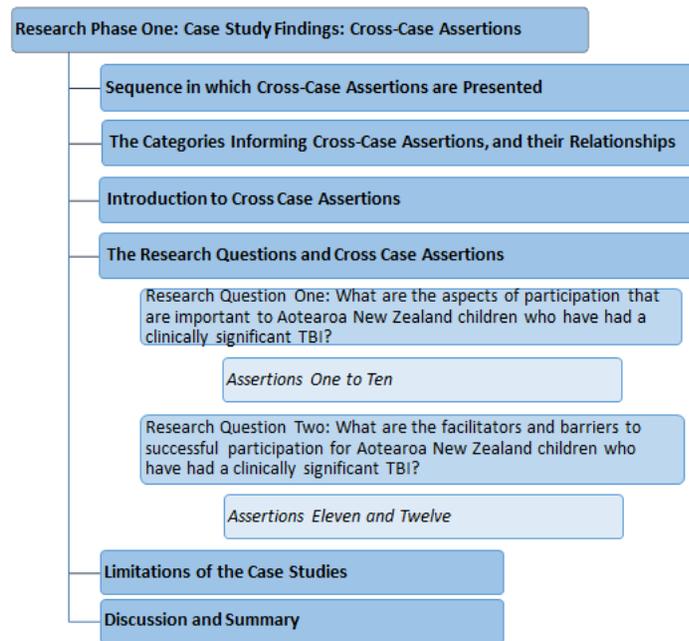


Figure 6.1: Contents and Sequence of Chapter Six

The Categories Informing Cross-Case Assertions, and their Relationships

Figure 6.2 displays the overall conceptual model that was developed in the course of diagramming and mapping the data for the individual case study reports and during the cross-case analysis. It is provided here to assist understanding of the cross-case assertions as they are presented in the subsequent sections. It illustrates the categories from the case studies and cross-case analysis that are discussed in the Assertions, and the way the categories were interpreted as relating to each other.¹³

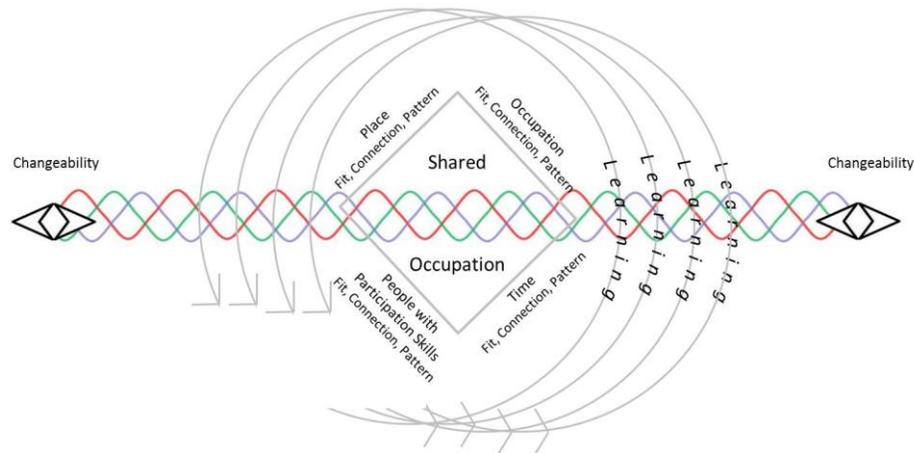


Figure 6.2: Conceptual Model of Relationships amongst Categories Informing Cross-Case Assertions

Introduction to Cross Case Assertions

The assertions which resulted from the cross-case analysis are presented next. Although the assertions are each presented separately for clarity, in line with Deweyan understandings of continuity, and complex transactions between the things that make up our world, it should be noted that there was overlap and connection between the ideas they express. The assertions are ordered according to their prioritization in the cross-case analysis, reflecting the prominent findings within and across individual cases, and also those ideas which were most important to answering the original research questions.

Twelve assertions were identified from the cross-case analysis. They are listed in Table 6.1.

¹³ An explanation of the model and its development is provided above on page 95. As explained on pages 142-144, the notion of Participation Skills was revealed in the cross-case analysis process rather than the individual case studies, and is an addition to the model as shown here. Understandings about people's Learning of Participation Skills was also added to the model during the cross-case analysis (refer pp. 150-151), and are indicated here by the blue spiralling line.

Table 6.1: List of Cross-case Assertions Relating to Research Questions One and Two

Assertions Relating to Research Question One: What are the aspects of participation that are important to Aotearoa New Zealand children who have had a clinically significant TBI?	
Assertion One	<i>Shared Occupation is central to the notion of participation</i>
Assertion Two	<i>Shared Occupation draws on People's Participation Skills in the areas of Driving, Leading, Including, and Performing</i>
Assertion Three	<i>Shared Occupation involves aspects of Place, including Opportunities, Terrain, Proximity, and Space</i>
Assertion Four	<i>Shared Occupation involves aspects of Occupation, including Value, Physicality, Risk, Challenge, Roles, Structure, and Product</i>
Assertion Five	<i>Shared Occupation involves aspects of Time, including Time Frames, Pace, and Schedule</i>
Assertion Six	<i>The Fit between aspects of people's Participation Skills, Place, Shared Occupation, and Time is important to the quality of participation</i>
Assertion Seven	<i>People who Share Occupation experience Connection</i>
Assertion Eight	<i>The Pattern of Shared Occupation is important to the quality of participation</i>
Assertion Nine	<i>The extent to which people's Participation Skills, Place, Occupation and Time can, and do Change, influences the Fit, Connections, and Patterns of the participation</i>
Assertion Ten	<i>Shared Occupation is a vehicle for Change in People's Participation Skills (learning)</i>
Assertions Relating to Research Question Two: What are the facilitators and barriers to successful participation for Aotearoa New Zealand children who have had a clinically significant TBI?	
Assertion Eleven	<i>Problematic participation is characterized by a Misfit of participation demands, fragile or broken Connections, and by confined, irregular, and imbalanced Patterns</i>
Assertion Twelve	<i>Solutions to participation involve Shared Occupation and Changes in People's Participation Skills. People use their Participation Skills to improve Fit, extend Connections, and to establish, maintain, and adjust Patterns</i>

Ten assertions relate to Research Question One, which asked about the important aspects of the children’s participation¹⁴. Although these assertions are also relevant to understanding Question Two, which was concerned with the facilitators and barriers to successful participation, it was the interactions between the features in the assertions that were found to be of greater importance for that question. Therefore, two further assertions are made that specifically relate to Research Question Two.

Each assertion is introduced and explained. Variations seen within different data sources and different cases are discussed. The assertions are illustrated with material drawn from the full data set obtained for all six case studies. These excerpts were selected for their ability to best illustrate an assertion, but also for the way they showed the variability across data sources and cases. For clarity, the excerpts have primarily come from adult participants, although the assertions also reflect information derived from the children’s interviews and actions. Throughout the discussion, words that represent a category, as identified in the individual case studies, are written as names, with the first letters capitalized.

The Research Questions and Cross Case Assertions

Research Question One: What are the aspects of participation that are important to Aotearoa New Zealand children who have had a clinically significant TBI?

Assertion One: Shared Occupation is central to the notion of participation.

Shared Occupation was a notion that was central to all cases when people talked of participation. Shared Occupation refers to taking part alongside others in an activity or activities that hold meaning. In the context of discussions about participation, people repeatedly described the children’s involvement or lack of involvement in an important activity (or activities) with others. I was invited to observe key activities that were shared with others, such as Ash’s drum playing, Tish’s Kapa Haka performance, Bob’s class swim, or Anton’s soccer and school holiday program. When I asked Anna what would be nice about her playing soccer she responded “*Then, well, like, I can be in like a team*”. (Case One, Anna, Child Interview, p. 10)

¹⁴ The term “children” as used in this chapter refers to children with TBI unless otherwise specified.

Engagement in occupations that are shared was seen as essential to the children's immediate and future health.

It's good for him to, to do things with other people... you could say he's living in his own world, and of course we want to shake him out of that, and you know, let him experience that he can have fun when you do things, you know, games with other people. (Case Three, Anton, Father Interview, p. 18)

Children Shared Occupation with peers in the community and adults. Occupations were also shared with non-human participants, such as pets, toys, insects, and movie or play station characters.

She'll sit out there and look for bugs and make fairy soup out of the flowers... Earlier in the year I was quite concerned at the amount of time ...she'd play in her room with just her little dollies just sat on the floor by herself. (Case One, Anna, Mother Interview, pp. 22-23)

Occupation was directly shared, sometimes in parallel (where children carried out an individual activity at the same time as others), and at other times collectively, where people collaborated in an occupation, or where a person carried out a task which contributed to the function and well-being of a wider group. On other occasions, occupation was indirectly shared, when people communicated their occupational experiences with others vicariously, through speech, writing, pictures, or using symbols such as certificates of achievement or objects associated with an occupation.

Erana [mother] asks if Dana has shown me her "Board"... a big sheet of white card with photos of people and their activities ... taken over her Christmas holiday... We go around the photos on the board, me asking questions or guessing where they were taken, and Dana explaining, with frequent referrals to her mother for help. The poster gives some interesting insights into what she has been up to over the school break. (Case Four, Dana, Observations Home Visit, p. 1)

Assertion Two: Shared Occupation draws on People's Participation Skills in the areas of Driving, Leading, Including, and Performing.

Multiple categories were identified across data sources and cases related to the People involved in Shared Occupation, including their understandings, their abilities, and their actions. The categories are captured collectively by the themes Driving, Leading, Including,

and Performing. Although these four areas were distinct in their purposes, there was some overlap of people's roles in the areas. Enacted Participation Skills in all of the areas were important for facilitating participation.

Participation Skills: Driving.

Driving refers to visioning, learning about, weighing up, planning for, preparing for, and pressing someone towards a Shared Occupation. Driving was often called “*having a go*,” and emphasized networking, communicating information with others, and facilitating children to express their preferences. Some of the children drove their shared occupations themselves, but the role was often taken on by adults.

I'm saying, just let him have a go [at kayaking] you know... I'm not quite as concerned about negative eventualities because I think we will get past them. In fact I'm determined that we will get past them you see. (Case Three, Anton, Mother Interview, pp. 21-22)

Children's ability to drive their occupation was frequently limited by a lack of confidence. “*Motivation and Tish's confidence when approaching an activity ... also appear to have a bearing on his test endurance, participation and accuracy*” (Case Two, Tish, Speech and Language Pathologist Report, p. 4).

Participation Skills: Leading.

Leading refers to those in a senior role directing, guiding, teaching, modeling, and coaching others to promote involvement in a Shared Occupation. Leading also meant regulating and adjusting that occupation to support involvement. Bob's teacher used her Leading Skills to facilitate group involvement during a class discussion.

Miss W. asks the class to share what they did yesterday. Bob does not speak during this discussion, but is listening. A lot of hands go up, and Miss W. points to them, inviting them to share with the class. The other children are engaged and interested, listening respectfully and commenting or laughing appropriately... I guess this is helping them to learn to be communicators, but also to feel part of a community. (Case Five, Bob, Observations Classroom Visit & Swimming, pp. 2-3)

Participation Skills: Including.

Including refers to actions used by adults and children to involve each other into a Shared Occupation. Multiple Including actions were identified, such as noticing, greeting,

introducing, inviting, touching, listening, asking, explaining, sharing resources, turn-taking, giving and receiving help, reciprocating and encouraging. It was important that actions group members used treated people in the same way, so that individuals were not singled out. Including actions were very evident in communities for Cases Two (Tish), Four (Dana), and Five (Bob), where they appeared to be a cultural norm.

If you took him anywhere, everybody ... would say hello to him but not as if they were singling him out you know... if they wanted to know anything about him they'd always talk to him ... ask him 'how are you feeling', or 'how are you getting on at school?' (Case Study Five, Bob, Family Interview [mother], p. 35)

Participation Skills: Performing.

Performing refers to people's performance and achievement of a Shared Occupation. This was an aspect of participation emphasized in rehabilitation documents, where Performing was more often than not related to participation limitations in rehabilitation activities.

[The] Speech Language Therapist reported that Anna's expressive language is at the level of a 6 ½ year old similar to her reading age. It was also reported that Anna has specific difficulty with word finding and planning of speech. Another area of concern is Anna's stammer which is being worked on with the Speech Language Therapist.... It was observed during the assessment that Anna had difficulty getting her message across or telling a story about what she had done at school that day. (Case Study One, Anna, Social Rehabilitation Assessment Report, p. 6)

Assertion Three: Shared Occupation involves aspects of Place, including Opportunities, Terrain, Proximity, and Space.

Shared Occupation was physically situated in Place. Features and objects associated with a Place created Opportunities for Shared Occupation. Terrain involved variability in gradients, surfaces, and obstacles, this being more relevant for children with mobility difficulties, but also providing enjoyable challenges. Proximity was the position of people in relation to each other, or to aspects of places, with closer proximity facilitating Shared Occupation. For example, when children were routinely removed from a room to participate in special learning or rehabilitation activities, Shared Occupation with providers of those activities was facilitated, but participation with peers was not. The Space in an environment also influenced Shared Occupation: More open spaces could provide more

Opportunities. Although crowded or enclosed spaces supported Proximity, they also meant higher noise and activity levels which often hampered Shared Occupation. Jan, Anna's mother was pleased with the physical aspects of the setting for the children's school holiday program.

There's lots of arts and craft... Big airy rooms and a neat garden ... because they've just moved there everything's sort of run down, but the gardens are all weeded and that, so there's lots for the kids to pitch in and help, and there's sort of little paths through the garden for them to explore. (Case One, Anna, Mother Interview, p. 8)

Assertion Four: Shared Occupation involves aspects of Occupation, including Value, Physicality, Risk, Challenge, Roles, Structure, and Product.

Value referred to the meaning and importance people attached to a Shared Occupation. Activities with heightened levels of touch and movement were interpreted as the Physicality of a Shared Occupation. Occupations which had a high level of Physicality were Valued by all children in the study. More Physical Shared Occupations were however associated with higher levels of Risk for the children, and were typically prohibited for fear of repeat head trauma.

Shared Occupations presented various degrees of Challenge to children's individual Participation Skills, but Challenge also arose through competition with others. In general children embraced Challenge, although reduced levels of confidence sometimes meant a fear of failure where children perceived a Challenge to be beyond their capacities. Where the level of Challenge meant children could Perform an occupation with less help, they experienced a sense of achievement.

The various Roles associated with a Shared Occupation presented children with opportunities to use their Participation Skills to contribute. The general Structure of an Occupation, with different steps and processes also influenced the way children took part. Where the Structure of an Occupation was unclear or very complex, participation was more difficult.

The Product refers to tangible outcomes of a Shared Occupation. This was present across all cases, but was not recognized as important until later in the analysis, when it was noticed how children valued the posters they made during data collection for the study. Similarly, children treasured art works or constructions they completed, or certificates.

Products represented children's achievement, but also supported children to indirectly Share those Occupations with others. The kapa haka competitions for Tish's community illustrated a Valued Occupation that provided Physicality, Challenge, diverse performer and audience Roles, a Structure that children had learned, and Product.

A compere at the front thanks [a group], and presents a certificate. The audience claps [paki paki] enthusiastically and the children file carefully off the stage to their families.... People clap and welcome the next group.... Little children spontaneously climb to stand on the chairs facing the stage, carry out the moves and sing.... On stage the children's moves are polished and slick. Rows of children melt back to bring others forward.... There are poi songs, led by the girls, and innovative haka, performed by bare-chested boys with fearsome faces. The ground shakes with their stamping. (Case Two, Tish, Observations Kapa Haka, pp. 2-5)

Assertion Five: Shared Occupation involves aspects of Time, including Time Frames, Pace, and Schedule.

Shared Occupations had Time Frames, where they occurred at a particular time-point, and were for a certain duration. Shared Occupations also had a Pace, or speed at which they were typically performed, and followed a Schedule in terms of their arrangement over time. Teaching staff typically talked of busy Schedules, with multiple Occupations fitted into short Time Frames, and this was borne out by observations. Anton's morning Schedule was very detailed, and the Time Frames of Occupations were precise, but were longer than those at school, allowing for early waking, and a slow Pace of completion.

We try and get him back to sleep because this morning it was 4 o'clock [waking]...But unfortunately it was a seizure and we think that might have woken him... that was almost five minutes....And then by about 6.15 he's up and he comes out here and plays with toys.... Then we get up, we go and have breakfast. And he sits down with his breakfast, he eats his [cereal] and his um, drinks his chocolate milk...Then we go off in to the bathroom and get changed...Comb his hair, wash his face, brush his teeth...after that. And um we sit him down on the bench, there's a bench in his bathroom, put his socks and shoes on. (Case Four Anton, Mother Interview, pp.6-12)

Assertion Six: The Fit between aspects of people's Participation Skills, Place, Shared Occupation, and Time is important to the quality of participation.

Fit refers to the relative match of different people's Participation Skills and the important aspects of Place, Occupation and Time. Fit influenced the quality of Shared Occupation. When Dana went to camp, there was a Misfit between the Opportunities for Physical Occupations, the Terrain and Proximity of Occupations, her reduced Performance Skills, and the Risks to her of a repeat head trauma so close to the Time Frame of the accident.

She can't go on parts of the confidence course, because it's above the ground... the boys and girls are going to be learning how to sail a small boat... And it will only fit one child. So Dana can't do that and we've explained to her ... she and Dean [adult cousin] are going to be in a double kayak... simple things like the boom... They've got this huge walk, Mr R. [teacher] said it's like this [indicates steep terrain]. But Dana will be allowed to skirt around the coast ... it's much shorter. (Case Four, Dana, Mother Interview, pp. 15-16)

Assertion Seven: People who Share Occupation experience Connection.

Connection occurred when there was Shared Occupation. It was about an experience of relationship, and of being joined with, involved with, or being a part of other People, and their Shared Occupation in Place and Time. It was often expressed using the word “*knowing*,” suggesting some relationship with understanding and learning. In contrast, rehabilitation documents expressed the relationships of people with each other or with aspects of an occupation more concretely, using words such as “*interacting*” “*influencing*” “*working with*” or “*remaining on task*” (Case Six, Ash).

Connection varied in quality, signified by the degree of closeness. Discrete and continuous connections were both noted. Children of Aotearoa New Zealand Māori descent and their whānau [family], also spoke of continuous Connection with a loving, extended whānau, making reference to connection with both living and ancestral whānau, and with their ancestral land and birthplaces.

Where there was Connection, change occurred in people's understandings about other people, a place, an occupation, or time. Dana and Mindy connected at school, and this was reinforced as they spent time in the hospital together after Dana's accident. The Connection was extended when they shared in computer games and swimming together

outside of school. Both girls increased their knowledge of how to perform the occupations, and their parents also formed a Connection.

Dana was always, um, I'd say she was more into like academic... Like reading wise, her reading level was above Mindy's [Dana's friend]. And so Dana taught Mindy how to read the manuals for video games! (p. 1). We used to invite Erana [Dana's mother] over for coffees after they'd play, and um [I] just got to know her. Oh, she's a wonderful friend... she's teaching me things that I need, beautiful things like art and music, um things that I didn't grow up with... (p. 2). We've been taking her [Mindy] over for a swim (p. 5)... Dana's been teaching Mindy how to swim properly, because she doesn't know how to... Dana's so gentle with her like 'no, no, put your head, try and put it under the water Mindy' and you know Mindy would listen to her... But now they're going swimming, just started swimming lessons together, in the same class on Wednesdays after school. (Case Four, Dana, Family Friend Interview, p. 8)

Assertion Eight: The Pattern of Shared Occupation is important to the quality of participation.

People's Shared Occupation formed patterns that reflected the people, places, occupations and time involved. Patterns showed variation in the balance, regularity, and diversity of Shared Occupation across these four aspects.

The degree to which there was balance amongst the relative time spent in Shared Occupation with particular People and in certain Places affected people's perceptions of the quality of participation. For example, concerns for children's fatigue levels and safety meant relatively greater amounts of time were spent with adults in the home setting. Whānau/parents were keen to address this imbalance, and increase time spent in the community with peers.

Regularity refers to the degree to which Time spent Sharing Occupation with particular People was consistent. The Special Education Needs Coordinator (SENCO) at Anna's school described the way her participation in classroom occupations with her peers would be unexpectedly interrupted to attend rehabilitation occupations, stretches, individual reading activities or medical appointments with adults.

Anna ... has historically been going to riding for disabled. Then [she] needs her stretching ... all the people that work with her. It's a huge amount of

disruption to her day” (p. 9). And I have actually said to the [rehabilitation] team ‘no, I know Anna’s at orthotics ... can we just forgo it [therapy session] this week ... we’ve had, the neuropsych [assessment].’ (Case One, Anna, SENCO Interview, p. 20)

Diversity refers to the amount of variability present in the People, Places, Occupations, and Times of children’s Shared Occupation. A certain level of Diversity provided interest and new learning opportunities. Where there was a rich pattern of diversity in the Skills amongst a group Sharing an Occupation, better Fit was supported for those with less skill, such as Anton when he attended the soccer game for children with disabilities.

The team, is made up of quite a lot of children of various ages, in fact some of them are adults, including the guy who is doing the one on one coaching with Anton ...They range in age from 11 ...Anton’s 10, there’s ... James, the same age as Anton, they’re the littlies. The rest of them are teenagers and above. He’s ... doing the drills of dribbling, from Ricki to Anton, Anton to Ricki, and I’m behind teaching him how to dribble.... When they do an actual game ...there’s parents involved and they mix in to the team. And, everybody’s rustling around and kicking the ball. (Case Three, Anton, Mother Interview, p. 21)

Assertion Nine: The extent to which people’s Participation Skills, Place, Occupation and Time can, and do Change, influences the Fit, Connections, and Patterns of the participation.

Sometimes Changes occurred which were beyond people’s control, such as the Changes in children’s Participation Skills following the accident, or a Change of school as children neared adolescence. Frequent Change in the children’s Participation Skills after the injury meant their own capacity to participate was highly variable. Other’s Participation Skills were tested when trying to support their involvement in Shared Occupation.

Sometimes you can just sit back and watch him [carry out a classroom task].... But he changes quite quickly as well you know and something might put him off where he’ll just go ‘ah, nah, nah I’m not doing it!’ And I’m like ‘oh.’ (Case Six, Ash, Teacher Aide Interview, p. 7)

Where there was extensive Change in a short Time Frame, participation was hampered, such as the frequent Changes of rehabilitation providers noted by many participants. Frequent Changes in routines also hampered participation.

We're not really into a routine. It's all changed now because [mother has new career]. Before, me and Jessica [Ash's mother] were both in the army you know, both always there, you know one week on, one week off and the only time it would change was when I would go on manoeuvres, or when she would go ... But see it'll change again. Come next year because I'm off to X [war zone] again ...and then he'll be with, she'll, she'll be the one who has to start juggling him around kind of thing. (Case Six, Ash, Father Interview, p. 3)

Conversely, some Change was desirable as a basis for learning. Where there were constraints on the degree to which People's Participation Skills, a Place, an Occupation, or Time could Change, there were few new opportunities. The degree to which things could be adjusted to enable better Fit and Connections, and to improve Patterns of participation was also constrained. Ash had a long-standing pattern of non-participation in his classroom. Even 6 ½ years after his injury, he was only attending school part time. Change to this situation was proving difficult from Ash's own perspective, and also from the perspective of his teacher and peers, although some glimpses of improvement had been noticed.

He'll say to us 'oh can we go and work outside' and you know if you said 'no, no you've got your workspace here, you'll work in the classroom with us', and that was a little bit of a battle. It's ... quiet in our normal writing lesson ... so it's not a noise thing but, I don't know how much he got done last year with that teacher aide ... she used to pull him out. ...And just to break it up a bit, 'let me have a walk' and he'll want to 'go to the library' and he'll sort of want to 'look at a book.' ... But now, he's quite good, we don't send him out too much... I send him out when he's actually more of a problem to the other children. When ... he's too unsettled and he's disruptive to the other children, then that's when I send him out. (Case Six, Ash, Teacher Interview, p. 2)

Assertion Ten: Shared Occupation is a vehicle for Change in People's Participation Skills (learning).

As people Shared in Occupation together, Change was seen in the understandings and capacities that underpinned their Participation Skills. People learned how to participate

together in a Shared Occupation more effectively as they understood more about each other, the Place, the Time, and the Occupation. In this way, learning how to Share Occupation was cyclical. Sharing Occupation led to Changes that enhanced further Shared Occupation.

When Anton spent time at the adventure playground, he and other boys there learned how to Share in a game of chase with each other. His mother drew on her Leading Skills, and the other children used their Inclusion Skills to facilitate Anton's participation in Shared Occupation.

He is actually quite good on a playground. I still have to hold his legs for monkey bars.... I just have to make sure his feet are in the right place.... There were quite a bunch of boys who were really nice to him, um similar age ... they'd ask me questions, 'oh why is he', or they'd say 'oh I can do monkey bars really well' and I'd say 'oh you're really good', yeah, yeah, and they'd ask me why he was a bit different so that I would explain it and, and there was a group that were very, very nice, to Anton around the same age and they would play with him (pp. 13-14). I would say 'come on Anton let's chase this boy' you know and we were on the monkey bars, look they're climbing like real monkeys, let's go and chase them, so there's one set of monkey bars that go round in a circle so we'd go round and the others climbing ahead of us and um, we'd follow them on the monkey bars. If they're doing something like football ... I've seen him going up to one or two children on the field, and they're ones who know him because there's a group around his age, they'd say 'Anton, do you want to kick the ball' occasionally. (Case Three, Anton, Mother Interview, pp. 17-18)

Research Question Two: What are the facilitators and barriers to successful participation for Aotearoa New Zealand children who have had a clinically significant TBI?

Assertion Eleven: Problematic participation is characterized by a Misfit of participation demands, fragile or broken Connections, and by confined, irregular, and imbalanced Patterns.

Participation was problematic at times for all of the children. After the accident, there were Misfits of other's Participation Skills and the children's Participation Skills, and the Places, Occupations, and Times in which they Shared Occupation. Children's Connections with aspects of other People, Places, Occupations, and Time were stretched, and sometimes lost. Many of the Shared Occupations they Valued posed Risks, and were Restricted; The Pattern of their Shared Occupation, therefore, lacked Diversity, and became Confined. Irregularities occurred, with the initial interruption of the accident and resultant hospitalization, and with interruptions to participate in assessments, rehabilitation, medical procedures, or specialized education occupations. The Balance of children's Shared Occupations also changed. More time was spent in Shared Occupation with adults and at home. Less time was spent with peers and in the wider community.

Anna was restricted from Sharing in a walk with the rest of her class at the school camp.

She got up in the morning and she got breakfast and got her stuff and got her bag ready to go and they says, 'we think the walk will be too far for you Anna'. And with that she burst in to tears. And I says 'well how far is it', and they sort of says 'oh it's a couple of k's'; and they says 'but it's really, really steep in places, you know she won't be able to get up and down and we'll walk through streams and things like that and her brace [orthotic]'. I really wish now we had just done it. Like bugger them. If I had to piggy back her I had to piggy back her. But she stood there and burst into tears and I sort of thought 'oh well they're saying we can't do it Anna'. You know it's like they all walked off and left us there (p. 30).... I hadn't even done the walk before. I didn't know what it consisted of.... Everyone was sort of back within an hour and a half. I was sort of like, 'well would it have, would it have mattered if we were half an hour late plodding along at the end?' But they said 'oh they want to keep all the kids

together.’ So. But I’m sure Anna, would have kept up, just from the excitement of being able to do it. So that was a bad call on my part, letting them talk us out of it. (Case One, Anna, Mother Interview, p. 31)

Assertion Twelve: Solutions to participation involve Shared Occupation and Changes in People’s Participation Skills. People use their Participation Skills to improve Fit, extend Connections, and to establish, maintain, and adjust Patterns.

When children were enabled to Share in Occupation with others, there were Changes in Participation Skills for them and for others, with learning occurring about how to Drive, Lead, Include, and Perform. Changes in Participation Skills were not a given however. Where there was less potential for Change, those with stronger Driving, Leading, Including, and Performing Skills used them to enhance Fit between the child’s and other’s Participation Skills, and with aspects of Place, Occupation, and Time. Connections were formed, and provided a basis for Connections with other People, Places, Occupations, and Times. With extending Connections, Patterns of Shared Occupation could be established that had greater diversity, were more regular, and which were better balanced.

Bob’s rugby coach used his Leading Skills to ensure that Bob remained involved with the team in roles that he was comfortable with. His continued involvement with the team as a water-boy led to involvement in wider football based occupations in the community through his own and his parent’s Connections.

He’s actually going to be involved again this year but purely as a water boy.

Yeah. Run the water on for his mates. ... His team kept him involved, and asked if he wanted to be involved so he, he’s been the water boy ever since” (Father).

He still goes, he does training. But when they start doing contact he doesn’t do it ...He stands aside but he’s down there” (Mother).

And I do play with the ball” (Bob).

Yeah but he, you know he does everything. He goes down there, and like, Ross, whose son is in it, that was Bob’s, quite a good mate with. They got the thing [provincial rugby tournament] out at X [sports centre] so they were out there being ball boys, so Bob went along there one day to watch him being ball boy, and one of the guys didn’t turn up so he got to be a ball boy out at X game (Mother). (Case Five, Bob, Family Interview, pp. 57-62)

When Ash struggled with his writing, his teacher directed another child to work with him on a publishing task. Ash connected with the occupation and the other child. He showed improving ability to manage his frustration. The child also formed a connection with Ash, using her own performance skills to support his, and demonstrating skills for including him into the class occupation.

I observe Mary standing beside Ash while he works at the computer. She helps him with starting the program, and prompts him as to where to click the mouse... Typing remains effortful for him, although he knows the location of several familiar letter sequences (e.g. and, the), and can perform these quickly. He seems to find it hard to look at the story his teacher wrote down for him from his oral dictation and to then shift his gaze between the computer screen and the keyboard.

Mary works patiently with him, standing at his side, responding gently to errors, reading the words out for him, and spelling the letters for most words. She waits patiently while Ash finds letters and the space bar. Sometimes, but not very often, she points to a letter on the keyboard. More often, she helps Ash with backspacing if he has made an error. Ash's story is about the Hindenburg disaster, and it is being typed as for a newspaper article. This feels laborious, but nonetheless Ash perseveres. I kneel beside him on his right, but try not to interrupt. Mary is at his other side, and his writing book is there too. Ash looks often to his book, and consults Mary for help, but speaks little, concentrating on the task. Half-way he becomes restless, but with a little encouragement from me, and praise from Mary he perseveres, and finishes the writing in time for the bell to go for lunch. (Case Six, Ash, Classroom Observations, pp. 10-11)

Limitations of the Case Studies

The study set out by asking about the aspects of participation that were important to Aotearoa New Zealand children after TBI from the perspectives of different stakeholders, including the children themselves. As the case studies progressed, some tensions arose with the use of the word “to” in the research question. It was difficult to always reflect the perspectives of the children, and often adult voices became predominant when reporting the findings. Although I desired to find out about those adult perspectives, and although no particular discrepancies were noted, it would have strengthened the findings if further

consideration was given as to how well those adult perspectives aligned with those of the children. Likewise, I came to realize that what was important to the children with TBI, was connected with and therefore important to others, such as their peers. Although the research question was maintained throughout the case studies, these shifts need to be recognized, and may form the basis for further research.

Some caution is required when considering the degree to which the findings of the case studies and the cross case assertions can be generalized to the participation of children with other disabilities. The studies were focused on children with TBI, who experience difficulties and changes in their function which may be different to those experienced by other children with disabilities. Examples of these difficulties noted in the case studies included a sudden change in their function after their accident, albeit with variable degrees of recovery over time. Some participants in the case studies were also concerned about the levels of fatigue experienced by the children, and by the risks associated with repeat head trauma.

Judgement is also needed in consideration of the degree to which the findings may be transferred to other populations of children with TBI and to other contexts. Only six cases of children aged 9-12 years were involved, and it must be acknowledged that findings may differ if applied across a wider number of cases or to children who are younger or older. Nonetheless, the information for those six cases was extensively triangulated, involving multiple other stakeholders, a total of 30 participants across the cases aiding transferability. The further involvement of 20 participants in the Action Research workshop in Phase Three of the study lends additional support to the interpretations. In addition, transferability of the information to similar populations is assisted by provision of demographic details for the participants, and depth of description. The no-faults accident insurance scheme provided by ACC in Aotearoa New Zealand may limit the degree to which the findings can be compared to those of other countries where rehabilitation is less readily available.

Although data collection involved the children, the challenges associated with cognitive and communication difficulties constrained the depth of information that those children were able to provide. Their voices, although present in the findings, are less prominent than those of the adult participants. Furthermore, the voices of the children's

peers are absent from the case studies. Future research could build on the understandings of these case studies by greater focus of data collection from child participants.

Discussion and Summary

Whilst recognizing the limitations of the case studies, the findings are supported by, and build on the understandings gained in the literature review in Chapter Three, which was undertaken before commencing the study. Concepts of Fit, Connection, and Pattern have previously gained some mention in the TBI research literature, supporting the findings of the present study. One qualitative study of teenagers with acquired brain injury reported their concerns about “fitting back in” (Sharp et al., 2006, p.770), while another study raised their concerns about being “singled out” (Mealings & Douglas, 2010, p. 6). In Sharp et al.’s study, “fitting back in” was conceptualized as the challenge to be “equal” and not “alienated” (p. 774). It was also described as endeavoring “to fit a square into a circle” (p.774). Sharp et al. identified that the quality of organization, including adaptations, supports, and knowledge of TBI, influenced people’s perceptions as to the children Fitting Back In. In this way, Sharp et al. interpreted “Fitting Back In” as an experience, which was influenced by people’s actions. In my study, which involved younger children, similar ideas were noted, but were expressed differently. The idea of Fit was interpreted as the degree of congruity of people and their skills, the place, the occupation, and aspects of time. This influenced the quality of people’s participation experience, or involvement, which was called Connection.

This concept of Fit for the present study perhaps better aligns with Fit as expressed in occupational therapy literature, and likely reflects the influence of that literature on my interpretations of the data. Like the present study, the Person Environment Occupation (PEO) model (Law et al., 1996) uses a transactional approach to relationships between a person, their environment, their occupations, and their performance of those occupations. As with the way those with Leading Skills in the present study adjusted the occupation and context to support participation, the PEO model explains the way the Fit between the Person, the Environment, and their Occupations can be changed by occupational therapy practitioners to enable occupational performance.

My arrival at the category of Connection in this study is probably shaped by its philosophical underpinnings, which acknowledge the continuity of humans with their world over time (Dewey, 1925/1981). However, the study by Roscigno et al. (2011), who also

gathered data from younger children, similarly found that after TBI, children defined the quality of their lives through the knowledge that life's meaning exists external to oneself, and is related to "a connectedness" with other people. However, differing from Rosigno et al.'s findings, which were concerned with social connection, the present research also draws attention to children's sense of Connection with Place, Occupation, and Time, which is engendered in the context of occupations shared with others. It may also be that such understandings reflect the influences of Māori cultural context on some of the data gathered and of the cultural guidance given to assist my interpretations.

My interpretation of Connection in the context of participation has congruence with the notion of Wairua, which Elder (2013) has defined as "connectivity between Maori people and all aspects of the universe" (p. 416). Elder's (2013) research, although concerned with more general goals after TBI, has also noted the centrality of Tangata (people), Wāhi (place), Wā (time), and peoples' cultural knowledge and actions. Collectively, the findings of this study and Elder's work suggest the utility of researchers and rehabilitation providers looking beyond an individual perspective, and rather considering the skills of groups involved in particular occupations, along with aspects of the places those occupations occur, the occupations themselves, and also their temporal contexts.

Patterns of occupation are widely discussed in the occupational therapy literature, and it is very possible that this sensitized me to the presence of such a category in the data. The relevance of balanced patterns of self-care, work, and leisure occupations have been well recognized, typically referring to the relative combination of self-care, work, and leisure occupations. Studies which have employed the CAPE-PAC instrument (King et al., 2007) have gathered information about the pattern of children's participation in terms of its diversity and intensity in particular types of occupation (Anaby et al., 2012; M. Law et al., 2011). The present study extends those concepts by drawing attention to the patterns of Occupation relative to People, Place, and Time.

The relevance of the things other people did to facilitate the children's involvement in Shared Occupation was highlighted by the data in the study, and was articulated in Assertions Two (pp. 142-144) and Twelve (pp. 153-154). Here, such actions were collectively called Participation Skills, encompassing Driving, Leading, Including, and

Performing. As with the ideas about Pattern, related concepts are present in earlier occupational therapy literature, and these lend valuable support for the study findings.

In 1973, Anne Cronin Mosey proposed that people develop and use group interaction skills alongside task skills when sharing in occupations. She suggested five levels of ability for group interaction, reflecting increasing degrees of cooperation in performing tasks and increasing amounts of interaction. In contrast with the present study, Mosey did not specify actions that are involved with the various levels of group interaction skills. Therefore it is unclear whether group interaction skills align with participation skills for facilitating each other's involvement, or whether they instead reflect individuals' skills for enabling themselves to take part. However, consistent with the study findings, Mosey (1973) did posit that group interaction skills are learned collectively in a context where people engage together in occupation.

Later, A. G. Fisher and Kielhofner (1995) proposed a Communication/Interaction Taxonomy, and a Social Interaction Taxonomy which outline the observable things people do as they interact with other people when engaging in an occupation. The skills in these two taxonomies have more recently been integrated in a list of Social Interaction Skills (Fisher & Griswold, 2014). Although a number of these skills are directed towards the things an individual does to support their own participation, some items, such as Touches, Questions, Replies, Thanks, Takes turns, Matches language, Clarifies, Acknowledges/Encourages, and Empathizes, suggest some overlap with the Inclusion Skills identified in my study, and are used to support the involvement of another person. Neither Mosey, nor Fisher and Griswold expand on the presence of skills in children.

More recently, G. M. Bedell et al. (2005) contributed specific information about things people did to facilitate children's participation after TBI. Focusing on parents' actions, one strategy directed at the environment rather than the children themselves involved Creating Opportunities. The actions Bedell et al. described in Creating Opportunities clearly align with the actions observed in the category of Driving in my own study. My study lends support from another context to Bedell et al.'s findings, but adds the finding that opportunities are not only created by parents, but also teachers, community support people, and peers. My study also suggests that creating opportunities, on its own, was not enough to support children's participation. People also needed to Lead in a way

that facilitated involvement, and Include the children in Shared Occupation. In this way, further learning of those involved was promoted.

Humphry's Processes Transforming Occupation (PTO) model (2005) goes some way towards explaining the significance of the range of skills observed in my study and in the study by G. M. Bedell et al. (2005). Humphry relates such skills to the way children learn to perform occupations, and how the meaning of those occupations develops in childhood. As found by myself and by Bedell, Humphry proposed the importance of constructing opportunities to take part in occupations. She drew attention to the role played by both directly and indirectly shared occupation in learning, a central finding in my own study. However my study suggests some further directions for the understandings contained in the PTO model, by suggesting its relevance to our understandings of children's participation. Children do not only learn about how to perform occupations but learn how to support one another to participate. My study further suggests the need to recognize the things that children do to support one another's involvement in Shared Occupation and hence, learning.

The literature review in Chapter Three highlighted diversity of participation outcomes for this population, and diversity of participation outcomes across different participation contexts. However, previous studies have made reference to a lack of rehabilitation resources and resultant concerns for children's participation (G. Bedell et al., 2013; G. M. Bedell & Dumas, 2004; Colver et al., 2012). This Aotearoa New Zealand study was carried out in a unique socio-political, and cultural context, where rehabilitation and support was, arguably, available to children after a TBI. Despite this, in line with international literature, participation difficulties were evident. The case studies indicated that children's participation was hindered when, after the accident, Misfits occurred between their Participation Skills, the Participation Skills of others, their Shared Occupations, and the timing and location of those occupations. Children became Disconnected from these things, and the regular Patterns of their participation were interrupted and confined. The balance of their Shared Occupations Changed, so that less time was spent with their peers and other adults in the community.

Rehabilitation interventions that were provided and observed in the cases studied did not address each of these important aspects of participation. Interventions were often directed towards the children with TBI alone, aiming to remediate their impairments or

develop their Performance Skills. For children, the time spent accomplishing this was time not spent participating in regular occupations. Even when children's Performance Skills improved, they lacked confidence, or others in their communities could inadvertently put up barriers to their participation. This was evident when Anna was prevented from taking part in the class walk when on camp (Case Study One Anna, Mother Interview, pp. 30-32), and when her classmates' parents excluded her from party invitations (Case Study One Anna, Mother Interview, pp. 14-15).

Other rehabilitation interventions in the case studies were aimed at adjusting the children's occupations or their routines, or educating adult supports to assist with task performance and care needs. Although these strategies appeared to assist with participation in the short term, it still took time for people to learn to how make adjustments themselves and how to provide support. This was most apparent when others were unfamiliar with how to participate with that child, for example, when there was a change of class or school, or a new activity in the community. Many of the skills needed were 'learned on the job' as expressed by teaching staff (e.g. Case One Anna, Teacher Interview, pp. 3, 8, 15; Case Two Tish, Teacher Interview, p. 15; Case Six, Teacher Aide Interview, p. 3), and information from rehabilitation providers was not available across all participation settings.

Moreover, it could be seen that rehabilitation and support, whilst conferring benefits, also had the potential to split the children apart from occupation shared with peers, by physically separating or Disconnecting them, by containing the Patterns of their participation to ensure their safety, or by singling them out as different or special. This was noticeable when Dana's peers, who would typically support one another with classroom tasks, avoided helping her, because they saw that was the role of the teacher aide (Case Four, Mother Interview, p. 12). In this way too, long-standing participation deprivation occurred for children like Ash. Whilst acknowledging the importance of re-building and developing children's Performance Skills for participation, and the need to prevent repeat head-trauma, it can be seen that rehabilitation providers also need to pay heed to the influence of their intervention delivery on participation.

Although there were concerns for the children's participation, it was equally clear that there was much that could be done to address those concerns. In this study, strategies that supported participation were being used by some in the children's communities, including whānau/parents, educators, support persons, leaders of leisure activities, and

peers. These strategies were immediately directed towards Shared Occupation. Through Driving the availability of Shared Occupation, Leading, and Including the children, the strategies helped promote Fit, re-establish Connections, and supported more even and balanced participation Patterns. However, stakeholders showed different levels of skill, and there were differences within and across cases in people's knowledge of and ability to implement such strategies. Information and resources to support and guide this learning were not consistently or readily available.

In summary, Phase One of the study pointed to an important role played by other people in the children's communities in facilitating their participation, and highlighted a need for interventions which targeted people's skills in the areas of Driving, Leading and Including. It was decided that further information needed to be sought about community focused interventions that had potential to address children's participation. A detailed review of this literature was undertaken in Phase Two of the research. The methods used for the review are described next in Chapter Seven.

Chapter Seven

Study Phase Two: A Review of Community-Focused Interventions to Facilitate Participation for Children with TBI: Methodology and Methods

The case studies discussed in the last two chapters revealed strategies that families and people in the wider community used to address the important aspects of participation. The strategies centered directly on participation, and involved Driving, Leading, Including in, and enabling the children to Perform Shared Occupation. I surmised that it might be useful to share some of the strategies identified in the case studies to enskill others to support the children's participation. I was uncertain however, whether my understandings about those strategies only related to the case studies, or if others had also found them, or similar strategies to be effective, and if they might therefore be applied to the wider population of children with TBI.

As discussed in Chapter Three, for children with TBI, interventions typically address their impairments and difficulties with carrying out activities (Braga et al., 2005; Catroppa, Anderson, & Muscara, 2009; Chen et al., 2004; Glang et al., 2004; Mallay, 2002; Marcantuono & Prigatano, 2008; S. L. Wade, Walz, et al., 2009; S. L. Wade et al., 2005; Woods et al., 2012). This gives some potential to facilitate participation through improved behaviors and task performance (Byard et al., 2011; T. Feeney & Ylvisaker, 2006; T. J. Feeney & Ylvisaker, 2003; T. J. Feeney & Ylvisaker, 2008; Gardner et al., 2003). However the case studies had revealed that barriers to participation were not immediately or consistently addressed by focusing intervention on the child. Additionally, I had found in the review that the few interventions which directly addressed participation for children after TBI appeared to be still in the preliminary stages of development, with limited research into their effectiveness or viability (Agnihotri et al., 2012; Glang et al., 1997; Sowers et al., 1996).

I wondered if further interventions were available in the wider literature that could enable others in the children's communities to facilitate their participation. The need for a sound understanding of the range of available intervention approaches in the literature, the strategies used within those approaches, and of evidence about the effectiveness of those interventions is important from my perspective as a rehabilitation practitioner. Such

knowledge should be part of the basis for advice to families and other stakeholders, and can help guide decision-making (Hoffman, Bennett, & Del Mar, 2013; M. Law & MacDermid, 2008). A lack of clear information constrains the range of interventions that might be considered, whilst implementation of interventions that are inadequately supported by evidence restricts accountability to families, funders, and policy-makers.

Similar concerns were highlighted from the perspective of the philosophical understandings that had guided the inquiry thus far (Dewey, 1938/2008b). From this point of view, I recognized that pre-existing information in the wider literature would form part of a continuous process, wherein that information would eventually be judged through its application. The risk was that taking prior knowledge for granted might result in unintended or unreliable outcomes (Dewey, 1938/2008b). The need for systematic and critical appraisal of information was therefore seen as essential. To learn more about the range of community-focused intervention approaches that could facilitate children's participation after a TBI, a second review of literature was proposed.

This chapter describes the methodology and methods used for that review. The contents and sequence of the chapter are outlined in Figure 7.1.

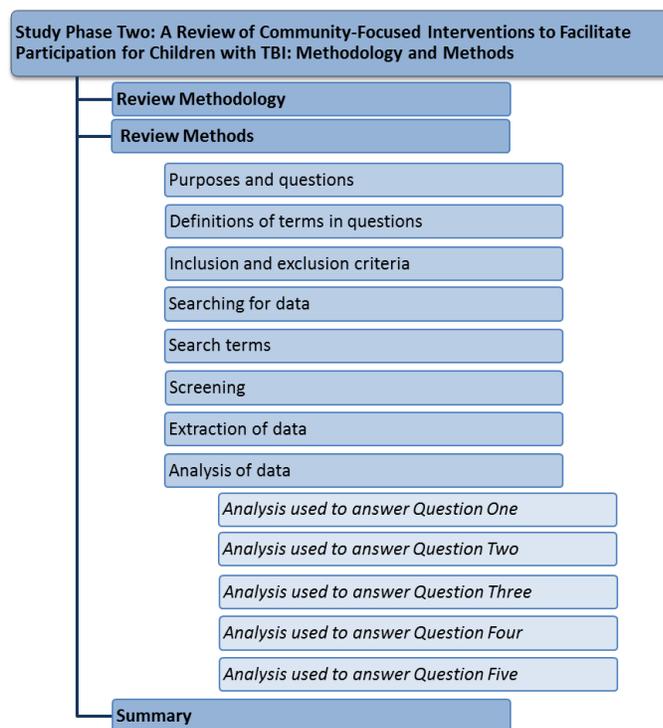


Figure 7.1: Contents and Sequence of Chapter Seven

Review Methodology

Several considerations influenced the methodology guiding the proposed review. Guided by Petticrew and Robert's (2006) descriptions of the different types of reviews, a "narrative review" (Petticrew & Roberts, 2006, p. 39) that drew on systematic principles and processes was conducted.

As opposed to more traditional reviews, which provide an overview of a topic area, systematic reviews are intended to address specific research questions using explicit, scientific methods that can be replicated. They systematically gather information relevant to those questions, and evaluate the quality of that information. Systematic reviews have traditionally had a focus on quantitative research (Dijkers & The Task Force on Systematic Reviews and Guidelines, 2009). However, it is also suggested that they are a useful way to analyze and integrate understandings obtained from a broad range of research designs, including qualitative study designs, especially where there is a lack of clarity or ambiguity around an issue (Petticrew & Roberts, 2006). Systematic reviews additionally aim to eliminate or to minimize bias, although biases may often be found (Dijkers & The Task Force on Systematic Reviews and Guidelines, 2009; Slavin, 1995).

The decision to use a narrative approach to the review synthesis responded to variations and complexities that I foresaw along a number of fronts. When conducting the case studies, variability had been observed in the strategies being used across different settings by different stakeholders. Further to this, literature had highlighted the variability in sequelae for children following a TBI, and the multiple intrinsic and contextual factors influencing those sequelae (V. Anderson, Spencer-Smith, et al., 2011). Additionally, the term "participation" is multi-faceted, incorporating understandings about activities and their social contexts (WHO, 2001; 2007) and, as found in the case studies, involves notions about Shared Occupation, Change, Fit, Connection, and Pattern. Early overviews of the literature pertaining to community focused intervention approaches with different populations had identified heterogeneity in the populations, settings, delivery of interventions, and the outcomes of concern. For the present project, therefore, it was decided that a narrative approach to synthesis was indicated to accommodate these variations and adequately integrate information. However the principles and processes of a systematic review were used to support rigor, by making processes, decisions, and the

influences on those decisions transparent to the reader (Fadyl & McPherson, 2009; Petticrew & Roberts, 2006; Slavin, 1995; Whitemore & Knafl, 2005).

The process of carrying out the present review included steps of defining questions, explicating the material to be included, searching the literature, scoping the results of the literature, critically appraising the items to be included, and integrating the findings (Petticrew & Roberts, 2006). The methods used in implementing these stages are outlined next.

Review Methods

Purposes and questions.

The purposes and questions that informed the review were developed using the Population, Intervention, Comparison, Outcome (PICO) strategy as a guide (Fineout-Overholt & Melnyk, 2005; Petticrew & Roberts, 2006; Rios, Ye, & Thabane, 2010; Whiting, 2009). When conducting the case studies, limited time and resources were noted to be an issue for many stakeholders and it was reasoned that in practice, unrealistic demands on time and resources may limit implementation of some intervention approaches. Therefore, consideration of the viability of the approaches was explicitly incorporated into the review questions.

The overall purposes of the review were, therefore, to name, describe, and compare current community-focused intervention approaches to facilitating children's participation after TBI, to evaluate the strategies used in the approaches against important aspects of participation identified in the case studies, and to evaluate the evidence for the effectiveness of the approaches in facilitating the children's participation after TBI. Specifically, the review asked the following questions:

1. What are the current, key community-focused intervention approaches to facilitating participation for children aged 9–12 years who have had a moderate to severe TBI?
2. What is the evidence for the effectiveness of the approaches in addressing the outcomes with which they were concerned?
3. What are the overall strengths and limitations of these approaches in terms of their effectiveness, applicability for children aged 9-12 years who have had a moderate to severe TBI, and viability?

4. What strategies are used in community-focused intervention approaches to facilitating participation for children aged 9-12 years who have had a moderate to severe TBI?
5. What is the potential of the strategies for addressing aspects of participation identified as important in the case studies? These aspects include:
 - Shared Occupation: the occupations shared by a child who has had a TBI that hold meaning to them, either personally or in terms of their development;
 - Driving: people learn to make opportunities available for children to directly and vicariously share occupations;
 - Leading: leaders of shared occupations learn to address the social and physical environments in order to involve children;
 - Including: those who share occupation with a child with TBI learn to use actions that include one another;
 - A child with TBI is facilitated to Perform shared occupation;
 - Other people's participation skills, the occupation, time, and place Fit with the abilities and needs of a child with TBI;
 - A child with TBI experiences Connection with and across people, occupation, place and time; and
 - Pattern: a child who has had a TBI shares occupations with their peers.

Definitions of terms in questions.

The review was guided by the following definitions to provide boundaries to the information included, and to support consistency of understandings when referring to the findings:

- Community-focused: Directed at the social environments that are inter-linked with, or that have the potential to be inter-linked with a child who has had a TBI.
- Intervention approach: A group of specified strategies that aim to address a particular outcome¹⁵.
- Strategy: A means or a method used to achieve a goal¹⁶.
- Participation: Sharing occupation with others. This definition varies from that originally developed for the case studies. At the point of carrying out the review, my

¹⁵ The definition of the term Intervention approach is included in the Glossary for further reference.

¹⁶ The definition of the term Strategy is included in the Glossary for further reference.

understanding about the notion of participation had shifted in response to the information that came from the case studies. Sharing denotes children being present at an occupation and contributing to the occupation as they are able. The occupation holds meaning for the child. The definition takes into account that the child may not value some occupations themselves (eg. a classroom occupation they find challenging), but that such occupations hold meaning for the child in terms of their development.

- TBI: An injury classified as moderate to severe, involving damage to the brain due to external force(s).

Inclusion and exclusion criteria.

The review included quantitative and qualitative research. The decision to include qualitative research was based on the notion that participation always takes place in a context (Dewey, 1925/1981) and, using the above definition, involves understandings about the “meaning” of particular activities for children. Qualitative research has a particular concern with “meaning,” and provides understandings that are grounded in people’s real-world experiences (Burns & Grove, 1993; Petticrew & Roberts, 2006; M. C. Taylor, 2003). It was also considered that given the early state of knowledge about interventions for children’s participation, an over-emphasis on evidence such as randomized controlled trials might limit exploration of as yet, little-documented approaches that could hold promise, but which are yet to be more fully researched (Ogilvie, Egan, Hamilton, & Petticrew, 2005).

Published expert opinion involving anecdotal experience from professionals and families was included into the review to facilitate a broad perspective of potential intervention approaches. Expert opinion was also recognized as a means of either supporting or raising practical questions about research information, and has been acknowledged elsewhere as providing insights into the application of knowledge in context (Enkin & Jadad, 1998; Sackett, Rosenberg, Gray, Haynes, & Richardson, 1996; M. C. Taylor, 2003; Turner-Stokes, Harding, Sergeant, Lupton, & McPherson, 2006).

Searching for data.

Specific electronic databases were targeted for searching according to their ability to contribute knowledge relating to the topic of children’s rehabilitation, participation, and occupations. The following databases were accessed via Ovid: ERIC, AMED, PsycINFO, and MEDLINE. The following databases were accessed via EBSCO: CINAHL and

MEDLINE. Slightly different results were obtained accessing Medline using the two different sources, therefore both were completed. The Scopus and Web of Science databases were also searched. Manual searches were also performed in relevant journals between the years 1990 to 2010, including the *American Journal of Occupational Therapy*, the *Australian Occupational Therapy Journal*, *Brain Injury*, the *Canadian Journal of Occupational Therapy*, *Developmental NeuroRehabilitation*, *Disability and Rehabilitation*, the *International Journal of Rehabilitation Research*, the *Journal of Head Trauma Rehabilitation*, *OTJR: Occupation, Participation and Health*, *Physical and Occupational Therapy in Pediatrics*, and *The British Journal of Occupational Therapy*. Experience during the earlier literature review had indicated that such journals frequently contained reference to information about participation. Email search alerts from the databases were run throughout the review process to identify further relevant publications in order that they might be incorporated into the analysis.

The search was commenced in February 2010. Because the review informed the development of the intervention approach which is discussed in Chapters Nine and Ten, the sequence and time frames of the overall project limited the search dates, and the search was stopped in October 2010.

Search terms.

Search terms were developed with reference to the relevant aspects of the PICO strategy (Whiting, 2009), but were kept broader than the research question to ensure generation of adequate information (e.g. the search was not limited to children with TBI). No search term was used for a comparison intervention, due to the exploratory focus of the questions. Likewise, no date or language limits were set at this stage, due to an intention to initially scope out the literature and to maximize insights into available approaches. Different search strategies were initially trialed, and results were briefly scoped for their manageability in terms of numbers of items retrieved, and for their relevance to the topic under focus. Some additional terms were then included, while other terms were changed. For example, an initial search included the term “particip” (truncation). However, this resulted in multiple studies that lacked relevance due to the truncation picking up the word “participants” which is used in most research studies. In response, the term “participat” was used, as this would retrieve “participating,” “participated,” and “participation”. The term “integration” was originally not included, but was added when the brief scope indicated its

occurrence in several abstracts. A proximity search strategy (n5) was applied to the population terms and to the outcome terms. A main heading search strategy was used with the EBSCO-sourced databases as this was found to result in several more hits that were relevant. The final search terms and Boolean operators are detailed in Table 7.1.

Table 7.1 Search Terms used for Literature Review

Population	<i>Proximity terms applied with population terms</i>	AND²	Intervention	AND	Outcome	<i>Proximity terms applied with outcome terms</i>
child*	disab* ¹		intervent*		integrat*	social
			OR²		OR	
	“brain injur*”		program*		includ*	friend*
			OR		OR	
			facilitate*		participat*	commun*
			OR			
			strateg*			
			OR			
			approach*			

¹ * denotes truncation.

² AND and OR are the Boolean operators used.

Screening.

Sourced articles were screened using PICO criteria to briefly identify the population, intervention(s), and outcome, and duplicates were removed. Although the review was intended to be broad in nature, a decision was made at this point to apply some further inclusion and exclusion criteria to keep the task of reviewing and synthesizing the data manageable, and to ensure the relevance of material. For articles to be included into the review the following criteria were required:

1. The article was in English language.
2. The article described a specific intervention approach that addressed one or more aspects of participation identified as important during the Case Studies.
3. The intervention was a) community-focused in nature, and b) was not solely directed at improving the task performance of the child(ren) who had the disability.

4. On the basis of the number of articles generated in the database search, dates for the review were limited to the range from 1990–2010.
5. Books or book chapters that cited earlier, existing material, or which offered expert opinion only were not included into the review. Likewise, unpublished items, such as theses, were excluded from the review. Given the number of items generated in the database search, it was decided that if thesis findings were sound and showed promise as an intervention approach, they would have been published in a peer-reviewed journal or a book.
6. The population of interest in the articles included children between the ages of 5 and 12. This age-range was expanded from that in the review questions in order to generate adequate, relevant information; but, given the number of articles generated, kept data analysis tasks manageable.

The age-range was expanded down rather than up acknowledging the significant changes that occur with social relationships as children move into adolescence, and the changes in school settings that typically occur at that time. For example, collaborative interventions involving activities for 15–17 year-old young adults about to leave college and/or take up employment were judged unlikely to be suitable for application with children who had just turned 9. Material limited to populations of pre-school children were excluded from the review on the basis that significant developmental differences would constrain the applicability of the interventions to the children of interest for this project (i.e. children aged 9–12 years). For example, one approach located in the original search involved a kindergarten using puppets to teach 3-year old children about communication strategies they could use with their disabled peers. There was a concern that use of puppets to depict disabled peers for children who are 12 and about to go to college had potential to be demeaning to both the children and the peers.

Some difficulties were experienced with ascertaining the age of child participants in the retrieved studies. There was marked variance in the way populations were described, with some authors referring to children's school grade, some failing to specify any developmental range, and others referring to age. Those references which described the population by school grade varied according to the country or school district in which the research took place. For example, in Aotearoa New Zealand, Primary School refers to

Years 1 to 6, and includes children aged 5-10 years. Kindergarten refers to children who are younger than 5. In the United States however, Elementary School involves Kindergarten through to Grade 5, with children aged 5 attending Kindergarten, and children entering Grade 1 at age 6 (UNESCO: United Nations Educational Scientific and Cultural Organization, 2012). To support clarity, a table was developed against which ages were checked (Refer to Disc 1, Appendix 7.1).

For some articles, a wider range of ages was spanned than that specified in the inclusion criteria of the present review, such as the study by Godeau and colleagues (2010) which included children aged 12 to 13. A decision was made to include such evidence into the review only where a portion of the population specifically fell within the range directly targeted in the *review question*, that is, 9 to 12 years.

Extraction of data.

After screening, and the application of the inclusion and exclusion criteria, 81 articles were included into the review. To prepare for analysis of the information, data were extracted from each article and entered onto a table (refer to Disc 1, Appendix 7.2). First the citation, the name of the intervention reported in each article (or recommended as in the case of expert opinion), and a brief description of the intervention process and details of the strategies used were entered. For each article, information was recorded about the intervention's purpose or key outcomes being addressed, any outcomes that were reported, the context of its application (e.g. home, community sports facility, inclusive school setting, school playground, school camp), the population it was applied with, the duration of the intervention (if stated), and any evidence as to its viability. Finally, after critical appraisal of each article, using an alpha-numeric system (Turner-Stokes et al., 2006), a grade was allocated that summarized the type, design, and quality of the evidence in the article. The process of critical appraisal, and the selection and application of the alpha-numeric system are described later when discussing the analysis used to address Questions Two and Three.

Analysis of data.

Analysis used to answer Question One: “What are the current, key, community-focused intervention approaches to facilitating participation for children aged 9-12 years who have had a moderate to severe TBI?”

After extracting data from the articles and entering it onto the data extraction table (Appendix 7.2), the data were analyzed in order to answer Question One. The articles in the review contained varied and overlapping combinations of strategies, involved different populations and contexts, and addressed various outcomes that related to participation. Many of the articles simply contained collections of strategies. Other articles named specific interventions, or variants of those interventions, and these involved particular strategies and processes. Such named interventions, and the articles which referred to them included;

- Cooperative Learning (Jacques, Wilton, & Townsend, 1998);
- Peer Tutoring (Bentley, 2008; Bolich, 2001; G. F. Harper, Maheady, Mallette, & Karnes, 1999; Hendrickson, Shokoohi-Yekta, Hamre-Nietupski, & Gable, 1996; Kamps, Barbetta, Leonard, & Delquadri, 1994; Klavina & Block, 2008; Roger, Gorevin, Fellows, & Kelly, 1992; Rynders et al., 1993)
- Circle of Friends (sometimes referred to as Support Circles or Friendship Circles) (Bentley, 2008; Frederickson & Turner, 2003; Goetz & O'Farrell, 1999; Hendrickson et al., 1996; Roger et al., 1992; Rynders et al., 1993; Schleien, Green, & Stone, 2003; G. Taylor, 1997; York & Vandercook, 1990)
- Building Friendships (Glang et al., 1997; Glang et al., 2004).

Some of these named interventions were adopted by several articles, albeit often in conjunction with other interventions and strategies. It was reasoned that despite showing promise for addressing some aspects of participation, due to the number and focus of strategies they employed, such interventions would, on their own, be insufficient to address the range of important aspects of participation derived from the case study assertions, as outlined on page 166.

For example, the classroom-based intervention called Peer Tutoring was described in several articles (Bolich, 2001; G. F. Harper et al., 1999; Hendrickson et al., 1996; Kamps et al., 1994; Rynders et al., 1993). Some (although not all) studies found this resulted in

improvements in academic performance for those subject areas, and also in increased social interactions between the children. Although the intervention and outcomes had some alignment with participation as I had defined it (i.e. Shared Occupation), the concept of the intervention (children with more ability teaching those with less ability in the classroom) did not sufficiently address important aspects of participation. Opportunities to involve children in other situations such as community settings (e.g. on a park playground) remained problematic. Rather than focusing on these named interventions, a broader look was needed across the evidence, and a deeper look was needed into the evidence to consider how different articles described facilitating participation.

To make sense of the data, and understand whether there were some common themes across the intervention approaches described in the articles, Strauss and Corbin's "systematic comparison" technique (1998, p. 95) was employed. The data extraction table was printed, and the articles on the table were cut out in strips.¹⁷ Each article was systematically compared with others. Articles using interventions with similarities were grouped together, noting on a large card the strategies employed, the outcomes of concern, and the contexts. With every new article added to a group, details on each card were updated, while dissimilar articles were placed apart until grouped with others. The process was continued until all the articles were categorized. Five approaches were identified out of this process. The approaches were named to reflect their aims and emphases. The order of the articles on the data extraction table was adjusted to reflect the five approaches (refer Disc One, Appendix 7.2).

Analysis used to answer Question Two: "What is the evidence for the effectiveness of the approaches in addressing the outcomes with which they were concerned?"

To address this question, each article needed to be critically appraised. A number of tools were considered for guiding critical appraisal. Articles that were primary research were critiqued using protocols developed by the Occupational Therapy Evidence-Based Practice Research Group at McMaster University (M. Law et al., 1998, 1998b; Letts et al., 2007, 2007b). These protocols provide a systematic structure for considering the quality of

¹⁷ An earlier version of the data extraction table than that shown in Appendix 7 was employed at this point. In this earlier table, the articles were simply arranged in the order in which they had been entered. The data extraction table shown on Disc 1 Appendix 7, Table 7.3 is the final version and shows the articles categorized by the intervention approaches.

qualitative or quantitative research. During the development of the protocols, it was reported that agreement of 75–86% was achieved between two investigators using the final version, lending some support for the reliability of the tool (McMaster University, 2008). Although a study by Dixon-Woods and her colleagues (2007) disputed this, discovering that the use of a structured tool did not ensure consistency of critique between reviewers, it was found that such tools did facilitate reviewers to clarify the rationale behind their appraisal decisions. For the present project, it was felt the structured appraisal tool would prompt consistent consideration of all aspects of the research material by providing a list of items and relatively detailed guidelines pointing to specific areas of potential limitations, and the implications of limitations. The McMaster guideline unfortunately does not provide a tool for critiquing Mixed Methods studies; in these instances both quantitative and qualitative forms were applied. Examples of two critical appraisals are included on Disc One, Appendices 7.3 and 7.4.

Another set of tools from the Critical Appraisal Skills Programme (CASP) (Public Health Resource Unit, 2010) was initially considered to guide evidence critique. The CASP contained several tools developed for appraisal of different types of experimental quantitative research, and a general tool for qualitative research. However, due to the preponderance of various quasi-experimental designs that were noted on scoping the data, it was felt that a more general appraisal tool for quantitative studies would be more appropriate.

After critically appraising each of the primary research articles, to answer Question Two, a means was still required of comparing the evidence from each article. Three systems were identified that showed promise. This was on the basis that they addressed diverse types of evidence, that they generated numeric evaluations reflecting the quality of the evidence, and, given a large number of items retrieved, that they could be readily implemented.

Goldsmith, Bankhead and Austoker (2007) developed a system to integrate quantitative and qualitative evidence. Every separate item of quantitative and qualitative evidence for each identified outcome is allocated a numerical quality score, then an adjusted overall quality assessment score is calculated for the combined quantitative studies and an overall quality assessment score calculated for the combined qualitative studies.

These overall quantitative and qualitative scores take into account adjustments for study quality, similarity of effects across studies, and applicability to the population in question. This tool was not selected for use for the current project because information was not provided regarding its reliability. Further, the system (Goldsmith et al., 2007) does not take into account experiential evidence such as expert opinion, which was felt to be a valuable addition for the present project.

A group of occupational therapy researchers developed a tool that, in addition to providing descriptive data about quantitative and qualitative studies, is able to critically appraise the studies and award a numerical evaluation of quality (Classen et al., 2008). The Systematic Process for Investigating and Describing Evidence-Based Research (SPIDER) tool has undergone psychometric testing, external review, and piloting. Using the SPIDER tool it would have been possible to identify an overall numerical evaluation of study quality. However, the tool is longer than the other two options, and emphasizes a full verbal description of each of the studies. Again, its focus is primary research, and it does not take expert opinion into account. Given the amount of data involved in the current review, it was felt that it was a less realistic option to apply.

In the United Kingdom, a research typology was developed and applied during the establishment of an evidence-base for best practice in managing long-term neurological conditions (Turner-Stokes et al., 2006). This typology provides a means of briefly describing the type of evidence, evaluating and synthesizing quality scores and the applicability of quantitative and qualitative studies, and also takes into account evidence in the form of expert opinion. The tool is practical for use with large amounts of data, and has undergone some psychometric testing. This typology was selected for use to support synthesis of information for the current review.

Using the typology, each article was initially addressed separately. The articles were first allocated either an E1 denoting client opinion, E2 denoting professional opinion, or an R, denoting research evidence. Research evidence was then given a further alpha-numerical category based on research design (Refer to Disc 1, Appendix 7.2 for the key to the different design categories).

Next, quality scores of 2 (yes), 1 (partially), or 0 (no) were awarded for the following criteria: (a) clarity of aims and design; (b) the appropriateness of the design; (c)

adequate description of the methods; (d) adequacy of the data for drawing interpretations or conclusions; and (e) the degree to which findings might be generalized (Turner-Stokes et al., 2006). For primary research, the critical appraisals which had been conducted in line with the protocols developed by the Occupational Therapy Evidence-Based Practice Research Group at McMaster University provided the basis for determining the typology quality scores. Articles which involved secondary analysis of data or which were reviews of existing research were allocated quality scores directly on the basis of the typology. Where there was any uncertainty as to the quality scores, this was resolved in discussion with my primary supervisor. The overall quality scores out of 10 for each article were then graded as high (7-10/10), medium (4-6/10), or poor (0-3/10).

The Applicability criteria used in the typology (Turner-Stokes et al., 2006) required some modification for use with a pediatric population with TBI. The typology classifies evidence as “Direct” if it involves people with “long-term neurological conditions” or “Indirect” if it involves people with different conditions (Turner-Stokes et al., 2006, p. 97). It was found that the phrase “long-term neurological conditions” not only identified information about studies of children with spinal conditions as directly applicable (although those children are unlikely to demonstrate the cognitive and behavioral difficulties experienced by children who have a TBI), but also identified evidence from populations with genetic conditions such as Down Syndrome as being less applicable (even though this condition results in cognitive impairments that might or might not bear similarities to children who have sustained TBI). Therefore the applicability criteria was modified to either Direct Applicability; “Moderate to Severe TBI” or Indirect Applicability; “Other Conditions”. Whilst most studies were classified as Indirect, consistency was increased.

Finally, each article was allocated an overall alpha-numeric code summarizing the type of evidence provided, the quality of that evidence, and its applicability (Turner-Stokes et al., 2006). The alpha-numeric codes were entered to the far right on the data extraction table. The key to the alpha-numeric codes is included on the data extraction table, on Disc One, Appendix 7.2. Examples of the alpha-numeric codes allocated for two articles are included with the critical appraisal examples on Disc One, Appendices 7.3 and 7.4.

Analysis used to answer Question Three: “What are the overall strengths and limitations of these approaches in terms of their effectiveness, applicability for children aged 9-12 years who have had a moderate to severe TBI, and viability?”

To answer Question Five, some general statements were required that drew together information from the earlier analysis. Taking information from the analysis of intervention approaches completed when answering Question Three, tables were developed for each of the five key intervention approaches. Each table stated the name of the intervention approach, and outlined the properties of that approach. The tables may be seen in Chapter Eight, Tables 8.7-8.11, pp. 260-271.

