

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

Disc One Appendices

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Appendix 4.1: Table of Case Study Methodology Assumptions and Characteristics

Assumptions of Case Study Methodology Identified by Researcher	Quoted Examples of Assumptions and Sources Illustrating Characteristics
People & the world are intricately connected in multiple & complex ways over time	<p>The qualitative case study researcher has tried to facilitate reader understanding, an understanding that important human actions are seldom simply caused, and usually not caused in ways that can be discovered. It is enough to recognize some of the many coexisting happenings (Stake, 1995, p. 39).</p> <p>Phenomena are intricately related through many coincidental actions (Stake, 1995, p. 43).</p> <p>The distinctive need for case studies arises out of the desire to understand complex social phenomena. In brief, the case study method allows investigators to retain the holistic and meaningful characteristics of real-life events (Yin, 2009, p. 4).</p> <p>Phenomena and context are not always distinguishable in real life situations (Yin, 2009, p. 18).</p> <p>[MacDonald] formulate[d] a rationale for the case study design element of the evaluation that took account of the variability of human action in institutions and the different influences that determine it, the interrelationships of acts and consequences, the judgements of those within, and the possible perceptions of the goals and purposes of the programme held by those who designed the programme and those who implemented it (Simons, 2009, p. 15).</p> <p>Case study is an in-depth exploration from multiple perspectives of the complexity and uniqueness of a particular project, policy, institution, programme or system in a 'real-life' context (Simons, 2009, p. 21).</p> <p>Each case turns out be profoundly embedded in its real world situation (Adelman, Jenkins, & Kemmis,</p>

1980, p. 51).

People's knowledge arises as they act with and experience the world. This means people bring existing knowledge to a situation and know things in multiple different ways.

Case studies recognise the complexity and 'embeddedness' of social truths (Adelman et al., 1980, p. 59).

The world we know is a particularly human construction. Infants, children, and adults construct their understandings from experience and from being told what the world is... (Stake, 1995, pp. 99-100)

Understanding them [phenomena] requires looking at a wide sweep of contexts: temporal and spatial, historical, political, economic, cultural, social, and personal (Stake, 1995, p. 41).

The desired result is for the investigator to create a rich dialogue with the evidence, an activity that encompasses 'pondering the possibilities gained from deep familiarity with some aspect of the world, systematizing those ideas in relation to kinds of information one might gather, checking the ideas in the light of that information (Becker as cited in Yin, 2009, p. 69).

Qualitative research tries to establish an empathetic understanding for the reader through description, sometimes thick description, conveying to the reader what experience itself would convey (Stake, 1995, p. 39).

The role of theory development prior to the conduct of any data collection, is one point of difference between case studies and related methods such as ethnography and grounded theory (Yin, 2009, p. 35).

Case study using qualitative methods in particular enables the experience and complexity of programmes and policies to be studied in depth and interpreted in the precise socio-political contexts in which programmes and policies are enacted.... Case studies written in accessible language including vignettes and cameos of people in the case, direct observation of events, incidents and settings, allows audiences of case study reports to vicariously experience what was observed and utilize their tacit knowledge in understandings its significance (Simons, 2009, p. 23).

Case study research offers a surrogate experience and invites the reader to underwrite the account, by appealing to his tacit knowledge of human situations (Adelman et al., 1980, p. 52).

The intention of the case study worker [is] to respond to the multiplicity of perspectives present in a social situation (Adelman et al., 1980, p. 55).

Case studies are down-to-earth and attention holding, in harmony with the reader's own experience, and thus provide a 'natural' basis for generalisation. A reader responding to a case study is consequently able to employ the ordinary processes of judgement by which people tacitly understand life and social actions around them (Adelman et al., 1980, p. 59).

Knowledge includes both generalized, theoretical knowledge &/or knowledge of unique instances

The case, the activity, the event, are seen as unique as well as common. Understanding each one requires an understanding of other cases, activities, and events but also an understanding of each one's uniqueness (Stake, 1995, p. 44).

Case study research includes both single- and multiple-case study designs. ...Yin 09 p. 19. The single case design is imminently justifiable under certain conditions-where the case represents (a) a critical test of existing theory, (b) a rare or unique circumstance, or (c) a representative or typical case, or where the case serves a (d) revelatory or (e) longitudinal purpose. (Yin 09, p. 52). Any use of multiple-case designs should follow a replication, not a sampling logic... The cases should serve in a manner similar to multiple experiments, with similar results (a literal replication) or contrasting results (a theoretical replication) (Yin, 2009, p. 60).

In many situations in which case study research is conducted, formal generalization for policy making is not the aim. The aim is particularization- to present a rich portrayal of a single setting, to inform practice, establish the value of the case and/or add to knowledge of a specific topic (Simons, 2009, p. 24).

The accumulation of case studies allows theory-building via tentative hypotheses culled from single instances. But the generalizations produced in case study are no less legitimate when about the instance (Adelman et al., 1980, p. 48).

Case studies allow generalisations either about an instance or from an instance to a class (Adelman et al., 1980, p. 59).

Knowledge that is generated democratically can bring about social change

The [case researcher] role I want to emphasize first is the role of teacher. The intention of research is to inform, to sophisticate, to assist the increase of competence and maturity, to socialize, and to liberate.... The teacher is also an advocate, the exemplar of a way to see, the persuader of a road to follow. So too the researcher (Stake, 1995, pp. 91-92).

The investigator may not have collected all the relevant evidence and only may have attended to the evidence supporting a single point of view.... This type of problem persists whenever studies of organizations appear to represent the perspectives of management and not workers, or when studies of social groups appear to be insensitive to issues of gender or multiculturalism, or when studies of youth programs appear to represent adult perspectives and ignore those of youths. To represent different perspectives adequately, an investigator must seek those alternatives that most seriously challenge the assumptions of the case study (Yin, 2009, p. 187).

In the late 1960s and 1970s, in the context of evaluation, the task was to determine the effects of social and education programmes in order to inform decision-making and improve social and educational action (Simons, 2009, p. 14).... [Stake] drew attention to the need to include antecedent data, data about transactions and judgements, and data on outcomes in order to 'tell the programme story'. Further papers argued for portrayal of the programme vis-à-vis analysis (Stake 1972) and the need to be responsive to issues identified by stakeholders, and participants iteratively throughout the evaluation (Stake, 1975) (Stake as cited in Simons, 2009, p. 15).

Beyond methodology, but closely connected with it, were other reasons for a shift to case study related to the purpose and role of evaluation in a democratic society Simons p. 17. I want now to explore this dimension further to illustrate how the methodology and political purpose are linked. The purposes are many but are generally recognized to fall into three broad categories- accountability, development (of the institution or agency) and knowledge. The major role is to inform and promote public decision-making (Chelimsky [2006] and Greene [2000] as cited in Simons, 2009, p. 17).

There was a growing awareness of the need for shift in the power of research relationships away from regarding the evaluator as the sole judge of what was worthwhile to acknowledge the perspectives of participants in the case and the judgements of those who have decisions to make in policy or practice contexts (Simons, 2009, p. 17).

Case study has the potential to engage participants in the research process. This is both a political and epistemological point. It signals a potential shift in the power base of who controls knowledge and recognizes the importance of co-constructing perceived reality through the relationships and joint understandings we create in the field (Simons, 2009, p. 23).

All accounts are considered to be expressive of the social position of each informant. Case study needs to represent, and represent fairly, these differing and sometimes conflicting viewpoints (Adelman et al., 1980, p. 55).

Case studies are a 'step to action'. They begin in a world of action and contribute to it (Adelman et al., 1980, p. 60).

The case study is capable of serving multiple audiences. It reduces the dependence of the reader upon unstated implicit assumptions (which necessarily underlie any type of research) and makes the research process itself accessible. Case studies, therefore, may contribute towards the 'democratisation' of decision-making (and knowledge itself) (Adelman et al., 1980, p. 60).

People judge and use knowledge according to the situation

In the face of those who might only see the need for a single research method, this book believes that, just as different scientific methods prevail in the natural sciences, different social science research methods fill different needs and situations for investigating social science topics (Yin, 2009, p. 3).

Case studies can be conducted and written with many different motives (Yin, 2009, p. 20).

[Case study] can have a more diverse set of potential audiences than most other types of research.... Because case studies have more potential audiences than other types of research, one of your essential tasks in designing the overall case study report is to identify the specific audiences for the report. Each audience has different needs, and no single report will serve all audiences simultaneously (Yin, 2009, p. 167).

The primary purpose [of case study] is to generate in-depth understanding of a specific topic ... programme, policy, institution or system to generate knowledge, and/or inform policy development, professional practice and civil or community action (Simons, 2009, p. 21).

Sometimes the audience for the study will be more concerned with the given systems, sometimes with the exploration of given issues (Adelman et al., 1980, p. 51).

Their insights may be directly interpreted and put to use; for staff or individual self-development, for within-institutional feedback; for formative evaluation; and in educational policy-making (Adelman et al., 1980, p. 60).

References

- 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.
- Simons, H. (2009). *Case study research in practice*. London: SAGE.
- Stake, R. E. (1995). *The art of case study research*. Thousand Oaks: Sage.
- Yin, R. K. (2009). *Case study research: Design and methods* (4th ed.). Los Angeles: SAGE.

Appendix 4.2a: Northern Y Regional Ethics Committee Approval January 2007

Community Participation for Children after TBI



Northern Y Regional Ethics Committee

Ministry of Health
3rd Floor, BNZ Building
354 Victoria Street
PO Box 1031
Hamilton
Phone (07) 858 7021
Fax (07) 858 7070

15 January 2007

Margaret Jones
Division of Rehabilitation & Occupation Studies
AUT University, PB 92006
Auckland 1310

Dear Margaret

Describing Community Participation for New Zealand Children after Traumatic Brain Injury.

Investigators: Margaret Anne Jones.

Ethics ref: NTY/06/12/134

Locations: Wilson Centre in WDHB.

The above study has been given ethical approval by the Northern Y Regional Ethics Committee. The Committee requests the final copies of the PIS and consent forms once the approval dates information is noted from the university and the ethics committee. Please note that this does not affect the application's ethical approval status.

Approved Documents

- Participant Information Sheet and Consent Form: Parents/Whanau dated 1 January 2007.
- Participant Information Sheet and Consent Form: Children dated 1 January 2007.
- Participant Information Sheet and Consent Form: Teacher dated 1 January 2007.
- Statement by relative/friend/whanau.
- Semi-Structured Interview Outline: Children
- Semi-Structured Interview Outline: Parents
- Semi-Structured Interview Outline: Teachers

Accreditation

The Committee involved in the approval of this study is accredited by the Health Research Council and is constituted and operates in accordance with the Operational Standard for Ethics Committees, April 2006.

Progress Reports

The study is approved until **30 July 2008**. The Committee will review the approved application annually and notify the Principal Investigator if it withdraws approval. It is the Principal Investigator's responsibility to forward a progress report covering all sites prior to ethical review of the project in **15 January 2008**. The report form is available on <http://www.newhealth.govt.nz/ethicscommittees>. Please note that failure to provide a progress report may result in the withdrawal of ethical approval. A final report is also required at the conclusion of the study.

Amendments

It is also a condition of approval that the Committee is advised of any adverse events, if the study does not commence, or the study is altered in any way, including all documentation eg advertisements, letters to prospective participants.



Northern Y Regional Ethics Committee

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PO Box 1031
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Please quote the above ethics committee reference number in all correspondence.

It should be noted that Ethics Committee approval does not imply any resource commitment or administrative facilitation by any healthcare provider within whose facility the research is to be carried out. Where applicable, authority for this must be obtained separately from the appropriate manager within the organisation.

Yours sincerely

A handwritten signature in dark ink, appearing to read 'Amrita'.

Amrita Kuruvilla
Northern Y Ethics Committee Administrator
Email: amrita_kuruvilla@moh.govt.nz

Appendix 4.2b: AUTECH Ethics Approval March 2007



MEMORANDUM

Auckland University of Technology Ethics Committee (AUTECH)

To: Clare Hocking
From: **Madeline Banda** Executive Secretary, AUTECH
Date: 24 March 2007
Subject: Ethics Application Number 07/24 **Describing community participation amongst a small group of New Zealand children after traumatic brain injury.**

Dear Clare

I am pleased to advise that the Auckland University of Technology Ethics Committee (AUTECH) approved your ethics application at their meeting on 12 March 2007. Your application is now approved for a period of three years until 12 March 2010.

I advise that as part of the ethics approval process, you are required to submit to AUTECH the following:

- A brief annual progress report indicating compliance with the ethical approval given using form EA2, which is available online through <http://www.aut.ac.nz/research/ethics>, including when necessary a request for extension of the approval one month prior to its expiry on 12 March 2010;
- A brief report on the status of the project using form EA3, which is available online through <http://www.aut.ac.nz/research/ethics>. This report is to be submitted either when the approval expires on 12 March 2010 or on completion of the project, whichever comes sooner;

It is also a condition of approval that AUTECH is notified of any adverse events or if the research does not commence and that AUTECH approval is sought for any alteration to the research, including any alteration of or addition to the participant documents involved.

You are reminded that, as applicant, you are responsible for ensuring that any research undertaken under this approval is carried out within the parameters approved for your application. Any change to the research outside the parameters of this approval must be submitted to AUTECH for approval before that change is implemented.

Please note that AUTECH grants ethical approval only. If you require management approval from an institution or organisation for your research, then you will need to make the arrangements necessary to obtain this.

To enable us to provide you with efficient service, we ask that you use the application number and study title in all written and verbal correspondence with us. Should you have any further enquiries regarding this matter, you are welcome to contact Charles Grinter, Ethics Coordinator, by email at charles.grinter@aut.ac.nz or by telephone on 921 9999 at extension 8860.

On behalf of the Committee and myself, I wish you success with your research and look forward to reading about it in your reports.

Yours sincerely



Madeline Banda
Executive Secretary
Auckland University of Technology Ethics Committee

Cc: Margaret Anne Jones margjone@aut.ac.nz

Appendix 4.2c: ACC Ethics Approval February 2009

4 February 2009

Margaret Jones

Division of rehabilitation & Occupation studies

AUT University

Private Bag 92006

AUCKLAND 1142

Dear Margaret

ACC Research Ethics Committee Decision Notification

**RE: Describing community participation amongst a small group of New Zealand Children after Traumatic Brain Injury. Margaret Jones, AUT.
#152**

Thank you for your research proposal which was considered by the ACC Research Ethics Committee at its meeting 4 February 2009.

The request is approved. However the committee did note that the exclusion from the study of those who do not understand or speak English will limit the extent to which findings can be extrapolated to the general population

Ethical approval for this study is given for one year at which time the Committee will ask you to complete a Monitoring Form. If for any reason the proposal is changed in any significant way the ACC Research Ethics Committee must be advised immediately.

Please complete the attached research ethics confidentiality form and return this to me.

The Committee wish you well with the research and trusts that it will have productive outcomes.

Yours sincerely

Fiona Conlon, Secretary
PP Sharron Cole, Co - Chair
ACC Research Ethics Committee

Appendix 4.2d: Northern Y Regional Ethics Committee Approval Amendments November 2007



5 November 2007

Margaret Jones
Division of Rehabilitation & Occupation Studies
AUT University, PB 92006
Auckland 1310

Northern Y Regional Ethics Committee

Ministry of Health
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Dear Margaret

Describing Community Participation for New Zealand Children after Traumatic Brain Injury.

Investigators: Margaret Anne Jones.

Ethics ref: NTY/06/12/134

Locations: Wilson Centre in WDHB.

List of amendments and associated documents

- Adjusting the wording of the research aims and question.
- Recruitment through additional ACC contracted rehabilitation providers.
- Ethical approval to gather photographic data of artefacts.
- Ethical approval for analyse documents from each child's ACC case file .
- Ethical approval to analyse child's current Individual Education Programme.
- Participation Information Sheet for Children dated 21 October 2007.
- Participation Information Sheet for Parent(s)/whanau dated 21 October 2007.
- Participation Information Sheet for Teachers dated 21 October 2007.
- Consent Form for the child dated 21 October 2007.
- Consent Form for parents dated 21 October 2007.
- Consent Form for teacher dated 21 October 2007.
- Statement by relative/friend/whanau.
- Revised application form received 23/10/07.

Thank you for submitting the above amendments and associated documents which was considered by the Chairperson of the Northern Y Regional Ethics Committee under delegated authority and approved.

Please quote the above ethics committee reference number in all correspondence.

Yours sincerely

Amrita Kuruvilla
Northern Y Ethics Committee Administrator

Email: amrita_kuruvilla@moh.govt.nz

Appendix 4.2e: Northern Y Regional Ethics Committee Approval Amendments December 2008



Margaret Jones
Division of Rehabilitation & Occupation Studies
AUT University, PB 92006
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Northern Y Regional Ethics Committee

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Dear Margaret

Describing Community Participation for New Zealand Children after Traumatic Brain Injury.

Investigators: Margaret Anne Jones.

Ethics ref: NTY/06/12/134

Locations: Wilson Centre in WDHB.

List of amendments and documents

- A letter of approval from the ACC Ethics Committee is required before approval can be given to employ a new Locality Provider.
- Approval has been given to extend the completion date for the above study to 30/08/09.
- Invitation Letter to ACC clients dated 22/09/08.
- Locality Assessment Form signed by Michelle Wilkinson, Project Manager ACC National Serious Injury Service.
- Progress report for the above study dated 02/10/08.

Thank you for submitting the above amendment and supporting documents, which was considered **by the Chairperson of the Northern Y Regional Ethics Committee under delegated authority** and approved.

Please quote the above ethics committee reference number in all correspondence.

Yours sincerely



Amrita Kuruvilla
Northern Y Ethics Committee Administrator
Email: amrita_kuruvilla@moh.govt.nz

Appendix 4.3: Pre-suppositions Interview

Interview 18/05/07: Margaret and LR:

Pre-Understandings & Reflections on Interview

Identity	Value	Understanding /Assumption	Influences/Sources	Potential Influence on Study
Occupational Therapist	<p><u>Occupational Therapist Role and our Service.</u></p> <p>Clinical work at W/Centre with children & families. I want families to feel satisfied with</p>		<p>Derive personal satisfaction from positive feedback from families and team. Feel I am “making a difference”</p> <p>My family and societal values of hard work and quality work.</p> <p>Being seen as a “skilled”</p>	<p>A strong motivator for the study....Motivator for precision and quality in this project.</p> <p>Understandings gained from past and current families are a strong influence on me. Could be an additional source of data and influence my understandings of data from this study. Negatives</p>

Identity	Value	Understanding /Assumption	Influences/Sources	Potential Influence on Study
	their rehabilitation. I want to “do a good job”.		therapist by ACC personnel.	<p>about W/Centre/rehab may not be easily expressed by some families if they perceive my strong links with this setting. I may be less open to seeing negatives about the setting/my own practice or that of my colleagues.</p> <p>Need to avoid implementing a “therapist” role when I am in my “researcher” role.</p> <p>I need to reconcile this conflict- In the study, I am seeing children in the context of their families. Perhaps it is recognizing there is a power differential, and facilitating children’s wishes to also be heard. Perhaps this conflict might also be apparent in my study, and might limit participation.</p>
			<p>Family Centered Care- at the time of beginning the study, I was aware of negative feelings towards this concept. There is a risk of enabling the wishes and</p>	

Identity	Value	Understanding /Assumption	Influences/Sources	Potential Influence on Study
			values of parents above those of the child, particularly if the child is unable to easily communicate their own concerns.	
Rehabilitation Professional		<p><u>Service Provision</u></p> <p>As therapists, we are not good at giving children the skills they need to be independent in class- to participate. We often focus on immediate health needs, rather than the occupation.</p> <p>We should be involved in preparing friends/family /helping them to interact with the changed child.</p> <p>ACC some times influences the habits of OTs- the legislation does not fund for eg) educating friends. It funds for measureable outcomes on a competitive contractual basis, and performance is reviewed by external assessors who are funded to seek out gaps in service provision- the assessments used do not guide a focus on participation, rather focusing on health needs. .</p>	<p>Observations, reflections</p> <p>Ylvisaker and Feeney</p>	<p>Assumption: The child will have changed.</p> <p>Assumption: The friends/family will need help.</p> <p>I have assumptions about the social influences on peoples' actions based on my own experience. These assumptions may not hold true or apply to all situations.</p>

Identity	Value	Understanding /Assumption	Influences/Sources	Potential Influence on Study
Occupational Therapist	<u>Children's self esteem-</u> important to ensure a sense of identity, confidence, and enable engagement in occupation	I see children's self-esteem and self-identity as going hand-in-hand with parent's acceptance of their changed children. I find it easiest to work with families who accept their children and any disability that comes with them.	Occupational Therapy Training. Working alongside Social Workers. Clinical experience- the children and families I meet and work with.	Potential to place less value on interventions /environmental supports that emphasise children's impairments. This might be at odds with participants' values, and may limit my interpretation of their data. I may find it difficult to relate to/see the viewpoint of families who have more difficulty accepting their children post-injury.
Occupational Therapist	<u>Occupation</u>	<u>Occupation</u> is essential to health and development. Occupation is about doing, being, and becoming. <u>Difference and Diversity</u> Accepting and celebrating differences	My training. My supervisor. The occupational therapy texts I read. Other members of the teaching team. OT colleagues at W/Centre.	I will tend to interpret things with an "occupational" eye. I want to enable children to "do". This may not be the value of the participants. I need to try to remain open to new ways of seeing and understanding things.

Identity	Value	Understanding /Assumption	Influences/Sources	Potential Influence on Study
		<u>Play as an occupation</u>	My own childhood, the neurodevelopmental paper I completed.	
	<u>Family</u> <u>Children</u>		My parents	It may be difficult to interpret data from families who hold the opposites of these values. Conversely, my own values may assist me with this. Where family ties have been broken as a result of the accident, I may interpret this data in a more emotional way. I don't think I would, but there is the potential for me to judge, if a family member was the cause of a loss of life (eg. parent/child killed).

Identity	Value	Understanding /Assumption	Influences/Sources	Potential Influence on Study
	<p>Participation – I describe it as a vision for the future of our service, a model to guide our service delivery, involving a whole team of people. I personally value time spent with other people.</p>	<p>Participation is “being part of things”. It is about being part of a family, <u>doing</u> stuff <u>with</u> other people. It is about “<u>being</u>” <u>with</u> other people and in “<u>different settings</u>”. A feeling of being part of a <u>bigger community</u>.</p> <p>These themes come through. The word “different” indicates that I might perceive variation and change in settings as positive. The word “bigger” could indicate I see participation as happening in layers.</p> <p>“Getting back into life experiences”</p>	<p>Perhaps my Occupational Therapy Training. Perhaps the influence of my supervisor.</p> <p>I think my understandings of the importance of participation have grown and developed as the world around me has changed- I have picked this up as I teach, as I attend conferences, as I look at others’ research, as I talk with colleagues.</p> <p>The ICF- it values participation as an endpoint, and this is held up as a good model of health/disability. I value research- and this is a pertinent and currently “researchable” topic- by focusing on this, I get to do what I enjoy. Being able to research this contributes to my</p>	<p>My valuing of participation may show in the way I interpret the data....I may pay more attention to it. I may be more keenly tuned to things that are limiting children’s participation. I may interpret the words and actions of those who place less value on participation in a negative light. I will be critical of factors and systems that limit participation.</p> <p>I need to understand that not all families may think participation is important. Families may define participation differently to me.</p>

Identity	Value	Understanding /Assumption	Influences/Sources	Potential Influence on Study
			<p>enthusiasm for it.</p> <p>I value the service I work in- I believe that it needs to take on these understandings about participation to remain a viable and relevant leading service in the future.</p> <p>As a teen, I found participation difficult in the setting I was in. Not feeling part of things impacted on my self-esteem and sense of efficacy. I know how important participation is, and how bad it feels not to participate</p> <p>Presentation by clients from BIA.</p>	
	<p>“Real” participation, not artificially created rehabilitation.</p>	<p>Community Participation: There is a risk of children/other clients participating in the “rehab” community, but not in their own “outside” community.</p>		<p>Clients may actually value this “created” participation more than being in their own community. I need to remain open to seeing this contradiction to my own values.</p>

Identity	Value	Understanding /Assumption	Influences/Sources	Potential Influence on Study
	I do not want to do a cultural study. I find it hard to relate to this concept- it is vague- amorphous, changing in meaning.	<p>Culture is not limited to ethnicity. It is a sense of belonging to a particular group. It influences how things are done, what is valued. It is interwoven with participation..</p> <p>Culture has values. Our culture often values intelligence and knowledge.</p>	OT training.	I may lack sensitivity to cultures other than my own. This is concerning, as the cultural environment may be a facilitator/barrier. I tend not to see influencing factors in terms of the word "culture"- more as social systems. I tend to make assumptions about others' cultural values. I can find it hard to get past my own pre-judgements of others' intelligence.
		<p><u>What aspects of P will be important?</u></p> <p>-Things children want and need to do...ie) I think factors will be individual and unique to the different people. But there will be some commonalities.</p> <p>-Being able to have a say in what they want and need to do</p>	<p>-Canadian Model of Occupational Performance. Symbolic Interactionism. Pragmatism.</p> <p>-Concept of "self determination" = Occupational Therapy.</p>	<p>I need to be careful not to let this pre-assumption of individuality/commonality pressure my interpretation of data. Other factors may be at work and I could miss them.</p> <p>I tend to see things in a critical/emancipatory light. I believe children have a right to do this. I will be critical of systems and factors that prevent</p>

Identity	Value	Understanding /Assumption	Influences/Sources	Potential Influence on Study
				them from doing so.
	The opinions of Mark, Kath, Michelle, and Clare. Clare tends no to express values that might influence the way I will interpret my data.	<p><u>Families fear</u></p> <p>Families are vulnerable, frightened for the future, fear leaving the shelter of rehab. They are fearful of the children going to school, and want to protect them. This is a normal parental reaction, but the feelings are exacerbated by the injury. It is important to build their confidence, and I value interventions that support, assure, and reassure.</p>	My MHSc study revealed this. I have also talked about this with Mark Ylvisaker, Kath and Michelle (ACC) who helped me to recognize the importance of endeavouring to normalize things for families- not catastrophizing, medicalising.	<p>I will empathise with families who feel like this.</p> <p>I will tend to see interventions that align with my values as facilitators. I need to understand that these may be different views to those expressed by people in the study.</p>
		<p><u>Changing Assumptions</u></p> <p>It is valid to change the people and their values that surround the child.</p>	Phillip Patston.	This understanding is one of the things driving my study. I need to understand the way these environmental factors act in order to understand how to change them. I assume that people's assumptions CAN be changed.

Identity	Value	Understanding /Assumption	Influences/Sources	Potential Influence on Study
Occupational Therapist		<p><u>Family Adjustment</u></p> <p>In the early stages of rehab, families want their children to eat, walk, talk, and go home. The medical world has strong influences during hospitalization and early rehab- some parents see the medical world as controlling the future. They see they face a battle and challenges to get the children back to where they were.</p> <p>Over time, parents grow to accept their “new child”. Some families seem to accept this new child immediately. This acceptance is important for the child to move forward.</p>	Michelle (ACC), clinical experience.	<p>These understandings form the back ground to my study. I am expecting that the families I see in the study will change and will have moved on from this. Families may not have experienced these things.</p> <p>These understandings also contribute back ground to my study. I am expecting that the families I see in the study will have moved on from this.</p>
		<p><u>Teachers view of Participation</u></p> <p>Teachers are under pressure from the Ministry of Education to deliver the curriculum within set time frames. They face challenges of having large numbers in their classes, and this creates additional challenges when a child has a disability who moves at a different pace to others. They may feel they don’t have the</p>	<p>Clinical experience and reflection.</p> <p>Mark Ylvisaker.</p>	Some of my understandings are unsubstantiated. I need to explore teachers’ feelings about what is difficult for them.

Identity	Value	Understanding /Assumption	Influences/Sources	Potential Influence on Study
		necessary skills. These stresses will mean teachers will see the services of a teacher aide as a facilitator. However, the teacher aide may also function as a barrier to children participating. Parents and teachers views of what participation is important will differ. Teachers will place higher value on social behavior while parents will value skills and performance components (reading, writing, vision). These values are influenced by therapy provision and ACC legislation which values improvements in skills and pays for measurable changes in skill quality and independence. Teachers will value participation across different areas at school. These will include academic learning, sports, manual training.	Clinical experience. Literature- teachers find behavior hardest to manage and see it as interfering with learning.	This may not be proved or may be disputed by my data. There is a particular risk that these pre-conceptions about the influence of ACC legislation will impact on my analysis of documents. I also need to be careful not to “lead” participants with my own views during interviews, and to identify where these understandings have impacted on the way I reflect on and interpret data. It will be good to have

Identity	Value	Understanding /Assumption	Influences/Sources	Potential Influence on Study
				opportunity to explore what the teachers' views are of different areas of participation.
	My words and the way I speak indicate I feel passionate about involving friends in rehab, rather than getting bogged down in medical details.	<p><u>What do schools do "right"? Facilitators</u></p> <p>Team meetings</p> <p>Open communication with other team members and families</p> <p>Nurture throughout the rehab process- aroha. Teacher/pupils visit and are involved in the rehab. They are seen as awaiting the child's return to them, regardless of how the child now presents. Not judging the child.</p>	<p>Experience.</p> <p>Mark Ylvisaker.</p> <p>My MHSc study.</p>	My values risk failing to acknowledge the contribution of medical stability to health. Particularly early in rehab, medical management is critical to progress.
		<p>What do schools do that is not so good? Barriers</p> <p>Child is not actively included, or is excluded</p>		I may tend to seek evidence of these actions as a barrier.