Next, in order to identify the overall quality of the evidence for each of the five intervention approaches, indicators were stated. Development of the indicators was guided by the research typology developed by Turner-Stokes and colleagues (2006). The indicators integrated the alpha-numeric codes allocated to the individual articles in each of the five intervention approaches as follows:

R: Indicates there is research evidence supporting the intervention approach.

- Grade A: One or more High quality studies with at least one of these directly involving children with TBI.
- Grade B: One High quality study, or more than one Medium quality study with at least one of these directly involving children with TBI.
- Grade C: One Medium quality study, or Lower quality studies only, or Indirect studies only.

E: Indicates the approach is also supported by Expert Opinion.

To further clarify the indicators, Bottom Line statements were written. The outcomes of the High and Medium quality research articles in each approach were summarized. Outcomes were not described for Lower Quality and Expert Opinion evidence, as it was considered that these items could not reliably demonstrate the findings. Lastly, information in the articles that addressed the viability of the approaches was entered into each table.

Analysis used to answer Question Four: “What strategies are used in community focused intervention approaches to facilitating participation for children aged 9-12 years who have had a moderate to severe TBI?”

Question Four, which asked what strategies were used in intervention approaches, was addressed next. Because there were multiple strategies and variability between strategies in the articles, some interpretation was required to clarify and integrate this disparate data. Strauss and Corbin’s (1998) analytical process that systematically compared data was again implemented to aid the interpretation. The check-box system inserted into the data extraction table facilitated and systematized the process. With each article that had been entered into the data extraction table (Disc 1, Appendix 7.2), the strategies used in that article were allocated names which captured their key properties. All strategies were compared with those identified from earlier articles, and boxes were checked where an article used previously identified strategies. New strategies were named as they became apparent. As more information was gathered about the strategies, further tables were started capturing the sources, features and dimensions of each strategy, and identifying any connections between the strategies (refer to Chapter Eight, Tables 8.8-8.11, pp. 202-211). New information sometimes meant revision of earlier ideas; strategies were sometimes re-named, some strategies were subsumed into others, whilst some strategies were split into two separate strategies.

As an example of this process, initially, a strategy, “Effective Communication” was identified. On further considering the category in the light of information from new items, it was decided that Communication was not a stand-alone strategy, but was consistently found as a part of the “Collaborative Team Planning” strategy, and was therefore included into that strategy.

Eventually no new strategies were emerging, and all information coming out of further articles was able to be captured by the existing strategies. As displayed in the next chapter in Table 8.7 (p. 201), to aid clarity when discussing the range and type of strategies identified, they were then grouped under four headings, guided by understandings from occupational therapy literature (Brown, 2009; Hemmingsson & Borell, 2000; Hemmingsson et al., 2003; Townsend & Polatajko, 2007). These included the therapeutic considerations of promoting client perspectives; making shared occupation available;

addressing the fit of a child's needs and abilities with the occupation and the context; and provision of human support.

To determine which strategies were used in the different approaches, the strategies used by each approach were then quantified. For each approach, the numbers and types of strategies used by Medium/High quality evidence and by Lower quality/Expert-opinion evidence were counted. The percentage of items using each strategy from the total items in each approach was calculated and graphed to explore differences. The graphs and detailed discussion of the graphed results may be seen in Appendix 8.1.

Analysis used to answer Question Five: "What is the potential of the strategies for addressing the aspects of participation identified as important in the case studies?"

Finally, to attend to Question Five, an interpretation was made as to whether each of the strategies derived from the articles could address the aspects of participation identified as important in the case studies. In particular, the properties and dimensions of each strategy as had been outlined in Tables 8.8-8.11, and the definitions of the important aspects of participation derived from the case study assertions and as outlined on page 166 were considered and compared.

The articles showed variation in the way strategies were delivered. They frequently described delivering a strategy in conjunction with varied combinations of other strategies, and emphasized different outcomes. Therefore, it was not possible to evaluate the overall quality of evidence for each strategy, or to determine conclusively from the articles whether a single strategy could facilitate the important aspects of participation. Consequently the interpretations were guided by the information in the case study data.

For example, one strategy in the articles was called *Providing Cooperative Occupation*. In the case studies, when children were provided with an occupation which required cooperation, they learned to use actions that Included one another, which I found to be an important aspect of participation. This was illustrated by Dana's teacher, Mr R., when he described the way he organized the children to work together in small teams to make movies.

[The children] all went into groups ... they couldn't have any more than five ... she [Dana] had a starring role... They were doing the read-throughs and table

reading and the film- she needed a lot of prompting with that and they were really good at helping her get through the script” (Case Study Four, Dana, TI, p. 12).

Therefore, when answering Question Five in the review, the strategy *Providing Cooperative Occupation* was interpreted as addressing an important aspect of participation, *Including*.

In carrying out the interpretation as to whether the strategies addressed important aspects of participation, several points were borne in mind:

- Shared Occupation, one of the important aspects of participation was considered here in terms of the child’s ability to share in an occupation that is meaningful, given that this is central to the definition in Chapter Six.
- Pattern was considered in terms of the child’s ability to share occupations with peers, as this was an imbalance particularly highlighted in Chapter Six.
- For clarity, when making the interpretation, optimal dimensions of the strategies were assumed. For example, in the articles, *Responsivity* was identified as a dimension of the *Adult Support* strategy. It was noticed in the case studies that when an *Adult Support* was optimally *Responsive* to a child’s need for independence, Occupation was then Shared with peers (an important aspect of participation). I interpreted that *Adult Support* could address the important aspect of participation, Sharing Occupation with peers, on the basis that the support person was *Responsive*. If the *Adult Support* was not *Responsive* to a child’s need for independence, that support would *not* address Sharing Occupation with peers.

The interpretations from this analysis were recorded in table format using check mark, and can be found in Chapter Eight, Table 8.12, p. 214.

Summary

This chapter has described the methodology and design of a review undertaken to identify, describe, and compare community-focused intervention approaches to facilitating children’s participation after TBI. The review also aimed to consider the strategies used by the approaches in relation to the important aspects of participation identified in the case studies, and to evaluate the evidence for the effectiveness of the different approaches. In Chapter Eight, the findings of the review are reported and discussed.

Chapter Eight

Study Phase Two: A Review of Community-Focused Interventions to Facilitate Participation for Children with TBI: The Findings

The previous chapter described the methodology and methods used to undertake a review of community-focused interventions to facilitate children's participation after a TBI. The present chapter goes on to describe and discuss the findings from that review. Initially, the results of the literature search and screening process are outlined using a diagram and described. Next, to answer the research questions, the findings of the analysis are presented.

Firstly, the results of the literature search and screening process are outlined. Then, answering Questions One, Two, and Three, the five broad intervention approaches¹⁸ evident in the literature are described in table format. For each approach, the overall quality of the evidence is summarized onto the table. The applicability of the approaches with the population of children with TBI, and their viability is outlined.

To answer Question Four, the strategies identified in the retrieved articles are presented according to four therapeutic considerations from the occupational therapy literature. Each strategy is described. The frequency with which the different strategies are used in each broad intervention approach is summarized. A more detailed discussion of this aspect of the analysis, including graphed findings, is included on Disc One, Appendix 8.1. Finally, in answer to Question Five, the strategies are considered in relation to the aspects of participation identified as important in Phase One of this research, and conclusions are drawn about their adequacy for working with children with TBI.

The chapter concludes with an examination of the implications of the findings for development of a resource to facilitate children's participation. The sequence and contents of the chapter are outlined in Figure 8.1 below.

¹⁸ The terms intervention approach, strategy, and therapeutic grouping are defined in the Glossary



Figure 8.1: Contents and Sequence of Chapter Eight

The following formatting convention is used when naming the strategies, therapeutic groupings, important aspects of participation, and intervention approaches:

- Intervention approaches are in bold font (e.g. **Structuring Shared Occupation**);
- Strategies are in italicized font (e.g. *Facilitating the Child's Perspective*);
- Therapeutic groupings are in bold, italicized font (e.g. ***Promoting Client Perspectives***);
- Important aspects of participation are in underlined font. (e.g. Shared Occupation).

Results of the Literature Search and Screening Process

The results obtained from the database search and screening process are outlined in Figure 8.2.

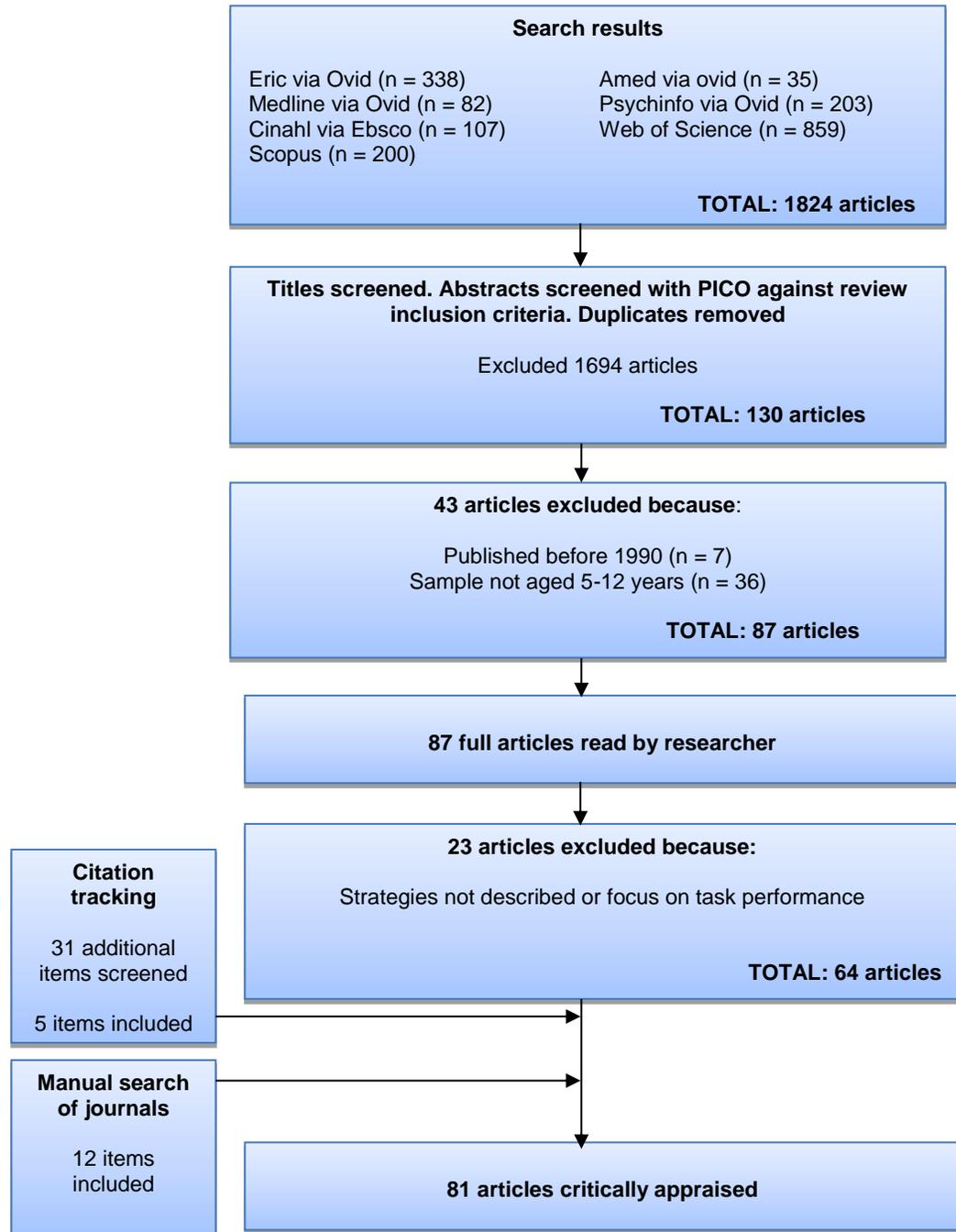


Figure 8.2: Flowchart of the Literature Search

The database search strategy retrieved a large number of articles (N = 1824), but on screening, the greater number of these articles did not adequately meet the inclusion criteria, or were duplicates, and were excluded. The remaining 87 articles were read in full. Of these, a further 23 were excluded because a) they did not specifically describe strategies or actions used by others that might support an aspect of participation identified as important in the case studies, or b) they described strategies solely aimed at improving task performance for children with disabilities and therefore were not community-focused.

Those articles remaining were supplemented by a manual search of relevant journals, and by citation tracking, yielding a further 17 relevant articles, resulting in a total of 81 articles of evidence being critically appraised. These comprised 48 items of primary research, 1 secondary analysis of research data, 8 descriptive reviews, and 24 items which were classified as expert opinion. The primary research included 21 quantitative, 14 qualitative, and 13 mixed methods studies.

Addressing Questions One, Two, and Three: Description of Community-Focused Intervention Approaches

Questions One, Two, and Three in the review are concerned with the broad intervention approaches and the evidence for those approaches. The questions are: (1) What are the current, key community-focused intervention approaches to facilitating participation for children aged 9–12 years who have had a moderate to severe TBI?; (2) What is the evidence for the effectiveness of the approaches in addressing the outcomes with which they were concerned?; and (3) What are the overall strengths and limitations of these approaches in terms of their effectiveness, applicability, and viability?

To answer these questions, as described in Chapter Seven, a critical appraisal was first performed on each of the research articles (M. Law et al., 1998, 1998b; Letts et al., 2007, 2007b; Turner-Stokes et al., 2006). The approaches used in all 81 articles were then categorized using a systematic comparison technique (Strauss & Corbin, 1998). Five broad intervention approaches were identified. Reflecting their properties, the context in which they were applied, and their purposes, they are called:

1. Structuring Shared Occupation;
2. Creating Opportunities to Experience Occupation with Others;
3. Developing Supportive Friendships;

4. Fostering Inclusive Communities;
5. Rehabilitation Service Provision Models and Modalities for Participation.

The five broad intervention approaches are presented next in Tables 8.1–8.5. Due to no one approach being considered of any more importance than others, they are presented in the order that they were revealed from the analysis. Each approach is first described. Indicators and bottom line statements identifying the overall quality of the evidence are derived and stated (Turner-Stokes et al., 2006). The overall quality and applicability of the evidence is rated with the following indicators:

- A, where the research includes one or more high quality studies with at least one of these directly involving children with TBI;
- B, where the research involves one high quality study, or more than one medium quality study, with at least one of these directly involving children with TBI;
- C, where the research involves one medium quality study, or lower quality studies only, or indirect studies only;
- E, where the approach is also supported by expert opinion.

The interventions and outcomes are summarized in the tables for High and Medium Quality primary research evidence, then information about the viability of the approaches is outlined. Following presentation of the tables, the overall findings are drawn together and summarized in relation to Questions One, Two, and Three.

Table 8.1: Description of Community-Focused Intervention Approach 1:**Structuring Shared Occupation**

Note. Key to Overall Evidence Indicator: R=there is research evidence supporting the approach. C=the research involves one medium quality study, or lower quality studies only, or indirect studies only. E=the approach is also supported by expert opinion.

Approach Name: Structuring Shared Occupation

Properties and Aims

Providing or shaping an occupation to enable the child's engagement and contribution together with peers. Occupations are central to the approach, and are structured to foster contribution, interdependence, and collaboration. Group members support each other and interact to achieve the occupation. Settings for the occupations included camps, classrooms, community sports or community arts and drama programs.

Eighteen items of evidence were categorized into this approach.

Overall Evidence Indicator for Approach: RC, E.

Explanation: The approach is supported by

- Medium quality studies (n = 5) (Hendrickson et al., 1996; Jacques et al., 1998; Kamps et al., 1994; Lederer, 2000; Schleien, Mustonen, & Rynders, 1995).
- Medium quality descriptive reviews (n = 3) (Bolich, 2001; G. F. Harper et al., 1999; Rynders et al., 1993).
- Several studies categorized into the approach were of Lower quality (n = 6) (Hobbs, Bruch, Sanko, & Astolfi, 2001; Klavina & Block, 2008; Rynders, Schleien, & Mustonen, 1990; Siperstein, Glick, & Parker, 2009; Tan & Cheung, 2008; Wilhite, Mushett, Goldenberg, & Trader, 1997).
- Expert opinion (n = 3) (Brookman et al., 2003; Hourigan, 2009; Leach & Duffy, 2009).
- Although one of the expert opinion items involved a child with TBI (Brookman et al., 2003), none of the studies involved children with TBI.
- One high quality study did NOT support the approach (Werts, Caldwell, & Wolery, 1996).

Limited weight is therefore placed on the evidence.

Bottom Line Statement: There is limited evidence **Structuring Shared Occupation** facilitates participation for children who have had a TBI.

Reported Outcomes for High and Medium Quality Primary Research Evidence**High Quality¹⁹**

Peers modeled steps of unfamiliar tasks to children with disabilities, who gained skill at the tasks. All children began and remained fully engaged in classroom activities during the study. No improvement occurred in low levels of social interaction between children with disabilities and their peers (Werts et al., 1996).

¹⁹ The study by Werts et al (1996) is not included in the overall evidence indicator for the approach because it did not result in any improvement in the outcomes of interest to this review.

Medium Quality

- A descriptive study found children without disabilities perceived that a variety of opportunities which on promoting joint involvement in activities, facilitated friendship with disabled students at home and school (Hendrickson et al., 1996).
- A 6-week classroom-based cooperative learning program resulted in a significant increase in peers' social acceptance of children with disabilities (Jacques et al., 1998).
- Eighty sessions of classwide peer tutoring involving disabled students and their peers resulted in increased duration of free-time social interactions between the children, and improved performance in reading fluency and comprehension for all the children (Kamps et al., 1994).
- Eight weeks of Reciprocal Teaching between students with disabilities and their peers resulted in significantly improved reading comprehension. Informal observations suggested improved social interactions (Lederer, 2000).
- A 7-month community arts program using Cooperative Goal Structuring principles developed by David and Roger Johnson and drawing from the Special Friends program by Voeltz and colleagues (as cited in Schleien et al., 1995) found significant increases in social interactions initiated by peers, but no increases in reciprocations by disabled students.

Evidence for viability of the approach

- Evidence in a review indicated teachers were satisfied with Peer Tutoring (Bolich, 2001).
 - Staff for 3 class-room based studies and for an outdoor education-based study indicated the strategies were feasible to implement (Kamps et al., 1994; Klavina & Block, 2008; Lederer, 2000; Rynders et al., 1990).
-

Table 8.2: Description of Community-Focused Intervention Approach 2:**Creating Opportunities to Experience Occupation with Others**

Note. Key to Overall Evidence Indicator: R=there is research evidence supporting the approach. B=the research involves one high quality study, or more than one medium quality study with at least one of these directly involving children with TBI. E=the approach is also supported by expert opinion.

Approach Name: Creating Opportunities to Experience Occupation with Others

Properties and Aims

Partnerships and processes are established with community agencies and groups, with a view to providing opportunities for children with disabilities to experience, and to take part in occupations along with non-disabled children. The occupations are already open to non-disabled children, but are not typically attended by disabled children. This approach is concerned with ascertaining feasibility of inclusion, with preparation, and with setting up the occupations to accommodate and integrate the disabled children. There is a concern for matching the occupations with the skills and preferences of the child. The occupations provide a group context for children to interact with each other, and often involve new experiences and learning. Many of the occupations that are described are cooperative in nature.

Eleven items of evidence were categorized into this approach.

Overall Evidence Indicator for Approach: RB, E.

Explanation: The approach is supported by

- A High quality study (n = 1) (Hutchison Mecke, & Sharpe, 2008)
- Medium quality studies (n = 3) (G. M. Bedell et al., 2005; Bernabe & Block, 1994; Scholl, Smith, & Davison, 2005)
- Expert opinion (n = 6) (Batorowicz, McDougall, & Shepherd, 2006; Becker & Dusing, 2010; Fennick & Royle, 2003; Ledman, Thompson, & Hill, 1991; T. E. Moran & Block, 2010; Scholl, Dieser, & Davison, 2005)
- One study categorized into the approach was of Lower quality (n = 1) (Rosenberg, 2000)
- Only one of the medium quality studies involved children with TBI (G. M. Bedell et al., 2005).

Some weight is therefore placed on the evidence.

Bottom Line Statement: There is some evidence **Creating Opportunities to Experience Occupation with Others** may facilitate participation for children who have had a TBI.

Reported Outcomes for High and Medium Quality Primary Research Evidence
High Quality

A qualitative case study reported children with disabilities were successfully included into an 8-week summer camp, and often participated in occupations with peers. The children successfully took part in new and challenging occupations (Hutchison et al., 2008).

Medium Quality

- A qualitative study which involved children with TBI reported that parents found that their children's social participation was promoted when they used strategies such as educating others, peer support, gaining their child's viewpoint, adaptations, parent involvement and sourcing opportunities for participation (G. M. Bedell et al., 2005).
- A pre-experimental study found modifications to softball rules supported a child with a disability to be as successful as her peers in batting, and did not affect the quality of the game for her team-mates (Bernabe & Block, 1994).
- A mixed methods descriptive study found parents and staff felt that the Together We Play inclusive recreation program was beneficial for children with and without disabilities, and that it supported positive self-concepts and acceptance for children with disabilities (Scholl, Smith, et al., 2005).

Evidence for viability of the approach

Most programs involved multiple strategies and collaborative planning with multiple team members, suggesting a level of complexity in their establishment.

- Parents of children who participated in a reading program and in a drama group felt the programs were cost-effective, and were very satisfied, whilst staff valued the learning they gained (Batorowicz et al., 2006).
 - The case report by Becker and Dusing (2010) argued that the strategies used to support a child in a performing arts program were feasible.
 - Parents in the study by Bedell (2005) discussed a lack of time to implement the strategies they described.
 - Continued inclusion of children with disabilities in community recreation activities was recommended by coaches and parents (Fennick & Royle, 2003).
 - The Everybuddy integrated after school program was argued to be simpler and more cost-effective than specialist care, and was to be continued (Ledman et al., 1991).
 - Parents in the Together We Play program felt that adaptations lacked viability and interfered with other children's enjoyment. Coaches felt that the services were less viable for children with severe disabilities (Scholl, Smith, et al., 2005).
-

**Table 8.3: Description of Community-Focused Intervention Approach 3:
Developing Supportive Friendships**

Note. Key to Overall Evidence Indicators: R=there is research evidence supporting the approach. B=the research involves one high quality study, or more than one medium quality study with at least one of these directly involving children with TBI. E=the approach is also supported by expert opinion.

Approach Name: Developing Supportive Friendships

Properties and Aims

Strategies and processes are implemented to develop friendships between a child with a disability and specific peers. Friendship is loosely defined by the quality of relationship and number of interactions that take place between these children, and was usually named as an outcome or area of focus. The friendship is generally characterized by the supportive role played by peers, although when the approach is driven by parents in the community, there is an emphasis on sourcing and creating opportunities for children to participate alongside peers with a view to developing friendships.

Eight items of evidence were categorized into this approach.

Overall Evidence Indicator for Approach: RB, E.

Explanation: The approach is supported by

- Medium quality studies (n = 4) (Eriks-Brophy et al., 2007; Frederickson & Turner, 2003; Glang et al., 1997; Heyne, Schleien, & McAvoy, 1994).
- Expert opinion (n = 3) (Callaway, Sloan, & Winkler, 2005; Salend, 1999; Schleien et al., 2003).
- One study categorized into the approach was of Lower quality (n = 1) (Nota, Ferrari, & Soresi, 2005).
- One of the medium quality studies involved children with TBI (Glang et al., 1997).

Some weight is therefore placed on the evidence.

Bottom Line Statement: There is some evidence **Developing Supportive Friendships** may facilitate participation for children who have had a TBI.

Reported Outcomes for High and Medium Quality Primary Research Evidence

Medium Quality

- A qualitative study found that a support group for parents and their children with hearing impairments resulted in enduring friendships, that facilitation of friendships resulted in improved social inclusion, and that social interactions increased (Eriks-Brophy et al., 2007).
 - A quasi-experimental study (Glang et al., 1997) of the Building Friendships Program (Sowers et al., 1996), found a significant increase in the number of social contacts children with TBI had with their peers at 10 and at 12 weeks. Parents and facilitators were significantly more pleased with children's involvement at school. Anecdotal evidence suggested however that improvements were not maintained.
 - A qualitative study of the Dowling Friendship Program which had run continuously
-

for 3 years led to friendships and improvements in disabled children's participation in activities with peers (Heyne et al., 1994).

- A quasi-experimental study found statistically significant improvements in peer ratings of how much they would like to play with disabled children following a 6-week Circle of Friends program (G. Taylor, 1997) and at 6-week follow-up (Frederickson & Turner, 2003).

Evidence for viability of the approach

- Qualitative data from one item of evidence suggests strategies implemented by parents to facilitate friendships were demanding, but that they were perceived to be worthwhile (Eriks-Brophy et al., 2007).
 - The Building Friendships process involved paid facilitators for 2-3 hours/week over 16 weeks (Glang et al., 1997).
-

Table 8.4: Description of Community-Focused Intervention Approach 4:**Fostering Inclusive Communities**

Note. Key to Overall Evidence Indicators: R=there is research evidence supporting the approach. B=the research involves one high quality study, or more than one medium quality study with at least one of these directly involving children with TBI. E=the approach is also supported by expert opinion.

Approach Name: Fostering Inclusive Communities

Properties and Aims

This approach draws together articles focused broadly on the notion of inclusion. Items in this approach are concerned with building settings which accept and value children with disabilities, and where those children can be included as members of a community along with their peers. The evidence is largely situated in school settings.

Some varied emphases were noted within this approach. For example, some evidence, promoted supportive attitudes and actions towards children with disabilities. Others however, argued for building a culture that promotes contribution, and cooperation between all members. Despite varied emphases, there was blurring and overlap, and it was not always possible in every instance to show that an item of evidence espoused one viewpoint or another. This meant that a separate evaluation of the merits and features of the various emphases was not realistic.

The approach is overarching, in that it encompasses approaches such as Structuring Shared Occupation and Developing Supportive Friendships. However, evidence which clearly focused on one or the other of these two approaches was analyzed under that approach separately, rather than being included into the umbrella approach of Fostering Inclusive Communities.

Thirty-three items of evidence were categorized into this approach.

Overall Evidence Indicator for Approach: RB²⁰, E.

Explanation: The approach is supported by

- High quality studies (n = 5) (Janney & Snell, 1996; McDougall, DeWit, King, Miller, & Killip, 2004; Mortier, Van Hove, & De Schauwer, 2010; Richardson, 2002; Salisbury, Gallucci, Palombaro, & Peck, 1995).
 - Medium quality studies (n = 8) (Bentley, 2008; Causton-Theoharis & Malmgren, 2005; Hemmingsson et al., 2003; Hunt, Alwell, Farron-Davis, & Goetz, 1996; Ison et al., 2010; Janney & Snell, 1997; Martinez & Carspecken, 2007; Ryan, 2008)
 - One Medium quality study which was a secondary analysis of qualitative evidence (n = 1) (Higgins, MacArthur, & Kelly, 2009).
 - Medium quality descriptive reviews (n = 2) (Goetz & O'Farrell, 1999; Soodak, 2003)
 - Expert opinion (n = 8) (Causton-Theoharis, 2009; DeZonia, 2009; Meadan & Monda-Amaya, 2008; Mickel & Griffin, 2007; Roger et al., 1992; Stivers, Francis-Cropper, &
-

²⁰ An anomaly was found with the system used for the evidence indicators at this point (Turner-Stokes et al., 2006). This intervention approach did not fully meet the criteria for any of the indicators. Although it involved six high quality studies and 8 medium quality studies, none of these involved children with TBI, therefore it did not meet the criteria for an A or B indicator. Although there was one lower quality study which involved children with TBI, neither did the approach meet the C criteria, which applies if there is only one medium quality study or lower quality studies only, or indirect evidence only. Given the number of high and medium quality studies, and the presence of a direct study, the approach was allocated a B indicator.

Straus, 2008; Walker, 1990; York & Vandercook, 1990).

- Six studies and two descriptive reviews categorized into the approach were of Lower quality (n = 8) (Adibsereshki, Tajrishi, & Mirzamani, 2010; Dumas, Bedell, & Hamill, 2003; Harrower, 1999; Harrower & Dunlap, 2001; Hutzler, Fliess-Douer, Avraham, Reiter, & Talmor, 2007; Mortier, Hunt, Desimpel, & Van Hove, 2009; Pavri & Monda-Amaya, 2001; Salisbury & Evans, 1993).
- One High quality study did not find an effect for the intervention (Godeau et al., 2010).
- Although there were 5 High quality studies and 8 Medium quality studies, none of them involved children with TBI. Only one Lower quality study (Dumas et al., 2003) focused on children with TBI.

Some weight is placed on the evidence.

Bottom Line Statement: There is some evidence **Fostering Inclusive Communities** may facilitate participation for children with TBI.

Reported Outcomes for High and Medium Quality Primary Research Evidence

High Quality

- One high quality cluster randomized controlled trial found no significant effect in terms of improved attitudes towards children with disability as a result of an educational intervention. The time frames for the study are unclear (Godeau et al., 2010).
 - A qualitative ethnographic study found that teachers used rules around helping peers, normalized a disabled child's presence and involvement in routines, and provided opportunity for children to spend time together without adult input, in order to facilitate interactions between children with and without disabilities (Janney & Snell, 1996).
 - Structural equation modeling of survey data in a high school found that use of "equitable" educational goals which reflected the diverse learning needs of all members of the student group, rather than competitive goals which drew attention to differences, was directly related to positive peer attitudes towards students with disabilities (McDougall et al., 2004, p. 287).
 - A qualitative study using case study methodology found that inclusion at school was facilitated through the use of adult support which was not solely on a child with a disability, and by the support person making adaptations to tasks and time frames, ensuring the child's presence, promoting inclusive and supportive actions by peers, involving parents, providing information, and liaising between school and home (Mortier et al., 2010).
 - A qualitative descriptive study found that at school, social interactions between children with disabilities and their peers occurred, and were of better quality, when reciprocity was encouraged, when adult support was not intrusive or singling the child out as different, and when the child engaged in play which they had initiated (Richardson, 2002).
-

-
- Another qualitative descriptive study found that positive social relationships occurred between children with and without disabilities when teachers actively promoted interactions, seating promoted cooperation during activities, collaborative problem solving was used with the whole class, children were provided with a choice of activity, a sense of community and acceptance was promoted, and when the presence of some familiar peers was maintained in class with a child with a disability. Teachers also used Cooperative learning, Peer tutoring, and Collaborative Problem Solving, although the authors and sources of these teaching strategies are not included (Salisbury et al., 1995).

Medium Quality

- A qualitative case study by Bentley (2008) found other children naturally adopted a variety of inclusive strategies when interacting with a peer who had a disability, including interpreting the child's actions and communication, identifying needs for assistance, facilitating "partial participation" (p. 554), planning, and sharing experiences. The Circle of Friends program developed by Hammill and Everington (as cited in Bentley, 2008) had been established, although its influence on the data was given limited consideration.
 - A quasi-experimental study by Causton-Theoharis and Malmgren (2005) found 25 times greater frequency of interactions between children with disabilities and their peers following paraprofessional training based on "Supporting students with disabilities in inclusive schools: A curriculum for job-embedded paraprofessional development" by Ghere, York-Barr, and Sommerness (as cited in Causton-Theoharis & Malmgren, 2005, p. 434).
 - School assistants were able to support participation with peers as well as task performance dependent on their proximity to the student, their availability, their facilitation of students' involvement in decision making, the involvement of peers, and the adaptation of activities in the qualitative study by Hemmingsson and colleagues (2003).
 - A mixed methods study by Hunt and colleagues (1996) which aimed to establish "Socially Supportive Environments" for students with disabilities (p. 53), resulted in increases in reciprocal interactions with peers, and increased initiation of interactions by students with disabilities. Support Circles described by Forest and Lusthaus (1989) and the Buddy System described by Haring and Breen (1992) were implemented alongside other strategies in the study.
 - After 2 weeks, the "Just like you" disability awareness program derived from the Whitehorse City Council's disability awareness kit (as cited in Ison et al., 2010) brought about a significant improvement in knowledge, attitudes, and acceptance of students with disabilities by their peers.
 - A qualitative study by Janney and Snell (1997) found that teachers used adaptations, support from teaching staff and peers, seated the students with disabilities in the same way as peers, and beside peers, and avoided singling them out as different, in order to include them as members of the class.
 - A mixed methods study using reading materials to educate students about people with disabilities, found a significant improvement in children's acceptance of peers with disabilities (Martinez & Carspecken, 2007).
-

-
- A qualitative study by Ryan (2008) found that parents used readily understandable “labels” as a means of informing others in the wider community about their children’s learning difficulties.

Evidence for viability of the approach

Few items of evidence provided information as to the viability of the strategies described. Some studies explored strategies teachers, parents and rehabilitation professionals were implementing, and it is possible to conclude that as these strategies are those stated as routinely being used, they are realistic (Dumas et al., 2003; Janney & Snell, 1997; Pavri & Monda-Amaya, 2001; Salisbury et al., 1995).

- Six teachers who took part in the disability awareness program implemented by Ison et al. (2010) indicated a high level of satisfaction. The program’s relevance, its interface with the curriculum, presentation, and content were all scored as good to excellent. One teacher indicated the session was too short, and other comments indicated the teachers felt the program was worthwhile.
 - An ethnographic study drew attention to the practical and cognitive demands placed on teachers to accommodate new information and programs, and suggested that the realistic option is to address additional student needs within existing routines (Janney & Snell, 1997).
 - In a study by Mortier and colleagues (2009), the team identified the strategies they used were practical and the meetings they held were efficient.
 - Stivers and colleagues (2008) noted that their month-by-month strategies for teachers would place additional demands, but argued for the rewards that would come with the extra work, and that strategies would fit with tasks that were already occurring.
-

**Table 8.5: Description of Community-Focused Intervention Approach 5:
Rehabilitation Service Provision Models and Modalities for Participation**

Note. Key to Overall Evidence Indicators: R=there is research evidence supporting the approach. A=the research includes one or more high quality studies with at least one of these directly involving children with TBI. E=the approach is also supported by expert opinion.

Approach Name: Rehabilitation Service Provision Models and Modalities for Participation

Properties and Aims

Several items of evidence were associated with delivery of rehabilitation services. These addressed inpatient settings, services at point of transition to the community, and longer-term community based services. Items focused on aspects of participation such as increased engagement in meaningful activities, and aspects of participation such as enhancing the fit of others' actions or bringing about a parent's satisfaction with the child's participation. Several of the items were focused on supporting children's participation in a family setting through their parents. Innovation was evident in some of the items, where there was delivery of services via the internet or audio-visual information packages. A number of these items were directly established for children who had sustained a TBI.

Eleven items of evidence were categorized into this approach.

Overall Evidence Indicator for Approach: RA, E.

Explanation: The approach is supported by

- High quality studies (n = 2) (Graham, Rodger, & Ziviani, 2010; McDougall et al., 2006).
- Medium quality studies (n = 3) (House, Russell, Kelly, Gerson, & Vogel, 2009; S. L. Wade, Michaud, & Brown, 2006; S. L. Wade, Oberjohn, et al., 2009).
- Expert opinion (n = 4) (R. J. Forsyth, Kelly, Wicks, & Walker, 2005; Glang et al., 2004; Scaletti, 1999; Sutter, Ditto, & Peterson, 2008).
- One study and a descriptive review were of Lower quality (n = 2) (Mu & Royeen, 2004; Verburg, Borthwick, Bennett, & Rumney 2003).
- One of the High quality studies and two of the Medium quality studies involved children with TBI (McDougall et al., 2006; S. L. Wade, Michaud, et al., 2006; S. L. Wade, Oberjohn, et al., 2009). Three Expert opinion items also involved children with TBI (R. J. Forsyth et al., 2005; Glang et al., 2004; Sutter et al., 2008).

Weight is therefore placed on the evidence.

Bottom Line Statement: There is good evidence **Rehabilitation Service Provision Models and Modalities for Participation** will facilitate participation for children with TBI.

Reported Outcomes for High and Medium Quality Primary Research Evidence
High Quality

- A mixed methods study by Graham and colleagues (2010) found Occupational Performance Coaching resulted in clinically significant increases in parents' perceptions of their own and their children's performance, and satisfaction with the
-

performance.

- A pre-test post-test design study of the Paediatric Acquired Brain Injury Community Outreach Program (PABICOP) which used a comparison group and had a follow-up, found the intervention group had significantly greater increases in knowledge of ABI than those receiving standard treatment. However children of families who participated for fewer sessions of PABICOP, participated more in activities than participants who had a greater number of sessions, or those who received standard treatment (McDougall et al., 2006).

Medium Quality

- A mixed methods study identified that for parents of children with spinal cord injury, 30% felt previous participation in community activities, 13% felt interactions with others with similar disability, and 13% felt general encouragement, facilitated participation in school or community activities (House et al., 2009).
- A randomized controlled trial found 80% of families in a problem-solving intervention group reached targeted functional goals with their children with TBI, and >90% of parents reported they knew strategies for managing future difficulties. All in the intervention group reported better parent-child relationships. For parent-child interactions, no significant effect was found for the intervention group (S. L. Wade, Michaud, et al., 2006).
- A pre-experimental study of a web-based parenting skills program reported significant increases for positive parenting behaviors and significant decreases in negative parenting behaviors with children with TBI (S. L. Wade, Oberjohn, et al., 2009).

Evidence for viability of the approach

Several articles evaluated the viability and participants' perceptions of interventions.

- Parents in the High Quality study of Occupational Performance Coaching by Graham and her colleagues (2010) indicated it was challenging implementing the changes, particularly at the start of the intervention.
 - Families were satisfied with PABICOP services, valuing staff support, communication, & information sharing. Services were generally useful (McDougall et al., 2006).
 - Parents rated the Family Centered Problem Solving intervention program easy to use, and extremely helpful, and felt they would recommend it to others (S. L. Wade, Michaud, et al., 2006).
 - Most families felt comfortable using web-based and internet resources, but technology needs to be familiar, available, reliable, and accessible (Verburg et al., 2003; S. L. Wade, Oberjohn, et al., 2009). Some identified reduced motivation to complete material on-line due to the flexibility it allowed (S. L. Wade, Oberjohn, et al., 2009).
 - For some research evidence, although the reason for drop-outs or decisions to decline participation was not considered as part of the evaluation, descriptions of the recruiting process suggest the amount of time involved with the intervention and assessments may have been a factor for families (S. L. Wade, Michaud, et al.,
-

2006; S. L. Wade, Oberjohn, et al., 2009). However, for the study by McDougall et al. into the PABICOP, 63 out of the 64 participants in the experimental group completed assessments at all 3 time points, including at 1-year follow-up, suggesting a very low attrition rate.

Summary of the five intervention approaches in Tables 8.1–8.5: Overall consideration of evidence, outcomes, applicability, and viability.

Tables 8.1–8.5 addressed the questions which asked: (1) What are the current, key community-focused intervention approaches to facilitating participation for children aged 9–12 years who have had a moderate to severe TBI?; (2) What is the evidence for the effectiveness of the approaches in addressing the outcomes with which they were concerned?; and (3) What are their strengths and limitations in terms of their effectiveness, applicability, and viability? In general, it can be seen that whilst all the identified intervention approaches were supported by research evidence, there was little high quality research, and even less research that had direct applicability. The greater part of the evidence was of low quality research or expert opinion. Only one of the eight high quality research articles and only four of the 23 medium quality research articles involved children with TBI. Notably, these few high–medium quality and directly applicable articles were spread across approaches which differed in their properties and focus. The one approach which had good evidence for its ability to facilitate participation for children with TBI did not address outcomes involving the social aspects of children’s participation with peers. There was limited evidence as to the viability of any of the approaches.

Table 8.6 draws together the key elements of Tables 8.1–8.5 that answer the above questions. Because it is intended to provide a summary of the key points from the preceding tables, for clarity, the citations are not repeated.

INTERVENTION APPROACH NAME	1: Structuring Shared Occupation (Table 8.1)	2: Creating Opportunities to Experience Occupation with Others (Table 8.2)	3: Developing Supportive Friendships (Table 8.3)	4: Fostering Inclusive Communities (Table 8.4)	5: Rehabilitation Service Models & Modalities for Participation (Table 8.5)
Overall Evidence Grade & Bottom Line	RCE Limited evidence	RBE Some evidence	RBE Some evidence	RBE Some evidence	RAE Good evidence
Statement regarding evidence for facilitating participation for children with TBI					
Effectiveness: Outcomes Described/Achieved	-Social acceptance -Social interactions -Performance -Friendship	-Acceptance -Inclusion -Social participation -New occupations -Performance success -Benefits child/peers	-Desire to play with peer with disability. -Social contacts with peers -Friendships. -Social inclusion. -Social interactions -Participation with peers	-Acceptance -Positive peer attitudes -Presence is normalized -Inclusion -Peers use inclusive strategies -Social interactions- peers -Positive social relationships -Participation with peers -Performance	-Parents & others gained increased knowledge re disability --Improved parenting -Performance & satisfaction -Achieved functional goals -Improved parent/child relationship
	One high quality article found no change in social interactions.		Improvements not maintained in 1 study.	One high quality article found no change in peer attitudes	More sessions associated with less participation in activities
Evidence for Applicability with Children with TBI	One expert opinion item involved a child with TBI	One medium quality study involved children with TBI	1 medium quality study involved children with TBI	1 lower quality study involved children with TBI	1 high, & 2 medium quality studies, and 3 items of expert opinion involved children with TBI
Evidence noted for Viability	Feasible Teachers satisfied	Feasible. Parents satisfied Cost effective Complex, lack of time, less viable for severe disability	Facilitators were funded for 1 study. Demanding but worthwhile Limited evidence	Strategies are routinely used Satisfied, practical Need to integrate with existing routines. Can place extra demands Limited evidence	Satisfied. Problem solving was easy Comfort with web-resources Coaching hard to implement Possibly too much time involved

Table 8.6: Summary of the Five Intervention Approaches described in Tables 8.1–8.5

Overall evidence for effectiveness. It can be seen in Table 8.6 that all intervention approaches were supported by both primary research evidence and expert opinion. The approach with the strongest evidence is 5: **Rehabilitation Service Models and Modalities for Participation**. There is limited evidence for Approach 1: **Structuring Shared Occupation**.

Overall outcomes achieved/described. Approaches 1-4 all describe improvements in social aspects of participation between children with disabilities and their peers. Approaches 1, 2, and 4 also describe improvements in children's performance skills. Approach 5, **Rehabilitation Service Models and Modalities for Participation**, contrasts with the other approaches, in that its community focus does not address social aspects of participation with peers. Outcomes for this approach include increased knowledge for family and support staff/educators, achievement of functional goals for the children with disabilities, and improved relationships between the children and their parents. One high quality study in each of approaches 1, **Structuring Shared Occupation** and 4, **Fostering Inclusive Communities** did not find improvements in social aspects of participation or peer attitudes respectively.

Overall applicability. There are few studies in any of the intervention approaches that involve children with TBI. However, the approach with the strongest applicability is Approach 5, **Rehabilitation Service Models and Modalities for Participation**, which includes one high quality study and 2 medium quality studies.

Overall viability. All of the intervention approaches have some evidence for their viability, although the evidence is limited for approaches 3 and 4. Approaches 2, 3, 4, and 5 all raise some concerns for the demands they place on time for parents and educators.

Addressing Question Four: Description of Strategies Used in the Intervention Approaches

The fourth question asked by the review is “What strategies are used in community-focused intervention approaches to facilitating participation for children aged 9–12 years who have had a moderate to severe TBI?” As discussed in Chapter Seven, the strategies were identified and described in the process of extracting data from the articles using systematic comparison of information (Strauss & Corbin, 1998). To view the extracted data and the sources of the strategies, refer to Disc One, Appendix 7.2. Most of the final 81

articles included general collections of strategies reported across the education and/or rehabilitation literature, or programs which include various combinations of strategies.

The strategies are presented next. To enhance clarity, the strategies are grouped according to four broad therapeutic notions deriving from occupational therapy literature (Brown, 2009; Polatajko, 1994; Townsend & Polatajko, 2007). First, Table 8.7 provides an overall depiction of the therapeutic groupings and the strategies within those groupings.

Therapeutic Groupings	Strategies Interpreted from Articles
1: Promoting Client Perspectives	<i>Facilitating Child's Perspective</i>
	<i>Parent Participation</i>
	<i>Collaborative Team Planning</i>
	<i>Collaborative Problem Solving</i>
2: Making Shared Occupation Available	<i>Sourcing Participation Opportunities</i>
	<i>Providing Cooperative Occupation</i>
	<i>Group Occupation Training</i>
3: Addressing Fit of Child's Needs & Abilities, Occupation, & Context	<i>Adjustments</i>
	<i>Proximity</i>
	<i>Reciprocity</i>
	<i>Challenge & Competition</i>
	<i>Linking Experiences</i>
4: Addressing Disability-Related Support Needs	<i>Impairment/ Needs Training</i>
	<i>Peer Support</i>
	<i>Adult Support</i>

Table 8.7: Strategies Identified from the Articles, Grouped according to Therapeutic Considerations

Next, the features and applications of the strategies are described in Tables 8.8–8.11. Excerpts from the articles are used to illustrate the properties of the strategies. Some strategies have dimensions that affect their implementation, and these are outlined. The strategies are not mutually exclusive; where there are interconnections between strategies these are described. As it is not possible to determine from the evidence whether any of the strategies might be more important or more effective than others, they are not presented in numbered order. Because each strategy occurs in multiple articles and most articles utilize multiple strategies, for brevity, the sources of the strategies are not included here.

Table 8.8: Features of Strategies Identified from the Articles: Therapeutic Grouping One: Promoting Client Perspectives

Strategy name, properties, & sources	Illustrative excerpt	Actions involved	Dimensions	Linkages
<p><i>Facilitating the Child's Perspective</i></p> <p>A child expresses their view of an occupation, chooses whether or not to participate, and acts guided by their unique experiences, interests and preferences.</p>	<p>"efforts were made to determine if Katie really wanted to play softball. Katie had always expressed an interest in sports in general and softball in particular (she enjoyed trying to play catch using a baseball mitt as well as hitting a ball off a batting tee...) ... When asked if she wanted to play in the softball league her immediate answer was yes" (Bernabe & Block, 1994, p. 25).</p>	<p>Opportunity is provided, and support is given to enable a child to express their perspective. Assistance or devices may be required to enable them to express themselves. Others may express the child's perspective for them. Occupations are structured by others to reflect the child's preferences.</p>		<p><i>Parent Participation.</i></p>
<p><i>Parent Participation</i></p> <p>Parents are involved in their child's occupations.</p>	<p>"plan for regular communication with families...include an easy way for families to communicate with you...consider asking them to lead small group discussions, assist with email exchanges, conference with students about their writing...review for quizzes, help with Internet searches and serve as an appreciative audience" (Stivers et al., 2008, p. 11).</p>	<p>Parent involvement is offered, facilitated, or sought. Communication aids their involvement. Some settings make opportunities for parents to meet with others. Parents may attend and observe, or may actively contribute to planning, educate others, or give assistance. They may express their child's wishes and needs & advocate for their child. They may create opportunities for children and their peers to spend</p>		<p><i>Facilitating the Child's Perspective.</i></p> <p>By creating opportunities for children to be with their peers, and by sharing experiences with other parents, the strategy of <i>Linking</i></p>

... continued over

Strategy name, properties, & sources	Illustrative excerpt	Actions involved	Dimensions	Linkages
		<p>time together. They may support peer participation during transportation, family outings, & at home.</p>		<p><i>experiences is facilitated.</i></p>
<p><i>Collaborative Team Planning</i></p> <p>Those involved with a child plan and collaborate in preparation for enabling the child to participate.</p>	<p>“teams included... parents, their general education teachers, and the schools’ care coordinators... Olivia’s speech therapist participated in her team meetings. The itinerant support teacher...participated... A collaborative teaming process was used to develop support plans...supports were designed to support the focal student’s full social and educational participation... a process that included sharing ideas and building on the suggestions of others” (Mortier et al., 2009, pp. 340-341).</p>	<p>Communication underpins planning, and may take a variety of forms. The strategy involves clarifying children’s abilities, preferences, and needs, establishing goals and interventions, negotiation, decision-making, and task-organization. A second tier of communication strategies ensures information is shared between parties. Resources are identified and accessed. Peers may be involved.</p> <p>Children are infrequently described as being involved in their own planning. Planning may occur at a group meeting, or an agent may liaise between parties in different contexts.</p>	<p><i>Child’s Perspective:</i> The degree to which the child’s perspective is facilitated in the planning influences their participation.</p> <p><i>Contextuality.</i> The degree to which planning takes account of multiple contexts or, conversely, focuses on one context.</p>	<p><i>Parent Participation.</i></p> <p>The process may <i>Facilitate the Child’s Perspective.</i></p> <p>The process may facilitate <i>Linking Experiences.</i></p>
<p><i>Collaborative Problem Solving</i></p> <p>Solutions are generated and</p>	<p>“you learn to work things out with other people so that everyone feels OK with the solution...we used [collaborative problem solving] CPS to find solutions that were good for all kids in our school...1. What’s</p>	<p>Problem solving processes are guided. A formal problem-solving model may be used to guide discussion.</p>	<p><i>Child’s Perspective.</i> The degree to which the child’s perspective is</p>	<p>The process is often associated with <i>Collaborative Team Planning.</i></p>

... continued over

Strategy name, properties, & sources	Illustrative excerpt	Actions involved	Dimensions	Linkages
delivered to support a child to be positively involved in an occupation when difficulties are perceived.	happening here? 2. What can we do? 3. What would really work? 4. Take action. 5. How did we do?" (Salisbury & Evans, 1993, p. 68).	Resources such as information and professional advice facilitate effective problem solving. Few articles describe a child with a disability contributing to problem-solving processes.	facilitated in the planning influences their participation. <i>Contextuality</i> : The degree to which problem-solving takes account of multiple contexts or, conversely, focuses on one context.	The process may facilitate <i>Linking Experiences</i> .

Table 8.9: Features of Strategies Identified from the Articles: Therapeutic Grouping Two: Making Shared Occupation Available

Strategy name, properties, & sources	Illustrative excerpt	Actions involved	Dimensions	Linkages
<p><i>Sourcing Participation Opportunities</i></p> <p>Opportunities are sought for children to be involved in shared occupation which fits with their preferences and abilities.</p>	<p>So, I'm trying to find alternative things for him to do that he can do pretty successfully so that he doesn't get frustrated. We thought that he'd be able to play baseball, but he's not ready. So, to compensate for that, we're going to do concession duty for the baseball team that we would have been on. So, we'll work at the concession stand and he can see his friends and he'll help serve food during the games just to let him be part of the baseball game because he can't play. (Bedell et al., 2005, p. 279).</p>	<p>Information is sought by parents, teachers, or leisure activity agencies about locations, times, costs, other participants, the availability of human & material supports, and groups' willingness to include children with disabilities.</p>	<p><i>Child's Perspective.</i> The degree to which the child's perspective is facilitated influences their participation.</p>	<p>Other strategies are usually required in conjunction with this strategy, including <i>Impairment/Needs Training, Group Occupation Training, Adult Support, or Adjustment.</i> A pre-cursor to <i>Cooperative Occupation.</i></p>

... continued over

<p><i>Providing Cooperative Occupation</i></p> <p>Children use their abilities to contribute with others to a mutual occupation.</p>	<p>Activities...were planned to engender cooperative interaction, but without forcing it... children were required to help each other assume a physical position representing an art image... large wedge-shaped pieces of cardboard were handed out... along with pieces of yarn, various types of seeds, jars of paint... the “pizza pieces” were created interdependently and then laid side-by-side to create a “whole pizza” (Schleien et al., 1995, p. 404).</p>	<p>Occupations are provided or existing tasks are structured in a way that requires members of a group of children to work cooperatively, with all members contributing to completion of a task.</p>	<p><i>Group Occupation Training</i> often supports this strategy.</p>
<p><i>Group Occupation Training</i></p> <p>Groups of children are facilitated to learn how to engage cooperatively and effectively in an occupation.</p>	<p>“Katie was integrated at the beginning of the season during the [softball] team’s first practice. She continued to practice with the team until the end of the season. Most of Katie’s teammates knew Katie from school, and, after introductions and explanations of rule modifications for Katie, they all accepted her. During practice, Katie worked on skills she would use to participate in the game... In addition, her teammates had the opportunity to practice skills that would provide Katie with natural supports. These skills included peer partner strategies and outfield responsibilities. These skills were appropriate to practice even if Katie was not playing” (Bernabe & Block, 1994, pp. 26-27).</p>	<p>Children are familiarized with the task, rules, norms, & processes of an occupation to support each other’s performance & collaboration. Appropriate interactions are modeled & prompted. Reinforcement may be provided for cooperation, effort & achievement.</p>	<p>Supports provision of <i>Cooperative Occupation</i>.</p>

Table 8.10: Features of Strategies Identified from the Articles: Therapeutic Grouping Three: Addressing Fit between a Child's Needs and Abilities, Occupation, and Context

Strategy name, properties, & sources	Illustrative excerpt	Actions involved	Dimensions	Linkages
<p><i>Adjustments</i></p> <p>An occupation is changed to better support participation.</p>	<p>“activities and schedules were modified to better accommodate the varying abilities of the campers in the group... shortening hikes, changing the order of activities, making activities less structured, and flexible scheduling” (Hutchison et al., 2008, p. 188).</p>	<p>A task, time frames, scheduling, and physical context may be altered.</p>	<p><i>Flexibility.</i> Less flexible occupations are less adjustable.</p>	<p>Not Applicable</p>
<p><i>Proximity</i></p> <p>A child is positioned, placed such that they are present at and better able to participate in an occupation with peers.</p>	<p>“One of the most basic ways teachers include the focus [disabled] students was to keep them in the classroom...teachers made a number of modifications to classroom routines and the physical environment in order to keep the student situated near peers... peers volunteered to walk with Peter on the way to physical education class... The decision whether to position Daniel on the floor, in his bolster chair, or in his wheelchair was based on achieving similarity to his peers’ seating arrangement” (Janney & Snell, 1997, p. 164).</p>	<p>A child is maintained in the room with peers. A child is positioned in relation to materials in a way that supports their engagement. They are located with peers who will facilitate their interactions.</p>	<p><i>Familiarity.</i> Over-familiarity sometimes limits interactions with a disabled child. Unfamiliarity may equally limit interactions.</p>	<p>Not Applicable</p>
<p><i>Reciprocity</i></p>	<p>“Others... did not give them [children with a disability] the chance to take a</p>	<p>Others expect, provide opportunity for, facilitate, & recognize turn-</p>		<p>Supports provision of</p>

... continued over

Strategy name, properties, & sources	Illustrative excerpt	Actions involved	Dimensions	Linkages
A child shares in an occupation.	productive role in activities. The lack of opportunity to take on the role of helpers marginalized their participation... teachers were inconsistent in conveying their expectations that the children do their fair share, although they expressed frustration that the children did not take responsibility for being contributing class members” (Richardson, 2002, p. 299).	taking, information sharing, communication, and contributions. Parents may reciprocate each other’s invitations.		<i>Cooperative Occupation.</i> Supports <i>Linking Experiences</i> when parents involved.
<i>Challenge & Competition</i> A child takes part in & achieves at an occupation which presents challenge or competition.	“During Scott’s first summer... he participated in the Leisure Services T-Ball program... Dad... thought that it would be too hard for Scott but Mom really wanted to give it a try. The first week of T-ball was really tough... By the end of the season, “Scott was on the field with the other kids playing the game... The subsequent summer Scott was signed up for the same program...each night got better and better for Scott... At the end of the summer... Scott was able to participate fully with his peers” (Scholl, Dieser et al., 2005, p. 305).	A child is provided with new occupations to try out. They are encouraged to use effort or extend their skills to achieve at an occupation. They may take part in a competitive occupation.	<i>Challenge.</i> Where the occupation is overly challenging or unchallenging, participation is limited.	<i>Adjustments, or Adult or Peer Support</i> are likely to be provided to moderate the degree of <i>Challenge.</i>
<i>Linking Experiences</i> Connections between a child &	“The student was provided with a conventional telephone-based Internet service linking his home, family and school friends. His friends created a website that included	Opportunity is made and support is provided to share occupational experiences with other people. Practical media facilitates a child’s communication. Occupations may		<i>Adult and/or Peer Support</i> may be required

... continued over

Strategy name, properties, & sources	Illustrative excerpt	Actions involved	Dimensions	Linkages
<p>other people & other occupations are supported between different time frames & settings. People gain understanding of each other's experiences. Experience of previous occupations provides a platform for participation in new occupations in a new context.</p>	<p>a bulletin board. This was used by his parents, grandmother, and by other friends, both at home and while they visited the student in the hospital. The student and his visitors could access the Internet via a notebook computer placed on the student's wheelchair tray or on a bedside table... an interview with the mother resulted in the following statement: "the Internet connection was the best thing for J. It made the world of difference and kept him in touch" (Verburg et al., 2003, p. 119).</p>	<p>be sought or provided on the basis that they build on previous experience or include others with whom occupation has previously been shared. Sharing experiences with other adults who have a disability is particularly thought to support participation and understanding for children with and without disabilities.</p>		

Table 8.11: Features of Strategies Identified from the Articles: Therapeutic Grouping Four: Addressing Disability-related Support Needs

Strategy name, properties, & sources	Illustrative excerpt	Actions involved	Dimensions	Linkages
<p><i>Impairment/Needs Training</i></p> <p>Others learn about disabilities, disabled peers' need for support, and how to provide that support.</p>	<p>"information included discussion of different types of disabilities, appropriate and inappropriate language use...communicating using the Braille and Australian Sign Language...comprehension activities based on the experiences and achievements of Paralympians... activities included simulation of daily activities with a disability...question and answer sessions with a person with a disability; and demonstration and use of various equipment items" (Ison et al., 2010, p. 364).</p>	<p>Instruction is provided to peers. Questions are answered. Interactions are modeled. Audiovisual media may support learning. The child with the disability is rarely described as being involved in the training.</p>	<p><i>Stigmatization.</i> When disability and difference are emphasized, participation is hampered.</p>	<p>May facilitate delivery of <i>Peer Support</i> and <i>Adjustments.</i></p> <p><i>Parent Participation</i> may be used to support understanding of a child's <i>Impairments & Needs.</i></p>
<p><i>Peer Support</i></p> <p>A child is assisted by peers to take part in an occupation, & to interact.</p>	<p>"classmates were not allowed to help one another... they were "supposed to help" the focus [disabled] students... physical assistance, giving verbal and physical prompts...retrieve positioning equipment... they do for him what he cannot do himself" (Janney & Snell, 1996, pp. 75-76).</p>	<p>Peers are trained in ways to assist and interact with a child.</p>	<p><i>Interdependence.</i> When interdependence is instilled as a group norm, & all children support each other, provision of peer support enables a child to be seen as a member of a group.</p>	<p>Often facilitated by <i>Impairment/Needs Training.</i></p> <p>May be required with <i>Challenge & Competition</i></p>

... continued over

Strategy name, properties, & sources	Illustrative excerpt	Actions involved	Dimensions	Linkages
<p><i>Adult Support</i></p> <p>A child is assisted by an adult to take part in an occupation and to interact.</p>	<p>“children... received substantial adult attention... from assistance with physical, self-care, and academic tasks to monitoring of academic and play activities... Although at times the adult assistance facilitated the children’s abilities to participate in activities, interaction with adults during recess and play times often served to remove them from the opportunity to be part of a peer interaction group and disrupted the flow of play activities” (Richardson, 2002, p. 300).</p>	<p>An adult is trained to provide physical & verbal support to aid a child with an occupation, communication, & interactions. The gender of a support-person is important to consider. Many recommend that paraprofessional support in the classroom should not supplant teacher support.</p>	<p><i>Responsivity.</i> When support is responsive to a child’s need for independence or to changes in their skill level, participation is supported.</p>	<p>Adult support is used to deliver other strategies (eg. <i>Group Occupation Training, Impairment/Needs Training, Adjustments</i> or <i>Linking Experiences</i>).</p> <p>May be required with <i>Challenge & Competition</i>.</p>

Following description of the strategies, further analysis was undertaken to ascertain the frequency with which of the strategies shown in Tables 8.8–8.11 were used by each of the intervention approaches described on pages 186-198. Out of the total articles in each intervention approach, for each strategy, the percentage of articles graded as lower quality/expert-opinion evidence, and the percentage graded as medium/high quality evidence using that strategy were calculated and graphed. This supported some overall conclusions about the strategies used by the different intervention approaches which are summarized next. For a more detailed discussion about the use of strategies by the different approaches, and to see the graphs that were generated, refer to Disc One, Appendix 8.1.

All of the strategies had some medium/high quality evidence supporting their implementation. However, this conclusion is tempered by the fact that strategies were employed in various combinations within the articles, therefore it is not possible to precisely identify the level of evidence for each strategy.

Although the intervention approaches adopted a variety of strategies, they emphasized particular strategies, suggesting the wisdom of using a multi-faceted intervention. However, this was less so the case for two of the approaches, **Fostering Inclusive Communities**, and **Rehabilitation Service Provision Models and Modalities for Participation**. Here, analysis showed that each article employed relatively few strategies, pointing to particular areas of focus for rehabilitation and inclusive education programs. In contrast, each article in the **Creating Opportunities for Participation** approach employed a range of strategies, suggesting a level of complexity in delivery of such services.

Impairment/Needs Training was a strategy that was frequently used by all the approaches, pointing to a possibility that most intervention approaches feel an understanding of children's impairments is necessary to support them to participate. However, as described next, data in the case studies suggests this strategy would facilitate relatively few of the important aspects of participation. The strategy of *Facilitating the Child's Perspective* was not emphasized in any of the approaches, although was used more frequently in some articles in the **Rehabilitation Service Provision Models and Modalities for Participation**. Similarly, the strategy of *Linking Experiences* was not prominent in any of the approaches, perhaps reflecting a focus of approaches on particular

contexts (e.g. school, or a single community setting). This gap is a concern, given the importance of Connection in the case studies.

Addressing Question Five: The Relationships between the Strategies and Important Aspects of Participation

The fifth question asked by the review was “What is the potential of the strategies to address aspects of participation identified as important in the case studies?” To answer this question, an interpretation was made as to whether the strategies aligned with the important aspects of participation. The interpretation was based on the properties and dimensions of the strategies, and the definitions of the aspects of participation, and was guided by case study data. The findings of this interpretation are presented in Table 8.12, and are discussed.

Table 8.12: Potential of Strategies from Articles to Address Important Aspects of Participation Identified in Case Studies

Therapeutic Groupings	Strategies Interpreted from Articles	Important Aspects of Participation Identified in Case Studies						
		Shared Occupation Child takes part in meaningful occupation with others	Driving the creation of opportunities to share occupations directly & vicariously	Leaders learn to address the social & physical environment to involve children	Group members learn to use actions that include one another	Child better Performs shared occupation	Participation skills, the occupation, time, & place Fit with child's abilities & needs	Child experiences Connection with & across people, occupation, place & time
Promoting Client Perspectives	<i>Facilitating Child's Perspective</i>	✓	✓		✓		✓	✓
	<i>Parent Participation</i>	✓	✓				✓	✓
	<i>Collaborative Team Planning</i>	✓	✓				✓	✓
	<i>Collaborative Problem Solving</i>			✓	✓	✓	✓	✓
Making Shared Occupation Available	<i>Sourcing Participation Opportunities</i>	✓	✓				✓	✓
	<i>Providing Cooperative Occupation</i>			✓	✓		✓	✓
	<i>Group Occupation Training</i>			✓	✓	✓	✓	✓
Addressing Fit of Child's Needs & Abilities, Occupation, & Context	<i>Adjustments</i>			✓		✓	✓	✓
	<i>Proximity</i>			✓	✓	✓	✓	✓
	<i>Reciprocity</i>				✓			✓
	<i>Challenge & Competition</i>	✓				✓	✓	✓
	<i>Linking Experiences</i>		✓			✓	✓	✓
Addressing Disability-Support Needs	<i>Impairment/ Needs Training</i>			✓			✓	
	<i>Peer Support</i>			✓	✓	✓	✓	✓
	<i>Adult Support</i>			✓		✓	✓	✓

One pattern that emerged from this analysis is that the strategies which involve the therapeutic grouping of *Promoting Client Perspectives* show potential to facilitate Shared Occupation that is meaningful, and that supports both Fit and Connection. Collectively, these strategies point to an important underpinning role played by collaboration and consultation amongst all team members, active involvement of a child, and the need for effective communication strategies in facilitating participation.

It is further noted that the important aspects of Fit and Connection are both supported by multiple strategies. This suggests that the two concepts may be related, and that there are currently a number of strategies in the literature with potential to support these aspects of participation.

Fewer of the strategies are directed at a) Driving the creation of opportunities for shared occupation, or b) people learning to use Including skills. This suggests that the need to address these aspects of participation may not be well recognized in the literature. It is also possible that those aspects of participation are more problematic to address, and that strategies that do align with those aspects of participation are likely to be of particular importance.

The strategy of *Impairment/Needs Training*, which focuses on others learning about a person's disability and how to provide support, is identified as facilitating few of the important aspects of participation, even when training is delivered in a way that is non-stigmatizing. It may be that to facilitate peers to enhance their Including participation skills, other means should be considered. From the table, it appears that training directed at diverse group members working collaboratively to complete an occupation through *Provision of Cooperative Occupation*, and *Group Occupation Training* may be better suited to address Including skills. However, in the case studies in Phase One of the study, providing information about a child's areas of difficulty and their needs was found to be useful when people were Leading.

All of the strategies were observed in the case studies, and play a role in addressing important aspects of participation. Overall, however, the table does highlight that it is unlikely single strategies will fully address all of the important aspects of participation. Many of the strategies, on their own, only address a few aspects. Multiple strategies are likely to be required, and the choice of strategy may best be guided by the aspect of participation that is of most concern.

Limitations of the Review

Some limitations to this review should be recognized. Firstly, the review was not exhaustive. Proximity terms were used in the search, and this potentially limited the number of items that were retrieved. Reference lists of the articles that were retrieved were not manually searched. It is acknowledged that the conclusions that can be drawn are therefore constrained by the relatively small numbers of articles included into each approach. This potentially limits the validity of the different approaches that were interpreted. Despite this, when constantly comparing data to identify intervention approaches and strategies, saturation was achieved.

Secondly, a number of the articles are from earlier literature, and may not reflect current trends. Nonetheless, the strategies they use were found to be used in the case studies. Another point to recognize is that the articles comprising the different approaches may have used more strategies than those discussed, but do not refer to them in the publication (e.g. a number of articles from the education sector in the Fostering Inclusive Communities approach did not describe team planning, although educational planning is required by law for students with disabilities, and was likely to have been completed).

Finally, it is important to acknowledge that the review included material relating to children with a variety of diagnoses. Articles that did not involve children with TBI may not adequately acknowledge the impact on interventions of issues such as fatigue, improving performance with recovery, or the risks associated with repeat head trauma. Such issues were an influence on the children's participation in the case study phase of this research. Whilst this concern is reflected in the overall evidence grading determined for each intervention approach in the review, it should be borne in mind when considering the utility of intervention approaches or strategies within those approaches for the population of children with TBI.

Discussion and Implications for Addressing Children's Participation

This literature review was both driven and informed by the findings of the case studies discussed in Chapters Five and Six. Therefore the implications of the findings of this literature review are considered here in conjunction with the findings of the case studies. The case studies raise concerns about children's participation in Aotearoa New Zealand, yet also provide practical information about things that were useful in facilitating

their participation. These things include providing opportunities for children to share a variety of meaningful occupations with their peers and others in the community, through promoting others' participation skills in the areas of Driving, Leading, Including, and Performing. Such skills were learned in the context of Shared Occupation, involving both direct and vicarious experiences. Participation is particularly supported in contexts and cultures where the use of inclusive actions is a cultural norm. A number of elements concerning the occupation itself, and its physical and temporal contexts require consideration. However, overall, it is important that a) interventions enable a Fit between a child's Participation skills and needs and those elements, b) the interventions support the child to experience a Connection with other people, place and time in the context of Shared Occupation, and that c) the child's overall Patterns of participation have balance, regularity, and diversity. Responding to this, the review of literature just described was carried out to establish whether there were existing interventions available which address these aspects of participation highlighted as problematic in the case studies. The review also aimed to establish whether there was adequate evidence to support adoption of an existing intervention approach to address those issues.

Few of the articles reviewed were specifically applicable to children with TBI. Analysis against the information from the case studies suggested that many of the interventions in those articles may only address participation in part, aiming to improve individual performance or behavior (Braga et al., 2005; Catroppa, Anderson, & Muscara, 2009; Chen et al., 2004; Glang et al., 2004; Marcantuono & Prigatano, 2008; S. L. Wade et al., 2005). Another intervention with this population established networks of peers who committed to providing support, friendship, and involvement in leisure activities for children with TBI (Glang et al., 1997), although may have inadvertently drawn attention to differences, and did not address longer term participation. One occupation-focused intervention used theatre-skills training to support participation for two teenagers with non-traumatic acquired brain injury, but this may only be of interest to a small number of children (Agnihotri et al., 2012).

Only two studies included in the review described strategies used by parents and practitioners to directly support participation for children after ABI. Parents in one study endeavored to create participation opportunities for their children by identifying activities that are of interest, adapting activities, inviting peers to visit, and educating other people

about the children's skills and needs in an effort to change attitudes (G. M. Bedell et al., 2005). To these ideas, in a study by Dumas and colleagues (2003), parents, specialist teachers, and rehabilitation professionals added further strategies, highlighting a need for multi-faceted intervention. Many strategies were focused on parents and professionals planning for and supporting performance of the children with ABI, but some involved peers, through inclusion in therapy or to assist with tasks, and peer modeling. Collectively, the strategies have potential to address the aspects of participation identified as important in the case studies, and align with some of the community-focused strategies identified for children with other diagnoses in this review. By turning to the wider literature however, the review gives some confirmation to the findings of G. M. Bedell et al. (2005) and Dumas et al. (2003), and contributes additional strategies to help address participation concerns.

Overall, in my review of literature in this chapter I identified three, broad intervention approaches which have some evidence for their ability to address participation (**Creating Opportunities to Experience Occupation with Others, Developing Supportive Friendships, and Fostering Inclusive Communities**), and one approach which has good evidence, **Rehabilitation Service Provision Models and Modalities for Participation**. I also explored the strategies used in the intervention approaches. I found that the strategies used in the literature align with those seen that were implemented to good effect in the case studies. However I found that no one strategy can address all the aspects of participation that are important, and that multiple strategies are likely to be needed. I noted general alignment between Medium and High quality evidence, and Low quality/Expert opinion evidence in terms of the strategies used, and that all strategies have been used in Medium/High quality evidence, albeit in conjunction with other strategies.

My analysis of the strategies used in the approaches indicates that most approaches use several strategies, but emphasize some more than others, and that some strategies are neglected, with consequent risk of neglecting some important aspects of participation identified in the case studies. Notably, the approach that had strongest evidence (**Rehabilitation Service Provision Models and Modalities for Participation**) employs fewest strategies, indicating again that certain aspects of participation may not be adequately addressed, despite some positive outcomes for certain aspects of participation. Further, the information points to the need to consider the challenges of addressing the multiple aspects of participation, and that it may not be realistic to expect that it is

achievable for families to fully address these on their own; involvement of the wider community is needed.

I therefore made a decision to develop a resource that incorporated the range of community-focused strategies that had been described and observed in the case studies and found in this review. Given that stakeholders in the case studies experienced multiple demands on their time, the resource aimed to convey the strategies in language that was straightforward and succinct. The resource was developed in draft form (refer Appendix 9.1, p. 379), then further feedback was sought from stakeholders to establish its utility. The process used for obtaining that feedback is described next.

Chapter Nine

Study Phase Three: Modeling of a Community-Focused Resource to Facilitate Participation for Children with TBI: Methodology and Methods

Consistent with Dewey's (1929/1988) pragmatist philosophical perspective, the first two phases of this study demonstrated that knowledge arises in action, and that it directs and supports further action. Dewey also argued that, in turn, the test of knowledge is in its application to action in the real world. "If we see that knowing is not the act of an outside spectator but of a participator inside the natural and social scene, then the true object of knowledge resides in the consequences of directed action" (Dewey, 1929/1988, p. 157). In this third phase of the study, that action took the form of developing and obtaining feedback on a community-focused intervention approach, comprising a resource to support the participation of children with a TBI in the Aotearoa New Zealand context. This chapter first describes the development of the resource. It then moves on to explain the methodology and design of a study used to gain feedback on the resource. Where Māori terminology is used, it is explained, and terms are also defined in the Glossary. Figure 9.1 outlines the contents of the chapter.

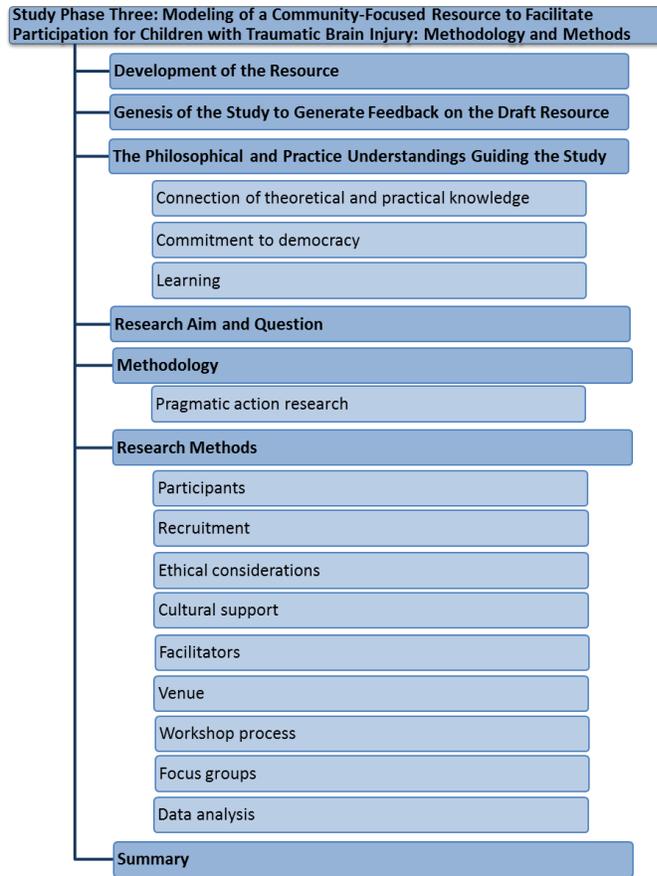


Figure 9.1: Contents and Sequence of Chapter Nine

The case studies for the first phase of the project prompted my concern about the children's participation. However the case studies and the review of community-focused interventions in the second phase also armed me with some knowledge of strategies that could facilitate the children's participation. Acting on this knowledge, a resource to address participation concerns was drafted. The draft resource is attached on Appendix 9.1, p. 379, and is also included in Disc One, Appendix 9.1.

Directed towards enskilling and mobilizing the social community, the draft resource had its foundations in the individual case study findings and cross-case assertions in Chapters Five and Six. It focused on the aspects of participation that were seen as important by different stakeholders, including Shared Occupation, Driving, Leading, Including, Fit, Connection, Pattern and Change. It drew those aspects together with strategies and intervention approaches described in the review in Chapter Eight that had some evidence for their effectiveness and applicability. It was intended that the resource would be viable for stakeholders to use, and would be flexible enough to be applied in different settings

with children who had brain injuries that varied in terms of time since injury, site of injury, and severity of injury.

The draft resource was in the form of a 32 page document that was named *Fit and Connect: A Kitset to Help Children Participate after TBI*. This name reflected some of the important aspects of participation (Fit and Connection) and the intent of the resource. It was termed “Kitset” to convey in everyday language that it involved a collection of tools that people could use.

First, a brief background was provided about the studies that led to the development of the resource, the people who might use the resource, and its purpose. The term participation was defined, and its importance for children after a TBI explained. The important aspects of participation were explained, including Fit, Connection, Balance, and Change, and the goals of the resource were stated. These included:

- Improving the Fit amongst a child, an activity, the physical context and timing of that activity, and other’s understandings and actions.
- Maintaining and building new Connections.
- Facilitating increased opportunities for participation.

The goals did not explicitly address Pattern, as, through provision of opportunities, it was understood that balanced patterns of participation would be promoted.

Next in the resource, the strategies were presented. In deciding on what strategies to incorporate, I was primarily guided by a desire to reflect the ideas of Shared Occupation, Changeability, Fit, and Connection that were identified in the case studies reported in Chapters Five and Six. I also endeavoured to capture from the case studies, the Participation Skills of Driving, Leading, Including, and Performing, the Learning that took place in these skills in the context of Shared Occupation, and the strategies that emerged from the review of community-focused interventions, as shown in Chapter Eight in Tables 8.8-8.11.

The process was complicated by a partial, but not complete degree of overlap between the important aspects in the case studies and the strategies in the review. It was also borne in mind that the strategies in the review derived largely from evidence that was not specific to children with TBI, therefore may not address concerns about fatigue and repeat head injury that had impacted on the patterns of participation in the case studies.

This first effort at integrating the important aspects of the case studies, and the strategies from the review was largely intuitive, but was guided by repeated reference to the assertions outlined in Chapter 6, and the definitions and descriptions of the strategies in Tables 8.8 - 8.11. In hindsight, other ways of presenting the strategies in the resource could have been considered or trialled. This might have including framing the strategies around the Participation Skills of Driving, Leading, Including, and Performing, as changes in these skills were key to bringing about change in the case studies. The notion of Pattern could have been more explicitly addressed.

Nonetheless, the integrated strategies used in the resource were worded as far as possible in everyday language to support accessibility for whānau/parents and others in the community. They were also worded as briefly as possible, recognizing concerns from the case studies and the review of community-focused interventions over demands on people's time. The order of the strategies reflected the general events that families referred to in the case studies, such as returning home after hospital, beginning to take part in activities in the community, and longer term participation needs. Table 9.1 shows the integrated strategies used in the resource in the order in which they appear. It relates them to the important aspects of participation from the case studies and to the strategies in the review which were incorporated.

Table 9.1: Integrated Strategies used in the Resource, and the Important Aspects of Participation from the Case Studies and Strategies from the Review they Incorporated

Integrated Strategies Used in the Resource		Aspects of Participation from Case Studies Incorporated	Strategies from the Review Incorporated
1. Connecting Participation Opportunities	for	Shared Occupation Fit Connection Learning Driving	Facilitating Child's Perspective Parent Participation Sourcing Participation Opportunities Linking Experiences
2. Planning Participation	for	Shared Occupation Changeability Fit Learning Driving	Collaborative Team Planning Collaborative Problem Solving Sourcing Participation Opportunities Adjustments Peer Support Adult Support
3. Teaming Participation	for	Shared Occupation Connection Learning	Facilitating Child's Perspective Parent Participation Collaborative Team Planning

			Driving	
4.	Maintaining Connections		Shared Occupation Changeability Fit Connection Learning Driving Performing	Linking Experiences Providing Cooperative Occupation
5.	Position Participation	for	Shared Occupation Fit	Proximity
6.	Activities Participation	for	Shared Occupation Changeability Fit Learning Leading	Providing Cooperative Occupation Group Occupation Training Adjustments
7.	Information Exchange		Shared Occupation Fit Connection Learning Leading Including Performing	Reciprocity Challenge & Competition Linking Experiences Impairment Needs Training Peer Support
8.	Participating Other Children	with	Shared Occupation Fit Learning Including Performing	Peer Support
9.	Participating Adults	with	Shared Occupation Fit Learning Leading Including Performing	Adjustments Proximity Adult Support

Each strategy in the resource involved a brief explanation and outline of what was involved. Photographs, illustrative excerpts from the case studies, and diagrams were included to help convey the main ideas in the resource.

Genesis of the Study to Generate Feedback on the Draft Resource

The ideas in the draft resource resulted from collective understandings gained from the first and second phases of my study. However, Dewey warned against prematurely accepting ideas as means to a solution. “Where a suggested meaning is immediately accepted, inquiry is cut short. Hence the conclusion reached is not grounded, even if it happens to be correct. The check upon immediate acceptance is the examination of the meaning” (1938/2008b, p. 115). He explained that where a problematic situation is extensive, several cycles of inquiry may be needed to achieve resolution.

Examination consists in noting what the meaning in question implies in relation to other meanings in the system.... Through a series of intermediate meanings, a meaning is finally reached which is more clearly relevant to the problem in hand than the originally suggested idea. (Dewey, 1938/2008b, p. 115)

At this stage, therefore, my understanding of the facts of the problematic situation and the ideas in the resource were provisional. I was still uncertain if there might be other aspects of the situation or features of the resource that might affect its implementation and effectiveness. Intervention approaches such as the resource, which include a number of inter-related constituents and which are directed towards groups or communities, have been described by Campbell and colleagues from the Medical Research Council as complex interventions (M. Campbell et al., 2000). With an aim of promoting greater rigor, a guiding framework for the development and evaluation of complex interventions is suggested by the group, consisting of five phases which employ both qualitative and quantitative understandings. Akin with Dewey’s argument for adequate reflection and inquiry before deciding on solutions, the framework involves several cycles of inquiry, moving from “observational” and “exploratory” stages through to “explanatory” and finally a “pragmatic” or applied stage, with a return to earlier stages if further data is required or changes are indicated. Although it was proposed that the phases be used iteratively, a later publication suggested that the first three phases could be considered simultaneously (N. C. Campbell et al., 2007). For the present project, Phase Zero and Phase One are considered. Subsequent phases will require to be addressed in future research.

Phase Zero is “Preclinical”, where relevant theoretical understandings that can inform an intervention and which will support its future evaluation are identified. At this point, the problem, contextual issues, and potential intervention avenues are explored. This

phase was likened to the case studies and review of community-focused interventions in Phases One and Two of the present study. Phase One generated theoretical information as to what was important about children's participation after TBI as well as factors that supported and hindered it; Phase Two provided information about the relationship of this theoretical information to potential interventions in the literature, and key features, strengths, and limitations of the interventions.

The next phase, Phase One of the Medical Research Council framework, consists of modeling the intervention, whereby the different constituents of the intervention, their relationship to theoretical understandings, possible barriers, and ways in which the intervention are expected to work are established. Campbell et al. (2000) suggested that attention to this phase is necessary to support optimal implementation. At this stage, qualitative research can contribute useful information about the various components of the intervention, and can provide insights from different stakeholders into its viability and application.

Responding to Dewey's concerns about adequately examining the meanings of ideas, and considering Phase One of the Medical Research Council Framework, a qualitative research project was proposed to further support the modeling of the draft resource. The study was guided by Pragmatic Action Research methodology (Greenwood & Levin, 2007; M. Levin & Greenwood, 2001). Participating stakeholders, including whānau/parents, teachers, rehabilitation providers, case managers, and community support staff were provided with a copy of the draft resource. They attended a one-day workshop to learn about the resource, participate in its evaluation, and to develop ideas for its implementation. Data were generated in rounds of focus groups. Following the workshop I analyzed the data using the cognitive mapping process described by Northcott (1996), and incorporated the participants' ideas into the draft resource. Copies of the modified resource were returned to the participants. The remainder of this chapter describes and discusses this study.

The Philosophical and Practice Understandings Guiding the Study

Connection of theoretical and practical knowledge.

In this third phase of the study I proposed both to draw on understandings generated from the previous case study research and existing literature, and to refer to the experiential knowledge of the different stakeholders, each of whom could contribute unique perspectives. In this way, I understood that practical solutions to children's participation problems would be optimized. The reality of research being blended with commonsense knowledge was considered by Dewey (1925/1981), who differentiated between the two, but saw them in practice as interwoven, foreseeing an increasing exchange of understandings.

Commonsense knowing has to do with the concerns of living; and nowadays living in an environment pervaded by the activities and consequences of scientific knowing involves a wide-ranging, diversified network of communications.... The remoteness of the formulae of physical science from the subject matters that are known in one kind or another of use-enjoyment—the characteristic of all commonsense knowing—does not remain in isolated remoteness. (Dewey, 1925/1981, pp. 344-345)

Commitment to democracy.

Knowledge about children's participation was held by a number of different stakeholder groups. In line with Dewey's valuing of democracy, I recognized that many understandings about the effectiveness and applicability of the intervention approach would be unique to people, and that these unique insights could bring new and creative ways of thinking about the approach and its application. However, I also recognized that discussion would result in some commonality of understandings. "Intercourse of human individuals with one another makes it necessary to find common ground" (Dewey, 1929/1988, p. 174). I anticipated that by drawing together commonalities, whilst valuing individual stakeholder perspectives, the applicability of the resource in a variety of real-life situations would be supported.

Dewey's democratic ideal makes a case for deliberate exchange between those who carry out research activities and those who have a stake in its application. Expressing the point that generation of scientific knowledge is often a specialist domain, he posited that

there remains a practical need to evaluate the utility of this knowledge in matters of daily living.

It is not necessary that the many should have the knowledge and skill to carry on the needed investigations; what is required is that they have the ability to judge of the bearing of the knowledge supplied by others upon common concerns. (Dewey, 1927/1982, p. 367)

Such words are echoed in occupational therapy literature. Here, when there are barriers to occupational performance, the active involvement of clients in decision-making processes is promoted, where research evidence is considered with the client against the background of their own experience to collaboratively guide a choice of intervention (Townsend, Egan, Law, Manojlovich, & Head, 2007). From my pragmatist philosophical understandings, and from an occupational therapy perspective, I sought people's involvement in the activities and decisions that affected them, their children's participation, and their communities.

Learning.

I believed that through this involvement, people's understandings and the ideas they contributed would support development and change as they dialogued with others in a problem solving process. Adopting a naturalistic view of human learning, Dewey (1929/1988) explained that changes in thought occur when people are involved in action to address problematic situations they encounter.

When... interactions are directed towards anticipated consequences, they gain the quality of intelligence, and knowledge accrues. Problematic situations when they are resolved then gain the meaning of all the relations which the operations of thought have defined. Things that were causally effective in producing experienced results became means to consequences; these consequences incorporate in themselves all the meanings found in the causes which intentionally produced them. (Dewey, 1929/1988, pp. 186-187)

In line with this contention, I saw that not only could useful changes be made to the draft resource by working collaboratively with stakeholders, but changes in those stakeholders' understandings would be more likely to support sustainable, ongoing actions related to children's participation.

Research Aim and Question

The aim of this third phase of the study was, therefore, to collaborate with stakeholders in the development of a resource describing a community focused intervention approach. The following question was asked: What are useful ways to enable people in the community to support the social participation of children aged 8-13 years, who have had a moderate to severe TBI?

The aim of the research, and the question asked, responded to a practical need to further develop the intervention approach and my occupational therapy practice concern with acting to enable people to “do” things they wanted or needed to do, and reflected my philosophical understandings. The aim included an intention to collaborate with others, and to bring about change through dialogue. The question was worded broadly to support openness to new thoughts and understandings that the participants might have. It had a practical concern with the utility of solutions. These notions contributed to selection of the methodology and design for the study.

Methodology

Considering my philosophical and practice understandings, and the research aim and question, a methodology was needed that could integrate theoretical understandings with practical knowledge, promote democratic values, support learning for those involved, and which would promote practical problem-solving. Aligning with these needs, action research methodology embraces a group of approaches which have a collective concern with practical goals and outcomes, the well-being and growth of communities, the involvement of communities in learning through action, and with bringing about sustainable change (Reason & Bradbury, 2001a).

Action research emerged through the work of Kurt Lewin, a psychologist, who developed and applied the methodology to give voice to those people who are from minority groups, and to empower those people as equal, independent, active agents in society (C. Adelman, 1997; Bargal, 2006; Lewin, 1946/1997). Contemporary action research approaches continue with this tradition, and are described by Reason and Bradbury as emergent and emancipatory in that they build “new abilities to create knowledge” (2001a, p. 2). Central to this is the idea that change can be brought about within and through dialogue amongst a small group of people who have a stake in a problem (Lewin,

1945/1997). Correspondingly, the validity of knowledge derived through action research is judged through its practical utility, and through the ability of the inquiry to enable communities to address issues that are important to them (Greenwood & Levin, 2007).

Action research methodology has a number of connections with the pragmatist philosophy of John Dewey, not the least a common concern with everyday or “commonsense” knowledge, practical outcomes, democratic involvement, and learning through action. Dewey valued and promoted linkages between scientific endeavors and peoples’ everyday lives (Dewey, 1927/1982), and towards this end helped to sponsor Lewin in setting up a program of action research (C. Adelman, 1997). Connections between Dewey’s philosophy and action research methodology can also be seen in their articulation of inquiry processes. Action research is cyclical in that it involves planning, acting, observing, and reflecting (McNiff & Whitehead, 2002). The meanings constructed during the research process form a basis for action. Further reflection on this action in turn constructs new meanings and understandings. Dewey’s conceptualization of an inquiry process similarly stresses its continuity, and refers to repeated interplay between establishing facts about a situation and generating ideas, reflecting on the relevance of those ideas, and actively testing solutions (Dewey, 1938/2008b).

Pragmatic action research.

For this study, a pragmatic action research approach was adopted. One of the family of contemporary action research approaches, pragmatic action research derives from the work of Greenwood and Levin (1998, 2007), who emphasized the situated, practical nature of inquiry. From this stance, it is argued that there is no one ideal version of action research, and that the forms taken by inquiries using this methodology should maintain their diversity, and must respond to the nature of situations encountered (Greenwood, 2007). Respecting the contribution made by professional expertise to action research processes, Greenwood (2007) further contended that action research “is highly personal, built around the abilities, mindsets, experiences, and ethical/political commitments of the action researchers who practise it” (p. 134).

For my study, I had already defined a problem using case study methodology, and I had generated an idea about a possible solution. Whilst action research ideally involves participants from the start of the research process, collaborating to formulate the problem that needs to be addressed, and planning together towards action, in pragmatic action

research, it is also recognized that researchers come to a group of stakeholders with professional understanding of a situation (Greenwood & Levin, 2007). It is respected that the stakeholders involved in the study have ownership of the issue. However, their local knowledge of the situation is valued equally alongside the professional knowledge (Greenwood & Levin, 2008). Researchers contribute their expertise and join with those involved as a “friendly outsider” (Greenwood & Levin, 2007, p. 115) to co-generate knowledge about issues in which they share a mutual concern.

In stressing the need to value equally the knowledge that all participants contribute to the process, democratic values are embraced. Diversity of viewpoints and experiences are seen as a source of innovation for driving change within social systems (Greenwood & Levin, 2007). Rather than achieving consensus, the intent is to generate and maintain conversations between the differing viewpoints, and work to achieve solutions that can accommodate different needs (Greenwood & Levin, 2007). Given the multiple stakeholders involved with the children’s participation, for my study, this approach would also support dialogue amongst those diverse groups, optimizing the outcomes that might be achieved.

Greenwood and Levin (2007) appreciated that some types of action research espouse a revolutionary approach to address power imbalances or to drive social change. While recognizing this need, their formulation of pragmatic action research emphasized provision of “space and tools” to partner with people and mobilize existing capacities and resources in their communities to address problems (p. 9). This emphasis suited the present project because (a) the case study phase of this research had highlighted issues with others’ participation skills rather than issues of power, (b) the intervention approach aimed to enskill others and thus mobilize their capacities, and (c) existing resources were available (e.g. funding through ACC legislation) which could potentially be directed towards addressing participation issues.

Proponents of pragmatic action research methodology do not advocate for specific, pre-determined methods to be used in inquiry. Instead, recognizing diverse settings and applications, methods are negotiated, and are responsive to the context (Greenwood & Levin, 2007). A central responsibility for pragmatic action researchers is establishing appropriate “arenas” or opportunities for dialogue, learning, testing out ideas, and decision-making (Greenwood & Levin, 2007). Arenas consider the physical location, time frames, and coordination of interactions between the groups involved. They should provide

physical space to support rapport and information sharing. Imbalances between local and professional understandings of issues must be accommodated. A shift of power should be promoted from the researcher, the friendly outsider who establishes the arena, over to the insiders or participants who have experiential knowledge of the situation (Greenwood & Levin, 2007). Greenwood and Levin (2007) described the features of the search conference, an arena they have found effective, but have also employed focus groups to achieve results (Greenwood, 2007). Data is generated in the context of small group work sessions, which are counterbalanced with plenary sessions involving the wider group.

Consistent with the belief in the contribution of perspectives from professionals and stakeholders alike, facilitators play a key role in the success of an arena. Supporting the emergent nature of the inquiry, their role is particularly important at the start, making direct contact with stakeholders early in the recruitment process; supporting participants to establish rapport and share their different histories; guiding the focus of discussion; taking responsibility for synthesizing data ready for further discussion; and gradually moving the leadership role over to the stakeholders. In this way, facilitators are not seen as being in a disinterested spectator role. Although their views should not dominate the data collected, their presence and contribution of knowledge from other cases and techniques helps shape the direction in which discussion moves.

Levin and Greenwood proposed a pragmatic perspective for considering the quality of action research, concerning themselves with the credibility and the workability of information generated. Drawing on Dewey's notion of the "warranted assertibility" of knowledge (1938/2008b, p. 15), they suggested that the validity of action research derives in large part from the fact that those very people who have a personal stake in the outcomes, believe in the "correctness of the knowledge" they have generated to the extent that they are willing to base their actions on it (M. Levin & Greenwood, 2001, p. 104). However the authors also acknowledged the importance of being able to demonstrate to others, the quality of projects undertaken. "It is now clear that we must make defensible arguments regarding the quality and validity of our work" (Greenwood & Levin, 2007, p. 220). To this end, they quoted the points made by Bradbury and Reason for considering the quality of action research. The points included addressing concerns such as the involvement of participants in the praxis of the research, the contribution of the project to practical and

sustainable outcomes, considering the significance of the outcomes, recognition of diverse understandings, and employment of appropriate research methods.

Research Methods

The research methods used in the present study are described and explained next. Excerpts from the findings are included at some points to illustrate the methods used and the processes involved.

Action research usually involves protracted engagement with participants, including several cycles of planning, action, and reflection. In this case, a single consultation meeting with feedback was envisaged. Despite the condensed time frames, the design of this third phase of the study was guided by the principles inherent to Pragmatic Action Research. The project provides a starting point for co-generation of knowledge in future projects to support the children's participation.

Participants.

It was proposed to involve several different stakeholder groups in evaluating the draft resource, including whānau/parents, teaching staff, community support people, therapists, and case-coordinators from the ACC rehabilitation funding agency. These stakeholders were all identified in the case studies as having influence over children's participation. Children with a TBI and their peers are central stakeholders in the participation. As part of the development of the resource, it was seen that their perspectives must be obtained. However, it was also seen that children's involvement alongside a group of other (adult) stakeholders could limit their ability to engage in the process. Therefore their participation in the development of the resource will be a further project to be conducted at a later stage.

Inclusion criteria. People were eligible to take part in the study if they were whānau/parents or professionals who had experience in supporting social²¹ participation for a child who a) was currently aged 8-18 years, b) had sustained a moderate–severe TBI as defined by the Glasgow Coma Scale (GCS) (Teasdale & Jennett, 1974; Teasdale, Murray, Parker, & Jennett, 1979) before the age of 14, and c) had been discharged from acute hospital care at least 12 months.

Although the focus of the intervention approach for this phase of the study was for children aged 8–13, it was proposed to include whānau/parents for a wider age range of children. The rationale for including only children aged 9–12 in the first case study phase of the project rested on the direct involvement of children in data collection, a view that Aotearoa New Zealand children who had already moved on to college at age 13 would experience significantly different participation issues, and an understanding that by age 9, children would have some notion of what would be required of them, and some ability to signal a decision that was not merely a response to adult presence. For this third phase of the project however, it was not planned to directly involve children, and it was also recognized that a number of Aotearoa New Zealand children aged 13 are still at primary school. Further, there was a desire to ensure the whānau/parents who participated had adequate experience, albeit retrospective experience. Therefore, whānau/parents who had experience in supporting social participation for a child who was currently aged 8–18 years were approached; provided the child had sustained their injury before the age of 14 years.

It is possible the length of time since injury for those with moderate injury might have limited memories for some parents. However it was anticipated parents were likely to register for the workshop on the basis that they felt they had information they could contribute. Those who recalled limited information were thought to be unlikely to register. Other similar studies have recruited participants for a number of years after an injury event and have gathered useful data which contributed themes alongside data from more recently injured children (G. M. Bedell et al., 2005).

The decision that it was necessary for children to have been discharged from acute hospital care for 12 months was guided by the need for parents to have adequate experience in community-based issues of participation. This criterion also meant that participants were

²¹ The term social participation was used to convey to participants and the ethics committees that information was sought about both social and activity-related aspects of participation.

unlikely to be approached if they were associated with me in my clinical role, with a consequent conflict of interests.

Exclusion criteria. Whānau/parents with a child who was a current client with me in my clinical role were not eligible to take part. This was to avoid possible coercion or conflict of interest. Children whose injuries were not accidental were also excluded due to potential difficulties gaining consent from guardians and the additional impact of the injury circumstances on people's experiences.

Participant numbers. It was aimed to include up to 3 people representing each stakeholder group, but to include 6 whānau /parents. A total of 18 participants were proposed. This decision was informed by a wish to cluster stakeholders into smaller groups with similar stakeholders (e.g. teachers, case coordinators, support people, and therapists; whānau/parents). Adequate numbers in these smaller stakeholder groups were therefore needed to facilitate *small-group* discussion (Lewin, 1945/1997). However, a full group of not more than 18 (allowing for some non-attendances) would be still enable effective *whole group* discussion, where ideas and perspectives from smaller stakeholder groups could be shared with the larger group (Bloor, Frankland, Thomas, & Robson, 2001; Greenwood & Levin, 2007; Krueger & Casey, 2000). Refer to Table 9.1, p. 317 to see the outline of the workshop process.

Recruitment.

Given that several different stakeholder groups would be involved in the project, careful planning was required to coordinate the recruitment process. Further to this, in the first case study phase of the research, difficulties and some delays were encountered with recruitment of children and families. There were inadequate numbers of children meeting the inclusion criteria in the geographic area covered by the ethics application, and locality providers²² had limited time available around their workloads to approach families via telephone, particularly those families with parents in paid employment. To prevent similar issues occurring again, for this third phase of the study several strategies were implemented.

Firstly, the viability of recruiting through a tertiary care setting was ascertained. Before commencing the ethics application, the statistician associated with the pediatric

²² Refer to Glossary for definition of locality providers.

department of the regional hospital was approached to obtain information from the database and ensure that the pool of children on their database meeting the age and injury severity criteria was of adequate size. It was also reasoned that because the hospital had access to the National Health Index numbers of both current and previous patients, it was likely that contact details obtained for potential participants would be current. The initial figures provided by the statistician suggested that at least 31 children would meet the criteria. On the basis of the numbers approached and recruited for the first case study phase, the figures also indicated that a lot of children were not accessing inpatient rehabilitation and were also not currently receiving community based rehabilitation. Therefore, more diverse perspectives were potentially available through those families who had received services at the hospital. A decision was made to recruit participants through the hospital, and an ethics application for the relevant District Health Board was commenced. This ethics application was additional to the regional ethics application which was also required. Refer to Disc One, Appendices 9.2–9.4 for copies of the ethical approvals.

Secondly, an Opt-out approach to recruitment was proposed, whereby, as discussed below in Figure 9.2, if people did not respond to a mailed advertisement and return a reply-form (refer to Disc One, Appendices 9.5, 9.6a and 9.6b) signalling their decision, I made a brief follow-up telephone call to check their interest in taking part, to answer any questions, or to identify their decision not to take part. Ethical and sampling issues associated with Opt-in approaches to recruitment (leaving it up to a person to communicate their willingness to take part) and Opt-out approaches (requiring a person to signal a decision *not* to take part) have been explored in the literature. In one study involving 510 participants where both recruitment approaches were compared, the more traditional Opt-in approach resulted in 10% fewer responses. Furthermore, those who did respond had significantly better health and function than those who were recruited using the Opt-out method. In that study, the researchers considered that the possibility of coercion affecting the Opt-out patients' decisions was unlikely, given that following recruitment Opt-out patients evidenced similar rates of actual attendance to those patients in the Opt-in arm. It was concluded that an Opt-out approach to recruitment results in a greater number of responses and less bias, and that where there is minimal risk to patients from participating in the study, an Opt-out approach should be considered (Junghans, Feder, Hemingway, Timmis, & Jones, 2005).

Third, care was taken to develop an advertisement that was colorful and child-focused (Refer to Disc One, Appendix 9.5), and which included the university logo and information about remuneration (discussed below). A small, brightly colored pen was included in the mail-outs, along with a very brief reply form and a stamped addressed envelope. A systematic review of strategies used to support return of mailed questionnaires found that the use of color, an invitation containing information of interest to those being approached, indication of a university association, brief questionnaires, pre-paid envelopes, and monetary incentives were among the strategies that increased the rate of return (Edwards et al., 2002). Dillman (2007) advised that the inclusion of a pen tends to draw interest to the mail-out before it is opened, and also has a modest influence on response rates to questionnaires.

Fourth, a decision was made to ensure participants were adequately remunerated for their time and travel costs in the form of vouchers of their choice. This decision acknowledged the skills and knowledge the participants would bring to the project, as well as their role as co-researchers (Grady, 2001). It also considered the relative lack of information about outcomes following brain injury for some ethnic groups in Aotearoa New Zealand, such as Māori and Pacific Island people, and that these groups are disproportionately represented in brain injury statistics (Barker-Collo, Wilde, & Feigin, 2009). It was reasoned people's decisions to contribute to research would likely be influenced by time pressures and costs (e.g. taking time off work, transport expenses, child-care, or inadequate time around household management tasks where there are large families or a child with a disability). The decision to offer remuneration to participants was weighed up against the possibility that some people might have attended the study for financial reward only, with no desire to contribute information or engage with others in the group. However, the benefits of supporting involvement of a diverse range of people were felt to outweigh this risk. Additionally, on the basis of the case study phase of the project and clinical experience, I respected that people who had been involved with a child who had a TBI would be concerned enough about the child's participation to talk of their experiences once attending.

A number of additional strategies were employed to make the workshop as accessible as possible for participants. A Free-Phone number was set up at the commencement of recruitment. The number was linked with (and it was hoped promoted)

the name of the project (0800 WE PARTICIPATE). I assumed responsibility for answering any calls to that number. It was reasoned that for families living out of area, a Free-Phone could facilitate them to make contact more easily, and likewise for parents who worked, the Free-Phone number could support them to feel comfortable to call, text, or leave a message at times that suited them. Several inquiries relating to the workshop were received on the Free-Phone number. Prior to the workshop, those participants who were in paid employment were offered letters explaining the project that they could pass on to their employer explaining their absence. Free parking was arranged through the university. Maps and parking instructions were sent out to participants who were travelling by private car, and taxi chits were sent to parents who did not have their own transport. Some parents requested to bring young children to the workshop, and they were supported to do so by providing appropriate food and toys, and a facilitator to assist as needed.

The recruitment process. A purposive sampling strategy (Jupp, 2006) was used with the intention of accessing a diverse range of stakeholders, who had experience in supporting participation with children with TBI. A snowball strategy was also applied to access carers and support people, and to maximize recruitment (Greenwood & Levin, 2007; Jupp, 2006). First, a table was developed to support the hospital statistician to identify bands of children who met the inclusion criteria (Refer to Disc One, Appendix 9.7). It was then planned to approach whānau/parents, carers, and community support persons as depicted in the process in Figure 9.2. Copies of the Whānau/Parent Information Sheet (Appendix 9.8) and Reply Form (Appendix 9.6a), and the Professionals and Community Support Information Sheet (Appendix 9.9) and Reply Form (Appendix 9.6b) are included on Disc One.

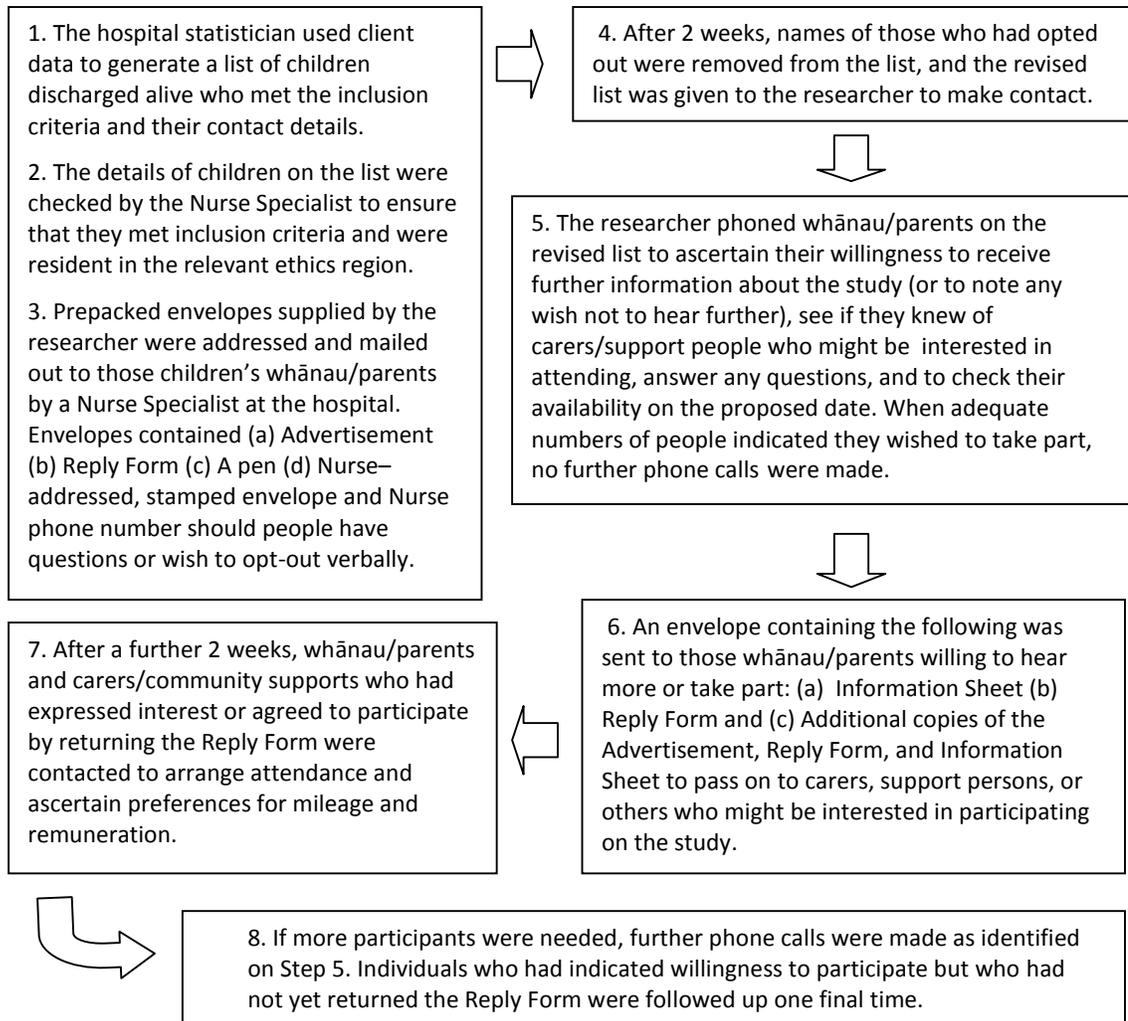


Figure 9.2: Planned Process for Recruiting Whānau/Parents, Carers, and Community Support People

To recruit teachers, teacher aides, and special education needs coordinators, the managers of teams providing rehabilitation services to children with TBI were contacted by phone, and the study explained. Those who expressed themselves willing to support recruitment were requested to provide information to me about the names of schools with teaching staff meeting the inclusion criteria (experience in supporting social participation for a child aged 8-18 years who had sustained a moderate-severe TBI). I then mailed advertisements, information sheets, and reply forms to those staff.

The same service provider managers also distributed information to rehabilitation personnel (e.g. assessors, therapists, nursing staff). After gaining written permission from

ACC Senior Management and a decision that ACC ethical approval was not required (refer to Disc One, Appendix 9.10), an ACC area manager was contacted, and was given written information about the study. The manager then passed on the names of case coordinators with the relevant experience who could take part, and information was sent to those people.

Modifications to planned process for recruiting whānau/parents, carers, and community support people. After the recruitment process had commenced, I was informed that the relevant hospital statistics had only been recorded for the previous four years. The implications were that children who had sustained injuries at a very young age but who currently fell inside the inclusion criteria were not captured in the statistics and their whānau/parents would not be approached. On the basis that these people would have several years of experience in addressing participation issues, it was felt they could contribute valuable information. An inpatient rehabilitation service was approached to facilitate recruitment for other whānau/parents that had not already been approached through the hospital. Ethical approval to proceed with recruitment through the rehabilitation service was obtained from the relevant District Health Board ethics department and the cultural support service (refer to Disc One, Appendix 9.11 to see the approval).

It also eventuated that statistics kept by the hospital did not record the severity of injury using the GCS (Teasdale & Jennett, 1974; Teasdale et al., 1979). Rather, the severity of injury was indicated using Abbreviated Injury Scale (AIS) scores (Association for the Advancement of Automotive Medicine & International Injury Scaling Committee, 2008). The AIS is an anatomical scoring system. It gives a numerical comparison of injury severity, and uses a standardized terminology for describing injuries. Injuries are ranked on a scale of 1 to 6, with 1 being minor, 4 severe, 5 critical and 6 non-survivable. For the purpose of the present study, the statistician searched the hospital's trauma register and identified patients that had an AIS score of 4 or 5 including injury to the head. The GCS score for severity of injury was later checked by the Nurse Specialist.

Once numbers for the study had been reached, two additional Pacifica parents who gained details about the study from other participants contacted me expressing a wish to take part. Given that Pacific Island people have limited mention in existing research in this area (New Zealand Guidelines Group, 2006) it was felt that their thoughts about the draft resource in relation to their experiences would be particularly valuable. The ethics

committee was approached, and permission was gained to include two additional participants. After this, no further approaches were made.

The results of the recruitment are presented in the next chapter. The combination of recruitment strategies and the process was more effective than that used for the case study phase of the research and efficiently recruited adequate numbers of parent participants in a relatively short space of time. In consideration of the Opt-out approach to recruitment, for the 39 families sent advertisements through the hospital, despite the use of additional strategies such as pens, a colorful and relevant advertisement, and an offer of remuneration, very few parents responded initially. However, when five of the families who had not replied were contacted to check on their wishes, those parents recalled being sent the earlier material, all expressed interest in the issue of children's participation, and all wished to attend. The positive response to follow-up phone calls when recruiting through the hospital suggests an Opt-out approach is an effective means of recruiting participants. The fact that whānau/parents recalled the information they were sent on being contacted back suggests the additional strategies such as pens and the use of color were worthwhile in terms of drawing attention to the project, given the relatively small cost accrued by the measures.

In contrast to those approached through the hospital, of the 11 families sent advertisements through the inpatient rehabilitation setting, six parents promptly returned replies, and of these five indicated they wished to attend. For one family, both parents wished to contribute. While numbers are too small to draw conclusions, informal comments made by the parents were that they wished to "give something back to the service," suggesting that the response rate in this case may have been influenced by their earlier relationship with the rehabilitation service.

While the recruitment strategy was effective for recruiting whānau/parent participants, it was less effective for recruiting rehabilitation personnel or teaching staff. These groups were sent emailed advertisements by their manager. It had been surmised that holding the workshop in the school holidays would provide greater flexibility for these groups to attend, but it was possible that the timing coincided with family commitments or trips away for a number of people. Further possibilities are that the groups did not see value in the workshop and did not respond from a lack of interest, had concerns attending alongside families they had worked with (making frank feedback difficult), were concerned over loss of income, had demanding workloads, or they felt that their existing practice

would be open to criticism. Any future related projects could consider offering separate workshops on-site for these groups at times nominated by staff, and delivery of individual mailed advertisements and invitations using a similar Opt-out approach to that employed with families.

Ethical considerations.

As discussed above, due in part to the need to recruit from several different locality providers, several ethical approvals were required. This was on the basis that contact details for patients were required in order to approach their parents. A further consideration was the use of the Opt-out approach to recruitment. However, the potential benefits of the study for children were felt to outweigh the potential for coercion, and this recruitment approach was approved.

The possibility of children's details being inadvertently shared outside the workshop setting by other participants was of some concern. To this end, signed informed consent was gained as participants arrived and registered for the workshop. Consent forms specifically mentioned the need to keep details of children and others attending the workshop confidential. Refer to Disc One, Appendices 9.12 and 9.13 to see the consent forms used. At the commencement of the workshop, a verbal reminder was provided to participants regarding confidentiality.

Cultural support.

To further address ethical considerations, when those who had agreed to take part in the study were contacted regarding remuneration, they were also asked as to their cultural background, in order that cultural support could be arranged. A Māori cultural support person had agreed to take part in the workshop, but unexpected commitments arose at short notice, and this person was unfortunately unable to attend. Māori cultural support through the university was provided with opening and closing the workshop however, and included the use of waiata (songs) and karakia (prayers). Cultural support was available through the university if needed during the workshop.

Cultural support was sought through two avenues for the Pacific Island families who were attending. One service was unable to send a support person due to too many commitments. Another service failed to respond to contacts. Families who requested to bring another family member as a support person were encouraged to do so. Following the

workshop, cultural support was obtained with analysis of the data from Pacifica families and from whānau at two, one-on-one sessions, and feedback was also gathered on the draft resource at these times.

Facilitators.

The short time-frame of the workshop meant that there was limited time for participants to become familiar with one another, and to gain skills in running the groups. Therefore, facilitators were used to support initial group processes, to ensure space for group members to contribute their thoughts, and to assist with data collection. Although facilitators added questions and suggestions from their professional perspective, as group members became more comfortable with speaking, they were encouraged to take the lead in decision-making and in generating feedback (Greenwood & Levin, 2007).

Three facilitators were needed to accommodate the three individual group sessions for the workshop (described below to Table 9.1). The facilitators included myself, and two other occupational therapists, one of whom was my primary supervisor. These two additional facilitators were approached on the basis that they had skills and experience in facilitating group discussion and data collection, and also had some awareness of the background to the project. As occupational therapists, they had a concern with people's right to make decisions about their occupations, a viewpoint that was in alignment with the aims of the research. A fourth staff member was present to provide support with parking directions, room set-up, registration processes on arrival, refreshments, and general queries. She also assisted with play activities for young children who attended with some families.

A meeting was held with facilitators one week prior to the workshop to orient them to the processes that would be involved, and to familiarize them with data collection strategies and audio-recorders. They were provided with written guidelines for their roles (Appendix 9.14). At this meeting, the facilitators provided comment on what was proposed, and some of the processes were modified. For example, it was originally proposed that after lunch, the participants would work collectively to collate and review the small stakeholder group feedback which had been presented to the whole group. On reflection with the facilitators, it was decided that the time frames were inadequate for this task. Instead, while the participants ate lunch, the facilitators typed up the key points of discussion ready for review in the small groups.

Venue.

The circumstances of this project meant that participants came from multiple different areas, and that there was no one, common setting in the community associated with the children's participation that would be favourable to use as a venue. To avoid disempowering any one group of stakeholders, a venue was required which was a neutral setting. It needed to be central for most participants, have adequate space for large group discussions, and also needed to include some nearby side rooms for small group discussions. Although several community-based venues were considered for holding the workshop, eventually classrooms at the university were selected. Classrooms were chosen that were adjacent to each other, and which had level rather than tiered seating. This was to minimize the risk of participants feeling as though they were attending a "lecture" as opposed to being equal contributors to a process. An additional room was booked for refreshments.

The classrooms had the advantage of desks for participants to spread written materials or make notes on, data-shows, and a whiteboard for diagramming or display of feedback. The rooms were quiet, and offered a "neutral" ground away from rehabilitation or education activities that might previously have been attended by families. In each of the small group discussion rooms, tables were arranged in a semi-circle facing away from the whiteboard (again to minimize the risk of participants feeling as though the facilitator was taking the role of a teacher) with the facilitator and recording devices at the open end of the circle.

Workshop process.

A workshop was selected as a practical "arena" for the project (Greenwood & Levin, 2007, p. 94). Workshops are forums involving small groups that support discussion, activities, and learning directed at a particular issue or topic (Merriam-Webster, 2010). It was expected that the term would help to convey the practical, involved nature of the event to potential participants.

Time frames. Points to be addressed in the workshop included providing adequate time for the participants to get to know one another and establish a climate of trust, introducing the resource, facilitating dialogue within and amongst a variety of stakeholder groups, the relatively small size of the group, and facilitating learning and action for

participants. However care-giving and employment demands, which were identified as issues in the Case Study phase of the research, needed to be accommodated, and time was needed for the participants' travel (some lived several hours away). There were some constraints on the scope of the project posed by my PhD framework, this balanced against the fact that some consultation about the problems, the context, and possible solutions had already been undertaken with different stakeholders during the case studies. Weighing these factors up, the workshop was contained within a limited time frame, and was run over half a day, between 8:45 AM and 1:30 PM, with a total time involved of 4 $\frac{3}{4}$ hours.

Establishing rapport. Several strategies were used to assist the participants to establish rapport with each other. This was particularly important given that a) most of the participants did not know each other; b) there was a possibility that some such as whānau/parents might see others such as rehabilitation providers or teachers in a position of power (Greenwood & Levin, 2007); or c) that people from different stakeholder groups might feel uncomfortable if they had previously worked with one-another in a rehabilitation or education context. To address these concerns, I first made contact with the participants on several occasions prior to the workshop, and was careful to use these contacts as an opportunity to establish a relationship, and to emphasize their role as co-researchers alongside myself. Second, the advertisement and information sheets alerted participants as to the involvement of other stakeholder groups at the workshop. Participants' comfort with the involvement of other stakeholder groups was also checked during the initial phone contacts. No concerns were expressed. Third, on participants' arrival at the workshop, time was deliberately scheduled to allow people to engage in informal conversation with each other and with the facilitators. Refreshments were available at this time, and copies of the draft resource were provided as a potential conversation starting point. Participants were initially very quiet, and after initial greetings and introductions, there was little conversation for the first 15 minutes. Shortly after this however informal conversations commenced, and by the time of the formal welcome, there was a general buzz of talk. It was noted that information gained over this time was later introduced by some participants into group discussions. Recordings from the formal small group and large group discussions suggest that for the first 5 minutes, participants were a little hesitant at contributing their ideas, but that this resolved fairly quickly after introductions were made.

Given the above observations, the short time frame for the workshop did not appear to constrain participants' dialogue with each other or with the facilitators.

Introducing the resource. Participants were provided with a copy of the resource when they registered at the workshop. This timing was to ensure that people were appropriately oriented to the resource. After some informal familiarization time, I gave a short presentation supported with power-point slides (refer to Disc One, Appendix 9.15). The presentation incorporated time for participants to ask questions. It briefly covered the background to the development of the resource, including gaps in our existing understandings about things people can do to facilitate participation, and how the first and second phases of my study led to development of the resource. The important aspects of children's participation and the changes that take place in participation after a TBI were outlined. The goals of the resource were introduced, and the strategies in the resource were explained. Points covered in the discussion were illustrated with examples from the case studies.

During the workshop discussions, two participants noted that they lacked familiarity with the resource, but also commented that if they had been sent it earlier, it was quite possible they would not have reviewed it in any case. In hindsight, sending the resource out to participants a few days prior to the workshop would have provided them with a better basis for discussion and time for reflection.

The process. The workshop followed the process outlined on Table 9.1. Although the time frames were tight, there appeared to be adequate time to generate discussion. Towards the end of the workshop, it was noted from the recordings that discussion for the parent groups began to decrease and it was evident that few new ideas or thoughts were emerging. At the close of the workshop, plans were reviewed with the participants, with time frames proposed for modifying the resource and providing it back to participants.

<u>Time</u>		<u>Content</u>
8:45-9:15	30m	Arrival. Registrations. Sign Consent Forms. Cup of tea/coffee available. Opportunity to get to know each other. Familiarization with resource.
9:15-9:30	15m	Formal welcome with waiata and karakia. Formal introductions to facilitators and orientation to setting and process.
9:30-10:00	30m	Presentation by Margaret Jones about a draft resource to facilitate participation for Aotearoa New Zealand children after TBI.
10:00-10:15	15m	Opportunity for questions, & clarification.
10:15-10:30	15m	Morning tea
10:30-11:30	60m	Move into three smaller groups: Discussing, and providing comment or ideas for draft resource. Responding to questions on Question Guide.
11:30-12:15	45m	Plenary session. Smaller groups presenting back to the group as a whole.
12:15-12:45	30m	Lunch
12:45-1:20	30m	Small groups reconvene. Responses to second group of questions on Question Guide.
1:20-1:30	10m	Thank you and formal close for workshop with waiata and karakia.

Table 9.2: Workshop Process

Focus groups.

The workshop employed a focus group format as a practical way to engage participants in discussion and develop detailed and thoughtful feedback relating to the resource and its application in real-life settings. Focus groups are a technique used in social

research for gathering data in a collective setting (Bloor et al., 2001). They are characterized by a concern with a particular topic of common interest, and the generation of in-depth information relating to group understandings, meanings, and processes (Carey & Asbury, 2012; Liamputtong, 2011). Literature also highlights their strategic use within research that is participatory and action focused research (Bloor et al., 2001; Greenwood, 2007; Krueger & Casey, 2000; Stewart, Shamdasani, & Rook, 2009).

I anticipated participants' responses to the resource and their contributions would be framed by their particular experiences and existing knowledge, and that dialogue for some participants may be constrained by the presence of stakeholders from different backgrounds. For example, there was the possibility some parents may have felt uncomfortable expressing their feelings if they felt their opinion was likely to be disapproved of by rehabilitation professionals. Conversely, it was understood that dialoguing with others who had shared similar experiences would prompt participants to co-generate ideas in relation to the resource. Therefore, stakeholder focus groups were used to provide participants with an opportunity to share their experiences and responses with others who from a similar background, providing a safe forum for sharing ideas, including those which were at variance from others in the group.

The participants were allocated into three small stakeholder groups according to notices placed on the whiteboard and in the morning tea room. The three groups comprised a group of five whānau/parents, a group of five Pacifica parents, which included four parents from Tonga and one from Samoa, and a group of seven professionals (rehabilitation and teaching personnel, and community support). For the small-group sessions, the three groups met in adjacent rooms, each group with its own facilitator.

Prior to the workshop, at the Facilitators' orientation meeting, there was debate as to the appropriateness of singling out a particular cultural group, and whether participants would feel comfortable with this. However, given the size of the group, it was felt that splitting the focus groups this way could support the Pacifica participants to express their unique perspective. This choice was borne out when interpreting the data, with Pacifica families stating and asserting ownership of viewpoints which they felt were different to those of other participants.

Group size is carefully considered when coordinating a focus group in order to adequately involve participants in open discussion of different viewpoints (Bloor et al.,

2001; Krueger & Casey, 2000). The groups at the workshop were small enough to allow each participant time to speak and to enable participants to feel comfortable with sharing sensitive information (e.g. a parent's feelings at the hospital after their child was injured). The numbers allowed some time for reflection, while providing some diversity of experience within each stakeholder group.

Introductions and focus of discussion. Focus groups opened with a brief round of introductions. Although most parents chose to introduce themselves by stating their names, then talking about their children's accidents and injuries, this demographic data, which related directly to specific children was not included into the transcriptions and was excluded from the analysis. While it is likely that these issues influenced parents' perceptions of the resource, these causal relationships were not the focus of the research. Rather, the data captured parents talking about how their readiness for information about participation changed as time passed since the injury, or how they coped when certain types of impairment limited participation.

Question guide. Discussion was prompted by the use of a loosely structured Question Guide which had been provided to participants and facilitators (Appendix 9.16). It was explained to facilitators that this was a "guide" only, and that discussions, while keeping the purpose of the study in mind, should be driven by issues the participants felt were important as they drew on their experiences. The Question Guide included two short lists of questions that were consistent with the purpose of the research. Literature suggests that overly long question lists can limit the depth of discussion and the time available to hear perspectives from all participants (Stewart et al., 2009).

The first list was used during the first round of focus groups, and aimed to stimulate initial discussion and critique of the draft resource in relation to its practical application. It included general questions such as "*Thinking back over your own experiences, how well do you think the suggested community focused intervention approach will work?*" Other questions aimed to prompt participants to generate new ideas and changes to the resource and to provide some specific feedback. For example, "*Think about some different situations in the community (school, shopping, sports events, church, family gatherings, visiting friends). Are there some situations where it might need to be modified? How?*"

The second list was used for the second round of focus groups. For this round, with the participants having heard the view of other groups, the aim was to capture their

responses to any different ideas that were raised, to explore any changes in their thoughts, and to gather information about the format and distribution of the resource. Questions included “*Having heard from the other groups, are there things you want to change or add to your earlier feedback?*” and “*How can the strategy be made available to parents, teachers, and community support people?*”

The recordings and transcripts of the focus groups reflect the emergent nature of the discussions. Participants generally took the lead on the direction of conversations, and facilitators playing a secondary, guiding role, prompting a return to the questions only when talk strayed too far from the purpose of the research, or checking that all areas had been covered as discussion time drew to a close. Noticeably more prompting was provided to Pacifica parents to generate discussion. However, for this group, when silences occurred, in time the parents generally filled these spaces themselves, with more reticent participants taking the opportunity that silence offered to provide their opinion.

Data collection. During the focus groups, notes were taken by the facilitators and audio recordings were made of the discussions. For the first round of focus groups, in a preliminary aspect of data analysis, key ideas were captured onto large poster sheets, and the ideas were checked with participants to ensure that they appropriately reflected the group’s thoughts. Where there was a divergence of ideas, these were also captured. Towards the end of this time, each group nominated a person who could verbally present their ideas from the poster sheet back to the other two stakeholder groups at the plenary session. The professionals group and the whānau/parent group nominated their facilitators for this role, but for the Pacifica family group one of the parents volunteered to speak.

Cycles of learning and reflection. Action Research involves a cyclical process, where participants collaborate, learn and reflect, act, then learn and reflect more. The short time frames of the workshop constrained this process. Nonetheless, learning and reflection was evident. I undertook the first presentation, and this was deliberately delivered informally, with questions and discussion encouraged as ideas were presented. Ideas were expanded on in response to questions. After the first round of individual focus group discussions, when the groups returned to the main classroom, and ideas were briefly presented to the group as a whole, some differing viewpoints emerged between groups, and there was some limited, although respectful, debate. For instance, some felt that the

resource was less applicable to teenagers; others felt that it still applied, but that the way the information was delivered might need to be changed.

Facilitator: *So, why do you, were you in the group that said that possibly, the kit possibly wouldn't work for the older child?*

K (Parent): *Now it wouldn't. The ideas when [child] first had his accident it would have been great and would have been useful. Now some of the strategies are great but it's we're now going into the, he's 16, he's over 6 foot um, he wants, he's at College.... he wants to be a teenager, he wants to go out with his mates and do things..... how to actually get involved and be accepted I think, is more the thing.... Um so actually getting back into the situation and getting back into the community was a huge thing, and to be, everyone knows him because of what happened, but actually being accepted back in is a completely different thing.*

D (Rehabilitation Provider): *Do you think it I mean, like I wondered whether the strategies are the right strategies, it's just there is a specific way that is different to apply them for teenagers. Do you know what I mean? Like these strategies are still the same.*

K: *Oh totally.*

M (Parent): *But can I just cut in there too, the opening statement was "hey mum I want to go drinking with my mates", I think in our kids' situation it's like "hey, wow, mates!" You know, starting with the basics where the um, that's where the hiccup is coming.*

Over lunch, the facilitators condensed the feedback from each of the stakeholder groups into points on a table, and this was photocopied to provide to participants for the second round of focus groups. This second round of smaller stakeholder focus groups was re-convened after lunch, and the feedback from the other groups was reviewed.

At this point, some of the ideas from the other groups were clearly questioned, and the recordings and transcripts reflect debate of the ideas from other stakeholders which were at odds with those of the group. There was also some debate within each group, with participants sounding out fresh ideas, and adjusting their opinions. For example, in the initial round of feedback, the professionals group expressed a concern that the draft

resource was “too Pākehā²³” (white person, or New Zealand European) in its format, with overuse of written language, and that a variety of media might help convey information effectively. At the second round of focus group discussions, the whānau/parent group responded to this initially with mirth and some indignation.

X (Whānau): *“Too Pākehā.”* Laughter....

M (Parent): *“Somebody saw it like that, that’s fine.”*

X: *“To me I was looking at it, the section of how to help me because my children’s had an accident.”*

K: (Parent): *“I’m sorry I wasn’t actually even on that wave-length. And D (rehabilitation professional) still sit there, laughs at me and says you don’t understand but I actually wasn’t even on that same wave-length.”*

L: (Whānau): *“Doesn’t worry me!”*

K: *“And I kind of smiled when she said more diagrams, and I’m thinking you know stick men with like, head hurting and things like that. I don’t know, no.”*

However, after some debate and consideration of the issues and contexts in which the resource might be used, the understandings of the parents and whānau shifted to an opinion that the resource might usefully be provided in different formats and languages.

M (Parent): *Do you need to change the languages or just state that this is a bicultural, information pack that may be, um useful?*

Facilitator: *What do you think X? Should we have a te Reo version?*

X (Whānau): *Nah. We all can read English. We all can read English.*

Facilitator: *Do you reckon that too L, you don’t think we should have a te Reo?*

L (Whānau): *Oh majority rules, oh it doesn’t worry me if it’s, yeah.*

N (Parent): *I think if you maybe just have it as an option.*

X: *Yeah.*

M: *Yeah, have it.*

Facilitator: *Because once it’s translated and on a computer...Then you just say what language you want it in.*

K (Parent): *Do you think I mean do you think it’s cultural or anything like that or, everything’s, just translating it, just straight is fine is it?*

Facilitator: *It’s important for some families and it’s not important often for others.*

M: *It doesn’t worry me because I don’t speak fluent Māori, te Reo.*

²³ Refer to Glossary for definition of Pākehā

X: *No I don't. I mean I understand it but I can't read it. But I know what it means, but if I had this [referring to resource] oh yeah!*

L: *You got that.*

K: *So whether it's supposed to be culturally correct to translate it nowadays because it seems to be the way.*

X: *Well everything seems to be getting translated.*

K: *And I think that's a cultural, it's supposed to be. So maybe you have to do it anyway.*

N: *I also think it's important just to um, to be so that, that you have that choice. You know.*

Facilitator: *I think a choice.*

N: *If you want it in Māori you should be able to have it in Māori.*

X: *Yeah fair enough too.*

N: *Given what went before I think that, you know.*

K: *And the people reacting in a situation with the accident or whatever has happened, react in different ways it becomes quite important, silly things become quite relevant.*

X: *I think it should be a choice.*

Information and resources relevant to children's participation were shared amongst some stakeholders for use after the workshop. Several participants spontaneously talked of what they had learned during the workshop. At the conclusion of the workshop, I explained to the participants that I would analyze the information they had given me, and use that to modify the resource. A date was set with the participants when copies of the modified resource would be provided back to them.

Data analysis.

The authors of pragmatic research methodology (Greenwood & Levin, 2007) do not specify particular approaches to data analysis. However, typically in action research, participants as co-researchers are involved in analyzing the data, and in developing and implementing action plans (Reason & Bradbury, 2001b; Stringer, 1996). For this study, some initial participant analysis of information occurred during the rounds of focus groups. Here, ideas for modifying and implementing the resource were captured and reflected back to participants to check their satisfaction that their ideas had been correctly interpreted.

Within the confines of completing the doctoral project however, I carried out the remainder of the analysis.

Choice of analytic methods. The analysis methods selected needed to be consistent with the aim of the research. That is, the methods needed to result in information that could answer the question, “*What are useful ways to enable people in the community to support the social participation of children aged 8-13 years, who have had a moderate to severe TBI?*” Analysis needed to generate practical information about the resource that could usefully guide modifications and support its application in context. However, it was also seen that this required more than a descriptive summary of raw data which was relevant to the resource and the context of its use. Participants were basing their thoughts about the draft resource in the context of their experiences, and the meaning of those experiences to them. Application of the resource with others undergoing similar experiences therefore required consideration and interpretation of those meanings.

Further to this valuing of experiences and meanings, an holistic view was desired, where the experiences and meanings were considered in the context of participants acting with their world. The understandings that underpinned the draft resource and which guide my thinking are that people are not separate from their world, but are part of it, and that as they do things with their world, there is not only result in change for participants but also change with the world (Dewey, 1925/1981). Therefore, to inform effective application of the resource, it was seen that the analysis needed to express the way different experiences and meanings might relate to each other in and over time and contexts, and how these things might undergo change. Likewise, drawing from an understanding that knowledge is contextualized (Dewey, 1938/2008b), and that information about the draft resource was expressed and shared in a particular context, an analytic strategy was sought that paid attention to the exchanges of information that occurred between individuals and groups as they engaged in discussion at the workshop.

Some useful ways of thinking about analytic strategies that attend to context were provided by Maxwell and Miller (2008), who sought to advance theoretical understandings about the ways in which qualitative analysis of data is undertaken. These authors plausibly argued that either categorizing or connecting strategies, or a combination of both, are typically used by researchers. Categorizing analytic strategies focus on the similarities and differences between pieces of information. Using coding processes, data is broken down

into discrete, decontextualized fragments of information, or categories, each category consisting similar information. Categories are later linked in terms of similarity or are distinguished by difference.

Although Maxwell and Miller (2008) are not dismissive of the contribution made by categorizing strategies in building insights and understandings, they are concerned that such strategies tend to split information away from its real-world “contextual connections” (p. 466), and they particularly promote the use of connecting analytic strategies. Such strategies are concerned with contiguous relationships of things in time and space, and aim to preserve the integrity of contextual relationships. The situatedness of data is also given consideration (e.g. the context in which an interview is conducted).

Some connecting approaches recite large amounts of un-analyzed, raw descriptive data, while others use narratives, or rely on reconstruction of events. Grounded Theory analyses, analytical network displays, and some computer software programmes employ connecting strategies, and help visualise linkages between concepts. However Maxwell and Miller (2008) correctly pointed out that the emphasis of such analyses remains on abstract relationships between conceptual categories, with little attention paid to tangibly situating understandings with real-world contexts.

Maxwell and Miller (2008) mentioned the use of a repeated listening process that can be used to focus a researcher on different aspects of an interview, including stories that emerge, the context of those stories, the person telling the stories, and various conceptual themes that emerge in the telling. While this combined approach appeared to be a strategy that could be applied to provide valuable contextual information for the current project, it was felt to be less practical to use with data from the groups, due to the multiple voices and, related to this, somewhat fragmented information. A similar strategy that combines features of network displays with repeated listening, but not mentioned by Maxwell and Miller is that of Cognitive Mapping (Northcott, 1996), and this strategy was selected to guide data analysis for the project.

Cognitive maps, when applied to qualitative data analysis, refer to a single-page “visual representation” of the data that depicts the concepts and meanings underlying participants’ experiences and the linkages that are involved (Northcott, 1996). Thus, the data is captured in a holistic way that immediately emphasizes connections rather than splitting information into discrete parts. The map reflects both the perspectives of the

participants as to their experiences and my interpretation of those perspectives, and is therefore consistent with the “co-researcher” model underpinning Action Research.

Northcott (1996) applied this approach as a practical strategy to analyze very large amounts of qualitative data from individual interviews. In applying the approach he also incorporated strategies that preserved the different shades of meaning in speech, and which recognized the context in which thoughts had been expressed. Although not a feature of Northcott’s analysis, it was seen that the map could also be used as a basis for expressing the linkages between experiences and their context. Guided by Northcott’s use of this approach, although, as recommended, adapting strategies to support interaction with the data my own way, and also responding practically to the focus group context in which data was generated, the following analytic process was undertaken.

Within days of the workshop, each of the audio-recordings from the six focus groups, the group questions that followed the presentation, and the feedback session was addressed individually. A recording was played through completely without a stop. Differing from Northcott (1996), who simply listened to this first playing, occasional brief words or phrases that stood out were jotted down on a notepad as the recording played. The recording was then listened to a second time in detail, whilst a draft map of the information was created using a large sheet of paper and colored felt pens. To view copies of the cognitive maps that were generated at this point, refer to Disc One, Appendices 9.17a-9.17c. For presentation purposes, the copies of the maps have been electronically drawn.

During this second listening, the recording was stopped and started as needed to clarify what was said, or to capture words. The recording was also stopped several times to allow for reflection and visualisation of the ways information related. I freely employed the use of visual strategies and participant words that seemed to me to best convey the information. For example, arrows were used to indicate connections between information or the passing of time, earlier temporal contexts were situated on the left of the page, the future was situated to the far right, things that changed over time were written in spread out letters, and words were written larger and bolder where there was emphasis and group agreement. Symbols that were suggested to me by the data were sketched. For example, the symbol of a door occurred to me through participants’ use of words including “gets them out there”, “big wide world”, and “not locked up”, although this symbol was eventually replaced with the idea of letting go of a net. A symbol of a mouth denoted the meaning of

phrases such as “making everyone aware”, “sharing experience”, and “go in and explain”. Words in smaller font at the outer edges of pages were used to capture themes that did not feel central, which were voiced as asides by single participants, or which were initially felt to be extraneous information. Actual words used by the participants were used to denote themes and contexts, although it was not realistically possible to capture longer verbatim quotes. My own comments, connecting lines, or framing groups of words together were strategies used to reflect where and how points were elicited (e.g. answering a question, prompted by researcher, adding to other’s discussion), that is, the context in which data emerged. Note was taken of contexts and information that was noticeably absent from discussion. The maps were peer reviewed by my supervisors, one of whom had also attended the workshop. Clarification was sought for some points, some interpretations were queried, and questions were posed as to the reasons for findings being different to those that would have been expected.

Although Northcott (1996) transcribed the interviews himself, due to the complexities and time involved transcribing group discussions, this was meanwhile being completed by a transcriptionist. This person was familiar with the research project and had signed a confidentiality agreement. When the transcribing was returned, each interview was then listened to a third time with the previous map close by. The transcribing was checked for accuracy and any corrections made at this stage. At the same time, a second version of the map was created. The second version drew together themes from the first map, but also reflected some new insights that occurred with the additional time for reflection and re-listening. Northcott only appeared to have created the one map for each interview. However I felt that this refining and reflection process supported me to move beyond my first impressions and better consider the implications of the data in terms of implementing the resource. It was also recognized that each of the interviews contained multiple voices, and this second map was a practical attempt to consolidate relationships between the various perspectives.

The very first map that was created was my first experience of this process. A black pen was used. The resultant map was messy and scattered, relied heavily on words, and was probably indecipherable to others, but captured the information that had stood out to me. I found that I needed to better hold the purpose of the research in my mind to prompt my thinking about how the various contexts might relate to it. Following this first effort, a

second map was generated while re-listening to the tape. Color (advised against by Northcott, due to difficulties reproducing the colors) was used the second time, and I felt bolder to group the data and use symbols, different positions on the page, frames, and emphasis. Thus the interview for the first whānau/parent focus group was mapped one extra time.

Northcott (1996) does not refer to his responses to the data as time progressed and as he developed further maps. As I moved on to listen to and map further groups, I found I was sensitive to the earlier maps I had created, and instinctively responded to similarities and differences in the themes and contexts that emerged. Additionally, the maps from the follow-up focus groups reflected some shifts in participant understandings that took place within discussions and in response to information from other groups. Linkages but also some disconnections were noted between the different focus groups, and these were interwoven with the contexts participants referred to and the context of the workshop. For example, all of the groups expressed a need to be provided with only small amounts of information to the early recovery phase in hospital after the injury. Although there was a question in the interview guide that related to the best time frames for implementation of the resource, without reference to this question, all groups spontaneously raised concerns as to the readiness of parents for information about participation in the acute context, and the importance of professionals alongside them in this setting to go about enabling participation and grading information for them. In contrast to these ideas which were common to all groups, words used by the professionals' group often suggested a view held of separateness or distinction from the two family groups, highlighting that this disconnection may also be experienced by people in the real-life context in which rehabilitation team services are delivered. However, it was possible this expression of "separateness" was engendered to some degree by the workshop context which deliberately separated the different groups.

After the individual maps were created, "second level or meta-analysis" maps (Northcott, 1996, p. 461) were developed. To complete this, all the individual maps were re-studied along with re-listening to the tapes. The individual maps were laid out side by side. Two large, meta-analytic maps were created (refer to Appendix 9.17d), which drew together information from the individual maps into themes, and which captured variations and linkages in the data from the different groups. The first of these two meta-analytic

maps drew from the individual maps of the first round of focus groups, reflecting the more open nature of the discussion in that first round. It depicted the participants' experiences of their children's participation. The second map was derived from the individual maps from the second round of focus groups, and depicted participants' ideas for formatting and dissemination of the resource.