Identity	Value	Understanding /Assumption	Influences/Sources	Potential Influence on Study
		from meetings and school activities Schools use the child as a tool/weapon to obtain resources and trappings- these resources are an outward “sign” of a good school setup, even though they can actively signal a difference.		
Occupational Therapist vs Researcher		<p><u>Other Barriers:</u></p> <p>Sometimes the physical environment impedes clients.</p> <p>Sometimes it is the client’s physical/cognitive/emotional capacities that impede them. Parents who want these capacities “fixed” have got a point.</p>	<p>Remediating/compensating for impaired capacities provides me with my clinical practice. I am adept at identifying these limitations, as well as strengths/skills, and using these things to make decisions with families about how to best enable participation.</p> <p><u>Pragmatism. Social constructionism.</u></p>	<p>I need to avoid looking at these situations from a perspective of “doing something” to address issues.</p> <p>I understand that my own perceptions are socially and pragmatically constructed. That these perceptions will influence the way I interpret data- they</p>

Identity	Value	Understanding /Assumption	Influences/Sources	Potential Influence on Study
				cannot be bracketed and “put aside”. That others may interpret things differently. That my understandings will change as a result of being in conversation and activities with families and children on the study. I will need to discuss the way my understandings are influencing the findings, and explain this to the reader.

Appendix 4.4: Definitions of Terms in Issue Statements

Definitions of Issue Statements

To provide boundaries for the case, the different terms within the case study issues were defined. There was an understanding that as the case study progressed the terms would be open to re-definition.

1. Clinically significant TBI: Sustained a Moderate to Severe accidental injury, involving damage to the brain due to external physical force(s), with a consequent Glasgow Coma Scale (GCS) Score of 3-12 and ongoing difficulties as sequelae (New Zealand Guidelines Group, 2006).
2. Chronic Stages; 6 or more months post injury and discharged from inpatient rehabilitation for at least 6 months.
3. Impairments- Problems in body function or structure such as a significant deviation or loss (World Health Organization, 2007).
4. Body Functions: The physiological and psychological functions of body systems (World Health Organization, 2007).
5. Body Structures: Anatomical parts of the body (World Health Organization, 2007).
6. Participation: Meaningful and satisfactory involvement in a life situation (Hemmingsson & Jonsson, 2005; Ueda & Okawa, 2003; World Health Organization, 2001).
7. Facilitators: Aspects of the person's cultural, institutional, physical, and social environment, which, through their absence or presence, improve a person's ability to participate (World Health Organization, 2007).
8. Barriers: Aspects of the person's cultural, institutional, physical, and social environment, which, through their absence or presence, limit a person's ability to participate (Canadian Association of Occupational Therapists, 2002; World Health Organization, 2007).
9. Cultural Environment: Ethnic, racial, ceremonial and routine practices, based on the characteristic ethos and value system of particular groups (Canadian Association of Occupational Therapists, 2002).
10. Institutional Environment: Societal institutions and practices, including policies, decision-making processes, procedures, accessibility, and other organizational practices. Includes economic, legal, and political components (Canadian Association of Occupational Therapists, 2002).
11. Physical Environment: Natural and built surroundings, and objects within them (Canadian Association of Occupational Therapists, 2002).

12. Social Environment: Social priorities about all elements of the environment, patterns of relationships of people living in an organized community, social groupings based on common interests, values, attitudes, and beliefs (Canadian Association of Occupational Therapists, 2002).

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Participant Information Sheet: Parent(s)/Whanau



Date Information Sheet Produced: 16 /11 /2006

Project Title

Describing Community Participation Amongst a Small Group of New Zealand Children after Traumatic Brain Injury

Participation in this study is entirely voluntary (your choice). You do not have to take part in this study, and if you and/or your child choose not to take part, this will not affect the rehabilitation your child receives in any way.

If you do agree to take part, you are free to withdraw from the study at any time, without having to give a reason. Your child will continue to receive their usual rehabilitation, and any future care or treatment will not be affected.

An Invitation

Dear Parent(s)/Whanau,

My name is Margaret Jones, and I am an occupational therapist who works at the Waitemata District Health Board Child Rehabilitation Service at Wilson Centre in Takapuna with children who have had traumatic brain injuries. I am undertaking this research project for my PhD studies at AUT University.

I would like to invite you to discuss this information with your child using this and the Child Information Sheet.

What is the purpose of this research?

The aim of the project is to hear the views of a small group of New Zealand children who have had a traumatic brain injury, of their parents/whanau, and the views of their teachers about what is important after they leave hospital and begin to take part in community activities again. I am especially interested in what helps them to be involved again, and what things have not helped.

There is very little information written about what happens for children in New Zealand after they have a traumatic brain injury, and I would like to learn more about this to help health professionals understand what works best when they provide rehabilitation for children. I hope to write up the findings of the study for publication in a health journal, and to present the findings in New Zealand and also overseas.

How were you chosen for this invitation?

Your name was passed on to me either through the Waitemata District Health Board Child Rehabilitation Service at Wilson Centre, or another rehabilitation provider after they contacted you about your willingness in being part of a research project. Children and their parents are eligible to take part in the research if their child has had a traumatic brain injury, is aged between 9-12 years, and have been discharged from hospital or inpatient rehabilitation for at least 6 months. Parents/whanau need to be able to communicate using

conversational English. Children who are part of the study need to be living in the community with parent(s)/whanau. I hope to involve up to 5 families in the research.

What will happen in the research?

If you and your child decide to take part, it will involve interviews with you and also with your child.

- For parents, this will involve up to 2 interviews of no more than an hour each, with a third interview at a later stage to check on details. The interviews will be relaxed and informal, so that you can talk about your experiences exactly as you wish to. I will first ask for some brief details as to how old your child was when the accident happened, how many brothers and sisters they have, which school they go to, and what therapy they have had. With your permission, I will request copies of your child's recent assessment and rehabilitation plans from their ACC Case File, and copy their current IEP (Individual Education Programme) so that I can analyse the ways these documents and the programmes might influence your child's participation.
- With your permission, I will check the details about the type of injury they had in the clinical records at Wilson Centre, or in the records of your therapy provider.
- I will also ask you to nominate up to 3 teaching personnel at your child's school who I might approach to interview about what is important to help your child to join in at school, and who would be comfortable with me visiting the class. If your child changes teachers during the study I would like to visit your child in class with the new teacher.
- I would also like to talk with your child at home, and to spend some time with them, observing as they go about their daily routines at home and at school. I will not ask them a lot of formal questions, but will ask them something to help prompt them to talk about what they do on a day-to-day basis. Initially I would like to spend two 1 ½ hour sessions with them over two weeks to get to know them, then I would like to visit them three times for up to 1 hour over the next 6 weeks. This might be at home, at school or in the community, depending on their routines and what is comfortable for you both. Later on, at six months and eight months, I would like to interview them (for no more than 1 hour) again to follow up with how things are going for them.

With permission from you and your child, I will audio-tape the interviews and have them typed up. As I interact and observe your child, I will also take brief notes, which I will write up as narratives, or stories, and take some photographs of important objects that are involved when they carry out activities. After this, I will give you the opportunity to check your typed interview, the narratives, and the photographs. You may ask for any material to be removed or changed at that point.

The information that comes out of the interviews will be studied, and compared with information from others who are on the study. You will only have access to your own interview and the interview/observations of your own child.

What are the discomforts and risks?

Talking about how things have been since the brain injury might bring about some sad feelings for you and your child. You and your child might find it stressful having an extra person in your home or in the classroom. In the unlikely event that you and/or your child became distressed, I would encourage you to talk with your general practitioner or rehabilitation provider. Participation in the study will stop if you or your child experience harmful effects, or if you or your doctor feel it is not in your own or your child's best interests to continue.

On the other side, many people, including children find it helpful to have their point of view heard, and feel they are better able to talk about their needs to other professionals. I would hope that you find being part of this project is a positive experience.

How will these discomforts and risks be alleviated?

You and your child will be reminded at the beginning of each visit that it is your own choice to be part of the study or talk about things. You will not have to answer any questions, or, have observations or photographs taken if you are not comfortable to do so. You do not have to allow me to copy the assessment, rehabilitation plan, and/or IEP.

During the interview you would be welcome to have a support person there with you, and children will be able to have their parent(s) with them when I am visiting. Any time I spend with you will be scheduled to work in best with your routines.

What are the benefits?

You and your child will have the chance to talk about your experiences and explain how you see things. This will be a chance for you to make your experiences and views known, and be part of a study that helps us to learn about what it is like after a child has a brain injury and how people can best assist.

How will your privacy be protected?

You and your child will be able to choose code names that will be used when the interviews and stories are written up. No details will be used that could identify you, such as the name of a place or school, or photographs of your child, other people, or parts of the surrounding environment. All documents will be stored securely. No details about you, your family, or child will be shared or passed on to any practitioner without your express permission to do so.

If you decide to take part, with your permission, I would like to inform your General Practitioner of your participation in the study. However, the only people who will be able to access your own or your child's information will be myself, and my supervisors. We will ensure your information is kept in a locked case or cabinets in my office. You will be able to access your own or your child's information.

Your information will be kept for 10 years after your child turns 16, then it will be returned to you or destroyed by deleting computer storage discs and shredding written material. Your child may withdraw consent to further use of the data after they turn 16. If you, or your child decides to withdraw from the study, your information will be returned to you at that point or destroyed.

What are the costs of participating in this research?

The main cost to you will be your time. There are no additional financial costs to participation.

What opportunity do you have to consider this invitation?

You may have a friend, family, whanau, or other support to help you understand the risks and/or benefits of this study and any further explanation you may require. If you would like the opportunity to ask more questions, please feel free to contact me as per the details below. If you would like to be part of this research, I would be very happy to hear back from you as soon as possible.

How do you agree to participate in this research?

If you would like to take part in the study, please fill in the enclosed consent form, and return it in the stamped addressed envelope. I will make a time to visit, and explain the project to your child again with you, and ensure that they still want to be involved. I will get permission from your child using a Child Consent Form.

Do you receive feedback on the results of this research?

I will give you a copy of your audio-recording and of the photographs. It will take about a year for the study to be completed, and the findings to be written up. When this happens, I will send you a report, and you will be invited to attend a presentation.

What do you do if you have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor.

Concerns regarding the conduct of the research should be notified to the Executive Secretary, ATEC, Madeline Banda, madeline.banda@aut.ac.nz, 921 9999 ext 8044.

Also, if you have queries or concerns about your rights as a participant in this study, you may contact the Health & Disability Consumer Advocates: 0800 42 36 38 (4 ADNET).

Whom do you contact for further information about this research?

Researcher Contact Details:

Margaret Anne Jones, Occupational Therapist. margjone@aut.ac.nz 09 921 9999 ext 7781.
AUT University, Private Bag 92 006, Auckland 1142.

Project Supervisor Contact Details:

Professor Kathryn McPherson. kathryn.mcpherson@aut.ac.nz 09 921 9999 ext 7110

Dr Clare Hocking, Associate Professor. clare.hocking@aut.ac.nz 09 921 9999 ext 7120

Approved by the Auckland University of Technology Ethics Committee on **12 March 2007**, ATEC Reference number **07/24**.

Approved by the Northern Y Regional Ethics Committee on **07 March 2008**, Reference number **NTY/06/12/13**

Participant Information Sheet For Children



Date Information Sheet Produced: 16 /11 /2006

Research Project: Finding out about the things New Zealand children do when they go home after they have a head injury

Invitation

Dear _____,

My name is Margaret Jones, and I am an occupational therapist who works with children who have had head injuries. I would like to invite you to take part in my study.

What is this project about?

I am interested to see and hear about the sorts of things you and other children do at home and out in other places such as school if you have had a head injury. I am keen to find out about the sorts of things you find helpful, and things that feel more difficult.

How are children chosen to be part of the project?

Children are chosen if they:

- are between 9-12 years old
- had a head injury and had rehabilitation at the Wilson Centre or other therapy provider
- live at home with their parents or whanau
- can understand and explain things to me in English.

What happens in the project?

I will visit you, and spend some time talking to you about what you do at home and at school each day, and watching to see the sorts of things you do. I would like to visit you with members of your family/whanau at home first, and later, I would also like to visit you at school. I would visit for up to an hour and a half on one day, and again the next week.

After that, I would like to visit you 3 times for just an hour a fortnight, and then again 6 months and 8 months later.

I hope that our talk will be relaxed and friendly, and that you can tell me about what you do in your own way. Even though I'm an adult, you don't need to let me watch, or talk to me about things you don't want to. Often I will ask a question if you run out of things to say.

With permission from you and your parents or whanau, I will record the interviews and get them typed up. I will also write some notes and take some photographs of items that are involved when you do things. I would like to copy and look at your therapy assessments and plans and education plan.

I will also interview your teachers if they are happy to do that. This is to find out about the sorts of things teachers think are important when children go back at school after a head injury.

I will look at the information from visiting you, and compare it to information from other children, to see what sorts of things are the same, and what is different. After all this has been done, the information will be written up as a story about what children do, and I will give you a summary of what it is about. If you like you can check it, and see if you think it is right.

Is anything in the project going to be hard for me?

Talking about how things have been since the head injury might not be easy, and having me there perhaps could make you feel uncomfortable. Your parents or whanau will be there when I visit.

If you don't want to talk about some things, or if there are times when you don't want me there, that's fine. You only need to talk about the things you want to, and I can go to a different room, or go away if you would like. You could choose not to answer me by saying "I don't think I'll talk about that", or ask me "can you leave me now". I won't take any photographs of things or copy any papers if you don't want me to.

What are the benefits?

You will be able to tell me about your experiences from your point of view. This will help other people to understand what it is like, and help adults to learn about how best to help you.

How will my privacy be protected?

I will ask you to make up a name, and this is the name I will use when the tapes and stories are written up. I won't use any other facts about you, such as the name of your school, or where you live. Other children at school won't be told that you are part of a study. I won't include people or the places where you do things when I take photographs. All the information about you will be stored safely.

I will ask your parents or whanau to read what we said in the interview, to make sure they are happy for other people to know those things, and we might agree to remove some of it. You and your parents will be able to access your information.

Finding out about the results of the project

I will give you a copy of your recordings and the photographs, after I have finished writing up about the research project, I will give a report that you can read about what was found out. You and your parent(s) whanau will be invited to hear me talk about the research at a presentation.

How do I join the project?

If you would like to be part of this research project, I would be very please to hear from you and your parent(s)/whanau. I would like you to talk about the project with your parent(s)/whanau, and they need to agree for you to take part.

If you would like to know more, you can contact me either by phone or email (with your parent's permission) and I will be pleased to answer any of your questions. If you decide you would like to take part, I will visit you, and go through the forms you and your parents need to sign to say you consent to be on the study.

No matter what you decide to do, thank you for being interested in my project.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor.

If you have queries or concerns about your rights as a participant in this study, you may contact the Health & Disability Consumer Advocates: 0800 42 36 38 (4 ADNET).

Whom do I contact for further information about this research?

Researcher Contact Details:

Margaret Anne Jones, Occupational Therapist. margjone@aut.ac.nz 09 921 9999 ext 7781.
AUT University, Private Bag 92 006, Auckland 1310.

Project Supervisor Contact Details:

Associate Professor Clare Hocking, clare.hocking@aut.ac.nz 09 921 9999 ext 7120

Professor Kathryn McPherson. kathryn.mcpherson@aut.ac.nz 09 921 9999 ext 7110

Approved by the Auckland University of Technology Ethics Committee on **12 March 2007**, AUTEC Reference number **07/24**.

Approved by the Northern Y Regional Ethics Committee on **07 Marchr 2008**, Reference number **NTY/06/12/134**.

Appendix 4.5c: Information Sheet Teacher July 2007

Participant Information Sheet: Teacher



Date Information Sheet Produced: 16 /11 /2006

Research Project Title

Describing Community Participation Amongst a Small Group of New Zealand Children after Traumatic Brain Injury

An Invitation

Dear Teacher,

My name is Margaret Jones, and I am an occupational therapist who works with children who have had traumatic brain injuries. I am undertaking this research project as part of my PhD studies at AUT University.

I would like to invite you to take part in the research.

What is the purpose of this research?

The aim of the project is to find out what is important for New Zealand children who have had a traumatic brain injury after they leave hospital and begin to take part in community activities again. I would like to find this out from the point of view of the children, their parents, whanau, and their teachers. I am especially interested in what helps the children to be involved again, and what things have not helped.

I am interested in talking with teachers who have children with traumatic brain injury in their class, to find out their perceptions of what activities at school are important, what helps the children to take part in activities, and what makes it difficult for them. I hope to involve up to 5 children, along with their parents and teachers in the study.

There is very little information written about what happens for children in New Zealand after they have a traumatic brain injury, and I would like to learn more about this to help health professionals understand what works best when they provide rehabilitation. I hope to write up the findings of the study for publication in a health journal, and to present the findings in New Zealand and also overseas.

How was I chosen for this invitation?

Your name was passed on to me by the parents of _____, who have consented to participate in the study. Prior to approaching you, I talked to the school principal and have his/her consent to approach you and to join class activities, as described below.

You do not have to take part in this study.

What will happen in the research?

One thing that would happen, is that I would interview you. This would be for up to an hour, and you will not have to answer questions if you are not comfortable to do so. With your permission, I will audio-tape the interview and have it typed up. I will give you the opportunity to check your typed interview. You may ask for any material to be removed or changed at that point.

I would also like to spend some time observing _____ as he/she takes part in class activities. This would be for no more than an hour, three times over the next 6 weeks. As I interact and observe _____, I will take brief notes, and would take photographs of items that are important to his/her activities. No persons or details of the surrounding environment will be included in the photographs. With the permission of _____ and his/her parents, I will analyse a copy of their ACC assessments, rehabilitation programme and Individual Education Programme that they provide to me. You do not have to agree to have me in the class to observe or take photographs.

Later on, at six months and eight months, I would like to visit the child again (for an hour each time) to follow up with how things are going. This might be at home or at school.

You are able agree to participate in only one part of the data gathering, the interview or the observation in the classroom, if you wish. Also, if you do agree to take part, you are free to withdraw from the study at any time, without having to give a reason.

The information that comes out of the interviews will be analysed, and compared with information from others who are on the study.

What are the discomforts and risks?

You may find it stressful having an extra person in the classroom. I appreciate also that your time is valuable, and that having an interview is extra time out of your day.

However, you may find it helpful having the opportunity to have your point of view heard.

How will these discomforts and risks be alleviated?

Any time I spend with you will be scheduled to work in best with your routines. Each time we meet I will remind you that you are not obliged to answer all my questions and that you can ask me to leave. In the unlikely event that you do experience distress, I can assist you to identify an appropriate counselling service.

What are the benefits?

You will have the chance to talk about your experiences and explain how you see things. This will be a chance for you to make your views known, and be part of a study that helps us to learn about what it is like after a child or student has a brain injury and how people can best assist.

What compensation is available for injury or negligence?

As this is an interview based study, there is very little risk to you. In the very unlikely situation of harm or injury, compensation is available through the Accident Compensation Corporation within its normal limitations.

How will my privacy be protected?

You will be able to choose a code name that will be used when the interviews and observations are written up. No details will be used that could identify you, other participants, other people in the school, or the school. No details about you will be shared or passed on to other participants or others associated with the school.

The only people who will be able to access your information will be myself, and my supervisors. We will ensure your information is kept in a locked case or cabinet in my office. Your information will be kept for 10 years after the child turns 16, then it will be returned to you or destroyed by deleting computer storage discs and shredding written material. If you, or the child decides to withdraw from the study, your information will be returned to you at that point or destroyed.

What are the costs of participating in this research?

The main cost to you will be your time.

What opportunity do I have to consider this invitation?

If you would like to be part of this research, I would be very happy to hear back from you as soon as possible.

How do I agree to participate in this research?

If you would like to take part in the study, please fill in the enclosed consent form, and return it to me in the stamped addressed envelope.

Will I receive feedback on the results of this research?

I will give you a copy of your transcript. It will take about a year for the study to be completed, and the findings to be written up. When this happens, I will send you a report, and you will be invited to attend a presentation.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor.

Also, if you have queries or concerns about your rights as a participant in this study, you may contact the Health & Disability Consumer Advocates: 0800 42 36 38 (4 ADNET).

Whom do I contact for further information about this research?

Researcher Contact Details:

Margaret Anne Jones, Occupational Therapist. margjone@aut.ac.nz 09 921 9999 ext 7781.
AUT University, Private Bag 92 006, Auckland 1142.

Project Supervisor Contact Details:

Associate Professor Clare Hocking, clare.hocking@aut.ac.nz 09 921 9999 ext 7120

Professor Kathryn McPherson. kathryn.mcpherson@aut.ac.nz 09 921 9999 ext 7110

Approved by the Auckland University of Technology Ethics Committee on **12 March 2007**, AUTEC Reference number **07/24**.

Approved by the Northern Y Regional Ethics Committee on **05 November 2007**, Reference number **NTY/06/12/134**.

Parent Consent Form



Project title: Describing Community Participation Amongst a Small Group of New Zealand Children after Traumatic Brain Injury

Project Supervisor: Professor Kathryn McPherson: Dr Clare Hocking, Associate Professor

Researcher: Margaret Anne Jones, Occupational Therapist

- I have read and I understand the information sheet dated 16 /11 /2006 for volunteers to take part in the study designed to describe children's participation in the community after they have a traumatic brain injury. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.
- I have had the opportunity to use whanau support or a friend to help me ask questions and understand the study.
- I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time and this will in no way affect my own or my child's continuing or future rehabilitation or health care.
- If I withdraw, I understand that all relevant information including tapes, transcripts, photographs, photocopies, and narratives, or parts thereof, will be destroyed or returned to me.
- I understand that my participation in this study is confidential and that no material that could identify me will be used in any reports on this study.
- I understand that the study will be stopped if it appears to be harmful to me, or to my child.
- I have had time to consider whether to take part.
- I know who to contact if I, or if my child have any side effects to the study.
- I know who to contact if I, or my child have any questions about the study.
- I consent to the interviews being audio-taped and transcribed, and notes being taken of observations.

YES/NO

- I consent to the researcher photographing objects important to my child's activities.

YES/NO

- I consent to the researcher accessing photocopies of my child's recent assessment and rehabilitation plans from their ACC Case File. These will include the following documents: YES/NO

Document Name	Example/Type	Version	Information Required
Social Rehabilitation Assessment-Complex		Most Recent	<p>Assessed current participation, functional needs (activity limitations) and environmental facilitators and barriers in the life areas of daily living skills, transport, communication, safety, and education.</p> <p>Rehabilitation options (eg) occupational therapy, physiotherapy, speech language therapy)/further assessments to be employed to address those needs.</p> <p>Explanation of how the rehabilitation options can meet the needs.</p>
Specialised Assessment (if any)	<p>Education Needs</p> <p>Wheelchair & Seating</p> <p>Assistive Technology</p> <p>Aids & Appliances</p>	Most Recent	<p>Assessed needs (if any)and recommended options (if any) to meet those needs in the areas of education, mobility and positioning, assistive technology to enable participation in communication & education, aids and appliances to enable participation in activities of daily living.</p>
Training for Independence Programme	Overall Programme Plan	Most Recent	<p>The broad rehabilitation functional outcomes to be addressed by therapy intervention (eg) occupational therapy, physiotherapy, speech language therapy) and anticipated broad time frames.</p> <p>Specific functional outcomes to be addressed by therapy intervention (eg) occupational therapy, physiotherapy, speech language therapy) and anticipated short-term time frames).</p> <p>Specific intervention strategies being</p>

			employed to address functional outcomes.
	Module Plan	Previous Most Recent	The number of hours involved for each discipline for delivering the above interventions.
	Reporting - Progress -Variance -Completion		Whether or not the claimant has achieved the functional outcomes in the life areas of daily living skills, transport, communication, safety, and education.
Lifetime Rehabilitation Plan (if any)			This is a long-term plan developed by ACC personnel to identify long term rehabilitation goals and needs (2-5 years) and strategies/interventions to be implemented to address those needs. Not all clients have a Lifetime Rehabilitation Plan completed.
Individual Educational Programme			The child's current abilities in terms of participating in the education curriculum, the barriers present that limit their involvement (eg. activity limitations) their educational goals, and strategies/personnel involved who will be assisting them to meet those goals (facilitators).

- I consent to the researcher photocopying my child's current Individual Education Programme:

YES/NO

- I consent to the researcher accessing my child's medical/clinical records
YES/NO

- I consent to the researcher contacting my child's school and to the researcher discussing my child with their teachers
YES/NO

- I wish to receive a copy of the report from the research:
YES/NO

- I agree to my GP or other current provider being informed of my participation in this study.
YES/NO

I _____ (full name) hereby consent to take part in this study

Date _____

Signature _____

Full names of Researcher: Margaret Anne Jones

Contact Phone Number for researchers: 09 921 9999 ext 7781

Project explained by: Margaret Anne Jones

Project role: Principal Researcher

Signature

Date

Participant's Contact Details (if appropriate):

.....
.....
.....
.....

Approved by the Auckland University of Technology Ethics Committee on 12 March 2007 AUTEK Reference number 07/24.

Approved by the Northern Y Regional Ethics Committee on 07 March 2008, Reference number NTY/06/12/134

Note: The Participant should retain a copy of this form.

REQUEST FOR INTERPRETER

English	I wish to have an interpreter.	Yes	No
Maori	E hiahia ana ahau ki tetahi kaiwhakamaori/kaiwhaka pakeha korero.	Ae	Kao
Cook Island	Ka inangaro au i tetai tangata uri reo.	Ae	Kare
Fijian	Au gadreva me dua e vakadewa vosa vei au	Io	Sega
Niuean	Fia manako au ke fakaaoga e taha tagata fakahokohoko kupu.	E	Nakai
Samoan	Ou te mana'o ia i ai se fa'amatala upu.	Ioe	Leai
Tokelaun	Ko au e fofou ki he tino ke fakaliliu te gagana	Ioe	Leai

	Peletania ki na gagana o na motu o te Pahefika		
Tongan	Oku ou fiema'u ha fakatonulea.	Io	Ikai

Appendix 4.6b: Consent Form Child July 2007

Child Consent Form



Project title: Describing Community Participation Amongst a Small Group of New Zealand Children after Traumatic Brain Injury

Project Supervisors: Professor Kathryn McPherson: Dr Clare Hocking, Associate Professor

Researcher: Margaret Anne Jones, Occupational Therapist

- I have been given information and understand what this research project is about.
- I have had my questions answered.
- I agree that my interview can be audio-taped and that the researcher can write notes, take photographs of things, and photocopy my latest ACC assessments, therapy plans and Education Plan.
- I am choosing to be part of the research project because I want to- it is my own choice.
- I understand that I can pull out of the project if I want to at any time.
- I agree to take part in this research project

I _____ (Participant full name-child) hereby consent to take part
in this study

_____ (Participant signature-child)

Date: _____

Full names of Researcher: Margaret Anne Jones

Contact Phone Number for researchers: 09 921 9999 ext 7781

Project explained by: Margaret Anne Jones

Project role: Principal Researcher

Signature

Date

Note: The Participant should retain a copy of this form

Approved by the Auckland University of Technology Ethics Committee on 12 March 2007 AUTEC Reference number 07/24.

Approved by the Northern Y Regional Ethics Committee on 05 November 2007, Reference number NTY/06/12/134

Appendix 4.6c: Consent Form Teacher July 2007

Teacher Consent Form



Project title: Describing Community Participation Amongst a Small Group of New Zealand Children after Traumatic Brain Injury

Project Supervisor: Associate Professor Clare Hocking, Professor Kathryn McPherson:

Researcher: Margaret Anne Jones, Occupational Therapist

- I have read and I understand the information sheet dated 16 /11 /2006 for volunteers to take part in the study designed to describe children's participation in the community after they have a traumatic brain injury. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.
- I have had the opportunity to talk with a support person to help me ask questions and understand the study.
- I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time.
- If I withdraw, I understand that all relevant information including tapes, transcripts, or parts thereof, will be returned to me or destroyed .
- I understand that my participation in this study is confidential and that no material that could identify me will be used in any reports on this study.
- I have had time to consider whether to take part.
- I know who to contact if I have any side effects to the study.
- I know who to contact if I have any questions or concerns about the study.
- I consent to the interviews being recorded and transcribed, notes being taken of observations, and photographs taken of objects that are important to the child's activities in the classroom. YES/NO
- I wish to receive a copy of a report from the research:
YES/NO

I

I _____ (full name) hereby consent to take part in this study

Date _____

Signature _____

Full names of Researcher: Margaret Anne Jones

Contact Phone Number for researchers: 09 921 9999 ext 7781

Project explained by: Margaret Anne Jones

Project role: Principal Researcher

Signature

Date

Participant's Contact Details (if appropriate):

.....
.....
.....
.....

Approved by the Auckland University of Technology Ethics Committee on 12 March 2007 AUTEK Reference number 07/24.

Approved by the Northern Y Regional Ethics Committee on 05 November 2007, Reference number NTY/06/12/134

Note: The Participant should retain a copy of this form.

Appendix 4.6d: Proxy Consent Form July 2007

Part 7: When a participant is unable to make an informed choice

To be completed when one or more participants in a project will likely not be able to make an informed choice about whether to take part. ***Do not complete this section if all participants in the study will be competent to make an informed choice and give informed consent themselves.*** Refer to the Guidelines for information about children in research.

1. Will any of the participants have a person with them who is available and entitled to make an informed choice on their behalf if they themselves are unable to do so. yes ☐
no ☐

If yes, that person can make a proxy informed choice for the potential participant. Include an appropriate consent form for that person legally entitled. (Note: Where possible the incompetent person should also orally consent to the level of his or her understanding.)

If no, complete section 1.1

- 1.1 Is there any person interested in the potential participant's welfare who knows the participant (eg family member/friend/whanau) and is willing and available to express a view as to what the potential participant would choose were he or she competent and fully informed about the study. yes ☐
no ☐

If yes, include an information sheet for the family member/friend/whanau statement as per page 24.

Please note: if it is appropriate that there be wider consultation with family, then this should be encouraged

If no, complete section 1.2

- 1.2 Explain why it is not possible for a potential participant to make an informed choice and why it is not possible for a proxy choice to be made or for a person interested in the potential participant's welfare to state what the participant would choose if he or she was competent and fully informed.
-

2. What would be the risks to the participants of taking part in this study?

No scientific evidence has been found of risks posed by this style of research. Some participants may experience stress after their TBI. Participants may find it stressful having an additional person in their home/school. The researcher will remind them on every occasion that they are welcome to refuse any questions, observations, photographs, or document photocopies, turn off tape recorders, delete material, or stop any interview/observations. The child's parents and/or teacher will be present. In the homes of the participants, the researcher will respect cultural issues to the best of her ability.