Peer review by a supervisor was also provided for these meta-analytic maps, and some concepts in the resource were re-considered in light of this feedback. For example, the supervisor questioned me "what is missing from the group's experience?" I realized that despite the intent of the resource, participants seldom talked about people in the community assisting them to support their child's participation, suggesting an entrenched view that this responsibility belonged to parents and professionals. This emphasized the need for the resource, and that those others with whom the child participates play a key role in crafting their participation. In response, the role of other people supporting participation was given prominence in an explanation of how the resource was expected to work.

Additional Māori cultural consultation was also sought at this stage. This was given by a kaumātua (elder), Whāea Louise Elia, who provided cultural support to the rehabilitation service which assisted me with recruitment. Whāea Louise provided me with advice in understanding the data coming from whānau involved in the project, with the use of Te Reo Māori, and feedback about the resource from Māori and Pacifica cultural perspectives. Advice was provided about Maori world views, and the notion of āta, or developing respectful relationships (Pohatu, n.d.). Whāea Louise encouraged me to use a metaphor to collectively embrace the ideas that had come out of the data from the workshop, and to help express those ideas to others. Metaphors are able to support our communication, but equally, they can influence our thinking (J. King, 2003). They have an important place in Aotearoa New Zealand Māori culture when needing to convey information in a way that is real to people, and which leaves an impression (Moon, 1997). It was felt that incorporating a metaphor would strengthen the resource, by providing an overall depiction of the interrelating themes that were characteristic of the way people saw the children's participation, aiding others' understanding of the underlying concepts, and by illustrating the application.

In searching for symbols that would communicate these various concepts, with support from Whāea Louise, I initially drew on the idea of a door, a woven mat, and of a

growing vine. However, none of these ideas adequately incorporated all of the notions that came out of the data. During exploration of texts that described the process of Māori weaving, I uncovered information about the traditional art of net-making, and realized that this craft captured the ideas I was endeavoring to convey. The themes contained in the meta-analytic maps were therefore interpreted collectively as Ta Kupenga, or Net-Making (Te Rangi Hiroa [P. H. Buck], 1926). Further cultural advice confirmed the use of this metaphor.

In the final stage of analysis, a written summary was built from the meta-analytic maps, incorporating the metaphor, and including more detailed quotes from the interviews to help convey contextual information. With a focus to outcomes, the maps, the metaphor, and the written summary were used to guide changes to the draft resource and to re-structure its format ready for application. A photograph which illustrated the notion of Ta Kupenga was purchased, and was incorporated into the front page of the resource (refer Disc One, Appendix 9.19 for purchase of copyright details). The revised, draft resource is attached in Appendix 9.18, page 416, and is also available on Disc One, Appendix 9.18. Copies of the amended draft resource were forwarded to participants along with an invitation to provide further written or verbal feedback if they wished.

Summary

This chapter has described and discussed the methodology and design used in Phase Three of the study, in which I worked with stakeholders to generate feedback on a draft resource. The next chapter reports on the results of the recruitment strategy. It describes the themes which were derived from the maps, framing these within the metaphor that was developed following the cultural consultation. The actions taken and further actions proposed in relation to the resource are outlined. The study is evaluated against Bradbury and Reason's validity criteria (2001a).

Chapter Ten

Study Phase Three: Modeling of a Community Focused Resource to Facilitate Participation for Children with TBI: The Findings

The third phase of the study asked “what are useful ways to enable people in the community to support the social participation of children aged 8–13 years, who have had a moderate to severe TBI?” The study aimed for a collaborative approach, working with stakeholders to further the development of a resource that was directed at facilitating the children’s participation.

Figure 10.1 shows the contents of this chapter. First, the results of the recruitment process used for the study are reported, and general demographic details of the participants are provided. Next the study findings are discussed. As described in Chapter Nine, the data from the workshop was interpreted collectively using the metaphor of Ta Kupenga or Net-making (Te Rangi Hiroa [P. H. Buck], 1926). In the present chapter, to support reader understanding of subsequent discussion, an overview of this metaphor is provided initially.

Following from this, the themes which support the notion of Ta Kupenga: Net-making are explained and illustrated, and the implications of the themes are discussed. The data yielded two types of themes, pointing to a need for different, albeit complementary responses with regard to the resource. Therefore, each type and its implications are presented separately. Firstly, themes related to participants’ experiences of children’s participation after TBI are presented. These themes provided background information about the context in which the resource might be used. The ways in which these experiential themes influenced and were incorporated into the resource are described. Secondly, themes which capture participants’ specific suggestions for the content, format and dissemination of the resource, and changes which were made to accommodate these suggestions are reported. The study is then evaluated against Reason and Bradbury’s (2001a) criteria for validity and quality. Lastly the information is considered in terms of how it confirms and extends the propositions that arose from the case studies, and for its contribution to the literature.

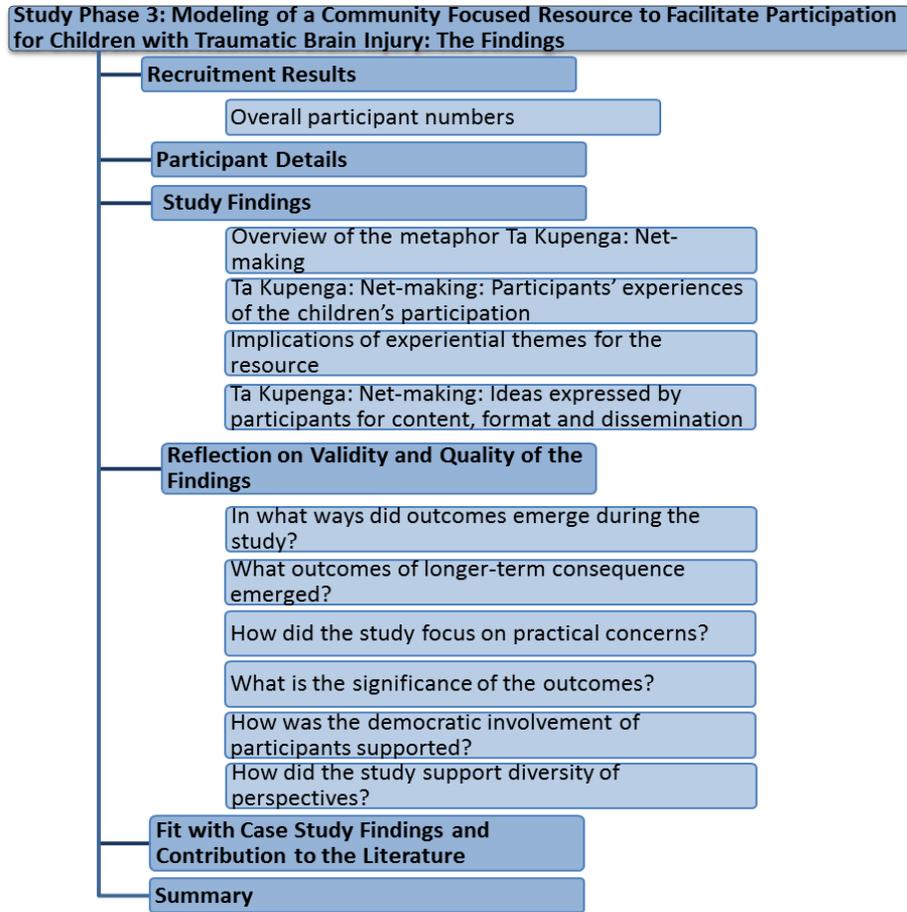


Figure 10.1: Contents and Sequence of Chapter Ten

Recruitment Results

The results from the recruitment process used are reported in Tables 10.1—10.3.

Total Children identified by the Hospital Statistician: 43					
Total Whānau/Parents sent Mail-outs by Nurse Specialist: 39					
Replied to first contact: Preferred not to take part	Replied-sent invitation in error/ no longer resident in area	Unable to attend but wished to receive information	Did not reply to mail-out	Follow up phone contact with families on list who had not responded	Parents who indicated they wished to attend in response to phone contact
4	2	1	32	5	5
TOTAL ATTENDED WORKSHOP					3

Table 10.1: Responses from Whānau/Parents Recruited through Hospital Locality

Total children identified by the Rehabilitation Service Manager: 11					
Total Whānau/Parents sent Mail-outs: 11					
Replied to first contact: Preferred not to take part	Sent invitation in error/ no longer resident in area	Unable to attend but wished to receive information	Did not reply to mail-out	Follow up phone contact to parents on list who had not responded	Parents who returned replies indicating they wished to attend
0	0	1	5	0	5
TOTAL ATTENDED WORKSHOP					6

Table 10.2: Responses from Whānau/Parents Recruited through Inpatient Rehabilitation Locality

For two families (one through the hospital locality and one through the rehabilitation locality), both parents requested to attend, although on the day of the workshop, the family from the hospital locality did not attend. One parent phoned me after she heard about the study through her therapist, and was recruited onto the study; because her child had sustained her injury prior to the date at which the hospital statistics commenced, and she was not approached through the rehabilitation locality, her details are not included in either table above.

The results for recruitment of teaching, rehabilitation, and community support staff are displayed in Table 10.3, p. 338. A Māori cultural support person indicated they wished to attend, but was unable to attend on the day. That person provided oral feedback at a later stage. Two ACC Case Coordinators were unable to attend, but later provided written feedback on the resource.

Responses from Teaching Staff, Therapists, Case Coordinators, & Community Support Staff		
Total managers of teams providing rehabilitation services to children with TBI approached: 5		
	Unable to attend but wished to receive information	Staff who indicated they wished to attend
Teaching Personnel		2
Rehabilitation Personnel		4
ACC Case Coordinators	2	
Community Supports		2
Māori Cultural Support		1
TOTAL ATTENDED WORKSHOP		7

Table 10.3: Responses from Teaching, Rehabilitation & Community Support Staff

Overall participant numbers.

As shown below in Table 10.4, a total of 17 participants attended the workshop. Subsequent to the workshop, written feedback about the resource was received from two further professional participants.

	Provided written/oral feedback	Attended workshop
Family members including 2 Māori and 5 Pacifica parents		10
Teaching Personnel		2
Rehabilitation Personnel		4
ACC Case Coordinators	2	
Community Supports		1
Māori Cultural Support	1	
TOTAL	3	17

Table 10.4: Total Numbers Participating in Study by Stakeholder Group

Participant Details

Demographic details of whānau/parent participants are shown in Table 10.5. Eight out of the ten parents were from an urban setting, and only two were male. Half of the participants identified themselves as Pacific Islander.

Parent Participants M/F	Culture/ Ethnicity Identified	Home setting Urban(U) Rural (R)
F	Māori	U
M	Māori	R
F	NZ European	R
F	NZ European	U
F	NZ European	U
F	Tongan	U
F	Tongan	U
F	Samoan	U
F	Tongan	U
M	Tongan	U

Table 10.5: Demographic Details of Whānau/Parent Participants

Table 10.6 displays the demographic details of the professional²⁴ participants. They included people from several disciplines and practice types, and all but one was female. All but one was New Zealand (NZ) European. All but one of their practice settings provided services to families from both urban and rural settings. Only two therapists participated, and these were both occupational therapists.

Discipline	Gender (M/F)	Culture/Ethnicity	Practice Type	Service Setting Urban (U) Rural (R) Mix (M)
Teacher	F	NZ European	Community School	U
Teacher	F	NZ European	Special School	M
Psychologist	F	NZ European	Private Practice	M
Caregiver	M	NZ European	Private Practice	M
Occupational Therapist	F	NZ European	District Health Board	M
Occupational Therapist	F	NZ European	Private Practice	M
Nurse	F	NZ European	Tertiary Care	M
ACC National Serious Injury Service Pediatric Support Coordinator	F	NZ European	Accident Compensation Corporation	M
ACC National Serious Injury Service Program Manager	F	NZ European	Accident Compensation Corporation	M
Māori Cultural Support	F	Māori	District Health Board	M

Table 10.6: Demographic Details of Professional Participants

²⁴ The term “professionals” is used to distinguish participants who were teachers, therapists, and funders from those participants who were whānau/parents. No difference in the level of expertise of their knowledge or input is implied by the term.

Study Findings

Overview of the metaphor Ta Kupenga: Net-making.

The metaphor Ta Kupenga: Net-making is a collective interpretation of the themes which emerged from this third phase of the research²⁵. Ta kupenga or net-making was described in 1926 by Te Rangi Hiroa, also known as Sir Peter Buck. Te Rangi Hiroa was well recognised as a medical practitioner, military leader, politician, writer and anthropologist from Taranaki in Aotearoa New Zealand (Sorrenson, 2012). The name Ta Kupenga has been employed in this phase of the study because the words convey a process. Ta Kupenga encompasses the participants' reports of their experiences of the children's participation after TBI, and the ideas they provided for modifying and implementing the resource. The notions that led to this metaphor are introduced next and an overview of the metaphor is given. Definitions of the Māori language used in this section are provided in the Glossary.

The data from this third phase of the study showed that following the initial tearing apart of the child's world with the accident, progress was made inch-by-inch, with the parents attempting new strategies and working alongside others to help their children participate. Although parents initially kept the children very close, gradually, as they and others learned how, children were assisted to extend their connections to other people. My interpretations of the participation changes experienced by children and their families identified the presence of both constant connections and also shifting connections. There was also a point at which parents felt their children needed to *go out* from their care into the world. They expressed that this participation in the community nourished their children's recovery and development.

As with the way children were helped to form connections with others, nets are woven from fibers that are knotted to connect with each other. The practical skills the participants described learning and using to promote the children's participation, and the ways they saw the resource working, are embodied by the skills learned and used when nets are woven and maintained for fishing.

Māori wove kupenga or fishing nets in order to gather fresh-water species and seafood. Net weaving and repairing the mesh (mata) of torn nets were occupations that drew

²⁵ In some Māori dialects, net-making may be referred to as te kupenga (Personal communication, Whāea Louise Elia, November 14, 2013)

on the skills and energies of the community, but were also occupations that provided nourishment and sustained community health and well-being. Ta kupenga, or net-making, was a practical skill handed down through demonstration and through language (te Reo). Nets were woven by hand, commonly using tough but elastic flax-plant fibers (harakeke). As the net was being made, the meshes were knotted around a firmly plaited, continuous cord, or ngakau; when the net was ready to take out the ngakau was no longer used, and for larger nets, the margins were drawn by kaharunga and kahararo (upper and lower ropes) (Best, 1934; The Waitangi Tribunal, 1988).

Some nets were small, and used more tightly woven, inflexible mesh (mata kutikuti), such as a hinaki, which was used for trapping eels. Other, larger nets, such as the seine net, or kaharoa, were woven loosely using a wider mesh (mata haere), with some kaharoa reported to extend as far as 900 meters up a coastline (Best, 1934). These nets were so big they were often constructed by families from several villages, each family creating a section, which were then bound together. Weaving new nets, and taking nets out for the first time were sacred (tapu) occupations, and were accorded respect through the use of special ceremonies and traditions (Best, 1934; The Waitangi Tribunal, 1988).

The themes that form the process of Ta Kupenga: Net-making are considered next. The themes were present across the cognitive maps analyzed from the data for the three different participant groups. However variations in the themes were noted between parent and professional groups; between cultural groups; for male participants; and for parents of older children, and these differences are discussed. Although the data did not indicate any variations that related to the home setting, the gender of the injured children, or the severity of the children's injuries, my analysis found that the time since a child's injury was reflected in the points parents had reached in the process of Ta Kupenga: Net-making. I also found that data from the professionals' focus group related to the contexts in which they practised and in which they therefore had greatest experience (e.g. teachers tended to talk more of school-based issues). The implications of demographic variations in the data with reference to the validity and quality of the findings are considered later in the chapter.

Excerpts are used from the data to illustrate the themes. The focus group session and the general grouping from which the excerpts derive are identified. However individual sources of the excerpts are not given, in order to support confidentiality. The sources of illustrative excerpts are identified using the following abbreviations;

- Parents-Māori (PM);
- Parents-New Zealand European (PNZE);
- Parents-Pacifica (PP);
- Professionals-Teacher (PrT);
- Professionals-Psychologist (PrP);
- Professionals-Caregiver (PrC);
- Professionals-Occupational Therapist (PrOT);
- Professionals-Nurse (PrN);
- Professionals-ACC Staff (PrACC); and
- Professionals- Māori Cultural Support (PrMCS)

Ta Kupenga: Net-making: Participants’ experiences of the children’s participation.

The themes which provide an experiential account of the children’s participation are addressed first. They were mainly derived from the first round of focus groups at the workshop, probably reflecting the more open nature of the prompts in the question guide used for that round (the question guide is explained in Chapter Nine, and is appended on Disc One, Appendix 9.16). The themes are presented here individually for clarity; however the cognitive mapping indicated that they do not always occur discretely, but rather that they overlap with each other, blending into a slowly unfolding temporal sequence.

The net is torn. Unprompted, parents referred back to the destruction the accident wrought on their own and their children’s lives, talking of the loss of the child, the relationships, and activities that had gone before. The theme was prominent for all three parent stakeholder groups, and remained in the forefront of their consciousness, even for those whose children were injured several years previously. Professionals tended to describe this tearing apart as “*grief*” or “*loss*”, but also spoke of families’ lives as “*shattered*” or of being turned “*upside down*”. Parents talked of “*shock*” and of being “*scattered*”. A father described the way the net of his child’s occupational routines and friendships were sundered. “*To him he’d lost it all...because he’d been out of school for a few months. He just gave up. Gave up even thinking it about it, kapa haka²⁶, everything he used to do, he didn’t want to do it*” (FG1, PM).

²⁶ Kapa haka is a Māori cultural group that is involved with traditional dance performances (Moorfield, n.d.).

At this time, many parents felt overwhelmed by the medical demands for their child. They remained by their child's side, and kept their focus on willing their child to live.

Because of the alarm and the care I came to him, all, all our team called. But I want to stay around because, the doctor said, to all the time that the accident happened, 'We have to take up[sic] the machine', that 'Your son's brain is all damaged', but what I have in mind and I pray for what God can save my son, and I leave all my prayers for my son. (FG1, PP)

At this frightening time, members of the community might make contact, and teachers and school-friends were sometimes described as being in touch, but parents had little energy to maintain these sorts of connections themselves. The torn net was laid aside, unused. However, as time passed, a return to the community and a need of activities and companionship began to drive the need for a new net of participation to be woven.

Weaving the net tightly. Initially after leaving hospital, parents responded by tightly restricting their children's routines and constraining their participation with other adults or children outside the home setting. As was found with the case studies, this was in part a response to being educated about the risks of a repeat head trauma "*he was told he couldn't get hit, ...he just can't hit his head again*" (FG1, PNZE); but was also awareness of the fragility of their children, and their vulnerability with people who did not know the ropes, parents talking of their own "*insecurity*". This need to draw their child in close was most strongly expressed by Tongan and Samoan parents, perhaps reflecting a need for support from those closest to their own culture. "*When something happens to our children, we're quite protective.....we're not letting them go...like we limit...*" (FG1, PP). Another parent from this group stated "*we don't really let our kids to go somewhere out. We want them to live us [sic] and we teach about our own culture. I don't let them to go away with [sic] us.*" Pacific Island parents explained that they were at their most protective when their children were young and injured "*we tend to keep them to ourselves*" (FG1, PP).

Education personnel also strove to provide close-knit adult support for the child in school settings. The groups of professionals and Pacific Island parents both drew attention to the way that this need to remain closely in with familiar adults could become habituated over time. This applied not only to the child, but also to those around them, trapping parents and child, or teacher aide and child, and narrowing the child's experiences. "*From*

the school's point of view... they don't want to be stuck with this child that needs support and they don't have the resources or the funding” (FG1, PrT).

The one-to-one with an adult. That is really, really hard to, for a child that is reliant on that and wants that attention and has come to get used to it...to actually get that person to try and withdraw...it's really hard. (FG1, PrT)

Continuous connections. Forming from this need to secure their child in closely, connections were created that were continuous. Pacific Island parents voiced this most strongly, although these themes of always being the one to be there for your child were also present for other parents. Like the way a ngakau is a line that secures the net as it is being woven, this presence was like a guiding rope beside the child, always there in case of need, along-side during their frustrations, and supporting their progress.

To be on his side every time. I know, I understand to my son, he recovered well and he recovered quickly because, I always on his side... As long as the OT and physio do things for him, but I am on his side. Sometimes he get mad, sometimes he need things from him, but I always cuddle him to let him know that I'm the parent on his side every time. (FG1, PP)

Growing the connections. As time passed, and with some signs of recovery, parents and professionals became aware of a need to begin to loosen the connections that bound the children in tightly to those adults closest to them. While the connections were seen as still being present, they were gradually relaxed a little, allowing for some movement and supporting growth and development. “*We went to the little primary and he was, because he was so tired all the time he only went for half an hour to an hour” (FG1, PNZE).* Connections were also loosened slightly to allow the parents a little distance from their child for short periods. Due to the way the tightly woven connections had become habituated, this process was not easy for the adults or for the children, and the need to take things slowly was emphasized. “*I found the biggest thing is patience, eh” (FG1, PM).* Sometimes, extended family contributed to this process.

When I'm going out shopping or something I ask my other sister to come and look after him but sometimes my mum's around I ask her to look after him. When I'm going out for just 10 minutes, I come back- 'Your son's sick' ...They asked me to leave your son here, go out and have a rest. (FG1, PP)

Learning to weave a new net of activities. With increasing realization of the sustenance provided through contact and friendship outside the family, the need to weave a new net became more pressing. Through trial and error, and using their creativity, children and their families slowly began to learn how to weave their participation in activities afresh. This involved new ways of doing things, as well as seeking out new activities. Although there were only three male participants, and although this theme was not prominent, for two males in particular there appeared to be greater openness for children to try modified participation in activities that posed a level of risk. *“He’s got his own way of playing. He plays his way so he doesn’t get hit in the head”* (FG1, PM). Learning to weave a new net felt unfamiliar and was performed hesitantly. *“A lot of people without the information just have to muddle along, and just, try and work out what, how to do it. How to implement different ideas”* (FG1, PNZE).

There was a tension between holding on and letting go, but the parents were clear that learning this different way of being with the world needed to happen for their child’s survival and growth.

We have to try and get out of that shell, for our children to be able to move on, we need to try and get out of that, be more positive, and we have to sort of learn that we do need to take our children to go get involved in community activities for them to be able to move forward. (FG1, PP)

Learning to weave a new net involved planning: there was preparation, and practice. *“Preparing them with planning...when we took him through and drove around and showed him where, he went, then he came on board...it was the unknown”* (Professional, FG1, PrT). New ways of doing old activities were found. Connections were loosened one knot at a time, and confidence was achieved incrementally; *“I think that it’s important that we...find that activity, and then when as they get better at it, it build up their confidence...but taking it one at a time”* (FG1, PP).

Progress was inconsistent; *“You may have a great two weeks and bang you’ll have five horrible days”* (FG1, PrT). Failure sometimes occurred; *“the first knock-back can be really devastating”* (FG1, PrOT), but could be countered by some resilience and an openness to letting some things go. *“Just think what the kid wants is, you can tell pretty quick if they...whether they enjoy it or not”* (Professional, FG1, PrC). Parents also identified the need for flexibility and for the child to be consulted. *“Be flexible and you can*

still have those things, but ...you have to change and you have to allow them that choice too” (FG1, PNZE). With an intention to follow a new pattern of doing things, *“they take it like a routine to them”* (FG1, PP), the beginnings of a new net started to emerge.

Shifting connections. With the transitions through hospital, post-acute rehabilitation, home, and school, and with the gradual introduction of activities based in the community, alongside the Continuous Connections the child held with those closest, connections with other people shifted in and out of their lives. Relationships changed, sometimes releasing a connection with people, and sometimes picking up a new strand to weave in. Although it is not unusual for children to adjust to new classmates, a new school, or a new home, participation for the children in this group was characterized by shifts across a number of rehabilitation settings, shifts in relationships with a variety of professionals across these settings, shifts from time spent with other children to time spent largely with adults, movements in and out of certain community groups, and changes of school to enable their injury to be accommodated.

Before the injury a child participates with their peers...And they have their injury, so they have a glitch where things change, then their interactions become predominantly with adults, predominantly with maybe a teacher aide, maybe the teacher, maybe with a therapist, parents because they're off school so their relationships change....The other thing too is that peer changes, and X's peers now are disabled children. (FG1, PROT)

Weaving the net with others. Linking with the shifts that occurred in connections with other people, there was a need to actively teach others how to take part in activities with the child, drawing them into the net-weaving. Parents and professionals both talked of the importance of seeking, approaching, and informing other people in the community who were willing to make space for the child to participate with them.

Let the people know what happened to your child. And they need some respect from them to our child...it's important for people to know what has happened to them and what...their limits are, and things they can do and what they can change. (FG1, PP)

Informing might involve simply letting people know what had happened in order to explain the difference, or it might involve educating others in how to interact with the child.

Teenagers are very um, clued in to any slight difference you know, all the nuances. Somebody slightly different you know, they really single them out and they get that, and they don't want to have anything to do with them. ...they had a speech competition at school and the subject was teenage issues...the OT said 'Do it about you, K...explain you're disabled, do it on you'. And he came second in the whole of the school. And, because he had them all there in one room, and he stood there and said 'Well actually mate I'm not different, I still want to go to the movies, I still watch tele, I still eat' ...it kind of explained to everyone, what had happened and I think that really helped. Around school now, everyone goes 'Hi K, how are you?' ... Okay he is different, but they actually know now what is different. (FG1, PNZE)

Some people were welcoming and flexible in accommodating the children in with their networks.

This guy waved, just next to us on the beach...it was the waka ama²⁷ crowd, and this chap was saying 'Yeah he's over here, he's alright'. So I went over there, and here's this waka ama group, and G. had wandered over there and they'd taken him in and put a hat on him...I said 'Oh god, that's great, thanks' you know, and they just sort of took care of G. just like that, and it was amazing. (FG1, PrC)

However, parents and professionals both spoke of the challenges of identifying groups where children could be assured of a welcome. In line with this, parents also identified an unmet need for children to form connections with those who had shared similar experiences. This was envisaged as a point for information exchange and learning.

It would be really great if there was a group of kids who are just like him you know. And I think it would...also give him a sense of you know you're not alone and there are other people who are struggling in life...it would be really good for him to sit there and say 'What do you feel about this' and 'How do you sort this out', and you know they talk. (FG1, PNZE)

Outside the net. Despite efforts, there were times when children were excluded from participating with others, their differences viewed as a reason not to involve them. *"He doesn't want to be left out and he doesn't want to be, marked as different" ... "Retard*

²⁷ Waka ama is the Māori term for an outrigger canoe (Moorfield, n.d.).

is the best word. That's what they are called" (FG1, PNZE). This was a particular risk when children spent time away from their peers, highlighting the importance of maintaining connections whenever opportunity allowed, ensuring the child remained enmeshed and that disconnections did not increase. With shifting relationships, however, connections were often lost, and it was much harder to re-weave the strand back into the mesh.

If you're not there then maybe the kid that you were friends with today has moved on to someone else of course. And the gap, the doors, it's like the doors close. It's like that person's not there for the day, so they just kind of reassemble their little groups without that. Yeah, and so that person then has to push their way back into that group. (FG1, PrOT)

The children's own limitations could complicate this process, such as physical inability to do an activity. However challenges also arose from less obvious disability such as decreased insight, slowed information processing, memory loss, or difficulties with conversation.

It is quite an invisible thing, because you could have a reasonable conversation with him...before you might pick up that there wasn't something not right...you do become even more socially on the outside because people don't realize you know what's actually happening in your head and how hard it is for you to actually just be there and participate and, you know teenagers talk quickly and things happen quickly and you know you're always rushing to catch up because you're not processing fast enough (FG1, PNZE).

Parents understood the need for their child to be involved in activities with others in the community, but were fearful of damage caused by other's words, exclusive actions, or lack of inclusive actions. *"If people start giving like, you know, bad remarks, negative remarks about our kids, we react to that badly"* (FG1, PP). *" 'Oh yeah, we'll catch up in the holidays' and the holidays come and, you know, the people he's texted have said 'Oh, nah, I'm too busy today you know' it's, it's hard"* (FG1, PNZE).

Taking the net out. As parents and children adjusted to new routines and new ways of doing things, and as others around them made space for the children to be part of their network, many, although not all parents, felt ready for their child to be *"out there"* in the world with others. This was discussed most by the parents of children who were older. Although there was a tension, parents talked of *"letting go"* and *"pulling back"*, as though

releasing their child. This is likened to the way a net is held taut by the upper and lower ropes when it is taken out and pulled back in, and recognizes the significance of taking a new net out.

And I think it's also for us to let go. I know I have a real problem with it and I've got a lot better...But actually, um, to send him to the cinema and say 'Well mate you're going to have to sort this out some point in your life...well off you go'. It's really hard for me to know...So we've got this big sort of step in our lives. (FG1, PNZE)

If plans were not adequately in place, or if others involved were inadequately informed, letting go was hampered, and thoughts of participation abandoned.

They wanted me to take V. down there and drop her at this location and they'd take her off sailing and I was to bugger off and not come back for three hours. I thought 'There's no way I'm letting you put my kid on a boat you know, with absolutely no idea of who she is or what her abilities are...You've got to be joking'. So some of them are just not realistic. (FG1, PNZE)

In spite of difficulties, letting go was a compelling need. A Pacific Island mother summed up the importance of letting go, highlighting the cultural influences that drove this need for their family.

In my ways, I come to New Zealand, I need something new, for my children. If we do the thing like that you put it, "at home", he feel like, not participate in the community. On my view, I need him to look at the whole world. To get some good environment. I support what you need to be participate, take your child to every, like, kindy, something like community, like your church. Just let him to know, and let the people know who [sic] really are. (FG1, PP)

Implications of experiential themes for the resource.

The themes that reflect participants' experiences of the process of Ta Kupenga: Net-making form the context within which the resource to support children's participation will be used. The implications of these themes for the resource are considered here, and modifications that were made are outlined. For reference, the modified draft resource is attached in Appendix Two, page 416, and is included on Disc One, Appendix 9.18.

Firstly, the resource was modified to incorporate the notion of Ta Kupenga: Net-making. This involved recognition of the phases that parents might be going through,

integrating words and concepts, and using appropriate illustrations to support recognition of the metaphor.

The themes that are part of Ta Kupenga: Net-making are processual, although they are not necessarily linear. They highlighted that families moved between different experiences of readiness for participation, including phases of a Net Being Torn, Weaving the Net Tightly, Continuous Connections, Growing the Connections, Learning to Weave a New Net, Shifting Connections, Weaving the Net with Others, and Taking the Net Out. The resource was modified to recognize these different phases by incorporating material into sections that related to the different contexts in which rehabilitation occurs across time. In this way, sections could be used separately with families, avoiding provision of irrelevant information and overloading, and sections could be provided or referred to again by professionals as needed. Where possible, the names of themes, and words or phrases used in the themes were included in relevant sections. For example, the theme of Growing the Connections was included with the name of the Participation During Rehabilitation section; the theme of Shifting Connections was included with the name of the Participation Back at Home and School section; and words and phrases were used from the themes, such as weaving, strands, and one knot at a time.

In the earliest phase shortly after the accident, parents had little time or energy to focus on a child's participation. Nonetheless, during the workshop this phase was identified by participants as being important. Parents and professionals flagged that even early on, trial and error processes were used to support their children to participate, and that the resource would have guided their efforts if it had been available to them. An additional consideration near the beginning of the Ta Kupenga: Net-making process, was the way schools and parents tightly constrained the children's participation (Weaving the Net Tightly), and the difficulties that were encountered changing this pattern. This also reinforced the importance of supporting participation from an early point, albeit in very small ways, and gradually building from these.

The phases of participation in hospital and in rehabilitation were therefore named in the resource, and specific strategies were included to provide guidance for others in the children's communities. However strategies were deliberately kept simple, and were those that could be driven by others such as staff, or participation that comes to the child to avoid overwhelming the family. For example, specific ideas were added to the Participation in

Hospital: Maintaining Connections section that had been described by participants in the case studies in Phase One of my research. These included information about how to visit, how to keep in touch, and how to continue sharing experiences.

Parents' continuous connection with their child, likened to the way a ngakau is the strand around which the mesh is woven, was seen as functional. Therefore the resource was correct in attending to and supporting parents' involvement with their child's participation. Whilst this has the potential to be maladaptive in some circumstances (Woolfson, 2004), parents at the workshop seemed well aware of the need to loosen their connections and eventually let go, and described doing so as the new patterns of participation were established.

The slow pace with which children progressed was highlighted by parents and professionals, and, although frustrating at times, was seen as the best way to achieve real gains. In line with this, the resource had highlighted small steps, one knot at a time, in order to maintain continuity of a pattern and gradually build a child's participation, rather than attempting to manage multiple participation strands at once. The importance of planning prior to participation was also confirmed, and this section was maintained in the resource, as was the idea of flexibility and choice, where it is acceptable for some activities to be tried out if that is the child's wish, then given away if they do not work. The need for resilience and a positive attitude in the face of failure was an aspect that was present in the resource but inadequately highlighted, and some additional material was included.

Data indicated that, where possible, connections with peers should be maintained to support constancy rather than the multiple shifts that were evident, and that interruptions to connections should be minimized as far as possible. This aspect had already been addressed in the resource, but what had not been anticipated was the need for participation with peers who had also sustained head injuries, and the learning opportunities that parents saw this as addressing. This idea remains to be incorporated, and, in the future, avenues for making contact with others the same age that have undergone similar experiences will be noted in an appendix.

In keeping with the case studies, the themes interpreted from the focus group data suggested a dichotomy, the child's desire not to be singled out from their peers as different at odds with the need for peers to understand the differences they perceived and to learn ways to appreciate and accommodate this difference. To address this, the resource had

encouraged exchange of information, with a focus on using natural opportunities for sharing the different experiences that children might have had. Ideas the parents talked about indicated this was a valid strategy, and activities such as class speeches had been utilized to this end with some success. It appeared that once a difference was confirmed and understood, this then mediated the amount of focus directed towards it. The resource additionally advised strategies that provided experiences embedded in shared occupations to further facilitate continued learning. In light of reported instances where children had been excluded or were not included, these sections were maintained. This also suggested the idea of an additional appendix where settings that provided inclusive participation opportunities in a child's residential area could be noted.

Ta Kupenga: Net-making: Ideas expressed by participants for content, format and dissemination.

Overall the resource was positively received by families and professionals. Families expressed the way such a resource might have helped them through the rehabilitation process, and professionals also felt that the resource filled a current gap in service delivery by drawing people's attention to participation issues, providing a framework, generating new ideas, and confirming strategies that had been shown to be effective in practice. *“It was great to read such a plain speaking, commonsense document. I think the strategy will work because it is so down to earth and full of practical advice”* (PrACC).

The workshop not only generated experiential data about the context with which the resource would be used, but provided ideas that directly related to improvements. Much of this data derived from the second round of focus groups. It was prompted by the question guide which, in addition to capturing shifts in perspectives after convening as a larger group, aimed to trigger discussion about the format and distribution of the resource. The information from this discussion was also noted onto the cognitive maps. It was categorized into themes which were used to guide additional content, changes to the format, and plans for dissemination of the resource. The themes unexpectedly aligned with the metaphor of Weaving a Net. These themes are discussed next.

Skilled support. Likened to the way the craft of net-making needs to be passed on by someone who already has the skill, participants expressed the need for a professional person to take responsibility for delivery of the resource to families and others involved

with the child, such as teachers or caregivers. As identified by contextual information, it was felt that early after the accident, families would be too involved with their children's medical issues to maintain contact with others in the community. Additionally, many thought that if the entire resource was provided at only one time point, families may read it initially, but over time could forget to refer to it. *"If you had given that to me in the hospital I would sort of put it in a drawer. We were running, hiding from people because you know everyone wanted to come and talk to us"* (FG2, PNZE).

It was felt that if professionals had ready access to copies of the resource, then they could implement some of the ideas for families at the earlier phases (e.g. contact classmates if the family is willing), provide relevant sections as an educational resource as a family becomes ready, or use the content with families or others at any time to guide planning. Professionals could also support understanding of the content. *"I think it needs somebody to describe you the kit, to make you understand what is next... and make you clear, and if you're by yourself, sometimes you can mix up something"* (FG2, PP). *"I agree that it needs to start very early. If medical specialists could be encouraged to give out a pack and discuss it with families and children, prior to discharge... would be a great start"* (PrACC).

A theme of Skilled Support was at odds with my own desire at the outset of the research to create a resource that could be driven by families and communities rather than professionals. Data from the case studies had noted that participation was often limited by professional concerns over safety and fatigue, or the need to attend rehabilitation activities. As I analyzed the data, I wondered whether this theme of Skilled Support was reflecting for parents at the workshop this same, professionally-implemented perception of a need to limit participation, and whether this might in fact limit the implementation and effectiveness of the resource. Nonetheless, the theme indicated the reality for families and children at various points of rehabilitation, and was a feature also for those families who appeared to have less professional support available to them. Perhaps it is unsurprising that Skilled Support would be needed over time rather than as a one-off, given the emerging participation difficulties that were revealed by those parents of older children. Therefore, a middle road will be adopted, whereby the resource could be delivered professionally but could also be available to parents and schools through community organizations and the internet.

Step-by-step. It was felt by parents and professionals that the timing and amount of information provided was important. The risk of presenting too much information at once was expressed, much like the risk of an over-full net bursting. Data suggested that the resource could be made so that it could be “*drip-fed*” (FG2, PrT), or delivered in sections, “*step-by-step*” (FG2, PPNZE), the way a kaharoa is woven in smaller sections first. “*A little bit first.*” “*Yeah I think, maybe something a bit more, um, like an introduction...and then we get this later on*” (FG2, PP). This idea coincided with the way families saw their child’s progress as occurring in phases.

Reviewable and renewable. Additionally, the need to revisit and update information was highlighted, much in the way nets need regular inspection and repair. Although not achievable in the scope of this thesis project, in the future, the resource will be presented in a way that allows the sections to be reviewed and renewed if they need to be referred to again. “*I just re-give them the same handout... hopefully if I give them the same information, hopefully it will re-link back in for them and re-jog their memory*” (FG2, PrOT). This could be a folder with sections that can be removed and copied, or downloaded again from a web-site. Having a central location such as a web-site would allow for an “*update if something changes*” (FG2, PrOT).

Flexible. Flexibility is required so that the ideas can be adapted to work for individual families and contexts. In the same way, the fibers used for making a net arguably need to be pliable to allow a net to be shaped, and to be designed in different ways for gathering food in different contexts. Participants indicated that the broad strategies in the resource needed the capacity to be personalized so they could be flexibly applied to specific activities with families and others in varied community contexts. To address this, in the future, the strategies may be best presented in a workbook format incorporating space to write, and places for pictures and diagrams to guide planning for specific activities.

Also, along this line, after convening as a large group, then debating amongst themselves in the second round of focus groups, participants came to the agreement that the tool should be available in different languages. “*I think it’s important... that you have that choice*” (FG2, PNZE). As discussed in the previous chapter, professionals were concerned that the resource may not be appropriate to use with some cultures, whereas this same concern was not voiced by parents. While this is beyond the scope of this doctoral study, in

the future, funding could be sought to develop translated versions to support accessibility by different cultures.

Flexibility of format was suggested too with parent participants signaling that paper (hard) copies of the Kitset would be the more useful, allowing it to be revisited, or sat-down with when quiet times were available. *“You want to be able to read it in the evenings”*; *“You’ve got a whole job to go and turn your computer on”*; and *“Maybe you just want to be sitting by your kid’s bed and reading through it, while they’re having a rest”* (FG2, PNZE). Professionals too suggested hard copy might be more accessible for many parents, and for extended family. However, they also indicated the benefits of on-line or digital material in terms of availability, and meeting different learning styles. *“You could say oh there’s this website, have a look on there and school could access it”* (FG2, PrOT); *“And that could be linked to the Brain Injury organization or links through other...sorts of organizations...I think it should have its own website and then other places that can link...into it”* (FG2, PrN); *“Video stories, maybe someone talking, somebody describing, somebody showing”* (FG1, PrOT). These points, coupled with a potential need for replacement or updating, suggest several formats could be adopted.

On the whole the participants felt that the resource lacked applicability with teenagers. Although the introduction to the resource stated that it had been developed with children aged 9-12 years, there was significant discussion about its lack of flexibility for this age group, first by parents, and later by parents and professionals. This may have reflected that for several of the parents, although the injuries were sustained earlier, their children were now in their teens. In general it was felt that a different resource would be required for teenagers, although some felt that the *“the tool is not the issue with teenagers, it’s how it’s applied”* (FG2, PrOT). There was also recognition that for a number of these families, if they had been provided with a resource such as this earlier, the process may have been easier, with less reliance on trial and error. *“We’ve now gotten to the stage where they have mostly implemented anyway. But if we had seen that, when X was at that stage, then I would have actually understood it”* (FG1, PNZE). The professional’s group facilitator drew the discussion together by suggesting that what was required was clarification of the age the resource was developed for, and a statement as to a potential lack of applicability with other ages. There was some agreement with this suggestion.

Simplicity. A number of participants suggested that the resource was overly complex, with too many words. *“I read through the [kitset] while I was waiting, and I found it okay but with people that have um, language limited you know, um I think it needs to be a bit more simplified and with, maybe pictures and yeah a bit more stories but nah, not too wordy”* (FG2, PP). This may have reflected the limited time the participants were given to look through the resource, but was also voiced in written feedback. *“If this was given to teachers... they may feel overwhelmed with the size...and put it on the reading pile...”* (WF, PrACC). Whilst there was some debate by parents, they arrived at the point of agreeing that simple tools often work best, and the second draft of the resource has therefore reduced the text, conveying ideas with pictures, anecdotes, and diagrams where possible. Some longer written illustrations were removed. Straightforward ways of communication were also felt to support varied ways of understanding; *“Pitch it to a broad audience”* (FG2, PNZE).

Linkages. The professionals’ focus group suggested that the Kitset might usefully be connected with other agencies and resources, and that having the resource available on-line would facilitate this. Agencies that the resource could be linked with or made available through were put forward, including; the children’s hospital information service; The Brain Injury Association; and the Ministry of Education’s catalogue of teaching and learning resources for schools. Whilst it was also suggested the resource could be available through ACC, there was a concern that this might discourage those with negative perceptions of that organization; rather, it was felt that it would be better to ensure that ACC was aware of and supportive of the resource. Written feedback from ACC staff indicated that the resource dovetailed with their philosophy and processes. *“I def [sic] think this will fit in really well with what ACC is trying to achieve and can easily see this being picked up by a TI [Training for Independence] provider to guide teachers/whānau along”* (PrACC).

Getting it out there. When the time came for the resource to be taken out and used, professionals suggested an entrepreneurial approach may be required. *“It really needs funding and media to distribute it.”*(FG2, PrP). This theme was closely associated with the theme of Linkages, with strategies such as a web-site also thought to support implementation. The theme was discussed most by professionals, but was only touched on in a limited way in discussions with parents, with the content of the audio-recordings indicating a lack of time to consider this, and for Pacifica parents, a slowing down of

discussion. However, both groups of parents talked of the need for generally “*increasing public awareness about brain injury*” (FG2, PP). One parent suggested that awareness might be raised through working with a popular public figure. “*It makes other people more accepting ... 'Oh, these top people are understanding, you know, well maybe some of us minor people should be a bit more understanding'”* (FG1, PNZE). Professionals’ ideas included targeting therapists, community groups, and education personnel, such as Special Education Needs Coordinators, Early Intervention Teachers, Early Childhood Centers, Resource Teachers for Learning and Behavior, and Learning Support Teachers to inform them about the resource. Some of these groups could be targeted through mailing lists, but presentations could also be made. An ACC Support Coordinator suggested “*perhaps a slot on TV’s Attitude program*” (WF, PrACC) which focuses on disability issues and resources.

Reflection on Validity and Quality of the Findings

Throughout the project, reflection occurred about aspects that were of merit, and about aspects that could have been conducted differently to enhance the process. Reflections were noted in a diary, were jotted down during the writing of the present chapter, and were also noted during discussions with supervisors. The reflections influenced my interpretation of the data, understandings of how the resource might be modified, and ideas for its future implementation. I found myself moving between mulling over an idea in the data, testing its possibilities out in my mind, then thinking further, sometimes moving to make further change.

This reflection typifies an important aspect of Action Research, which is emergent in nature, emphasizing changing cycles of knowing and doing. Considering the study dynamically in this way was seen not only as supporting the quality of this current project, but also as influencing the quality of future projects. My reflection has been guided by the questions suggested by Reason and Bradbury (2001) to frame judgments about the validity and quality of Action Research projects. The six questions I asked myself as to the strengths and limitations of this phase of the study, and the action-focused conclusions I arrived at are discussed next. Data are presented at times through this section to highlight influences on my thinking.

In what ways did outcomes emerge during the study?

Firstly, I reflected on the outcomes of the study. Outcomes were not arrived at immediately, but grew during the process of the workshop, over the time of evaluation of the data, and during the write-up of the study. Participants spoke of the learning that took place for them during the workshop, and changes in their thinking were evident during the groups, between the two focus groups, and even over the time taken for informal discussions over a shared meal. *“I was interested in hearing about the teenagers, the parents’ experience...there obviously needs to be something there to help parents with teenagers (FG2, PrCG). This comment triggered further conversation about the difficulties facing this age-group. “It was interesting, talking to, at lunchtime, her son still doesn’t have friendships” (FG2, PrOT). At the same time, in a different group, this topic had prompted thoughts for one parent about practical application to her own situation.*

I’m glad that was brought up, because I never thought about that...the whole thing keeping the interaction, like the communication going with his class...maybe I could take in a message saying hi to his class, or his class could...write him letters. (FG2, PP)

The influence of the resource on the participants was reflected in their language, with discussion referring to “*connection*” and “*kitset*” showing ready adoption of the terminology it had incorporated. As described in the previous chapter, the draft resource was provided to participants on arrival at the workshop. However, some expressed that they would have benefitted from more time to look through the resource; in hindsight their feedback may have been better supported if it had been sent out some days before the event.

Shifts in my own understandings of the data are evident in the changes in the cognitive maps that were developed with each listening, and through building on and shifting in my knowledge as the different groups were listened to. These shifts were, no doubt, influenced by discussion with my supervisors and by the cultural support provided to me by Whāea Louise.

For example, on my first listen to Focus Group One for the parents’ focus group, Māori and NZ European, an idea stood out which I initially captured as “Changing Possibilities”. During the second listen, the ideas that contributed to this theme were felt to be better captured by the words “Looking for Opportunities” (denoted by a symbol of an

eye). This involved parents searching for and finding new ways in which their child might participate in the community. Some ideas which fitted with this notion, but which were framed differently and built on the concept, were discovered in the Focus Group One with the professionals. For the first listen with the data from the professionals, this theme was labeled “Seek”, and involved identifying people in the community who were accepting of disability, and actively seeking out welcoming environments. This seemed to sit alongside the concepts identified as Unknown Participation, Preparing the Child, and Planning. Set-backs, failures, and refusals were also characteristics that went hand-in-hand with attempts to try to engage again in participation. Parents indicated that as time went on, with trial and error, they became more competent. After further reflection, these notions were captured together with the themes of Learning to Weave a New Net of Activities and Weaving the Net with Others.

It is acknowledged that for me, personally, life-events had a particular influence on the emergence of my understandings. A serious illness interrupted my study between data gathering and completion of the analysis, and the longer time-frames gave additional time for reflection on the data. It was over this period that the prominence of connections between people in the data became highlighted. This notion, and the time my illness lent me for thought, allowed for insights into the metaphor of Ta Kupenga: Weaving the Net.

What outcomes of longer-term consequence emerged?

The second question that guided my reflection was concerned with longer term consequences of the study (Reason & Bradbury, 2001a). Whilst the workshop itself was a time limited project, data informing the development of the resource was gathered with stakeholders over the period of the case studies, and the workshop further contributed to an emergence of outcomes. The longer term outcome will be implementation of the resource, and this will be guided by the ideas generated by those attending the workshop. A future goal will be to consult further with stakeholders as to their experience of the resource in practice, and to generate ideas about ways to formally evaluate its utility and effectiveness in supporting children’s participation.

Perhaps the most important long-term outcome will be seen in the development of avenues to promote the ongoing shared learning of participants. While several spoke of the understandings they gained at the workshop, there was also discussion about the need for

ongoing connection with others who had undergone the same experience, and for the learning that might be achieved in the context of this connection.

It would be really good, like we were saying to actually have a group of, not just children together to say oi, he's not the only this has happened to at that age, but also to have the parents... just say, we're feeling the same as that, and I understand that and what did you do? And actually knowing what the parents allow their children to do. (Feedback from first round of focus groups, PNZE)

Therefore, alongside further development and implementation of the resource, consultation will be undertaken with the Brain Injury Association and other stakeholders to initiate opportunities for families to meet.

Although participants were invited to provide further feedback when the modified resource was returned to them, and although the Free Phone remained available, none took up this offer. This meant member checking from participants on the modifications to the resource was lacking. It is possible that no further changes were felt necessary, or more likely, other activities limited the time available for participants to be involved further. The process may have been improved by sending participants a stamped addressed envelope or form to facilitate return of further ideas anonymously. In terms of my own learning about Action Research, in future, ethics permission would be sought to ask participants at the workshop to indicate their willingness to take part in further shared learning activities and consultation.

How did the study focus on practical concerns?

The practical aspects of the study were the third question guiding my reflection on the validity and quality of the study findings (Reason & Bradbury, 2001a). The study purpose was immediately practical in nature, aiming to consult with stakeholders in developing a resource to facilitate children's participation. It was hoped that formally undertaking this project would move beyond paying lip-service to; consultation with those involved, by engaging with people in some depth inviting criticism and practical problem-solving; by systematically analyzing the information people provided; and by integrating the findings into a resource with a clear intent to implement it in the future. Analysis of the data moved beyond the practical to theoretical understandings about the context in which

the resource would be implemented, but this theory was related back to the question asked at the start of the project, and used in considerations of modifications to the resource.

What is the significance of the outcomes?

The fourth question posed about validity and quality was concerned with the significance of what was found (Reason & Bradbury, 2001a). Participants highlighted the significance of participation for their children, and their comments clearly indicated a need for the resource to guide efforts to support participation after a child's injury. The workshop resulted in further modifications to the resource and dissemination of the changed resource to those who attended the workshop. It is envisaged that, in line with advice from participants, some further development will be required in the way of presentation and networking. Evaluation of the resource in the field will need to be undertaken. The outcomes from the present study fall short of achieving this point, but provide a firm basis on which to proceed further.

How was the democratic involvement of participants supported?

Action research promotes democratic involvement of participants, therefore the fifth question I reflected on was an important foundation for the quality and validity of the study (Reason & Bradbury, 2001a). There was a concern that participants' availability and willingness to attend the workshop might be negatively influenced by concerns over transport or child-care costs. It was also recognized that for some, attending the workshop would involve time away from paid employment and loss of income. Participants were not seen as people who were studied, but rather as co-researchers (Greenwood & Levin, 1998, 2007). For these reasons remuneration was offered (Grady, 2001). This strategy helped ensure that the opportunity to take part was not limited for any groups by financial constraints.

Flexibility was another strategy that facilitated involvement of participants who otherwise may have found it difficult to contribute. One parent asked if she could bring children, and this was supported. Toys and meals for the children were made available, and during the interviews they played close to their parent. Another parent participant required assistance with organizing transport, while two professional participants were unable to attend on the day, but their offer of written feedback was accepted.

When a number of Pacific Island families expressed interest in taking part in the workshop, consideration was given as to the best way to group participants for the different focus groups. At the risk of singling out participants on the basis of culture, it was decided that by grouping these participants together, they may be better empowered to give voice to their perceptions and experiences (Bloor et al., 2001; Greenwood & Levin, 2007; Krueger & Casey, 2000). This decision was supported when this group was able to explain the way cultural concerns, such as the reasons underlying decisions to move to a new country, and their attitudes towards children with disabilities, had a bearing on their responses to their children's participation. Unfortunately, due to low numbers, this same strategy was not workable for participants who were of Māori descent. This may have limited the understandings that were gained from this group, although their viewpoints were still reflected in the data.

The democratic involvement of participants who identified as Māori may have been particularly constrained by the location and format of the workshop. The two Māori participants attended a workshop with Pākehā participants, and may not have felt comfortable expressing their perspectives. Māori participants may have felt more confident speaking if a workshop (hui) for their group had been held at a local meeting place that they nominated themselves. In this way, the involvement of participant's whānau, hapu, or iwi could have been facilitated. The support and perspectives of the wider group would have assisted cultural responsiveness to those participants, and would have contributed in a meaningful way to the findings (Health Research Council of New Zealand, 2010).

Efforts were made to obtain cultural support during the workshop for Pacific Island and Māori families to ensure they were adequately facilitated to contribute. Although all participants who expressed interest in taking part were able to converse in English, it was anticipated that cultural support would also assist with providing interpretation should the need arise. Unfortunately this was not possible on the day. Cultural support was obtained with the opening and closing of the workshop. Cultural advice was also provided to assist with interpreting the data from these participants. Despite this, it must be recognized that cultural support was only provided by the one person. To move the study forward, and adequately ascertain the cultural safety of the resource, in the future, consultation and establishment of partnerships with Māori needs to be more extensive (Health Research Council of New Zealand, 2010).

There was also a possibility that my own presence, or that of the facilitators, may have constrained the participants from fully giving voice to criticisms of the resource (Torbert, 1991). Whilst this possibility cannot be fully explored, it was addressed by involving group rather than individual discussions (drawing on peer support), by deliberately inviting criticism, and by referring to the need for criticism to improve the resource. As it eventuated, participants openly expressed concerns over the length of the resource, the communication strategies it employed, and its suitability in the earlier phases of rehabilitation.

The lack of involvement of participants in the analysis of the data was inconsistent with the tenets of Action Research. Nonetheless, as described in Chapter Nine, the use of Northcott's (1996) data analysis strategy supported me to consider the connectedness and contextualization of information. In this way I was enabled to recognize the voices of those who were less well represented in the groups, or who spoke less. The cognitive maps did not aim to only capture themes that were reported or confirmed by greater numbers of participants, but rather captured themes that stood out as I listened and read, as being relevant, or having potential to bring about practical improvements. In this way, some comments mentioned only briefly, or being expressed by a voice less prominent in the discussion stood out, and were sometimes interpreted as having relatively greater practical value, especially when seen in the context of other notions, and were incorporated into the map.

Democratic processes were also supported through employing two rounds of discussions. In this way, viewpoints were shared with those from other groups, and could be reflected on. Discussion within the groups reflected differences of opinion which stood, but also some resolutions where there were differing perspectives.

How did the study support diversity of perspectives?

Lastly, I considered how the diversity of perspectives in my study was supported. The study involved participants from a variety of stakeholder groups, and this was supported by the recruitment strategy I employed. However, potentially the diversity of perspectives was limited to those who were particularly motivated, and this may have limited the comment which was made on the resource.

As noted in the demographic details of participants in Tables 10.5 and 10.6, some participant groups were less well represented. There was only one professional caregiver,

one psychologist and one nurse present, and therapists were only represented by occupational therapy practitioners. During analysis, thought was given to the possibility that the data from the two male parent participants, the two Māori participants, and from less-well represented professional groups may not have been as prominent in the findings. However inspection of the data did not reveal this to be the case, and members of these groups were all found to have contributed to the discussion, with this captured in the themes. Further to this, the focus was less on ensuring representedness of the sample than it was on ensuring those who attended could provide depth and variation of experience for the phenomena of concern.

Ironically, although it was in part the intent of the resource to mobilize others in the community to play their part in supporting children to participate, parents and professionals denoted that they felt it was their responsibility to drive the process. There was only one phase, soon after the accident and hospitalization, where parents clearly felt unable to contribute further time or energy beyond their child's immediate medical needs. At this point, they indicated that others in the community could be proactive in helping their child feel that they remained connected beyond the hospital. A similar anomaly was identified with the recruitment process. Although the resource was aimed, in part, at supporting connections between children and their families, and others in their communities, no efforts were initiated to include people from the wider community, such as children's peers or parents of peers, into the workshop. Whilst a range of stakeholders were involved, this gap remains to be addressed in the context of future learning opportunities organised for stakeholders, consultation, and evaluation of the resource.

The utility of the resource also needs to be considered from the point of view of its acceptability with diverse populations. The workshop went some way towards establishing that, but given the small numbers, and low representation of Māori, further consultation will be needed. One particular point that will require exploration is the name of the resource. Although it was interpreted as capturing the ideas that emerged from the workshop, the name "Ta Kupenga" may not be easily understood in all Maori dialects, and given Sir Peter Buck explained this term in 1926, may not be as easily understood in a contemporary context. The name may limit its acceptability with people from non-Māori cultures.

Fit with the Case Study Findings and Contribution to the Literature

In this section, the findings from this third phase of the research are first considered in relation to the findings from the case studies in the first phase. They are then discussed in relation to the extant literature about children's participation after TBI.

Firstly, acknowledging the participation difficulties experienced by children in the case studies in Phase One, the findings from this third phase of the research have been used to further develop and refine a resource in a move to address those difficulties. In this third phase, the participants' experiences of the children's participation, and their suggestions for modification and implementation of the resource helped improve some of its components. They clarified the relationships between those components and theoretical knowledge from the case studies, and more clearly established the means of disseminating and using the resource (M. Campbell et al., 2000).

Other broad, community-focused intervention approaches were categorized in the literature review and are described in Chapter Eight. These approaches differed in their aims, and emphasized different contexts and strategies. They included Structuring Shared Occupation, Creating Opportunities to Experience Occupation with Others, Developing Supportive Friendships, Fostering Inclusive Communities, and Rehabilitation Service Models and Modalities for Participation. The approach of Rehabilitation Service Models and Modalities for Participation had good evidence for its ability to facilitate participation for children with TBI, but few articles in that approach included strategies that directly supported participation in occupations with peers, a pattern that was of concern in the case studies. There was limited high quality research evidence for any of the other intervention approaches, and even less research evidence that was directly applicable to children with TBI. There was only limited information about the viability of any of the approaches.

The Ta Kupenga resource that was developed and modified in the third phase of my research was aimed at tackling some of those concerns. Rather than aligning with any one of the other approaches, it embraces them, drawing together the range of strategies identified in the literature review. The resource specifically situates the strategies within the theoretical understandings about the important aspects of participation needing to be addressed for children with TBI that were derived from the case studies. The central focus of the resource is on promoting Shared Occupation, and it draws on the case study understandings to recognize the changes that take place in people's learning about how to

support one another's participation using this modality. Holding to this focus, the resource encompasses the different participation contexts that children move through as their recovery progresses, a consideration that was highlighted by Dumas et al.'s study (2003). Although further research will be needed to establish its viability, the resource responds to the findings from Phase One and Three of this study in recognizing the demands on families and educators, and also their needs for information (Bedell et al., 2005; Glang et al., 2010; Linden et al., 2013). It is therefore intended to be in a format that is accessible to, and which can enskill and mobilize, through Shared Occupation, the everyday people in children's lives. This differs from interventions in some of the approaches which involved training, or which needed to be delivered or overseen by professionals (for example, Glang et al., 1997; Glang, Tyler, Pearson, Todis, & Morvant, 2004; Graham, Rodger, & Ziviani, 2010; C. Salisbury & Evans, 1993; McDougall et al., 2006).

The findings of this third phase of the research have also contributed some confirmation for the findings from the Case Studies. In Phase One, it was found that people's ability to Drive, Lead, Include, and support one another to Perform were important to the children's participation. Those findings indicated that participation did not occur passively, but resulted from peoples' action, or doing, and that those skills were learned in the context of Shared Occupation. Additionally, notions such as Fit, Connection, and Pattern were all found to be important aspects of participation. Such ideas correspond with, and are supported by, the metaphor of Ta Kupenga: Net-making, which embraces and conveys the meanings interpreted from the data in Phase Three. Net-making, like participation, requires people's actions in shared occupation, as they weave, maintain, and repair nets. In net-making, as with the idea of participation, strands are fitted to the ngakau and to one another. They are connected, and patterns are built. Some of these similarities are also suggested by Figure 6.2, p. 139, in Chapter Six, which depicts the constructs that informed the cross-case assertions. Here also, like part of a net, interwoven strands, and a central, connected pattern may be seen.

However this third phase of the study not only supports, but also builds on the findings of the first phase, by situating people's experiences and actions within a process that takes place over time. The name, Ta Kupenga: Net-making, was given to that process as a means of promoting others' understanding of those experiences and actions. The data from the focus groups at the workshop particularly generated insights into the changes in

people's skills for facilitating the children's participation at different points within the process encompassed by Ta Kupenga: Net-making, and in whānau/parents' readiness for deploying those skills. In doing so, it endorses the importance of other people in children's communities who are able to Drive, Lead, and Include the children in Shared Occupation when parents are less able to do so themselves. Attention is also directed to the role of rehabilitation providers within this process, who can assist with implementing the resource, and who were seen by the study participants as being in a position to enskill others in supporting the children's participation.

The metaphor of Ta Kupenga: Net-making, and the themes that are embraced by that metaphor, resonate with some of the information coming from literature, but draws together and gives name to that information. This phase of the study particularly highlighted the importance of involving others in facilitating the children's participation, called Weaving the Net with Others. Supporting such findings, the importance of the social context to children's participation after TBI is prominent throughout the literature, and the role the family plays in participation outcomes has been underlined (V. A. Anderson et al., 2005; G. M. Bedell et al., 2005; Robson et al., 2005; Sharp et al., 2006; H. G. Taylor et al., 2001; Woods et al., 2011; Yeates et al., 2010). As with other literature (Rosignano & Swanson, 2011), the present study noted that others sometimes excluded the children, a theme called Outside the Net. However, what was revealed in this study was the way people actively learned and then taught others how to share in occupations with their children, a point that has received only limited attention in the literature to date (G. M. Bedell et al., 2005; Sharp et al., 2006).

Often highlighted by other studies is the traumatic effect for families of a child's brain injury and subsequent disability (V. A. Anderson et al., 2005; Gauvin-Lepage & Lefebvre, 2010; Hermans et al., 2012; Micklewright et al., 2012; Prigatano & Gray, 2007; Robson et al., 2005; Stancin et al., 2010). In the present study, this was expressed as The Net is Torn, and led to people's desire to Weave the Net Tightly, providing close and protective support for the children, an effect noted in several qualitative studies (G. M. Bedell et al., 2005; A. Clark et al., 2008; Foster & Carlson-Green, 1993; Gauvin-Lepage & Lefebvre, 2010; M. Jones et al., 2010; Robson et al., 2005; Rosignano & Swanson, 2011). Although contextual factors also play a role, this response may account for some of the restricted participation that quantitative studies have identified (for example, G. M. Bedell

& Dumas, 2004; F. P. Rivara et al., 2011; F. P. Rivara et al., 2012). Nonetheless, in the present study, the level of closeness and continuity engendered over this time equally provided a basis from which to grow and weave the children's participation anew. Over this time, connections shifted, with some relationships dropping away, an effect noted in some other studies (Chleboun & Hux, 2011; Gauvin-Lepage & Lefebvre, 2010), but also with some new connections being introduced, and parents eventually coming to grips with the need to let their child go and take part in the world with others.

One newly developed intervention in Aotearoa New Zealand that recognizes the importance of connections with others is the Te Waka Oranga indigenous intervention framework (Elder, 2013) for guiding service delivery with Māori. Deriving from her recent research with Māori communities, Elder (2013) proposed the framework to help navigate service delivery with Māori children who sustain TBI, and their whānau. The framework is based on an understanding of wairua, an essential component of health. As explained by Elder, wairua involves “an unique connection between Māori and all elements of the universe” (2013, p. 416). In establishing protocols and ways for working collectively towards shared goals, Elder's framework also embraces people and their skills and resources, place, and time. Elder's findings lend support to the resource developed and modified in this phase of my study. In Phase Three, the conceptualization of participation after TBI as Ta Kupenga, or Net-making, similarly emphasizes connectedness amongst people and their skills, and the physical and temporal contexts in which they work together. Thus, the resource for facilitating children's participation developed in the third phase of this study holds potential to align with Elder's framework, but extends beyond engaging with whānau, to involving people from a range of community settings and cultures. Although further work will be needed to ensure the cultural appropriateness of Ta Kupenga, and to clarify the interface between the two approaches, similarities in their theoretical underpinnings signals some promise for delivering services which can address participation in a culturally meaningful way.

Summary

This chapter has reported the findings of Phase Three of the study, which was undertaken in collaboration with stakeholders to further the development of a resource aimed at facilitating the children's participation. The following, final chapter, provides a discussion of all three study phases.

Chapter Eleven

Discussion of the Study as a Whole

The previous chapter presented the findings of the third phase of the research. This final chapter integrates and discusses the findings of all three phase as of the research in relation to existing literature. Discussion emphasizes the concepts of Shared Occupation, Participation Skills, and the metaphor of Ta Kupenga- Net-making, these ideas being central to the findings and to intervention strategies. The contribution of the research to the body of knowledge is highlighted, and the strengths and limitations of the work are considered. Key implications for rehabilitation and policy are explored, and recommendations are made for further research. Throughout this discussion, words representing categories identified in the research are written as names, with the first letter capitalized. The contents of the chapter are outlined below in Figure 11.1.



Figure 11.1: Sequence and Contents of Chapter Eleven

Summary of the Study

The study has been underpinned by the pragmatist philosophical perspective of John Dewey. This perspective prompted a view of people as connected and continuous with their world, and as evolving along with that world. I understood that through this connection, and in the process of occupation, changes are effected in people and the world (Dewey, 1916, 1925/1981). Dewey's pragmatist perspective shaped the questions I asked, the methodology and design of the study, and my interpretation of the findings.

The first, case study phase of the research aimed to answer questions about a) the aspects of participation that are important to NZ children who have had a clinically significant TBI, and b) the facilitators and barriers to their successful participation. In response to concerns that were raised for the children's participation, and the finding that others' understandings and actions were key to children's participation, a review of the literature was conducted in Phase Two of the study. This described, compared, and evaluated community-focused intervention approaches for facilitating children's participation. In Phase Three of the study, guided by the information in the case studies, and the evidence in the review that addressed the important aspects of participation, a draft resource for facilitating participation was developed. A workshop was held with families, practitioners, and educationalists to learn about the acceptability of the resource, and to generate ideas for its implementation and dissemination.

The three phases of the study provide a view of participation that makes a shift from a focus on individuals who endeavor to participate, to a more holistic view of participation as being actively woven, and as drawing together People, Places, and Time in context of Shared Occupation. It shows a mixed picture of participation for children with TBI, including instances of participation that were positive, supporting satisfaction and learning for those involved, but also examples of participation and themes which were cause for concern.

The findings draw attention to Participation Skills, which are the skills people use to facilitate one another's participation. They include the things people do to Perform, Drive, Lead, and Include others in Shared Occupation, Further, the study proposes that these skills are learned, and that they are learned in an ongoing manner as changes are encountered in the environment. They are learned in the context of Shared Occupation.

Situating the Findings with Existing Literature

Research about children's participation after TBI.

This study is the first to specifically investigate Aotearoa New Zealand children's participation after TBI. Despite a unique cultural makeup (Statistics New Zealand: Tatauranga Aotearoa, n.d.), concerns over rates of TBI for children (Feigin et al., 2013), and availability of state-funded rehabilitation (Accident Compensation Corporation, 2013), no other projects were found that explored children's participation after TBI in this country. Notably, the study has included participants who are of Māori descent, and may therefore provide some answers to Elder's (2012) call for research to inform culturally relevant approaches to rehabilitation for children who sustain a TBI.

Whilst there have been international studies which examine children's participation after TBI (G. Bedell, 2009; G. M. Bedell et al., 2005; G. M. Bedell & Dumas, 2004; Foo et al., 2012; Galvin et al., 2010; F. P. Rivara et al., 2011; F. P. Rivara et al., 2012), none have taken an in-depth view of the different aspects of participation for school-age children across multiple participation settings, or gathered information from a range of stakeholders associated with their participation. In the present study, information was obtained about participation contexts beyond the home and classroom, such as school camps, rugby, soccer, kapa haka, scouts, fishing, family holidays, and visiting the homes of extended family. The first to use case study methodology to explore participation with younger children after TBI, the study contributes a more detailed picture of the important aspects of their participation to the literature.

By adopting a holistic perspective of participation, and endeavoring to see the different contexts and the children's participation as continuous, insights were not only gained into what was important for the children, but also into changes that took place for them and their environment through participation. Significantly, information was generated about changes that took place in other people through that participation. The findings contribute to a deeper understanding of the reasons underlying difficulties are experienced, and provoke awareness of potential avenues towards solutions.

Social networks.

Participation after TBI was conceptualized as Ta Kupenga, or Net-making. It was found to involve Fit, Connection, and Pattern amongst people who Share in Occupation

(including children with TBI, their peers, and adults), and the spatial and temporal context of their occupation. Connections and Patterns were not restricted to single instances of a Shared Occupation, but were linked across a range of situations, and underwent change.

A concern not previously discussed in depth are the associations noted between families who participate in a range of valued occupations, and the participation of their children with disabilities (Gauvin-Lepage & Lefebvre, 2010; Heah et al., 2007; G. King et al., 2006; G. King et al., 2003; Palisano et al., 2011). Such associations suggest the relevance of networks, although this has lacked closer attention. This theme was highlighted in the present study, where, for some families, their own Connections, forged through Shared Occupation, provided a network that then supported and extended the participation of their children after they sustained a TBI. However, after their child's TBI, not all families were well placed to meet this need, and some, such as Anna's mother struggled to create participation opportunities outside the home for their children. It is possible that friendships are more likely to result from participation in Shared Occupation. The literature reviewed in Chapter Three has already demonstrated the difficulties children have with friendships after TBI (Chleboun & Hux, 2011; Gauvin-Lepage & Lefebvre, 2010; Hawley et al., 2002; Prigitano & Gupta, 2006; Roscigno et al., 2011; Sharp et al., 2006), and interventions such as the Building Friendships Process (Glang et al., 1997; Sowers et al., 1996) were specifically developed to meet this need.

In this study, linkages were also found between the effects of a child's injury and the participation of whānau/parents. Mirroring themes described in the review of literature in Chapter Four (G. M. Bedell et al., 2005; Hawley et al., 2003; Robson et al., 201; Roscigno & Swanson, 2011; Sharp et al., 2006), after the accident, for the parents in this study, there was frequently a Misfit of available time-frames and parents' ability to meet competing demands. Connections with friends and workmates were stretched, and Patterns of parents' involvement in leisure and employment were interrupted. Parents who were juggling caring for the injured child with attendance at medical and rehabilitation appointments, home-making roles, parenting siblings, and employment requirements, were not well placed to Share Occupations outside the home with their injured child. In this way, they were less able to maintain or build networks with others, further constraining the child's participation. Whilst literature has recognized risks for parents' psychological well-being after a child's TBI (V. A. Anderson et al., 2005; Hawley et al., 2003; Micklewright et

al., 2012; Prigatano & Gray, 2007; Roscigno & Swanson, 2011; Stancin et al., 2010; S. L. Wade, Taylor, et al., 2006), the present findings build on such themes in extant literature, flagging a potential need to provide services that can also address participation issues for parents.

Participation skills.

In line with international research (T. B. Fay et al., 2009), the study painted a varied picture of the children's participation after TBI, likely reflecting the large number of factors which come into play (F. P. Rivara et al., 2011; F. P. Rivara et al., 2012). In particular, studies of children's participation have noted the influence of the social environment, with people's attitudes and actions a common concern (Anaby et al., 2013; G. M. Bedell & Dumas, 2004; Colver et al., 2012). Countering this, a study by Bedell and his colleagues (2005) contributed information about the strategies parents learn that facilitate their children's participation. This thesis draws attention to the presence of Participation Skills such as those used by the parents in the study by Bedell and colleagues (2005), recognizing these as the things communities of people do to help one another to take part in a Shared Occupation. It extends our understanding of those skills beyond strategies learned and used by parents, finding that such skills are also learned and used by children and adults in the wider community. Noting similar themes in the occupational therapy literature (Fisher & Griswold, 2014; Humphry, 2005; Mosey, 1973), the study has given name to those skills, identifying them as Driving, Leading, Including, and Performing. It has described the actions encompassed by those skills, and has proposed that they are learned in the context of Shared Occupation.

Participation skills may be differentiated from the broader concept of social skills, which have been defined as "the interaction between an individual and the environment and the tools used to initiate and maintain vital interpersonal relations" (Phillips, as cited in Elliott and Gresham, 1987, p. 96). Social skills are reflected in levels of peer acceptance, the behaviors used towards others, and the role of those behaviors in social functioning (Elliott & Gresham, 1987; Griswold & Townsend, 2012). Social skills assessments are often applied with children who are demonstrating developmental concerns (Elliott and Gresham, 1987). In contrast, this study found that it was not only the children with TBI who experienced interaction problems, but that peers also had difficulties adjusting their interactions to the changes in their class-mates.

Items in a number of social skills assessments (e.g. K. Forsyth, Lai, & Kielhofner, 1999; A. G. Fisher & Griswold, 2010; Gresham & Elliott, 1990; L. Meyer et al., 1995) comprise individual social skills that people or children might use towards their own involvement, such as asserting oneself, focusing, or contacting others. Other skills contained in such assessments are likely to facilitate others' involvement in a Shared Occupation, such as asking, collaborating to achieve a task, generating ideas for activities, sharing, offering assistance, or giving feedback, but the effect of those skills on how they support others' participation has not always been well recognized in assessment processes (Griswold & Townsend, 2012). Moreover, such skills do not include the actions associated with Driving and Leading that were found in this study. However, aligning with the present study's concept of participation skills that occur in the context of Shared Occupation, it has been argued that social skills assessments should be conducted in a way that takes account of the physical, social, and activity setting (Fisher, 2009; Doble & Magill-Evans, 1992; Law, 2002). Establishing the relationship of the Participation Skills identified in this study and definitions of Social Skills remains for future clarification.

Situating the Findings with Theoretical Understandings

The World Health Organization definition of participation.

Since the WHO (2001) proposed in the ICF that participation is an essential element of health, there has been debate over what is meant by participation. Some have proposed that participation should be seen separately to the notion of social participation (Piškur et al., 2013). In light of the WHO explanation that participation involves “a societal perspective of functioning” (2001, p. 213), for the purposes of this study, there was an initial assumption that participation involved a social element. Given this assumption, for the stakeholders who took part in this study at least, all participation was seen as being social in nature, even when performed alone, because all occupations are shaped by social expectations and conventions (Yerxa, 1990). Additionally, the concept of Shared Occupation was central to the notion of participation. Where other adults or children were not available, participation was shared with pets, toys such as teddies or dolls, or, as was the case with Anna, even insects. At other times, participation was carried out as independently as possible, but was conducted with an aim of sharing in other participation experiences, such as Anna learning to wash her face preparatory to participating with other

children in the playground. This view of all participation involving a social element is in accord with Khetani and Coster's (2014) observation that "any life situation can be social" (p. 732).

The need for rehabilitation providers to extend their view of participation beyond that of individuals engaged in activities, and to see those individuals as socially connected with one another and with the wider environment through Shared Occupation, has recently been given attention in occupational science literature. Here it is argued that by adopting a broader, macroscopic perspective, we are able to see the way the environment can promote learning and development when it prompts and provides opportunities for occupation (Coppola, 2013; Humphry & Wakeford, 2006, 2013). As people participate with and transform their environment, so too does the environment play a role in transforming the people.

In line with these ideas, the study provides a cohesive picture of the children's participation. It allows for glimpses inwards into the experiences of individuals, but equally supports outwards inspection of the children's and others' collective participation in continuity with their environments. Importantly, this approach generated insights into transformations that took place over time when people shared in occupations together, and learned skills that could facilitate one another's participation.

Social change: Dewey's pragmatist philosophy.

Aspects of these findings about social change are explained by Dewey's pragmatist philosophy. Arguing for a moral and democratic society, Dewey envisioned schools as the instrument by which social change could come about. By providing access to quality, practical, occupation-based education, Dewey believed children would build skills for working cooperatively, with "free exchange of ideas," supporting their ability to move past habitual ways of thinking, and to generate novel ways of solving the problems facing society. Progressive education was the means of developing "social power and insight" (Dewey, 1907, p. 32), thereby promoting citizenship and social justice (Saltmarsh, 1996).

Dewey's work provides a broad means of understanding how individuals learn in transaction with their environment including instruction, imitation, reinforcement of behavior, and, most importantly, through practical experience (1916, 1938/2008a). It remains to articulate the learning processes involved when children (and sometimes adults) cooperate to complete tasks, as in this study, where Shared Occupations are central. Whilst

Dewey had a vision of practical, cooperative education creating a more democratic society, a fuller explanation is needed of how such social changes might eventuate (Schutz, 2001).

Social change: Activity theory.

Activity Theory suggests a way forward. Humphry previously made this link in 2005, drawing on Activity Theory to frame her understandings about social influences that contribute to children learning to perform and experience the meaning of occupations. An approach founded by Russian psychologists, including Vygotsky, Leont'ev, and Luria, Activity Theory derives its philosophical underpinnings from Karl Marx and Friedrich Engels (Engeström & Miettinen, 1999). Reflecting Dewey's pragmatist understandings about continuity and transaction between people and their environment, the theory adds to and complements his vision of the social changes that take place when people act together in practical doing. Activity Theory has been applied in diverse fields, including (but not limited to) education and learning, and is concerned with the idea of systems of "object-oriented, collective, and culturally mediated human activity" (Engeström & Miettinen, 1999, p. 9). Stresses and conflicts within aspects of an activity system provide a driver for change and transformation.

The process of collective learning draws from Vygotsky's concept of a "zone of proximal development" (Vygotsky, 1978, p. 86), and pays attention to the social medium in which people learn to carry out activities (Tolman, 1999). In a process of cooperative activity, expanding cycles of learning commence when people are socialized and enskilled in routine ways of performing an activity (Engeström, 1999). This aspect of a cycle is termed "internalization". As people gain skills in using tools and information, they become increasingly able to respond to any conflicts and contradictions that arise, critically reflecting on the various aspects of the system, and seeking out and creating discrete solutions, a phase called "externalization" (p. 33). Eventually, a new way of performing the activity is established, and internalization again dominates the learning.

The internalization and externalization phases within the cycle were apparent in the study when at the start of the year, Anna's teacher was oriented to teaching Anna, then introduced a program that established expectations for children's behaviors towards each other. The teacher and the children came to know one another and the occupations they shared and by the end of the year, they had learned about each other's challenges and were initiating changes that helped to overcome obstacles to shared activities. As part of the

class, Anna also began to adjust, and contributed her opinions as to her needs. Social changes had taken place.

Engstrom (1999) suggested Activity Theory is well suited to informing the development and testing of interventions in collaboration with communities, to bring about social transformation. The evolving nature of participation identified in the present study, the centrality of Shared Occupation, and the collective and individual changes seen in people's understandings which overcame obstacles to participation, suggest Activity Theory holds promise for informing further studies of people's participation. Recognition of the relevance of Activity Theory arising from this study adds credence to Humphry's (2005) previous scholarship.

Limitations and Strengths of the Study

When considering the applicability of research findings to other situations, it is important to reflect on the overall limits of the information, and weigh those up against its strengths (Hoffman, Bennett, & Delmar, 2013). In so doing, I draw attention to points that are central to judging the merits of each of the three phases of the study.

Firstly, the extent to which the findings of the study can be transferred to other settings is constrained by the involvement of only six cases in Phase One. Further caution is needed when considering how well the findings can be applied to children with other diagnoses, or who are of different ages to the 9-12 year olds in the study.

Some constraints on the applicability of the study also arise from the fact that the study took place in the Aotearoa New Zealand context, where people who acquire a disability as the result of an accident are covered by a society-wide, no-fault insurance scheme. This may limit transferability to those countries where similar schemes exist, or to children whose rehabilitation needs are met by private insurers.

Although Phase One of the study directly gathered information from a range of perspectives, including the children, their families, and teaching staff, it relied on observations and second-hand reports of children's interactions with peers. As experienced by Roscigno et al. (2011), data collection with the children themselves was hampered by the children's cognitive and communication difficulties. The depth of information that could be provided about the children's perspectives, and those of their peers is therefore limited.

In Phase Two of the Study, the review of community-focused interventions, the limitations imposed on the search for evidence need to be recognized. These included the use of a proximity search, the application of date limits, and limited use of manual searching, such as checking reference lists or items which cited retrieved material. A number of books, and items that were not published in peer-reviewed journals were excluded. Nonetheless, the review generated practical information about a variety of approaches available to families and professionals, gives consideration to the congruity of those approaches with important aspects of participation, and provides some basis for determining their effectiveness. In particular, the review highlights gaps in our understandings as to the applicability of such approaches with school-age children with TBI, and highlights a need to establish their viability in current contexts.

Phase Three of the study, whilst gaining invaluable feedback from a range of stakeholders about a draft resource, took place over a short time frame. As such, there was limited time for the participants in the study to acquaint themselves with the resource, to become confident with taking part in the research process, and to explore all the ideas generated. Although much useful information was gathered at the workshop, further inquiry will be needed to fully establish the viability and acceptability of the resource to stakeholders. In particular, wider and deeper consultation will be required with Māori.

Finally, in undertaking a qualitative study, I acknowledge the influence of my own beliefs and values on the findings of all three phases. My experience as an occupational therapist in a pediatric rehabilitation setting has undoubtedly contributed to an emphasis on occupational concepts in the interpretations, perhaps at the expense of alternative interpretations. This is apparent in some similarities between the model of participation that was developed out of the study, and models of occupation in occupational science and therapy literature (For example, Dunn, Brown, & McGuigan, 1994; Dunn, Brown, & Younstrom, 2003). Equally however, it should be recognized that the existing models and these findings lend support to each other. Moreover, the perspectives of several other disciplines were explored. New information emerged from the study which also has relevance to those other disciplines, particularly the notion of Participation Skills, and the changes that took place through participation.

Although some much needed understandings emerged from data gathered with participants who were of Māori descent, I myself am not Māori, but New Zealand

European. This has likely influenced the information gathered with whānau, and the way that information has been interpreted. To aid involvement of Māori participants, cultural support was sought, and generously given, by Whāea Louise Elia, who has long experience in working with tamariki (children) and their whānau. Whāea Louise has also supported with interpretation of whānau information, and with the use of te Reo where it better conveys the meaning of the information involving those participants.

All three phases of the study have been framed by Dewey's pragmatist philosophical perspective. This has consistently supported a broad focus that encompassed each child and his or her environment as one. It played a part in adopting a perspective that looked to the past as well as to the future, and a concern with change over time. Importantly, the philosophy prompted a concern with practical application of the information, and, in part, drew me towards development of a draft resource that can be used to facilitate participation. It should be acknowledged, however, that this philosophical perspective might also have constrained the findings, limiting other ways of viewing or interpreting the information. A more critical perspective might have further uncovered power relationships, whilst a phenomenological perspective may have provided greater depth of understanding into key issues. Nonetheless, as guided by Stake's case study methodology (1995), where alternative interpretations suggested themselves, these have been articulated. Additionally, the study has provided a basis for subsequent research that can develop further insights into the participation concepts and process uncovered in this study. As Dewey (1929/1988) pointed out, the true test of the knowledge rests with its application to practice. This remains to be undertaken.

Implications of the Study Findings for Rehabilitation

Service delivery.

In consideration of the overall limitations and strengths of the study, the findings hold several implications for provision of rehabilitation services. The pattern of children's regular participation was interrupted following the accident and their abilities no longer fitted with the demands of their previous shared occupations. Hospitalization, a need for rest, attendance at medical appointments, rehabilitation sessions, and involvement of support personnel changed the balance of their participation. Concerns for children's safety ruled out participation in many of the physical occupations which they valued. The pattern

shifted after the accident, so that increased time was spent in the home setting and more occupations were shared with adults. In spite of fatigue, additional involvement was needed in specialized rehabilitation occupations. Concomitantly, there was less participation with teachers, peers and other adults and children from their community, and some of the connections with these people were stretched, or fell away.

The findings further indicate that where there is this lack of participation for an injured child, others will then be less likely to learn how to involve them. Equally, the children themselves are not well placed to learn participation skills, apart from those they use with family members, rehabilitation personnel, or support workers.

The finding about the importance of Shared Occupation to participation, and particularly shared physical occupation, implies that rehabilitation and supports, such as those funded by the Accident Compensation Commission in Aotearoa New Zealand, are important in regaining and developing performance skills. However, to enable participation, services also need to be delivered in a way that maintains and facilitates children's involvement in their usual shared occupations.

Likewise, although research clearly indicates further head trauma should be avoided (Wetjen, Pichelmann, & Atkinson, 2010), information provided about safety risks needs to weigh up such risks against the degree to which this might curtail participation in enjoyed physical occupations. This is particularly relevant for parents who are already vigilant about their children's safety (Gauvin-Lepage & Lefebvre, 2010; M. Jones et al., 2010; Robson et al., 2005). Whilst being sensitive to families' circumstances and values, as found by Bedell et al. (2005), an important focus of intervention should be supporting those involved to identify alternative opportunities available in the community that fit with the child's abilities, safety needs, and valued occupations.

Assessment.

In carrying out the case studies, it was recognized that the aspects of participation that were important were complex, including aspects of people, places, occupations and times as they transected in a Shared Occupation, and as they supported satisfactory Fit, Connections, and Patterns of participation and Learning over time. At the time I undertook this study, existing measures of participation did not mesh well with all those aspects. Concerns included:

- an emphasis on performance and amounts or frequency of participation, at the expense of qualitative concerns such as feelings of connection, satisfaction, achievement, and overall patterns of participation;
- focusing inwards to individual participation, rather than seeing participation as one with its social, physical, occupational, and temporal contexts;
- focusing on single environments, meaning that other measures were required for other environments;
- comparing participation to same-age peers, when this was not seen as important by families in this study;
- the amount of time taken to administer assessments risking further disruption to participation; and
- adoption of specific lists of occupations, which then neglected occupations which were unique to children, families, or certain cultures.

In the meantime, similar concerns over the assessment of participation prompted Wendy Coster and her colleagues to develop a new participation measure, the Participation and Environment Measure - Children and Youth version (PEM-CY; W. Coster et al., 2011; W. Coster et al., 2012). Features of the PEM-CY align with and support a number of findings in the present study. Importantly, the studies which provided the conceptual basis for the PEM-CY concluded that children's participation and the environment were interconnected, and should not be evaluated apart from each other. Other features congruent with the findings of the present study include evaluating the degree to which aspects of the environment fit with a child's abilities (demands), the pattern of participation (frequency and range), and the level of engagement or connection with a task and others (involvement) (G. M. Bedell et al., 2011; W. Coster et al., 2012). Equally, the findings of the present study provide some validation for the assessment, and suggest its potential as a suitable tool for assessing children's participation after TBI in Aotearoa New Zealand.

Again however, the PEM-CY (W. Coster et al., 2011; W. Coster et al., 2012) is focused on individual participation, and this is conceived broadly across a range of occupations. To adequately intervene to address the social barriers to participation, concepts such as the participation skills of a group of children and adults involved in a particular occupation would need separate assessment. The body of work in this study

contributes some insights into potential areas of focus for such an assessment, namely people's ability to Drive, Lead, and Include each other in Shared Occupation.

Intervention.

Recognizing the need for children to be enabled to participate at all phases of their rehabilitation, the study findings were integrated with understandings from the wider literature, and used to develop a draft resource of strategies to support participation. The resource is called Ta Kupenga, or net-making, recognizing that enabling participation after a child's TBI is a skill that is learned by those who share in the children's occupations. The craft of ta kupenga involves learning to adjust the Fit of threads that make up the net of children's participation, repairing and strengthening Connections, and gradually instituting Patterns that are balanced, include diversity, and which are not overly confining. Ta Kupenga aims to recognize, strengthen, and build people's skills for involving children in Shared Occupation at different phases of the rehabilitation process after TBI.

To date, few interventions are available that directly support participation, and evidence for those interventions is emergent. Of note, a relatively recent invitation by the editor of the *Child: Care, Health and Development* journal to submit reports for a special edition of interventions addressing participation resulted in only one manuscript (Raghavendra, 2013). As in the discussion in Chapter Eight, the literature review necessarily turned to the wider literature to explore approaches and strategies that could support participation for children with TBI.

Corresponding with the development of the resource in this study, there is increasing awareness of interventions which are directed at contextual elements of children's occupations. For instance, a recent study by Darrah and colleagues (2011) drew attention to the relative effectiveness of therapy which aims to change features of tasks, provide alternative items for use within tasks, or change physical and social aspects of the environment for pre-school children with cerebral palsy. The study results are promising, with short and longer term improvements in performance and participation that were similar to those made by children receiving therapy focused on remediating impairments and developing task skills. However, while Darrah et al. state that social and attitudinal influences were encompassed within the context-focused interventions, there is limited explanation as to how these were addressed, beyond providing "assistants" or changing "attitudes" (2011, p. 617).

As seen in Chapter Eight, the wider literature provides information about addressing social and attitudinal change. Five intervention approaches directed at the community were analysed in the review. The approaches were identified as having discrete aims, contexts, and emphasis in the strategies they employed. The approaches had limited evidence for their applicability with children with TBI. The Rehabilitation Service Models and Modalities for Participation approach contrasted in this respect, but did not incorporate strategies that addressed children's participation with peers, a gap for several children in the case studies. Although a need for multiple strategies was indicated by the review, the viability of implementing all five approaches was questioned.

As discussed in Chapters Nine and Ten, the Ta Kupenga: Net-making resource was developed in response to these concerns. The resource is a context-focused intervention for children with TBI. It proposes multiple strategies to generate social and attitudinal change, enabling participation at all phases of the rehabilitation process and in a range of contexts. The strategies are drawn from the case studies, and from broader literature which provides evidence of efficacy. They are situated in relation to theoretical understandings about participation for children with TBI coming from the case studies. In contrast to interventions which focus in on the individual child, the resource encompasses those involved at the nexus of participation in a Shared Occupation.

Informing Legislation and Policy

Service delivery, including assessment and intervention, is influenced by wider government policy. The first draft of the World Health Organization Action Plan 2014-2021: Better Health for Persons with Disabilities was published in 2013. For people who experience disability such as that reported after a TBI, this document points the way forward at an international level, giving direction to government policies and funding priorities that are intended to support their "health, well-being and human rights" (p. 2). The document acknowledges that disability is an issue at a world-wide level, that it will affect all people at some point in their lives, that it particularly affects vulnerable groups such as indigenous people and children, and that there is a self-perpetuating relationship between disability and poverty. The Action Plan includes an objective to "strengthen and extend habilitation and rehabilitation services, including community based rehabilitation, and assistive technology" (WHO, 2013, p. 2).

The document promotes a vigorous focus on provision of health and rehabilitation services for individuals with disabilities, and research into their function and limitations. Access to services is articulated as a right, and is, arguably, seen as contributing to participation and health. Absent from the document, however, is any mention of intervention at the level of others in the communities, with whom people who have disabilities need to participate. This is in spite of studies which consistently highlight the social environment as a barrier to children's participation (G. M. Bedell & Dumas, 2004; Colver et al., 2012; M. Law et al., 1999; M Law et al., 2007).

Given the above studies, and the contribution of the findings from the present study, the WHO document should arguably include a requirement to build skills in people in the wider community for enabling the participation of people with disabilities. Further, it should be recognized that an over-emphasis on access to, and participation in rehabilitation programs may be at the detriment of time spent participating in and with the wider community. Service delivery needs to be tailored so that it minimally disrupts, and brings about participation of people with their communities.

In the Aotearoa New Zealand context, for people from Māori and Pacifica cultures who have disabilities, policy-makers state the importance of providing services that are responsive to those cultures, and which uphold those people's right to take part in their communities along with others (Ministry of Health, 2001; Office for Disability Issues: Te Tari Mō Ngā Take Hauātanga, 2013). The present study shed light on the differing concerns and capacities amongst the various communities involved in the study, and provided information about the meanings associated with occupations that were unique to those communities. In this way, the findings reinforce the importance of generating culturally nuanced understandings about people's rehabilitation needs in a given context, and delivering rehabilitation in a way that addresses people's specific needs. It suggests the benefits of developing rehabilitation resources which resonate with people from particular communities, and which address the participation issues that are valued by them.

Further Research

The resource which was developed from the findings of the case studies, and from information generated by the review of literature about community-focused interventions, was appraised by stakeholders in Phase Three of the study. It was modified in response to

those people's feedback. Further research now needs to be undertaken to move the resource towards implementation.

As mentioned in Phase Three, there is a need to thoroughly understand how a complex intervention will work, and to establish the presence of any barriers to change for those involved with the intervention (M. Campbell et al., 2000; N. C. Campbell et al., 2007). In occupational therapy literature, Clark and Lawlor (2009) similarly stated the need to adequately develop theoretical understandings as a basis for developing and evaluating interventions. In this way, scientific understandings are systematically translated into effective solutions to existential problems. Phase Three of the study generated useful insights into ways to make the Ta Kupenga: Net-weaving resource more acceptable to stakeholders, and provided ideas for its dissemination. However, recognizing that the resource is a complex intervention (M. Campbell et al., 2000), adequate testing will be required prior to undertaking an exploratory trial. Testing can determine the viability of the resource in practice, whether any adaptations are needed, the most appropriate timing for its delivery, and how consistently it can be implemented.

Therefore, a pilot of the resource is proposed with a small number of children and their families. Before undertaking any such study, more adequate consultation with Māori will be necessary to establish the cultural safety of the resource, and to obtain further advice regarding its utility. In initiating a pilot study, acknowledgement will need to be given to the ethical issues posed by withholding a potentially beneficial intervention from participants. The study must also address the reality of potentially small numbers of children with TBI. Consistent with the findings of the present study about the benefits of implementing the resource as early as possible after the accident, and the ongoing nature of its use, the pilot will need to capture information over an extended time. Further, the influence of multiple stakeholders in different participation experiences and contexts will need to be taken into account, including the children's peers.

Recognizing such concerns, the mechanisms by which the resource is expected to work, and the intent of the resource, a cautious and collaborative approach is proposed in moving it towards operationalization. A case study design is proposed, reflecting the need to implement the resource over a range of rehabilitation phases and in a range of contexts. Case studies have been widely applied in education-based research, and were the methodology used for the first phase of this study, effectively supporting involvement of a

range of stakeholders as appropriate for each case. Case study design will also allow for the individual tailoring of the resource to meet the particular needs of different children and their contexts. Optimally, participating children with TBI and their families will be recruited onto the study during the acute or post-acute stages after the accident, then network sampling (Merriam, 2009) will be employed to recruit other stakeholders from the child's community onto the study. Given the focus of the resource on participation, the importance of enabling those involved to further develop their Participation Skills, and the reality of ongoing change for children, their families, and communities, it is anticipated that the case studies would be informed by Action Research principles, with participants in the role of co-researchers.

Reflection on Terminology

In conversation with others, it is apparent that the broad framing of Participation Skills presented in this thesis can be misconstrued as a much narrower focus on the performance of the individual child with a health condition such as TBI. This realization prompts a need to reconsider the terminology adopted, perhaps re-framing as the participation-enabling skills that all people in a community hold. Furthering this line of thinking will need to be addressed in future publications.

Conclusion

The study provides a view of participation as a single connected whole, encompassing people engaging together in occupation in context. It advances our knowledge of participation, by contributing understandings about the aspects of participation that people in Aotearoa New Zealand see as important after children sustain a TBI. Shared Occupation is center-most to these understandings, intertwining people and the skills they bring to enable one another to participate, the occupations in which they engage, and the temporal and physical contexts of that Shared Occupation. Critically, the study highlights the importance of changes that occur in Shared Occupation through time, and reveals changes as providing participation challenges that go hand-in-hand with advancing community knowledge of how to participate, and thus growth and learning.

International rehabilitation research suggests that whilst some existing interventions make a difference, much is still to be learned. Strategies available in the wider literature, and the day-to-day things that people in communities do that facilitate children's

participation have too often been overlooked, and are overshadowed by a focus in on individual deficits. In establishing the potential of facilitators in the social community, drawing them together, and giving name to them, the findings of this study point to new and practical ways forward for whānau/parents, service providers, and communities.

The findings have practical implications for the future development of instruments to evaluate children's participation. Considerations arising from this study are that such instruments should encompass aspects of participation such as the Fit between contextual demands and children's needs, abilities and preferences; the quality of the Connections forged during participation; and the Pattern of children's participation are important considerations. Further, the findings point to the importance of evaluating the extent to which other people are able to Drive, Lead, Include in, and support the children to Perform Shared Occupation.

Looking beyond assessment, the findings have also established the theoretical basis for an intervention resource to mobilize and equip members of children's communities with the skills needed to facilitate their participation. In collaboration with stakeholders, the resource has been moved further towards implementation, with practical information gathered about its content and suitable modalities for dissemination. As yet, it is not fully clear how this can be implemented.

What is required to gain further traction in these new directions is a willingness to embrace change, to shift the view outwards towards an understanding of people's participation as one with context and doing, and a determination to shift the focus from individuals to the whole. In order to make a sustainable difference to children and their families, rehabilitation providers must show equal concern for those with and surrounding the children, respecting their part in the participation relationship. Rehabilitation should enable the skills of family and whānau, teachers, support persons, peers, and others in the community to share co-operatively in occupation, to mediate barriers for others, and to support one another's learning. As with weaving and maintaining a strong net, attention should not only be given to the individual torn thread. We must be heedful of the whole net, ensuring its fit, connections, and patterns are adequate for sustaining the well-being of the community.

References

- Accident Compensation Corporation. (2013). *Welcome to ACC*. Retrieved October 19, 2013, from <http://www.acc.co.nz/about-acc/index.htm>
- Achenbach, T. M. (1991). *Manual for the Child Behavior Checklist and 1991 Profile*. Burlington, VT: University of Vermont.
- Addams, J. (1912). *Twenty years at Hull House*. New York: MacMillan. Retrieved from <http://pds.lib.harvard.edu/pds/view/2859492>
- Addams, J. (2004). *My friend, Julia Lathrop*. Champaign, IL: University of Illinois Press. (Original work published 1935)
- Adelman, C. (1997). Action research: The problem of participation. In R. McTaggart (Ed.), *Participatory action research: International contexts and consequences* (pp. 79-106): SUNY Press.
- Adelman, C., Jenkins, D., & Kemmis, S. (1980). Rethinking case study: Notes from the second Cambridge conference. In H. Simons (Ed.), *Towards a science of the singular: Essays about case study in educational research and evaluation* (pp. 47-61). Norwich, United Kingdom: Centre for Applied Research in Education: University of East Anglia.
- Adelson, P. D. (2010). Clinical trials for pediatric TBI. In V. Anderson & K. O. Yeates (Eds.), *Pediatric traumatic brain injury: New frontiers in clinical and translational research* (pp. 54-67). New York: Cambridge University Press.
- Adibsereshki, N., Tajrishi, M. P., & Mirzamani, M. (2010). The effectiveness of a preparatory students programme on promoting peer acceptance of students with physical disabilities in inclusive schools of Tehran. *Educational Studies*, 36(4), 447-459. doi:10.1080/03055690903425334
- Adolph, K. E., Bertenthal, B. I., Boker, S. M., Goldfield, E. C., & Gibson, E. J. (1997). Learning in the development of infant locomotion. *Monographs of the Society for Research in Child Development*, 62(3), 1-162. Retrieved from <http://www.wiley.com/bw/journal.asp?ref=0037-976x>
- Agnihotri, S., Gray, J., Colantonio, A., Polatajko, H., Cameron, D., Wiseman-Hakes, C., ... Keightley, M. (2012). Two case study evaluations of an arts-based social skills intervention for adolescents with childhood brain disorder. *Developmental Neurorehabilitation*, 15(4), 284-297. doi:10.3109/17518423.2012.673178
- Åhlander, A. C., Persson, M., & Emanuelson, I. (2013). Fifteen-year follow-up of upper limb function in children with moderate to severe traumatic brain injury. *Journal of Rehabilitation Medicine*, 45(8), 815-819. doi:10.2340/16501977-1203

- American Psychological Association. (2010). *Publication manual of the American Psychological Association* (6th ed.). Washington, DC: Author.
- Anaby, D., Hand, C., Bradley, L., DiRezze, B., Forhan, M., DiGiacomo, A., & Law, M. (2013). The effect of the environment on participation of children and youth with disabilities: A scoping review. *Disability & Rehabilitation, 35*, 1589-1598. doi:10.3109/09638288.2012.748840
- Anaby, D., Law, M., Coster, W., Bedell, G., Khetani, M., Avery, L., & Teplicky, R. (2014). The mediating role of the environment in explaining participation of children and youth with and without disabilities across home, school, and community. *Archives of Physical Medicine and Rehabilitation*, Advance online publication. doi:10.1016/j.apmr.2014.01.005
- Anaby, D., Law, M., Hanna, S., & Dematteo, C. (2012). Predictors of change in participation rates following acquired brain injury: Results of a longitudinal study. *Developmental Medicine & Child Neurology, 54*, 339-346. doi:10.1111/j.1469-8749.2011.04204.x
- Anderson, R. A., Wilson, P. T., & Fielding, L. G. (1988). Growth in reading and how children spend their time outside of school. *Reading Research Quarterly, 23*(3), 285-303. Retrieved from <http://www.reading.org/General/Publications/Journals/RRQ.aspx>
- Anderson, S. W., Barrash, J., Bechara, A., & Tranel, D. (2006). Impairments of emotion and real-world complex behavior following child- or adult-onset damage to ventromedial prefrontal cortex. *Journal of the International Neuropsychological Society, 12*, 224-235. doi:10.1017/S1355617706060346
- Anderson, V., Brown, S., & Newitt, H. (2010). What contributes to quality of life in adult survivors of childhood traumatic brain injury? *Journal of Neurotrauma, 27*, 863-870. doi:10.1089/neu.2009.1169
- Anderson, V., Brown, S., Newitt, H., & Hoile, H. (2009). Educational, vocational, psychosocial, and quality-of-life outcomes for adult survivors of childhood traumatic brain injury. *Journal of Head Trauma Rehabilitation, 24*, 303-312. doi:10.1097/HTR.0b013e3181ada830
- Anderson, V., Brown, S., Newitt, H., & Hoile, H. (2011). Long-term outcome from childhood traumatic brain injury: Intellectual ability, personality, and quality of life. *Neuropsychology, 25*, 176-184. doi:10.1037/a0021217
- Anderson, V., & Catroppa, C. (2005). Recovery of executive skills following paediatric traumatic brain injury (TBI): A 2 year follow up. *Brain Injury, 19*(6), 459-470. doi:10.1080/02699050400004823
- Anderson, V., Catroppa, C., Godfrey, C., & Rosenfeld, G. V. (2012). Intellectual ability 10 years after traumatic brain injury in infancy and childhood: What predicts outcome? *Journal of Neurotrauma, 29*, 143-153. doi:10.1089/neu.2011.2012

- Anderson, V., Catroppa, C., Morse, J. M., Haritou, F., & Rosenfeld, J. (2000). Recovery of intellectual ability following traumatic brain injury in childhood: Impact of injury severity and age at injury. *Pediatric Neurosurgery*, 32(6), 282-290. Retrieved from <http://www.karger.com/PNE>
- Anderson, V., Catroppa, C., Morse, S., Haritou, F., & Rosenfeld, J. (2005). Functional plasticity or vulnerability after early brain injury? *Pediatrics*, 116(6), 1374-1382. doi:10.1542/peds.2004-1728
- Anderson, V., Le Brocque, R., Iselin, G., Eren, S., Dob, R., & Davern, T. J. (2012). Adaptive ability, behavior and quality of life pre and posttraumatic brain injury in childhood. *Disability & Rehabilitation*, 34, 1639-1647. doi:10.3109/096382882012.656789
- Anderson, V., Spencer-Smith, M., & Wood, A. (2011). Do children really recover better? Neurobehavioural plasticity after early brain insult. *Brain*, 134, 2197-2221. doi:10.1093/brain/awr103
- Anderson, V., & Yeates, K. O. (2010). Introduction: Pediatric traumatic brain injury: New frontiers in clinical and translational research. In V. Anderson & K. O. Yeates (Eds.), *Pediatric traumatic brain injury: New frontiers in clinical and translational research* (pp. 1-6). New York: Cambridge University Press.
- Anderson, V. A., Catroppa, C., Haritou, F., Morse, S., & Rosenfeld, J. V. (2005). Identifying factors contributing to child and family outcome 30 months after traumatic brain injury in children. *Journal of Neurology, Neurosurgery & Psychiatry*, 76, 401-408. doi:10.1136/jnnp.2003.019174
- Appleton, R. (2006). Epidemiology- incidence, causes, severity and outcome. In R. Appleton & T. Baldwin (Eds.), *Management of brain injured children* (2nd ed., pp. 1-19). New York: Oxford University Press.
- Appleton, R., Furlong, L., & Baldwin, T. (2006). Head (brain) injury rehabilitation team. In R. Appleton & T. Baldwin (Eds.), *Management of brain injured children* (2nd ed., pp. 41-63). New York: Oxford University Press.
- Arroyos-Jurado, E., Paulsen, J. S., Merrell, K. W., Lindgren, S. D., & Max, J. E. (2000). Traumatic brain injury in school-age children: Academic and social outcome. *Journal of School Psychology*, 38(6), 571-587. doi:10.1016/S0022-4405(00)00053-4
- Arsanow, R. F., Satz, P., Light, R., Lewis, R., & Neumann, E. (1991). Behavior problems and adaptive functioning in children with mild and severe closed head injury. *Journal of Pediatric Psychology*, 16(5), 543-555. doi:10.1093/jpepsy/16.5.543

- Association for the Advancement of Automotive Medicine, & International Injury Scaling Committee. (2008). *Abbreviated Injury Scale (AIS) 2005 © - Update 2008*. Barrington, IL: Author.
- Atwool, N. (n.d.). *Different approaches to child-focused research*. Retrieved 15 October, 2013, from http://www.hrc.govt.nz/sites/default/files/23773%20HRC%20Ethics_1013_online.pdf
- Backhouse, M., & Rodger, S. (1999). The transition from school to employment for young people with acquired brain injury: Parent and student perceptions. *Australian Occupational Therapy Journal*, 46(3), 99-109. doi:10.1046/j.1440-1630.1999.00183.x
- Barbour, R. S. (2001). Checklists for improving rigour in qualitative research: A case of the tail wagging the dog? *BMJ*, 322, 1115-1117. doi:10.1136/bmj.322.7294.1115
- Bargal, D. (2006). Personal and intellectual influences leading to Lewin's paradigm of action research: Towards the 60th anniversary of Lewin's "Action research and minority problems" (1946). *Action Research*, 4, 367-388. doi:10.1177/1476750306070101
- Barker-Collo, S. L., Wilde, N., & Feigin, V. (2009). Trends in head injury incidence in New Zealand: A hospital-based study from 1997/1998 to 2003/2004. *Neuroepidemiology*, 32(1), 32-39. doi:10.1159/000170090
- Batorowicz, B., McDougall, S., & Shepherd, T. A. (2006). AAC and community partnerships: The participation path to community inclusion. *Augmentative and Alternative Communication*, 22(3), 178-195. doi:10.1080/07434610500468498
- Baum, C. (2002). Adolph Meyer's challenge: Focus on occupation in practice and in science. *OTJR: Occupation, Participation & Health*, 22(4), 130-131. Retrieved from <http://www.otjronline.com.ezproxy.aut.ac.nz/>
- Beauchamp, M., Catroppa, C., Godfrey, C., Morse, S., Rosenfeld, J. V., & Anderson, V. (2011). Selective changes in executive functioning ten years after severe childhood traumatic brain injury. *Developmental Neuropsychology*, 36(5), 578-595. doi:10.1080/87565641.2011.555572
- Becker, E., & Dusing, S. (2010). Participation is possible: A case report of integration into a community performing arts program. *Physiotherapy Theory & Practice*, 26(4), 275-280. doi:10.3109/09593980903423137
- Beckung, E., & Hagberg, G. (2002). Neuroimpairments, activity limitations, and participation restrictions in children with cerebral palsy. *Developmental Medicine & Child Neurology*, 44, 309-316. doi:10.1111/j.1469-8749.2002.tb00816.x
- Bedell, G. (2009). Further validation of the Child and Adolescent Scale of Participation (CASP). *Developmental Neurorehabilitation*, 12(5), 342-351. doi:10.1080/17518420903087277

- Bedell, G., & Coster, W. (2008). Measuring participation of school-aged children with traumatic brain injuries: Considerations and approaches. *Journal of Head Trauma Rehabilitation, 23*, 220-229. doi:10.1097/01.HTR.0000327254.61751.e7
- Bedell, G., Coster, W., Law, M., Liljenquist, K., Kao, Y. C., Teplicky, R., ... Khetani, M. A. (2013). Community participation, supports, and barriers of school-age children with and without disabilities. *Archives of Physical Medicine and Rehabilitation, 94*, 315-323. doi:10.1016/j.apmr.2012.09.024
- Bedell, G. M. (2004). Developing a follow-up survey focused on participation of children and youth with acquired brain injuries after discharge from inpatient rehabilitation. *Neurorehabilitation, 19*, 191-205. Retrieved from <http://www.iospress.nl/10538135.php>
- Bedell, G. M., Cohn, E. S., & Dumas, H. M. (2005). Exploring parents' use of strategies to promote social participation of school-age children with acquired brain injuries. *The American Journal of Occupational Therapy, 59*, 273-284. doi:10.5014/ajot.59.3.273
- Bedell, G. M., & Dumas, H. M. (2004). Social participation of children and youth with acquired brain injuries discharged from inpatient rehabilitation: A follow-up study. *Brain Injury, 18*(1), 65-82. doi:10.1080/0269905031000110517
- Bedell, G. M., Haley, S. M., Coster, W. J., & Smith, K. W. (2002a). Developing a responsive measure of change for paediatric brain injury inpatient rehabilitation. *Brain Injury, 16*, 659-671. doi:10.1080/02699050210128924
- Bedell, G. M., Haley, S. M., Coster, W. J., & Smith, K. W. (2002b). Participation readiness at discharge from inpatient rehabilitation in children and adolescents with acquired brain injuries. *Pediatric Rehabilitation, 5*(2), 107-116. doi:10.1080/1363849021000013540
- Bedell, G. M., Khetani, M. A., Cousins, M. A., Coster, W. J., & Law, M. C. (2011). Parent perspectives to inform development of measures of children's participation and environment. *Archives of Physical Medicine & Rehabilitation, 92*, 765-773. doi:10.1016/j.apmr.2010.12.029
- Bendixen, R. M., Senesac, C., Lott, D. J., & Vandenborne, K. (2012). Participation and quality of life in children with Duchenne muscular dystrophy using the International Classification of Functioning, Disability, and Health. *Health & Quality of Life Outcomes, 10*(43), 1-9. doi:10.1186/1477-7525-10-43
- Bentley, J. K. C. (2008). Lessons from the 1%: Children with labels of severe disabilities and their peers as architects of inclusive education. *International Journal of Inclusive Education, 12*(5-6), 543-561. doi:10.1080/13603110802377599
- Bernabe, E. A., & Block, M. E. (1994). Modifying rules of a regular girls softball league to facilitate the inclusion of a child with severe disabilities. *Journal of the Association for*

- Persons with Severe Handicaps (JASH)*, 19(1), 24-31. Retrieved from <http://www.tash.org/publications/RPSD/RPSD.html>
- Best, E. (1934). *The Māori as he was: A brief account of Māori life as it was in pre-European days*. Retrieved from <http://www.nzetc.org/>
- Blackburn, S. (Ed.). (2005). *The Oxford dictionary of philosophy* (2nd ed.). Oxford, UK: Oxford University Press.
- Bloor, M., Frankland, J., Thomas, M., & Robson, K. (2001). *Focus groups in social research*. London: SAGE.
- Bohnert, A. M., Parker, J. G., & Warschausky, S. A. (1997). Friendship and social adjustment of children following a traumatic brain injury: An exploratory investigation. *Developmental Neuropsychology*, 13(4), 477-486. doi:10.1080/87565649709540688
- Bolich, B. J. (2001). Peer tutoring and social behaviors: A review. *International Journal of Special Education*, 6(2), 16-30. Retrieved from <http://www.internationaljournalofspecialeducation.com>
- Bowden, S. (1995). Development of a research tool to enable children to describe their engagement in occupation. *Journal of Occupational Science*, 2, 115-123. doi:10.1080/14427591.1995.9686401
- Boylan, A., Linden, M., & Alderdice, F. (2009). Interviewing children with acquired brain injury (ABI). *Journal of Early Childhood Research*, 7, 264-282. doi:10.1177/1476718X09336970
- Braga, L. W., Da Paz Junior, A. C., & Ylvisaker, M. (2005). Direct clinician-delivered versus indirect family-supported rehabilitation of children with traumatic brain injury: A randomized controlled trial. *Brain Injury*, 19, 819-831. doi:10.1080/02699050500110165
- Brain Injury Association of America. (n.d.). *About brain injury*. Retrieved October 27, 2013, from <http://www.biausa.org>
- Breines, E. (1990). Genesis of occupation: A philosophical model for therapy and theory. *Australian Occupational Therapy Journal*, 37(1), 45-49. Retrieved from <http://www.blackwellpublishing.com.ezproxy.aut.ac.nz/journals/AOT>
- Brenner, L. A., Dise-Lewis, J. E., Bartles, S. K., O'Brian, S. E., Codleski, M., & Selinger, M. (2007). The long-term impact and rehabilitation of pediatric traumatic brain injury: A 50-year follow-up case study. *Journal of Head Trauma Rehabilitation*, 22(1), 56-64. doi:10.1097/00001199-200701000-0000
- Brookman, L., Boettcher, M., Klein, E., Openden, D., Koegel, R. L., & Koegel, L. K. (2003). Facilitating social interactions in a community summer camp setting for children with autism. *Journal of Positive Behavior Interventions*, 5(4), 249. Retrieved from <http://pbi.sagepub.com>

- Brown, C. E. (2009). Ecological models in occupational therapy. In E. B. Crepeau, E. S. Cohn, & B. A. Boyt Schell (Eds.), *Willard & Spackman's occupational therapy* (11th ed., pp. 435-445). Philadelphia, PA: Lippincott Williams & Wilkins.
- Bruce, D. A., Schut, L., & Sutton, L. N. (1984). Brain and cervical spine injuries occurring during organized sports activities in children and adolescents. *Primary Care, 11*(1), 175-194.
- Bult, M. K., Verschuren, O., Jongmans, M. J., Lindeman, E., & Ketelaar, M. (2011). What influences participation in leisure activities of children and youth with physical disabilities? A systematic review. *Research in Developmental Disabilities, 32*, 1521-1529. doi:10.1016/j.ridd.2011.01.045
- Burleigh, S. A., Farber, R. S., & Gillard, M. (1998). Community integration and life satisfaction after traumatic brain injury: Long term findings. *The American Journal of Occupational Therapy, 52*(1), 45-52. doi:10.5014/ajot.52.1.45
- Burns, N., & Grove, S. K. (1993). *The practice of nursing research: Appraisal, synthesis, and generation of evidence* (6th ed.). St Louis, MO: Saunders Elsevier.
- Byard, K., Fine, H., & Reed, J. (2011). Taking a developmental and systemic perspective on neuropsychological rehabilitation with children with brain injury and their families. *Clinical Child Psychology and Psychiatry, 16*, 165-184. doi:10.1177/1359104511403582
- Callaway, L., Sloan, S., & Winkler, D. (2005). Maintaining and developing friendships following severe traumatic brain injury: Principles of occupational therapy practice. *Australian Occupational Therapy Journal, 52*(3), 257-260. doi:10.1111/j.1440-1630.2005.00492.x
- Calley, A., Williams, S., Reid, S., Blair, E., Girdler, S., Valentine, J., & Elliott, C. (2012). A comparison of activity, participation and quality of life in children with and without spastic diplegia cerebral palsy. *Disability and Rehabilitation, 34*, 1306-1310. doi:10.3109/09638288.2011.641662
- Campbell, M., Fitzpatrick, R., Haines, A., Kinmonth, A. L., Sandercock, P., Spiegelhalter, D., & Tyrer, P. (2000). Framework for design and evaluation of complex interventions to improve health. *BMJ, 321*(7262), 694-696. doi:10.1136/bmj.321.7262.694
- Campbell, N. C., Murray, E., Darbyshire, J., Emery, J., Farmer, A., Griffiths, F., ... Kinmonth, A. L. (2007). Designing and evaluating complex interventions to improve health care. *BMJ, 334*, 455-459. doi:10.1136/bmj.39108.379965.BE
- Canadian Association of Occupational Therapists. (n.d.). *Who am I: Jessie Luther*. Retrieved May 29, 2009, from <http://www.caot.ca/default.asp?pageid=1524>
- Carey, M. A., & Asbury, J. (2012). *Focus group research*. Walnut Creek, CA: Left Coast Press.
- Carlson, M. E., & Clark, F. A. (1991). The search for useful methodologies in occupational science. *The American Journal of Occupational Therapy, 45*(3), 235-241. doi:10.5014/ajot.45.3.235

- Carney, J., & Schoenbrodt, L. (1994). Educational implications of traumatic brain injury. *Pediatric Annals*, 23(1), 47-52. Retrieved from <http://www.pediatricsupersite.com/>
- Carrel, A. L., Clark, R. R., Peterson, S., Eickhoff, J., & Allen, D. B. (2007). School-based fitness changes are lost during the summer vacation. *Archives of Pediatrics and Adolescent Medicine*, 161, 561-564. doi:10.1001/archpedi.161.6.561
- Carson, P. (1993). Investing in the comeback: Parent's experience following traumatic brain injury. *Journal of Neuroscience Nursing*, 25(3), 165-173. Retrieved from <http://journals.lww.com/jnnonline/pages/default.aspx>
- Case-Smith, J., Law, M., Missiuna, C., Pollock, N., & Stewart, D. (2010). Foundations for occupational therapy practice with children. In J. Case-Smith & J. C. O'Brien (Eds.), *Occupational therapy for children* (6th ed., pp. 22-55). Maryland Heights, MO: Mosby Elsevier.
- Catroppa, C., & Anderson, V. (1999). Recovery of educational skills following paediatric traumatic brain injury. *Pediatric Rehabilitation*, 3(4), 167-175. doi:10.1080/136384999289432
- Catroppa, C., & Anderson, V. (2010). Pediatric TBI: Challenges for treatment and rehabilitation. In V. Anderson & K. O. Yeates (Eds.), *Pediatric traumatic brain injury: New frontiers in clinical and translational research* (pp. 192-206). New York: Cambridge University Press.
- Catroppa, C., Anderson, V., & Muscara, F. (2009). Rehabilitation of executive skills post-childhood traumatic brain injury (TBI): A pilot intervention study. *Developmental Neurorehabilitation*, 12, 361-369. doi:10.1080/17518420903087335
- Catroppa, C., Anderson, V. A., Morse, S. A., Haritou, F., & Rosenfeld, J. V. (2008). Outcome and predictors of functional recovery 5 years following pediatric traumatic brain injury (TBI). *Journal of Pediatric Psychology*, 33, 707-718. doi:10.1039/jpepsy/jsn006
- Catroppa, C., Anderson, V. A., Muscara, F., Morse, S. A., Haritou, F., Rosenfeld, J. V., & Heinrich, L. M. (2009). Educational skills: Long-term outcome and predictors following paediatric traumatic brain injury. *Neuropsychological Rehabilitation*, 19(5), 716-732. doi:10.1080/09602010902732868
- Causton-Theoharis, J. N. (2009). The golden rule of providing support in inclusive classrooms: Support others as you would wish to be supported. *TEACHING Exceptional Children*, 42(2), 36-43. Retrieved from <http://journals.cec.sped.org/tec/>
- Causton-Theoharis, J. N., & Malmgren, K. W. (2005). Increasing peer interactions for students with severe disabilities via paraprofessional training. *Exceptional Children*, 71(4), 431-444. Retrieved from <http://www.cec.sped.org/>

- Chadwick, O., Rutter, M., Brown, G., Shaffer, D., & Traub, M. (1981). A prospective study of children with head injuries: II. Cognitive sequelae. *Psychological Medicine*, *11*(1), 49-61. Retrieved from <http://journals.cambridge.org/action/displayJournal?jid=PSM>
- Chapman, S. B., McKinnon, L., Levin, H. S., Song, J., Meier, M. C., & Chiu, S. (2001). Longitudinal outcome of verbal discourse in children with traumatic brain injury: Three year follow-up. *Journal of Head Trauma Rehabilitation*, *16*, 441-455. doi:10.1097/00001199-200110000-00004
- Chen, C. C., Heinemann, A. W., Bode, R. K., Granger, C. V., & Mallinson, T. (2004). Impact of pediatric rehabilitation services on children's functional outcomes. *American Journal of Occupational Therapy*, *58*(1), 44-53. doi:10.5014/ajot.58.1.44
- Cherryholmes, C. H. (1992). Notes on pragmatism and scientific realism. *Educational Researcher*, *21*(6), 13-17. doi:10.3102/0013189X021006013
- Chleboun, S., & Hux, K. (2011). Support network responses to acquired brain injury. *The Qualitative Report*, *16*, 764-781. Retrieved from <http://www.nova.edu/ssss/QR/index.html>
- Clark, A., Stedmon, J., & Margison, S. (2008). An exploration of the experience of mothers whose children sustain traumatic brain injury (TBI) and their family. *Clinical Child Psychology and Psychiatry*, *13*(4), 565-583. doi:10.1177/1359104508090607
- Clark, F., & Lawlor, M. C. (2009). The making and mattering of occupational science. In E. B. Crepeau, E. S. Cohn, & B. A. Schell (Eds.), *Willard & Spackman's occupational therapy* (11th ed., pp. 2-14). Philadelphia, PA: Lippincott, Williams & Wilkins.
- Clark, P., & MacArthur, J. (2008). Children with physical disability: Gaps in service provision, problems joining in. *Journal of Paediatrics and Child Health* *44*, 455-458. doi:10.1111/j.1440-1754.2008.01327.x
- Clark, P., MacArthur, J., McDonald, T., Simmons Carlsson, C., & Caswell, P. (2007). *Research project on integrated effective service provision for children and young people with physical disabilities: Two part research project*. Wellington, New Zealand: Ministry of Education New Zealand. Retrieved from www.educationcounts.govt.nz/publications
- Clarke, A. E. (2005). *Situational analysis: Grounded theory after the postmodern turn*. Thousand Oaks, CA: SAGE.
- Classen, S., Winter, S., Awadzi, K. D., Garvan, C. W., Lopez, E. D. S., & Sundaram, S. (2008). Psychometric testing of SPIDER: Data capture tool for systematic literature reviews. *American Journal of Occupational Therapy*, *62*(3), 335-348. doi:10.5014/ajot.62.3.335
- Cody, W. K. (2006). Values-based practice and evidence-based care: Pursuing fundamental questions in nursing philosophy and theory. In W. K. Cody (Ed.), *Philosophical and*

- theoretical perspectives for advanced nursing practice* (4th ed., pp. 5-12). Sudbury, MA: Jones and Bartlett.
- Collings, C. (2007). That's not my child anymore! Parental grief after acquired brain injury (ABI): Incidence, nature and longevity. *British Journal of Social Work*, 38, 1-19. doi:10.1093/bjsw/bcm055
- Colver, A., Thyen, U., Arnaud, C., Beckung, E., Fauconnier, J., Marcelli, M., ... Dickinson, H. O. (2012). Association between participation in life situations of children with cerebral palsy and their physical, social, and attitudinal environment: A cross-sectional multicenter European study. *Archives of Physical Medicine and Rehabilitation*, 93, 2154-2164. doi:10.1016/j.apmr.2012.07.011
- Coppola, S. (2013). Deweyan educational philosophy in occupation-centred curricula. In M. P. Cutchin & V. A. Dickie (Eds.), *Transactional perspectives on occupation* (pp. 199-213). New York: Springer. doi:10.1007/978-94-007-4429-5_16
- Corbin, J., & Strauss, A. (2008). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (3rd ed.). Thousand Oaks, CA: Sage.
- Coster, W., Bedell, G., Law, M., Khetani, M. A., Teplicky, R., Liljenquist, K., ... Kao, Y. C. (2011). Psychometric evaluation of the Participation and Environment Measure for Children and Youth. *Developmental Medicine & Child Neurology*, 53, 1030-1037. doi:10.1111/j.1469-8749.2011.04094.x
- Coster, W., Law, M., Bedell, G., Khetani, M. A., Cousins, M. A., & Teplicky, R. (2012). Development of the participation and environment measure for children and youth: Conceptual basis. *Disability & Rehabilitation*, 34, 238-246. doi:10.3109/09638288.2011.603017
- Coster, W., Law, M., Bedell, G., Liljenquist, K., Kao, Y. C., Khetani, M. A., & Teplicky, R. (2013). School participation, supports and barriers of students with and without disabilities. *Child: Care, Health & Development*, 39, 535-543. doi:10.1111/cch.12046
- Coster, W. J., & Khetani, M. A. (2007). Measuring participation of children with disabilities: Issues and challenges. *Disability and Rehabilitation*, 30(8), 639-648. doi:10.1080/09638280701400375
- Cresswell, J. W. (2007). *Qualitative inquiry and research design: Choosing among five approaches* (2nd ed.). Thousand Oaks, CA: SAGE.
- Cresswell, J. W., & Plano Clark, V. L. (2007). *Designing and conducting mixed methods research*. Thousand Oaks, CA: Sage.
- Crothers, I. R., Linden, M. A., & Kennedy, N. (2007). Attitudes of children towards peers with acquired brain injury (ABI). *Brain Injury*, 21, 47-52. doi:10.1080/02699050601149054

- Crotty, M. (1998). *The foundations of social research: Meaning and perspective in the research process*. St Leonards, Australia: Allen & Unwin.
- Crowe, L. M., Catroppa, C., Babl, F. E., & Anderson, V. (2013). Executive function outcomes of children with traumatic brain injury sustained before three years. *Child Neuropsychology*, *19*(2), 113-126. doi:10.1080/09297049.2011.651079
- Crowe, L. M., Catroppa, C., Babl, F. E., Rosenfeld, J. V., & Anderson, V. (2012). Timing of traumatic brain injury in childhood and intellectual outcome. *Journal of Pediatric Psychology*, *37*(7), 745-754. doi:10.1093/jpepsy/jss070
- Curtin, M., & Murtagh, J. (2007). Participation of children and young people in research: Competence, power and representation. *British Journal of Occupational Therapy*, *70*, 67-72. Retrieved from <https://www.cot.co.uk/british-journal-bjot/british-journal-occupational-therapy>
- Cutchin, M. P. (2004). Using Deweyan philosophy to rename and reframe adaptation to environment. *The American Journal of Occupational Therapy*, *58*, 303-312. doi:10.5014/ajot.58.3.303
- Cutchin, M. P. (2007). From society to self (and back) through place: Habit in transactional context. *OTJR: Occupation, Participation & Health*, *27*, 50S-59S. Retrieved from <http://www.otjronline.com.ezproxy.aut.ac.nz/>
- Cutchin, M. P., & Dickie, V. A. (Eds.). (2013). *Transactional perspectives on occupation*. New York: Springer. doi:10.1007/978-94-007-4429-5
- Daley, B. J. (1996). Concept maps: Linking nursing theory to clinical nursing practice. *The Journal of Continuing Education in Nursing*, *27*(1), 17-27. Retrieved from <http://www.jcenonline.com>
- Dalton, T. C. (2002). *Becoming John Dewey: Dilemmas of a philosopher and naturalist*. Bloomington, IN: Indiana University Press.
- Darrah, J., Law, M. C., Pollock, N., Wilson, B., Russell, D. J., Walter, S. D., ... Galupp, B. (2011). Context therapy: A new intervention approach for children with cerebral palsy. *Developmental Medicine & Child Neurology*, *53*, 615-620. doi:10.1111/j.1469-8749.2011.03959.x
- DeMatteo, C. A., Cousins, M. A., Lin, C. A., Law, M. C., Colantonio, A., & Macarthur, C. (2008). Exploring postinjury living environments for children and youth with acquired brain injury. *Archives of Physical Medicine and Rehabilitation*, *89*, 1803-1810. doi:10.1016/j.apmr.2008.02.025

- Dennis, M. (2010). Margaret Kennard (1899–1975): Not a ‘principle’ of brain plasticity but a founding mother of developmental neuropsychology. *Cortex*, 46, 1043-1059. doi:10.1016/j.cortex.2009.10.008
- Dewey, J. (1902). *The child and the curriculum*. Chicago: The University of Chicago Press. Retrieved from <http://archive.org/details/childandcurricul00deweuoft>
- Dewey, J. (1907). *The school and society*. Chicago, IL: Chicago University Press. Retrieved from http://www.brocku.ca/MeadProject/Dewey/Dewey_1907/Dewey_1907a.html
- Dewey, J. (1916). *Democracy and education: An introduction to the philosophy of education*. Retrieved from http://en.wikisource.org/wiki/Democracy_and_Education
- Dewey, J. (1949). Common sense and science. In J. Dewey & A. F. Bentley (Eds.), *Knowing and the known* (pp. 270-286). Boston, MA: The Beacon Press.
- Dewey, J. (1981). Experience and nature. In J. A. Boydston (Ed.), *John Dewey: The later works, 1925-1953* (Vol. 1). Carbondale, IL: Southern Illinois University Press. (Original work published 1925)
- Dewey, J. (1982). The public and its problems. In J. A. Boydston (Ed.), *John Dewey: The later works, 1925-1953* (Vol. 2). Carbondale, IL: Southern Illinois University Press. (Original work published 1927)
- Dewey, J. (1988). The quest for certainty: A study of the relation of knowledge and action. In J. A. Boydston (Ed.), *John Dewey: The later works, 1925-1953* (Vol. 4). Carbondale, IL: Southern Illinois University Press. (Original work published 1929)
- Dewey, J. (1988). Time and individuality. In J. A. Boydston (Ed.), *John Dewey: The later works, 1925-1953: Essays, reviews, and miscellany* (Vol. 14, pp. 98-114). Carbondale, IL: Southern Illinois University Press. (Original work published 1939)
- Dewey, J. (1998). Creative democracy: The task before us. In L. A. Hickman & T. M. Alexander (Eds.), *The essential Dewey: Pragmatism, education, democracy* (Vol. 1, pp. 340-343). Bloomington, IN: Indiana University Press. (Original work published 1939)
- Dewey, J. (1998). The moral training given by the school community. In L. A. Hickman & T. M. Alexander (Eds.), *The essential Dewey: Volume 1: Pragmatism, education, democracy* (pp. 246-249). Bloomington, IN: Indiana University Press. (Original work published 1909)
- Dewey, J. (1998). What I believe. In L. A. Hickman & T. M. Alexander (Eds.), *The essential Dewey: Volume 1: Pragmatism, education, democracy* (pp. 22-28). Bloomington, IN: Indiana University Press. (Original work published 1930)
- Dewey, J. (2005). Common sense and science: Their respective frames of reference. In N. Stehr & R. Grundmann (Eds.), *Volume II. Knowledge and society: Forms of knowledge*. (pp. 3-13). New York: Routledge. (Original work published 1948)

- Dewey, J. (2007). *Human nature and conduct: An introduction to social psychology*. New York: Cosimo (1922)
- Dewey, J. (2008a). Experience and education. In J. A. Boydston (Ed.), *John Dewey: The later works, 1925-1953: Experience and education, freedom and culture, theory of valuation, and essays* (Vol. 13, 1938-1939, pp. 1-62). Carbondale, IL: Southern Illinois University Press. (Original work published 1938)
- Dewey, J. (2008). Importance, significance, and meaning. In J. A. Boydston (Ed.), *John Dewey: The later works, 1925-1953* (Vol. 16, pp. 318-332). Carbondale, IL: Southern Illinois University Press. (Original work published 1949)
- Dewey, J. (2008b). Logic: The theory of inquiry. In J. A. Boydston (Ed.), *John Dewey: The later works, 1925-1953* (Vol. 12). Carbondale, IL: Southern Illinois University Press. (Original work published 1938)
- Dewey, J., & Bentley, A. F. (1949a). Interaction and transaction. In J. Dewey & A. F. Bentley (Eds.), *Knowing and the known* (pp. 103-118). Boston, MA: Beacon.
- Dewey, J., & Bentley, A. F. (1949b). A trial group of names. In J. Dewey & A. F. Bentley (Eds.), *Knowing and the known* (pp. 287-306). Boston, MA: Beacon Press.
- Dewey, J., & Bentley, A. F. (Eds.). (1949c). *Knowing and the known*. Boston, MA: Beacon.
- Dey, I. (2007). Grounding categories. In A. Bryant & K. Charmaz (Eds.), *The Sage handbook of grounded theory* (pp. 167-190). London, United Kingdom: Sage.
- DeZonia, K. (2009). Mobility: Not just the ability to move: Tips for gaining acceptance and moving toward community connections. *Exceptional Parent*, 39(5), 30-31. Retrieved from <http://www.eparent.com/>
- Dickie, V., Cutchin, M. P., & Humphry, R. (2006). Occupation as transactional experience: A critique of individualism in occupational science. *Journal of Occupational Science*, 13(1), 83-93. doi:10.1080/14427591.2006.9686573
- Dijkers, M. P. J. M., & The Task Force on Systematic Reviews and Guidelines. (2009). The value of "traditional" reviews in the era of systematic reviewing. *American Journal of Physical Medicine & Rehabilitation*, 88(5), 423-430. doi:10.1097/PHM.0b013e31819c59c6
- Dillman, D. A. (2007). *Mail and internet surveys: The tailored design method* (2nd ed.). Hoboken, NJ: John Wiley & Sons.
- Dise-Lewis, J. E., Calvery, M. L., & Lewis, H. C. (2002). *Brain STARS: Brain injury: Strategies for teams and re-education for students*. Denver, CO: The BrainSTARS Program.
- Dixon-Woods, M., Sutton, A., Shaw, R., Miller, T., Smith, J., Young, B., ... Jones, A. (2007). Appraising qualitative research for inclusion in systematic reviews: A quantitative and

- qualitative comparison of three methods. *Journal of Health Services Research & Policy*, 12(1), 42-47. doi:10.1258/135581907779497486
- Doble, S. E., & Magill-Evans, J. (1992). A model of social interaction to guide occupational therapy practice. *Canadian Journal of Occupational Therapy*, 59, 141-150. doi: 10.1177/000841749205900304
- Donaldson, S. J., & Ronan, K. R. (2006). The effects of sports participation on young adolescents' emotional well-being. *Adolescence*, 41(162), 369-390. Retrieved from http://www.vjf.cnrs.fr/clt/php/va/Page_revue.php?ValCodeRev=ADO
- Donders, J., & Warschausky, S. (2007). Neurobehavioral outcomes after early versus late childhood traumatic brain injury. *Journal of Head Trauma Rehabilitation*, 22, 296-302. doi:10.1097/01.HTR.0000290974.01872.82
- Douglas, J. M. (2013). Conceptualizing self and maintaining social connection following severe traumatic brain injury. *Brain Injury*, 27(1), 60-74. doi:10.3109/02699052.2012.722254
- Dumas, H. M., Bedell, G. M., & Hamill, M. S. (2003). Strategies to promote activity and participation in children and youths with acquired brain injuries. *International Journal of Rehabilitation Research*, 26(4), 303-308. doi:10.1097/01.mrr.0000102063.48781.fe
- Dumas, H. M., & Carey, T. (2002). Motor skill and mobility recovery outcomes of children and youth with traumatic brain injury. *Physical and Occupational Therapy in Pediatrics*, 22(3-4), 73-99. doi:10.1080/J006v22n03_06
- Dunn, W., Brown, C., & McGuigan, A. (1994). The ecology of human performance: A framework for considering the effect of context. *American Journal of Occupational Therapy*, 48, 595-607. Retrieved from <http://ajot.aotapress.net/> doi:10.5014/ajot.48.7.595
- Dunn, W., Brown, C., & Younstrom, M. (2003). Ecological model of occupation. In P. Kramer, J. Hinojosa, & C. B. Royeen (Eds.), *Perspectives on human occupation: Participation in life* (pp. 222-262). Philadelphia: Lippincott Williams & Wilkins.
- Durie, M. (1998). *Whaiora: Māori health development* (2nd ed.). Melbourne, Australia: Oxford University Press.
- Edwards, P., Roberts, I., Clarke, M., DiGuseppi, C., Pratap, S., Wentz, R., & Kwan, I. (2002). Increasing response rates to postal questionnaires: Systematic review. *BMJ*, 324(7347), 1183-1185. doi:10.1136/bmj.324.7347.1183
- Egilson, S. T., & Hemmingsson, H. (2009). School participation of pupils with physical and psychosocial limitations: A comparison. *The British Journal of Occupational Therapy*, 72(4), 144-152. Retrieved from [http://www.cot.co.uk/Homepage/Library_and_Publications/British_Journal_of_Occupational_Therapy_\(BJOT\)/](http://www.cot.co.uk/Homepage/Library_and_Publications/British_Journal_of_Occupational_Therapy_(BJOT)/)

- Egilson, S. T., & Traustadottir, R. (2009). Participation of students with physical disabilities in the school environment. *American Journal of Occupational Therapy*, 63(3), 264-272. doi:10.5014/ajot.63.3.264
- Elardo, R., Bradley, R., & Caldwell, B. M. (1977). A longitudinal study of the relation of infants' home environments to language development at age three. *Child Development*, 48(2), 595-603. Retrieved from <http://www.wiley.com/bw/journal.asp?ref=0009-3920>
- Elder, H. (2012). An examination of Māori tamariki (child) and taiohi (adolescent) traumatic brain injury within a global cultural context. *Australasian Psychiatry*, 20(1), 20-23. doi:10.1177/1039856211430147
- Elder, H. (2013). Te Waka Oranga: An indigenous intervention for working with Māori children and adolescents with traumatic brain injury. *Brain Impairment*, 14, 415-424. doi:10.1017/BrImp.2013.29
- Elliott, S. N., & Gresham, F. M. Children's social skills: Assessment and classification practices. *Journal of Counseling and Development*, 66, 96-99. doi: 10.1002/j.1556-6676.1987.tb00808.x
- Emanuelson, I., Von Wendt, L., Beckung, E., & Hagberg, I. (1998). Late outcome after severe traumatic brain injury in children and adolescents. *Pediatric Rehabilitation*, 2, 65-70. doi:10.3109/17518429809068157
- Engel-Yeger, B., Jarus, T., Anaby, D., & Law, M. (2009). Differences in patterns of participation between youths with cerebral palsy and typically developing peers. *American Journal of Occupational Therapy*, 63(1), 96-104. doi:10.5014/ajot.63.1.96
- Engeström, Y. (1999). Activity theory and individual and social transformation. In Y. Engeström, R. Miettinen, & R.-L. Punamäki (Eds.), *Perspectives on activity theory* (pp. 19-38). Cambridge, UK: Cambridge University Press.
- Engeström, Y., & Miettinen, R. (1999). Introduction. In Y. Engeström, R. Miettinen, & R.-L. Punamäki (Eds.), *Perspectives on activity theory* (pp. 1-16). Cambridge, UK: Cambridge University Press.
- Enkin, M. W., & Jadad, A. R. (1998). Using anecdotal information in evidence-based health care: Heresy or necessity? *Annals of Oncology*, 9(9), 963-966. doi:10.1023/A:1008495101125
- Eriks-Brophy, A., Durieux-Smith, A., Olds, J., Fitzpatrick, E., Duquette, C., & Whittingham, J. (2007). Facilitators and barriers to the integration of orally educated children and youth with hearing loss into their families and communities. *The Volta Review*, 107(1), 5-36. Retrieved from <http://nc.agbell.org/NetCommunity/Page.aspx?pid=501>
- Eriksson, L. (2005). The relationship between school environment and participation for students with disabilities. *Pediatric Rehabilitation*, 8(2), 130-139. doi:10.1080/13638490400029977