3. Could the research be carried out on people who are able to consent

yes

☐

no

☐

4. Explain why approval is being sought to use this participant/population/.patient group.

Approval is sought to involve these 9-12 year old child participants with Traumatic Brain Injury. Children of this age frequently sustain traumatic brain injuries (Accident Compensation Corporation, 2006). Their experiences will be different to those of older children or children who have never had this type of injury.

5. What is the potential health interest for the group of patients/population of which the participant would be a member?

The perceptions of this group about what participation involves, what is helpful, and what is not helpful after the injury is central to health professionals' understandings about what we need to consider when we are evaluating their progress and providing interventions.

STATEMENT BY RELATIVE/FRIEND/WHANAU

Lay Title: Describing Community Participation Amongst a Small Group of New Zealand Children after Traumatic Brain Injury

Principal Investigator Margaret Anne Jones, Occupational Therapist

Participant's Name _____

I have read and I understand the information sheet dated _____ for people taking part in the study designed to _____. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.

I believe that _____ (participant's name) would have chosen and consented to participate in this study if he/she had been able to understand the information that I have received and understood.

I understand that taking part in this study is voluntary and that my relative/friend may withdraw from the study at any time if he/she wishes. This will not affect his/her continuing health care.

I understand that his/her participation in this study is confidential and that no material which could identify him/her will be used in any reports on this study.

I understand that the study will be stopped if it should appear to be harmful.

I know whom to contact if my relative/friend has any side effects to the study or if anything occurs which I think he/she would consider a reason to withdraw from the study.

This study has been given ethical approval by the **Northern Y Regional Ethics Committee**. This means that the Committee may check at any time that the study is following appropriate ethical procedures.

I/my relative/friend would like a copy of the results of the study. **YES/NO**

I believe my relative/friend would agree to his/her GP being informed of his/her participation in this study **YES/NO**

Signed: _____ Date _____

Printed Name: _____

Relationship to Participant: _____

Address for results : _____

STATEMENT BY PRINCIPAL INVESTIGATOR

I (name of investigator) declare that this study is in the potential health interest of the group of patients of which (name of participant) is a member and that participation in this study is not adverse to (name of participant)'s interests.

(if applicable)

I confirm that if the participant becomes competent to make an informed choice and give an informed consent, full information will be given to him/her as soon as possible, and his/her participation will be explained. If the participant makes an informed choice to continue in the study, written consent will be requested and if the participant does not wish to continue in the study, he/she will be withdrawn.

Signed: _____
Principal Investigator

Date _____

(If applicable at a later stage)

I _____ (participant) having been fully informed about this study agree to continue taking part in it.

Signed: _____
Participant

Date _____

STATEMENT BY INDEPENDENT CLINICIAN

I confirm that participation in the study is not adverse to _____ (participant)'s interests.

Signed: _____
Clinician

Date _____

Printed Name : _____

Appendix 4.7: Data Gathering Plan and Protocol

Describing Community Participation Amongst a Small Group of New Zealand Children after Traumatic Brain Injury

1) Overview

Investigators & Contact Details:

Investigator

Margaret Anne Jones, Occupational Therapist. margjone@aut.ac.nz 09 921 9999 ext 7781. AUT University, Private Bag 92 006, Auckland 1020.

Supervisors

Professor Kathryn McPherson. kathryn.mcpherson@aut.ac.nz 09 921 9999 ext 7110

Dr Clare Hocking, Associate Professor. clare.hocking@aut.ac.nz 09 921 9999 ext 7120

Ethics Committees:

Northern Y Regional Ethics Committee, Ministry of Health, PO Box 1031, Hamilton;
Administrator: Amrita Kuruvilla: Ph: 07 858 7021. Email Amrita_Kuruvilla@moh.govt.nz
Ref: NTY/ 06/12/134

Report Due: Progress Report 15 January 2008. Final Report 15 July 2008. Forms on
www.newhealth.govt.nz/ethicscommittees

AUT Ethics Committee, Private Bag 92006, Auckland 1020.

Secretary: Madeline Banda

Ref: 07/24

Report Due: Annual Progress Report 12 March 2008 using EA2. Final Report 12/03/10 using EA3

ACC Research Ethics Committee, Research Services, Accident Compensation Commission,
POBox 242, Wellington

Senior Programme Manager (Research): Peter Larking (PhD). Ph 04 918 7656. Email

Peter.Larking@ACC.co.nz

Ref 104

Monitoring Report Form Due: 5 September 08

Recruitment Localities & Auspices:

Deleted to support confidentiality

Maori Cultural Support:

Deleted to support confidentiality

Rationale for Localities & Recruitment Procedures

Advantages	Disadvantages
Convenience – location to researcher Personally known to researcher- supportive of	Slower response- waiting for several locality signoffs and time for them to contact

<p>study</p> <p>Close relationship with participants → positive communication re study, prepared to listen, face to face interactions with potential participants/personalised</p> <p>Knowledge- well positioned to identify suitable participants & provide explanation to them if needed</p> <p>Enthusiastic re the project.</p> <p>Small in scope- leaves other options open for further recruitment</p> <p>Sending out written information- participants have time to consider what will be involved.</p> <p>Face to face explanation to child- ensure understanding. Can answer parent's questions as needed.</p> <p>*** (Deleted for confidentiality): usually receives referrals for more severe injuries- opportunity to capture participants who would be sure of having experience of changes to their participation. Additionally provides access to participants nationwide, as well as both rural and urban living families.</p> <p>Additional localities than *** ensure that children can be recruited who did/didn't take part in in-patient (Active) rehabilitation.</p>	<p>participants</p> <p>Possibly few participants (already encountered) → delays in contacting and processing further localities.</p> <p>Additional time involved in processing and liaising with multiple localities.</p>
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Rationale for Numbers

Very few overseas studies to date have directly researched participation, or facilitators and barriers to participation for this group. Few have focussed on the participants' perceptions of their experiences. Those that inform us about aspects of participation have shown variation in the research methods used and in numbers of participants involved.

While some Case Studies contain a single case only (eg. in instances when a "typical" case is required to represent a phenomena, for a longitudinal study, or as a critical test of existing theory), this study proposes to involve up to five cases. Evidence from multiple cases creates a more robust study, by involving replication logic to test out theory which is developed and/or refined from an initial case. Subsequent cases are carefully selected with either similarities or variations in the conditions, to investigate their ability to either predict similar results, or, to predict contrasting results that are due to a particular circumstance. By "testing out" the cases in this way, a stronger and richer theoretical framework can be developed (Yin, 2003).

The criterion for identifying the number of replication cases is at the discretion of the researcher, and depends on the level of certainty that is desired, the level of complexity of the conditions involved with the phenomenon, and practical limitations of resources and time. Yin (2003) recommends that 3 - 10 replications be completed, while Cresswell (2007) states that he would not include more than 5 cases. Due in part to the diverse nature of the population under study (eg. variations in geographic and physical locations, culture, family make-up, and presentation) up to 5 case studies are proposed here. Ethical consent to include further cases will be sought should further replications be necessary.

Rationale for Multiple Sources of Evidence

Advantages	Disadvantages
<p>↑ depth of understanding</p> <p>Insight → new dimensions/aspects of an issue</p> <p>Confirm understandings</p>	<p>Challenge of mastering multiple data collection techniques</p>

Different contexts and experiences Provide increased information about the contexts and experiences Seeing things from the insiders eyes → experiential understandings Data triangulation + consultations from different analyses Crossing boundaries if needed (complexity theory) Insights into linkages, communication channels.	Longer time frames- impact on project management.
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Background:

References:

Aims:

1. To describe and explain the aspects of participation that are important for NZ children with clinically significant TBI, in general, and as perceived by key stakeholders, including the children, their parents/whanau, and their teachers.
2. To describe and explain the facilitators and barriers to successful participation in general, and as perceived by key stakeholders, including the children, their parents/whanau, and their teachers.

Questions:

1. What are the aspects of participation that are important to NZ 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 parent's/whanau perspective
 - c. The teacher's perspective
 - d. An observational perspective (within the family, school, and/or community settings)?

Conceptual Structure: Declarative Issue Statements:

1. For NZ children aged 9-12 yrs 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 also by key stakeholders to be facilitators or to be barriers to the children's participation.

Definitions:

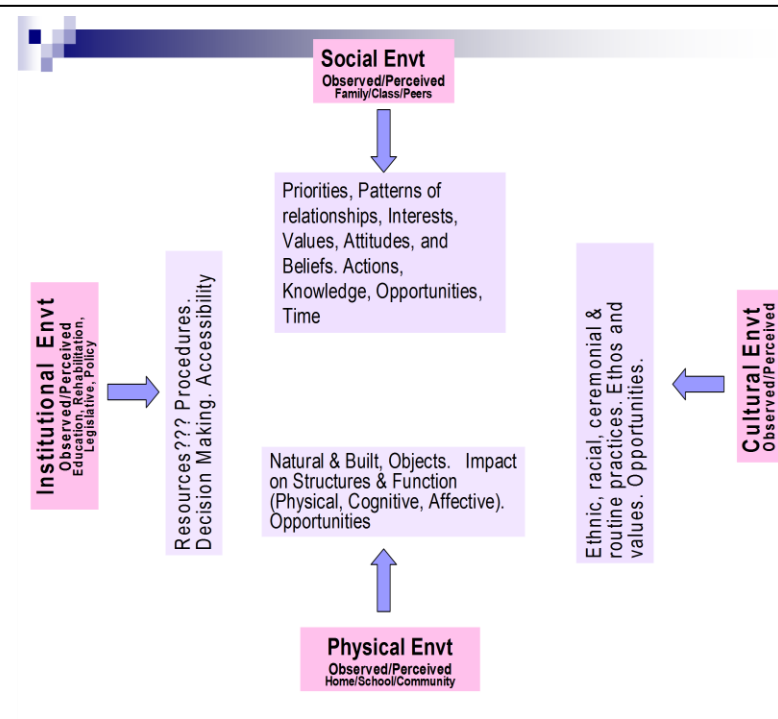
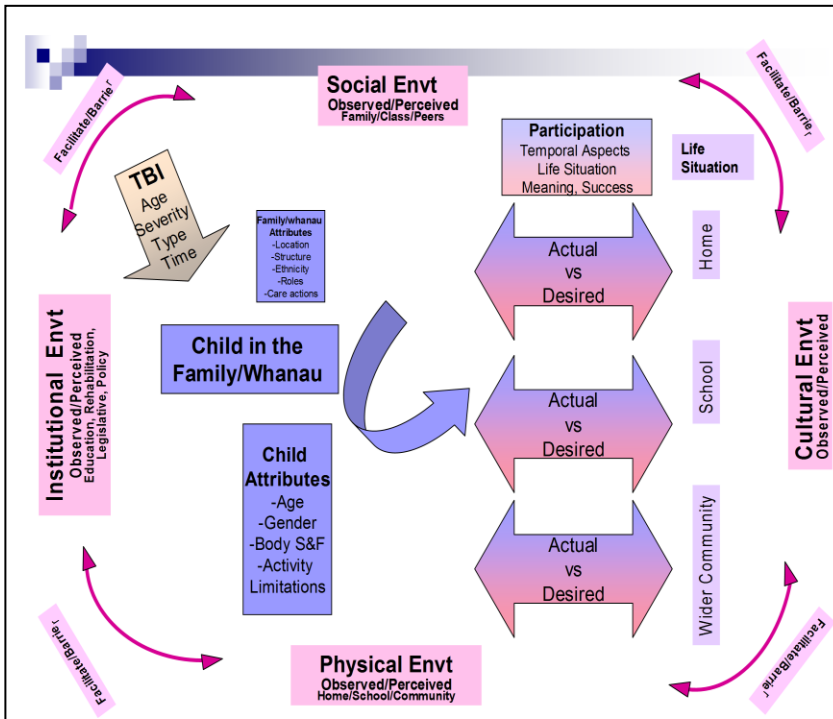
- Clinically significant TBI: Sustained a Moderate to Severe injury, involving damage to the brain due to external physical force(s), with a consequent Glasgow Coma Scale Score of 3-12 and ongoing difficulties as sequelae.
- Chronic Stages; 6 or more months post injury and discharged from inpatient rehabilitation for at least 6 months.
- Impairments- Problems in body function or structure such as a significant deviation or loss.
- Body Functions: The physiological and psychological functions of body systems.
- Body Structures : Anatomical parts of the body.
- Activity: Difficulties an individual may have in executing tasks or actions
- Participation: Meaningful and satisfactory involvement in a life situation.
- Facilitators: Aspects of the person's cultural, institutional, physical, and social environment, that, through their absence or presence, improve a person's ability to participate.
- Barriers: Aspects of the person's cultural, institutional, physical, and social environment, that, through their absence or presence, limit a person's ability to participate.
- Cultural Environment: Ethnic, racial, ceremonial and routine practices, based on the characteristic ethos and value system of particular groups.
- Institutional Environment: Societal institutions and practices, including policies, decision-making processes, procedures, accessibility, and other organizational practices. Includes economic, legal, and political components.
- Physical Environment: Natural and built surroundings, and objects within them.
- Social Environment: Social priorities about all elements of the environment, patterns of relationships of people living in an organized community, social groupings based on common interests, values, attitudes, and beliefs.

Rationale for Definitions and References

<ul style="list-style-type: none">• Concepts of Body Structures and Functions, Activity, Participation, Facilitators, Barriers. (International Classification of Function, World Health Organisation, 2001). I have also included "where participation takes place" in my definition- this denotes the transactional aspects of participation across and in many different interlinking envts. I have also added meaning and satisfaction to the concept of participation (Canadian Association of Occupational Therapists, 2002).	
<ul style="list-style-type: none">• Developed by a body with international expertise, and concepts tested extensively.• Widely recognised- aids reader understanding and interpretations.• Facilitators/barriers = definition indicates different degrees (improve/limit- not quantifying- this is good as it might vary for individuals). Definition is broad enough to include connections between envts that might help/hinder.• Concise. Clear.	<ul style="list-style-type: none">• Definition of Impairment is expressed in negative terms.• It is unclear what significant is- I assume this is from the perspective of the person experiencing the impairment.• Participation does not include the concept of activity- an important notion to occupational therapists.

	<p>Although the ICF classifies activity and participation together (ie. participation must be carrying out activity in particular life situation(s)), activity is actually given a separate definition. Therefore, do I need to specifically address it in my questions and aims and definitions?</p> <ul style="list-style-type: none"> • Participation by ICF definition does not include meaning or satisfaction- the person is simply involved. However, as an OT, and in line with CAOT thinking, I believe that being involved in something that has no meaning or provides no sense of achievement is pointless. • Focus is on presence/absence of facilitators/barriers- does not indicate any modalities.
<p>Environments: Canadian Model of Occupational Performance (Canadian Association of Occupational Therapists, 2002).</p>	
<ul style="list-style-type: none"> • A comprehensive consideration of all the different environments. • Broad enough that it can be applied across cultures, ages, and communication styles. • Concise, means practical use in explaining concepts to participants if needed. • Some acknowledgement of transactions and meanings within the environments. 	<ul style="list-style-type: none"> • Splits environments apart into separate entities- does not capture the interactive aspects between different environments.
<p>Traumatic Brain Injury: My own definition, based in part on TBI Guidelines (New Zealand Guidelines Group, 2006).</p>	
<ul style="list-style-type: none"> • Differentiates between injury to the brain resulting from a medical condition (eg. tumour, stroke). • External physical force captures both open and closed head injury (eg. a skull fracture with direct damage to brain matter, or rapid movement of the brain in the skull arising from coup/contra-coup forces). • Clinically significant- these terms capture the severity of the injury from an external perspective, in the need to “bound” the case study. It is acknowledged that some people who may have a TBI that is clinically insignificant subsequently experience significant personal difficulties, but this group is not the focus of this study. • NZGG recommends that Severity is classified using the GCS which is in line with international consensus. Classification using duration of PTA is arguably more closely related to outcomes. Clinically in NZ however, the children referred for rehabilitation typically have their GCS scale recorded post injury and on arrival at hospital, while many do not have their length of PTA recorded. • Specified on going difficulties- There is variation in the rate and degree of recovery. Despite severe injuries, some children do make a remarkable recovery with few 	<p>It is never specified which version of the GCS has been used with the children. *** Could check on this with Starship.</p>

<p>residual difficulties. Sometimes however, minor difficulties increase over time for children as they grow and develop.</p> <ul style="list-style-type: none"> • Six or more months post-injury and discharged from hospital for at least 6 months – this criteria is to consider recovery from the acute period of the injury (which would influence the responses children are able to give) and a relative stabilising of function. It also considers that by this stage, children and families will have some experience of community participation with a TBI to inform the study. Both focal and diffuse neuronal changes occur in the brain after injury, with different phases in the recovery period and variable time frames for each. Povlishok and Katz propose that the phase of PTA and confusion may continue for weeks to months, although dynamic changes may continue for up to 5 years. Sohlberg & Mateer propose that for moderate to severe injury, recovery is most rapid for the first 6 months with ongoing changes for up to 2 years. Bach y Rita (1989) suggests that recovery of function may still occur in response to rehabilitation for up to 20 years post injury. • No cap is placed on the amount of time lapsed since injury other than that of the childrens' age. Some children may experience an injury at a very young age, and be several years post-injury. However, I wish to be able to include them in the study if it is felt a particular participant may be able to contribute valuable information. Increased amounts of time in the community will provide greater depth of knowledge about the area of focus. It will also contribute useful insights as to how changes might happen over time (a focus of Complexity Theory). 	<p>Such time frames do not specifically refer to children. As initial recovery is often faster in children, these time frames may vary.</p>
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Theoretical Understandings and Contributions to project

Pragmatism:

Occupational justice

Meaning and knowledge arise through activity and transaction with the environment.

Human activity arises from habit, but is able to adapt to hindrances in the environment.

The transactions that occur between humans and the environment are complex, and resulting in complex changes beyond the immediate environment.

To bring about change, we need to understand some of the transactions. We need to look at history as well as envision the future.

Change and adaptation is ongoing.

There is no one "truth", but only different degrees of agreement as to what is the most plausible truth.

Complexity Theory

Complex systems

Importance of communication and linkages.

Adaptation of systems

Case Study Design

Instrumental and Collective Case Study (Stake, 1995)

Data Collection Procedures

Issue Number	1	3	1	2	2	2	2	1, 2, 3	3	3	3
UNITS OF ANALYSIS: <i>Unit Being Characterised;</i> <i>Features</i>	The Injury- Age at injury, severity, type, time since injury.	Family Attributes- Location, Structure, Ethnicity, Roles	Child Attributes- Age, Gender, Health, Genetic inheritance, Body Functions and Structures , affected, <i>Activity Limitations?</i>	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. (remove success)	Needed/Desired Participation	Description of Life Situation /Envt in which Participation takes/ place. Home, School, Community x Physical, Social, Cultural, Institutional . Changes.	Observed features of Environment that Facilitate/Limit Participation & Action/Modality.	Perceived things that are Facilitators to Participation- How do they facilitate?	Perceived things that are barriers to Participation- How do they limit?
UNITS OF DATA COLLECTION: <i>Data Source & Perspectives</i>											
Child Perspective				✓	✓	✓	✓	✓ Changes		✓	✓
Parent Perspective				✓	✓	✓	✓	✓ Changes		✓	✓
Teacher Perspective				✓	✓	✓	✓	✓ Changes		✓	✓
Observed by Researcher			✓	✓	✓	✓ (Satisfacn)		✓	✓	✓ - How	✓ - How
Artifacts				✓		✓		✓			
Questionnaire- Supports & Services									?- draw attention to agents	?- draw attention to agents	?- draw attention to agents
Parent Report		✓	✓					✓			

Locality Organisation File	✓		✓								
Demographic Questionnaire	✓	✓	✓		✓						
Doc Analysis- Legislation,							✓	✓ institutional	✓	✓ How	✓ How
Doc Analysis ACC File			✓	✓	✓	✓	✓	✓	✓	✓	✓

Topical Information Questions: Observations

P1: What impairments to body structures and functions are observable as a consequence of the child's TBI?

What activity limitations are observed? What activities does the child cope easily with?

P2: What does the child's current participation look like? What are the features of the activities involved in the participation? What do participation restrictions experienced look like? How has the participation changed at follow-up?

P2: How long does the child engage in activities? What is the temporal pattern of their participation?

P2: How satisfactory is the child's participation? What are the results? Does the child express satisfaction with their participation? How is this expressed?

P2,3: What are the features of the environments (physical, social, cultural) at home, at school, and in the community in which the participation takes place?

P3: What are the observable features of the environments that facilitate the child's participation? In what ways do they appear to be facilitating?

P3: What are the observable features of the environments that limit the child's participation? In what ways do they appear to be limiting?

Topical Information Questions: Interviews

P3: What are the key features of the family?

P1: What are the key attributes of the child (Age, gender, health, Genetic inheritance, body structures & functions)?

P1,2: What is current participation like?

Where does it happen?

What activities are involved? What are the activities like?

How has the participation changed since the accident/over time?

P2: What are the temporal aspects of the participation?

When does it happen?

How long for?

How often?

How has this changed?

P2: How satisfied is the interviewee with the participation?

How satisfied do you think the other interviewees are with the child's participation?

What is the meaning of these activities?

How successful is the participation?

Is the amount of time spent in different aspects of participation satisfactory?

P2: What participation is needed?

What participation is desired?

Why are these activities important?

P1,2,3: How have the environments/situations changed where the participation takes place?

P3: What things/who helps the participation to happen?

How does this help?

What information/resources are needed?
How are information/resources provided/transmitted?

P3: What things/who limits the participation?
How does this limit?

Rationale for Case Selection: First Participant

Advantages	Disadvantages
Not a complex case in terms of recovery Accessible Time constraints- project management- Delays have resulted from inadequate numbers available through first locality and lack of clarity about methodology. Pragmatics- need to begin. Complexity is acknowledged in theoretical background- outliers are important to study. NZ is a multi-cultural society, and TBI is not unique to European NZers.	↓ Language at interview, May influence the depth of data that can be gathered. Complex family and cultural issues may also be influencing participation. ↓ language may influence participation.

Participant Contact Details

Data Gathering Preparation

Safety & Planning

Leave 1 ½ hours early!
Phone (parent/office) to check visit is expected and confirm time
Check if interpreter needed
Inform somebody at university of visit

Equipment

2 Tape Recorders – New batteries, Set ready to begin recording, Instruction book
Name, address and phone contact
Child Information Sheet and Consent Form
Stamped Addressed Envelopes
Questionnaire
Interview form/guide
Observation form/guide
Notepad and 3 pens
Camera and battery charged
Paper/Drawing materials & scissors for poster
Diary for next appointment
Mobile phone (charged) and Phone book
Map
Wristwatch
(Muffins)
Wallet
Fuel

Data Collection Schedule

Time Frame	Contact	Details	Time
	Name passed on by Provider	Contact parent, thank for interest, and explain will be posting information sheets and consent forms. Participant explains project to child, and returns their own + proxy signed consent	
	Interview- Parent & Child Parent Contact	Make appointment to meet child to explain project, and check their informed consent, oral/ written. Gather demographic and ACC health professional service data. Parents and child nominate key teacher.	½ hr
	Phone principal, outline project, make appt.	School visit, introduce project to principal, teacher, and BOT if necessary. Consent forms left.	
	Interview- Parents	Parent Interview #1	1 hr
	Home Visit- Child	Child Interview/Participant Observations #1 Block1	1½ hr
2 wks	Home Visit-Child	Child Interview/Participant Observations #2 Block1	1½ hr
	Interview Teacher	Teacher Interview 1	1 hr
2 wks	School visit Child	Child Interview/Participant Observations #1 Block2	1 hr
2 wks	School visit Child	Child Interview/Participant Observations #2 Block 2	1 hr
2 wks	Home/Other visit child	Child Interview/Participant Observations #3 Block 2	1 hr
	Interview Parents	Parent Interview #2	1 hr
6 mth	Home Visit Child	Child Interview/Participant Observations #1 Block 3	1 hr
8 mth	Home visit Child	Child Interview/Participant Observations #2 Block 3	
	Interview Parents	Parent Interview #3	½ hr

Semi-Structured Interview Outline: Parents

Warm Up

Remind the participant that their own choice to be part of the study, and check that they are still wish to take part. Thank the participant for agreeing to be part of the study.

Introduce the interview by saying what its' purpose is and the sort of things we will be talking about. Check that they are comfortable for the interview to be audio-taped. Remind the participant that they may stop the interview at any time, and that they can ask me to delete any information they wish.

Ask the participant how the day has been for them and their child.

Schedule of Questions

Tell me about some of the things _____ (your child) does during the day now.

Where do these things happen?

What others are around when your child does these activities?

How easily do you feel your child is fitting in with this group/

How does this fit into your child's daily/weekly routine?

Can you talk to me a little about how your child came to be involved in these activities?

How important do you think these things are for your child to do?

How do you think your child feels about doing these things?

Has it been easy/difficult for your child to get involved?

How has this changed since your child first came home after the accident?

Do other people help your child to join in when they do these things?

How well do you feel your child is coping/getting on with these things?

Are there some other sorts of things you would like to see your child doing over the next few years?

What makes it hard for your child to get involved with these activities?

What are some things that have helped your child to be involved?

Closing

Is there anything else you'd like to say?

Thank the participant very much for talking about their experiences. Explain that you will be in touch and give them a copy of the recording and the transcript when it is ready. Remind them of my contact details in case they want to check anything, and that if they want to change anything, just to let me know.

Sample Prompts

Can you tell me some more about that? Why was that? How was that for you/your child? What did/does that mean to you/your child? What do you/does your child do then? What tends to happen then? What was it that led to it being like that? Earlier on you talked about----. Can you explain more about that?

Semi-Structured Interview Outline: Children

The Warm-up is deliberately brief, as the children potentially do not cope easily with long explanations, and may lose interest or concentration if I do not get to the point. I am also not classifying the activities into areas of play/school/self-cares, as the children may not see the activities in these categories. Additionally, the question about future activities is deliberately vague- children with TBI may have difficulty with understanding concepts about the future/making choices.

Warm Up

Say hello, and ask how they are today. Thank them for saying you will talk to me today. Check that they still wish to take part. Check that they are comfortable for our talk to be audio-taped. Remind them they can ask me to stop the interview at any time, and that they also can ask me to delete any information they wish.

Introduce the interview by explaining that I am interested in finding out more about the things that children do after they have a head injury.

Schedule of Questions

I wonder what sorts of things you have already been doing today? Can you tell me about them? What other things will happen today? How is this different on other days? What happens at the week/weekend? Are there other people/children there that do this with you? How is it being with them?

Tell me about the things do you like doing best? Are there other people/children there when you do those things? Why do you like these things so much? How do these things make you feel?

Are there some hard things that you have to do? What feels difficult about these things? What makes these things go a little better?

Are you part of any groups? Can you tell me a bit about this? What sorts of things do you do together?

What sorts of things do you want to go on to do? What would you like to aim for next year?

Is there anything else you'd like to say?

Sample Prompts

Can you tell me some more about that? Why was that? How was that for you? What does that mean?

What do you do then? Before, you said that.....Can you explain a bit more about that?

Conclusion:

Thank the child very much for talking to me.

Semi-Structured Interview Outline: Teachers

Warm Up

Remind the participant that their own choice to be part of the study, and check that they are still wish to take part. Thank the participant for agreeing to be part of the study, and re-iterate that the child and their parents have given permission for the teacher to be interviewed.

Introduce the interview by saying what its' purpose is and the sort of things we will be talking about. Check that they are comfortable for the interview to be audio-taped. Remind the participant that they may stop the interview at any time, and that they can ask me to delete any information they wish.

Schedule of Questions

How many hours is _____ (the child) attending school now?

What sort of routine do they have when they are at school?

Tell me about some of the activities (curricula and extra-curricula) _____ (the child) does during the day when they attend school.

How does (the child) fit in as part of a group with others in the class during those activities?

How has this changed since they first began going back to school after the accident?

Are there some activities that _____ (the child) is not able to join in? Why is that? Do you think this might change as time passes?

What sorts of things would you like to see _____ (the child) move on to doing?

How important do you think all these things are for _____ (the child)?

What sorts of activities are hard for _____ (the child)? What are they coping well with?

What sorts of things have you done to help _____ (the child) to be involved in these activities?

Can you tell me about some other things/or types of assistance from people or children that have been useful to help them to be included in class and playground activities?

What are some of the things that have made it more difficult for _____ (the child) to join in?

Closing

Is there anything else you'd like to say?

Thank the participant very much for talking about their experiences. Explain that you will be in touch and give them a copy of the recording and the transcript when it is ready. Remind them of my contact details in case they want to check anything, and that if they want to change anything, just to let me know.

Sample Prompts

Can you tell me some more about that? Why was that? How did you feel that was for _____ (the child)? What do you/does _____ (the child) do then? What tends to happen then? What was it that led to it being like that? Earlier on you talked about----: can you explain more about that?

Observation Guide

Warm Up

Say hello, and ask how they are today. Thank them for allowing me to visit them today. Check that they still wish to take part. Check that they are comfortable for notes to be taken during my visit. Remind them they can ask me to stop the visit at any time, and that they also can ask me to delete any information they wish.

Introduce the visit by explaining that I am interested in finding out more about the things that children do after they have a head injury. Explain that I will be spending time in their classroom/home, and that during the visit, I might sometimes watch, or I might join in, or I might ask questions/answer questions, or help out.

- Strengths/Limitations for Body Structures & Functions that impact on participation. What is performance like for the different activities? What activities appear more difficult, what activities appear easier?

- Describing current participation

Features of the activities involved in the participation.

Aim of the activities.

Objects used

What is involved?

Actions required

Actions used by (the child)

Differences between how (the child) is involved and how the others are involved? Levels of activity associated with task by (the child), other children.

Engagement in the activity- flow/distractibility.

Interactions required by the activity

Interactions that occur between others and by (the child) with others (siblings, classmates, peers, teacher, parent).

- Describing temporal aspects of participation

Duration of participation. Frequency of participation.

- Success/Disappointment of participation

Results

Responses to completion. How is this expressed?- Body language, movement, facial expression, verbal communication.

Repetition of actions, interactions

Actions/interactions not observed.

- Description of environment

Physical

Layout, size, access, storage, furniture

Objects/equipment

Noises/sounds

Visual /light/ colour/movement

Tactile and proprioceptive sensory input

Temperature

Social

Who is involved? Groupings.

Location to others involved (eg. siblings, classmates, peers, teacher, parent).

Ages/genders of others

How are other children involved?

What information is being used/needed to support the activity?

Where does the information come from?

Responses to the researcher by parent, children, teacher.

Cultural

Cultural makeup of group

Rules/norms for behaviour

Rituals/routines

Values

- Facilitators

What can I observe that appears to help the child's participation?

How does this seem to be acting?

What strategies do others (siblings, classmates, peers, teacher, parent) use to support participation?

How do these work?

What are the child's responses to these strategies?

- Barriers

What can I observe that appears to limit the child's participation?

How does this seem to be acting

What do participation restrictions experienced look like?

What are child's responses to restrictions?

Demographic Questions

Date questionnaire completed	Parent(s)/whanau name(s)
	Name of Child with Traumatic Brain Injury

Address	Phone Numbers: Home, Work, Mobile

Child's age	Child's sex	Date of Injury	Which ethnic group(s) do you and your child identify yourselves with?					
			European	Māori	Asian	Pacific peoples	*MELAA	**Other

*Middle Eastern, Latin American, & African ** Includes New Zealander

How many other children live at home and how old are they?	Number	Ages
How many other adults live at home?	Number	

What life roles do you and (if applicable), your husband/wife/partner) have (eg. Home-maker, paid worker (full time/part-time), student, parent, volunteer)

What school does your child attend?	Phone	Address
Name of child's teacher for interview?		
Name of school principal?		
Name of teacher aide?		
How many hours per week is your child attending school/preschool?		

What is the best time for me to talk with you?
Day of week: Time:

What would be the best times for me to visit you and your child at home next?
Day of week: Time:

Any other comments?

Code Names		
	Name	Code Names Chosen by Family/Whanau
Child		
Parent/Whanau 1		
Parent/Whanau 2		
Sibling- eldest		
Sibling		
Sibling- youngest		
Other Family/Whanau		

Protocols for Gaining Access

Informed Consent

Parents/whanau who express interest in participating will be sent information sheets (one for parent(s)/whanau, & one for children), a consent form for themselves, and a proxy consent form for their child, and a stamped addressed envelope to return if they wish. They will be requested to explain the project to their child and ascertain their willingness to participate. If the parents return their signed consent and the signed proxy consent form, consent will be sought from the child by the researcher in a face to face contact during which she will explain the project to the child with a parent/whanau present.

While every effort will be made to explain the study to the children, it is unclear whether they will all have adequate understanding to make a fully informed choice. This is due to their injury, which is known to have frequent, but variable impact on attention, memory, and executive functions (ie. including the ability to make decisions and to predict consequences) (Ylvisaker, 1998). Some children may be unable to write their name. Therefore, for all children, their parents/whanau will be asked to sign a proxy informed consent for them on an appropriate consent form. The child will be asked to make oral or written consent as far as they are able to their level of understanding. This form will be completed during the first meeting.

Whanau will initially be approached by the WDHB Whaea and/or Kaumatua. If they express interest in participating, follow-up contact with the whanau will be made by the Whaea and/or Kaumatua to introduce the researcher and further research processes (eg. gaining informed consent, gathering & analysing data) will be guided by the Whaea and/or Kaumatua in collaboration with the individual, their whanau, hapu, and/or iwi, and the researcher.

Parents/whanau & child will be asked to nominate a key teacher who could be available for interview & to support participant observations. The principal of the school will be contacted, the project explained to them and the teacher, and the Board of Trustees if appropriate, and a locality assessment form will be developed and submitted. If this is approved, the principal will be contacted again & permission gained to contact the teacher & ascertain his or her willingness to be part of the project. Signed informed consent will be sought from the teacher before proceeding with the interview and classroom observations.

Participant Safety

The researcher will remind participants on every occasion that they are welcome to refuse any questions or observations, turn off tape recorders, delete any material, or terminate any interview/observations. A person may elect to have a support person present. In the homes of the participants, the researcher will respect cultural issues to the best of her ability.

The researcher will carry a mobile phone at all times & ensure that the supervisory team is aware of where she is carrying out data collection.

Parent(s)/whanau/children/teachers will be monitored by the researcher during interviews and observations. Parent(s)/whanau will be contacted following the interviews/ observations, and it will be checked if the contact has had any adverse consequences for them and/or their child (eg. undue stress/anxiety). If this is the case, they will be encouraged to discuss this with the researcher, one of the researcher's supervisors, with referral to GP and rehabilitation provider as appropriate (the researcher is a qualified health professional). The research will be suspended until the participant wishes to proceed, or they wish to withdraw from the study.

Appendix 4.8: Demographic Questionnaire

Demographic Questions

Date questionnaire completed	Parent(s)/whanau name(s)
	Name of Child with Traumatic Brain Injury
	ACC Claim No

Address	Phone Numbers: Home, Work, Mobile

Child's age	Child's sex	Date of Injury	Which ethnic group(s) do you and your child identify yourselves with?					
			European	Māori	Asian	Pacific peoples	*MELAA	**Other

*Middle Eastern, Latin American, & African

** Includes New Zealander

How many other children live at home and how old are they?	Number	Ages
How many other adults live at home?	Number	

What life roles do you and (if applicable), your husband/wife/partner) have (eg. Home-maker, paid worker (full time/part-time), student, parent, volunteer)

GP Name & Address	Phone Number

What school does your child attend?	Phone	Address
Name of child's teacher(s) for interview?		
Name of school principal?		
Name of teacher aide?		
How many hours per week is your child attending school/preschool?		

What is the best time for me to talk with you?	
Day of week:	Time:

What would be the best times for me to visit you and your child at home next?	
Day of week:	Time:

Any other comments?

Code Names		
	Name	Code Names Chosen by Family/Whanau
Child		
Parent/Whanau 1		
Parent/Whanau 2		
Sibling- eldest		
Sibling		
Sibling- youngest		
Other Family/Whanau		

Appendix 4.9a: Semi-structured Interview Guide Parents

Warm Up

Remind the participant that their own choice to be part of the study, and check that they are still wish to take part. Thank the participant for agreeing to be part of the study.

Introduce the interview by saying what its' purpose is and the sort of things we will be talking about. Check that they are comfortable for the interview to be audio-taped. Remind the participant that they may stop the interview at any time, and that they can ask me to delete any information they wish.

Ask the participant how the day has been for them and their child.

Schedule of Questions

Tell me about some of the things _____ (your child) does during the day now.

Where do these things happen? How are these things different to how they were before the accident? How has this changed over time?

What others are around when your child does these activities?

How easily do you feel your child is fitting in with this group/

How does this fit into your child's daily/weekly routine?

Can you talk to me a little about how your child came to be involved in these activities?

How important do you think these things are for your child to do? Why are these things important for **? What might make you think that?

How do you think your child feels about doing these things?

Can you describe some things that you would like your child to do more of? Are there activities that you feel your child spends too much time doing? Why is this?

Has it been easy/difficult for your child to get involved?

How has this changed since your child first came home after the accident?

Do other people help your child to join in when they do these things? How do these people help? How did they come to be involved? What information do you share with these people? How do you communicate/be in touch with them? How often do you speak with them?

How well do you feel your child is coping/getting on with these things? How happy do you think (your child) is with what he/she is involved with? How satisfied are you?

Are there some other sorts of things you would like to see your child doing over the next few years? What sorts of things are important about these activities?

What makes it hard for your child to get involved with activities?

What are some things that have helped your child to be involved? How does that happen?

How does the environment at home or at other places help them or limit their involvement?

Have there been any important positive events or upheavals that stand out for you in terms of your child being part of things?

Closing

Is there anything else you'd like to say?

Thank the participant very much for talking about their experiences. Explain that you will be in touch and give them a copy of the recording and the transcript when it is ready. Remind them of my contact details in case they want to check anything, and that if they want to change anything, just to let me know.

Sample Prompts

Can you tell me some more about that? Why was that? How was that for you/your child? What did/does that mean to you/your child? What do you/does your child do then? What tends to happen then? What was it that led to it being like that? Earlier on you talked about----. Can you explain more about that? How did that happen/come about?

Appendix 4.9b: Semi-structured Interview Guide Teacher

Warm Up

Remind the participant that their own choice to be part of the study, and check that they are still wish to take part. Thank the participant for agreeing to be part of the study, and re-iterate that the child and their parents have given permission for the teacher to be interviewed.

Introduce the interview by saying what its' purpose is and the sort of things we will be talking about. Check that they are comfortable for the interview to be audio-taped. Remind the participant that they may stop the interview at any time, and that they can ask me to delete any information they wish.

Schedule of Questions

How many hours is _____ (the child) attending school now?

What sort of routine do they have when they are at school?

Tell me about some of the activities (curricula and extra-curricula) _____ (the child) does during the day when they attend school. What about activities the class has off site?

How have the activities changed over time/since the accident?

How does (the child) fit in as part of a group with others in the class and outdoors during those activities?

How has this changed since they first began going back to school after the accident?

Are there some activities that _____ (the child) is not able to join in? Why is that? Do you think this might change as time passes?

How important do you think all these things are for _____ (the child)? What is important about these activities for (the child)? Can you describe some things that you would like (the child) to do more of? Are there activities that you feel he/she spends too much time doing? Why is this?

What sorts of activities are hard for _____ (the child)? What are they coping well with? How satisfied do you think (the child) is? How satisfied are you with their participation?

What sorts of things have you done to help _____ (the child) to be involved in these activities?

Can you tell me about some other things/or types of assistance from people or children that have been useful to help them to be included in class and playground activities? Are

there some people that you see regularly or that you rely on? Are some people central to (the child) being involved in the activities? How did they come to be involved? How has their involvement changed? What things do you think are important for people to know about to be able to help? How do they get/share the information?

Are there things outside of school that are able to help (the child)? How are they helpful?

How is the environment at school able to help (the child) join in?

What are some of the things that have made it more difficult for _____ (the child) to join in? How do these things affect (the child)'s participation?

What sorts of things would you like to see _____ (the child) move on to doing? Can you explain why it is important for (the child) to move on to this?

Have there been any out of the ordinary events that changed (the child's) participation? How did that happen?

Closing

Is there anything else you'd like to say?

Thank the participant very much for talking about their experiences. Explain that you will be in touch and give them a copy of the recording and the transcript when it is ready. Remind them of my contact details in case they want to check anything, and that if they want to change anything, just to let me know.

Sample Prompts

Can you tell me some more about that? Why was that? How did you feel that was for _____ (the child)? What do you/does _____ (the child) do then? What tends to happen then? What was it that led to it being like that? Earlier on you talked about----: can you explain more about that?

Appendix 4.9c: Semi-structured Interview Guide Children

The Warm-up is deliberately brief, as the children potentially do not cope easily with long explanations, and may lose interest or concentration if I do not get to the point. I am also not classifying the activities into areas of play/school/self-cares, as the children may not see the activities in these categories. Additionally, the question about future activities is deliberately vague- children with TBI may have difficulty with understanding concepts about the future/making choices.

Warm Up

Say hello, and ask how they are today. Thank them for saying you will talk to me today. Check that they still wish to take part. Check that they are comfortable for our talk to be audio-taped. Remind them they can ask me to stop the interview at any time, and that they also can ask me to delete any information they wish.

Introduce the interview by explaining that I am interested in finding out more about the things that children do after they have a head injury.

Schedule of Questions

I wonder what sorts of things you have already been doing today? Can you tell me about them? What other things will happen today? How is this different on other days? What happens at the week/weekend? Are there other people/children there that do this with you? How is it being with them?

Where do these things happen? Has it always been like this? How do you get on when you are there? Who helps you? What do they do that's special/good? How come they do this? Who organises that?

Are there any things that you would like to do more of? Are there some things it feels like you do too much of? Why is this?

What are you good at doing? Tell me about the things do you like doing best? Are there other people/children there when you do those things? Why do you like these things so much? How do these things make you feel? What do you think your parents think about how you are doing? What about your teacher- how does he/she think you are doing? (may not be able to answer this if difficulty with metacognitive skills).

Are there some hard things that you have to do? What feels difficult about these things? What makes these things go a little better?

Are you part of any groups? Can you tell me a bit about this? What sorts of things do you do together?

What sorts of things do you want to go on to do? What would you like to aim for next year? Can you tell me a bit about why these things that you'd like to do are special?

Are there any really important things that have happened since the accident that you can tell me about?

Is there anything else you'd like to say?

Sample Prompts

Can you tell me some more about that? Why was that? How was that for you? What does that mean? What do you do then? Before, you said that.....Can you explain a bit more about that?

Conclusion:

Thank the child very much for talking to me.

Appendix 4.10: Observation Guide

Warm Up

Say hello, and ask how they are today. Thank them for allowing me to visit them today. Check that they still wish to take part. Check that they are comfortable for notes to be taken during my visit. Remind them they can ask me to stop the visit at any time, and that they also can ask me to delete any information they wish.

Introduce the visit by explaining that I am interested in finding out more about the things that children do after they have a head injury. Explain that I will be spending time in their classroom/home, and that during the visit, I might sometimes watch, or I might join in, or I might ask questions/answer questions, or help out.

- Strengths/Limitations for Body Structures & Functions that impact on participation. What is performance like for the different activities? What activities appear more difficult, what activities appear easier?
- Describing current participation
 - Features of the activities involved in the participation.
 - Aim of the activities.
 - Objects used
 - What is involved?
 - Actions required
 - Actions used by (the child)
 - Differences between how (the child) is involved and how the others are involved?
 - Levels of activity associated with task by (the child), other children.
 - Engagement in the activity- flow/distractibility.
 - Interactions required by the activity
 - Interactions that occur between others and by (the child) with others (siblings, classmates, peers, teacher, parent).
- Describing temporal aspects of participation
 - Duration of participation. Frequency of participation.
- Success/Disappointment of participation
 - Results
 - Responses to completion. How is this expressed?- Body language, movement, facial expression, verbal communication.
 - Repetition of actions, interactions
 - Actions/interactions not observed.
- Description of environment
 - Physical*
 - Layout, size, access, storage, furniture
 - Objects/equipment
 - Noises/sounds
 - Visual /light/ colour/movement
 - Tactile and proprioceptive sensory input
 - Temperature

Social

Who is involved? Groupings.

Location to others involved (eg. siblings, classmates, peers, teacher, parent).

Ages/genders of others

How are other children involved?

What information is being used/needed to support the activity?

Where does the information come from?

Responses to the researcher by parent, children, teacher.

Cultural

Cultural makeup of group

Rules/norms for behaviour

Rituals/routines

Values

- Facilitators

What can I observe that appears to help the child's participation?

How does this seem to be acting?

What strategies do others (siblings, classmates, peers, teacher, parent) use to support participation?

How do these work?

What are the child's responses to these strategies?

- Barriers

What can I observe that appears to limit the child's participation?

How does this seem to be acting

What do participation restrictions experienced look like?

What are child's responses to restrictions?

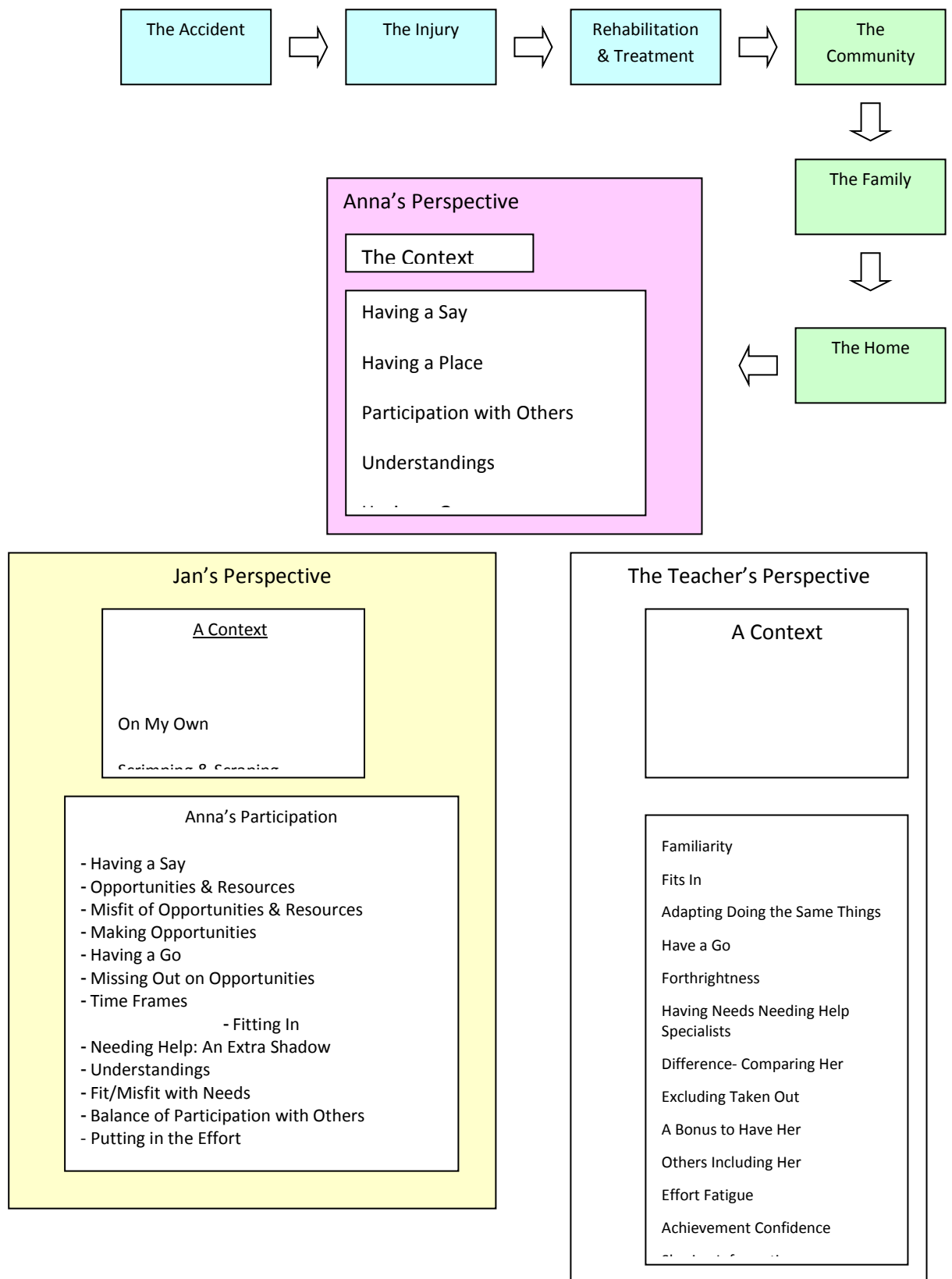
Appendix 4.11: Case Study One Anna Draft Report

The following chapter reports on the case study of Anna's community participation. The chapter opens with an overview of contextual factors relevant to Anna's accident and injury. Discussion then moves on to information gathered through observations and interview with Anna. Following this, data from home-based observations and the interviews completed with Jan, Anna's mother is presented. Information gathered from Anna's school is discussed next, including observations and interview with teaching personnel. Anna's rehabilitation programme is considered in more depth in relation to the information it conveys about Anna's participation, and the ways in which it might influence her participation.

Anna and her mother, Jan both provided informed consent to be part of the study. When I explained the purpose of the study to Jan, Anna's mother, she identified with some of the aspects of participation I mentioned, and was keen to talk about the family's own experiences. By taking part in the study, she hoped to help other people to understand more about the issues. She explained the study to Anna, and when I visited, Anna remembered me from previous episodes of inpatient rehabilitation.

The themes that emerged from the home visit (HV1) and interviews with Jan (PI1) are explained and illustrated below using excerpts from transcripts and narrative reports of observations. These are written in smaller font. The numbers accompanying the excerpts refer to the paragraph of the original transcription or report containing the excerpt. Comments or questions made by the researcher within the excerpts are italicized.

Discussion Topic Outline



Contextual Factors

Anna's participation is set in the historical background of the accident event, the resultant injuries and activity limitations, and the provision of treatment and rehabilitation. These factors are outlined in the following section. Participation also takes place in a context of place and people. Anna's home community, her family, and her home are described. The information about her home community was gathered from the demographic questionnaire completed by Jan, from my interview with her, from observations, from her ACC rehabilitation assessments, and from Anna's case file held by the Locality Provider who assisted with recruitment.

The Accident

This section has been omitted to support participant confidentiality.

Anna: Her Injury and Activity Limitations

In the accident, Anna sustained (**Omitted for confidentiality**). At the scene of the accident, ambulance staff recorded her GCS as ****. She experienced a seizure at the scene of the accident. A skull fracture occurred which increased in size over time, eventually requiring *****. This was addressed 6 months after the accident.

As a result of the injury, Anna has a dense hemiplegia, which limits sensation and movement in her upper and lower limbs on her right side. She has reduced vision in her right eye. Her most recent neuropsychological assessment identified limitations with visuospatial abilities, categorization, and speed of information processing as well as delayed recall of verbal information and reduced working memory.

Anna has learned to walk, run, and manage steps independently. She wears an ankle-foot orthosis (splint) on her R) leg inside her shoe. Her gait is a little slow and unsteady. She has limited use of her R) hand, which is often held at her side with her wrist and elbow flexed. She uses her L) hand effectively for many activities where manipulation is required, but requires assistance with more complex activities needing two hands, such as tying laces or managing a zipper.

During my visits, Anna appeared to understand basic content of our conversations, but had significant difficulty expressing herself, with a marked stammer evident, and her speech lacking clarity, particularly if she were excited or stressed. Fatigue is noted in her Individual Education Plan, was discussed by her teacher and her mother and was also observed. At the age of 10 years, Anna was reported to have a reading age of 6 ½ years, a similar expressive language level, and a receptive language age of 7 years.

Anna: Overview of her Rehabilitation and Treatment

Following the accident, Anna was airlifted to ** hospital, then to a children's hospital in a main centre where she remained for 22 days. She was discharged to the ** Rehabilitation Service for a 6 ½ month period of inpatient rehabilitation, with her parents and siblings staying with her. At this time she was seen by physiotherapists, occupational therapists, and speech language therapists. Nursing cares and social work intervention also supported the family. A buggy and seating were provided for her to assist her sitting posture and mobility.

Seven months after the accident, Anna was discharged home. At this point, rehabilitation providers in her local community continued to meet her rehabilitation needs. This included training from physiotherapists, occupational therapists, and speech language therapists, attendant care support, and provision of equipment, such as special chair for mealtimes and a height adjustable desk. Some rails were fitted in the bathroom areas in the home.

Anna went on to attend pre-school, and when she turned 5 she was enrolled in her local primary school where she is supported by a teacher aide funded directly by ACC. She has attended Riding for the Disabled, and also swimming classes where she was supported by a personal tutor. A special tricycle was provided for her from the *** Charity.

Regular orthopaedic reviews have been carried out.

Section omitted to support confidentiality.

An ankle-foot orthosis was made on each occasion to support a more stable and efficient gait, and to help maintain her muscle length. The AFO is adjusted as needed for growth and change at her local hospital.

Anna also wears a small neoprene splint to maintain joint range of movement in her right wrist and thumb, and this is provided through the orthotics service at *** hospital. **Section omitted to support confidentiality.**

The Kingsville Community

Anna has lived in Kingsville since the time of the accident. Part of rural New Zealand, this is a busy coastal township on the edge of an inlet and river, and is approximately an hour's drive from the nearest city. Surrounded by small farms, orchards, garden centres, craft shops, cafes, and small businesses, Kingsville has a comprehensive shopping centre, library, community police centre, and a large new supermarket. There are a number of tourist landmarks and motels. The primary school and secondary school are adjacent to each other and are within easy walking distance from the shops. Growth is evident with new building underway on the outskirts of town, a new bridge to be built, and the construction of a new highway through the back of the town; heavy machinery noises can be heard alongside the early morning bird chorus coming from the tall stands of bush and exotic trees growing behind the town centre. A river runs through the bush.

The Family

Section omitted to support confidentiality. During the term breaks when Jan is working, Anna and Ben attend a Holiday Programme. They spend one night a week with their father, when he picks them up after school, and he drops them off again at school the following morning. They also have some holidays with him. Jan's parents have not had good health recently. They live in a main centre, and, and Jan has visited as often as she is able.

Anna's Home

The family home is just off the main street of the town, and is at the end of a cul-de-sac, with the bush on one side of the house. Neighbours are on the other side and across the street. An older home, similar in age to others in the street, the 3 bedroom house is surrounded by a carefully kept garden with mown lawns and flowers, strawberry plants, and a fence. The house is on one level, with steps to enter. At the front of the house is a wide, covered deck with a low railing which Jan built herself, and Anna and her brother often play out here. There is a sandpit and a trampoline in the garden for the children to play with, as well as a bird feeding tray on a pole belonging to Anna. Inside, I am greeted by the cat, Smudge, and there is a bird-cage with a budgie, and also a well populated fish tank. The children's toys are kept in their bedrooms, but are often brought out to the lounge to play. As the new road is being put through this area, the house is shortly to be purchased by the council, and Jan and the children will have to move. Jan has been looking for properties.

Anna Describing her Participation

The Context

Anna was assisted to provide her perspective of her participation. Anna has difficulty with her speech which had the potential to limit her ability to communicate her perspective. I was also concerned she would find it difficult to concentrate if the focus was only on talking, as she had previously expressed dislike of therapy sessions where the focus was on her using language. Therefore, the interview was delivered in the context of a joint poster-making session, using photos taken earlier of some of Anna's activities. The interview was held at home. Anna's brother Ben was present at the beginning of the session, and Jan, Anna's mother participated briefly when she came to check progress. Anna was encouraged to talk about the activities, and to also talk about some of the activities that weren't there, but that she would like to do. This data was supplemented by information gathered and recorded in observations during a previous home visit.

The photos and poster effectively triggered several areas of conversation, and provided avenues for extending the discussion outside immediate topics. However, the poster also posed a disadvantage of being a distraction on occasion, where Anna would stop talking to work on gluing, or would shift the focus of her discussion when she noticed something else on the poster. The activity was concluded after 45 minutes when I felt that Anna was losing interest and becoming ready for a change of activity.

Anna's view of her participation revealed themes relating to her having a say about her participation, (*During the interview my attention was drawn to the way other people's actions were able to either support or prevent Anna from having a say*), the settings in which participation took place, the others she participated with, shared understandings about participation, the requirements and form of activities, the scheduling of activities, the importance of having a go at activities, and her experience of missing out. When Anna participated, she experienced feelings of achievement and contribution.

Expressing Participation Goals and Preferences

During my interview and observations, Anna was able to express her ideas about what she wanted or disliked doing, but needed to be given time to do so. Her answers to questions could be decisive, but were sometimes short, and were hampered by her stuttering at times.

HV1 Obs. 1665. Ooh, I know what to do, I know I know what he's doing. He's up, like like like it's like ah ah ah us are making cars like I make like um... *Ben's going to make them?* Yeah.

519. *Are we going to put any more decoration on this or have we finished?* I want, I'm not like going to stick just anything on, but. *You've drawn a heart.* Hmm.

I was aware of the way her hesitations influenced my own responses, where rather than allowing time, I would sometimes step in to fill a silence with a question requiring a yes/no answer. I would sometimes fail to probe answers she had given, if I felt it might be hard for her to formulate a response. When Ben was present at the start of the interview, it was evident that he too would speak for Anna (albeit sometimes providing incorrect information) and inadvertently preventing her from giving her own viewpoint.

Anna was clearly familiar with Ben doing this however, and was not hesitant in arguing with him and using his information as a foundation for stating her own position. However, it is likely to be more difficult for her to express her wishes in a group setting, or with those who are less familiar with her. I reflected that participating in these sorts of interactions and rivalry with her family potentially provides Anna with good opportunity to practice and extend her communication skills, and might therefore help facilitate further participation.

40. *M: What's your favourite treat to cook, your favourite Anna?* A: Um. B: Cheesecake. A: Scones. *M: You like scones?* A: I like, more like... B: She can't cook scones. A: No um, like um, not, not like scone, scone dough but at, but a different, but a different thing. B: Oh you made an Oscar. A: Yeah. B: It's not actually cooking. A: Yeah, yes it is actually. B: No. A: Yes. B: Making the dough is cooking. A: Yeah, I, I made the dough. B: Yeah right. A: I did. B: You hardly done a thing. A: I did so.

Anna expressed goals for her future participation. These seemed to be related to her current participation experiences. She enjoys playing with insects, but also spends time with her animals. She seems to admire her new teacher.

214. *Last time you said that you were going to be, wanted to be a bug doctor?* Yeah (satisfied). *Is that, you still want to do that?* Yeah and a vet, and a teacher. *And a vet.* And a teacher. *And a teacher.* Yeah. *Does, have you got a special teacher that you would like to be like?* Yeah. *Whose your special teacher?* My teacher what I go have I have this year. *Oh, who's that?* Miss D.

Anna talked with enjoyment of activities that involved a strong sensory component, or which gave her opportunity to use her movement skills competitively and to demonstrate her abilities. However, her words also indicated that it was being part of a team that gave the value to these activities for her, even when the activity was likely to be physically challenging. Her relationship with the other people participating was an important influence on whether she enjoyed the activity or not.

168. *Tell me a little bit about doing soccer? What's nice about doing soccer?* Then well like I can be in like a team. *Oh. You like being a part of the whole, with other kids.* Yeah. Not just like one or two.

196. *What's so good about cricket? Why do you like that?* That um, I can um, that I can, like, that I can um, that I can like, that I can bowl like I've been I like throwing. *There you go, oh throwing.* Yeah. *Are you quite good at throwing?* Yeah and like bowling.