- Eriksson, L., Welander, J., & Granlund, M. (2007). Participation in everyday school activities for children with and without disabilities. *Journal of Developmental and Physical Disabilities, 19*(5), 485-502. doi:10.1007/s10882-007-9065-5
- Ewing-Cobbs, L., Levin, H. S., & Fletcher, J. M. (1998). Neuropsychological sequelae after pediatric traumatic brain injury: Advances since 1985. In M. Ylvisaker (Ed.), *Traumatic brain injury rehabilitation: Children and adolescents*. (2nd ed., pp. 11-26). Newton: Butterworth-Heinemann.
- Fadyl, J. K., & McPherson, K. M. (2009). Approaches to vocational rehabilitation after traumatic brain injury: A review of the evidence. *Journal of Head Trauma Rehabilitation, 24*(3), 195-212. Retrieved from <http://www.headtraumarehab.com>
- Faleafa, M. (2009). Community rehabilitation outcomes across cultures following traumatic brain injury. *Pacific Health Dialogue, 15*(1), 28-34. Retrieved from www.pacifichealthdialog.org.fj/
- Fama, T. (1937). Māori Fishing. *The New Zealand Railways Magazine, 11*(11), 45. Retrieved from <https://web.archive.org/web/2/http://nzetc.victoria.ac.nz/>
- Families USA. (2006a). *No shelter from the storm: America's uninsured children*. Washington DC: Campaign for Children's Health Care. Retrieved from www.children'shealthcampaign.org
- Families USA. (2006b). *No shelter from the storm: America's uninsured children*. Retrieved June 20, 2008, from <http://www.children'shealthcampaign.org/tools/reports/Uninsured-Kids-report.PDF>
- Farmer, J. E., & Johnson-Gerard, M. (1997). Misconceptions about traumatic brain injury among educators and rehabilitation staff: A comparative study. *Rehabilitation Psychology, 42*, 273-286. Retrieved from <http://www.apa.org/pubs/journals/rep/index.aspx>
- Fay, G. C., Jaffe, K. M., Polissar, N. L., Liao, S., Rivara, J. B., & Martin, K. M. (1994). Outcome of pediatric traumatic brain injury at 3 years: A cohort study. *Archives of Physical Medicine and Rehabilitation, 75*, 733-741. Retrieved from <http://www.archives-pmr.org/>
- Fay, T., & Barker-Collo, S. (2003). Sibling behaviours and relationships following mild to moderate childhood traumatic brain injury: Preliminary findings. *Brain Impairment, 4*, 91-105. Retrieved from <http://journals.cambridge.org/action/displayJournal?jid=BIM>
- Fay, T. B., Yeates, K. O., Wade, S. L., Drotar, D., Stancin, T., & Taylor, G. H. (2009). Predicting longitudinal patterns of functional deficits in children with traumatic brain injury. *Neuropsychology, 23*, 271-282. doi:10.1037/a0014936
- Feeney, T., & Ylvisaker, M. (2006). Context-sensitive cognitive-behavioral supports for young children with TBI: A replication study. *Brain Injury, 20*, 629-645. doi:10.1080/02699050600744194

- Feeney, T. J., & Ylvisaker, M. (2003). Context-sensitive behavioral supports for young children with TBI: Short-term effects and long-term outcome. *Journal of Head Trauma Rehabilitation, 18*(1), 33-51. Retrieved from <http://journals.lww.com/headtraumarehab> doi:10.1097/00001199-200301000-00006
- Feeney, T. J., & Ylvisaker, M. (2008). Context-sensitive cognitive-behavioral supports for young children with TBI: A second replication study. *Journal of Positive Behavior Interventions, 10*, 115-128. doi:10.1177/1098300707312540
- Feigin, V. L., Theadom, A., Barker-Collo, S., Starkey, N. J., McPherson, K., Kahan, M., ... Ameratunga, S. (2013). Incidence of traumatic brain injury in New Zealand: A population-based study. *The Lancet Neurology, 12*, 53-64. doi:10.1016/S1474-4422(12)70262-4
- Fennick, E., & Royle, J. (2003). Community inclusion for children and youth with developmental disabilities. *Focus on Autism and Other Developmental Disabilities, 18*(1), 20-27. doi:10.1177/108835760301800104
- Fernando, K., Eaton, L., Faulkner, M., Moodley, Y., & Setchell, R. (2002). Development and piloting of the Starship Post-traumatic Amnesia Scale for children aged between four and six years. *Brain Impairment, 3*(1), 34-41. Retrieved from <http://journals.cambridge.org/action/displayJournal?jid=BIM>
- Fineout-Overholt, E., & Melnyk, B. (2005). Building a culture of best practice. *Nurse Leader, 3*(6), 26-30. doi:10.1016/j.mnl.2005.09.007
- Fisher, A., & Griswold, L. A. (2014). Performance skills: Implementing performance analyses to evaluate quality of occupational performance. In B. A. Boyt Schell, G. Gillen, & M. E. Scaffa (Eds.), *Willard & Spackman's occupational therapy* (12th ed., pp. 249-264). Baltimore, MD: Wolters Kluwer Health/Lippincott Williams & Wilkins.
- Fisher, A., Reilly, J. J., Kelly, L. A., Montgomery, C., Williamson, A., Paton, J. Y., & Grant, S. (2005). Fundamental movement skills and habitual physical activity in young children. *Medicine and Science in Sports and Exercise, 37*, 684-688. doi:10.1249/01.MSS.0000159138.48107.7D
- Fisher, A. G., & Griswold, L. A. (2010). *Evaluation of social interaction* (2nd ed.). Fort Collins, CO: Three Star Press.
- Fisher, A. G., & Kielhofner, G. (1995). Skill in occupational performance. In G. Kielhofner (Ed.), *A model of human occupation: Theory and application* (2nd ed., pp. 113-137). Baltimore: Williams & Wilkins.
- Fisher, E. P. (1992). The impact of play on development: A meta-analysis. *Play and Culture, 5*, 159-181. doi:apa.org/?uid=1992-42498-001

- Fletcher, J. M., Ewing-Cobbs, L., & Francis, D. J. (1995). Variability in outcomes after traumatic brain injury in children: A developmental perspective. In S. H. Broman & M. E. Michel (Eds.), *Traumatic head injury in children* (pp. 3-21). New York: Oxford University Press.
- Fletcher, J. M., Ewing-Cobbs, L., Miner, M. E., Levin, H. S., & Eisenberg, H. M. (1990). Behavioral changes after closed head injury in children. *Journal of Consulting and Clinical Psychology, 58*(1), 93-98. doi:10.1037/0022-006X.58.1.93
- Foo, W. S., Galvin, J., & Olsen, J. (2012). Participation of children with ABI and the relationship with discharge functional status. *Developmental Neurorehabilitation, 15*(1), 1-12. doi:10.3109/7518423.2011.623142
- Forest, M., & Lusthaus, E. (1989). Promoting educational equality for all students: Circles and maps. In S. Stainback, W. Stainback, & M. Forest (Eds.), *Educating all students in the mainstream of regular education* (pp. 43-57). Baltimore, MD: Paul H. Brookes.
- Forsyth, K., Lai, J.-S., & Kielhofner, G. (1999). The Assessment of Communication and Interaction Skill (ACIS): Measurement properties. *The British Journal of Occupational Therapy, 62*, 69-74. Retrieved from <https://www.cot.co.uk/british-journal-bjot/british-journal-occupational-therapy>
- Forsyth, R., Colver, A., Alvanides, S., Woolley, M., & Lowe, M. (2007). Participation of young severely disabled children is influenced by their intrinsic impairments and environment. *Developmental Medicine & Child Neurology, 49*(5), 345-349. doi:10.1111/j.1469-8749.2007.00345.x
- Forsyth, R. J., Kelly, T. P., Wicks, B., & Walker, S. (2005). 'Must try harder?': A family empowerment intervention for acquired brain injury. *Pediatric Rehabilitation, 8*(2), 140-143. doi:10.1080/13638490400023996
- Foster, M. A., & Carlson-Green, B. (1993). The transition from hospital to home: Family readjustment and response to therapeutic intervention following childhood-acquired brain injury. *Family Systems Medicine, 11*, 173-180. doi:10.1037/h0089055
- Frederickson, N., & Turner, J. (2003). Utilizing the classroom peer group to address children's social needs: An evaluation of the circle of friends intervention approach. *Journal of Special Education, 36*(4), 234-245. doi:10.1177/002246690303600404
- Fulgini, A., & Stevenson, H. (1995). Time use and mathematics achievement among American, Chinese, and Japanese high school students. *Child Development, 66*, 830-842. doi:10.1111/j.1467-8624.1995.tb00908.x
- Galvin, J., Froude, E. H., & McAleer, J. (2010). Children's participation in home, school and community life after acquired brain injury. *Australian Occupational Therapy Journal, 57*(2), 118-126. doi:10.1111/j.1440-1630.2009.00822.x

- Gardner, R. M., Bird, F. L., Maguire, H., Carreiro, R., & Abenaim, N. (2003). Intensive positive behavior supports for adolescents with acquired brain injury: Long-term outcomes in community settings. *Journal of Head Trauma Rehabilitation, 18*, 52-74. Retrieved from <http://journals.lww.com/headtraumarehab>
- Gauvin-Lepage, J., & Lefebvre, H. (2010). Social inclusion of persons with moderate head injuries: The points of view of adolescents with brain injuries, their parents and professionals. *Brain Injury, 24*(9), 1087-1097. doi:10.3109/02699052.2010.494593
- George, A. L., & Bennett, A. (2005). *Case studies and theory development in the social sciences*. Cambridge, MA: Belfer Center for Science and International Affairs, John F. Kennedy School of Government, Harvard University.
- Gerring, J. (2007). *Case study research: Principles and practices*. New York: Cambridge University Press.
- Gerring, J. P., Grados, M. A., Slomine, B. S., Christensen, J. R., Salorio, C. F., Cole, W. R., & Vasa, R. A. (2009). Disruptive behaviour disorders and disruptive symptoms after severe paediatric traumatic brain injury. *Brain Injury, 23*, 944-955. doi:10.3109/02699050903285531
- Gerring, J. P., & Wade, S. (2012). The essential role of psychosocial risk and protective factors in pediatric traumatic brain injury research. *Journal of Neurotrauma, 29*, 621-628.
- Gfroerer, S. D., Wade, S. L., & Wu, M. (2008). Parent perceptions of school-based support for students with traumatic brain injuries. *Brain Injury, 22*, 649-656. doi:10.1080/02699050802227162
- Ghaffarpasand, F., Razmkon, A., & Dehghankhalili, M. (2013). Glasgow Coma Scale score in pediatric patients with traumatic brain injury; Limitations and reliability. *Bulletin of Emergency and Trauma, 1*, 135-136. Retrieved from <http://beat-journal.com/index.php/BEAT>
- Gill, D. J., & Wells, D. L. (2000). Forever different: Experiences of living with a sibling who has a traumatic brain injury. *Rehabilitation Nursing, 25*, 48-53. Retrieved from [http://onlinelibrary.wiley.com/journal/10.1002/\(ISSN\)2048-7940](http://onlinelibrary.wiley.com/journal/10.1002/(ISSN)2048-7940)
- Giza, C. C., Griesbach, G. S., & Hovda, D. A. (2005). Experience-dependent behavioral plasticity is disturbed following traumatic injury to the immature brain. *Behavioural Brain Research, 157*(1), 11-22. doi:10.1016/j.bbr.2004.06.003
- Glang, A., Todis, B., Cooley, E., Wells, J., & Voss, J. (1997). Building social networks for children and adolescents with traumatic brain injury: A school-based intervention. *Journal of Head Trauma Rehabilitation, 12*(2), 32-47. Retrieved from <http://www.headtraumarehab.com>

- Glang, A., Todis, B., Sublette, P., Eagan Brown, B., & Vaccaro, M. (2010). Professional development in TBI for educators: The importance of context. *Journal of Head Trauma Rehabilitation, 25*, 426-432. doi:10.1097/HTR.0b013e3181fb8f45
- Glang, A., Todis, B., Thomas, C., Hood, D., Bedell, G., & Cockrell, J. (2008). Return to school following childhood TBI: Who gets services? *NeuroRehabilitation, 23*(6), 477-486. Retrieved from <http://www.iospress.nl>
- Glang, A., Tyler, J. S., Pearson, S., Todis, B., & Morvant, M. (2004). Improving educational services for students with TBI through statewide consulting teams. *NeuroRehabilitation, 19*(3), 219-231. Retrieved from <http://www.iospress.nl>
- Glick, J. (2004). The history of the development of higher mental functions. In R. W. Rieber & D. K. Robinson (Eds.), *The essential Vygotsky* (pp. 345-400). New York: Kluwer Academic/Plenum.
- Godeau, E., Vignes, C., Sentenac, M., Ehlinger, V., Navarro, F., Grandjean, H., & Arnaud, C. (2010). Improving attitudes towards children with disabilities in a school context: A cluster randomized intervention study. *Developmental Medicine & Child Neurology, 52*(10), e236-e242. doi:10.1111/j.1469-8749.2010.03731.x
- Goetz, L., & O'Farrell, N. (1999). Connections: Facilitating social supports for students with deaf-blindness in general education classrooms. *Journal of Visual Impairment & Blindness, 93*(11), 704-715. Retrieved from <http://www.afb.org/Section.asp?SectionID=54&DocumentID=4575>
- Goldsmith, M. R., Bankhead, C. R., & Austoker, J. (2007). Synthesising quantitative and qualitative research in evidence-based patient information. *Journal of Epidemiology and Community Health, 61*, 262-270. doi:10.1136/jech.2006.046110
- Gorman, S., Barnes, M. A., Swank, P. R., Prasad, M., & Ewing-Cobbs, L. (2012). The effects of pediatric traumatic brain injury on verbal and visual-spatial working memory. *Journal of the International Neuropsychological Society, 18*(1), 29-38. doi:10.1017/S1355617711001251
- Grady, C. (2001). Money for research participation: Does it jeopardize informed consent? *The American Journal of Bioethics, 1*(2), 40-44. doi:10.1162/152651601300169031
- Graham, F., Rodger, S., & Ziviani, J. (2010). Enabling occupational performance of children through coaching parents: Three case reports. *Physical and Occupational Therapy in Pediatrics, 30*(1), 4-15. doi:10.3109/01942630903337536
- Granlund, M., Arvidsson, P., Nii, A., Bjorck-Akesson, E., Simeonsson, R., Maxwell, G., ... Pless, M. (2012). Differentiating activity and participation of children and youth with disability in Sweden: A third qualifier in the International Classification of Functioning, Disability, and

- Health for Children and Youth? *American Journal of Physical Medicine & Rehabilitation*, 19(13 supplement 1), S84-96. doi:10.1097/PHM.0b013e31823d5376
- Gray, J., Agnihotri, S., Keightley, M., Colantonio, A., James, J., & Morin, S. (2011). An arts-based approach to co-facilitation of a theatre programme for teenagers with acquired brain injury. *Journal of Applied Arts & Health*, 2, 221-235. doi:10.1386/jaah.2.3.221_1
- Green, S. M. (2011). Cheerio laddie! Bidding farewell to the Glasgow Coma Scale. *Annals of Emergency Medicine*, 58, 427-430. doi:10.1016/j.annemerg.med.2011.06.009
- Greene, J. C., & Caracelli, V. J. (2003). Making paradigmatic sense of mixed methods practice. In A. Tashakkori & C. Teddlie (Eds.), *Handbook of mixed methods in social and behavioral research* (pp. 91-110). Thousand Oaks, CA: SAGE.
- Greenwood, D. J. (2007). Pragmatic action research. *International Journal of Action Research*, 3, 131-148. Retrieved from http://www.hampp-verlag.de/hampp_e-journals_IJAR.htm
- Greenwood, D. J., & Levin, M. (1998). *Introduction to action research: Social research for social change*. Thousand Oaks, CA: SAGE.
- Greenwood, D. J., & Levin, M. (2007). *Introduction to action research: Social research for social change* (2nd ed.). Thousand Oaks, CA: SAGE.
- Greenwood, D. J., & Levin, M. (2008). Reform of the social sciences and of universities through action research. In N. K. Denzin & Y. S. Lincoln (Eds.), *The landscape of qualitative research* (3rd ed., pp. 57-86). Thousand Oaks, CA: SAGE.
- Gresham, F. M., & Elliott, S. N. (1990). *Social Skills Rating System manual*. Circle Pines, MN: American Guidance Service.
- Griswold, L. A., & Townsend, S. (2012). Assessing the sensitivity of the Evaluation of Social Interaction: Comparing social skills in children with and without disabilities. *American Journal of Occupational Therapy*, 66, 709-717. doi.org/10.5014/ajot.2012.00405
- Guba, E. G., & Lincoln, Y. S. (1989). *Fourth generation evaluation*. Newbury Park, CA: SAGE.
- Hagedorn, R. (1992). *Occupational therapy: Foundations for practice: Models, frames of reference and core skills*. Edinburgh: Churchill Livingstone.
- Haley, S. M., Coster, W. J., Ludlow, L. H., Haltiwanger, J., & Andrello, P. (1992). *Administration manual for the Pediatric Evaluation of Disability Inventory*. Boston: New England Medical Centre.
- Haley, S. M., Dumas, H. M., Rabin, J. P., & Ni, P. (2003). Early recovery of walking in children and youths after traumatic brain injury. *Developmental Medicine and Child Neurology*, 45(10), 671-675. doi:10.1111/j.1469-8749.2003.tb00869

- Hammal, D. (2004). Participation of children with cerebral palsy is influenced by where they live. *Developmental Medicine & Child Neurology*, 46(5), 292-298. doi:10.1111/j.1469-8749.2004.tb00488.x
- Hammel, J., Magasi, S., Heinemann, A., Whiteneck, G., Bogner, J., & Rodriguez, E. (2008). What does participation mean? An insider perspective from people with disabilities. *Disability and Rehabilitation*, 30(19), 1445-1460. doi:10.1080/09638280701625534
- Hammer, C. S., & Weiss, A. L. (2000). African American mothers' views of their infants' language development and language-learning environment. *American Journal of Speech-Language Pathology*, 9(2), 126-140. Retrieved from <http://ajslp.asha.org/>
- Hammersley, M., & Gomm, R. (2000). Introduction. In R. Gomm, M. Hammersley, & P. Foster (Eds.), *Case study method: Key issues, key texts* (pp. 1-16). London: SAGE.
- Harding, J., Harding, K., Jamieson, P., Mullally, M., Politi, C., Wong-Sing, E., ... Petrenchik, T. (2009). Children with disabilities' perceptions of activity participation and environments: A pilot study. *The Canadian Journal of Occupational Therapy*, 76(3), 133-145. Retrieved from <http://www.sagepub.com.ezproxy.aut.ac.nz/journals/Journal202151>
- Haring, T. G., & Breen, C. G. (1992). A peer-mediated social network intervention to enhance the social integration of persons with moderate and severe disabilities. *Journal of Applied Behavior Analysis*, 25(2), 319-333. doi:10.1901/jaba.1992.25-319
- Harper, D. (1992). Small N's and community case studies. In C. C. Ragin & H. W. Becker (Eds.), *What is a case? Exploring the foundations of social inquiry* (pp. 139-158). Cambridge: Cambridge University Press.
- Harper, G. F., Maheady, L., Mallette, B., & Karnes, M. (1999). Peer tutoring and the minority child with disabilities. *Preventing School Failure*, 43(2), 45-51. doi:10.1080/10459889909603301
- Harrower, J. K. (1999). Educational inclusion of children with severe disabilities. *Journal of Positive Behavior Interventions*, 1(4), 215-230. doi: 10.1177/109830079900100404
- Harrower, J. K., & Dunlap, G. (2001). Including children with Autism in general education classrooms. *Behavior Modification*, 25(5), 762-784. doi:10.1177/0145445501255006
- Hart, B., & Risley, T. R. (1995). *Meaningful differences in the everyday experience of young American children*. Baltimore, MD: Brookes.
- Harvey, A. G., Brewin, C. R., Jones, C., & Kopelman, M. D. (2003). Coexistence of posttraumatic stress disorder and traumatic brain injury: Towards a resolution of the paradox. *Journal of the International Neuropsychological Society*, 9, 663-676. doi:10.1017/S1355617703940069

- Hawley, C. A. (2003). Reported problems and their resolution following mild, moderate and severe traumatic brain injury amongst children and adolescents in the UK. *Brain Injury, 17*(2), 105-209. doi:10.1080/0269905021000010131
- Hawley, C. A. (2004). Behaviour and school performance after brain injury. *Brain Injury, 18*, 645-659. doi:10.1080/02699050310001646189
- Hawley, C. A. (2012). Self-esteem in children after traumatic brain injury: An exploratory study. *Neurorehabilitation, 30*(3), 173-181. doi:10.3233/NRE-2012-0742
- Hawley, C. A., Ward, A. B., Magnay, A. R., & Long, J. (2002). Children's brain injury: A postal follow-up of 525 children from one health region in the UK. *Brain Injury, 16*, 969-985. doi:10.1080/02699050210147239
- Hawley, C. A., Ward, A. B., Magnay, A. R., & Long, J. (2003). Parental stress and burden following traumatic brain injury amongst children and adolescents. *Brain Injury, 17*(1), 1-23. doi:10.1080/0269905021000010096
- Hawley, C. A., Ward, A. B., Magnay, A. R., & Mychalkiw, W. (2004). Return to school after brain injury. *Archives of Disease in Childhood, 89*, 136-142. doi:10.1136/adc.2002.025577
- Hay, E., & Moran, C. (2005). Discourse formulation in children with closed head injury. *American Journal of Speech Language Pathology, 14*, 324-336. doi:10.1044/1058-0360(2005/031)
- Hayley, S. M., Dumas, H. M., Rabin, J. P., & Ni, P. (2003). Early recovery of walking in children and youths after traumatic brain injury. *Developmental Medicine & Child Neurology, 45*, 671-675. doi:10.1017/S0012162203001257
- Heah, T., Case, T., McGuire, B., & Law, M. (2007). Successful participation: The lived experience among children with disabilities. *Canadian Journal of Occupational Therapy, 74*(1), 38-48. doi:10.2182/cjot.06.10.
- Health Research Council of New Zealand. (2010). *Guidelines for researchers on health research involving Māori: Version 2*. Retrieved from <http://www.hrc.govt.nz>
- Hemmingsson, H., & Borell, L. (2000). Accommodation needs and student-environment fit in upper secondary schools for students with severe physical disabilities. *Canadian Journal of Occupational Therapy, 67*(3), 162-172. doi:10.1177/000841740006700311
- Hemmingsson, H., Borell, L., & Gustavsson, A. (2003). Participation in school: School assistants creating opportunities and obstacles for pupils with disabilities. *OTJR: Occupation, Participation & Health, 23*(3), 88-98. Retrieved from <http://www.otjronline.com>
- Hemmingsson, H., & Jonsson, H. (2005). An occupational perspective on the concept of participation in the International Classification of Functioning, Disability and Health- Some critical remarks. *The American Journal of Occupational Therapy, 59*, 569-576. doi:10.5014/ajot.59.5.569

- Hendrickson, J. M., Shokoohi-Yekta, M., Hamre-Nietupski, S., & Gable, R. A. (1996). Middle and high school students' perceptions on being friends with peers with severe disabilities. *Exceptional Children, 63*(1), 19-28. Retrieved from <http://www.cec.sped.org/Content/NavigationMenu/Publications2/ExceptionalChildren/>
- Hermans, E., Winkens, I., Te Winkel-Witlox, S., & van Iperen, A. (2012). Caregiver reported problems of children and families 2-4 years following rehabilitation for pediatric brain injury. *NeuroRehabilitation, 30*, 213-217. doi:10.3233/NRE-2012-0747
- Hesse-Biber, S. N., & Leavy, P. (2011). *The practice of qualitative research* (2nd ed.). Thousand Oaks, CA: SAGE.
- Heyne, L. A., Schleien, S. J., & McAvoy, L. H. (1994). *Making friends: Using recreation activities to promote friendship between children with and without disabilities*. Minneapolis, MN: University of Minnesota.
- Hickman, L. A., & Alexander, T. M. (Eds.). (1998). *The essential Dewey: Volume 1: Pragmatism, education, democracy*. Bloomington, IN: Indiana University Press.
- Higgins, N., MacArthur, J., & Kelly, B. (2009). Including disabled children at school: Is it really as simple as "A, C, D"? *International Journal of Inclusive Education, 13*(5), 471-187. doi:10.1080/13603110701791452
- Hill, M. (2005). Ethical considerations in researching children's experiences. In S. Greene & D. Hogan (Eds.), *Researching children's experience: Approaches and methods* (pp. 61-86). London: SAGE.
- Hilton, C. L., Crouch, M. C., & Israel, H. (2008). Out-of-school participation patterns in children with high-functioning autism spectrum disorders. *American Journal of Occupational Therapy, 62*(5), 554-563. doi:10.5014/ajot.62.5.554
- Hobbs, T., Bruch, L., Sanko, J., & Astolfi, C. (2001). Friendship on the inclusive electronic playground. *Teaching Exceptional Children, 33*(6), 46-51.
- Hoffman, T., Bennett, A., & Delmar, C. (Eds.). (2013). *Evidence-based practice across the health professions* (2nd ed.). Sydney: Churchill Livingstone Elsevier.
- Hoffman, T., Bennett, S., & Del Mar, C. (2013). Introduction to evidence-based practice. In T. Hoffman, S. Bennett, & C. Del Mar (Eds.), *Evidence-based practice across the health professions* (2nd ed., pp. 1-15). Sydney, Australia: Elsevier.
- Hoffnung, M., Hoffnung, R. J., Seifert, K. L., Burton Smith, R., & Hine, A. (2010). *Childhood: First Australasian edition*. Milton, Queensland: John Wiley & Sons Australia, Ltd.
- Holton, J. A. (2007). The coding process and its challenges. In A. Bryant & K. Charmaz (Eds.), *The Sage handbook of grounded theory* (pp. 263-289). London, United Kingdom: Sage.
- Holzman, L. (2009). *Vygotsky at work and play*. Hove, East Sussex: Routledge.

- Hoogsteen, L., & Woodgate, R. L. (2010). Can I play? A concept analysis of participation in children with disabilities. *Physical and Occupational Therapy in Pediatrics, 30*, 325-339. doi:10.3109/01942638.2010.481661
- Hooper, B., & Wood, W. (2002). Pragmatism and structuralism in occupational therapy: The long conversation. *The American Journal of Occupational Therapy, 56*(1), 40-50. doi:10.5014/ajot.56.1.40
- Hooper, S. R., Alexander, J., Moore, D., Sasser, H. C., Laurent, S., King, J., ... Callahan, B. (2004). Caregiver reports of common symptoms in children following a traumatic brain injury. *NeuroRehabilitation, 19*, 175-189. Retrieved from <http://www.iospress.nl/10538135.php>
- Houghton, C., Casey, D., Shaw, D., & Murphy, K. (2013). Rigour in qualitative case-study research. *Nurse Researcher*. Retrieved from <http://rcnpublishing.com/journal/nr>
- Hourigan, R. M. (2009). The invisible student: Understanding social identity construction within performing ensembles. *Music Educators Journal, 95*(4), 34-38. doi:10.1177/0027432109335435
- House, L. A., Russell, H. F., Kelly, E. H., Gerson, A., & Vogel, L. C. (2009). Rehabilitation and future participation of youth following spinal cord injury: Caregiver perspectives. *Spinal Cord, 47*(12), 882-886. doi:10.1038/sc.2009.64
- Hudspeth, W., & Pribram, K. (1990). Stages of brain and cognitive maturation. *Journal of Educational Psychology, 82*, 881-884. doi:10.1037/0022-0663.82.4.881
- Hughes, C. (2011). Changes and challenges in 20 years of research into the development of executive functions. *Infant and Child Development, 20*, 251-271. doi:10.1002/icd.736
- Humphry, R. (2005). Model of processes transforming occupations: Exploring societal and social influences. *Journal of Occupational Science, 12*(1), 36-44. doi:10.1080/14427591.2005.9686546
- Humphry, R., & Wakeford, L. (2006). An occupation-centred discussion of development and implications for practice. *The American Journal of Occupational Therapy, 60*, 258-267. doi:10.5014/ajot.60.3.258
- Humphry, R., & Wakeford, L. (2013). Educational implications of taking a transactional perspective of occupation in practice. In M. P. Cutchin & V. A. Dickie (Eds.), *Transactional perspectives on occupation* (pp. 215-228). New York: Springer. doi:10.1007/978-94-007-4429-5_17
- Hunt, P., Alwell, M., Farron-Davis, F., & Goetz, L. (1996). Creating socially supportive environments for fully included students who experience multiple disabilities. *Journal of the Association for Persons with Severe Handicaps (JASH), 21*(2), 53-71.

- Hutchison, P., Mecke, T., & Sharpe, E. (2008). Partners in inclusion at a residential summer camp: A case study. *Therapeutic Recreation Journal, XLII*(3), 179-196. Retrieved from <http://www.nrpa.org/trj>
- Hutzler, Y., Fliess-Douer, O., Avraham, A., Reiter, S., & Talmor, R. (2007). Effects of short-term awareness interventions on children's attitudes toward peers with a disability. *International Journal of Rehabilitation Research, 30*(2), 159-161. doi:10.1097/MRR.0b013e32813a2eb6
- Ikiugu, M. N., & Schultz, S. (2006). An argument for pragmatism as a foundational philosophy of occupational therapy. *Canadian Journal of Occupational Therapy, 73*(2), 86-98. doi:10.2182/cjot.05.0009
- Imms, C. (2008). Children with cerebral palsy participate: A review of the literature. *Disability and Rehabilitation, 30*, 1867-1884. doi:10.1080/09638280701673542
- Imms, C., Reilly, S., Carlin, J., & Dodd, K. J. (2009). Characteristics influencing participation of Australian children with cerebral palsy. *Disability & Rehabilitation, 31*(26), 2204-2215. doi:10.3109/09638280902971406
- Independent Living Service and Tiaho Trust. (2013). *Funding & disability*. Retrieved 19 October, 2013, from http://supportoptions.co.nz/support/funding_G.aspx
- Ison, N., McIntyre, S., Rothery, S., Smithers-Sheedy, H., Goldsmith, S., Parsonage, S., & Foy, L. (2010). 'Just like you': A disability awareness programme for children that enhanced knowledge, attitudes and acceptance: Pilot study findings. *Developmental Neurorehabilitation, 13*(5), 360-368. doi:10.3109/17518423.2010.496764
- Jacques, N., Wilton, K., & Townsend, M. (1998). Cooperative learning and social acceptance of children with mild intellectual disability. *Journal of Intellectual Disability Research, 42*(1), 29-36. Retrieved from <http://www.wiley.com/bw/journal.asp?ref=0964-2633>
- Jaffe, K. M., Polissar, N. L., Fay, G. C., & Liao, S. (1995). Recovery trends over three years following pediatric traumatic brain injury. *Archives of Physical Medicine and Rehabilitation, 76*, 17-26. doi:10.1016/S0003-9993(95)80037-9
- Janney, R. E., & Snell, M. E. (1996). How teachers use peer interactions to include students with moderate and severe disabilities in elementary general education classes. *Journal of the Association for Persons with Severe Handicaps, 21*(2), 72-80. Retrieved from <http://www.tash.org/publications/RPSD/RPSD.html>
- Janney, R. E., & Snell, M. E. (1997). How teachers include students with moderate and severe disabilities in elementary classes: The means and meaning of inclusion. *Journal of the Association for Persons with Severe Handicaps, 22*(3), 159-169. Retrieved from <http://www.tash.org/publications/RPSD/RPSD.html>

- Jansen, P., Bacal, K., & Crengle, S. (2008). *He ritenga whakaaro: Māori experiences of health services*. Retrieved from www.mauriora.co.nz
- Jarus, T., Anaby, D., Bart, O., Engel-Yeger, B., & Law, M. (2010). Childhood participation in after-school activities: What is to be expected? *The British Journal of Occupational Therapy*, *73*, 344-350. doi:10.4276/030802210X12813483277062
- Johansen, R. K. (2002). *Listening in the silence, seeing in the dark: Reconstructing life after brain injury*. Berkeley: University of California Press.
- Johnson, B. P. (1995). One family's experience with head injury: A phenomenological study. *Journal of Neuroscience Nursing*, *27*(2), 113-118.
- Jones, M., Hocking, C., & Wright-St Clair, V. (2010). Parents caregiving for children after a traumatic brain injury: Structuring for security. *New Zealand Journal of Occupational Therapy*, *57*(1), 4-13. Retrieved from <http://www.nzaot.com/publications/journal/index.php>
- Jones, P., Drummond, A., & Vella, K. (2007). Occupational therapy for children with acquired brain injury: A survey of current practice. *The British Journal of Occupational Therapy*, *70*, 154-160. Retrieved from [http://www.cot.co.uk/Homepage/Library_and_Publications/British_Journal_of_Occupational_Therapy_\(BJOT\)/](http://www.cot.co.uk/Homepage/Library_and_Publications/British_Journal_of_Occupational_Therapy_(BJOT)/)
- Jonsson, C. A., Horneman, G., & Emanuelson, I. (2004). Neuropsychological progress during 14 years after severe traumatic brain injury in childhood and adolescence. *Brain Injury*, *18*(9), 921-934. doi:10.1080/02699050410001671900
- Josie, K. L., Peterson, C. C., Burant, C., Drotar, D., Stancin, T., Wade, S. L., ... Taylor, H. G. (2008). Predicting family burden following childhood traumatic brain injury: A cumulative risk approach. *Journal of Head Trauma Rehabilitation*, *23*, 357-368. doi:10.1097/01.HTR.0000341431.29133.a8
- Junghans, C., Feder, G., Hemingway, H., Timmis, A., & Jones, M. (2005). Recruiting patients to medical research: Double blind randomised trial of "opt-in" versus "opt-out" strategies. *BMJ*, *331*(7522), 940-942. doi:10.1136/bmj.38583.625613.AE
- Jupp, V. (2006). *The SAGE dictionary of social research methods*. doi:10.4135/9780857020116
- Kamps, D. M., Barbeta, P. M., Leonard, B. R., & Delquadri, J. (1994). Classwide peer tutoring: An integration strategy to improve reading-skills and promote peer interactions among students with autism and general-education peers. *Journal of Applied Behavior Analysis*, *27*(1), 49-61. doi:10.1901/jaba.1994.27-49
- Kao, H. S., & Stuifbergen, A. K. (2004). Love and load- the lived experience of the mother-child relationship among young adult traumatic brain-injured survivors. *Journal of Neuroscience Nursing*, *36*(2), 73-81. Retrieved from <http://journals.lww.com/jnnonline/pages/default.aspx>

- Katz-Leurer, M., Rotem, H., Lewitus, H., Keren, O., & Meyer, S. (2008). Relationship between balance abilities and gait characteristics in children with post-traumatic brain injury. *Brain Injury*, 22(2), 153-159. doi:10.1080/02699050801895399
- Keenan, H. T., Runyan, D. K., & Nocera, M. (2006). Longitudinal follow-up of families and young children with traumatic brain injury. *Pediatrics*, 117, 1291-1298. doi:10.1542/peds.2005-1883
- Keith, T. Z., & Page, E. B. (1985). Homework works at school: National evidence for policy changes. *School Psychology Review*, 14(351-359). Retrieved from <http://www.nasponline.org/publications/spr/abstract.aspx?ID=672>
- Kendall, E., Buys, N., & Larner, J. (2000). Community-based service delivery in rehabilitation: The promise and the paradox. *Disability and Rehabilitation*, 22(10), 435-445. doi:10.1080/09638280050045901
- Kersel, D. A., Marsh, N. V., Havill, J. H., & Sleight, J. W. (2001a). Neuropsychological functioning during the year following severe traumatic brain injury. *Brain Injury*, 15, 283-296. doi:10.1080/02699050010005887
- Kersel, D. A., Marsh, N. V., Havill, J. H., & Sleight, J. W. (2001b). Psychosocial functioning during the year following severe traumatic brain injury. *Brain Injury*, 15, 683-696. doi:10.1080/02699050010013662
- Khetani, M. A., & Coster, W. J. (2014). Social participation. In B. A. Boyt Schel, G. Gillen, M. E. Scaffa, & E. S. Cohn (Eds.), *Willard & Spackman's occupational therapy* (12th ed., pp. 731-744). Baltimore, MD: Lippincott Williams and Wilkins.
- Kielhofner, G. (1992). *Conceptual foundations of occupational therapy*. Philadelphia, PA: F. A. Davis.
- King, G., Law, M., Hanna, S., King, S., Hurley, P., Rosenbaum, P., ... Petrenchik, T. (2006). Predictors of the leisure and recreation participation of children with physical disabilities: A structural equation modeling analysis. *Children's Health Care*, 35, 209-234. doi:10.1207/s15326888chc3503_2
- King, G., Law, M., Hurley, P., Petrenchik, T., & Schwellnus, H. (2010). A developmental comparison of the out-of-school recreation and leisure activity participation of boys and girls with and without physical disabilities. *International Journal of Disability, Development and Education*, 57(1), 77-107. doi:10.1080/10349120903537988
- King, G., Law, M., King, S., Rosenbaum, P., Hanna, S., Kertoy, M., & Young, N. (2004). *Children's Assessment of Participation and Enjoyment and Preferences for Activities of Children*. San Antonio, TX: The Psychological Corporation.

- King, G., Law, M., King, S., Rosenbaum, P., Kertoy, M. K., & Young, N. L. (2003). A conceptual model of the factors affecting the recreation and leisure participation of children with disabilities. *Physical & Occupational Therapy in Pediatrics*, 23(1), 63-90. doi:10.1080/J006v23n01_05
- King, G., Tucker, M. A., Baldwin, K. P., Lowry, K., LaPorta, J., & Martens, L. (2002). A life needs model of pediatric service delivery: Services to support community participation and quality of life for children and youth with disabilities. *Physical and Occupational Therapy in Pediatrics*, 22(2), 53-77. Retrieved from <http://www.informaworld.com>
- King, G. A., Law, M., King, S., Hurley, P., Hanna, S., Kertoy, M., & Rosenbaum, P. (2007). Measuring children's participation in recreation and leisure activities: Construct validation of the CAPE and PAC. *Child: Care, Health & Development*, 33, 28-39. doi:10.1111/j.1365-2214.2006.00613.x
- King, J. (2003). 'Whaia Te Reo: Pursuing the Language': How metaphors describe our relationships with indigenous languages. In J. Reyhner, O. Trujillo, R. L. Carrasco, & L. Lockard (Eds.), *Stabilizing indigenous languages symposium: Nurturing native languages*: (pp. 105-124). Wisconsin Dells, AZ: Northern Arizona University.
- King, S. M., Rosenbaum, P., Armstrong, R. W., & Milner, R. (1989). An epidemiological study of children's attitudes toward disability. *Developmental Medicine & Child Neurology*, 31, 237-245. doi:10.1111/j.1469-8749.1989.tb03984.x
- Kingi, T. K. R. (2006). The Treaty of Waitangi and Māori health: A paper presented at the Te Mata o te Tau lunchtime lecture series. Retrieved from http://temata.massey.ac.nz/massey/fms//Te%20Mata%20O%20Te%20Tau/Publications%20%20Te%20Kani/T%20Kingi%20Treaty_of_Waitangi_Māori_Health1.pdf
- Klavina, A., & Block, M. E. (2008). The effect of peer tutoring on interaction behaviors in inclusive physical education. *Adapted Physical Activity Quarterly*, 25(2), 132-158. Retrieved from <http://hk.humankinetics.com/APAQ/journalAbout.cfm>
- Klonoff, H., Clark, C., & Klonoff, P. S. (1993). Long-term outcome of head injuries: A 23 year follow-up study of children with head injuries. *Journal of Neurology, Neurosurgery and Psychiatry*, 56, 410-415. Retrieved from <http://jnnp.bmj.com/>
- Kohlberg, L. (1976). Moral stages and moralization: The cognitive developmental approach. In T. Lickona (Ed.), *Moral development and behavior*. New York: Holt, Rinehart & Winston.
- Kolb, B., & Gibb, R. (2010). Integrating multidisciplinary research for translation from the laboratory to the clinic. In V. Anderson & K. O. Yeates (Eds.), *Pediatric traumatic brain injury: New frontiers in clinical and translational research* (pp. 207-224). New York: Cambridge University Press.

- Kramer, J. M., Olsen, S., Mermelstein, M., Balcells, A., & Liljenquist, K. (2012). Youth with disabilities' perspectives of the environment and participation: A qualitative metasynthesis. *Child: Care, Health and Development*, 38(6), 763-777. doi:10.1111/j.1365-2214.2012.01365.x
- Kriel, R., Krach, L., & Panser, L. (1990). Closed head injury: Comparison of children younger and older than six years of age. *Pediatric Neurology*, 82, 881-884. Retrieved from <http://www.pedneur.com>
- Krueger, R. A., & Casey, M. A. (2000). *Focus groups: A practical guide for applied research* (3rd ed.). Thousand Oaks, CA: SAGE.
- Lah, S., Epps, A., Levick, W., & Parry, L. (2011). Implicit and explicit memory outcome in children who have sustained severe traumatic brain injury: Impact of age at injury (preliminary findings). *Brain Injury*, 25, 44-52. doi:10.3109/02699052.2010.531693
- Law, M. (2002). Participation in the occupations of everyday life. *The American Journal of Occupational Therapy*, 56, 640-649. doi:10.5014/ajot.56.6.640
- Law, M., Anaby, D., Dematteo, C., & Hanna, S. (2011). Participation patterns of children with acquired brain injury. *Brain Injury*, 25(6), 587-595. doi:10.3109/02699052.2011.572945
- Law, M., Anaby, D., Teplicky, R., Khetani, M. A., Coster, W., & Bedell, G. (2013). Participation in the home environment among children and youth with and without disabilities. *British Journal of Occupational Therapy*, 76, 58-66. doi:10.4276/030802213X13603244419112
- Law, M., Baptiste, S., Carswell, A., McColl, M. A., Polatajko, H., & Pollock, N. (1994). *Canadian Occupational Performance Measure* (2nd ed.). Toronto, ON: CAOT Publications ACE.
- Law, M., Cooper, B., Strong, S., Stewart, D., Rigby, P., & Letts, L. (1996). The person-environment-occupation model: A transactive approach to occupational performance. *Canadian Journal of Occupational Therapy*, 63, 186-192. doi: 10.1177/000841749606300103
- Law, M., Finkelman, S., Hurley, P., Rosenbaum, P., King, S., King, G., & Hanna, S. (2004). Participation of children with physical disabilities: Relationships with diagnosis, physical function, and demographic variables. *Scandinavian Journal of Occupational Therapy*, 11, 156-162. doi:10.1080/11038120410020755
- Law, M., Haight, M., Milroy, B., Willms, D., Stewart, D., & Rosenbaum, P. (1999). Environmental factors affecting the occupations of children with physical disabilities. *Journal of Occupational Science*, 6(3), 102-110. doi:10.1080/14427591.1999.9686455
- Law, M., King, G., King, S., Kertoy, M., Hurley, P., Rosenbaum, P., ... Hanna, S. (2006). Patterns of participation in recreational and leisure activities among children with complex physical

- disabilities. *Developmental Medicine and Child Neurology*, 48(5), 337-342. doi:10.1017/S0012162206000740
- Law, M., & MacDermid, J. (2008). Introduction to evidence-based practice. In M. Law & J. MacDermid (Eds.), *Evidence-based rehabilitation: A guide to practice* (2nd ed., pp. 3-14). Thorofare, NJ: Slack.
- Law, M., Petrenchik, T., King, G., & Hurley, P. (2007). Perceived environmental barriers to recreational, community, and school participation for children and youth with physical disabilities. *Archives of Physical Medicine and Rehabilitation*, 88, 1636-1642. doi:10.1016/j.apmr.2007.07.035
- Law, M., Stewart, D., Pollock, N., Letts, L., Bosch, J., & Westmorland, M. (1998). *Critical review form- Quantitative studies*. Retrieved 11th August, 2010, from <http://www.srs-mcmaster.ca/Default.aspx?tabid=630>
- Law, M., Stewart, D., Pollock, N., Letts, L., Bosch, J., & Westmorland, M. (1998b). *Guidelines for critical review form- Quantitative studies*. Retrieved 11 August, 2010, from <http://www.srs-mcmaster.ca/Default.aspx?tabid=630>
- Law, M. C., Darrach, J., Pollock, N., Wilson, B., Russell, D. J., Walter, S. D., ... Galupp, B. (2011). Focus on function: A cluster, randomized controlled trial comparing child- versus context-focused intervention for young children with cerebral palsy. *Developmental Medicine and Child Neurology*, 53, 621-629. doi:10.1111/j.1469-8749.2011.03962.x
- Lawlor, K., Mihaylov, S., Welsh, B., Jarvis, S., & Colver, A. (2006). A qualitative study of the physical, social and attitudinal environments influencing the participation of children with cerebral palsy in northeast England. *Pediatric Rehabilitation*, 9, 219-228. doi:10.1080/13638490500235649
- Laws, G., & Kelly, E. H. (2005). The attitudes and friendship intentions of children in United Kingdom mainstream schools towards peers with physical or intellectual disabilities. *International Journal of Disability, Development & Education*, 52, 79-99. doi:10.1080/10349120500086298
- Leach, D., & Duffy, M. L. (2009). Supporting students with autism spectrum disorders in inclusive settings. *Intervention in School and Clinic*, 45(1), 31-37. doi:10.1177/1053451209338395
- Leatham, J. M., & Body, C. M. (1997). Neuropsychological sequelae of head injury in New Zealand adolescent sample. *Brain Injury*, 11, 565-575. doi:10.1080/026990597123269
- Leatham, J. M., & Body, C. M. (1998). Adolescents' understanding of the causes and consequences of traumatic brain injury. *Applied Neuropsychology*, 5(3), 139-142. Retrieved from <http://www.tandf.co.uk/journals/titles/09084282.asp>

- Lederer, J. M. (2000). Reciprocal teaching of social studies in inclusive elementary classrooms. *Journal of Learning Disabilities, 33*(1), 91-106. Retrieved from <http://ldx.sagepub.com>
- Ledman, S. M., Thompson, B., & Hill, J. W. (1991). The EveryBuddy Program: An integrated after-school program. *Children Today, 20*(2), 17-20. Retrieved from <http://www.act.dhhs.gov/>
- Leone, C. M., & Richards, M. H. (1989). Classwork and homework in early adolescence: The ecology of achievement. *Journal of Youth and Adolescence, 18*, 531-548. Retrieved from <http://link.springer.com/journal/10964>
- Letts, L., Wilkins, S., Law, M., Stewart, D., Bosch, J., & Westmorland, M. (2007). *Critical review form: Qualitative studies (Version 2.0)*. Retrieved 11 August, 2010, from <http://www.srs-mcmaster.ca/Default.aspx?tabid=630>
- Letts, L., Wilkins, S., Law, M., Stewart, D., Bosch, J., & Westmorland, M. (2007b). *Guidelines for critical review form: Qualitative studies (Version 2.0)*. Retrieved 11 August, 2010, from <http://www.srs-mcmaster.ca/Default.aspx?tabid=630>
- Levi, R. B., Drotar, D., Yeates, K. O., & Taylor, G. H. (1999). Posttraumatic stress symptoms in children following orthopedic or traumatic brain injury. *Journal of Clinical Child Psychology, 28*(2), 232-243. doi:10.1207/s15374424jccp2802_10
- Levin, H. S. (2003). Neuroplasticity following non-penetrating traumatic brain injury. *Brain Injury, 17*(8), 665-674. doi:10.1080/0269905031000107151
- Levin, M., & Greenwood, D. (2001). Pragmatic action research and the struggle to transform universities into learning communities. In P. Reason & H. Bradbury (Eds.), *Handbook of action research: Participative inquiry and practice* (pp. 103-113). London: SAGE.
- Lewin, K. (1997). Action research and minority problems. In K. Lewin (Ed.), *Resolving social conflicts and field theory in social science* (pp. 143-152). doi:10.1037/10269-013 (1946)
- Lewin, K. (1997). Conduct, knowledge and acceptance of new values. In K. Lewin (Ed.), *Resolving social conflicts and field theory in social science* (pp. 48-55). doi:10.1037/10269-004 (1945)
- Lezac, M. D. (1986). Psychological implications of traumatic brain injury damage for the patient's family. *Rehabilitation Psychology, 31*, 241-245. doi:10.1037/h0091551
- Li, L., & Liu, J. (2013). The effect of pediatric traumatic brain injury on behavioral outcomes: A systematic review. *Developmental Medicine and Child Neurology, 55*(1), 37-45. doi:10.1111/j.1469-8749.2012.04414.x
- Liamputtong, P. (2011). *Focus group methodology: Principle and practice*. Thousand Oaks, CA: SAGE.

- Lieh-Lai, M. W., Theodorou, A. A., Sarnaik, A. P., Meert, K. L., Moylan, P. M., & Canady, A. I. (1992). Limitations of the Glasgow Coma Scale in predicting outcome in children with traumatic brain injury. *The Journal of Pediatrics*, *20*, 195-199. doi:10.1016/S0022-3476(05)80426-3
- Linden, M. A., Braiden, H.-J., & Miller, S. (2013). Educational professionals' understanding of childhood traumatic brain injury. *Brain Injury*, *27*, 92-102. doi:10.3109/02699052.2012.722262
- Liptak, G. S., Kennedy, J. A., & Dosa, N. P. (2011). Social participation in a nationally representative sample of older youth and young adults with autism. *Journal of Developmental and Behavioral Pediatrics*, *32*, 277-283. doi:10.1097/DBP.0b013e31820b49fc
- Lloyd, V., Gatherer, A., & Kalsy, S. (2006). Conducting qualitative interview research with people with expressive language difficulties. *Qualitative Health Research*, *16*, 1386-1404. doi:10.1177/1049732306293846
- Longoria, L., & Marini, I. (2006). Perceptions of children's attitudes towards peers with a severe physical disability. *Journal of Rehabilitation*, *72*(3), 19-25. Retrieved from http://nationalrehabvaassoc.weblinkconnect.com/cwt/external/wcpages/membership/publications_and_journals.aspx
- Luis, C. A., & Mittenberg, W. (2002). Mood and anxiety disorders following pediatric traumatic brain injury: A prospective study. *Journal of Clinical and Experimental Neuropsychology*, *24*(3), 270-279. doi:10.1076/jcen.24.3.270.982
- Magalhães, L. C., Cardoso, A. A., & Missiuna, C. (2011). Activities and participation in children with developmental coordination disorder: A systematic review. *Research in Developmental Disabilities*, *32*, 1309-1316. doi:10.1016/j.ridd.2011.01.029
- Majnemer, A., Shikako-Thomas, K., Chokron, N., Law, M., Shevell, M., Chilingaryan, G., ... Rosenbaum, P. (2009). Leisure activity preferences for 6-12-year-old children with cerebral palsy. *Developmental Medicine & Child Neurology*, *52*, 167-173. doi:10.1111/j.1469-8749.2009.03393.x
- Malinowski, B. (1922). *The argonauts of the Western Pacific*. London: Routledge.
- Mallay, J. N. (2002). Art therapy, an effective outreach intervention with traumatized children with suspected acquired brain injury. *The Arts in Psychotherapy*, *29*, 159-172. Retrieved from <http://www.journals.elsevier.com/the-arts-in-psychotherapy/>
- Mandich, A. D., Polatajko, H. J., & Rodger, S. (2003). Rites of passage: Understanding participation of children with developmental coordination disorder. *Human Movement Science*, *22*(4-5), 583-595. doi:10.1016/j.humov.2003.09.011

- Marcantuono, J. T., & Prigatano, G. P. (2008). A holistic brain injury rehabilitation program for school-age children. *NeuroRehabilitation*, *23*, 457-466. Retrieved from <http://www.iospress.nl/journal/neurorehabilitation/>
- Margulies, S. S., & Coats, B. (2010). Biomechanics of pediatric TBI. In V. Anderson & K. O. Yeates (Eds.), *Pediatric traumatic brain injury: New frontiers in clinical and translational research* (pp. 7-17). Cambridge, United Kingdom: Cambridge University Press.
- Marks, M., Sliwinski, M., & Gordon, W. A. (1993). An examination of the needs of families with a brain-injured child. *NeuroRehabilitation*, *3*, 1-12. Retrieved from <http://www.iospress.nl/>
- Marsh, N. V., & Whitehead, G. (2005). Skull fracture during infancy: A five-year follow-up. *Journal of Clinical and Experimental Neuropsychology*, *27*, 352-366. doi:10.1080/13803390490515685
- Marshall, S. J., Biddle, S. J. H., Gorely, T., Cameron, N., & Murdey, I. (2004). Relationships between media use, body fatness and physical activity in children and youth: A meta-analysis. *International Journal of Obesity*, *28*, 1238-1246. doi:10.1038/sj.ijo.0802706
- Martinez, R. S., & Carspecken, P. (2007). Effectiveness of a brief intervention on Latino children's social acceptance of peers with special needs. *Journal of Applied School Psychology*, *23*(1), 97-115. doi:10.1300/J370v23n01_05
- Mâsse, L. C., Miller, A. R., Shen, J., Schiariti, V., & Roxborough, L. (2013). Patterns of participation across a range of activities among Canadian children with neurodevelopmental disorders and disabilities. *Developmental Medicine & Child Neurology*, *55*, 729-736. doi:10.1111/dmcn.12167
- Mather, F. J., Tate, R. L., & Hannan, T. J. (2003). Post-traumatic stress disorder in children following road traffic accidents: A comparison of those with and without mild traumatic brain injury. *Brain Injury*, *17*, 1077-1087. doi:10.1080/0269905031000114045
- Matsumoto, J. H., Caplan, R., McArthur, D. L., Forgey, M. J., Yudovin, S., & Giza, C. C. (2013). Prevalence of epileptic and nonepileptic events after pediatric traumatic brain injury. *Epilepsy & Behavior*, *27*, 233-237. doi:10.1016/j.yebeh.2013.01.024
- Mawson, B. (2013). Young children as active agents. *HRC Ethics Notes*. Retrieved from http://www.hrc.govt.nz/sites/default/files/23773%20HRC%20Ethics_1013_online.pdf
- Max, J. E., Arndt, S., Castillo, C. S., Bokura, H., Robin, D. A., Lindgren, S. D., ... Mattheis, P. J. (1998). Attention-deficit hyperactivity symptomatology after traumatic brain injury: A prospective study. *Journal of the American Academy of Child and Adolescent Psychiatry*, *37*(8), 841-847. doi:10.1097/00004583-199808000-00014
- Max, J. E., Koele, S. L., Lindgren, S. D., Robin, D. A., Smith, W. L., Yutaka, S., & Arndt, S. (1998). Adaptive functioning following traumatic brain injury and orthopedic injury: A

- controlled study. *Archives of Physical Medicine and Rehabilitation*, 79, 893-899. doi:10.1016/S0003-9993(98)90084-3
- Maxcy, S. J. (2003). Pragmatic threads in mixed methods research in the social sciences: The search for multiple modes of inquiry and the end of the philosophy of formalism. In A. Tashakkori & C. Teddlie (Eds.), *Handbook of mixed methods in social and behavioral research* (pp. 51-89). Thousand Oaks, CA: SAGE.
- Maxwell, G., Alves, I., & Granlund, M. (2012). Participation and environmental aspects in education and the ICF and the ICF-CY: Findings from a systematic literature review. *Developmental Neurorehabilitation*, 15, 63-78. doi:10.3109/17518423.2011.633108
- Maxwell, G., Augustine, L., & Granlund, M. (2012). Does thinking and doing the same thing amount to involved participation? Empirical explorations for finding a measure of intensity for a third ICF-CY qualifier. *Developmental Neurorehabilitation*, 15, 274-283. doi:10.3109/17518423.2012.689780
- Maxwell, J. A., & Miller, B. A. (2008). Categorizing and connecting strategies in qualitative data analysis. In S. N. Hesse-Biber & P. Leavy (Eds.), *Handbook of emergent methods* (pp. 461-477). New York: The Guilford Press.
- Maxwell, W. L. (2012). Traumatic brain injury in the neonate, child and adolescent human: An overview of pathology. *International Journal of Developmental Neuroscience*, 30(3), 167-183. doi:10.1016/j.ijdevneu.2011.12.008
- McDonald, C. M., Jaffe, K. M., Fay, G. C., Polissar, N. L., Martin, K. M., Liao, S., & Rivara, J. B. (1994). Comparison of indices of traumatic brain injury severity as predictors of neurobehavioral outcome in children. *Archives of Physical Medicine and Rehabilitation*, 75(3), 328-337. Retrieved from <http://www.archives-pmr.org>
- McDougall, J., Bedell, G., & Wright, V. (2013). The youth report version of the Child and Adolescent Scale of Participation (CASP): Assessment of psychometric properties and comparison with parent report. *Child: Care, Health & Development*, 39, 512-522. doi:10.1111/cch.12050
- McDougall, J., DeWit, D. J., King, G., Miller, L. T., & Killip, S. (2004). High school-aged youths' attitudes toward their peers with disabilities: The role of school and student interpersonal factors. *International Journal of Disability Development and Education*, 51(3), 287-313. doi:10.1080/1034912042000259242
- McDougall, J., Servais, M., Sommerfreund, J., Rosen, E., Gillett, J., & Gray, J., . . . Hicock, F. (2006). An evaluation of the Paediatric Acquired Brain Injury Community Outreach Programme (PABICOP). *Brain Injury*, 20, 1189-1205. doi:10.1080/02699050600975541

- McKinlay, A., Grace, R. C., Horwood, L. J., Fergusson, D. M., & MacFarlane, M. R. (2010). Long-term behavioural outcomes of pre-school mild traumatic brain injury. *Child: Care, Health and Development*, *36*(1), 22-30. doi:10.1111/j.1365-2214.2009.00947.x
- McKinlay, A., McLellan, T., & Daffue, C. (2012). The invisible brain injury: The importance of identifying deficits following brain injury in children with intellectual disability. *NeuroRehabilitation*, *30*(3), 183-187. doi:10.3233/NRE-2012-0743
- McMahon, M. A., Noll, R. B., Michaud, L. J., & Johnson, J. C. (2001). Sibling adjustment to pediatric traumatic brain injury: A case-controlled pilot study. *Journal of Head Trauma Rehabilitation*, *16*, 587-594. Retrieved from <http://www.headtraumarehab.com>
- McMaster University. (2008). *Evidence-Based Practice Research Group*. Retrieved 7th December, 2013, from <http://www.srs-mcmaster.ca/Default.aspx?tabid=630>
- McNiff, J., & Whitehead, J. (2002). *Action research: Principles and practice* (2nd ed.). New York: RoutledgeFalmer.
- Meadan, H., & Monda-Amaya, L. (2008). Collaboration to promote social competence for students with mild disabilities in the general classroom: A structure for providing social support. *Intervention in School and Clinic*, *43*(3), 158. Retrieved from <http://isc.sagepub.com>
- Mealings, M., & Douglas, J. (2010). 'School's a big part of your life...': Adolescent perspectives of their school participation following traumatic brain injury. *Brain Impairment*, *11*, 1-16. doi:10.1375/brim.11.1.1
- Merriam-Webster. (2010). *Free Merriam-Webster Dictionary*. Retrieved from <http://www.merriam-webster.com/info/welcome.htm>
- Merriam, S. B. (1998). *Qualitative research and case study applications in education* (Rev. ed.). San Francisco: Jossey Bass.
- Merriam, S. B. (2009). *Qualitative research: A guide to design and implementation* (Rev. ed.). San Francisco: Jossey-Bass.
- Meyer, A. (1977). The philosophy of occupation therapy. *The American Journal of Occupational Therapy*, *31*, 639-642 (Original work published 1922).
- Meyer, L., Reichle, J., McQuarter, R., Cole, D., Vandercook, T., Evans, I., ... Kishi, G. (1995). Appendix D: Assessment of social competence: A scale of social competence functions. In S. J. Schleien, L. H. Meyer, L. A. Heyne, & B. B. Brandt (Eds.), *Lifelong leisure skills and lifestyles for persons with developmental disabilities* (pp. 277-308). Baltimore, MD: Paul Brookes.
- Michelsen, S. I., Flachs, E. M., Uldall, P., Eriksen, E. L., McManus, V., Parkes, J., ... Colver, A. (2009). Frequency of participation of 8-12-year-old children with cerebral palsy: A multi-

- centre cross-sectional European study. *European Journal of Paediatric Neurology*, 13(2), 165-177. doi:10.1016/j.ejpn.2008.03.005
- Mickel, J., & Griffin, J. (2007). Inclusion and disability awareness training for educators in the kids like you, kids like me program. *Young Children*, 62(4), 42-45. Retrieved from <http://www.naeyc.org/files/yc/file/200707/Mickel.pdf>
- Micklewright, J. L., King, T. Z., O'Toole, K., Henrich, C., & Floyd, F. J. (2012). Parental distress, parenting practices, and child adaptive outcomes following traumatic brain injury. *Journal of the International Neuropsychological Society*, 18, 343-350. doi:10.1017/S1355617711001792
- Mihaylov, S. I., Jarvis, S. N., Colver, A. F., & Beresford, B. (2004). Identification and description of environmental factors that influence participation of children with cerebral palsy. *Developmental Medicine and Child Neurology*, 46(5), 299-304. doi:10.1111/j.1469-8749.2004.tb00489.x
- Miller, P. H. (2002). *Theories of developmental psychology* (4th ed.). New York: Worth.
- Ministry of Education: Te Tāhuhu o te Mātauranga. (2007). *The New Zealand curriculum: For English medium teaching and learning in Years 1-13*. Wellington, New Zealand: Learning Media Limited. Retrieved from <http://nzcurriculum.tki.org.nz/Curriculum-documents/The-New-Zealand-Curriculum>
- Ministry of Health. (2001). *The New Zealand disability strategy: Making a world of difference: Whakanui oranga*. Wellington, New Zealand: Author.
- Ministry of Health: Manatū Hauora. (2013). *Māori health models – Te Whare Tapa Whā*. Retrieved 18th October, 2013, from <http://www.health.govt.nz/our-work/populations/Māori-health/Māori-health-models/Māori-health-models-te-whare-tapa-wha>
- Missiuna, C., Moll, S., King, S., King, G., & Law, M. (2007). A trajectory of troubles: Parents' impressions of the impact of Developmental Coordination Disorder. *Physical & Occupational Therapy in Pediatrics*, 27(1), 81-101. doi:10.1300/J006v27n01_06
- Mitchell, R. (1999). Community-based rehabilitation: The generalized model. *Disability and Rehabilitation*, 21(10-11), 522-528. doi:10.1080/096382899297369
- Mohr, J. D., & Bullock, L. M. (2005). Traumatic brain injury: Perspectives from educational professionals. *Preventing School Failure*, 49(4), 53-57. Retrieved from <http://www.tandf.co.uk/journals/titles/1045988X.asp>
- Moon, P. (1997). Traditional Māori proverbs: Some general themes. *Deep South*, 3(1). Retrieved from <http://www.otago.ac.nz/deepsouth/2011/index.html>
- Moorfield, J. C. (n.d.). *Te Aka Māori-English, English-Māori dictionary and index*. Retrieved from <http://www.Māoridictionary.co.nz/>

- Moran, C., & Gillon, G. (2004). Language and memory profiles of adolescents with traumatic brain injury. *Brain Injury, 18*(3), 273-288. doi:10.1080/02699050310001617415
- Moran, T. E., & Block, M. E. (2010). Barriers to participation of children with disabilities in youth sports. *Teaching Exceptional Children Plus, 6*(3), 1-13. Retrieved from <http://escholarship.bc.edu>
- Morgan, A. T., & Skeat, J. (2011). Evaluating service delivery for speech and swallowing problems following paediatric brain injury: An international survey. *Journal of Evaluation in Clinical Practice, 17*, 275-281. doi:10.1111/j.1365-2753.2010.01436.x.
- Mortier, K., Hunt, P., Desimpel, L., & Van Hove, G. (2009). With parents at the table: Creating supports for children with disabilities in general education classrooms. *European Journal of Special Needs Education, 24*(4), 337-354. doi:10.1080/08856250903223021
- Mortier, K., Van Hove, G., & De Schauwer, E. (2010). Supports for children with disabilities in regular education classrooms: An account of different perspectives in Flanders. *International Journal of Inclusive Education, 14*(6), 543-561. doi:10.1080/13603110802504929
- Mosey, A. C. (1973). *Activities therapy*. New York: Raven Press.
- Mu, K., & Royeen, C. (2004). Facilitating participation of students with severe disabilities. *Physical & Occupational Therapy in Pediatrics, 24*(3), 5-21. doi:10.1300/J006v24n03_02
- Mulcahey, M. J., DiGiovanni, N., Calhoun, C., Homko, E., Riley, A., & Haley, S. M. (2010). Children's and parents' perspectives about activity performance and participation after spinal cord injury: Initial development of a patient-reported outcome measure. *American Journal of Occupational Therapy, 64*(4), 605-613. doi:10.5014/ajot.2010.08148
- Mulligan, L., Specker, B. L., Buckley, D. D., O'Connor, L. S., & Ho, M. (1998). Physical and environmental factors affecting motor development, activity level, and body composition of infants in child care centers. *Pediatric Physical Therapy, 10*(4), 156-161. Retrieved from <http://journals.lww.com/pedpt/pages/default.aspx>
- Munhall, P. L. (2007). A phenomenological method. In P. L. Munhall (Ed.), *Nursing research: A qualitative perspective* (4th ed., pp. 145-210). Sudbury, MA: Jones & Bartlett.
- Muscara, F., Catroppa, C., Eren, S., & Anderson, V. (2009). The impact of injury severity on long-term social outcome following paediatric traumatic brain injury. *Neuropsychological Rehabilitation, 19*, 541-561. doi:10.1080/09602010802365223
- Nadebaum, C., Anderson, V., & Catroppa, C. (2007). Executive function outcomes following traumatic brain injury in young children: A five year follow-up. *Developmental Neuropsychology, 32*(2), 703-728. doi:10.1080/87565640701376086

- National Ethics Advisory Committee. (2012a). *Ethical guidelines for intervention studies*. Retrieved from www.neac.health.govt.nz
- National Ethics Advisory Committee. (2012b). *Ethical guidelines for observational studies: Observational research, audits and related activities* (Rev. ed.). Retrieved from www.neac.health.govt.nz
- Nestmann, F., & Hurrelmann, K. (Eds.). (1994). *Social networks and social support in childhood and adolescence*. New York: Walter de Gruyter.
- New Zealand Guidelines Group. (2006). *Evidence-based best practice guideline: Traumatic brain injury: Diagnosis, acute management and rehabilitation*. Wellington, New Zealand: Author.
- New Zealand Ministry of Education. (2013). *Operational protocol - Ministry of Education and ACC*. Retrieved October 19, 2013, from <http://www.minedu.govt.nz/NZEducation/EducationPolicies/SpecialEducation/PublicationsAndResources/FormsAndGuidelines/OperationalProtocolBetweenACCAndEducation.aspx>
- Northcott, N. (1996). Cognitive mapping: An approach to qualitative data analysis. *Journal of Research in Nursing, 1*, 456-464. doi:10.1177/174498719600100610
- Nota, L., Ferrari, L., & Soresi, S. (2005). Elementary school children's willingness to help and be friends with disabled peers. *International Journal on Disability and Human Development, 4*(2), 131-137. doi:10.1515/IJDHD.2005.4.2.131
- Nowicki, E. A. (2006). A cross-sectional multivariate analysis of children's attitudes towards disabilities. *Journal of Intellectual Disability Research, 50*, 335-348. doi:10.1111/j.1365-2788.2005.00781.x
- O'Brien, J. C., Bergeron, A., Duprey, H., Olver, C. S., & Onge, H. (2009). Children with disabilities and their parents' views of occupational participation needs. *Occupational Therapy in Mental Health, 25*(2), 164-180. doi:10.1080/01642120902859196
- O'Connor, S. S., Zatzick, D. F., Wang, J., Temkin, N., Koepsell, T. D., Jaffe, K. M., ... Rivara, F. P. (2012). Association between posttraumatic stress, depression, and functional impairments in adolescents 24 months after traumatic brain injury. *Journal of Traumatic Stress, 25*(3), 264-271. doi:10.1002/jts.21704
- Oates, A., Bebbington, A., Bourke, J., Girdler, S., & Leonard, H. (2011). Leisure participation for school-aged children with Down syndrome. *Disability & Rehabilitation, 33*, 1880-1889. doi:10.3109/09638288.2011.553701
- Office for Disability Issues: Te Tari Mō Ngā Take Hauātanga. (2013). *Towards an inclusive and non-disabling New Zealand: The annual report form the Minister for Disability Issues to the House of Representatives on implementation of the New Zealand Disability Strategy*.