For example, activities where she participated as part of a group, but working in parallel rather than interacting and contributing, and where there was no competition were less valued.

248. *What about um, fitness?* Really, really boring. *Oh really?* Yeah. No, fitness is sometimes fun. But not when we have jump jam. *Jump jam, is that like music?* It's like a dance thing. *Yeah.* And like um, I go with scissors. *Oh your legs.* Yeah. Your whole, you like do like run, and it's like straighten the legs. *Yes.* And like straight arms. *Oh.* Straight arms and straight back. Something like that. *Is that, can you do that?* On the spot no.

Activities such as going to the beach were more valued than going to the swimming pool, and this seemed to be related to the sensory experiences and multiple opportunities for creating activities in that environment, as well as spending time in competitive physical games with her father and cousin.

281. *I thought you were having swimming at a pool?* Yeah, little dippers. *Pardon.* Like little dippers. *Oh yes, little dippers.* Yeah. *Which do you like best? At the beach or do you like being at the pool?* Um, beach. *Do you?* Yeah. *Ah because of Ben being there?* No. *Um, because, it's warm?* Because you can like, because you can like build sand castles as well. *Oh.* I like, like, like I build a sand castle. *Yeah.* But for like, both hits are, um the, the sand castle. *Yes.* And that, they have a bit of a game. And, and they, that, then I go in then out, then in then out. *When the waves come and go.* And because we, we, I do it in like wet sand. *Right.* Like at ah, like wet sand. *Yeah.* And like um. *Is that because it stays together better?* Yeah. *Yeah.* *But it gets hits by the waves doesn't it?* Yeah. And it's fun doing that. *Oh. Is there someone special that you like going to the beach with?* Dad.

Activities were highly valued if they involved someone who was a friend. For example, Anna explained that she liked horses, and that she enjoyed touching them, but that she didn't want to go to riding any more. Jan later explained to me that Anna's friend Simon had recently stopped attending riding.

339. *Don't you do something with horses?* I used to. *Oh you don't anymore.* No. And I like horses. *You like horses.* Yeah. *Do you want to do more riding?* No. No more any more riding for me. *No more riding.* No. *But you like horses.* Yeah. *But you don't want to ride.* No. *You just like to look?* Yeah. *Oh.* And, and touch.

Anna also expressed that maths was a favourite activity, although she found it difficult. I was unclear as to what was important about maths, and noted that it would be useful to gather more information about this aspect of her participation at a later occasion.

Places for Participation

Anna's descriptions drew attention to the situatedness of her participation. Her activities are associated with specific places and with resources.

122. I'll do it up at the table now. *You want to go up to the big table? Okay.....*

Which is your chair Anna, this one or this one? This one, I've got three chairs. *Oh okay.* One for, this one for, um breakfast. *Yes.* And lunch. *Right.* And that one for, dinner. *This one's for dinner.* Yeah. *Okay.* And pudding. *And which one is when you're doing.* That one.

Competition for place and resources with her brother seemed to be the norm when they were participating together.

186. *Who do you do sand pit with?* Ben. *Is it nice playing with Ben?* No. *No!* Not always. *Not always, what happens?* We had a big fight like. Rose and Jim have got a digger. *Yes.* And like normally it digs up like the whole sand pit. *Ben normally takes, oh the digger takes up the whole sand pit?* No, Jim always wants to dig up the whole sand pit. *Oh.*

98. A: Ahh, don't push me off the couch. J: Don't push her off the couch. B: Well it is my couch. J: Oh don't grizzle, he just wants to be part of it Anna.

HV1. 1565. A. He don't like bug me. *(Angrily)* With all his cars and everything. M. *I think it's just boys do like that stuff eh?* B. Hey Anna! A. I'm going to take all his cars. B. Hey Anna, can I play your um *(unintelligible)* game? A. No. No. No Ben! J. Is there a reason why he can't play it? A. Bause, because he might like stuff all the places up. He might, you might stuff all my good places up.

Participation with Others

While we made the poster, Anna often referred to the others who were involved in her participation. While it was evident that her relationship with the others involved was important to her enjoyment of the participation, I was aware that her participation was often with her brother or other family members.

156. *You told me that you liked to play cricket.* Yes. *Have you been playing cricket?*

Yes at Dad's. When, when, when, Michael, when my cousin comes out um, my cousin, well my cousin, cousin comes. Yes. And I like, every Wednesday on the weekend. Or on holidays.

412. And, oh I know, and then Dad and Ben and my cousin Mark, we made up a new game. *Right.* After I've been in water. It's a rugby game in the water. *A rugby game in the water?* Yeah and you, in the pool, and you have to touch down in the, like you have a touch down line *Yes.* And you have to touch it down in the, in the, in the um, in the, in the sand. *And do you use a normal rugby ball?*

Yes. And like instead of running you float *Oh. That would be nice.* And, and and like um, like and you don't use your arms at all. You, you hold the ball *Yeah* With your um, with your hands *Right.* And like, and like kick. *Yeah.* And put it over the line. *Did dad invent that game?* Me and Michael, me and Mark and Ben.

Additionally, Anna talked often of participating with her pets and insects, and with her soft toys. Her favourite teddy bears had been given names and each had a special place on the shelf in her bedroom. Her participation with the insects seemed to involve caring activities towards them.

134. *Who's that? (laughter).* My teddies! Do you know what my pet name is for them, what this one name is? *No.* Cassie. *Kissie or Cassie.* Cassie. *Yeah. That's a nice name, where did you get that.* And shadow. *Shadow.* Shadow, powder. *Keep telling me.* Powder, lambie. *Yes.* Whitie, um, haven't got a name for him. *Okay.* And haven't got a name for him.

435. *You've told me a lot about the animals at your Dads.* There's like, we've got like three cats. *Yeah.* Big cat and little cat. *Yeah.* Big puss and little puss. *Big puss and little puss and if there was another one you'd call it medium puss.* Yeah or tiny puss. *Yeah.* And they've got a dog. *Yes.* Do you like animals? *Yeah.*

208. *And what do you do with these worms and these slugs and snails?* I, some of them I feed to the ants? *Ooh, yuck! And what else?!* And oh, I'll tell you, a funny thing about the butterflies. *Yes.* Um I've got, I, I've got, I, I, had a pet butterfly once. *Right.* And like, um I left it outside on the grass. And, and, and my um, and like it was lying down. *Yes.* And it, and it was, and, and it got really big ants on the wing. *Oh.* It's wing. And, and, it, it, try to fly but it couldn't. *And because of the ants on it.* Yeah. *Oh did you help it?* Yeah. *What did you do?* Let it free.

446. *Oh the bird feeder really is for you? Because Ben puts the food on it doesn't he?* No I do sometimes. *Oh, can you climb up on the tramp and do that?* Yeah. *That's good. Maybe that's why you want to be a vet?* Hmm. *Because you like being with animals.* Yeah. And like helping um, animals.

During my observations, Anna also talked of other children she played with at school, naming several boys unprompted before she stated the name of a girl she played with.

1849. *Have you got some friends?* Yeah. *(As if to say "of course").* Simon, Tim, Nate. *Are they all boys?* Yeah *(as if to say, "of course").* *Have you got a girlfriend?* Lindy.

On school camp, she participated in a blindfold course where she was expected to assist someone, but with her teacher aide rather than with another child like others in the class. Anna appeared accepting of this, as though this were the norm and to be expected.

317. So did you help somebody who was blind folded? Yeah, yep. And did the blind folded person you were helping Yeah. Did they fall over, or did you look after them? Nah, I look after them. Who did you go with? Mrs K. Oh did you not go with one, do it with one of the other kids. Nah. But um, because um, because um, but it was like this on this hand Yes. And this one went on this hand first and when one person go to the end we swap over Right. And go back. So you did yours with Miss K? Yeah. Right okay.

When the behaviour of others who are participating does not match with Anna's needs, participation is harder for her. Anna stated a preference for a quieter environment, explaining at one point that she needed this to concentrate at the activity. She was enjoying her new teacher, because when she was there, the other children in the classroom were much quieter. It appeared too that it was quieter with a smaller class.

433. Um, well should we put a sticker or a little glitter or something on that one?.....How do you get them off? I haven't done these before. You have to like rip them off. Okay. Carefully. They've got some sharp staples. Could be tricky. Need to take the other one. I could think these would make a big mess if they fall on the floor. You could get some scissors. Be careful you don't trim your thumb. I'm not. Okay I'll be quiet, sorry. And, and if, and if you tell me like a million times I'll lose my concentration. Okay. Don't want that.

218. Who's your special teacher? My teacher what I go have I have this year. Oh, who's that? Miss D. Miss D. Is she pretty nice? Yeah. What's she, why's she nice? She, because she's like much more quieter. Oh. She like used to like quiet spots. And like the other teacher move around, she would like appear a bit loud. Right. And she said quiet, quiet, quiet and when it's like, really noisy, she, she said, quiet and she like would go like that, that and then why I said, when I, but, then we like all noisy again. Hmm.....How does Miss D. do it? She um, she like um, she's, (big sigh) she's um, she, um, she's just like, bause I got like, um much more quieter class this year. Instead of a big loud class. Right. So it might be the children as well? Yeah.

Shared Understandings

Participation was particularly valued by Anna when it involved sharing of information or understandings with another person or group. This tailoring of each others understandings supported participation at a practical level, and sometimes gave the participation special meaning, supporting Anna to feel part of things. Anna and Ben participated closely together, and were both privy to important information about their activities. During my visit, family jokes were shared with me- situations that were recognised and funny to family members, but which would have had little meaning to those who had not participated. Secrets and popular words were shared with an elite group of other children, where Anna's knowledge of special

plans, codes, signs or passwords was a key to entry into games. Knowledge resulted from participation, and signs of achievement were shared with others who participated.

327. *Are you alright to keep doing the gluing?* At school when I was little, we have to be like told to do that. Like five dots like that. *Oh did somebody teach you about that?* No um, we had to do it.

Oh. How else did you use to do it? We, huh? *How else do you do it?* Um we, like now we do it like that.

32. B. Where's that cookbook? A: Um, at Dad's, maybe. M: *You tell me.* B: Oh no it's still here. A: Um. Ben: I kept it in um, I kept it in the bag. A: I did I saw it at Dad's in my room. B: I put it in the bag.

HV1 Obs. 1. 693. Yeah. When we we we. Do you know, um um, we said, "you should go on TV Dad". "Better go on 'are you smarter than a ten year old'". *I laugh at this. Do you think Dad would be?* No. *You don't?* *Oh! Poor Dad!* He thinks he's smart but he's not.

384. *You don't have to tell me about Simon but you could tell me about what you do.* No. No? He, we tell secrets, our secrets. We tell secrets a lot. *You and Simon tell secrets.* Yeah.

592. B. Leslie Pritchard is the other sort of Vice Principal, but she's in charge of she's the Special Needs Coordinator at school. M. *Oh. Right. We better write that one down eh.* J. Yeah. She's lovely. A. She always gives me a certificates. M. *Did she?* A. Yeah. J. You'll have to show Margaret the ones on the fridge. A. I got like 9 of them. On the fridge there. J. They get taken off each year, so the new ones go on the fridge. M. *So you've only got, you got 9 for this year?* Wow. A. Because like I like got like heaps like 5. And um like 5 in Term One. M. *What are they for? For reading and stuff?* A. Yeah. M. *My goodness. Well done.* Anna. And I'm trying get another one to get um to get 400 books or something else. J. One hundred books. Isn't it? M. *One hundred books? How many have you done?* A. About like seventy something.

530. Do you know what, how I would do if I made up a curse? *What.* Um I want, a was allowed a curse. *What would you do?* I'd like make it a, like say, say, like a million, I count up to like every year. Um you, you, you count really, really, really very fast up to a million. *Up to a million.* Yeah. *You have to count really fast up to a million.* Yeah. *I couldn't do that. If I was going to do a curse I would do it like the Harry Potter movies.* Whatever. *Oh yeah, whatever.* No, no, no, no. No the curse makes you do it.

Having a Go

The right to have a go was something that Anna valued. Frustration was experienced if this was prevented in some way. It is possible that this resulted in some way from decreased ability to predict what might happen, but it also seemed to signal a "can do" attitude, and a drive to

be part of new experiences. Her talk of Having a Go was associated with unfamiliar, physically demanding, outdoors activities. There was a feeling of facing challenges head on. Anna displayed pride in her endeavours, seeing her attempts as an achievement. We talked about her attending her school camp this year, and Anna explained the way she tried out all the activities at camp the previous year.

307. So I wonder what sort of things you'll do at Coopers Beach? I d'know. Playing on the beach. Um, um, blind fold like a confidence course, rock climbing and stuff. *Are you going to do those things?* Yeah. *And what if it's hard? Will you still do it?* Yes and a flying fox. *Right. You've done flying fox before haven't you?* Yes. Last, but last year I done like everything, I done like everything a go. *You give it a go.* Yeah, done the blind fold course last year. *Yeah.* The blind fold course was cool.

Missing Out

Sometimes, Anna talked of instances where she had missed out on participating in an activity. This appeared to occur when there was a mismatch between Anna's schedule and the timing of the activities. Anna was irritated when participation in therapy activities meant that she couldn't join in the same activities as her classmates, such as news time, when important information was shared with the class. She talked to me about the notices voluntarily, and also mentioned the negative knock-on effect for her participation when the information from notices was not shared with her, feeling a need to explain the reason for non-participation to her teacher. She attributed the blame for this mis-match to her teacher aide who completed the stretching activities. She was aware of similar feelings when she was excluded from participating in activities at camp, or when attending riding for the disabled meant she missed out on morning tea play with her classmates. She perceived she was unable to try out for soccer because her practice time would have clashed with Bens.

482. You got Mrs K. still this year? Yeah. She's annoying at stretches time. *Hmm, you don't like doing stretches much.* No. Do you know why? *No.* Because I miss out on every notice. *Oh.* Like camp, I miss out. I have to get, I have to say to my teacher, I did not, hmm, get one. *Oh. Do you do stretches at home too, or do you just do them at school?* At school. Better. *Better at school?* Yep. *But not missing out.*

On many occasions, Anna saw that other children deliberately excluded her from their play, citing a belief that she would be unable to carry out the activity. This was at odds with Anna's belief in having a go. Being excluded in this way engendered feelings of anger.

504. Are some kids easy to play with at school? Not, no. *Just, it's quite hard.* Hmm. But, but every game, what the girls play, they say I can't play because it's too tricky for you, like that. *Do you want to give it a go?* Yes. *And they won't let you.* No. *That's no good.* Hmm. *Maybe somebody needs to teach them.* Teach them a lesson, I'll say. *Well not a bad lesson.* *Maybe they just don't understand.* Hmm. Feel like punching them. *Yeah, makes you feel pretty mad.* Hmm, I feel like punching them. *Well don't.* I won't, we can tell Anna. *Don't hurt me.* *That's a gentle one, that's nice.* *I can cope with that.* *Oh, no! I don't want you to hurt me.* I was going like this. I was going like this. Like this.

Achievement

As a result of participation, Anna came away proud when she had achieved new knowledge about how to do things. She talked on several occasions of things she know how to do, and was keen to demonstrate her skills to me. This was less about academic achievement than practical skills that had also been valued by her classmates.

528. I know how to make a friendship bracelet. *Do you? Yeah. Have you got one? No. Who showed you how to do the friendship bracelet? At school. Was it your teacher? Yeah. The girls or the teacher? The teacher. Yeah. Have you given one to anyone? No because I, but I know how.....Do you need beads? No. Do you need a sort of cotton stuff? Any kind of string.*

Jan: Anna's Mum.

Jan: A Context

Jan's perspective of her own life provides insight into the things that guide her own actions, but also provides a background for Anna's own participation. On a Saturday I spend an afternoon with the children and Jan at home, taking part in their day. I tape our conversations. I later visit Jan to interview her. This is in the evening at her request, as the children are in bed by this point, and she felt she could talk more freely. She works full time during the day. Jan is a single mother, and has separated from Anna's father. Being on her own with two young children, one of them with a disability, has been demanding financially and also at a practical level.

On my own

Being on her own crops up several times as Jan talks. "With, being on my own, you can only do so much in a day" (111). Along with full time employment and bringing up her children, Jan copes with sole responsibility for all aspects of running the household, and she maximizes use of every bit of her time. She repairs things, and drives projects through herself. She built the deck for the children to play on.

PI1: 222. You get these little braces, and just screw into the, it was actually a lot easier, once you start doing it. Cause that's the trouble, with some of that stuff, it's just that you don't know how? But once you see what there is that you can use...and have a go at it, it's a lot easier than you realise. It's just that know-how that gets you.It was a big on-taking that, like it wasn't just a matter of putting it up in the weekend, it was ongoing. You know, digging the holes, digging them deeper, and it just seemed to go on and on for ages. It's a bit like when you start painting and stuff like that.

As I interview her this evening, we sit at the table, and her hands are busy repairing a blind she wants to put up at the window before they move out of the house. Although she perceives limited support from Anna and Ben's father, she values the support of Martha, an integral part of the household who takes the children to school in the morning, and also cares for them after school.

PI1: 30. Martha gives her a help and they do it together. Martha's the after school girl. *Ah, right.* Ah so Martha's been there to help work in some of these bits. *Is it Martha who walks her to school?* Yes. Martha is brilliant, she's a lovely kid, she's really nice.

Jan also uses the evening the children spend with their father to spend time for herself, sometimes going out. As the interview progresses however, I am increasingly aware that Jan has few close supports she can turn to. I become further attuned to the challenges of bringing up her two youngest children on her own, and her strength in doing this.

Scrimping and Scraping:

Financially Jan describes herself as "not very wealthy" and as "perhaps we do look a bit needy via our situation" (127). When I asked her about the changes she is dealing with in moving out of the house and buying a new house, she explains to me how this has been for her on her own.

PI1: the council didn't come up with the amount I needed, and the buyers won't come down to the amount I need. I could have gone and got a mortgage but I've been poor for so long, I'm sick of it. You know. Not that I'll be any better off but the thought of adding another 10 years of, scrimping and scraping. I mean Anna and Ben get to high school you know I mean I'm starting to get in to uniforms and stuff like that.

Social policy has played a part in her decision to work in addition to managing her roles in bringing up her children and running the household. Jan feels as though it is carrying the load unshared that is harder than Anna's disability.

PI1: ...I, have to work full time. That's catching on that little hole (*referring to repair job on blind*). Um I don't really have any choice about that. WINZ has a great, thing of getting people off the benefit by just cutting their pay further and further down so you've got no choice but to, up and up your hours I mean it's a grand scheme and yeah I could sit on the benefit and stay super, super broke I don't actually know if I'm any better off or not but I think am would be, hope I would be. Um, but it has, it's made it really hard. Probably just because I'm on the, my own, more then the fact that Anna is disabled.

You Just Have to Carry On

As Jan speaks however, I am not sensing self-pity. Rather her voice is low and calm, but firm, conveying some tiredness, but also a certain amount of frustration at her inability to change things. Her words later reflect doggedness, a drive to keep on going, to just get on with it, despite the curved balls life has thrown at her. She talked about needing to work through the school holidays, while the children have to attend a holiday programme.

PI1: 36. Yeah they both have to because I have to work. So. *Right.* Yeah no I don't use it after school, I just use it um through the school holidays. Which is tough, I mean every set of holidays they go in to Oscar Programme and you just have to carry on you know. It's just the, the grind of it.

Been there and done that before

Jan is an experienced parent. She has already brought up 3 children, and she values the things she learned, using it to guide her actions with Anna and her brother. She draws on the

experience to help her tease out what is typical pre-teen behaviour for her daughter and participation issues that are arising from Anna's disability.

PI1: 21 At the moment her and Ben seem to be arguing over who is going to do their wash first, neither being the willing participant! Um, yeah I mean that's just kids stuff, that's just standard, I certainly, have been there and done that before...

In contrast to this example, some isJoannes do arise from Anna's injury, and create further challenges for Jan to meet the demands on her time. This has become more obvious to Jan with the passage of time since the accident, where she realises that Anna is not making developmental changes towards independence that she is familiar with in her other children, and that others in the community assume have occurred.

PI1: 47. And people don't realise that as they get bigger, you try and get other stuff done but with Anna I'm still, doing all that hands on stuff um, I can send Ben to have his wash, whereas with Anna, I'll send her but I have to go and help her. *Right.* Um. Whereas I can be doing other stuff.. *So. Even, some of those little things.* There's heaps of little things. *That people take for granted.* That's right, that you don't even notice. And I think I've done it so long on my own that, you know even Mum and them, I was saying, people don't realise that I've still got all this stuff to do, that you do for little kids.

Valuing Participation

Jan's view is that participation is seen as delivering health benefits that carry through to the future. Her hope is that positive participation experiences for Anna will sustain her through any hard times in her adult years. Participation is viewed as laying down a store of memories that can impart a protective or preventive effect.

PI1: 145. I want to keep it, as, as, good a childhood as I can possibly make it, so when she looks back and when she's feeling excluded, she's got good stuff, to look back on. I mean we've all got the normal childhood ups and downs and we have to deal with them, they're life, but I don't want anything nasty in there um, is going to end up making her really depressed or really feeling excluded so.

PI1: 100.as she gets older and perhaps, segregated more, I don't know but as she gets older, I know as you get older, different things can haunt you.

PI1: 103. If Anna can get in to her teenage-hood and feel like she had those special moments, that can replace the feeling of missed out *Yep.* Um, they will carry her through.

Jan: Describing Anna's Participation

My interview and observations with Jan provided information about her perceptions of Anna's participation. From Jan's perspective, Anna's participation is characterised and influenced by the degree to which she is able to Have a Say in her participation, Opportunities & Resources available, Time Frames associated with activities, Having a Go at activities, the

involvement of Other people, the Effort required to participate, and Achievement. These themes are described next.

Having a Say

Increasingly Jan is aware of Anna's determination to have a say about the activities in which she participates. "I tend to be coming up with more of these battles, with her, and she just doesn't, comprehend that, at all that it's for her own good." (26). This is in line with Anna's peers, who are also likely to begin to push for greater independence around this age.

However, many aspects of participation are not optional for Anna, and are directed by others. To some degree, this may arise from Anna's communication difficulties, where it is hard to understand what she is saying, or she is unable to get her words out quickly. Jan and others often take the lead on what they want Anna to do, especially where they have particular goals in mind, and see certain activities as being necessary or healthy options. Where there has not been developmental change in Anna's choices of participation, Jan gradually and gently directs change.

PI1: 30. I've started a few new little things that she's protested profoundly about.

PI1: 123. Um, and I have started saying to Anna um, it's nice now, like on your birthday and things that you can get more big girls stuff. And she said, yeah it's cool. And um making her realise there's, just a gentle transition. You know I'm certainly not going to get all her dolls and put them in a box and say that's it, you're too old. I would never do that to her, and I would never have done it to Jessie either, it's sort of like they're allowed to hold on to their stuff, for as long as they want. *Yeah*. Um and I won't take it away, but I will encourage her to go through um.....

Teachers at school may be concerned about imbalances in her participation, and regulate her participation away from old patterns and playmates. This limited Anna's participation for some time.

PI1: 102. She had a really bad year when the, second year Ben's at school because the teacher decided they shouldn't be playing together, her and Ben. *Right*. That they needed to be making their own friends. The two of them were miserable as sin, really were.

HV1. 55. So they sort of kept her back. Which at the time was quite hard because a lot of her friends had started already as well. And the first lot went through and she stayed back and did that first year again.

Jans words also suggest that she sees that Anna's participation in medical appointments such as visits to hospitals for orthopaedic reviews and for ***, are controlled by and at the call of health professionals.

PI1: 26.they're going to look at her hand sometime this year anyway.

HV1. 746. They're going to do some stuff next year aren't they Anna.....Try and probably do it in 2 lots. A bit of botox in the elbow to try and straighten that back out. And.....To be able to turn her wrist over...

However, at home, Jan is aware Anna is beginning to state her own preferences, and is showing a tendency to resist or refuse what she has been directed or asked to do. This seems to occur when there is incongruity between Jan's own goals and the things that matter to Anna.

PI1: 119. I'm not saying set the table or things like that, but just come on we'll go and do a bit of gardening. *Do something together.* Yeah but I am getting a fair bit of attitude lately it's like "well I don't want to you know".

PI1: 24. Like I've been hounding her just to take a sweatshirt because if it cools off, or after she's had a swim at school she's going to need something warm on. "I'm not taking a sweatshirt, I don't need it Mum!" and away she goes, and you end up in a semi-argument trying to say, "well just put it in your bag", "it makes my bag too heavy."

Jan is an experienced parent, but talks as though this is an unexpected concern-something she is unsure of dealing with. She wants to teach Anna how to have her say in ways that are acceptable. On Anna's part, her resistance may be a desire for increasing autonomy where much of her participation is directed by adults, or where she participates in the shadow of a helping adult. At worst, the battles lead to Anna becoming very upset.

HV1. 1170. Can you get a tissue and blow your nose please and just wipe round your mouth. *(Anna) Then can I?* No. Why would you think by having a big paddy I would let you? *Please?* Not right now. I said later on!

PI1: 162. It's hard to explain. And then she's had a big paddy and when she wants to have a paddy, boy she can have a paddy. *I think I saw a little one when I was here* Yeah *In her bedroom* Yeah.....Oh that, yeah but I can't remember what that was about but yeah, they're pretty regular.

PI1: 1096. At the moment I'm just having to break through this barrier of that she can't have what she wants when she has a paddy. And sometimes it's a fine line of not pushing it too far, but trying to make a point as well that this won't work. Or it's not the way to do it.

Jan is aware that Anna has her own goals and participation preferences, although these were not a prominent feature of her discussion during the interview. Nevertheless she values these, explaining them to me, and sharing with Anna as she shows me her favourite activities at home. As with most children, Anna's goals and participation preferences shift and change. Many of Anna's preferences expressed by Jan during my visits involved craft or outdoors activities in close proximity around the home. Change appears to occur gradually, and as discussed above, where change doesn't occur, Jan will direct her activities.

PI1: 75. You know she's, she's starting to come out with goals and things she wants to do.

HV1. 519. She loves glitter and gluing.

HV1. 863. Anna's got some favourite books, haven't you Anna. Have you heard of K. H.? She was this little girl used to go down to the garden- fairies.

PI1: 125. I mean she's got her tape deck and her, CD, it's got a CD player on it. *Right*. And she's got a few different CD's that she likes um and she'll go in there and play them.

PI1: 175.well she's probably getting a wee bit out of the Barbies but.....

I notice also that several of Anna's participation preferences are expressed by Jan as family preferences.

HV1. 683. We haven't really got any favourites at the moment have we. We've got a few shows that we watch, like they quite like the zoo. And, "are you smarter than a ten year old."

Conversely, Jan is also aware that certain day-to-day activities hold less interest for Anna. This lack of interest means that Anna generally needs more help to achieve the activities. learning skills to carry out daily activities independently is hindered and increased direction is necessary.

PI1: 50. She would rather, someone else put her togs and towel out and get her clean ones.

PI1: 24. *Is she choosing all her own clothes and things?* Nah, she's just not really interested.

Jan also voiced concerns over instances where Anna relies on her to provide an occupation that interests her, but refuses to express interest in any of Jan's suggestions. Anna will articulate a need to participate in an activity, but does not take a part in saying what she wants to do, only expressing boredom and saying what she doesn't want to do. At other times, Jan sees that Anna doesn't really want to participate in anything, and endeavours to direct her into an activity, perhaps feeling that she will benefit from participation rather than doing nothing.

HV1. 1256. Do you want a game of Guess Who Anna? (Anna) *Nah*. Yeah, I don't think anything is going to suffice today is it..... We had this problem before you arrived I was...trying to find something to do for her. And she was adamantly saying no she didn't want to do anything.

The meaning of activities plays an important part in Anna's participation preferences. Participation in certain play activities that Jan described, and in activities I observed seems imbued with symbolic meaning rather than direct purpose, and were treasured by Anna. Playing outside with insects and with her Lego often included medical themes. I am aware of Anna's frequent medical appointments, and also that her grandfather has had extended time in hospital this year.

HV1. 1410. And she likes playing with her bugs and stuff, so she'll make up little.....Oh she'll go and find some slaters and make a concoction of mud and a little house for them and (Anna) *When I grow up I'm going to be a bug doctor.*

Playing with a special stone held meanings in relation to a new friendship.

PI1: 103. Anna came home, with this um, present, and it was all carefully wrapped up in a tissue and I says, what have you got Anna and she says something really, really special. And I said, this was after we'd been to the movies with Simon um, and she unwrapped this tissue and here's this great lump of rock. And I says, oh goodness, tell me about this. And she said, it's a rock. And I says well I can see that. And she said yeah, um, Simon and I were playing with this rock and we put it up really high and it, and dropped down on the ground and it broke in half so I've got one half and Simon's got the other half.

Jan clearly recognised the importance of these activities, but was cautious over the value of activities where there was the potential for conflicting meanings for Anna and her own goals.

PI1: 167. I have just brought, um, I'll show you them, they're a hand laser.....they slip on through their fingers, lights on the back of their hand. *Yeah.* And I thought, it would be absolute, different coloured lights. It would be absolutely brilliant for Anna to see if, to maybe encourage a wee bit of finger movement or just use of that hand. *Right.* And then I thought, how on earth do I give her a present and tell her that she has to wear it on the hand that doesn't work. So then I decided I'd buy two. *Right.* One for each hand. And then I thought well she's not going to use the one the hand doesn't work, she's just going to use the other hand. And I thought I can't give it to her as a present and expect her to use it for physio the way I want it. And it's like now I don't know what to do with them. Um.

When Jan talks of Anna's own interests and future goals for participation, they reflect a care-giving theme, where Anna adopts the role of looking after others. However, Jan also shows her concerns as to how Anna will cope with these types of activities.

PI1: 189. Anna talks about changing nappies and things like that on babies and, Anna loves babies, she loves puppies, kittens and I guess as kids, and even as girls we all do. So, that thought of looking out in to the future, as a one handed, person. *Ah.* Requires, me to look at, an awful lot of extra help um.

Opportunities and Resources

As Jan described Anna's participation, and when I spent time at their home, my attention was drawn time and again to the way that her participation is shaped by Opportunities and Resources that are available in the immediate and wider environments in her community. Anna's participation frequently features outdoors activities. Jan's interest in and value placed on gardening and the outdoors means that Anna's home environment provides her with multiple opportunities for growing plants along with her mother and brother, and for play involving garden creatures such as birds and insects. The bush and mature trees around the town provides opportunities for walks and play involving natural materials at hand.

PI1: 115. She'll sit out there and look for bugs and make fairy soup out of the flowers and.....yeah she'll change her mind and make all sorts of things. *So sometimes she'll make soup.* Yeah. *Right.* Yeah just whatever's out there, some sand and some dirt and a few bugs chucked in there and stir it all up, put some flower petals in.

HV1. 11. We planted all the sunflowers didn't we? And if you go and have a look, some are popping up.....On the outside of our fence every year we put the sunflowers in. There's this track going off into the bush. In time it winds down to the river. But um. There's a big loop you can do and quite a few people walk their dogs through the bush. It's just a nice pleasant bush that they can have a smell and a walk through. And um so we plant our sunflowers on the outside of the fence cause we haven't really got room on the inside cause of all my garden. (Ben) *And we made a hut. Just made out of a broken chair and some sticks.* In the bush.....

PI1: 131. (The Real Estate Agents) did a promotion and they gave.....They gave everyone a packet of seeds.....Every now and again, cause people know that I plant them out along the fence um.....Yeah I get extra packets put in our letterbox.

PI1: 105.they play games and she goes down and throws acorns and he, you know it's just *So they're doing acorn throwing.* Yeah and acorns get used for lots of things. They get to be money to pay to get in the huts and if you can't get in the huts you throw all your acorns in there. *Where is this, at school?* Oh at school, they've got imaginary huts. *Ben talked about building a hut when I visited, that was a home hut was it?* Yeah he's got a few in the bush.....

HV1. 343.*when Jan showed me around the garden she showed me the bird feeder. Anna enjoys watching the birds using it. Mum says she often sits and watches the birds.* (Jan) Do you want to see if there's some crusts?.....We'll put peanut butter on a pinecone, and then roll them in the seed.

Jan's evaluation of a holiday programme for the children considered the opportunities the environment provided for them to participate in art & craft, as well as exploration and gardening activities.

PI1: 38. Big airy rooms and a neat garden and because everything, 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.

The school camp includes outdoors challenges offered in the surrounding environment. In the wider environment of the small town which is a short walk down the road, opportunities for participation are close by, including the shops or market, and the movies, while other places in the community such as the library and the post-office provide resources that support participation in after-school projects.

HV1. 427.quite often we'll go for a walk on. Like Sunday morning they have the market in town which is just a farmer's market, produce. Go for a walk there, or um. We would have gone for a walk this morning. To do some of our Xmas shopping, but it was raining so we had to take the car but.And sometimes we just go for a walk to get bread and milk and stuff.

PI1: 69. For a while Anna had a once a week project to do and you had to do it about anything you like, each week was a different letter of the alphabet and that was actually quite hard and it was for them to source information from different places. Well I'm not actually on the internet, um her dad is, so you know we sort of had to try and use as much of other stuff as we could. She did one on posting letters so we went to the post office and got a few pamphlets and things like that which is sort of on the way home from school, we detour and um I think it does you good to realise that there's other places to get information from, not just at the computer.

Misfit of Opportunities & Resources

Some opportunities and resources do not support participation in that they heighten her sense of differentness to others, or when they do not tailor appropriately with Anna's needs or abilities. Items such as her hand splints are a resource provided through her rehabilitation, but single her out as different. Her ankle-foot orthosis, whilst assisting her to walk and participate in activities requiring mobility, conversely limits her ability to participate in dressing as she is unable to put it on herself. Jan is also aware that the clothing resources available to Anna do not match with her need for one-handed fastenings, and therefore reduce her ability to manage independently and participate in dressing without help alongside other children. Some resources change the activity to a degree that is unacceptable to Anna.

PI1: 44. her new brace, you got to, it took all that independence away, I'm so annoyed with it. Um, because she had a brace that she could put on by herself. They um, this new one, you have to actually open it up to put her foot in, which means she can't get it on, *Right* and because they made it so wide the only pair of shoes that I could actually find to fit it were lace ups so we've lost all that independence of her being able to put her socks and shoes on. Because the old brace she just slipped her foot on it basically and did the Velcro straps up, actually there's her old one there. *She was doing it herself*. That's right and we had Velcro shoes which made it easy but I couldn't find any Velcro shoes.

PI1: 181.there's hardly any shorts in her size now, that are made with elastic waists so she can just pull them up and down with one hand. They've all got domes and Velcro. And you try and do domes and Velcro and pull your pants up at the same time with one hand, you can't do it.

PI1: 183. Yeah, it's about coping, in a world that's not, set up for, her. Like *One handedness*. Yeah because all the kids from her age now, if you go and have a look around the [department store], I can guarantee there's absolutely no shorts with elastic waist past a size 7. They've all got the surfy, sit on your hips Velcro and domes. *And a dome is hard*. Yeah and all, even buttons on the jeans and things like that um, there's so, I mean in a, in a long term situation um, it's not,

PI1: 183.it's not just clothes it's like peeling potatoes and yeah I know there's a board with a nail on it and you, put bloody million holes in your potato trying to.....

The physical environment in Anna's community presents multiple opportunities for participation, but also presents obstacles and hazards, such as uneven ground or steep terrains. These things are at odds with, and are occasionally beyond Anna's physical capabilities. It is noted however that such features are generally talked about by Jan as being a concern when they are unexpected, and that their ability to limit Anna's participation is mediated by having time for familiarisation or by other's acceptance of Anna carrying out the activity in a different way or with support.

PI1: 152. I hadn't even done the walk before. I didn't know what it consisted off and when they're all saying to me "oh, it's pretty, pretty steep, she won't be able to manage it"

PI1: 177. Because they sort of put it, put it on us, that morning. *And given you that bit of extra time*. That we don't think Anna will be able to do this, you know you guys perhaps do, do the other course. And without, seeing the track or knowing what I was in for, I was forced to make that call.

PI1: 149. If I had to piggy back her I had to piggy back her.

PI1: 152. 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.

Creating Opportunities

Jan is proactive in making opportunities and providing resources for Anna to participate, and voices some sense of guilt when she is not able to do this. One of the reasons for building the deck was for the children to have a place to play. She sourced a solid table and chairs for them to use when they were out there, and built the sandpit (HV1, p. 205, 330). However she

is was sensitive to the way that financial constraints and time constraints limit her ability to do this, with most opportunities for participation being focussed in her own home environment.

PI1: 69. Well I'm not actually on the internet.....But I'm certainly not rubbishing the computer or, at the moment it's just another cost that, um and hopefully in our new house that will be something that we work in to our budget, to have. *Yeah*. Access to the internet, so.

PI1: 125. We were having a dance the other day, um my CD player is broken down but sometimes if you play the radio long enough it seems to warm up something that will let the CD player work, but I got it working anyway, and I was, telling them, showing them some of my funny CDs, there's um Def Leppard one that's really loud, and it's like "get your butt out of bed and walk the dog and take out the trash". And it's really, heavy rock, fast and loud and they thought that was absolutely hilarious you know.....

HV1: 225. they pretty much have to entertain themselves while you try and get that stuff done. A bit like mowing the lawn. You know, there's no one here to take them for a walk for an hour. So, I usually sort them out with something inside to do, um, and so, right, you know it's an hour that Mummy get this lawn mowed, and then we can do something afterwards. And you just have to sort of leave them to it, and get on with the job, and.....

Missing Out on Opportunities: Other's Exclusion or Failure to Include

As can be seen in the example above, other people may limit Anna's participation by not involving her in activities they are doing. This is graded through from merely failing to include her in participation opportunities, through to actively excluding her. Jan's words hint at the role other children's parents might play in including or excluding Anna.

PI1: 128. Anna and Primrose are in the same class, they're born two weeks apart. *Oh really*. That's right. Um Primrose has been invited to every one of Anna's birthdays, Anna has never been invited to one of Primrose's parties. Um. *That sounds hard*. It is, it is. The fact that I thought Karina was quite nice and for them to deliberately exclude, or not so much exclude but invite everyone else.

PI1: 79. *How come they don't [include Anna]?* I don't know. Just when she was little it was actually, um the parents. Um. *The other girls' parents*. 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 Anna's capabilities.....

As will be discussed below, Jan considers the role that inadequate knowledge or the presence of adult help accompanying Anna plays a role in failure to include her. She shared her feelings of grief over all the times when Anna has missed out.

PI1: 94. Um, I used to regularly, cry. Just, I, for the stuff I could see that she was missing out on.....Um, as time's gone on, um, you know I can remember when it was quite regularly sort of once a week and then it was like maybe a good bawl once a month, *Right* I mean we're

probably down to once a year now which is pretty cool. Um, but it doesn't change the fact that the hurt's still there and the fact that you know that you are being, excluded and, there's not a lot that you can do about it.

Having a Go

Along with others in her class, Anna enjoys and expects to participate in opportunities. Jan is clear that Anna doesn't want to be singled out as different. Although extra effort may be involved, Anna is determined to join in the same activities as her classmates, and relishes challenges. She may not always be successful, but Jan feels this shouldn't preclude her from trying. Jan believes in the value of people having a go or being able to try new experiences. When she describes wanting to trial a new intervention with Anna's right hand, she explains that "it would just have been a sheer dive in" (187), as though it is better just to try, than stand around and think about it. Likewise, she encourages Anna's older sister to try out different career paths.

HV1. p. 96. I think she might want to actually try something else by the time she's finished the apprenticeship? And I would actually encourage her to see if there's some other line she wants to follow?

This "have a go" attitude seems to have rubbed off on Anna, who was upset at not being able to attempt the same tramping activity on camp as others in her class when teachers were concerned for her safety and ability to complete the course.

PI1: 149. 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 and..... PI1: 152. 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. Because I think it is important for her to feel like she can do everything that they can do.

Jan, consistent with her "carry on" or "just get on with it" attitude, is of the mind that would have been better to have "just done the walk" (152). Anna may not always be successful, but Jan feels this shouldn't preclude her from having a go, and accepts that she will experience occasional failures. I mean on the odd occasion Anna has dropped me in it for me thinking she can do stuff and she can't (162).

Time Frames for Activities

The Time Frames associated with activities are seen by Jan as an important influence on Anna's participation. Participation appeared to be harder for Anna as the day wore on and Jan described the way that Anna's own perceptions of her participation were shaded by her fatigue levels after a day at school (p.5). During my visit Anna became increasingly irritable in the later part of the afternoon, resulting in increased conflict with Ben and reduced ability to achieve tasks for any length of time (HV1). Anna performs activities at a slower pace, requiring

longer time frames, and as I observed, her stutter means she also takes longer to communicate. Jan is aware of tensions or mismatches between the demands on her own and other's time, and the additional time needed by her daughter.

PI1: 179. I mean I've still got to go 90 miles an hour and, as well as that, stay at her level.

PI1: 173. With Anna, especially when she's trying to say something that's important with her, you just have to be patient and, and give her that time. *Yeah* Which in a classroom situation is really hard when you're trying to move things along and keep things flowing. And I find here, when I'm busy and trying to get the dinner going and seeing whose got togs and towels out of their bags and stuff like that, I'm really pushed to stop and concentrate and listen to what *Give her time*. That's right. I mean it sounds awful you can't give your kid time. You do but Anna takes so much longer.

Some activities needed to be completed in relatively short time frames, and Jan was aware that inflexibility of time frames had the potential to indirectly place constraints on Anna's participation. Apart from the physical challenges posed, Anna would have been slower than her peers going on the walk at school camp, and she was given at the time to understand that the time available could not be changed.

PI1: 152. 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.

Sometimes, in addition to inflexible time frames, there are conflicts between activities, where participation in one activity will impact negatively on participation in another. Some medical interventions were able to scheduled at times where they would not take Anna out of school. Given Jan's own schedule however, this creates some challenges and additional demands.

HV1. 185. Yeah. We, I take her up to **** hospital once a month, every 28 days on the dot.....Yeah. Well, it's just, I do it every 4th Monday. It makes it easier for me.....No, well I finish work early at 3, and we get her up to the hospital by 4:30 before they, the office girls and that go, and then they just put us through to A&E, and R has what they call a frequent flier folder, which explains how much..... I have to pick this medicine up myself. The hospital can't have it for me, so I've got to make sure that the chemist has ordered it in every month, a couple of days before she's due, which is sort of like, oh man. When you get caught up in a busy week, you got to remember to get to the chemist to.....and, to tell them "you know, I need to pick R's medicine up" either on Saturday AM or on Monday PM, but I try and get it before Monday PM so I can just pick her up. Finish work at 3, shoot home and get her and go straight up there so we don't miss the office girls. But that way she's not missing school.

Fitting In

A feeling of fitting in appears to underpin the notion of participation from Jan's perspective.she just wants to fit in (HV1, p. 644). Fitting in relates to Anna's participation alongside her peers, and includes concerns for both physical appearance and also for doing similar activities. "Um, she's starting to get a bit fashion conscious at ten" (26). The importance of fitting in may relate to Anna's age, where being part of a group begins to become important, where children become more aware of their appearance, and may be sensitive to appearing different in any way Anna dislikes having to wear her neoprene hand splint, as it flags her as its presence flags her apart from other children.

PI1: 26. she is realising that none of the other kids have to wear these blimen splints and things.....she just doesn't, comprehend that, at all that it's for her own good. All she sees is I'm just being a pain in the butt, making her different from the other kids. *She wants to be the same.* That's right, yeah. Which any normal 10 year old child does, they want to fit in and be playing all the games, like the other kids.

Fitting in also seems to relate to a sense of being accepted by others who are participating. Other's acceptance of Anna, as whole and complete, seeing her differences as normal supports her to "fit" into a place, the way a puzzle piece fits into a gap because it has its own special shape. Acting on this acceptance, treating her the same, including her along with others in greetings, in general teasing and in competition is also important. Fitting in therefore is easiest amongst her family where her identity includes her disability, her looks, and her ways. The fact that Anna has grown up from toddlerhood through to her pre-teen years with her disability helps people who have known her over this time see her as whole the way she is.

PI1: 167. People like Mum and um, some people just treat her like normal. I've got a friend who drops in occasionally, um, and he'd come in and he says oh, how's the brats? And Anna looked at him and says, "we're not brats!" You know. Um quite taken back that she had this greeting, to be referred to as a brat! Um just, just the, you know he didn't, didn't, molly coddle her with some, baby talk or greeting or anything. He just came in and, was himself and treated her like, yeah, like a normal kid.

PI1: 100. Oh yeah. *Yeah.* 100%. *Yeah.* I mean to us, especially since she's, this has been right from a baby um, it's just Anna. We don't know any different this is, um. *I notice that a lot with Ben eh.* And lots of, um that's right, he doesn't see her as disabled he sees her as his pain in the arse sister.

PI1: 105. I mean at this age, he doesn't see her as being, behind or dumb or, or different or, he just sees her as Anna and she's his friend, they play games and she goes down and throws acorns and he, you know it's just.

PI1: 102. I think that they are really close. And they do, do all the normal things, fight like cats and dogs and.....

Jan also gives me insight into her view that other's acceptance of Anna doing an activity differently supports her to participate. Acceptance of different ways of doing things requires others to be flexible in thinking about how things might be done. This notion is seemingly at odds with Anna's desire to fit in, not to appear different, and not to do different activities to her peers, but there is a fine distinction. It is evident that Jan sees Anna's

preference is to just get on and do the same activity as her peers, but in her own way if necessary. The focus is on just doing it, as opposed to how she does it. The notion tailors with Jan's valuing of "Having a Go". This was poignantly illustrated when Anna's teachers had concerns for her ability to complete a walk when the class was on school camp.

PI1: 149.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 and. 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.

Needing Help: Having an Extra Shadow

Whilst arguing for Anna's right to have a go, Jan characterises Anna's participation at home and in the wider community with her need for help. This may be in part a response to rehabilitation policy and processes. Jan is well-versed in detailing the help she provides to Anna for ACC assessors. This is in order for them to identify Anna's need for funded supports such as attendant care. However, she does feel that the help is more complex in nature than that elicited during the assessments. "They, they only really want to know real basically, you know, they do a plan, she gets up and has her breakfast and has her wash and *Okay* goes, goes to school you know. But there's lots more, you know" (20). However, Jan's focus on Anna's need for help to participate did not appear to arise from concerns over inadequate funding for attendant care support, and this theme did not arise. Neither did Jan describe any need for Anna to be helped in the classroom during my interview with her, although she explained Anna being given help with other types of activities at school such as personal cares.

Anna is helped in a variety of ways, and while this can facilitate her participation, at times Jan feels it can also be a barrier. Jan's discussion flags that help is provided largely by adults; that is, herself or by Martha, Anna's attendant carer. Jan describes Anna's participation in "the basics" (routinised tasks such as getting dressed or hair-brushing) as needing "a little bit of extra help" PI1: (?) or "giving her a hand" PI1: (?).

PI1: 21.....yes well she needs help to brush her hair

PI1: 22. I help her get dressed.....

PI1: 83.the odd party she's invited to, um generally I have stayed. Um, well the last one was a pool party so I had to stay um. But you, *Why did you stay?* Well because she went for a swim and um, she needed *You were worried about supervision or the dressing and stuff?* She needed help to be changed

At other times, Anna may need help to stay safe, resulting from physical concerns, where she is prone to losing her balance easily, and also from emotional concerns, where Jan perceives her as being more "vulnerable" (136) to negative emotional experiences, such as teasing or abuse. She describes a situation where she attended a party with Anna, and observed the other girls teasing her in the context of a game.

PI1: 136 the kids just kept running away from her and she'd get close and they'd all scream and run away and that was cool the first few times.....But when it went on and on through the afternoon, they wouldn't let her catch up or they, none of them swapped to be the one they run away from.....Well had I not been there, I would not have known that that was happening at the party.....There's a lot more, protectiveness needed and I have a lot more fears of, that, of what perhaps, yeah. Sort of situations I'm a lot more careful um, I guess.

However the amount of help Anna needs with "the basics" fluctuates, depending on her whims, but also on her energy levels. Anna shows preferences for being given help with routine tasks, possibly Janrned, possibly too reflecting tiredness, or a lack of interest. Anna's preference for help also tempers her brother's willingness to carry out tasks independently.

PI1: 20. "sometimes depending on what mood she's in as to whether she'll put her own toothpaste on".

PI1: 30. Ben's caught on to a heap of stuff with, because Anna has to have help, he won't do it either. *Right*. I've started a few new little things that she's protested profoundly about. Like when you get home you take your wet togs and towel out then and there and go and change them and put the dry ones in and it's like, she just didn't want to, didn't want to sort it. Fortunately, Martha gives her a help and they do it together.

PI1: 50. So there's things that you can do, just generally trying to encourage her but, yeah but you've got to be quite assertive to get her to make the effort because she spends such a long time having stuff done for her. Um, and she knows. She would rather, someone else put her togs and towel out and get her cJann ones.

PI1: 22. *Is she choosing all her own clothes and things?* Nah, she's just not really interested.

Jan values and nurtures independence for Anna, even while she continues to help her. Encouraging Anna to manage with less help suggests the extra demands that this entails for Jan during her busy day. In the light of Anna sometimes being unwilling to carry out tasks herself, it is possible that there might be times when it is easier just to continue to help her although Jan did not mention this, instead mentioning continued efforts to independence. However, she did emphasise the tensions faced over directing Anna to do activities herself versus giving her help when that was Anna's preference. Jan describes this as a "fine line" suggesting a need to balance and adjust her helping actions rather than adopt a rigidly fixed position.

PI1: 50. a few things I said to her lately, like I said you know you're ten now Anna and I brush my hair with one hand, I don't need two hands to brush my hair. So there's things that you can do, just generally trying to encourage her.....

PI1: 75. I, I've got to keep, trying to keep this girl, um, independent.

PI1: 189. I mean you're always encouraging them to be independent.....

PI1: 190.you're almost caught in a battle with yourself is to try and encourage the independence um, but you have to let her be able to help you as well. Or you help her, um. Finding that fine line where you're not pushing her.....

Jan describes being available to deliver help when Anna needs it as being a "Shadow" (192). Shadowing is being available to ensure task completion. By "pointing out" (p. 88) immediate risks where there are physical barriers in the environment, shadowing can reduce the risk of injury. By monitoring interactions and task performance it can reduce the risk of failure, but is also a means of providing a swift response if needed. More help is needed if Anna is tired or in an unfamiliar place. On the other hand, where Anna is familiar with a routine, she is able to carry out tasks without even being prompted (98).

PI1: 192. ".....you've got to kind of shadow her. *Right*. She wants to be independent, she wants to be doing it, but sometimes she needs help, so you've sort of got to be around to. *To shadow*. Yeah an extra shadow, yeah."

PI1: 87. And when you go in to a new environment like that anyway, you've got to find all the things that she's um, a stair down the hallway, I don't know if you've seen different houses where, that somewhere along or the start of the hallway it drops down, there's a stair and things like that, but the carpet's all the same colour. And that's just an example but there's usually in a house lots of little things. When Anna and Ben and I go for a walk in to town, *yeah* if she's tired I actually have to point out the kerbs and the cracks and things in the footpath. Um "just watch that kerb Anna" or "it's a bit bumpy here". Especially if she's tired because she done. *If you don't do that does she* She falls over, yeah she, she'll kick her toe and, that'll knock her whole centre of balance off....

Jan compares Anna's need for help to that of Ben and her two older sons.

PI1: 46. I can send Ben to have his wash, whereas with Anna, I'll send her but I have to go and help her.

PI1: 190. If Don and Zion wanted to go and play in the bush it's absolutely fine, they're not going to trip over a tree and, end up flat on their face. Um, I can guarantee Anna wouldn't even get in to the bush before she fell over. *Right*. Um. You know she'd only have to pass, start getting in to a little bit of rough and that would be her gone over. Um and sometimes when she falls over and gets her one good arm trapped under her, she can't get up.

Although the amount of help with individual tasks is not great, cumulatively this can be demanding, and as Jan described above, she has become gradually more aware that Anna is needing help past the time when her other children were independent. Always being available

to help means that Anna seldom participates without an adult there behind her, an extra shadow signalling adult presence.

PI1: 190. I think it, it is different with Anna though. I mean I've been there with my big kids and raised them and I know what my, I knew when to let go, I knew when to, give them that space. And it's not, the line's not quite clear with Anna because she does still need, um. Well she needs the extra help which tends to keep you there.

Although help can be important for Anna's participation by supporting task performance, or to ensure safety, Jan suspects that it can equally act as a barrier to her participation. Having an extra shadow around potentially singles Anna out as different, and therefore might limit her ability to fit in.

PI1: 128. they don't include her. I don't know whether they don't want the adults hanging around that, that come with Anna um. *I don't know*. No I don't know either but.

PI1: 138.most of the other parents weren't there, they all sort of left their kids and went.

Other's Understandings

Several times Jan spoke of other adult's lack of awareness and misperceptions of Anna's abilities or the ways in which she might need help. It could be possible to interpret people's comments as an excuse to exclude Anna, but Jan didn't see their words in this light. At times people made inaccurate judgements as to her participation in rehabilitation activities, based on prior knowledge or experience of similar situations. This is particularly hard for Jan who places value on hard work and effort to achieve results.

PI1: 183. Um, I've had other people compare her to other brain injury people and, say well, you know they just, sheer hard work got their hand to work and I've found that really insulting and really hurtful. It's like, I have put that little black brace on her hand, every single day for the last, six years, since that wee brace was made.....

PI1: 185. People think that you are, haven't bothered making the effort and that's why things are the way they are, and it's not the case. You know, or we know such and such who had a brain injury and they're absolutely fine now. It's sort of like, um, yeah but. There's another lady, she's older, she used to have the boyfriend over here, Marie her name is, and as a baby she got a fever, so her hand has never really worked very well, but they got it to go with lots of encouragement of carrying things and stuff like that. And it's like when I was being told this, I was also told so you just need to put the effort in for Anna.

Other parents sometimes made incorrect assumptions as to Anna's levels of ability, automatically precluding her from participating, or inappropriately expecting her to participate without help. On other occasions, Jan has felt that a lack of understanding as to the type of help she might need has led people to fail to include Anna in activities. What concerns Jan most however, is that it is a failure to inquire or seek knowledge about Anna's need for help that results in the misfit between people's understandings and Anna's capabilities. Being open in this way to changing their understandings might have better enabled other parents to support Anna's participation.

PI1: 83. 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 Anna's capabilities.....I guess these people sort of, the thought of having to change her or something like that. But 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.

PI1: 153. *So you've played quite a busy role in making sure that she stays part of things.* Yeah, well you have to really, because there's lots of it, there's no reason she can't. Apart from the fact that she needs a little bit extra help.....*Is it other people's perceptions of what she can't do?* Well it was, it was them telling me, that this track was going to be too steep *Right* And too wet and too hard. Um but when I saw the other kids coming back um, in such a short period of time, I, I sort of, was annoyed that we hadn't, or I hadn't made the decision for us to just go.....Yeah well I think she would done the whole lot of it. *Right.* Quite honestly. But she was standing there in tears and because she was crying..... And because she was crying, I was crying and it was sort of like, you know I, I seem to feel it, just as bad if not worse than she does. But never mind we, you learn these things as you go along.

PI1: 94. the little, never ever malicious comments, but, little comments that people would say and um, oh no you can't come you've got to look after Anna. Um I don't, just funny little bits that will come out. Oh um Anna wouldn't cope with that would she.

PI1: 132. Um, it took me by surprise, I wasn't prepared to being, someone inviting her over for a sleep over.....Um, and I was surprised, and I thought, I don't even think you realise that, Anna needs help with stuff yet. Like on the odd occasion.....um her pyjamas at the moment is a t-shirt top and every time I wash it, it seems to shrink a bit more and because it's got tight she needs a help taking it off.

On the opposing end of this scale, where people have had better awareness, this has supported her participation and resulted in positive outcomes.

Fit/Misfit of Others with Needs

In addition to the balance between the "others" in Anna's participation, the qualities of the other are important to supporting participation. Jan explains how well the caregiver, Martha's personal qualities fit with Anna's needs, and are thereby are suited to facilitating her participation. Anna appears to respond to someone who is quiet, and who does not direct her to multiple activities, but carries out essential activities with her in the manner of a companion. In contrast to this, a caregiver who was louder and energetic provided Anna with multiple activities, leaving Anna exhausted. These qualities were at odds with Anna's needs, and this misfit meant the caregiver was not successful in supporting her participation after school.

PI1: 32. She's patient, she's quiet and gentle and. Martha had a few days off last Christmas and they put this other woman in and honestly, she only did half a day and she was, that was at the Oscar Programme um in the school holidays. She was loud and, just, I mean I think I would have had a personality clash with her and Anna's so, um what's the word, tolerant, that, it didn't surprise me that she couldn't cope with her.

PI1: 73. No Martha's like I said more like a big sister. *Yeah.* Um and she'll sit and watch TV with the kids and it's not a hassle you know.

PI1: 73. Um, one lady was so enthusiastic, she absolutely exhausted Anna, she really did. And we had to get the, head lady to come in and because I mean how do you explain to someone that they're just doing, too good a job. But Anna wasn't coping, she was getting sick all the time and she was tired and she was, it was really dragging her down it was just too much to. I mean this lady would go home and think of ten activities to do for the next day I mean and put lots of, she made um, fairy skirts for her and ribbons and really, really put the effort in, I mean it was such a, um, she really tried hard and was, so enthusiastic. But it was just too much, Anna couldn't cope with it, I was having trouble coping with it because, maybe, to a child with ADHD it's alright to put ten different things in, in a couple of hours in a day but, to someone who really just needed that, gentleness and quietness and, um.

I note that after explaining about these difficulties, Jan went on to talk of Anna's plodding along, emphasising the importance of people's energy pace aligning with Anna's own pace. This need of Anna's appears to reflect her fatigue levels after school, and potentially her difficulty coping with an overload of information. Additionally participation at home is positive for Anna when it is with someone who will take a back seat, enabling her to direct her own participation as far as possible. Anna's enjoyment of play with non-human companions also reflects these preferences.

Balance of Participation with Others

When I explore Jan's perspective of Anna's participation, the involvement of an "other" recurrently appears as a component, and the identity of the "other" is an important consideration. The other may be other people- parents, children her own age, cousins, her brother, a special friend, or a caregiver.

PI1: 28. Yeah me and Anna and Ben sit down and have breakfast. Um I make it. Um and set the table and we sit at the table and have breakfast and they put their plates on the bench and um.

PI1: 102. Um she's got Simon she plays with and she's got Ben she played with.

Having a friend who participates in activities with her seems to lend a special quality to the participation, enhancing Anna's enjoyment. Jan pointed out to me that although Anna has had friends or other children she does things with from time to time, this has been infrequent, and she has had few close, sustained friendships. Jan felt that Anna seemed to form friendships more easily with boys than with girls. She was unsure why this was, but perhaps it reflected that boy's activities at that age have less emphasis on communication, an area of difficulty for Anna and more emphasis on movement related play. It may also derive from variations between children's development at this age, or that Anna spends a lot of time playing with her brother and sharing in his interests.

PI1: 75.she's got her new little friend, um that we took to the pictures. Finally gave her, the phone number. *He's not in her class though is he?* No which is actually really nice. The fact that even though, he's not right there, he's kept that friendship and she's kept that friendship. *You, you talked a bit last time I saw you, that you felt that the boys were a little bit less, or a little bit more open to being friends and difference.* Yeah, definitely in comparison with the girls. Anna doesn't and hasn't had, any girl friends. I take that back actually. Caitlyn B is her friend on occasion.....

PI1: 102. She's made her own world at school. Um she's got Simon she plays with and she's got Ben she played with.