- Wellington, New Zealand: Office for Disability Issues, Ministry of Social Development.
Retrieved from www.odi.govt.nz
- Ogilvie, D., Egan, M., Hamilton, V., & Petticrew, M. (2005). Systematic review of health effects of social interventions: 2. Best available evidence: How low should you go? *Journal of Epidemiology and Community Health*, *59*(10), 886-892. doi:10.1136/jech.2005.034199
- Olson, L. J. (2010). A frame of reference to enhance social participation. In P. Kramer & J. Hinojosa (Eds.), *Frames of reference for pediatric occupational therapy* (3rd ed., pp. 306-348). Baltimore, MD: Lippincott Williams & Wilkins.
- Orange, C. (2004). *An illustrated history of the Treaty of Waitangi*. Wellington, New Zealand: Bridget Williams Books.
- Palisano, R. J., Orlin, M. N., Chiarello, L. A., Oeffinger, D., Polansky, M., Maggs, J., ... Stevenson, R. (2011). Determinants of intensity of participation in leisure and recreational activities by youth with cerebral palsy. *Archives of Physical Medicine and Rehabilitation* *92*, 1468-1476. doi:10.1016/j.apmr.2011.04.007
- Parkin, A. E., Maas, F., & Rodger, S. (1996). Factors contributing to successful return to school for students with acquired brain injury: Parent perspectives. *Australian Occupational Therapy Journal*, *43*, 133-141. Retrieved from <http://onlinelibrary.wiley.com/>
- Parlett, M., & Hamilton, D. (1976). Evaluation as illumination: A new approach to the study of innovatory programmes. In G. Glass (Ed.), *Evaluation studies review annual, I* (pp. 140-157). Beverly Hills, CA: Sage. (Original work published 1972)
- Parliamentary Counsel Office/Te Tari Tohutohu Pāremata. (2013). *Accident Compensation Act 2001*. Retrieved from http://www.legislation.govt.nz/act/public/2001/0049/latest/DLM99494.html?search=ts_act_injury+prevention+rehabilitation+compensation
- Paschal, R., Weinstein, T., & Wahlberg, J. (1984). The effects of homework on learning: A quantitative synthesis. *The Journal of Educational Research*, *78*, 97-104. Retrieved from <http://www.tandfonline.com/loi/vjer20>
- Pate, R. R., Dowda, M., & Ross, J. G. (1990). Associations between physical activity and physical fitness in American children. *Archives of Pediatrics and Adolescent Medicine*, *144*, 1123-1129. Retrieved from <http://archpedi.jamanetwork.com/journal.aspx>
- Patrick, D. L., Patrick, S. T., & Duncan, E. (2006). Neuropsychological recovery in children and adolescents following traumatic brain injury. In J. Leon-Carrion, K. R. H. von Wild, & G. A. Zitnay (Eds.), *Brain injury treatment: Theories and practices* (pp. 401-440). London: Taylor & Francis.
- Paulin, C. D. (2007). Perspectives of Māori fishing and techniques: Ngā āhua me ngā pūrākau me ngā hangarau ika o te Māori. *Tuhinga*, *18*, 11-47. Retrieved from

<http://www.tepapa.govt.nz/ResearchAfTePapa/ResearchAndMuseumPapers/Pages/Tuhinga242013.aspx>

- Pavri, S., & Monda-Amaya, L. (2001). Social support in inclusive schools: Student and teacher perspectives. *Exceptional Children*, 67(3), 391-411. Retrieved from <http://www.cec.sped.org/Content/NavigationMenu/Publications2/ExceptionalChildren/>
- Peart, N., & Holdaway, D. (2000). Ethical guidelines for health research with children. *New Zealand Bioethics Journal*, 1(2), 3-9.
- Pellegrini, A. D. (1987). Rough-and-tumble play: Developmental and educational significance. *Educational Psychologist*, 22, 23-43. Retrieved from <http://www.tandfonline.com/loi/he dp20>
- Pellegrini, A. D., & Smith, P. K. (1998). Physical activity play: The nature and function of a neglected aspect of play. *Child Development*, 69, 577-598. doi:10.2307/1132187
- Pereira, E., la Cour, K., Jonsson, H., & Hemmingsson, H. (2010). The participation experience of children with disabilities in Portuguese mainstream schools. *British Journal of Occupational Therapy*, 71(12), 598-606. doi:10.4276/030802210X12918167234244
- Petticrew, M., & Roberts, H. (2006). *Systematic reviews in the social sciences: A practical guide*. Malden, MA: Blackwell.
- Pinto, P. S., Poretti, A., Meoded, A., Tekes, A., & Huisman, T. A. G. M. (2012). The unique features of traumatic brain injury in children. Review of the characteristics of the pediatric skull and brain, mechanisms of trauma, patterns of injury, complications and their imaging findings-part 1. *Journal of Neuroimaging*, 22(2), e1-e17. doi:10.1111/j.1552-6569.2011.00688.x
- Piškur, B., Beurskens, A. J. H. M., Jongmans, M. J., Ketelaar, M., Norton, M., Frings, C. A., ... Smeets, R. J. E. M. (2012). Parents' actions, challenges, and needs while enabling participation of children with a physical disability: A scoping review. *BMC Pediatrics*, 12. doi:10.1186/1471-2431-12-177
- Piškur, B., Daniëls, R., Jongmans, M. J., Ketelaar, M., Smeets, R. J. E. M., Norton, M., & Beurskens, A. J. H. M. (2013). Participation and social participation: Are they distinct concepts? *Clinical Rehabilitation, Advance online publication*. doi:10.1177/0269215513499029
- Pitt, V., & Curtin, M. (2004). Integration versus segregation: The experiences of a group of disabled students moving from mainstream school into special needs further education. *Disability & Society*, 19(4), 387-401. doi:10.1080/09687590410001689485
- Platt, J. (1988). What can case studies do? In R. Burgess (Ed.), *Studies in qualitative methodology* (Vol. 1, pp. 1-23). New York: JAI Press.

- Platt, J. (1992a). "Case study" in American methodological thought. *Current Sociology*, 40, 17-48. doi:10.1177/001139292040001004
- Platt, J. (1992b). Cases of cases...of cases. In C. C. Ragin & H. W. Becker (Eds.), *What is a case? Exploring the foundations of social inquiry* (pp. 21-52). Oxford: Oxford University Press.
- Pohatu, T. W. (n.d.). *Āta: Growing respectful relationships*. Retrieved November 2, 2009 from <http://www.kaupapamaori.com/assets//ata.pdf>
- Polatajko, H. J. (1994). Dreams, dilemmas, and decisions for occupational therapy practice in a new millennium: A Canadian perspective. *The American Journal of Occupational Therapy*, 48, 590-594. doi:10.5014/ajot.48.7.590
- Polatajko, H. J., Davis, J., Stewart, D., Cantin, N., Amoroso, B., Purdie, L., & Zimmerman, D. (2013). Specifying the domain of concern: Occupation as core. In E. A. Townsend & H. J. Polatajko (Eds.), *Enabling occupation II: Advancing an occupational therapy vision for health, well-being, & justice through occupation* (2nd ed., pp. 13-36). Ottawa, Ontario: CAOT Publications ACE.
- Poon, K. K. (2011). The activities and participation of adolescents with autism spectrum disorders in Singapore: Findings from an ICF-based instrument. *Journal of Intellectual Disability Research*, 55, 790-800. doi:10.1111/j.1365-2788.2011.01397.x
- Poulsen, A. A., Ziviani, J. M., Cuskelly, M., & Smith, R. (2007). Boys with developmental coordination disorder: Loneliness and team sports participation. *American Journal of Occupational Therapy*, 61(4), 451-462. doi:10.5014/ajot.61.4.451
- Prigatano, G. P., Fulton, J., & Wethe, J. (2010). Behavioral consequences of pediatric traumatic brain injury. *Pediatric Health*, 4(4), 447-455. doi:10.2217/phe.10.43
- Prigatano, G. P., & Gray, J. (2008). Parental perspectives on recovery and social reintegration after pediatric traumatic brain injury. *Journal of Head Trauma Rehabilitation*, 23(6), 378-387. doi:10.1097/01.HTR.0000341433.67251.01
- Prigatano, G. P., & Gray, J. A. (2007). Parental concerns and distress after paediatric traumatic brain injury: A qualitative study. *Brain Injury*, 21(7), 721-729. doi:10.1080/02699050701481605
- Prigatano, G. P., & Gupta, S. (2006). Friends after traumatic brain injury in children. *Journal of Head Trauma Rehabilitation*, 21(6), 505-513. Retrieved from <http://www.headtraumarehab.com>
- Prins, M. L., Giza, C. C., & Hovda, D. A. (2010). Neurobiology of TBI sustained during development. In V. Anderson & K. O. Yeates (Eds.), *Pediatric traumatic brain injury: New frontiers in clinical and translational research* (pp. 18-35). New York: Oxford University Press.

- Public Health Resource Unit. (2010). *Appraisal tools*. Retrieved 11 August, 2010, from <http://www.phru.nhs.uk/Pages/PHD/resources.htm>
- Raghavendra, P. (2013). Participation of children with disabilities: Measuring subjective and objective outcomes. *Child: Care, Health and Development*, 39, 461-465. doi:10.1111/cch.12084
- Raghavendra, P., Olsson, C., Sampson, J., McInerney, R., & Connell, T. (2012). School participation and social networks of children with complex communication needs, physical disabilities, and typically developing peers. *Augmentative & Alternative Communication*, 28(1), 33-43. doi:10.3109/07434618.2011.653604
- Reason, P., & Bradbury, H. (2001a). Introduction: Inquiry and participation in search of a world worthy of human aspiration. In P. Reason & H. Bradbury (Eds.), *Handbook of action research: Participative inquiry and practice* (pp. 1-14). London: SAGE.
- Reason, P., & Bradbury, H. (Eds.). (2001b). *Handbook of action research: Participative inquiry and practice*. London: SAGE.
- Renström, B., Söderman, K., Domellöf, E., & Emanuelson, I. (2012). Self-reported health and influence on life situation 5-8 years after paediatric traumatic brain injury. *Brain Injury*, 26, 1405-1414. doi:10.3109/02699052.2012.694559
- Richardson, P. K. (2002). The school as social context: Social interaction patterns of children with physical disabilities. *American Journal of Occupational Therapy*, 56(3), 296-304. Retrieved from http://www.aota.org/Pubs/AJOT_1.aspx
- Rios, L. P., Ye, C., & Thabane, L. (2010). Association between framing of the research question using the PICOT format and reporting quality of randomized controlled trials. *BMC Medical Research Methodology*, 10, 11-18. doi:10.1186/1471-2288-10-11
- Rivara, F. P., Koepsell, T., Wang, J., Temkin, N., Dorsch, A., Vavilala, M. S., ... Jaffe, K. M. (2011). Disability 3, 12, and 24 months after traumatic brain injury among children and adolescents. *Pediatrics*, 129, e1129-e1138. doi:10.1542/peds.2011-0840
- Rivara, F. P., Vavilala, M. S., Durbin, D., Temkin, N., Wang, J., O'Connor, S. S., ... Jaffe, K. M. (2012). Persistence of disability 24 to 36 months after pediatric traumatic brain injury: A cohort study. *Journal of Neurotrauma*, 29, 2499-2504. doi:10.1089/neu.2012.2434
- Rivara, J. B., Jaffe, K. M., Fay, G. C., Polissar, N. L., Martin, K. M., Shurtleff, H. A., & Liao, S. (1993). Family functioning and injury severity as predictors of child functioning one year following traumatic brain injury. *Archives of Physical Medicine and Rehabilitation*, 74, 1047-1055. doi:10.1016/0003-9993(93)90060-N
- Rivara, J. B., Jaffe, K. M., Polissar, N. L., Fay, G. C., Liao, S., & Martin, K. M. (1996). Predictors of family functioning and change 3 years after traumatic brain injury in children. *Archives*

- of Physical Medicine and Rehabilitation*, 77, 754-764. doi:10.1016/S0003-9993(96)90253-1
- Rivara, J. B., Jaffe, K. M., Polissar, N. L., Fay, G. C., Martin, K. M., Shurtleff, H. A., & Liao, S. (1994). Family functioning and children's academic performance and behavior problems in the year following traumatic brain injury. *Archives of Physical Medicine and Rehabilitation*, 75(4), 369-379. doi:10.1016/0003-9993(94)90157-0
- Roberts, C. M., & Lindsell, J. S. (1998). Children's attitudes and behavioural intentions towards peers with disabilities. *International Journal of Disability Development and Education*, 44(2), 133-145. doi:10.1080/0156655970440205
- Robson, T., Ziviani, J., & Spina, S. (2005). Personal experiences of families of children with a traumatic brain injury in the transition from hospital to home. *Brain Impairment*, 6(1), 45-55. doi:10.1375/brim.6.1.45.65477
- Rodger, S., & Ziviani, J. (Eds.). (2006). *Occupational therapy with children: Understanding children's occupations and enabling participation*. Oxford, United Kingdom: Blackwell.
- Roger, B., Gorevin, R., Fellows, M., & Kelly, D. (1992). *Schools are for all kids: School site implementation. Level II training. Participants manual*. San Francisco, CA: San Francisco State University.
- Roscigno, C. I., & Swanson, K. M. (2011). Parents' experiences following children's moderate to severe traumatic brain injury: A clash of cultures. *Qualitative Health Research*, 21, 1413-1426. doi:10.1177/1049732311410988
- Roscigno, C. I., Swanson, K. M., Vavilala, M. S., & Solchany, J. (2011). Children's longing for everydayness: Life following traumatic brain injury in the USA. *Brain Injury*, 25(9), 882-894. doi:10.3109/02699052.2011.581638
- Rosema, S., Crowe, L., & Anderson, V. (2012). Social function in children and adolescents after traumatic brain injury: A systematic review 1989-2011. *Journal of Neurotrauma*, 29, 1277-1291. doi:10.1089/neu.2011.2144
- Rosenberg, A. E. (2000). Conducting an inventory of informal community-based resources for children with physical disabilities. *Physical & Occupational Therapy in Pediatrics*, 20(1), 59-79. doi:10.1080/J006v20n01_05
- Russell, M. L., Krouse, S. I., Karas Lane, A., Leger, D., & Robson, C. A. (1998). Intervention for motor disorders. In M. Ylvisaker (Ed.), *Traumatic brain injury intervention: Children and adolescents* (2nd ed., pp. 61-84). Boston: Butterworth-Heinemann.
- Ryan, S. (2008). "I used to worry about what other people thought but now I just think ... well I don't care": Shifting accounts of learning difficulties in public places. *Health and Place*, 14(4), 730-739. doi:10.1016/j.healthplace.2007.11.004

- Rynders, J. E., Schleien, S. J., Meyer, L. H., Vandercook, T. L., Mustonen, T., Colond, J. S., & Olson, K. (1993). Improving integration outcomes for children with and without severe disabilities through cooperatively structured recreation activities: A synthesis of research. *Journal of Special Education, 26*(4), 386. doi:10.1177/002246699302600404
- Rynders, J. E., Schleien, S. J., & Mustonen, T. (1990). Integrating children with severe disabilities for intensified outdoor education: Focus on feasibility. *Mental Retardation, 28*(1), 7-14. Retrieved from <http://aaidjournals.org/loi/mere.1>
- Sackett, D. L., Rosenberg, W. M. C., Gray, J. A. M., Haynes, R. B., & Richardson, W. S. (1996). Evidence based medicine: What it is and what it isn't. *BMJ, 312*(7023), 71-72. Retrieved from <http://www.bmj.com/>
- Salend, S. J. (1999). Facilitating friendships among diverse students. *Intervention in School and Clinic, 35*(1), 9-15. Retrieved from <http://isc.sagepub.com>
- Salisbury, C. L., & Evans, I. M. (1993). *Using a collaborative problem solving strategy to facilitate the mainstreaming of students with severe handicaps (The Collaborative Education Project): Final report*. Albany, NY: New York State Univ. System. (ERIC Document Reproduction Service No. ED357535).
- Salisbury, C. L., Gallucci, C., Palombaro, M. M., & Peck, C. A. (1995). Strategies that promote social-relations among elementary students with and without severe disabilities in inclusive schools. *Exceptional Children, 62*(2), 125-137. Retrieved from <http://journals.cec.sped.org/ec/>
- Saltmarsh, J. (1996). Education for critical citizenship: John Dewey's contribution to the pedagogy of community service learning. *Michigan Journal of Community Service Learning, 3*(1), 13-21. Retrieved from <http://ginsberg.umich.edu/mjcs1/>
- Sambuco, M., Brookes, N., Catroppa, C., & Lah, S. (2012). Predictors of long-term sibling behavioral outcome and self-esteem following pediatric traumatic brain injury. *Journal of Head Trauma Rehabilitation, 27*, 413-423. doi:10.1097/HTR.0b013e3182274162
- Sambuco, M., Brookes, N., & Lah, S. (2008). Paediatric traumatic brain injury: A review of siblings' outcome. *Brain Injury, 22*, 7-17. doi:10.1080/02699050701822022
- Scaletti, R. (1999). A community development role for occupational therapists working with children, adolescents and their families: A mental health perspective. *Australian Occupational Therapy Journal, 46*, 43-51. doi:10.1046/j.1440-1630.1999.00175.x
- Schenker, R., Coster, W., & Parush, S. (2005). Participation and activity performance of students with cerebral palsy within the school environment. *Disability & Rehabilitation, 27*(10), 539-552. doi:10.1080/09638280400018437

- Schleien, S. J., Green, F. P., & Stone, C. F. (2003). Making friends within inclusive community recreation programs. *American Journal of Recreation Therapy*, 2(1), 7-16. Retrieved from <http://www.recreationtherapy.org/pn10000.html>
- Schleien, S. J., Mustonen, T., & Rynders, J. E. (1995). Participation of children with autism and nondisabled peers in a cooperatively structured community art program. *Journal of Autism and Developmental Disorders*, 25(4), 397-413. doi:10.1007/BF02179375
- Scholl, K. G., Dieser, R. B., & Davison, A. (2005). Together we play: An ecological approach to inclusive recreation. *Therapeutic Recreation Journal*, 39(4), 299-311. Retrieved from <http://www.nrpa.org>
- Scholl, K. G., Smith, J. G., & Davison, A. (2005). Agency readiness to provide inclusive recreation and after-school services for children with disabilities. *Therapeutic Recreation Journal*, 39(1), 47. Retrieved from <http://www.nrpa.org/trj>
- Schutz, A. (2001). John Dewey's conundrum: Can democratic schools empower? *Teachers College Record*, 103, 267-302. doi:10.1111/0161-4681.00116
- Schwartz, K. B. (2009). Reclaiming our heritage: Connecting the founding vision to the centennial vision. *The American Journal of Occupational Therapy*, 63, 681-690. doi:10.5014/ajot.63.6.681
- Scott, J., & Marshall, G. (2009). *Oxford dictionary of sociology* (3rd rev ed.). Retrieved from <http://global.oup.com/>
- Scott Johnston, J. (2006). *Inquiry and education: John Dewey and the quest for democracy*. Albany, NY: State University of New York Press.
- Sharp, N. L., Bye, R. A., Llewellyn, G. M., & Cusick, A. (2006). Fitting back in: Adolescents returning to school after severe acquired brain injury. *Disability & Rehabilitation*, 28(12), 767-778. doi:10.1080/09638280500386668
- Sherwin, E. D., & O'Shanick, G. J. (1998). From denial to poster child: Growing past the injury. In M. Ylvisaker (Ed.), *Traumatic brain injury rehabilitation: Children and adolescents* (2nd ed., pp. 331-343). Boston: Butterworth-Heinemann.
- Sherwin, E. D., & O'Shanick, G. J. (2000). The trauma of paediatric and adolescent brain injury: Issues and implications for rehabilitation specialists. *Brain Injury*, 14(3), 267-284. doi:10.1080/026990500120745
- Shikako-Thomas, K., Majnemer, A., Law, M., & Lach, L. (2008). Determinants of participation in leisure activities in children and youth with cerebral palsy: Systematic review. *Physical & Occupational Therapy in Pediatrics*, 28(2), 155-169. doi:10.1080/01942630802031834
- Shikako-Thomas, K., Shevell, M., Lach, L., Law, M., Schmitz, N., Poulin, C., & Majnemer, A. (2013). Picture me playing- A portrait of participation and enjoyment of leisure activities in

- adolescents with cerebral palsy. *Research in Developmental Disabilities*, 34, 1001-1010. doi:10.1016/j.ridd.2012.11.026
- Siebert, R., & Levack, W. (2005). *TBI tools review & supplementary report: Best practice in rehabilitation*. Wellington, New Zealand: Rehabilitation Teaching and Research Unit, Wellington School of Medicine and Health Sciences, University of Otago.
- Silver, C. H. (2000). Ecological validity of neuropsychological assessment in childhood traumatic brain injury. *Journal of Head Trauma Rehabilitation*, 15(4), 973-988. doi:10.1097/00001199-200008000-00002
- Simmeonsson, R. J., Carlson, D., Huntington, G. S., Sturtz McMillen, J., & Lytle Brent, J. (2001). Students with disabilities: A national survey of participation in school activities. *Disability and Rehabilitation*, 23(2), 49-63. doi:10.1080/096382801750058134
- Simons, H. (2009). *Case study research in practice*. London: SAGE.
- Singer, G. H. S. (1996). Constructing supports: Helping families of children with acquired brain injury. In G. H. S. Singer, A. Glang, & J. M. Williams (Eds.), *Children with acquired brain injury: Educating and supporting families* (pp. 1-22). Baltimore, MD: Paul H. Brookes.
- Singer, G. H. S., & Nixon, C. (1996). A report on the concerns of parents of children with ABI. In G. H. S. Singer, A. Glang, & J. M. Williams (Eds.), *Children with acquired brain injury: Educating and supporting families* (pp. 23-52). Baltimore, MD: Paul H. Brookes.
- Singer, J. (1997). One mother's story: Including her son in coma in a general education first-grade class. In A. Glang, G. H. S. Singer, & B. Todis (Eds.), *Students with acquired brain injury: The school's response* (pp. 73-105). Baltimore, MD: Paul J. Brookes.
- Siperstein, G. N., Glick, G. C., & Parker, R. C. (2009). Social inclusion of children with intellectual disabilities in a recreational setting. *Intellectual and Developmental Disabilities*, 47(2), 97-107. doi:10.1352/1934-9556-47.2.97
- Slavin, R. E. (1995). Best evidence synthesis: An intelligent alternative to meta-analysis. *Journal of Clinical Epidemiology*, 48(1), 9-18. doi:10.1016/0895-4356(94)00097-A
- Slomine, B. S., McCarthy, M. L., Ru Ding, E. J., MacKenzie, E. J., Jaffe, K. M., Aitken, M. E., ... Chat Study Group. (2006). Health care utilization and needs after pediatric traumatic brain injury. *Pediatrics*, 117(4), 663-674. doi:10.1542/peds.2005-1892
- Smith, K. S., Haley, S. M., & Coster, W. J. (2005). Development of the Pediatric Functioning after Brain Injury (FABI) Scales: Paper presented at the 12th Annual Conference of the International Society for Quality of Life Research (ISOQOL). *Quality of Life Research*, 14, 2032. Retrieved from <http://springerlink.metapress.com/openurl.asp?genre=journal&issn=0962-9343>

- Smith, L. M. (1978). An evolving logic of participant observation, educational ethnography and other case studies. *Review of Research in Education*, 6, 316-377. Retrieved from <http://rre.sagepub.com/>
- Smith, P. K., & Boulton, M. J. (1990). Rough-and-tumble play, aggression and dominance: Perception and behaviour in children's encounters. *Human Development*, 33, 271-282. doi:10.1159/000276524
- Sokol, D. K., Ferguson, C. F., Pitcher, G. A., Huster, G. A., Fitzhugh-Bell, K., & Luerssen, T. G. (1996). Behavioural adjustment and parental stress associated with closed head injury in children. *Brain Injury*, 10(6), 439-451. doi:10.1080/026990596124296
- Soodak, L. C. (2003). Classroom management in inclusive settings. *Theory Into Practice*, 42(4), 327-333. doi:10.1207/s15430421tip4204_10
- Sorrenson, M. P. K. (2012). 'Buck, Peter Henry', from the dictionary of New Zealand biography. Retrieved from <http://www.TeAra.govt.nz/en/biographies/3b54/buck-peter-henry>
- Sowers, J., Glang, A., Voss, J., & Cooley, E. (1996). Enhancing friendships and leisure involvement of students with traumatic brain injuries and other disabilities. In L. E. Powers, J. H. S. Singer, & J. Sowers (Eds.), *Promoting self-competence in children and youth with disabilities* (pp. 347-372). Baltimore: Paul H. Brookes.
- Sparrow, S. S., Balla, D., & Cicchetti, D. (1984). *The Vineland Adaptive Behavior Scales*. Circle Pines, MN: American Guidance Services.
- Stake, R. E. (1995). *The art of case study research*. Thousand Oaks: SAGE.
- Stake, R. E. (2005). Qualitative case studies. In N. K. Denzin & Y. V. Lincoln (Eds.), *The Sage handbook of qualitative research* (3rd ed., pp. 443-466). Thousand Oaks, CA: SAGE.
- Stake, R. E. (2006). *Multiple case study analysis*. New York: The Guilford Press.
- Stancin, T., Wade, S. L., Walz, N. C., Yeates, K. O., & Taylor, H. G. (2010). Family adaptation 18 months after traumatic brain injury in early childhood. *Journal of Developmental and Behavioral Pediatrics*, 31, 317-325. doi:10.1097/DBP.0b013e3181dbaf32
- State Services Commission. (2005). *All about the Treaty: The Treaty of Waitangi information programme*. Wellington, New Zealand: Author.
- Statistics New Zealand: Tatauranga Aotearoa. (n.d.). *Top statistics*. Retrieved 14th December, 2013, from http://www.stats.govt.nz/browse_for_stats/snapshots-of-nz/top-statistics.aspx
- Stewart, D. W., Shamdasani, P. N., & Rook, D. W. (2009). Group depth interviews: Focus group research. In L. Bickman & D. J. Rog (Eds.), *The Sage handbook of applied social research methods* (2nd ed.). Thousand Oaks, CA: SAGE.

- Stivers, J., Francis-Cropper, L., & Straus, M. (2008). Educating families about inclusive education: A month-by-month guide for teachers of inclusive classes. *Intervention in School and Clinic, 44*(1), 10-17. doi:10.1177/1053451208318683
- Stores, G., & Stores, R. (2013). Sleep disorders in children with traumatic brain injury: A case of serious neglect. *Developmental Medicine and Child Neurology, 55*(9), 797-805. doi:10.1111/dmcn.12163
- Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (2nd ed.). Thousand Oaks, CA: Sage.
- Stringer, E. T. (1996). *Action research: A handbook for practitioners*. Thousand Oaks, CA: SAGE.
- Subrahmanyam, K., Kraut, R. E., Greenfield, P. M., & Gross, E. F. (2000). The impact of home computer use on children's activities and development. *The Future of Children, 10*(2), 123-144. Retrieved from <http://www.futureofchildren.org/>
- Sullivan, J. R., & Riccio, C. A. (2010). Language functioning and deficits following pediatric traumatic brain injury. *Applied Neuropsychology, 17*(2), 93-98. doi:10.1080/09084281003708852
- Sutter, C., Ditto, G., & Peterson, J. (2008). Chalkboards and wheelchairs: Helping schools re-integrate the pediatric ABI patient. *Journal of Head Trauma Rehabilitation, 23*(5), 344. doi:10.1097/01.HTR.0000336857.44822.39
- Swaine, B. (2012). Participation following pediatric acquired brain injury and some inherent problems with outcome studies. *Developmental Medicine & Child Neurology, 54*, 296-297. doi:10.1111/j.1469-8749.2011.04210.x
- Swift, E. E., Taylor, G. H., Kaugars, A. S., Drotar, D., Yeates, K. O., Wade, S. L., & Stancin, T. (2003). Sibling relationships and behavior after pediatric traumatic brain injury. *Journal of Developmental and Behavioral Pediatrics, 24*, 24-30. Retrieved from <http://journals.lww.com/jrnldb/pages/default.aspx>
- Tan, T. S., & Cheung, W. S. (2008). Effects of computer collaborative group work on peer acceptance of a junior pupil with attention deficit hyperactivity disorder (ADHD). *Computers & Education, 50*(3), 725-741. doi:10.1016/j.compedu.2006.08.005
- Taylor, B. (2013a). Case study research. In B. Taylor & K. Francis (Eds.), *Qualitative research in the health sciences* (pp. 116-133). Retrieved from <http://www.routledge.com/>
- Taylor, B. (2013b). Introduction: Differentiating methodologies, methods and processes. In B. Taylor & K. Francis (Eds.), *Qualitative research in the health sciences* (pp. 3-29). Retrieved from <http://www.routledge.com/>
- Taylor, G. (1997). Community building in schools: Developing a circle of friends. *Educational and Child Psychology, 14*(3), 45-50. Retrieved from <http://www.bps.org.uk/decp/jeditions.cfm>

- Taylor, H. G. (2010). Neurobehavioral outcomes of pediatric traumatic brain injury. In V. Anderson & K. O. Yeates (Eds.), *Pediatric traumatic brain injury: New frontiers in clinical and translational research* (pp. 145-168). New York: Cambridge University Press.
- Taylor, H. G., Yeates, K. O., Wade, S. L., Drotar, D., Klein, S. K., & Stancin, T. (1999). Influences on first year recovery from traumatic brain injury in children. *Neuropsychology, 13*(1), 76-89. doi:10.1037/0894-4105.13.1.76
- Taylor, H. G., Yeates, K. O., Wade, S. L., Drotar, D., Stancin, T., & Burant, C. (2001). Bidirectional child-family influences on outcomes of traumatic brain injury in children. *Journal of the International Neuropsychological Society, 7*, 755-767. Retrieved from <http://journals.cambridge.org/action/displayJournal?jid=INS>
- Taylor, H. G., Yeates, K. O., Wade, S. L., Drotar, D., Stancin, T., & Minich, N. (2002). A prospective study of short- and long-term outcomes after traumatic brain injury in children: Behavior and achievement. *Neuropsychology, 16*(1), 15-27. Retrieved from <http://www.apa.org/pubs/journals/neu/index.aspx>
- Taylor, M. C. (2003). Evidence-based practice: Informing practice and critically evaluating related research. In G. Brown, S. A. Esdaile, & S. E. Ryan (Eds.), *Becoming an advanced healthcare practitioner* (pp. 118-144). Edinburgh: Butterworth Heinemann.
- Te Rangi Hiroa [P. H. Buck]. (1926). The Māori craft of netting. *Transactions and Proceedings of the Royal Society of New Zealand 1868-1961, 56*, 597-646. Retrieved from http://rsnz.natlib.govt.nz/volume/rsnz_56/rsnz_56_00_007290.html
- Teasdale, G., & Jennett, B. (1974). Assessment of coma and impaired consciousness: A practical scale. *Lancet, 2*(7872), 81-84. doi:10.1016/S0140-6736(74)91639-0
- Teasdale, G., Murray, G., Parker, L., & Jennett, B. (1979). Adding up the Glasgow Coma score. *Acta Neurochirurgica, 28* (Suppl.), 13-16.
- Tham, S. W., Palermo, T. M., Wang, J., Jaffe, K. M., Temkin, N., Durbin, D., & Rivara, F. P. (2013). Persistent pain in adolescents following traumatic brain injury. *Journal of Pain, 14*, 1242-1249. doi:10.1016/j.jpain.2013.05.007
- The Office for Disability Issues. (2007). *New Zealand Disability Strategy implementation review: 2001-2007*. Retrieved from <http://www.odi.govt.nz/nzds/index.html>
- The Waitangi Tribunal. (1988). *Report of the Waitangi Tribunal on the Muriwhenua fishing claim*. Retrieved from www.waitangi-tribunal.govt.nz
- Thickpenney-Davis, K. L., Ogden, J. A., & Fernando, K. (2005). The Starship Post-traumatic Amnesia Scale: Does it predict outcome after mild to moderate traumatic brain injury in children aged 3-7 years? *Brain Impairment, 6*, 101-108. Retrieved from <http://journals.cambridge.org/action/displayJournal?jid=BIM>

- Thomas-Stonell, N., Johnson, P., Rumney, P., Wright, V., & Oddson, B. (2006). An evaluation of the responsiveness of a comprehensive set of outcome measures for children and adolescents with traumatic brain injuries. *Pediatric Rehabilitation, 9*(1), 14-23. doi:10.1080/13638490500050097
- Tilford, J. M., Aitken, M. E., Anand, K. J. S., Green, J. W., Goodman, A. C., Parker, J. G., ... Adelson, P. D. (2005). Hospitalizations for critically ill children with traumatic brain injuries: A longitudinal analysis. *Critical Care Medicine, 33*(9), 2074-2081. doi:10.1097/01.CCM.0000171839.65687.F5
- Todis, B., Glang, A., & Fabry, M. A. (1997). Family-school-child: A qualitative study of the school experiences of students with ABI. In A. Glang, G. H. S. Singer, & B. Todis (Eds.), *Students with acquired brain injury: The school's response* (pp. 33-72). Baltimore: Paul H. Brookes.
- Tolman, C. W. (1999). Society versus context in individual development: Does theory make a difference? In Y. Engeström, R. Miettinen, & R.-L. Punamäki (Eds.), *Perspectives on activity theory* (pp. 70-86). Cambridge, United Kingdom: Cambridge University Press.
- Torbert, W. (1991). *The power of balance: Transforming self, society, and scientific inquiry*. Newbury Park, CA: SAGE.
- Townsend, E. A., Egan, M., Law, M., Manojlovich, M., & Head, B. (2007). Escalating participation in scholarly practice for enabling occupation. In E. A. Townsend & H. J. Polatajko (Eds.), *Enabling occupation II: Advancing an occupational therapy vision for health, well-being, and justice through occupation* (pp. 277-296). Ottawa, Canada: CAOT Publications ACE.
- Townsend, E. A., & Polatajko, H. J. (2007). *Enabling occupation II: Advancing an occupational therapy vision for health, well-being, and justice through occupation*. Ottawa, Ontario: CAOT Publications ACE.
- Tripp, A., French, R., & Sherrill, C. (1995). Contact theory and attitudes of children in physical education programs toward peers with disabilities. *Adapted Physical Activity Quarterly, 12*, 323-332. Retrieved from <http://www.APAQ-Journal.com>
- Turner-Stokes, L., Harding, R., Sergeant, J., Lupton, C., & McPherson, K. (2006). Generating the evidence base for the National Service Framework for long term conditions: A new research typology. *Clinical Medicine, 6*(1), 91-97. Retrieved from <http://www.rcplondon.ac.uk/publications/Clinical-Medicine/Pages/Clinical-Medicine.aspx>
- Ueda, S., & Okawa, Y. (2003). The subjective dimension of functioning and disability: What is it and what is it for? *Disability and Rehabilitation, 25*(11-12), 596-601. doi:10.1080/0963828031000137108
- UNESCO: United Nations Educational Scientific and Cultural Organization. (2012). *ISCED 1997 mappings*. Retrieved 7th December, 2013, from <http://www.uis.unesco.org/Education>

/ISCEDMappings/Pages/default.aspx

- Valois, R. F., Zullig, K. J., Huebner, E. S., & Drane, J. W. (2004). Physical activity behaviors and perceived life satisfaction among public high school adolescents. *Journal of School Health, 74*(2), 59-65. doi:10.1111/j.1746-1561.2004.tb04201.x
- Van Heugten, C. M., Hendriksen, J., Rasquin, S., Kijcks, B., Jaekin, D., & Vles, J. H. S. (2006). Long-term neuropsychological performance in a cohort of children and adolescents after severe paediatric traumatic brain injury. *Brain Injury, 20*(9), 895-903. doi:10.1080/02699050600832015
- van Tol, E., Gorter, J. W., Dematteo, C., & Meester-Delver, A. (2011). Participation outcomes for children with acquired brain injury: A narrative review. *Brain Injury, 25*, 1279-1287. doi:10.3109/02699052.2011.613089
- Vavilala, M. S., Muangman, S., Tontisirin, N., Fisk, D., Roscigno, C., Mitchell, P., ... Lam, A. M. (2006). Impaired cerebral autoregulation and 6-month outcome in children with severe traumatic brain injury: Preliminary findings. *Developmental Neuroscience, 28*(4-5), 348-353. doi:10.1159/000094161
- Verburg, G., Borthwick, B., Bennett, B., & Rumney, P. (2003). Online support to facilitate the reintegration of students with brain injury: Trials and errors. *Neurorehabilitation, 18*(2), 113-123. Retrieved from <http://www.iospress.nl/10538135.php>
- Vilela, T., Phillips, M., & Minnes, P. (2008). A comparison of challenges faced by parents of children with ABI with and without access to third party funding. *Developmental Neurorehabilitation, 11*, 149-158. doi:10.1080/017518420701780115
- von Benzon, N. (2010). Moving on from ramps? The utility of the social model of disability for facilitating experiences of nature for disabled children. *Disability & Society, 25*(5), 617-626. doi:10.1080/09687599.2010.489313
- Vu, J. A., Babikian, T., & Asarnow, R. F. (2011). Academic and language outcomes in children after traumatic brain injury: A meta-analysis. *Exceptional Children, 77*(3), 263-281. Retrieved from <http://www.cec.sped.org/Content/NavigationMenu/Publications2/ExceptionalChildren/>
- Vygotsky, L. S. (1978). *Mind in society: The development of higher psychological processes*. Cambridge, MA: Harvard University Press.
- Waaland, P., Burns, C., & Cockrell, J. (1993). Evaluation of the needs of high- and low-income families following paediatric traumatic brain injury. *Brain Injury, 7*(2), 135-146. doi:10.3109/02699059309008167
- Wachs, T. D. (1990). Must the physical environment be mediated by the social environment in order to influence development? A further test. *Journal of Applied Developmental*

- Psychology*, 11, 163-178. Retrieved from <http://www.journals.elsevier.com/journal-of-applied-developmental-psychology/>
- Wade, D. (2003). Community rehabilitation, or rehabilitation in the community? *Disability and Rehabilitation*, 25(15), 875-881. doi:10.1080/0963828031000122267
- Wade, D. T. (2001). Community rehabilitation. *Clinical Rehabilitation*, 15(6), 575-581. doi:10.1191/0269215501cr449ed
- Wade, S. L., Cassedy, A., Walz, N. C., Taylor, H. G., Stancin, T., & Yeates, K. O. (2011). The relationship of parental warm responsiveness and negativity to emerging behavior problems following traumatic brain injury. *Developmental Psychology*, 47, 119-133. doi:10.1037/a0021028
- Wade, S. L., Michaud, L., & Brown, T. M. (2006). Putting the pieces together: Preliminary efficacy of a family problem-solving intervention for children with traumatic brain injury. *Journal of Head Trauma Rehabilitation: Focus on Clinical Research and Practice*, 21(1), 57-67. Retrieved from <http://www.headtraumarehab.com/>
- Wade, S. L., Oberjohn, K., Burkhardt, A., & Greenberg, I. (2009). Feasibility and preliminary efficacy of a web-based parenting skills program for young children with traumatic brain injury. *Journal of Head Trauma Rehabilitation*, 24(4), 239-247. Retrieved from <http://www.headtraumarehab.com/>
- Wade, S. L., Taylor, G. H., Drotar, D., Stancin, T., & Yeates, K. O. (1998). Family burden and adaptation during the initial year after traumatic brain injury in children. *Pediatrics*, 102(1), 110-116. Retrieved from <http://pediatrics.aappublications.org/>
- Wade, S. L., Taylor, G. H., Yeates, K. O., Drotar, D., Stancin, T., Minich, N. M., & Schluchter, M. (2006). Long-term parental and family adaptation following pediatric brain injury. *Journal of Pediatric Psychology*, 31(10), 1072-1083. doi:10.1093/jpepsy/jsj077
- Wade, S. L., Taylor, H. G., Drotar, D., Stancin, T., Yeates, K. O., & Minich, N. M. (2003). Parent-adolescent interactions after traumatic brain injury. *Journal of Head Trauma Rehabilitation*, 18, 164-176. doi:10.1097/00001199-200303000-00007
- Wade, S. L., Walz, N. C., Carey, J. C., & Williams, K. M. (2009). Brief report: Description of feasibility and satisfaction findings from an innovative online family problem-solving intervention for adolescents following traumatic brain injury. *Journal of Pediatric Psychology*, 34(5), 517-522. doi:10.1093/jpepsy/jsn081
- Wade, S. L., Wolfe, C. R., Maines Brown, T., & Pestian, J. P. (2005). Can a web-based family problem-solving intervention work for children with traumatic brain injury? *Rehabilitation Psychology*, 50, 337-345. doi:10.1037/0090-5550.50.4.337

- Wake, Y., & Reeves, S. (2012). Factors that influence obesity in children at primary schools in England and France. *International Journal of Health Promotion and Education, 50*, 2-9. doi:10.1080/14635240.2012.661951
- Walker, P. (1990). *Resources on integrated recreation/leisure opportunities for children and teens with developmental disabilities*. Syracuse, NY: Syracuse University.
- Walker, T. (2006). *Whānau is whānau*. Retrieved from <http://www.familiescommission.org.nz/publications/research-reports/whānau-is-whānau>
- Wells, G. (1981). *Learning through interaction: The study of language development*. New York: Cambridge University Press.
- Werts, M. G., Caldwell, N. K., & Wolery, M. (1996). Peer modeling of response chains: Observational learning by students with disabilities. *Journal of Applied Behavior Analysis, 29*(1), 53-66. Retrieved from <http://seab.envmed.rochester.edu/jaba/>
- Wetjen, N. M., Pichelmann, M. A., & Atkinson, J. L. D. (2010). Second impact syndrome: Concussion and second injury brain complications. *Journal of the American College of Surgeons, 211*, 553-557. doi:<http://dx.doi.org/10.1016/j.jamcollsurg.2010.05.020>
- Wheeldon, J., & Faubert, J. (2009). Framing experience: Concept maps, mind maps, and data collection in qualitative research. *International Journal of Qualitative Methods, 8*, 68-83. Retrieved from <http://www.ualberta.ca/~ijqm/>
- White, H. C. (1992). Cases are for identity, for explanation, or for control. In C. C. Ragin & H. W. Becker (Eds.), *What is a case? Exploring the foundations of social inquiry* (pp. 83-104). Cambridge: Cambridge University Press.
- Whiting, L. (2009). Systematic review protocols: An introduction. *Nurse Researcher, 17*(1), 34-43. Retrieved from <http://nurseresearcher.rcnpublishing.co.uk>
- Whittemore, R., & Knafl, K. (2005). The integrative review: Updated methodology. *Journal of Advanced Nursing, 52*(5), 546-553. doi:10.1111/j.1365-2648.2005.03621.x
- Wilhite, B., Mushett, C. A., Goldenberg, L., & Trader, B. R. (1997). Promoting inclusive sport and leisure participation: Evaluation of the Paralympic Day in the Schools model. *Adapted Physical Activity Quarterly, 14*(2), 131-146. Retrieved from <http://hk.humankinetics.com/APAQ/journalAbout.cfm>
- Wilkening, G. N. (1997). Long-term outcome after moderate to severe pediatric traumatic brain injury. In E. D. Bigler, E. Clark, & J. E. Farmer (Eds.), *Childhood traumatic brain injury: Diagnosis, assessment, and intervention*. (pp. 79-100). Austin, Texas: PRO-ED.
- Wong, D. K. P. (2008). Do contacts make a difference? The effects of mainstreaming on student attitudes toward people with disabilities. *Research in Developmental Disabilities, 29*(1), 70-82. doi:10.1016/j.ridd.2006.11.002

- Wongvatunyu, S., & Porter, E. (2005). Mothers' experience of helping young adults with traumatic brain injury. *Journal of Nursing Scholarship*, 37(1), 48-56. Retrieved from <http://www.nursingsociety.org/Publications/Pages/JNS2.aspx>
- Woods, D. T., Catroppa, C., Barnett, P., & Anderson, V. A. (2011). Parental disciplinary practices following acquired brain injury in children. *Developmental Neurorehabilitation*, 14, 272-282. doi:10.3109/17518423.2011.586371
- Woods, D. T., Catroppa, C., Giallo, R., Matthews, J., & Anderson, V. A. (2012). Feasibility and consumer satisfaction ratings following an intervention for families who have a child with acquired brain injury. *NeuroRehabilitation*, 30, 189-198. doi:10.3233/NRE-2012-0744
- Woolfson, L. (2004). Family well-being and disabled children: A psychosocial model of disability-related child behaviour problems. *British Journal of Health Psychology*, 9, 1-13. doi:10.1348/135910704322778687
- World Health Organization. (2001). *International classification of functioning, disability and health (ICF)*. Geneva, Switzerland: Author.
- World Health Organization. (2007). *International classification of functioning, disability and health: Child and youth version: ICF-CY*. Geneva, Switzerland: Author.
- World Health Organization. (2013). *World Health Organization action plan 2014-2021: 'Better health for persons with disabilities'*. Retrieved 17th November, from http://www.who.int/disabilities/policies/actionplan/disability_action_plan_en.pdf
- Yeates, K. O., Bigler, E. D., Gerhardt, C. A., Rubin, K. H., Stancin, T., Taylor, H. G., & Vannatta, K. (2012). Theoretical approaches to understanding social function in childhood brain insults: Towards the integration of social neuroscience and developmental psychology. In V. Anderson & M. H. Beauchamp (Eds.), *Developmental social neuroscience and childhood brain insult: Theory and practice* (pp. 207-230). New York: Guilford Press.
- Yeates, K. O., Swift, E., Taylor, H. G., Wade, S. L., Drotar, D., Stancin, T., & Minich, N. (2004). Short-and long-term social outcomes following pediatric traumatic brain injury. *Journal of the International Neuropsychological Society*, 10, 412-426. doi:10.1017/S1355617704103093
- Yeates, K. O., Taylor, H. G., Barry, C. T., Drotar, D., Wade, S. L., & Stancin, T. (2001). Neurobehavioral symptoms in childhood closed-head injuries: Changes in prevalence and correlates during the first year postinjury. *Journal of Pediatric Psychology*, 26(2), 79-91. doi: 10.1093/jpepsy/26.2.79
- Yeates, K. O., Taylor, H. G., Drotar, D., Wade, S., Stancin, T., & Klein, S. (1997). Preinjury family environment as a determinant of recovery from traumatic brain injury in school-age

- children. *Journal of the International Neuropsychological Society*, 3, 617-630. Retrieved from <http://journals.cambridge.org/action/displayJournal?jid=INS>
- Yeates, K. O., Taylor, H. G., Walz, N. C., Stancin, T., & Wade, S. L. (2010). The family environment as a moderator of psychosocial outcomes following traumatic brain injury in young children. *Neuropsychology*, 24, 345-356. doi:10.1037/a0018387
- Yeates, K. O., Taylor, H. G., Woodrome, S. E., Wade, S. L., Stancin, T., & Drotar, D. (2002). Race as a moderator of parent and family outcomes following pediatric traumatic brain injury. *Journal of Pediatric Psychology*, 27, 393-403. doi:10.1093/jpepsy/27.4.393
- Yerxa, E. J., Clark, F., Frank, G., Jackson, J., Parham, D., Pierce, D., ... Zemke, R. (1990). An introduction to occupational science, a foundation for occupational therapy in the 21st century. *Occupational Therapy in Health Care*, 6(4), 1-17. doi: 10.1300/J003v06n04_04
- Yin, R. K. (2003a). *Applications of case study research* (2nd ed., Vol. 34). Thousand Oaks, CA: SAGE.
- Yin, R. K. (2003b). *Case study research: Design and methods* (3rd ed.). Thousand Oaks, CA: SAGE.
- Yin, R. K. (2009). *Case study research: Design and methods* (4th ed.). Los Angeles: SAGE.
- Yin, R. K. (2014). *Case study research: Design and methods* (5th ed.). Thousand Oaks, CA: SAGE.
- Ylvisaker, M. (1998). Traumatic brain injury in children and adolescents: Introduction. In M. Ylvisaker (Ed.), *Traumatic brain injury rehabilitation: Children and adolescents* (2nd ed., pp. 1-10). Newton, MA: Butterworth-Heinemann.
- Ylvisaker, M. (2006). Self coaching: A context sensitive, person-centred approach to social communication after traumatic brain injury. *Brain Impairment*, 7, 246-258. doi:10.1375/brim.7.3.246
- Ylvisaker, M., Adelson, D., Braga, L. W., Burnett, S. M., Glang, A., Feeney, T., ... Todis, B. (2005). Rehabilitation and ongoing support after pediatric TBI: Twenty years of progress. *Journal of Head Trauma Rehabilitation*, 20(1), 95-109. doi:10.1097/00001199-200501000-00009
- Ylvisaker, M., & Feeney, T. (2007). Pediatric brain injury: Social, behavioral, and communication disability. *Physical Medicine and Rehabilitation Clinics of North America*, 18, 133-144. doi:10.1016/j.pmr.2006.11.007
- Ylvisaker, M., & Feeney, T. J. (1998). *Collaborative brain injury intervention: Positive everyday routines*. San Diego: Singular Publishing Group.
- Ylvisaker, M., Hanks, R., & Johnson-Greene, D. (2002). Perspectives on rehabilitation of individuals with cognitive impairment after brain injury: Rationale for reconsideration of

- theoretical paradigms. *Journal of Head Trauma Rehabilitation*, 17, 191-209. doi:10.1097/00001199-200206000-00002
- Ylvisaker, M., Shaughnessy, M. F., & Greathouse, D. (2002). An interview with Mark Ylvisaker about students with traumatic brain injury. *North American Journal of Psychology*, 4, 291-308. Retrieved from <http://najp.8m.com/>
- Ylvisaker, M., Szekeres, S. F., & Feeney, T. J. (1998). Cognitive rehabilitation: Executive functions. In M. Ylvisaker (Ed.), *Traumatic brain injury rehabilitation: Children and adolescents* (2nd ed., pp. 221-265). Boston: Butterworth-Heinemann.
- Ylvisaker, M., Szekeres, S. F., & Haarbauer-Krupa, J. (1998). Cognitive rehabilitation: Organization, memory, and language. In M. Ylvisaker (Ed.), *Traumatic brain injury rehabilitation: Children and adolescents* (2nd ed., pp. 181-220). Newton, MA: Butterworth-Heinemann.
- York, J., & Vandercook, T. (1990). Strategies for achieving an integrated education for middle school students with severe disabilities. *Remedial and Special Education (RASE)*, 11(5), 6-16. doi:10.1177/074193259001100503
- Zambon, A., Morgan, A. K., Vereecken, C., Colombini, S., Boyce, W., Mazur, J., ... Cavallo, F. (2010). The contribution of club participation to adolescent health: Evidence from six countries. *Journal of Epidemiology and Community Health*, 64, 89-95. doi:10.1136/jech.2009.088443

Glossary of Aotearoa New Zealand Māori Terminology (Te Reo)²⁸

New Zealand Māori Term (Te Reo Māori)	English Translation
Aotearoa	The Māori name for New Zealand
Aroha	“Affection”, “love”
Haka	“Posture dance - vigorous dances with actions and rhythmically shouted words. A general term for several types of such dances”
Hapu	“Kinship group, clan, tribe, subtribe”
Harakeke	“New Zealand flax” plant
Hinaki	“Eel trap”
Hōhā	To “be boring” or “tiresome”
Hui	A “gathering, meeting, assembly, seminar, or conference”
Iwi	“Extended kinship group” or “tribe”
Kaitiakitanga	“Guardianship, stewardship”
Kaharoa	Very long seine net made in sections by families in a community or villages (Fama, 1937; Paulin, 2007)
Kahararo	Rope along the bottom of a fishing net (Best, 1934; The Waitangi Tribunal, 1988)
Kaharunga	Rope along the top of a fishing net (Best, 1934; The Waitangi Tribunal, 1988)
Kahawai	“An edible greenish-blue to silvery-white schooling coastal fish”
Kanohi ki te kanohi	“Face to face”
Kapa haka	“Concert party, haka group, Māori cultural group, Māori performing group”

²⁸ Unless otherwise stated, translations are those used in the New Zealand Māori Dictionary (Moorfield, n.d.)

Karakia	“Ritual” or “chant” (noun). “To recite rituals or chants”, or “to pray” (verb)
Karanga	“Formal call, ceremonial call - a ceremonial call of welcome to visitors onto a marae”
Kaumātua	“Elder”
Marae	“Open area” at the front of a meeting house
Mata	Mesh of a net (Te Rangi Hiroa [P. H. Buck], 1926)
Mata haere	Wide mesh (Te Rangi Hiroa [P. H. Buck], 1926)
Mata kutikuti	Narrow mesh (Te Rangi Hiroa [P. H. Buck], 1926)
Ngakau	Loop or a supporting strand from which a net is formed (Te Rangi Hiroa [P. H. Buck], 1926)
Pākehā	Refers to New Zealanders of European descent. “Exotic – introduced from or originating in a foreign country”
Paki	“To slap, pat, clap, strike together, make a clapping noise”
Poi	“Light ball on a string of varying length which is swung or twirled rhythmically to sung accompaniment”
Rerekētanga	Honoring differences (personal communication, Whāea Louise Elia, November 14, 2013)
Ta kupenga	“Net-making” (Te Rangi Hiroa [P. H. Buck], 1926, p. 600). Advice from a cultural mentor is also that in some dialects, net-making may be referred to as te kupenga (Personal communication, Whāea Louise Elia, November 14, 2013).
Tangi	“Rites for the dead, funeral - shortened form of <i>tangihanga</i> ”
Taha wairua	“The spiritual side” (Durie, 1998, p. 69)
Taha hinengaro	“The mental side” (Durie, 1998, p. 69)
Taha tinana	“The physical side” (Durie, 1998, p. 69)
Taha whānau	“The extended family side” (Durie, 1998, p. 69)
Tamariki	“Children”

Tūpato	“Be cautious” or “careful” (verb). “Caution (noun)”
Tapu	“Sacred”
Te Reo Māori	The Māori language
Te Tiriti o Waitangi	The Treaty of Waitangi (New Zealand’s founding document). A document signed between many of the Māori chiefs and representatives of the British monarchy in 1840 (Orange, 2004).
Te Waka Oranga	An intervention approach developed for working with Māori children and adolescents after TBI (Elder, 2013). Literal translation is the canoe of healing or health (Elder, 2013).
Tikanga	“Correct procedure or custom”
Tuarā	“To assist, help”, or “support”
Turangawaewae	“Place where one has rights of residence and belonging through kinship and genealogy”
Waiata	“Song, chant”, or “psalm”.
Waka ama	“Outrigger canoe”
Whāea	Mother, aunt, aunty
Whaikōrero	Formal speech
Whakapapa	“Genealogy”
Whānau	“Extended family, family group”
Whare tapa whā	“Four sided house” (Durie, 1998, p. 68)

Glossary of Terminology

Term Used in Thesis	Definition
Assent	An affirmative agreement by a child that they wish to take part in a study (Peart & Holdaway, 2000)
Assertions	The overarching findings of a group of case studies that relate to a phenomenon of interest (Stake, 2006)
Assertion Statements	Statements that are “a researcher’s summary of interpretations and claims” (Stake, 1995, p. 169)
Category	A group of ideas in data which are similar or which contribute to a similar idea (Merriam, 2009)
Conceptual structure	“Big ideas or themes giving focus to a study” (Stake, 1995, p. 170). The conceptual structure is typically built around issue statements
Cross case analysis	An analysis of findings across individual cases in a multi-case or instrumental case study to develop assertions about the cases (Stake, 2006). The analysis considers the themes that link the cases together, the uniqueness of different cases, the utility of cases to generate information about the themes, and the findings of the cases
Findings Strips	Findings from individual cases that are part of a cross-case analysis. Each finding is printed onto paper or card, then cut apart from the others onto its own strip (Stake, 2006)
Informed consent	A free and informed decision is made about whether or not to take part in a study. “Informed consent has two basic components. (a) The decision is informed by adequate understanding of any information that is relevant to that decision. (b) The decision is voluntary, and is therefore free from undue influence such as manipulation or coercion.” (National Ethics Advisory Committee, 2012a, p. 20)
Instrumentalism	“The view that a scientific theory is to be regarded as an instrument for producing new predictions or new techniques for controlling events, but not as itself capable of literal truth or falsity” (Blackburn, 2005, p. 187)
Instrumental case study	“Research on a case to gain understanding of something else” (Stake, 1995, p. 171). The case is used to generate information about a wider issue

Intervention approach	A group of specified strategies that aim to address a particular outcome
Intrinsic case study	“When the case itself is of primary, not secondary, interest” (Stake, 1995, p. 171)
Issue statements	Questions and/or statements (propositions) about the main concepts which are the concern of a case study
Locality Provider	A locality which provides resources or information to assist with carrying out a research project (e.g. support for recruitment processes)
Merged Findings	Findings from different cases in a cross-case analysis that are integrated into groups around similar topics (Stake, 2006)
Naturalistic	Aligns with the assumptions of naturalism. Naturalism is a philosophical position that believes that everything derives from the natural world and can be explained using the methods of the natural sciences. Supernatural or spiritual explanations of phenomena, and mind-body dualism are rejected (Blackburn, 2005)
Occupation	“An activity or set of activities that is performed with some consistency and regularity, that brings structure, and is given value and meaning by individuals and a culture” (Polatajko et al., 2013, p. 19)
Open coding	A stage of qualitative data analysis when data are read and notations are made about a range of potential meanings that might relate to the research question. The coding is open because the researcher remains open to possibilities (Merriam, 2009)
Positivist	A philosophy of science. As such it stands squarely within the empiricist tradition. Metaphysical speculation is rejected in favor of ‘positive’ knowledge based on systematic observation and experiment. The methods of science can give us knowledge of the laws of coexistence and succession of phenomena, but can never penetrate to the inner ‘essences’ or ‘natures’ of things (Scott & Marshall, 2009)
Pragmatist philosophy	“The philosophy of meaning and truth especially associated with Peirce and James....The core is the belief that the meaning of a doctrine is the same as the practical

effects of adopting it” (Blackburn, 2005, p. 287). Dewey progressed the pragmatism of Peirce and James, significantly influencing education and democracy, and understandings about inquiry (Blackburn, 2005)

Proxy Consent	“If a person is not competent to make an informed decision about participating in a therapeutic study, then the decision may be made by an individual who is legally entitled to decide on behalf of that person.” (National Ethics Advisory Committee, 2012a, p. 24)
Purposive Sampling	A form of sampling in which “decisions concerning the individuals to be included in the sample are taken by the researcher, based on a variety of criteria which may include specialist knowledge of the research issue, or capacity and willingness to participate in the research” (Jupp, 2006, p. 244)
Reductionism	“Any intellectual strategy for reducing apparently diverse phenomena to some primary or basic explanatory principle” (Scott & Marshall, 2009)
Shared Occupation	Taking part alongside others in an activity or activities that hold meaning
Strategy:	A means or a method used to achieve a goal
Structuralist	The common feature of structuralist positions is the belief that phenomena of human life are not intelligible except through their interrelations. These relations constitute a structure, and behind local variations in the surface phenomena there are constant laws of abstract structure (Blackburn, 2005, p. 353)
Themes	“Binding concepts ... that string the cases together” in a cross-case analysis (Stake, 2006, p. 39). Themes may be an “issue, phenomenon, or functional relationship” (p. 39). The original research questions were used as the themes for the cross case analysis in the present study. For this study, the term is also used outside the context of case study methodology to refer to a topic or group of ideas that have a common central concept
Therapeutic Groupings	The classification of a group of similar strategies according to therapeutic considerations drawn from occupational therapy literature

Topical questions	Questions that are developed around the information sought from different data sources (Stake, 1995)
Transaction	The knowing-known taken as one process in cases in which in older discussions the knowing and known are separated and viewed as in interaction. The knowns and the named in their turn taken as phases of a common process in cases in which otherwise they have been viewed as separated components, allotted irregular degrees of independence, and examined in the form of interactions (Dewey & Bentley, 1949b, p. 304)
Triangulation	“A means of cross-checking the relevance and significance of issues or testing out arguments and perspectives from different angles to generate and strengthen evidence in support of key claims” (Simons, 2009, p. 129)



DRAFT

"FIT & CONNECT"

**A KitSet to Help Children
Participate after Traumatic
Brain Injury**



Background

- The KitSet has been developed from studies completed with Aotearoa New Zealand children aged 9-12 years old who have had traumatic brain injuries, and with families, teachers, and community supports.
- The information from the studies forms the basis for commonsense strategies that can be used to support their participation. Literature provides further evidence for a number of the strategies.
- The KitSet can be applied to Participation in activities with whānau/family, activities at school, and activities in the wider community.
- The KitSet is developed for use by Whānau/Family, Friends, Schools, and Community Support People. While all the strategies aim to support participation, they are formulated as a KitSet so that people can select the strategies they feel are appropriate for them to implement with a particular Activity at a particular point in time.
- The Focus of the KitSet is on working with the Community to improve participation. There are a number of other approaches available that focus on developing the skills of the child to enhance participation. Strategies in the KitSet do not preclude the use of these Child-focussed approaches, and they may be delivered concurrently.

What is Participation?

Sharing in Meaningful Activities with Others

This image has been removed by the author of this thesis for copyright reasons

"...how he fits into the scheme of things" (Julie, 2010).

"...James and Matthew made a hoop out the backyard, last week, and then he just gets James up on the ladder to paint it, but he was a bit wary of that, but you know just little things like getting the hammer out, he does a lot of things like that with him...Yeah, they do a lot of bike riding. They ran, they went for a run um, last week I think it was, or the week before.....Yeah. Like he does boy's things, like takes him to (hardware store) and like you know that kind of stuff? Or takes him down to a rugby, to watch a rugby game or, but real boy things so the whole, three of them like and Sammy, they all just go and do boy things" (Julie, 2010).

Why is Participation Important for Children after a Traumatic Brain Injury?

- Building & Strengthening Social Networks
- Context for Developing Friendships
- Provides Opportunities for new Experiences
- Essential for Learning & Skill Development
- Rehabilitation of Function
- Necessary for Health
- Neurological Development

Anderson & Catroppa, 2006; Bell, Pellis, & Kolb, 2010; Law, 2002; Lewis & Carpendale, 2009; World Health Organization, 2007)

What are Important Aspects of Participation?

FIT

CONNECTION & EXCHANGE

BALANCE

CHANGE



FIT of PEOPLE & CONTEXT

- Fit with Place
- Fit with Time
- Fit with Activity
- Fit with Others' Understandings
- Fit with Others' Actions
- MISFIT of people, environment, occupation & time limits Participation.

CONNECTION & EXCHANGE BETWEEN PEOPLE & CONTEXT

Children's Participation is Connected with the Participation of their Whānau,/Family and others in their Community

When People Share in meaningful Activities with others, there is an Exchange of information about the activity, those involved, their actions, and their experiences.

Exchange of information can support FIT for those involved.

Exchange also has the potential to strengthen & extend CONNECTIONS, creating new Opportunities for Participation

BALANCE OF SHARED ACTIVITIES

The Degree of Fit and the Strength & Extent of Connections

influences the pattern of Activities children are involved with, and the people with whom they share them. More time may be spent in Activities where there are CONNECTIONS & FIT, and less time where there are no opportunities, or where there is MISFIT. This can create IMBALANCES in Participation & reduces satisfaction.

CHANGE

- Takes place both suddenly and over time in people and places.
- Can Influence Participation for Good & for Bad.
- Happens to ALL those Participating through their Participation.
- The Possibility of Change means Participation can be Improved.

Aiden's Grandparents talk together about his Participation

...He feels comfortable, he interacts with [his cousins] really, really, really well and you're talking from say 3, through to 12... he feels comfortable in that realm... when he's with his own relations, his whānau... because as I say, he's probably grown up with them, he's mixing with his first cousins...They're just treated, they're treated as a whole it's, um, probably because they're all just treated the same... yeah they're all the treated as a whole...

It's not as though he's left out at any stage.

... Because they've just known him all the way through... as he is.

Through the years I've explained to them too that you know, you've got to include Aiden in these things. I used to have to sit down and say hey listen, you know Aiden's been through a bit of trauma in his life, you've got to, you know you've got to look after him, take care, and, include him in your games and stuff like that... have a bit of patience with him. And they, and they start to realise that you know. So just explaining that to them, through the years you know when they were growing up and they're sort of starting to cotton on now.....

I try and promote Aiden mixing, mixing with other kids outside the family. I don't go and look for it but, at the same time like, when he's here.

You'll quite often ring up, one of the boys down the road and say oh would you like to come up here.

Yeah, now Daniel is up there, which I'll probably get him down for a couple of days because I think it is, I just think it is important for Aiden to, to just spread his wings a bit further.

Mix with other kids.

Just, have those other outlets, you know what I mean? Where, I guess I'm of the opinion where if something shuts down in one area, there's other avenues. And, and like, if he can, it opens a whole new door for him, regarding others... It's just another avenue for him...

The other day Daniel had been with Aiden all day and he'd actually taken his socks and shoes off like Aiden does.

And Daniel's on the trampoline and he's got his t-shirt off too... So it was a bit like, ... you've got Aiden on the other side teaching Daniel a thing or too as well. (Jim and Erana, 2010)

Changes After a Child has a Traumatic Brain Injury can Limit Participation

- Change in Child and Whānau/Family
- Change in Place
- Change in Routines
- Interrupted Participation
- Misfit
- Disconnection
- Reduced Opportunities
- Imbalances and dissatisfaction

"Sports? A big change. Robbie swam twice a week. He played soccer on Saturdays with two trainings. He played t-ball, he played tennis on Wednesdays. And all that stopped. All of it. So he's gone from, usually having a sport every, at least every second day during the week, some days, he'd have tennis and swimming on the same day. But um yeah he went from being a very active, boy...To nothing. It was a big struggle for him. He loved soccer. And it wasn't necessarily just the game. He loved playing, so now he, now that he knows he can't play... he hasn't kicked a soccer ball since. Not even in the yard... It might be being part of a team, because they were a good little team. They were doing very well, and he was little compared to the other boys in his team, but he was still as fast and, he still got goals and, yeah he just liked it. The winning and achieving and..." (Lynne, 2009)

Important Features of Participation Interventions

- Begin Straight Away!
- Meaningful Activity should be Central
- The Activity is one Shared With other Adults & Children
- The Child has a Say
- The Child and Significant Others are Satisfied with the Participation
- Participation Experiences are Shared.
- Quality not Quantity
- Focus on Fit not Difference; Being "A Part" not Being "Apart"
- Flexible
- Do-Able

KitSet Goals

The Strategies Contained in the KitSet aim to Increase Satisfaction with a Child's Participation after they have had a Traumatic Brain Injury by:

- Improving the Fit amongst a Child, the Physical Context of a Meaningful Activity, the Timing of the Activity, the Activity itself, Other's Understandings, and Other's Actions.
- Maintaining and Building New Connections
- Facilitating Increased Opportunities for Participation

Strategies in the KitSet

- 1) Connecting for Participation Opportunities
- 2) Planning for Participation
- 3) Teaming for Participation
- 4) Maintaining Connections
- 5) Position for Participation
- 6) Activities for Participation
- 7) Information Exchange
- 8) Participating with Other Children
- 9) Participating with Adults

1) CONNECTING FOR FAMILIAR AND NEW PARTICIPATION OPPORTUNITIES

A CONNECTION GOES TWO WAYS!

As a child moves through the rehabilitation process, Connections with whānau, extended family, friends, the school, and people in the community all play a very important role in providing ongoing opportunities for participation. Maintaining and building these Connections is necessary to support a child's rehabilitation and their involvement for the longer term. Connection is also essential for others in the community to learn about changes and how to be involved. This process needs input not only from whānau/family, but also from the wider community. It needs to continue over time.



BEGIN STRAIGHT AWAY!

At earlier stages in their rehabilitation, children are happy to watch and just be with their peers, while at other times, children are ready to be more involved in an activity. What is important is that people provide them with time to share in an activity with others from their family and community. Begin early on in the rehabilitation process to talk with the child, their friends and family, and others from their community about their interests, activities they would like to try out, and activities they have enjoyed at school. As the child is able, seek out, take, and set up small opportunities for visits from others, and outings. Communication aids and other media can help the child's involvement.

ENERGY AND SAFETY

When considering Opportunities for Participation, it is necessary to take into account a child's energy levels after participating in educational & other activities, so Quality not Quantity is important, as is the Timing of sessions. Within reason, children may have some safety restrictions. If you are unsure if an activity is Safe for your child, contact the neurologist or rehabilitation specialist.

FORMALISING THE PROCESS

It can be helpful to formally develop a list of a child's Participation preferences, Participation Opportunities and contacts that are available in your community (Appendix to be Inserted). Some New Zealand community groups are pro-active in catering for a range of abilities, and it is useful to share information about these groups with other parents.

Appendix could be a Sheet with a Table to help work out Activity Preferences, Important Connections, and ways these could be formed or maintained.

2) PLANNING FOR PARTICIPATION

ONE ACTIVITY AT A TIME

Participation in an activity is more likely to be successful if there is some prior planning. Activities vary in terms of the setting, timing, what's involved, who's involved, and how flexible all these things are. This means that rather than trying to increase participation across a whole range of activities, focus on *One Activity at a Time*. This might be participation in a class-room activity, an activity in the playground, a social activity at the weekend, an activity at school camp, a cultural activity, or a sports-based activity. When this is working well, then you can focus on another activity if that is needed.

CHECK IT OUT

To plan for Participation in an Activity, some background information is required. Check out the Physical Setting, Time Frames involved (when, how long, what activities happen next), What the children will be doing, and Who else is involved (other children and other adults). Explore how things such as the Setting, Times, and Activities can be changed or adjusted to Fit with the child's abilities. Also think about how well the others involved know the child and their abilities, and whether they can support their involvement in some way. When other adults and children share in an activity with a child, this is how they begin to learn about what to do to help them be included.

ALLOW TIME

Planning needs to be specific, and takes time. It can be really difficult to check out and organize things at short notice, so whenever possible, begin planning early on. This way, the team can work together to come up with solutions that Fit.

EXAMPLE

Jonathan was going on the school camp, and it was decided with his teacher for his father to go with him. At the camp, an adventure tramp was organized as the first activity of the day. Jonathan enjoyed walking, and although he needed a bit of extra time to get places, and some reminders of obstacles, he was looking forward to going. As it happened, information that the walk was happening was not communicated to Jonathan and his father until that morning. The class with the teachers and parent-helps needed to finish the walk within an hour so they could be ready for the next activity, and the walk included some steep ground. As there were concerns that Jonathan couldn't finish the walk quickly enough, and might not cope safely with the steep bits, his teacher decided it would be best if he stayed behind. Jonathan and his father were disappointed.

How could this have been planned so that Jonathan could have shared in the activity with other adults and children?

This image has been removed by the author of this thesis for copyright reasons

3) TEAMING FOR PARTICIPATION

A TEAM IS 2 OR MORE PEOPLE

Setting up for a child to Participate in an activity can be really challenging on your own. This is where Connections are great. Having another person or a small group shares the responsibility, and can contribute additional experience, skills and information.

WHO CAN BE ON THE TEAM?

It depends on the activity. Parents /whānau are usually the first involved, or if the Participation involves a school-based activity, it may begin with a teacher. The child themselves, and sometimes other children should be part of the team; they may be consulted first, or after some adult-team discussion. Sometimes there is a key support person, such as a family friend, a community caregiver or a teacher aide. If there is a key person involved with the activity, such as a coach for a sports activity, or a bus-driver when learning to walk home from school, they might be the first person to approach.

FORMAL OR INFORMAL?

Sometimes, a formal planning session may be needed (Bernabe & Block, 1994). This involves coordinating a meeting where those involved are invited and there is a formal goal-setting and problem solving process. Formal team planning for Participation may be incorporated with an Individual Education Plan (an IEP) at school, or as part of Rehabilitation Planning. At other times, an informal discussion is fine to work things through.

STAYING IN TOUCH

Communication is essential to good Teaming and Connection. When people have busy schedules, it is helpful to be able to get hold of others in the team easily to give an update, or to raise an issue or a new idea. Identify the most efficient and reliable ways and times to contact each other, and regularly review your communication strategies.

ROLES

Think about who might be responsible for what on the team. Who will drive this process? Is there someone on the team who can check out the activity and the context? Is there somebody who can talk with the child and, if appropriate, other children about the plan? Who can oversee any changes that need to be made? And who would be a good person to monitor the child's participation?

4) MAINTAINING PARTICIPATION CONNECTIONS

Participation is hard if you are not there! After a Traumatic Brain Injury, children may spend time in hospital, in rehabilitation, or may need time away for medical procedures. Sometimes, they may not be able to cope with being present for the full duration of activities, and need a rest. And sometimes, rehabilitation activities need to take place, with potential interruptions to participation in other routines.