The friendship that involved the play activity with the rock was a relatively recent friendship, but seemed to be resulting in increased episodes of shared participation with a peer. Jan thought the friendship might have resulted from Simon's need for a special friend subsequent to his parent's separation and being an only child. She had noticed that there was a clear connection between the two of them, and that he showed little concern for Anna's disability, with the focus on participation in activities together. Her words also include reference to the fact that Sean may have identified in part with the sense of difference that Anna experiences. Perhaps other children in Anna's community have less experience of feeling different, or are less sensitive to their own differences.

PI1: 105. I think, Simon's sort of a wee bit understanding and I think feeling like he's different.his dad's in England and it's such a long way away and because mum and dad are divorced now. So he's, and maybe being an only child too. I had a friend who was an only child and, the devotion levels are quite different. The fact that they want someone to look after and play with and to be friends. And, he shone to Anna and Anna shone to him and he doesn't care about the, [in]differences of only one hand working

The "other" may also be non-human, albeit with a particular identity. I observed that left to her own devices, Anna spends time participating in activities without other people, although with the company of her dolls, teddies, the people in her Play Station, Lego-people, imaginary beings, or with insects.

PI1: 115. Yeah well Anna's been more of a fairy girl than a explorer, you know. She'll sit out there and look for bugs and make fairy soup out of the flowers and. *There was a bug hospital* Yeah, she's *When I visited, or worm hospital, what was it?* Yeah she'll change her mind and make all sorts of things.

She spends time watching birds on her bird feeder. Smudge the cat is a frequent companion as Anna participates in certain daily activities, and in fact, is the centre of some of the chores Jan requests her to do. From this perspective therefore, Anna's play is seldom solitary.

The balance of time spent participating with a particular "other" had implications for the quality of participation from Jan's point of view. She expressed concerns as to the amount of time Anna spent in her room playing with her dolls, and deliberately directed her to participate in activities that involved more human interaction.

PI1: 119. Um, earlier in the year I was quite concerned at the amount of time, yeah the amount of time she'd play in her room with her, just her little dollies just sat on the floor by herself. And she still does it quite a bit and she gets annoyed if I call her out to do jobs but I'm not really calling her out to do jobs, I'm actually calling her out to change the subject and make her be a bit more interactive, um.

As might be expected for children this age, but also due to a perceived need for “shadowing,” it appears that a large proportion of Anna’s time outside of school is spent in the presence of adults, usually her mother or father, or her Martha her caregiver. The adult presence supports safe participation, and also achievement. For example, although the distance is not far, the children need to cross the main highway on their home from school.

PI1: 56. Martha gets them home after school and she helps with the homework. Um which is really good. Um I quite often if I can. *Do they, they walk back after school?* Yeah. Yeah, she goes and meets them at school. *She’s getting a lot of exercise.* Yeah. It’s not that far because they cut through.....

PI1: 65.Martha spends quite a bit of time with Anna’s reading.

Anna’s participation is also weighted towards involvement with direct family. In addition to Martha presence, Jan often talks of “we” (her and Anna) participating together. As Jan talks, I notice too frequent instances when she talks of Anna participating with Ben, including sharing “basic” tasks such as bathing and eating, but also at play. Community outings such as going to the shops generally seem to involve Jan and both children, as do home projects such as going to an auction to buy timber for the deck. Jan’s use of “we”, “them” and “they” highlights instances of involving both children. On Sunday, Anna and Ben play together while Jan mows the lawn.

HV1. 215.....they had a um auction on at the ah, Mount, the timber place anyway, and we sat there me and R and J sat there all day, and finally there was these 2 bundles of um, decking, *Oh.* And we got, and well it ended up costing me \$100.00.....so it worked out really well. We managed to get it.

HV1. 231. But in situations like that, with being on my own, um, basically they just have to get, I wouldn’t say ignored, cause I’m always very conscious of where they are and what they’re doing, but they pretty much have to entertain themselves while you try and get that stuff done. A bit like mowing the lawn. You know, there’s no one here to take them for a walk for an hour. So, I usually sort them out with something inside to do, um, and so, right, you know it’s an hour that Mummy get this lawn mowed, and then we can do something afterwards. And you just have to sort of Janve them to it, and get on with the job, and.....But they’re pretty good now. They’re a lot better. They’ll answer the phone for me now, whereas before, they’d come out and be standing on the deck yelling at me, and it’s like, by the time I’ve realised that they’re yelling that the phone is ringing.....Yeah, now they answer it, which is good.

This seems a practical response by Jan to the complexities of ensuring both children’s needs are met along with household management and coping with her budget. She notes that spending so much time participating together exerts an influence on Anna, but that Anna also exerts an influence on Ben, highlighting bi-directional changes. Ben’s caught on to a heap of stuff with, because Anna has to have help, he won’t do it either. (30). As discussed previously when considering Anna’s ability to have a say in her participation, Jan explained that Anna’s teachers had in fact voiced concerns about the amount of time the two siblings spent together, in terms of their wellbeing, and implemented strategies to ensure they played with other children. I notice too that Jan is aware that there have been limited occasions when Anna plays with children her own age, and that she would dearly like to change that balance.

PI1: 79. Anna doesn't and hasn't had, any girl friends. I take that back actually. Cathy B is her friend on occasion, but then I've seen Cathy out with other girls, at pictures and, um, different places, the gala you know her and another couple of girls are there together and in those situations they haven't included Anna. So.

PI1: 90. *So when she's going to go out with her friends, you still have that concern?* Well she hasn't been out with her friends.

Getting Tired: Grinding to a Halt

Jan is aware that participation demands extra effort from Anna. "... the fact that it's going to be so much harder for her to do all the normal stuff, because only one hand works." (184). She sees that often, Anna can't be bothered with the extra effort for more mundane tasks- it is easier just to continue to have someone else do it for her. Despite this she acknowledges Anna's efforts to participate in other tasks such as her neuropsychological assessment. ".....she does try really hard....." (94) or her reading "She's really really trying hard" (HV1. 652). She believes that Anna's fitness is important to supporting her participation, but that the benefits of activities to support her fitness are tempered by fatigue.

PI1: 165. Well the walking to school and stuff like that has built her strength up. Even though it's not very far, like I said if I just drive her and dropped her in the car and that was it well *Right*. She wouldn't cope with as much as she did and I think that physical, fitness is important even though she does get really tired. But just to keep trying to improve it.

She notices that tiredness is quick to set in. This tiredness can alter Anna's ability to participate, but also Anna's perception of her participation.

HV1. 1111. A's absolutely had it by 8:30 so she needs to be in bed at 8:30

PI1: 5. Yeah she, when she gets tired like this evening she started sort of moaning cause she's like oh today was bad and, but it's only because she's tired. Like when she gets home from school she's still got a bit of oomph in her and she tells you about the good stuff, so. *Hmm, think we can all get a bit like that*. Yeah it does look different when you're worn out.....Yeah, no she grinds to a halt pretty quickly.

Achievement: Plodding Along and Huge Strides

The pace at which Anna makes achievements is a theme that marks Jan's descriptions of Anna's participation, and includes notions of plodding as well as huge strides.

PI1: 73. People say how's Anna going and the usual comment's oh she's, you know she's plodding along. There's no quick fix and there's never going to be a quick fix for Anna you know, but, she's improving all the time and that's what counts.

At the level of body structures and functions, Jan is aware Anna takes longer to communicate, to move, and to think. She is frustrated by a lack of improvement in Anna's functions, such as being able to use her R) hand or eating, and is sad that neuropsychological testing did not reflect Anna's abilities. Plodding along suggests to me slow but steady

movement along a pathway, just keeping on going. I notice this fits with my observations of Jan's own "carry on" attitude towards the demands and difficulties she faces.

In contrast to the lack of change at a body structure and function level, Jan highlights the milestones Anna has reached in her participation with other people. These changes in participation are particularly treasured by Jan, and seen as giant steps in her progress. Anna is able to participate in spite of differences in body structures and function, and these achievements are valued by her mother.

PI1: 95.with that, psychological assessment, that Anna had that it didn't come out, as well as I had hoped. Um, because she does try really hard, I mean, like you said she's such a happy kid and bubbly and um, a neat personality that is, it's unfair when they put, um, can't score any lower, you know. Anna, there is no lower scoring and you think, oh okay. I, I was disappointed because I've seen the improvements on Anna and I thought that they would show, but they didn't. They were. *What sort of improvements do you see?* It's hard to understand. *In what she does or her interactions or?* Um her perceptiveness. Which is not something that you can test. *Like her insight in to* That's right, her family you know, we can laugh because I can say "Anna", and she'll say "I was just doing it Mum." You know. *Sort of reading your mind.* That's right, it's our family, the way it works, our routine our, um and I'll say, I might, you know Smudge will be under my feet and Anna will be standing there talking to me and I'll say "oh can someone pJanse" and she'll say "do you want Smudge's bowl?" you know. You can see all those improvements.

PI1: 189we have put the effort in and we have made improvements. Um, some have been all so minimal and others have been great huge strides you know. *Yeah.* The fact that this wee girl, as a wee girl was toilet trained and, um. The fact that she has made herself a friend and the fact that she does do all the normal things that *She walks to school* Ten year old kids do. The fact that she does have attitude with her brother and he has attitude with her and *Yeah.*

PI1: 169.so this is, this is a couple of years of working on, and I'm always saying like straight after dinner I say Anna go and wash your face, because it doesn't matter what she eats, she spreads it all over her face. *Right.* Um yes so. *So you've been working on it for a couple of years?* Yeah and so there's no quick fix with Anna. But it's, in a sense like that she's very slow. *Right.* But in the other sense, that she gets what those kids are doing *Oh yes* You know and she's right on to it and she's excited and it's funny and it's, it's a wee bit naughty and it's exciting. I mean she's right up there with them *Yeah* She's being part of it and, so it's hard for, to explain to people where Anna's not disabled but she's not, not disabled either.

HV1. 652. She's made some brilliant progress when she's doing her reading.

PI1: 65. She's got certificates on the fridge you can see for doing 100 books this year.....So she's very proud of her certificates and so she should be, she's worked hard.

Anna's School

Information about the school was gathered through observations, and through interviews with staff, including the Special Education Needs Coordinator, Anna's teachers, and her teacher aide. Some demographic information was obtained from the school web-site. Kingsville

Primary School is situated behind the town, and is across the road from Kingsville High School. It is approximately a 20 minute walk from Anna's home, which is on the other side of the town.

At the time the case study was completed, Kingsville School was rated as a Decile 6 school. It has between 540-620 pupils. Sixty six percent of the students are identified as New Zealand European, and 28 percent are identified as Maori. "A school's decile indicates the extent to which the school draws its students from low socio-economic communities. Decile 1 schools are the 10% of schools with the highest proportion of students from low socio-economic communities, whereas decile 10 schools are the 10% of schools with the lowest proportion of these students. A school's decile does not indicate the overall socio-economic mix of the school." However, "deciles are used to provide funding to state and state integrated schools to enable them to overcome the barriers to learning faced by students from low socio-economic communities. The lower the school's decile, the more funding they receive" (<http://www.minedu.govt.nz>, Accessed 06/09/09). A concern with funding was particularly reflected in my interview with the SENCO, who talked of Anna's needs being met through ACC rather than needing to find other sources of funding to support her.

At the school, all students participate in setting personal learning goals with their classroom teacher. These are reviewed twice a year. For those students identified as having special education needs, an Individual Education Plan is also coordinated, and this includes establishing learning outcomes, and developing plans to support students to achieve those outcomes.

When I visited the school for the case study, 76 children were identified as needing additional learning support. These included ten students at the school who were needing English language based assistance (English for Speakers of Other Languages, commonly called ESOL). None of the current children needing additional Learning support at the school were receiving funding through the Ministry of Education Ongoing and Reviewable Resourcing Schemes (ORRS). This scheme provides "resources for a very small group of school students throughout New Zealand who have the highest need for special education" (<http://www.minedu.govt.nz>, Accessed 06/09/09). Previously however, the school had been attended by 3 children qualifying for ORRS funding, and this had helped build team experience with supporting children who had a high level of need.

As they are unable to draw on ORRs funding for any of the students with learning difficulties, Anna's school provides a number of programmes to support their learning needs and accesses other supports. These include a perceptual motor programme, literacy programmes, a learning support tutor for those who need extra assistance to develop writing skills, and Resource Teachers for Learning and Behaviour (RTLBs). Children may also be supported by one of the seven teacher aides. These programmes and supports are resourced through a combination of the Special Education Grant (SEG) grant (which is based on the school roll number and decile rating), the ESOL grant, the pool of Resource Teachers for Learning and Behaviour, and funding from the School Board. Three of the children who needed learning supports, including Anna were funded directly by ACC. Unlike some schools, the school decile rating precludes it from receiving funding for a social worker. There is an active group of parents who volunteer and assist within the school, such as on school outings, or in the playground with the Sun-Smart programme.

The school has an explicit “zero tolerance” policy to bullying. This policy is underpinned by the school values of “Care, Courtesy, and Cooperation” and by behaviour plans developed from these values for each class. Staff reported that they had not seen any instances of bullying towards Anna, and in fact emphasised other children’s positive attitudes towards her.

.....we’ve got a whole school wide programme around zero tolerance to bullying. Now we don’t say we don’t have zero bullying, but we have zero tolerance. So that comes out under our three Cs, Care, Courtesy, Cooperation. *Yeah*. That’s a school wide programme. We also have um, a behaviour plan in our school which is school wide. And every child has to buy in to it, every parent should sign and return and that’s just talking about caring for ourselves, respecting others, being kind to people and property and, we stipulate, um certain rules within the class (SENCO Interview, 34).

Natalie, Anna’s Teacher

The Context of Natalie’s Teaching

Natalie presented as an enthusiastic young teacher, and was very positive when talking about her class. She showed a keen interest in drama and music, and musical productions were a feature of her classes, providing participation opportunities for Anna. Natalie explained that she was new to teaching- at the time of the interview she was approaching the end of her second year of teaching, and had been working with Anna for all of that year. This was her first year at Kingsville. She explained that while her training had given her valuable teaching knowledge, “so much of what is valuable I learned on the job”.

Anna was attending school full-time, and was in a composite class of 30 children with Natalie. That is, the class was a mix of Year 5 and 6 students. At the end of the year, the Year 6 children would be moving on to the High School across the road, and a new group of Year 5s would begin alongside the previous Year 5. This arrangement means that the children generally get consistency of teachers, as they keep a teacher for 2 years, and also that they will always be working alongside a mix of both new children and familiar peers.

The arrangement also means that each class includes children with a wide range of abilities. For some activities, children were “mainstreamed”, that is there was an expectation that a group with a range of skill development would be doing curriculum tasks. For other activities such as maths, children were “streamed” off into ability groups, where they were provided with work focussed specifically to their level. Sometimes, as was the case for maths, this would involve a different teacher and classroom.

For Natalie, the implications of this wide range presented logistical demands, and she had needed to learn organisational skills to deliver her teaching flexibly to this “diverse range” throughout the day. She talked of “spreading herself”, and of “the, balance, the juggling act of catering for so many different needs.....” The topic came up when we discussed the challenges of Natalie learning how to adapt work for Anna.

30. It has. I mean it’s been a process but in saying that, there are so many different needs, regardless it hasn’t been anything too, too over the top. *So you would change it routinely anyway for* For various, across the curriculum I’ve got children where I’m extending or, you know. So it’s, it does come, with the job. *Flexibility*. Absolutely.

Although staying with the same composite class was the usual arrangement, Natalie mentioned that she was scheduled to change to a new class next year, teaching “a gifted and talented learning enrichment class” so it was planned that Anna would be having a change of teacher.

We discussed some of the things that happened before Natalie began as a new teacher to Anna’s class. Information was shared about Anna at the start of the year in order to prepare her. A little later on, an Individual Education Plan was developed for the year for Anna. This included teaching staff, Jan and Tony, and also Anna’s therapists. Anna herself did not attend her IEP.

The class also underwent some preparatory “groundwork” at the commencement of the year. This included Learning about school and class rules, about the School Values of “Caring, Courtesy, and Cooperation”, and about being a good class member and friend. Reward systems were established to reinforce a culture of positive behaviours within these parameters.

98. I try and nurture that throughout the programme, throughout the year. And I have a smiley system. Anytime they’re caught being caring or courteous, showing the 3 C’s, outstanding work, just being caught being good, to have a smiley. *I heard you say something about that today I think.* Yeah, hmm. And so that’s continually reinforcing positive relationships and all those kind of things.

Natalie involved parents in her programme at a number of levels. For example, parents were free to drop in after school, attended and supported the school camp, and also attended the music productions.

The class timetable included maths in the morning, a “middle block” of “literacy and inquiry based Learning” (“reading and writing based around a topic”), and less structured activities in the afternoon such as Te Reo and art. Fitness was taken daily first thing in the morning, and once a week there were sports activities such swimming or cross country.

Fitting In

Words used by Natalie conveying Anna’s participation tended by use the component “in”. Fitting in was a feature of Anna’s participation that was also articulated by her teacher. One of the first questions I asked Natalie was about Anna’s routines. Her immediate comment was that Anna “fits in to ...the mainstream routines” (14), indicating that Anna participates in the same activities and timeframes as other children in the class. As our interview progressed, I gained a sense of Natalie seeing Anna as slotting in to a place within the group, a space for her where she was interlocked as a necessary part of the whole. “But I was told at the end of last year, that she loved to be part of any whole class situation” (64). Natalie went on to talk of Anna being “so involved” (18), signifying perhaps the degree to which she engaged in normal class occupations, but possibly also the closeness to which she fitted in to her place.

During these aspects of our discussion, Natalie did not raise the issue of inclusive teaching practice as a topic. Rather, her comments signified that fitting in was primarily driven

by Anna's expectation that she would be included as part of the group, contributing to and sharing in what they were doing. There was an emphasis on doing those same activities as the rest of the class. Natalie described Anna as fitting in to sports activities, curriculum maths and language activities, and also into several extracurricular activities such as musicals and lunch time activities such as choir. She saw Anna's response to fitting in as "she loved it".

18. She's so involved in the physical activities it's amazing. *Does she really like that?* She loves it yeah and she would be horrified to be, not included.

28. Where possible she wants to do exactly what everyone else is doing.

54. But we have done like an assembly for the school and she's been part, she's just a part of everything, she really does, she's, insists on being part of it, she's just as mainstream as. You know she really wants to be as mainstream as possible. So she finds speaking, she can stutter, but that doesn't stop her. She did a speech like everybody else..... So she was involved with our production and she did a speech and we had two classes together just the other day and she doesn't even hesitate in standing in front of 60 children and sharing what she's created

Comparing Abilities

Natalie's conversation reflected a strong awareness of different levels of function between children in her class. This is likely to reflect a teacher's practical concern with monitoring progress and assessing children's learning against established norms, and may also reflect her everyday teaching tasks where she needs to accommodate the mixed abilities within the two age brackets in her class "there is a diverse range" (118). The next year, Natalie had also been selected to teach a class of children with exceptional abilities, alerting her to the extent of differences in learning. Her language shows frequent use of terms denoting position or level, such as "quite behind" (94), "slower" (104), "slightly above" (104), and "lower level" (106).

Although Natalie clearly admired the way Anna was able to Fit In, I also noticed her awareness of Anna's differentness to others in the class. "And the different abilities. Perhaps just not to such an extreme as with Anna" (118). She was sensitive to other children's awareness of Anna's difference, and whether it affected the way they participated together.

26. And she's to have a teacher aide on a certain side of her because one, side of her is paralysed, yeah she doesn't use one arm. And so yeah they're very aware but, no big deal to them. *No*. Which is awesome.

Often, Natalie's awareness of difference, of Anna being at the further end of a spectrum of appearance or ability, was bound with an understanding of children having "needs". This may reflect the common use of the term "special needs" when talking of children with a disability, and may also show staff's concern with having inadequate resources to support children with "special needs". Having "needs" seemed to flag difference or a sense of apartness from others, but also showed Natalie's and other's awareness of her need to ensure Anna (and others) had adequate support to participate.

30. there are so many different needs

84. there she is with her needs

86. theyare aware of her needs

Help with Activities

The activity was an essential component of participation. Even with the range of different skill levels she was teaching across, Natalie perceived that certain classroom activities were very difficult for Anna. For some activities, this appeared to be at a cognitive level, whereas other activities were too difficult physically. Natalie was concerned for Anna if she were to fail at activities, and wanted to ensure she was able to achieve.

One way of ensuring Anna was able to participate in activities with the rest of her class was through having help. Natalie stated that Anna herself was becoming proactive in seeking help if she was unable to perform a task “I like the way that she asks for help” (166), although this was not consistent, and Anna often preferred to manage on her own.

78.....she does still need a lot of, you know one to one help. And, at times she would, she would, rather not let you know do you know what I mean? So that I, she has her moments..... So I do have to keep monitoring her as well. She doesn't, I can't leave it entirely up to her to let her needs be known. I check in with her at the start off, you know throughout.

However Natalie's own ability to provide help was hampered by class numbers. Generally help was provided by Anna's ACC funded teacher aide, but at other times, the children noticed her difficulties themselves and responded by providing assistance. Help from other children was seen as a real positive, but the words Natalie used when describing it tended to identify it as something out of the ordinary, or as a little above and beyond what would typically be expected. She identified the way the children themselves learned and changed through participating with Anna, feeling that some of their attitude arose from topics covered in Term One looking at people's differing needs. Reward systems were in place, where the children got a “smiley” for demonstrating the 3 Cs.

24. But the class actually helps her to be part of that. Very much so, they're very supportive. Do you need, has that taken time for you to build that up, for them to be like that? I must admit they've been pretty awesome, they just do it. *They've just done it.* They've just done it yeah. I think it's a bonus to have her in a way because it has made them a lot more sensitive to other's needs, so. They really strive to help her. *Yep.* I mean, I, we did the ground work in Term one about different needs and you know, we did our rule setting and what makes a good class, so I guess the ground work would have been done in Term one, but naturally the children have risen to the occasion.

122.....normally I don't need a teacher aide for art activities yet when we're collaging, a teacher aide is just awesome but then the kids step up to the challenge too, and will often offer to help so they can kind of see if there's something Anna's struggling with that they'll support. So it's quite nice to have that peer support as well.

My response to Natalie stating the advantages to other children of having Anna in the class was at first critical. This theme of the other children who will “benefit from her very presence” (92) in the class was mentioned several times. Coming from a professional background that aims to empower people with disabilities, I felt concern that Anna was being valued primarily for what she could teach others “she’s taught me and the rest of the kids a lot.....” (84). In my eyes, this placed Anna apart, identifying her by her disability rather than accepting her as an equal. It could be possible to interpret these types of comments from a perspective of power relationships.

Later however, I also reflected that Natalie’s comments would have arisen based on her own experiences of people with disabilities, which may have been limited. At face value, in everyday routines, she would now be observing how other children changed as a result of participating with Anna, and noticing her own changed understandings about having a disability. From a practical point of view, the benefits of these children Learning better about other a variety of people’s needs and how to assist them, could later support them to make a valuable contribution to the community. Equally, Anna was also changing and Learning about others as a result of her own participation.

Having a teacher aide was not necessarily conducive to ensuring participation. Although tasks could be achieved, supporting one aspect of participation, Natalie could see that the presence of the teacher aide also created a dichotomy, signalling Anna as “different”, and therefore preventing her from feeling she was participating.

80.we’ve had times where our teacher aides have been absent, sick, whatever, for whatever reason and, I think she and I both realise just how awesome it is to have their support. But I do think she still, likes her space and notices that she’s different when she has that TA support, *Right* but it is necessary. Yeah.

Skill was needed on the part of the teacher aide to “float”, working with a group of children, giving Anna “breathing space”, all the while monitoring her and “judging the moment” (112) to step in to provide some individual help. The preference was for providing Anna with the same activities as others in her class or group. Natalie talked of Anna being “incorporated”, as though the help could ensure Anna was enveloped within the whole group and their activity, rather than working as a separate entity.

103. *What helps you, to help her, to take part in like those literacy activities?* Again, teacher aide support. So that she’s getting the quality one on one. And I’m not trying to spread myself between my 29 others and her. That’s huge. Joanne H’s been fabulous. I still really enjoy, with teacher aide help, I can incorporate her into a group activity. A streamed group activity, she can be with my, slower learners. *Right*. They’re still slightly above her but with teacher aide support she gets that group interaction, whereas she would be kind of, I would be, creating a whole new set of activities do you know what I mean? Without, if I didn’t have the teacher aide support..... But because of the teacher aide she gets that group interaction which is what she loves. She doesn’t like being individualised and here’s this group, this group, this group and here’s yours Anna. If I can incorporate with that, with groups, she feels so much more part of the unit. *Okay* Which I think is really important.

Although Natalie felt that help was needed on a lot of occasions to enable Anna to participate, she also valued independence, and reduced reliance on others to assist with

carrying out the activity. Her use of the word “leaning” to describe Anna’s need for help could point to a view of a child with a disability as a burden to others, but may also communicate a concern that help could become habitual when it wasn’t always necessary. She was pleasantly surprised when Anna could achieve an activity without help. Independence showed learning, and was seen as an outcome of improved function.

160.....it would be very nice to see her quite independent with word lists and actually checking words she wasn’t sure of and things like that, she possibly. It’s hard to know, to know how much she leans on.

Where do you think, why do you, why do you feel so strongly about that? It’s just recently with this writing sampler I was quite, impressed with what she did independently.

Adapting Activities

Another strategy that was used to support Anna’s participation was adaptation of classroom activities. “I just adapt everything” (82). Adaptation could reduce the need for help, but also assisted Anna to work at similar activities to others in the group which Natalie saw as important to Anna’s own sense of participation.

28. She’s involved, any type of school, swimming sports or cross country it’s adapted ever so slightly but she would, not like to think it’s adapted you know what I mean?

Learning assessments posed particular difficulties because they needed to be based on a child’s ability to complete the test without assistance, but were altered so that Anna’s progress could still be monitored.

“What springs to mind is kind of standardised testing. Where you can’t have, really you can’t have teacher aide support. We’ve done things like Astel testing. We’ve adapted them to, there’s a test that you can have below level two.....” (82).

Some activities were more readily adapted than others. Art activities such as using scissors to cut items were perceived as being less adaptable, and more help was needed. When activities such as sports activities had greater flexibility, they could be changed in order to fit or align with Anna’s abilities. The whole class could be drawn in to the adapted activity to support Anna to be a part.

64.I kind of, came with that approach really, where possible, rather than giving her something completely different, just adapt what we’re doing to suit her needs.

20. The kids have been really supportive with that too, we just adapt all of our games to suit her. So if it’s a chasing type activity they hop, when she’s, when it’s her turn etc, so she’s 110% active.

Having Her Say

Natalie had noticed that Anna could be very up front about expressing her needs and preferences to others, and valued this characteristic, although I sensed that this may have resulted in some awkwardness. In addition to being comfortable about asking for help as

discussed above, Anna readily let others know what she wanted, or if she was annoyed when she felt left out.

54.she's, insists on being part of it.....

46. Um she can be, she can be quite honest really. She can be very honest and say I don't, you know get quite upset that I miss out on certain things. *Right* So she's just to the point, so you always know where you stand! Which is a good thing! But I have no problems with it, it's a positive thing.

However, when it came to Anna's Individual Education Planning, Anna was not included in identifying her goals. Ironically, Natalie felt that she herself was better able to engage in the process when she, as Anna's teacher, was directly involved.

68. that mid year IEP has been the, the one that I, that meant the most to me because I was part of the process and I knew a little bit about her then. *And does information in that IEP, that comes from teaching staff who've been involved before?* Support staff. *ACC.* Yes and parents *Yeah* Are involved as well, as well the. *Right.* So *Jan* was contributing to the IEP. Yes and I think, if I was remembering correctly so was Anna's dad, they were both there I think. *And Anna?* No Anna wasn't there. *She didn't participate?* No.

Being Taken Out

There were times in Anna's day when she was removed from activities the rest of the class was involved in. Natalie used the words "taken out" (44) to convey the times Anna was not participating with her peers. Sometimes, this was when Anna needed to participate in therapy activities. These types of activities were regarded as specialised, and as being beyond Natalie's area of knowledge, highlighting that Anna had needs that were different to those of other children. She was non-specific as to what the therapy sessions involved. Although efforts were made for therapy activities to fit with school routines, and the sessions were now infrequent, these interventions were viewed as standing apart from the usual, and as being necessary to address impairments rather than supporting participation.

42. Generally they take her out and they have special things. Speech language therapist takes her out and does certain exercises and things with her. But again they just, I'm very flexible and they will, just doesn't really matter what we're doing, they kind of just come in and fit in with us. *So, for your overall picture of Anna, would you say that she's in class most of the time?* Hmm. And that's the way she likes it. *Yeah.* And people are very aware of that, the people who come to take her out, she absolutely hated being taken out of maths time for example. So they've, they changed their time to suit with, her.

123. *Does the therapist provide input with the teacher aide?* They do, the occupational therapist with certain stretches and things. So Joanne will take Anna out at the end of the day as well and do stretches. *Oh okay.* So she does.. *So it's more about physical function.* Yes that part of it is purely about physical function and stretches and certain exercises and stuff.

The school camp was another time when Anna was outside the participation of the rest of the group. Despite this being a time of adventures and challenges, Natalie explained that when it was time for the bush walk, a decision was made by Natalie and Jan for Anna not to participate, and that she “stayed back”, denoting the way non-participation is about being outside others and their activity. The time frames for the walk were short, and the physical challenges were seen as marked. Options for adapting the route or time frames were not discussed. Natalie talked of Anna submitting to staying back as though it was inevitable, but expressed pity for Anna over what she perceived as an impractical situation for her participation. She saw Anna as being deeply sad.

140.....we had a bush walk which was pretty intense and, we chose for her not to participate with that because there were just so many steep hills and it would have just, she would have been too slow to actually, we only had a half day to do it. She felt a bit sad about that. So there are times when she accepts her fate and doesn't necessarily you know, she was gutted but there was nothing we could do. She stayed back and got to choose to play on the flying fox again or do the other things with her mum. And that was a call that mum and, her mum and I made. But you've got to feel sorry for her at those times. *Did you feel a bit...* Oh yeah, yeah. Everyone felt a bit sad, it wasn't quite the same without her, but.