BRINGING PARTICIPATION TO THE CHILD

When the child is away from those with whom they usually share participation, there are some things that those people can do to help maintain those connections and support Participation from a distance. Visiting is a way of directly facilitating sharing in an activity (i.e. the visitors share in the rehabilitation activity!). In the early phases of the rehabilitation process however, visiting does need to be responsive to the child's need for rest, and visitors should check with parents and staff first if they are comfortable for this to happen. Classmates can keep in contact and share participation experiences via email and other technologies such as web-cams, Facebook, or phone. Classes or teams can put together posters of activities the class has been doing, with messages, letters, photos and drawings. Continuity of shared participation experiences facilitates ongoing participation as the child returns home.

PARTICIPATION FOR REST TIMES

Fatigue is a common symptom after Traumatic Brain Injury and rest is important. However going away, or going out for a rest singles the child out, and reduces participation alongside peers. When Rest-Times need to happen away from usual participation settings (eg. going home from school for a rest) it can be helpful to share information about the need for rest with others who are involved. Share the information in a way that normalizes the experience, and helps children link this need with their own experience of being tired. Often, the rest-times can be usefully be incorporated into the normal school routine, and it might be possible for 1-2 other children to share in the rest activity. Going to a quiet area close to the classroom, and using relaxation techniques, or listening to a very quiet tape of music or a story is a way of supporting participation while still managing fatigue.

PARTICIPATION IN REHABILITATION

Rehabilitation Activities have the potential to limit participation if the child is "Taken Out" to do different, therapy activities on their own. Rehabilitation can involve and address skill development for normal classroom activities or for normal extra-curricular activities directly. While individual rehabilitation sessions in a quiet area are appropriate for some issues, at other times rehabilitation can be integrated into classroom or group routines and environments.

One approach that optimizes participation is to include other children in the therapy activity, working directly with a small group. There are usually a range of abilities in a group or class, and other children may also benefit from training and skill development. This approach has the

added benefit of increasing motivation through involving peers, and building in an element of competition, as well as increasing fit by supporting other children's understandings about a shared activity. Strategies can be modeled for others in the setting.

(The Early Education Team- The Capper Foundation, 1990).

5) POSITION FOR PARTICIPATION

Position is relative to other people or things. Being out of Position means things don't Fit, while Positioning correctly means things Fit together more easily.

This image has been removed by the author of this thesis for copyright reasons

BEST POSITION

Being Positioned as part of a group can work well for children, but make a considered decision about where they are positioned relative to others in the group. Being right on the edge of a large group can mean a child has more space, they can get up and down, and move away more easily, or they can be closer to support people, but reduced proximity to other children also means others are less able to share with them. Likewise, if a child is positioned at a desk on their own with an adult support person's chair routinely beside them, they may concentrate better, but this can flag them as different, and limits their ability to share in an activity with other children.

SHIFTS IN POSITION

Regularly rotating classroom group seating positions is a strategy some teachers use to support children to learn how to work at activities with a variety of children, and while there can sometimes be personality clashes, there can always be another adjustment if required. Regularly changing group positions for school and for community based activities is also a way of supporting children to share activities with peers who have different abilities.

6) ACTIVITIES FOR PARTICIPATION

STRUCTURED ACTIVITIES

Activities with more Structure facilitate Participation. When the processes and actions required for an activity are loosely defined, children need to think harder to actually organize and carry out the activity. They have less capacity to concentrate on interacting with each other, and sharing in the activity together. While we all benefit from activities that are loosely structured that we can direct as we please (eg. children enjoy some undirected time for free play at lunch-time), by clarifying the requirements for a particular activity, this will support participation. Structured activities are more likely to incorporate familiar routines, which support involvement for children after traumatic brain injury.

(DeKlyen & Odom, 1989; Ylvisaker, 1998)

GROUP ACTIVITIES

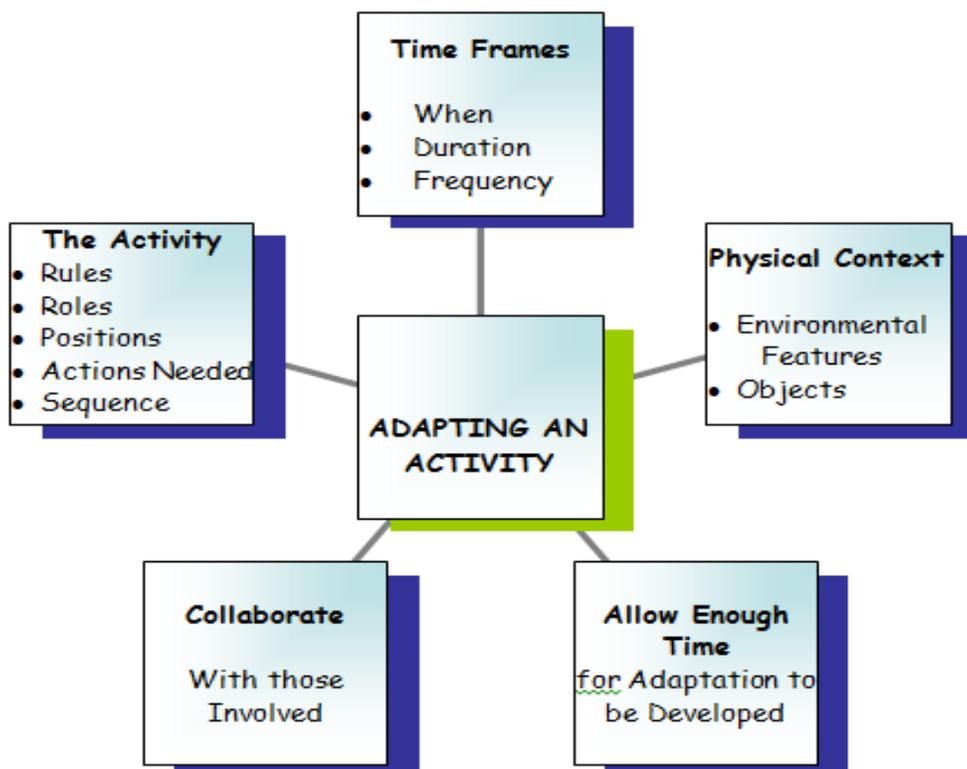
Activities that require Group Cooperation or Team-Work also facilitate Participation. This is where children need to work together to carry out an Activity. This gives all children an opportunity to contribute their own special skills, and to share in Problem Solving. For this to work effectively, establish clear understandings around the task, ground-rules for communication and clarify roles and time-frames before beginning

(Zionts, 1997)

ADAPTED ACTIVITIES

Adapting an Activity and the Context in which it is carried out can enable Participation (Refer above to Planning). This increases the Fit

between a Child's skills and abilities and the requirements of the activity. Aspects of the activity that can be changed include Time Frames, the Physical Context, and the Activity itself. As described in Planning, for more formal activities such as a team sport, some time may be needed to work this through. Collaborate with the key people involved, including other children. Others sharing the activity will need to understand how the activity will be affected for them, if at all, but can also contribute their expertise and creativity. Collaboration may be done formally at a planning meeting, sequentially (eg. adult discussion, then informing children and getting their feedback), or may simply be negotiated on the spot.



Examples:

Structured Activity

Sarah's school routinely included a formal teacher-supervised sports-activity over the lunch hour. Sarah was able to take part in the base-ball game, and she and four other children were given extra time to a count of two to make the run to the bases. This was agreed with the other children who played. Having a structured activity to participate in at lunch time was easier than trying to join in with some of her other classmates who moved between different groups and made up their own activities on the field.

Group Cooperation in Activity

It was now 3 years since Millie had her accident. Millie's class was learning about Leadership. Mrs Jackson, her teacher decided that the children would work in small groups rather than making individual posters. Millie's group made a poster about Sir Edmund Hillary. Each child was given a small aspect of Sir Edmund's life to research- Millie researched Sir Edmund's friendship with Sherpa Tenzing Norgay on the internet with her friend Jasmine, and brought along a book about Sir Edmund Hilary from home to share. With Brandon, who had finished his research early, Millie typed out three sentences about Sherpa Tenzing using Publisher. Two of the children drew a picture of the conquering of Mt Everest, and Millie coloured it in. Another child took responsibility for making a title for the poster. Each child cut out their own research summary, Millie glued them, and Jasmine stuck the summaries onto the poster. Together the children brainstormed ideas about what made Sir Edmund Hillary a leader, and presented these to the class (Zionts, Vannest, & Devore, 2005).

Adapted Activity

At the start of the New Year, Ben made his first visit back to his school on the same day he returned home from hospital after his accident. The children in his class were very excited to see him, and he was invited to participate in a "where you went on holiday" memory game they were playing to get to know each other. Ben's teacher was aware his memory hadn't fully recovered, so quickly adapted the sequence of the activity so he could take part successfully. Rather than coming into the game at Number 20, Ben was given his turn to join at number 3 so he only had to remember information from 2 other children.

Ben was disappointed that due to the risk of a "second impact" head injury, he wasn't able to play rugby, which was previously one of his top sports. Ben's coach invited him to remain part of the team, and talked with Ben, his Mum, and his team-mates about adapting the role he played. Ben began again to take part in all the training exercises except those involving direct contact, and attended all the games. He was given the roles of "water boy" and "ball boy" for all the games. Ben really enjoyed remaining involved, and on one occasion, supported his team-mates by loaning his boots when a player had forgotten his own.

This image has been removed by the author of this thesis for copyright reasons

7) INFORMATION EXCHANGE FOR PARTICIPATION

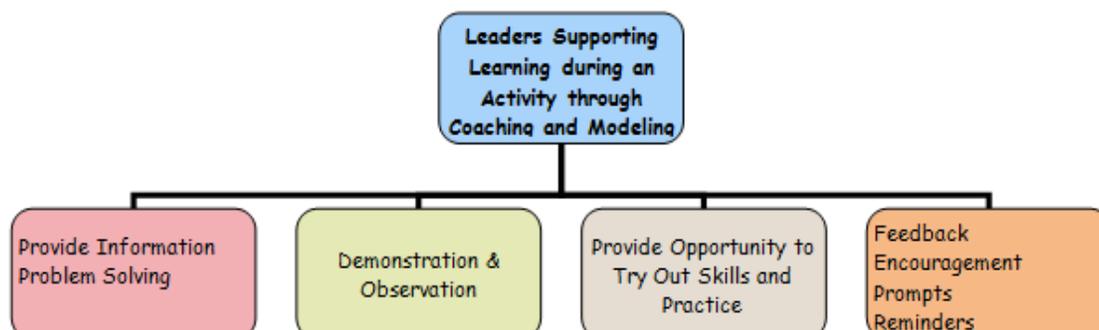
People's understandings about their world form a basis for their actions, or what they do. Sometimes after a child has a traumatic brain injury, adults and other children lack understanding, or have understandings that do not match with the child's actual abilities and needs. This Misfit can prevent the child sharing in an activity.

Katie wasn't invited to a party with other girls in her class. "Yeah the kids' parents didn't include her or didn't encourage to be included. And, I kind of understand that they didn't know Katie's capabilities..... I guess these people sort of, the thought of having to change her, or something like that. She never needed it, but no one ever came and asked. They just stayed away if you can understand. And the only, reasoning maybe to keep myself sane, is that they just, never knew or if they could cope with her or not". (Katie's Mum).

People's understandings can be changed through learning. People can learn through direct instruction, watching others, questioning, sharing information, and experience gained when they do things together.

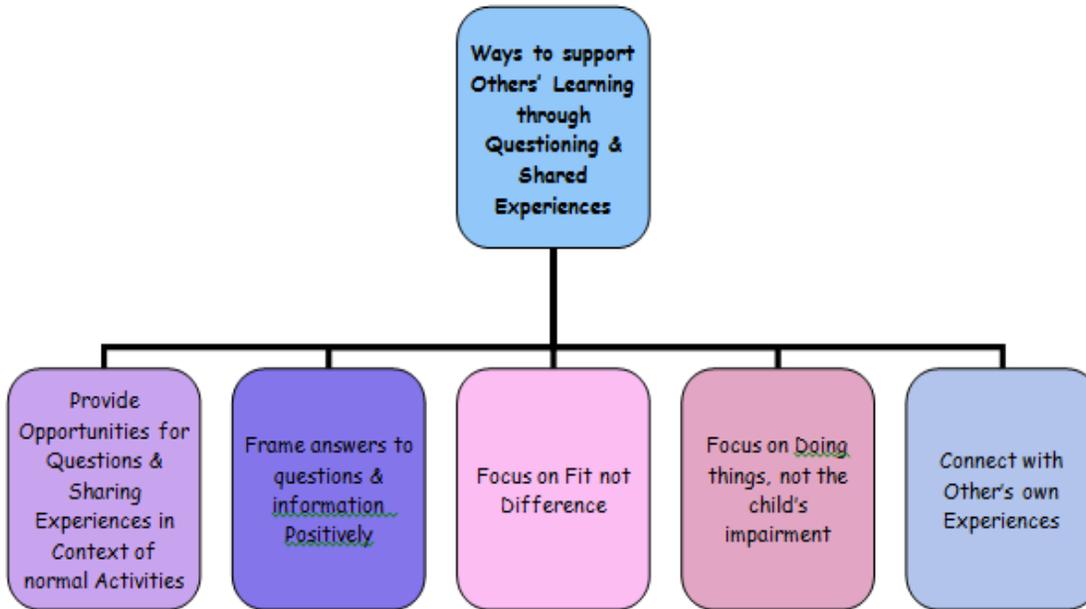
ON THE SPOT LEARNING: COACHING AND MODELING

When other children and adults are sharing in an Activity with a child, such as a group of girls and leaders at Girl Guides, or in a classroom, there are opportunities for a leading adult who is familiar with the child's abilities and needs, to Coach and Model actions that support the child to Fit in.



LEARNING: QUESTIONS & SHARED EXPERIENCES

Children explore their environment through touch, observation, experimentation, and questioning. As people get older, they may refrain from asking or getting involved.



At the start of the year, as part of the curriculum, Wiremu's new class was learning about Health. They talked about the activities that they do to keep healthy, and places they go for help with being healthy. Children shared the healthy activities they do, and Wiremu's teacher helped him show pictures of the things he enjoys doing, such as going Body-boarding, and Riding his Go-Kart. At the next session, Wiremu's mother, Mere visited his class, and Wiremu showed the class some pictures of himself and his whānau in the hospital. Other children in the class talked about the times when they had been to hospital. His mother helped him to talk about some of the things he did when he was having rehabilitation. Some of the children had been to a physiotherapist to help get moving again. Mere said that Wiremu could hold things with his right hand, but that his left hand got a bit stiff sometimes, a bit like when you sit on your leg and it gets pins and needles. Two children who didn't know Wiremu wanted to know about his hand-splint. Mere and Wiremu showed them his hand splint and how it helped him open his water-bottle. Some of the other children tested it for fit, and helped him put it on his hand. Marama said her father had to wear a brace on his wrist when he played basketball.

DIRECT INSTRUCTION

Sometimes, when a child is going to Participate in an Activity, information needs to be directly shared. It is important other adults in the community have adequate information to ensure their actions Fit appropriately to the child's needs. Information can be shared in writing or verbally. Some parents advocate having a small booklet of Positive stories that inform about the child's needs (DeZonia, 2009). Key points could be noted on a card. Similar rules apply- frame the information Positively, focus on Fit not difference, Focus on Doing, involve hands-on Practice, and Connect with others' own experiences.

Kim's class was going on a trip to the beach to count cockles because they were taking part in a shell-fish monitoring survey. His father was going along with him. Two other parent helpers went, as well as the teacher and a teacher aide. Kim and his Dad walked beside the other parents on the way down. Kim was encouraged to have a short rest when they got to the beach. His Dad explained that this was Kim's after-lunch forty-winks to set him up for the afternoon and that he needed this because he got tired and could also move so quickly. On the walk back, Kim's Dad walked with a different group of children and had a chat with the teacher. He asked one of the other parents to stay close to Kim and monitor him at crossings.

This image has been removed by the author of this thesis for copyright reasons

LEARNING ACTIONS FOR PARTICIPATION

Children and adults use particular actions when they share in an activity together. Encouraging others to use these actions with a child who has had a traumatic brain injury helps the child fit in and participate in the activity, supporting further exchange of information. These actions include:

- Greeting
- Inviting
- Noticing (a need for help or to be involved)
- Planning Roles
- Offering Help
- Reciprocating
- Competing
- Encouraging
- Sharing (Experiences, Products, Objects)
- Farewelling

SHARING PARTICIPATION EXPERIENCES

When children participate in an activity together, they routinely Exchange information about their participation experiences during the activity. They show work to each other, comments and opinions are given, and ideas are exchanged. Participation experiences outside the current activity are recalled, and can form a basis against which other experiences can be compared, supporting reflection and learning. Connections with other people through their experiences are facilitated.

It can be more difficult sharing Participation Experiences after a Traumatic Brain Injury. Information can be forgotten, or ineffectively retrieved, and may be difficult to communicate. The need to attend to

the doing of the activity itself may limit the degree to which the child can Exchange information. The use of Visual Media such as photo books, drawings, written stories or poems, and other concrete symbols such as awards, or objects produced during the participation become particularly important tools to help in sharing the participation with others. Provision of regular opportunities to formally share participation experiences (eg. at mat time, for class speeches, after a sports game) also assists the exchange of information needed for Fit and Connections.

This image has been removed by the author of this thesis for copyright reasons

8) PARTICIPATING WITH OTHER CHILDREN

When sharing in an activity, other children can use actions (refer above) that support the child to Fit in. These actions can be set up on the spot, or can be a Formal Arrangement that is set up in advance.

PROMPTING IMPROMPTU SHARING.

Other children familiar with the child can be requested on the spot by adults to share in an Activity with the child, or the child can be invited to join in with the other children. Often, some children finish a task early, or have good skill-sets for a particular activity, and enjoy the chance to share their skills. Others may enjoy having a special support role in an activity. If there is already an established culture of children helping each other, this is seen as a normal part of the activity, and the approach does not place the child who has had the traumatic brain injury as being in a position of having a "special" need. Less is needed in terms of set-up. Studies focusing on children's social interactions have shown that in the longer term, informally spending time together results in as many interactions as those interactions brought about more formal approaches such as training peers to interact (Esposito & Reed, 1986).

This image has been removed by the author of this thesis for copyright reasons

ARRANGING FOR FORMAL SHARING

Formally nominating a Buddy or a Peer Tutor involves making specific longer-term arrangements for a peer to join the child in activities, or to teach them skills for a particular activity. The approaches generally involve formal arrangements between the child with the disability, their family and/or teacher, and non-disabled peers, along with a clear recognition of others' responsibilities, and commitment to carry out the role. Monitoring is provided, and outcomes are ascertained (Zionts, 1997).

There is a place for more formal arrangements, and they can support the child to take part in activities. Given a focus on Fitting In that emerged in the case studies underpinning this KitSet, by routinely allocating a special person or group to the child, there is a concern that such approaches may contribute to Understandings of the child as being different and as requiring help. Some of the approaches, such as having a Buddy or providing a Peer Tutor may minimize this concern if they are a normal part of learning for all children at different points in the school and community. It is also possible that the formal arrangement may work as a catalyst for others' involvement.

This image has been removed by the author of this thesis for copyright reasons

9) PARTICIPATING WITH ADULTS

Adults often share in children's participation. They may be a parent, a teacher, a coach, or a leader of an activity. Adults provide supervision, lead activities, support children to physically carry out activities, and play an important role in facilitating interactions. However, there is evidence that shows that the close presence of adults can also limit interactions between children, and thus reduce the quality of participation (Batchelor & Taylor, 2005). For a child who has had a traumatic brain injury, there is a fine balance between providing adult support to enable them to complete an Activity, whilst optimizing their interactions with other children. The constant presence of an adult in close proximity to a child can enable Fit of the child's abilities with the demands of the Activity, but can equally single a child out as different, reducing their Fit with other children and limiting the connections they form.

Adult Support

Effective provision of Adult Support requires skill and flexibility. It should limit barriers to peer interactions, should facilitate the child to use their own skills as far as possible, and should also ensure the child has a say in the support that is provided. That is not to say that there is no need for support, but that the way the support is delivered needs to be carefully tailored. A number of strategies can be used by Adult support people that Facilitate Participation (

- Position permanent adult seating away from the child's activity or group, and move in and out as needed.

- Whenever possible, use environmental cues rather than verbal cues, such as marking a page with an adhesive label, or providing a sheet of clear steps, or provide only a few steps or problems at a time.
- Develop a plan with the child about aspects of the Activity they can do themselves, environmental cues, and help they might need, then move away to a monitoring and responding role.
- Work with a small group of children to support completion of an activity rather than an individual child.
- Encourage peer support with activities. Ask other children to help, or give some children an "Ask Me" role on a rotating basis. Get children to check things with their neighbours. Allocate partners for all children for particular activities, such as Lunch-Time Partners, or Moving Room Partners, or Maths Partners.
- Plan to Fade the support. This means developing a plan from the start with strategies that will gradually make a shift from "hands on assistance" through to provision of environmental cues, and task adaptation.

(Causton-Theoharis, 2009).

Sharing Adult Participation

If one particular adult consistently shares with the child during Activities, then that adult will become very skilled in providing support, but other adults will not have that chance. As opportunity presents, hand over to other adult supports, particularly other parents or activity leaders. This facilitates Connection with other adults and children in the community. The key support person can still be available for information or to step in if needed.

Ten year old Tony was attending Scouts with his Attendant Care person, Stephen. On arrival, other parents were standing at the door, and they greeted Tony and Stephen enthusiastically. In the hall, Stephen stepped back from Tony, and sat on the bench at the side of the room. Some of the other parents were interested to know why I had come to be with Tony. Other children came up to Tony, and they played games of "chase and fall over" together until the session was ready to start. Sometimes, if Tony became over-enthusiastic, Stephen stepped in and calmed him. Part of the session was relays, with teams of children going across the room using different ways of moving such as running, hopping, crawling, or commando crawling. Lines were marked on the floor with tapes. Stephen physically supported Tony to stand in line with his team, then called another older boy to come and work with him. This boy accompanied Tony each time it was his turn to do the relay, with encouragement and fun with other children every time Tony went off line. A few times Stephen stepped in and prompted the boy on how to support Tony if he was not keeping to the activity.

This image has been removed by the author of this thesis for copyright reasons

References

- Anderson, V., & Catroppa, C. (2006). Advances in postacute rehabilitation after childhood-acquired brain injury: A focus on cognitive, behavioral, and social domains. *American Journal of Physical Medicine and Rehabilitation, 85*, 767-778. doi:10.1097/01.phm.0000233176.08480.22
- Batchelor, D., & Taylor, H. (2005). Social inclusion-the next step: User-friendly strategies to promote social interaction and peer acceptance of children with disabilities. *Australian Journal of Early Childhood, 30*(4), 10-18. Retrieved from <http://www.earlychildhoodaustralia.org.au/>
- Bell, H. C., Pellis, S. M., & Kolb, B. (2010). Juvenile peer play experience and the development of the orbitofrontal and medial prefrontal cortices. *Behavioural Brain Research, 207*, 7-13. doi:10.1016/j.bbr.2009.09.029
- Bernabe, E. A., & Block, M. E. (1994). Modifying rules of a regular girls softball league to facilitate the inclusion of a child with severe disabilities. *Journal of the Association for Persons with Severe Handicaps (JASH), 19*(1), 24-31. Retrieved from <http://www.tash.org/publications/RPSD/RPSD.html>
- Causton-Theoharis, J. N. (2009). The golden rule of providing support in inclusive classrooms: Support others as you would wish to be supported. *TEACHING Exceptional Children, 42*(2), 36-43. Retrieved from <http://journals.cec.sped.org/tec/>
- DeKlyen, M., & Odom, S. L. (1989). Activity structure and social Interactions with peers in developmentally integrated play groups. *Journal of Early Intervention, 13*, 342-352. doi:10.1177/105381518901300406
- DeZonia, K. (2009). Mobility: Not just the ability to move: Tips for gaining acceptance and moving toward community connections. *Exceptional Parent, 39*(5), 30-31. Retrieved from <http://www.eparent.com/>
- Esposito, B. G., & Reed, T. M. I. (1986). The effects of contact with handicapped persons on young children's attitudes. *Exceptional Children, 53*, 224-229. Retrieved from <http://journals.cec.sped.org/ec/>
- Law, M. (2002). Participation in the occupations of everyday life. *The American Journal of Occupational Therapy, 56*, 640-649. doi:10.5014/ajot.56.6.640
- Lewis, C., & Carpendale, J. I. M. (2009). Introduction: Links between social interaction and executive function. *New Directions in Child and Adolescent Development, 123*, 1-15. doi:10.1002/ed.232
- The Early Education Team- The Capper Foundation, &. (1990). *Project Kidlink: Bringing together disabled and nondisabled preschoolers*. Tucson, Arizona: Communication Skill Builders.
- World Health Organization. (2007). *International classification of functioning, disability and health: Child and youth version: ICF-CY*. Geneva, Switzerland: Author.
- Ylvisaker, M. (Ed.). (1998). *Traumatic brain injury rehabilitation: Children and adolescents* (2nd ed.). Newton, MA: Butterworth-Heinemann.

Zions, P. (1997). *Inclusion strategies for students with learning and behavior problems: Perspectives, experiences, and best practices*. Austin, TX: PRO-ED.

DRAFT 2



“Ta Kupenga” “Net-Making”

**A KitSet to Help Children
Participate after Traumatic Brain
Injury**



Background

- Ta Kupenga has been developed from studies completed with Aotearoa New Zealand children who have had traumatic brain injuries, and their whānau/families, teachers, rehabilitation providers, and community support people.
-
- In the studies, commonsense ideas or strategies were found that helped the children to be involved in activities. These have been put together into a kitset. Writings and research from others in teaching and rehabilitation fields provide further evidence for some of the strategies.
-
- The focus of Ta Kupenga is on working with people's communities to assist children to participate. It can be applied to activities at home, in rehabilitation settings, at school, and in the wider community. It is designed for children aged 9-12 years.
-
- Ta Kupenga can be used by Whānau/Family, Friends, Schools, and Community Support People and Rehabilitation Providers. People can choose the things they feel are useful for them to implement with a particular activity at a particular point in time.
-
- There are a number of other approaches available that focus on developing the skills of the child to enhance participation. The strategies in Ta Kupenga can be used alongside these other approaches.

What is Participation?

Doing things together



Participation is like a woven net. It is about whānau/family being connected into the community with others. Like the way nets are used to provide food to nourish a community, a participation net helps keep people healthy.

At school participation is about contributing to, and feeling a part of things in the classroom, in the playground, and wider school life such as camps and outings. In the community participation involves joining in sports, art, recreational, cultural, and spiritual occupations.

"...how he fits into the scheme of things" (Julie, 2010).

Why Participate after a Traumatic Brain Injury?

- Build & Strengthen Social Networks
- Develop Friendships
- Opportunities for new Experiences
- Learning & Development
- Rehabilitation of Functional Skills
- Health

(Anderson & Catroppa, 2006; Bell, Pellis, & Kolb, 2010; Law, 2002; Lewis & Carpendale, 2009; World Health Organization,

Changes after a Traumatic Brain Injury Tear the Net of Participation

Change in Child and Whānau/Family

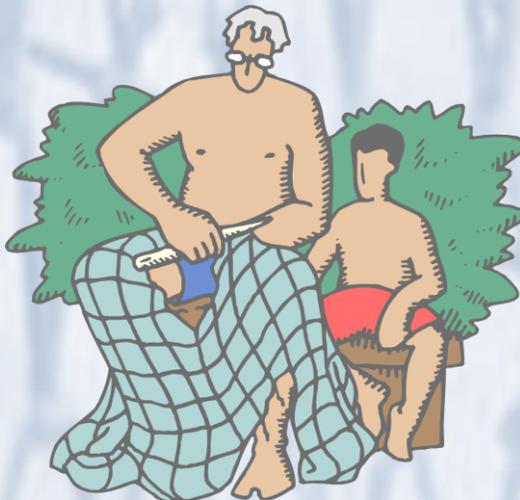
Change in Place

Change in Routines

Interruptions to Participation

Disconnection from people in the Community

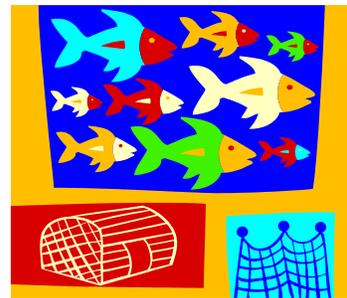
Fewer Opportunities



Sports? A big change. Robbie swam twice a week. He played soccer on Saturdays with two trainings. He played t-ball, he played tennis on Wednesdays. And all that stopped. All of it. So he's gone from, usually having a sport every, at least every second day during the week, some days, he'd have tennis and swimming on the same day. But... he went from being a very active, boy... To nothing." (Lynne, 2009)

How Does Ta Kupenga Work?

Ta Kupenga is based on the idea that after a child has a traumatic brain injury, through doing things together, people can make or maintain connections, and exchange understandings about each other. When this happens, they are better able to help that child join in, and can weave further opportunities for that child to participate.

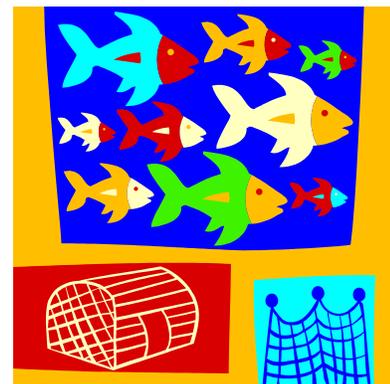


Ta Kupenga aims to increase participation by:

- Supporting others to Share Occupations with the child
- Making and Maintaining Connections with other people
- Meshing together the Child's needs, with an Activity, the Place it occurs, its Time Frames, Other's Understandings, and Other's Actions.
- Creating more Opportunities for Participation

Weaving a Participation Net: What's Important?

- Plan for Participation as soon as possible
- Occupations should be Central
- Occupations are Shared With other Whānau/Families & Children
- Ensure your Child has a Say
- A Child & others involved should be Satisfied with the Participation
- Focus on Similarities not Differences
- Quality not Quantity
- Flexible
- Do-Able



Phases and Strategies in the Ta Kupenga Kitset

1: Participation in Hospital: Maintaining Connections

- a) Visit
- b) Keep in Touch
- c) Share Experiences

2: Participation during Rehabilitation: Growing Connections

- a) Begin to Weave!
- b) Quality not Quantity
- c) Record Experiences
- d) Weave a Pattern
- e) Crafting Visits Out

3: Participation back at Home & School: Shifting Connections

- a) Planning to Weave
- b) Weaving the Strands that Support Participation
- c) Teaching Others How
- d) Interwoven Participation
 - Other Children
 - Adult Support
 - Rehabilitation Activities
 - Rest Times
 - Parent's Participation



**1: Participation in Hospital:
Maintaining Connections**

1: Participation in Hospital: Maintaining Connections

After a Traumatic Brain Injury, children spend time with their whānau/family in hospital. Participation is very hard if you are not at home and are unwell. Parents talk of feeling overwhelmed, scattered, and in shock. Many parents want to remain near to their child's side, like a closely woven net, wrapping them safely and continuously in the face of change.

At these early times, when you and your child are away from family, friends and community in a medical setting, it can help to hold together connections in small ways with those people. Those who share the experiences with you after the accident can provide reassurance and support, both early on, and as recovery progresses. They can bring a sense of familiarity at a time of uncertainty. They will gain understanding of the challenges you and your child face, and can use this knowledge to help with participation when you return home.

a) VISIT

Visiting is a way of beginning to share in an activity again. Parents, with help from staff, might think about some special people in the community close to their child and whānau/family who could visit and provide support, such as a child's friend and their parent, a teacher, a special neighbor, or a coach. It may be possible to nominate a friend or person from the extended family to help with keeping in touch, and staff may also assist.

Visiting does have to be responsive to a child's need for rest. It is important that visitors check with parents and staff first.

Visitors might simply "be there". They can talk quietly about the things that your child has enjoyed doing, and let them know what their friends and classmates are doing. They might bring in a photo of a special activity or place, or might bring a familiar toy to talk about. Visitors can sometimes join in a rehabilitation activity.



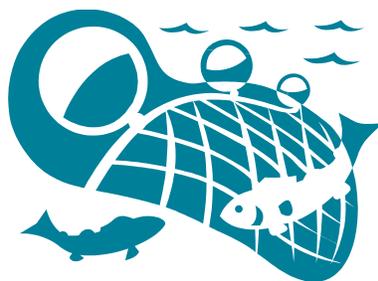
b) KEEP IN TOUCH

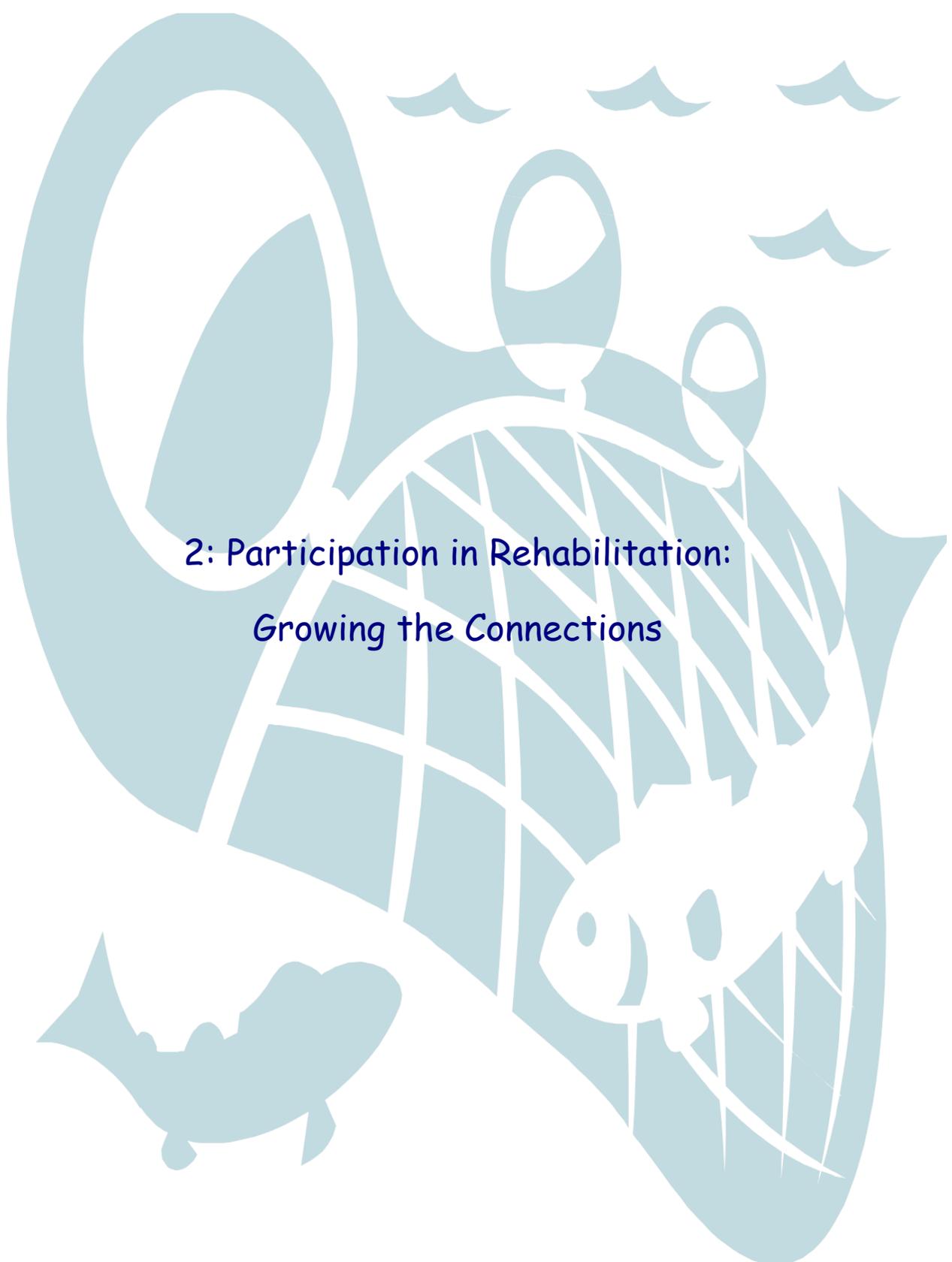
Classmates can also keep in contact and share participation experiences via email and other technologies such as web-cams, Facebook, texts, or phone.



c) SHARE EXPERIENCES

Classes or teams can put together posters of activities they have been doing, with messages, letters, photos and drawings. It will also be reassuring to them to hear news of their absent classmate or team member.





2: Participation in Rehabilitation: Growing the Connections

2. Participation during Rehabilitation:

Rehabilitation is a process that unfolds over time. At earlier phases of their rehabilitation, children may participate by simply watching and being with their peers, while at other times, they are ready to be more involved. What is important is that during rehabilitation, children are helped to share activities with their family and community.



a) BEGIN TO WEAVE!

Start early in rehabilitation to talk with your child, their friends and family, their teacher, and others from your community about your child's interests, activities they would like to try out, places they have been, and activities they have enjoyed. Some of these activities will be built into their rehabilitation and school sessions, while other activities become future goals. As your child becomes more able, the rehabilitation team can help you set up opportunities for short visits and outings. Communication aids and other media can help your child's involvement.



b) QUALITY NOT QUANTITY

Think carefully about your child's energy levels after participating in activities. Quality not quantity of Participation is important, as are Time Frames such as the time of day and for how long. Within reason, children may have some Safety restrictions. If you are unsure if an activity is Safe for your child, talk with the neurologist or rehabilitation specialist.

c) RECORD EXPERIENCES

As in the hospital, your child and their peers will benefit from exchanging information about the things they have been doing. It can be useful to keep a folder or scrapbook, or an electronic resource that records progress and activities. Records like this help your child to remember and share their experiences later on. Messages from classmates and team-mates that are kept can remind your child they are still part of the group, and help them recognise familiar faces and settings.



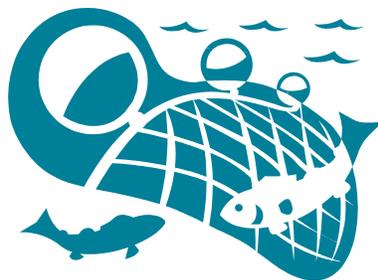
d) WEAVE A PATTERN

When time nears to returning home, it can be helpful to develop a routine of things your child will be able to do, and places they can visit when they go back. Your rehabilitation team will be able to help you with this. The pattern will often include some time at school, and some "quiet" time, but the pattern should also be balanced with time for some activities your child would like to do. Having a pattern for the day builds your child's confidence, and will help them to adjust back.

e) CRAFTING VISITS OUT

As your child progresses, they may be helped to take part in an initial visit to their school or to another setting such as church or their marae. This can be an opportunity for them to be welcomed back, and to take part in a low-key activity for a short time.

It is also an opportunity to communicate a little of their experience, and, at school, to interact with their teacher and classmates. Your rehabilitation team will be able to help you with ways to do this. What is important is that the focus is on them sharing their experience of the things they have been doing. Your child might be able to show pictures of where they have been, or with help could explain some of the things they do in rehabilitation.





**3: Participation Back at Home & School:
Shifting Connections**

3: Participation Back at Home & School: Shifting Connections

Moving out from hospital and rehabilitation to go back home is an important step. There will be times when the weaving of a child's participation net needs to be moved along. Participation might need addressing when there is a change in a child's life such as a school camp, a trip, or a new class or school. Sometimes some new occupations may need to be introduced.

a) PLANNING TO WEAVE

Planning is needed for Participation to be successful!

WEAVE ONE KNOT AT A TIME

Rather than trying to increase participation across a whole range of occupations, focus on One Occupation at a Time. This might be participation in a class-room occupation, an activity in the playground, a social occupation at the weekend, an occupation at school camp, a cultural occupation, or a sports-based occupation. When this is working, then you can start to focus on another occupation.

PREPARE

Some background information is required. Your rehabilitation team will be able to help with this process. Check out:

- The Physical Setting
- Time Frames (when, how long, the things that happen before and after),
- What the children will be doing
- Who else is involved (other children and other adults).
- How others Know your child and their abilities, and if they can support their involvement in some way.

- Whether things can be Changed to fit with your child's abilities.

ALLOW TIME

Planning takes time. It can be really difficult to check out and organize things at short notice, so whenever possible, begin planning early on. This way, people can work together to come up with solutions that Fit.

EXAMPLE

Jonathan was going on the school camp, and it was decided with his teacher for his father to go with him. At the camp, an adventure tramp was organized as the first activity of the day. Jonathan enjoyed walking, and although he needed a bit of extra time to get places, and some reminders of obstacles, he was looking forward to going. As it happened, information that the walk was happening was not communicated to Jonathan and his father until that morning. The class with the teachers and parent-helps needed to finish the walk within an hour so they could be ready for the next activity, and the walk included some steep ground. As there were concerns that Jonathan couldn't finish the walk quickly enough, and might not cope safely with the steep bits, his teacher decided it would be best if he stayed behind. Jonathan and his father were disappointed.



BRING IN OTHERS TO HELP WEAVE

Setting up for a child to Participate in an activity can be really challenging on your own. Involving another person or a small group shares the responsibility, and they may be able to contribute additional experience, skills and ideas. Parents /whānau are usually the first involved, or if the Participation involves a school-based activity, it may begin with a teacher. The child themselves, and sometimes other children must be part of the team; they may be consulted first, or after some adult-team discussion. Sometimes there is a support person, such as a family friend, a community caregiver, rehabilitation staff, or a teacher aide. If there is

a key person involved, such as a coach for a sports activity, or a bus-driver when learning to get home from school, they might be the first person to approach.

FORMAL AND INFORMAL

A formal planning session may be needed (Bernabe & Block, 1994). People are invited and there is a formal goal-setting and problem solving process. Formal team planning for Participation may be incorporated with an Individual Education Plan meeting (an IEP) at school, or as part of a Rehabilitation Planning meeting.

At other times, an informal discussion is fine to work things through.

Planning needs to consider people's roles in helping the Participation- who will do what.



COMMUNICATE WITH EACH OTHER

Communication is essential to good Planning. When people have busy schedules, it is helpful to be able to get hold of others in the team easily to give an update, to share happenings, or to raise an issue or a new idea. Be sure to identify the best ways and times to contact each other, and regularly review your communication strategies. Some ways to keep in

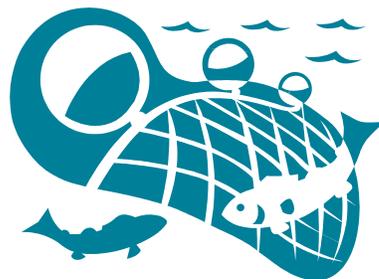
contact are through phone, by text, by email, via a web-site, through regularly calling in (e.g. checking in with a teacher after school), or through a communication notebook.

PRACTICE RUN

Some whānau /families and children find it helpful to visit a participation setting first for a "practice run", at a time when fewer people are around. This means they can scope the environment and activities out at a pace that suits them.

EXAMPLE

When Mary moved to intermediate school, she was keen to join in her school cross country. A week before practices started, her Dad checked out the course with her teacher. He and Mary walked around the course at the weekend. They decided that as this was her first cross country since her accident, she would do the first half of the course, and also the final lap.



b) WEAVING STRANDS THAT SUPPORT PARTICIPATION

Some types of occupations support participation more than others. Occupations can sometimes be presented differently to better involve your child.

STRUCTURE

Occupations with more Structure facilitate Participation. When the processes, rules, and actions required for an occupation are loosely defined, all children need to think harder to actually organize and carry it out. They have less capacity to concentrate on interacting with each other, and sharing in the occupation together. We all benefit from some loosely structured activities which we can direct as we please (e.g. children enjoy some undirected time for free play at lunch-time). However clear requirements for how an occupation is to be done will support participation. Structured activities are more likely to incorporate familiar routines, which support involvement for children after traumatic brain injury (Ylvisaker, 1998)

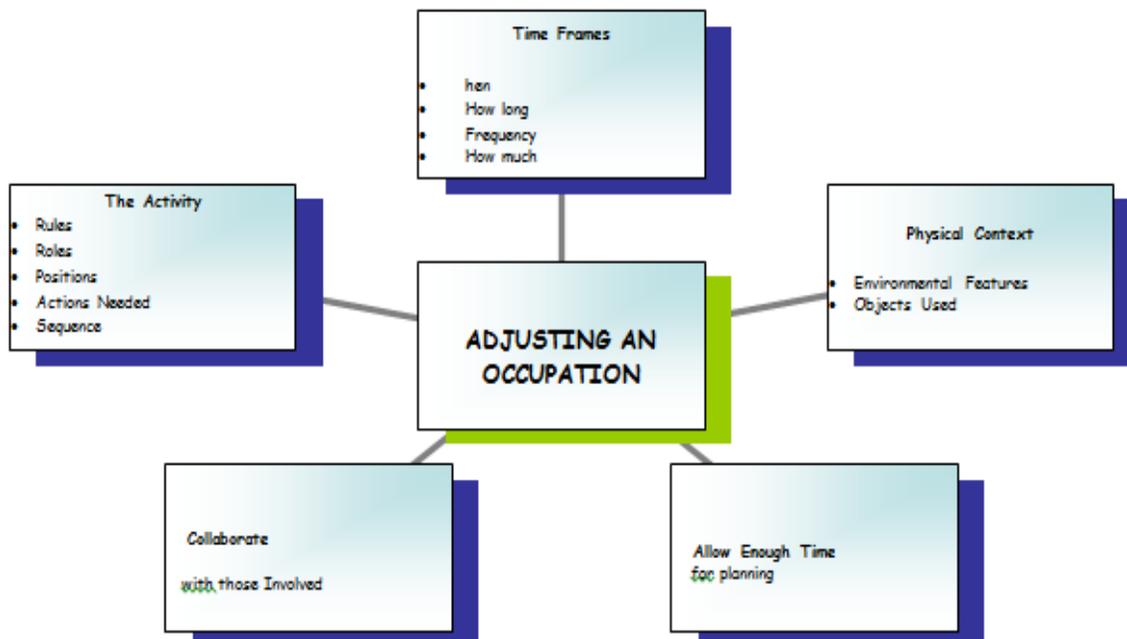
WORKING TOGETHER

Participation is supported by occupations that require Group Cooperation, where children need to work together to complete a task. This gives all children an opportunity to contribute their own special skills, and to share in Problem-solving. For this to work effectively, establish clear ground-rules for the task, communication, roles and time-frames. Children should be given recognition for how well they worked together as a group, as well as for their achievement. (Zionts, 1997)



ADJUSTING THINGS

Adjusting an occupation or the context in which it is carried out can enable Participation. This will improve the Fit between your child's skills and abilities, and the requirements of the occupation. Aspects of the occupation that can be adjusted include Time Frames, the Physical Context, and the Activity itself. As described in Planning, for more formal activities such as a team sport, some time may be needed to work this through. Collaborate with the key people involved, including your child and other children.



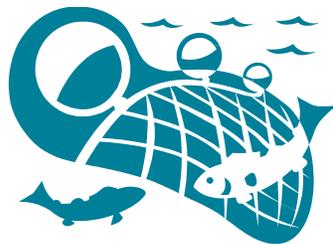
EXAMPLE:

Millie's class was learning about Leadership. The teacher decided that the children would work in small groups to make posters. She re-scheduled the activity to early morning to ensure Millie would not be too tired. Millie's group made a poster about Sir Edmund Hillary. With Brandon, who had finished his research early, Millie typed out a 3-sentence summary about Sir Edmund using Publisher. Two of the children drew a picture of Mt Everest, and Millie coloured it in. Another child took responsibility for making a title for the poster. Each child cut out their own research summary, Millie glued them, and Jasmine stuck the summaries onto the poster. Together the children brainstormed ideas about what made Sir Edmund Hillary a leader. Because they worked so well together, their group got extra points (Zionts, Vannest, & Devore, 2005).

LET SOME THREADS GO

Remember that at this age, Participation is often about children "Having a Go" at things. Some of the things your child tries simply may not be right for them. Talk together about how it went when they tried it. You might decide to persevere, or to change something. For other activities, having tried it out, it is also OK sometimes to just let it go.

For some activities, there may not be a choice, and they just have to be done (e.g. a classroom activity). In these cases, strategies can be used to make the activity more achievable (Ylvisaker, 1998) - you could talk with your rehabilitation provider about some of these options, and also refer to Adjusting Occupations (p.21) and Adult Support (p. 28).



c) TEACHING OTHERS HOW

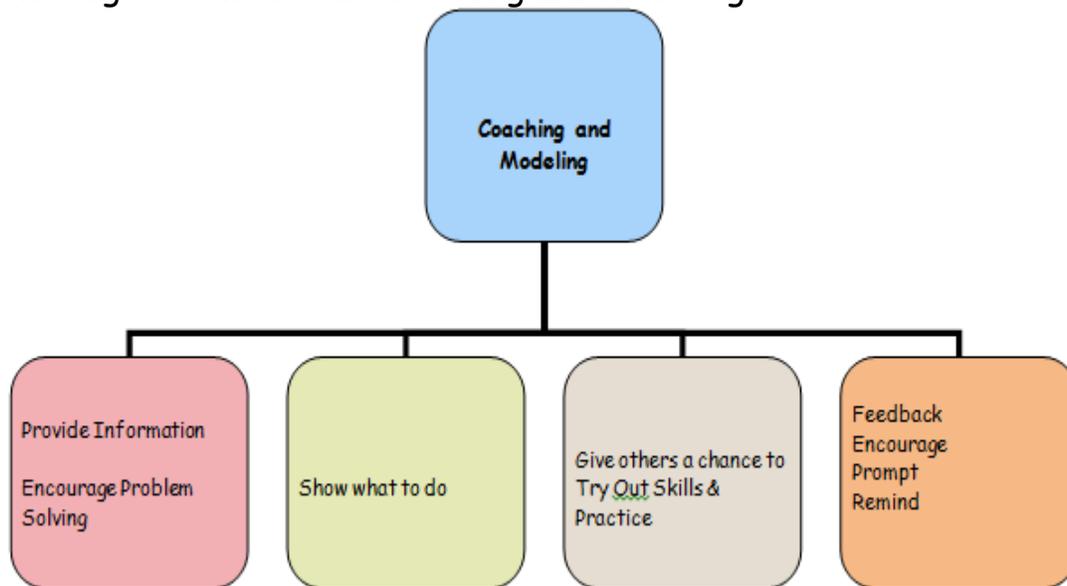
People's understandings about their world form a basis for their actions, or what they do. Sometimes, after a child has a traumatic brain injury, adults and other children lack understanding, or have understandings that do not match with the child's actual abilities and needs. This can prevent the child sharing in an activity.

Katie wasn't invited to a party with other girls in her class. "Yeah the kids' parents didn't include her or didn't encourage to be included. And, I kind of understand that they didn't know Katie's capabilities..... I guess these people sort of, the thought of having to change her, or something like that. She never needed it, but no one ever came and asked. They just stayed away if you can understand. And the only, reasoning maybe to keep myself sane, is that they just, never knew or if they could cope with her or not". (Katie's Mum).

People's understandings can be changed through learning, and this way they can better support the child to take part.

TEACHING OTHERS HOW TO HELP PARTICIPATION THROUGH COACHING AND MODELING

When other children and adults are sharing an occupation with a child, such as at Girl Guides, or in class, there are opportunities for a leading adult who is familiar with that child's abilities and needs, to Coach and Model ways to involve them. The diagram shows what Coaching and Modeling involves.



Children and adults use particular actions when they share in an activity together. Encouraging other children and adults to use these actions with a child who has had a traumatic brain injury helps the child fit in and participate in the activity, supporting others' further understanding. These actions include:

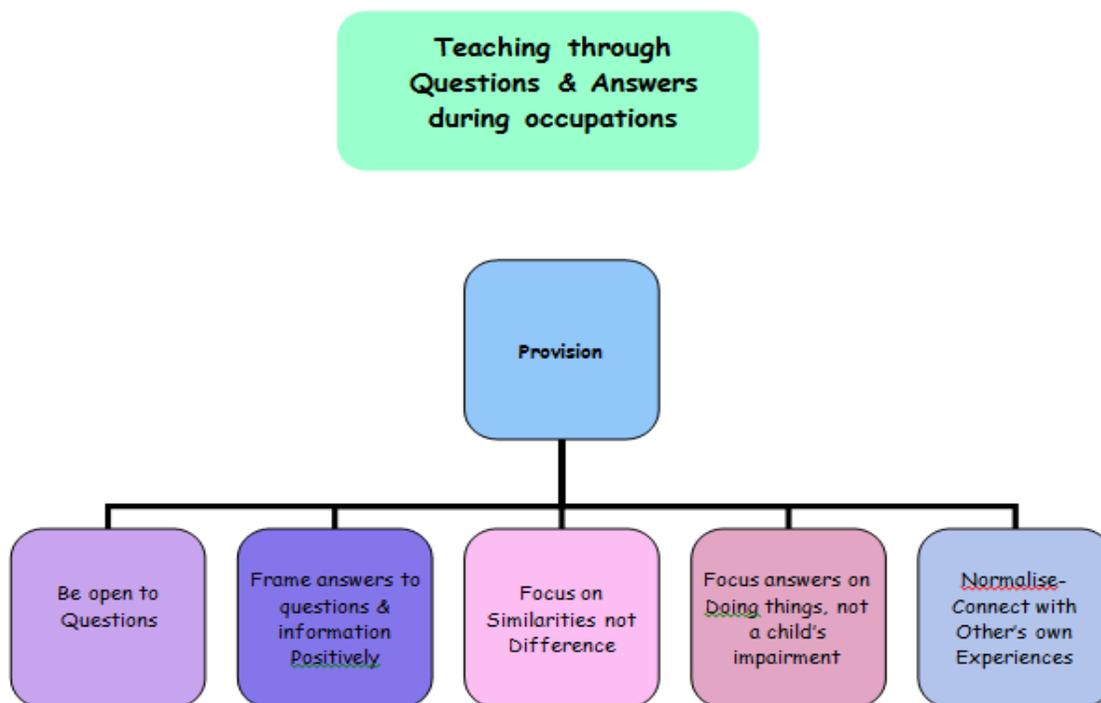
- Noticing (needing help/wish to join in)
- Greeting
- Inviting Contribution
- Planning
- Offering Help
- Reciprocating/Taking Turns
- Competing
- Encouraging
- Sharing (Products, Objects)
- Farewelling



TEACHING THROUGH QUESTIONING AND INFORMATION

Children explore their environment through touch, observation, experimentation, and questioning. When people get older, as in Katie's case, they may refrain from asking or getting involved. However, by asking questions and getting answers, others can learn how to assist someone to participate.

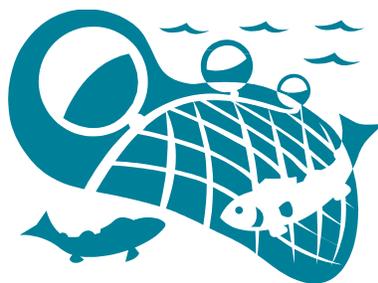
Sometimes, information needs to be directly provided to ensure other people in the community have adequate information. Information can be shared in writing or verbally. Some parents advocate having a small booklet of Positive stories or pictures that inform about the child's needs (DeZonia, 2009), or key points could be noted on a card.



TEACHING THROUGH SHARED EXPERIENCE

When children are occupied together, they routinely share information about their experiences. They show work to each other, give comments, and exchange ideas. Shared experiences support reflection and learning about each other and other areas of their lives.

It can be more difficult sharing Participation Experiences after a Traumatic Brain Injury. Information can be forgotten, and may be difficult to communicate. The need to attend to doing the activity may limit the degree to which the child can simultaneously share information. Media such as photo books, drawings, written stories, poems, and other symbols such as awards, or objects produced during the participation become particularly important tools to help in sharing the participation with others. Providing regular opportunities to formally share participation experiences (e.g. at mat time, for class speeches, after a sports game, after school) also assists the exchange of information.



d) INTERWOVEN PARTICIPATION

INTERWEAVING WITH OTHER CHILDREN

Impromptu Peer Participation

Adults can prompt, invite, or request other children "on the spot" who are familiar with your child to share an occupation. Often, some children in a group finish a task early, or have good skill-sets for a particular task, and enjoy the chance to share their skills. Other children may enjoy having a special support role in an occupation. If there is already an established culture of children helping each other, this is seen as a normal part of the activity, and the approach does not place a child who has had the traumatic brain injury as being in a position of having a "special" need.



Formal Peer Participation

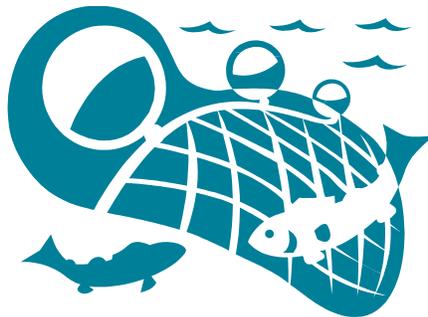
Formally nominating a group of children to be part of a Friendship circle, or nominating a Buddy or a Peer Tutor involves making specific, longer-term arrangements for peers to join the child in activities, or to teach them skills for a particular activity. The approaches generally involve a meeting between a child, their family and/or teacher, and non-disabled peers, along with a clear recognition of others' responsibilities, and commitment to carry

out the role. Monitoring is provided, and outcomes are identified (Zionts, 1997). This arrangement can work as a catalyst for others' involvement.

There is a place for such arrangements, and they can support the child to take part in activities. However, by routinely allocating a special person or group to the child, there is a possibility that the arrangement may contribute to understandings of a child as being different and as requiring help. By ensuring that having Buddies for activities or taking turns at being a Peer Tutor is normal for all children in the class or group, there is no longer a concern.

Position for Participation

Children need to be near others to participate with them. Situating your child as part of a group will help, although some thought might need to be given as to the best people for your child to be beside. Rotating classroom group seating positions is a strategy some teachers use to support children to learn how to work at activities with a variety of children. While there can sometimes be personality clashes, there can always be another adjustment if required. Regularly changing group positions for school and for community based activities is also a way of supporting children to share activities with peers who have different abilities.



INTERWEAVING WITH ADULT SUPPORT

After a traumatic brain injury, children tend to spend greater amounts of time with grown-ups, and less time with other children. Unfortunately, the close, constant presence of adults can also limit interactions between children, and reduce the quality of participation (Batchelor & Taylor, 2005).



There is a fine balance between providing adult support to enable a child to engage in an occupation, whilst optimizing a child's interactions with other children. It is important that adults negotiate with your child about the help they need, then "step back" when they can, and nominate children to work in pairs or teams to support each other. This helps other children to join in, to learn about how your child can contribute, and about how they can interact with them.

Weaving Flexibly

Effective provision of Adult Support requires skill and flexibility. It should limit barriers to peer interactions, should facilitate the child to use their own skills as far as possible, and should also ensure the child has a say in the support that is provided. That is not to say that there is no need for support, but that the way the support is delivered needs to be carefully tailored. A number of strategies can be used by Adult support people that facilitate participation (Causton-Theoharis, 2009).

- Position adult seating away from the child's occupation or group, and move in and out as needed.
- Work with a small group of children rather than an individual child.
- Whenever possible, use environmental cues rather than verbal cues, such as marking a page with an adhesive label, providing a sheet of clear steps, or providing only a few steps or aspects of a task at a time.
- Develop a plan with the child about aspects of the occupation they can do themselves, and environmental cues or help they might need, then move away to a monitoring and responding role.
- Encourage peer support with activities. Ask other children to help, or give some children an "Ask Me" role on a rotating basis. Get children to check things with their

neighbours. Allocate partners for all children for particular activities, such as Lunch-Time Partners, or Moving Room Partners, or Maths Partners.

- Plan to Fade the support. This means developing a plan from the start with strategies that will gradually make a shift from "hands on assistance" through to provision of environmental cues, and task adaptation.
- Share the support with other people. If one adult consistently shares with the child during Activities, then that adult will become very skilled in providing support, but other adults will not have that chance. As opportunity presents, hand over to other adult supports, particularly other parents (e.g. a parent help) or activity leaders. This facilitates Connection with other adults and children in the community. The key support person can still be available for information or to step in if needed.

EXAMPLE

Ten year old Tony was attending Scouts with his Attendant Care person, Stephen. On arrival, other parents were standing at the door, and they greeted Tony and Stephen enthusiastically. In the hall, Stephen stepped back from Tony, and sat on the bench at the side of the room. Other children came up to Tony, and they played games of "chase and fall over" together. If Tony became over-enthusiastic, Stephen stepped in and calmed him. When the session began, Tony sat with the other children and listened to the scout leader. He watched the flag-raising. Part of the scout session was relays, with teams of children going across the room using different ways of moving such as running, hopping, or commando crawling. Stephen physically supported Tony to stand in line with his team, then called another senior scout to come and help Tony. The scout accompanied Tony each time it was his turn to do the relay. Other children encouraged and laughed with Tony if he went off line. A few times Stephen stepped in and prompted the scout on how to support Tony if he was not keeping to the activity.

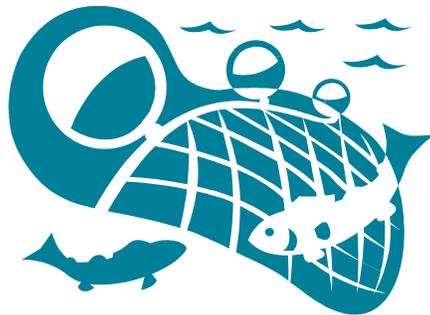
INTERWEAVING WITH REHABILITATION ACTIVITIES

Rehabilitation Activities have the potential to limit participation if the child is "Taken Out" to do different, therapy activities on their own. Rehabilitation can involve skill development for normal classroom occupations and other occupations directly. While individual rehabilitation sessions in a quiet area are appropriate for some issues, at other times

rehabilitation is best integrated into classroom or group routines and environments.



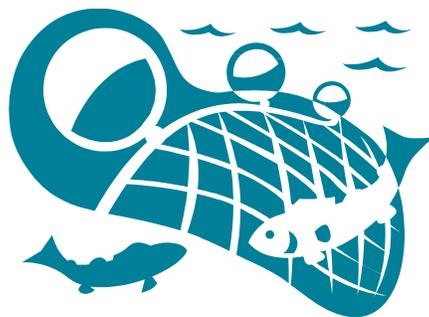
One approach that optimizes participation is to include other children in the therapy activity, working directly with a small group. There are usually a range of abilities in a group or class, and other children may also benefit from training and skill development. This approach has the added benefits of increasing motivation through involving peers, and building in an element of safe competition, as well as supporting other children's understandings about how to share activity. Strategies can be modeled for others in the setting (The Early Education Team- The Capper Foundation, 1990).



INTERWEAVING WITH REST TIMES



Fatigue is a common symptom after Traumatic Brain Injury and some regular "down-time" is important. However going away from school, or going out of class for a rest reduces participation alongside peers. When rests need to happen, share information about the need in a way that normalizes the experience, and which helps other children link this need with their own experience. Often, the rest-times can usefully be incorporated into the normal school routine, and it might be possible for 1-2 other children to share in the rest activity. Going to a quiet area close to the classroom, and using relaxation techniques, or listening to a very quiet tape of music or a story is a way of supporting participation while still managing fatigue.

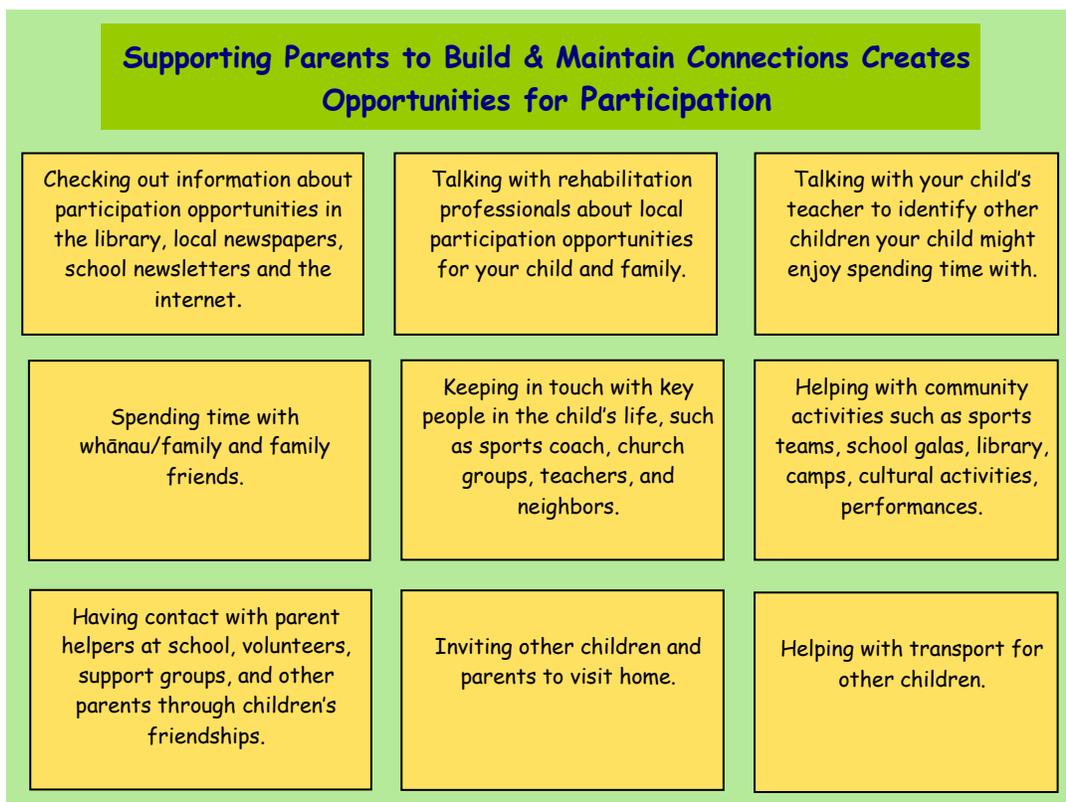


INTERWEAVING WITH PARENTS' PARTICIPATION

It is important that parents are supported to participate and build connections too! After a child has a traumatic brain injury, studies show the important role played by community in family and child wellbeing (Jones, Hocking, & Wright-St Clair, 2010; Robson, Ziviani, & Spina, 2005). As a child moves through the rehabilitation process after a traumatic brain injury, their parents' connections with whānau, extended family, friends, the school, and people in the community all play a very important role in providing ongoing opportunities for this child's participation.

Parents' connections help others in the community to learn about changes and how to be involved (Hendrickson, Shokoohi-Yekta, Hamre-Nietupski, & Gable, 1996). The process is two-way! While whānau/family might start the process, it equally needs input from people in the community around them.

The diagram shows different ways parents talk about being involved with their community to help build and maintain connections



References

- Anderson, V., & Catroppa, C. (2006). Advances in postacute rehabilitation after childhood-acquired brain injury: A focus on cognitive, behavioral, and social domains. *American Journal of Physical Medicine and Rehabilitation*, 85, 767-778. doi:10.1097/01.phm.0000233176.08480.22
- Batchelor, D., & Taylor, H. (2005). Social inclusion-the next step: User-friendly strategies to promote social interaction and peer acceptance of children with disabilities. *Australian Journal of Early Childhood*, 30(4), 10-18. Retrieved from <http://www.earlychildhoodaustralia.org.au/>
- Bell, H. C., Pellis, S. M., & Kolb, B. (2010). Juvenile peer play experience and the development of the orbitofrontal and medial prefrontal cortices. *Behavioural Brain Research*, 207, 7-13. doi:10.1016/j.bbr.2009.09.029
- Bernabe, E. A., & Block, M. E. (1994). Modifying rules of a regular girls softball league to facilitate the inclusion of a child with severe disabilities. *Journal of the Association for Persons with Severe Handicaps (JASH)*, 19(1), 24-31. Retrieved from <http://www.tash.org/publications/RPSD/RPSD.html>
- Causton-Theoharis, J. N. (2009). The golden rule of providing support in inclusive classrooms: Support others as you would wish to be supported. *TEACHING Exceptional Children*, 42(2), 36-43. Retrieved from <http://journals.cec.sped.org/tec/>
- DeZonia, K. (2009). Mobility: Not just the ability to move: Tips for gaining acceptance and moving toward community connections. *Exceptional Parent*, 39(5), 30-31. Retrieved from <http://www.eparent.com/>
- Hendrickson, J. M., Shokoohi-Yekta, M., Hamre-Nietupski, S., & Gable, R. A. (1996). Middle and high school students' perceptions on being friends with peers with severe disabilities. *Exceptional Children*, 63(1), 19-28. Retrieved from <http://www.cec.sped.org/Content/NavigationMenu/Publications2/Exceptional Children/>
- Jones, M., Hocking, C., & Wright-St Clair, V. (2010). Parents caregiving for children after a traumatic brain injury: Structuring for security. *New Zealand Journal of Occupational Therapy*, 57(1), 4-13. Retrieved from <http://www.nzaot.com/publications/journal/index.php>
- Law, M. (2002). Participation in the occupations of everyday life. *The American Journal of Occupational Therapy*, 56, 640-649. doi:10.5014/ajot.56.6.640
- Lewis, C., & Carpendale, J. I. M. (2009). Introduction: Links between social interaction and executive function. *New Directions in Child and Adolescent Development*, 123, 1-15. doi:10.1002/ed.232
- Robson, T., Ziviani, J., & Spina, S. (2005). Personal experiences of families of children with a traumatic brain injury in the transition from hospital to home. *Brain Impairment*, 6(1), 45-55. doi:10.1375/brim.6.1.45.65477

- The Early Education Team- The Capper Foundation, &. (1990). *Project Kidlink: Bringing together disabled and nondisabled preschoolers* Tucson, Arizona: Communication Skill Builders.
- World Health Organization. (2007). *International classification of functioning, disability and health: Child and youth version: ICF-CY*. Geneva, Switzerland: Author.
- Ylvisaker, M. (Ed.). (1998). *Traumatic brain injury rehabilitation: Children and adolescents* (2nd ed.). Newton, MA: Butterworth-Heinemann.
- Zionts, P. (1997). *Inclusion strategies for students with learning and behavior problems: Perspectives, experiences, and best practices*. Austin, TX: PRO-ED.