It appears likely that the decision to exclude Anna lay in part with a lack of knowledge. Natalie also talked of the way that unfamiliar activities and environments presented the greatest challenges to Anna's participation on the camp. The camp was held in the summer term at the start of the year, so Natalie at that stage had limited knowledge of Anna's abilities, needs, and goals for participation. Additionally, the camp was in a context that was new to Anna and to Natalie, and concerns were expressed for her ability to cope without help.

132. We had camp at the start of the year *Oh, yeah*. Which I, was hesitant about. I didn't know what to expect at the start of the year *Anna*? She's brand new, first camp that she would have been on. You don't go on camp until you're Year 5 and 6, so that was a bit of a potentially scary thing because we've got flying foxes and confidence courses and all sorts that could have been, that were definitely going to be challenging but I didn't know if they would be achievable.....So having that um, parental support at that time was crucial.

This explanation for Natalie's decision to exclude Anna is supported by her acknowledgement of the benefits of having continuity of teaching staff and classmates. She described Anna as being “settled” as though she were established in her place in the class, and flagging some mild concern at the effect that the planned change of teacher and new classmates the next year might have on Anna's participation.

90..... ideally they try and keep, some children together in the transition. I'm teaching um, a gifted and talented Learning enrichment class next year.....So unfortunately it's not going to happen for my Year 5's this year.Which is a shame because Anna is very settled and we've

had a neat year.....it will be everyone coping with that change. But I don't think there are many of my current children in her class, so it will be interesting to see, hopefully she'll be fine.

Giving Things a Go

As with Anna and Jan, Natalie talked about the way Anna was motivated have a go at most activities. Although some activities were difficult, Anna simply assumed that she would be participating along with others in her class.

152. She gives things a go. Like if we do it for a fitness rotation, she'll still give things a go, she know her kind of limitations and.

Aware of how difficult some things could be for Anna, Natalie was admiring of her attitude towards new challenges. Aligning with Jan's just getting on with it attitude, Natalie talked of Anna as "getting on with the job" (84), as though she didn't fuss when something was difficult, and simply applied herself to the situation as best she could. Natalie felt that this hadn't always been the case, and that Anna was now more confident about trying things out.

64. So she always has been very keen to participate, but I think her confidence as grown a lot.

84. She's taught me and the rest of the kids a lot about resilience and just getting on with the job and giving things a go and there she is with her needs and yet she, rises to the challenge continually and it's just awesome, yeah.

140. But she was, amazing on camp. Again, she just, gave everything a go, there was so many challenges.....She gave the flying fox a go! Even I gave the flying fox a go!

Anna seemed to evidence a bounce-back disposition. If she had a go and it didn't work out, she took it all in her stride, not letting it prevent her from trying again.

144. Her attitude, prevents anything from being too difficult because she's got such a um, an "I can", attitude.....But it's just awesome. I don't know where it's come from. She must have had, she's just so resilient, I don't know. Cause I've only ever know her for this year and she's been that child all year really.

In the staffroom before, you described her as one of the bravest kids. Absolutely she falls over, she dusts herself off and doesn't, off no fuss required and I joke with her, you're braver than the boys, she's got a good sense of humour and she cracks up, you know

Giving 110 Percent

Whilst Anna was keen to give activities alongside her peers a go, Natalie recognised the amount of effort that went into this. "She gives everything 100%" (54). Anna's hard work was

seen in the context of her disability, admired all the more, and held up as a standard others should aspire to. "She's an inspiration actually....." (54).

20.even though she's, you know obviously restricted and limited she gives 110%.....so she's 110% active. *Yeah*. It's awesome.

As a result of the effort expended, Natalie had also noticed Anna's energy levels falling off markedly by the end of the day. "I know she gets very tired" (164). This limited the degree to which she was able to achieve at activities, and meant that timing of activities and provision of help needed to be considered to support participation.

158. I think tiredness is a factor, she gets tired quite easily and timing is important, do you know.

So the time of the day that you do it, do you mean? The time of the day, what's happened before and afterwards, probably all contributes.....

78. If she's struggling, she'll tell me, but then she also gets very exhausted by the end of the day, and you could see her just drifting off and you know.

Sharing Information

When things were unfamiliar, such as when there was a change of people or environment, sharing of knowledge was important to supporting Anna to participate. When I asked Natalie who helped her to understand how to have Anna as part of the class, Natalie described the process for sharing information with a new teacher, but also indicated that participating in teaching Anna resulted in acquiring knowledge about how best to support her.

66. Um we had transition meetings at the end of each year where you meet with the last years teacher, so I actually met with Jinny Rush..... she taught her for one year in Year four. So I met with her and I actually met with the occupational therapist and speech therapist, those people too, so I had a bit of a snapshot of what to expect, as well as all the, the data, the folders and stuff like that, that were passed on. The IEP helped.....and I knew a little bit about her then.

Although Natalie had regular contact with Tony, Anna's father, and valued this opportunity to catch up with him on relevant news, because Jan's work hours precluded her from taking the children to and from school, there was less opportunity to share information with her.

132. I don't think I've seen Jan since. I don't have much contact with Jan at all, I know she's really busy but Anna spends Wednesday night with her Dad in the middle of the week and he pops in and says hi and I see a bit of him too which is really nice to touch base. *Just to talk about how she's doing or?* Just a general hi and yeah if he's got any queries he'll he'll ask, but generally it's just to touch base and say hi.

Friends

As with Jan and Anna, Natalie highlighted the importance of Anna participating with friends outside of classroom time and outside of school. Natalie praised Anna's interactions in the classroom, but hinted at a need to spend more time with groups of children in the

community. She describes other children's interactions with Anna as supportive, possibly placing Anna in a "needing" role, rather than an equal player. This could place Anna at a disadvantage if she were to ask other children to spend time at her home.

94. Ah I think the continued social development is awesome because, friendships-wise, I think that's quite vital because although I've got a very supportive class and we have, when we have their earned free time on a Friday, she interacts beautifully. On the playground she has one or two friends, so she doesn't have a large circle of friends. I think that social kind of friendship thing is really valuable for her. And it's, part of her IDP too, is to um, *Right* actually have children over to play and go to children's homes to play, to get that kind of friendship.

Joanne, Anna's Teacher Aide

The Context of Joanne's Teacher Aide Assistance

Joanne has been working with Anna since she was in Year Two, a total of almost 4 years. She provides Anna with assistance for reading, writing, and self care activities such as clothing changes for swimming. A parent herself, Joanne works part-times, and is employed by the school for 15 hours a week. Not all of these hours are spent with Anna, and she also assists some other children. She does not work with Anna for maths or sports, where Anna now works independently. When Anna begins college over the road next year, Joanne won't be moving across with her, as she prefers to continue working with younger children. In addition to assisting Anna to achieve classroom and self-care tasks, Joanne sees her role as also supporting Anna with skill development, and talked often of "working" with Anna to improve her abilities in different areas such as reading or writing. "She has really started to enjoy reading and ah, we're really working on that, yeah" (136).

Joanne's work with Anna was supported by information sharing between key people. Formal information sharing took place at scheduled meetings, including a weekly teacher aide meeting with the Special Education Needs Coordinator (SENCO), where concerns and strategies to address them were discussed. If Anna was unable to attend due to medical appointments, Joanne was informed with a written note from the SENCO. Joanne did not discuss Anna's IEP, but did talk of informal information sharing with Tony once a week when he picked Anna up, and they would "catch up" with any concerns. Joanne seldom saw Jan. "I have absolutely no contact with Jan because she doesn't come in to the school very often. She goes in to work and Martha walks Anna to school." (100).

My interview with Joanne was hesitant at first, and I tended to provide a lot of prompting and explanation to elicit responses from her. However, as the interview drew to a close, Joanne appeared to become more comfortable to share her thoughts, and the last few pages of the transcript contain information that provides a number of deeper insights into some of the issues facing Anna. A number of themes that fitted with those described by Anna, Jan, and Natalie were apparent, but the interview expands on these themes, and provides

some new understandings about them. Joanne's length of experience with Anna was able to provide information about change over time.

Increases in Participation

Joanne felt that there had been gradual increases in Anna's participation "I think she's participating more in, most activities now then she was" (9). Joanne saw however, that Anna's increased participation was not only about performing activities, but was also about her involvement with other children. Changes in participation with others appeared to be processual in nature. Initially, other children held back, unsure of how to interact. As they gradually spent more time with her, particularly in play, they came to know her better, and thus seemed better able to include her in their activities. Getting to know Anna meant an exchange of knowledge, and this supported further participation. "I think they respond to her more that as, as just a part of their class. *Right*. Um you know they include her more" (11). The exchange of knowledge worked in both directions however. As Anna participated and became more familiar with the other children, she also felt more at ease to communicate with them. "Her speech has improved and um, she was quite reserved towards the other children but I feel she's coming out of herself" (13). This process had been largely passive, and the changes had begun to occur without intervention.

22.....when she's in a class and there's new children that haven't actually been in a class with her before, how do they react to her? Um they usually, you can see them looking at her a lot, they look a lot, and they stand, very, yeah they do stand back. *Right*. Until I think they get the cues from the other children. *Right*. And then they just accept her.

Joanne talked of other girls who had recently begun participating in a game of tiggy with Anna before going into class. Play was an aspect of participation that Joanne particularly described as supporting this process of getting to know Anna.

19.today I saw her running around with a couple of girls before school and I was really impressed and they were playing tiggy and she was really in to it, she was really part of it which was nice, it was really *good* nice to see. 29.they were including her. *Mm*. And apparently they um, her teacher has said that those same girls, well one of them anyway has been playing with her sometimes at lunchtime as well. So that's fantastic.

42. And I, I know that most times, in other years I've gone in and Anna might be just, sort of hanging around waiting for somebody to play a game with. But I've noticed a couple of times, just the last few days, that I've been in there she's, I've gone in and she's actually playing a game with other children, from her maths group, which is just great.

Anna had been at this school since she was a new entrant, and many of the children now knew her by name. Actions such as greeting her assisted Anna to feel part of the school.

64. I think most of them have seen her through the years through the class, different classes and everyone knows Anna. *Yeah*. Everyone knows her name and everyone says hi to her in the playground and you know, so most of them know her and there are.....*Maybe that's one of the good things that she's been here right along* Yeah, yes. *And hasn't changed schools a whole lot*.....And even the younger ones they get to know her name, and it's hi Anna, hi Anna and she goes, oh everyone knows me!!

Although Joanne was pleased that Anna had been playing with other children, she expressed concerns that Anna had a limited number of friends, relating this back to her own parenting experience.

178. Hmm and the one thing I would really like to see actually is for Anna to have more um, friendships out of school as well. Because I actually, as a mother myself feel that's really important.

17. the friendship issue has always been quite tricky..... She's often had friends but usually boys.

The goal of having more involvement with other children outside of school had been discussed at Anna's IEP. Joanne felt this needed to be supported by Jan and Tony; "Leigh or Tony needs to really um, work on that themselves, because they're the ones that can have other children over and um, get it going....." (180). She showed some awareness of the difficulties that might limit this from happening, and described the same lack of understanding on the part of other parents as that described by Jan.

182. I think other parents are, um, find it a little bit difficult to have Anna because they're not, they don't, if they don't know her, they're not sure of her needs. *Right*. And I think that's a lot of the problem too. *Because it's sort of a two way thing isn't it*. Hmm and I mean I know myself, I had never worked with special needs children um, when I first met Anna I, I wasn't sure of her needs you know and until you get to know her, *It's that unknown*. It's the unknown.

When writing this case study report, I had opportunity to reflect on my earlier interpretations of this situation, reflecting on other issues that might be involved. I gained some further insights into what might be happening when I placed my knowledge about the demands facing Jan in her parenting role in the context of my own increased knowledge about participation.

Due to financial demands, Jan needed to be in paid employment. The hours she worked did not fit with school hours, and this precluded her from taking Anna and Ben to school or picking them up. This placed limits on Jan's own ability to participate in school activities and to share knowledge with teaching staff and other parents. Both the teacher and the teacher aide admitted to having little contact with Jan. Resulting from decreased participation, Jan would have decreased knowledge of school activities, of the other parents, and of the children who might be able to play with Anna. Additionally, they would have decreased knowledge of Jan, and of her concerns. This potentially poses double risks to Anna and her out of school participation; not only are there constraints directly associated with her disability, but participation constraints at the school are also present for her mother, which could further impact on Anna.

Saying What She Wants

As with Natalie, Joanne had noticed that Anna was not backwards in coming forwards about what she wanted and needed. Jan too had discussed Anna' being more determined in saying what she did and didn't want to do. Although Natalie had felt this was an advantage, I

had sensed that this had created some difficulties at times. Joanne directly mentioned the negative impact Anna's forthrightness could have on her participation with other children, drawing my attention to the two way changing relationships that characterise participation.

15. She's very definite about what she, wants and what she doesn't want. *Is that..... with the other kids too or with adults.* Yeah, yeah with the other kids. And in fact she can be a little bit off putting because of her manner she'll um, how could I say. She's quite abrupt when she's speaking to the other children. *Okay.* She can be. And I'm trying to, we're trying to work on that.

Others Reactions to Difference

One of Joanne's tasks was to assist Anna to learn to wipe her face after eating. Anna had some apparent sensory impairments around her mouth, and was unaware if she had food around her mouth. Joanne felt that the other children responded to this differently to the way they would if it had been anybody else. She had deliberately endeavoured to involve them in helping Anna address this.

75. whether the children don't say anything to her um, yeah I um, you know other kids might say oh you've got a dirty face to their peers but whether because Anna's just a little bit different they don't say, that to her, they just accept it. *Oh.* And um, so yeah, we're trying to get her to wipe her face before. *You think they notice it though.* Oh definitely because I actually asked one of the children. I went in and it was a real mess and I said 'oh Anna, that's not a good look' and she said, 'what?' And I said, 'your face has got chocolate all around it.' I said, 'you ask Briar', because they were sitting on the mat, I said 'you ask Briar if she thinks it's a good look.' And Briar said, 'oh not really!' So I thought that was you know, one way of yeah.....So off we went and she wipes it clean and looks in the mirror. *Yeah.* We've got a little programme going.

Having a Go

The notion of "having a go" was a theme that was also central in Joanne's description of Anna's participation. ".....she'll give anything a go....." (70). As with Natalie, Joanne was also admiring of this attitude, seeing it as key to Anna's successes, and comparing it to other children. Having a go involved effort and also resilience when failure occurred, for academic as well as physical activities; "she's pretty tough, she gets up and dusts herself down and moves on!!" (172). Anna was seemingly accepting of failure, understanding that this is part of life and, like her mother, displayed a dogged determination to simply get on with whatever is put in front of you.

71. Yeah it's really interesting on cross country day, days like that because there's children that come to school and they've got a sore leg and you know a sick tummy and all this and Anna just gets in there and does her absolute, best.

139. *I was thinking you know, she talked about golf the other day. And the other kids would all have been able to use two hands and do the right swing.* Yeah I know, she'll have a go.....Sometimes, if she can't do it, and there are some things that she can't do, and she'll just

say, she'll have a go first and then she'll just say no, I can't do it and walk away. And then usually we'll say to her, oh well you can help count score or you know, stand on the side and do take the score or do something so that she's involved. *Does that make her sad? Or do you think she gets upset about that sort of thing?* No, no, no it doesn't seem to.....I think that's because she's, you know she wouldn't remember being any other way, so to her, that's just life isn't it? *Right.* It's part of her life, it's just the way she is. And she's never ever said oh you know, I wish I could do it like they do or anything, no never, never, not to me anyway.....but yeah she just gets on with whatever's put in front of her. Hmm

122. she's actually quite patient with her writing. If she makes a mistake she just sort of laughs and rubs it out and does it again.....Or she says 'oh doh'. That's what she says 'oh doh'. I don't know quite how to say it but it's off *The Simpsons*".

As with Jan and Natalie, when discussing the effort Anna put in, Joanne talked of Anna's fatigue, and the short term effects this had on her subsequent participation. Yeah she does have tired days, days where she really doesn't want to do too much (134).

Different Paces

Anna found it hard to move at the same pace as her peers. Others moved around more quickly, and although she was independently mobile and loved physical activity, she wasn't always able to keep up to participate in play activities with them.

26. *They all move very fast at this stage don't they?* Yeah they do. And that's very difficult for her and that's why I think it's always been a bit harder to make friends because she just gets left behind.

Her slower pace when getting changed made it difficult to be ready in the same time frames as the others to participate in swimming. However time allowed for her to begin a little earlier than the others, and with some help, this enabled her to join in.

78. *And what about swimming, do you help her with her dressing?.....* She can do most things but it's very, very slow of course. So by the time she gets changed to get in the water she misses half the swimming lesson, so I take her a bit early and get her dressed and so she's all ready and then dress her again afterwards.....She keeps up with most things, just a little bit behind.....but swimming's definitely a tricky one.

Anna worked at a slower pace than others in her class, and this often made it difficult to complete tasks in the available time frames. Joanne assisted her with activities such as writing to enable Anna to communicate her ideas efficiently.

118. Handwriting's still, well below, par and, um often I will write for her. *Hmm.* Um just to keep her up to speed. If she's writing a story or something like that because it just, keeps the, flow going you know, otherwise it takes her so long to write the story that she doesn't get much done. She might only get three or four lines. But if, I'm writing she'll get a whole page.

Joanne talked of Anna learning to use a computer in order to speed up the writing process. She felt this would be even more necessary at college, perceiving even less time in the new environment. "Computer is um, the way she's going to be able to keep up, you know" (124).

At other times however, her classmates would slow down their own pace to match Anna's, and this meant that Joanne's help was not needed.

35. they're so patient, if she's a little bit slower they, wait for her, it's really nice I just sat in and watched because it was just, I didn't want to get in, you know I thought oh, I'm not needed it's just fantastic.

Anna also learned more slowly than her peers. This meant that Joanne spent extra time with her away from participation with other children in the timetabled classroom activities, doing extra work on some of the basics such as reading, and practicing to advance her skills so that they better matched those of her peers. Extra time spent practicing activities such as reading and computer at home was also seen as important to progressing her skills, although had the potential to mean she had less time available to her to participate in play with her peers.

128. Tony said that she's been practicing at home and I actually thought that when she was typing it, when she started typing that story and I thought oh she's picking up already because before she would be taking a long time looking for a letter oh where's the A, where's the A and it would take her so long.And it's just practice isn't it? Yes. So she needs lots of practice on the computer and she'll be away.

Differences between Abilities and Task Requirements

Because Joanne worked so closely with Anna, she was able to provide greater understandings about the mismatches between Anna's abilities and task requirements. Although Anna could complete many tasks, as discussed in the previous section, cognitive requirements of tasks such as maths or reading stretched her capabilities, and help was needed to enable her to participate. From a physical perspective, tasks that required that required the use of two hands that were particularly difficult for her. Sometimes, the resources or materials such as clothing associated with a task lent themselves to being adapted, while for other items such as her ankle-foot orthosis, adaptation was not possible.

76. *Do you need to worry about that all?....With sweatshirts and stuff?.....*She needs a little bit of help with some of it was, but they seem to be on to it, the parents, and you know they buy her clothes that she can get on and off. *Okay.* But definitely her shoes of course, she can't get her shoes on and off, especially over the brace it's too tricky for her.

At art time the activities seemed less able to be adapted to support her to achieve without help.

60. Um some, um particularly um, when they're doing art and things like that, there's often things she can't quite manage, with scissors, oh I mean she can cut but you know she can't cut things out the same as the other children you know, it's always a bit rough. Um she does need a bit of help with things like that. Plus they've been doing, for art they've been doing, making fish and um, out of, wire. Well of course you know, there's no way she could bend the wire, she

couldn't cut the wire, it was all too tricky with one hand, it's hard with two hands actually! And so she really needed my help for that.

Joanne too saw that Anna preferred not to have help if possible as it singled her out from the other children. The previous year had been a bit of a turning point, when it was realised that Anna had been overloaded with too many adults interrupting her participation with others in her class. Some of this was felt to be attributed to therapists who took her out of class, but having teacher aide help had also contributed to the problem. Thus, while teacher aide and training was perceived as supporting Anna to complete activities in order to participate, this was less important than being alongside classmates and completing activities in her own way as she was able.

56. Last year um, she had had enough and I think, you know so many people come to see her and she'd really had enough. Um she had more teacher aide, she had another teacher aide working with her more as well, because I only work three days a week. So she had, on the other two days a week she had quite a bit of help from someone else as well. And I think it, yeah she just, had had enough and she just wants to be like the other kids, she doesn't, want to have help really. But she needs it.

Being Taken Out

In spite of these concerns, there were still times when Anna was regularly removed from her class to participate with Joanne in therapy activities, although efforts were made to limit this. "we try not to take her out much....." (31). Anna was taken out each day to do her reading in a resource room at the back of the classroom. Joanne also described the stretching programme put in place by the physiotherapist and carried out on a daily basis during the school week. Anna showed dislike of being taken out on her own to do this programme, and Joanne incorporated it into a game to increase her enjoyment. The programme was delivered towards the end of the school day, perhaps to limit disruption to Anna's participation in class.

.....the only thing I really take her out for is exercises.....stretching exercises.....and that's just a short you know sort of ten, fifteen minutes at the end of the day usually, depending on what they're doing, though.....that's, the time that suits Anna best because she doesn't like being taken out, you know. And she hates doing it. We just do um, stretches really. *Right, so for her leg and arm?* Yeah. And a lot of time we play Simon Says so she doesn't actually know she's exercising.....I'm reaching for the sky and you know she..... not a lot because she's not very cooperative. I try to keep it fun if I can.....I still find, even after working with her for all these years, I find it quite difficult because um, mostly probably because she doesn't really like doing it.....Hmm um, yeah they um, the physio has shown me how to do them, gave me a sheet of exercises to do with her.....she goes for stretches, unless they're doing something else and I think well I won't take her today because *Right*. Don't want to interrupt the, if she's having fun, if they're doing something fun and she misses out she gets really stropy.

Anna's participation was also interrupted when she needed to be taken out of school to attend various medical appointments. Whilst understanding that this was necessary, she particularly expressed her dislike of going for her monthly injections.

103, *And sometimes she has time off, off her school work as well doesn't she.* Yes. To go to all these different appointments.....Yes, she has quite a bit.....I don't think she really seems to mind..... Hmm, I suppose she's so used to them, she's always had to do that.

Enjoyment

Joanne talked of Anna's degree of enjoyment when she was participating in different activities. This seems to reflect the degree to which Anna is engaged in, or immersed in "doing" the activity. Enjoyment was most noticeable when it was associated with achievement, where there was a good match between Anna's strengths and what the activity involved.

118. Yeah she's got great ideas, she's a great poet Anna. She loves, I think because they're short usually, and she does beautiful poems. *Isn't that neat*. She's got beautiful ideas, you know lovely ideas, and original.

However, instances of Anna's enjoyment described by Joanne also seem to be associated with the other children who are involved in any activity with her.

94. And she's actually quite, she's pretty well up to the rest of her group with maths you know. It's interesting when they have their maths group um with the teacher, their little group of six or seven that they, um, Anna's hand will go up um you know, before some of the other children sometimes you know. *Um* She's not the last to put her hand up.

When Anna expressed aversion to an activity, this seemed to be associated with activities where she was taken out of class, and doing an activity that was different from and apart from other children.

31. that's, the time that suits Anna best because she doesn't like being taken out, you know. And she hates doing it. We just do um, stretches really.

As with all of us, Anna's enjoyment of activities fluctuated. If she was particularly tired, she had reduced capacity to engage in the activity, and her enjoyment was lessened. Joanne used the strategy of giving her some extra space and time to think about what she would like to write. If Anna still did not involve herself in the activity, as with the other children, Joanne talked to her of staying in at lunch to complete the work, and this was effective. These actions coincidentally aligned her better with the other children involved in the activity and with the class knowledge about consequences for not completing tasks.

132. Sometimes she needs a bit of *Prompting*. Yeah, hmm. Or she does the old shrug, shrug the shoulders. What are you going to write about today, *Oh*. So she uses that quite a bit..... I will just ah instead of just hanging over her I'll just say, well I'll just go away and look at some other, children's work and you just sit there and have a little think and I'll come back and by then you know hopefully you'll have some ideas. *Does that work?* Yeah..... it can do. And then, if, you know if that doesn't work and it gets closer to the bell- time, "oopsy you might be in here at lunch time, that would be terrible!" Oh and away she goes!! We've never had to keep her in at lunch time but she does, you know you have to do that with all of them sometimes don't you?

Leslie, Associate Principal and the Special Education Needs Coordinator at the School

Leslie's Role and her Experience

Leslie was invited to participate in an interview for the study, as she had long standing experience of working with Anna and her family, commencing her role at the school in 1998. She clearly recalled the time when Anna's accident took place. The accident was a shock to the community, and Leslie conveyed the way it gave her a heightened awareness of Anna.

.....Anna's accident was virtually at the time I arrived in Kingsville and I was aware of her accident, not knowing Anna or her mum. But, it was one if not the biggest accident sort of recorded for the local district in my time of arriving and it was just huge. And so, from the minute she stepped in the door, I had already known about Anna

As a SENCO, Leslie viewed her role as an "umbrella"(37) for children who needed Learning support, providing a shelter to them as they transitioned from class to class, then on to college. Her role also included responsibility for literacy and numeracy programmes, as well as managing visual art activities and bus transport.

I have, huge interest, in catering for children's needs. So I just felt.....it was a lovely healthy thing to take on. *Yeah*. There were a few changes I wanted to make, sure. Um, you know bringing in the teacher aides in to the staff room and making them feel part of the staff, hugely important (14).

She was proud of the way she had nurtured team work within the school, valuing the contribution and skills of different members of the staff in working with children with special needs, and establishing communication processes that ensured that this value was enacted. As with her inclusive attitude towards the whole teaching team, Leslie set store by parents spending time in the school, believing that this resulted in spin-offs for supporting children's participation in learning activities between home and school.

To bring those families in to school you know, I mean some of our children are, entering school with, a writing and reading and socialising and, physical, [of a] you know three year old. If we could just get those families in, and make them, feel welcome, and have them observe and work in the classrooms, that knowledge, to then take home (43).

Directly spending time with Anna, and working with her parents, therapists, teachers and teacher aides as part of a team, meant that Leslie had gained some broad insights into Anna's participation at school. She had also gained an overview across longer time frames of things within the school that had helped Anna's participation, or that had made it more difficult. Anna communicated some of her concerns to Leslie, and in turn, Leslie responded to her concerns, acting in an advocacy role for Anna.

I do spend time and I do have Anna in my office. You know a lot, she comes over and she does lots of work with me as well. (70).

Oh yes she comes and sees me, hmm. Excuse me Mrs Pritchard if it's all the same with you, I am so sick and tired, of going out in to the Lions Den. Why can't I have my support, in the back room, of room 18. Right Anna. (54).

As discussed previously, funding to meet Anna's needs was provided directly through ACC. "Anna pulls no other funding than ACC" (39). This difference meant that Leslie did not feel funding resources were being "stretched a bit higher, a bit longer, and a bit wider" for her as was usually the case for other children with more pronounced special education needs (39).

Unlike other the children with Learning difficulties, Anna was not accessing any of the additional programmes running at the school.

Change

Leslie's discussion highlighted the impact that Change had on Anna's participation. Change could come from within Anna herself "she has her ebbs and flows" (55), or could be in her environment. This outside change could make it particularly difficult for Anna to participate because it meant that new people and children involved had limited understanding about her, and were less able to support her participation. The challenges that changes placed on Anna's participation were moderated by familiarity. Over time, as people became more familiar with Anna, and with established processes that supported sharing of knowledge, shifts in their understanding meant people felt they were better equipped to support her.

.....we did pop her very carefully with Natalie J. last year, and the concept was that she would be a year five with Natalie and she would also be a year six with Natalie and that would be a two year really, really getting to know Anna as a teacher (22).

Of concern to Leslie were the frequent changes of staff in the therapy team, which she described as frustrating, pointing to their limited understandings about Anna. She was also aware of the difficulties posed by Anna having a new teacher each year and new children in class. However, Leslie saw this as balanced by long-standing members of the teaching team, and ensuring that some children from Anna's old class would remain with her in any new class. The school policy of mixed year classes facilitated this.

Anna, was therefore with one teacher aide, and that's been consistent in her time here. *Right*. And that's been huge so every transition year, yes she's had a new teacher, but she's retained the team that's working with her. She has however had six speech language therapists in her time.That has been frustrating. Not disrespectful to any speech language therapist but it's just, it's just the way it's been. And she's, she's had three physios, different ones. *Right*. Um, and she's had, I think, two if not three occupational therapists. So for Jan and Tony...I'm sure they feel there's an element of frustration around new faces. So, the team with myself, and the teacher aides being consistent has been, tremendously valuable, because had that changed as well, every year, and had to, understand Anna's needs, as well as the OTs changing and the speech language therapists and the physical, physiotherapists changing that would be too, that would be just awful (17-19).

Each year, Leslie undertook the organisation of children's new class placements. She signalled that Anna's placement was more complex than for many other children with special education needs, and that extra thought and planning was needed to ensure a good fit between Anna, the other children in the class, and the teacher. Her words suggest an interlocking or slotting Anna into a place, as one might come to know the shape of a puzzle piece, then try out and fit it into the correct, accepting space, pressing other pieces into place around to form a bigger picture.

.....Anna would be probably out of the 600 odd children at the end of every year, she would be the child we placed first and then we place her friendships around her. *Right*. Because she's possibly our most, high need pupil and that doesn't mean to say, she can't be with other

children, but her teacher's vital and we've hoped we've got it right every year. And I think our choices of staff, we look at our staffing and we look at our teachers for the following year, as early as October and then we start placing our children in the November, for the following year. Anna's the first child we place. And then we think who does she get on with, and we pop those little one's around her and then we go from there.Um it doesn't mean to say though that if I thought it wasn't working I wouldn't pull her out, because I would (21).

At this age, perhaps the biggest change facing Anna was her transition to college next year, and similar themes about moderating the impact of change were echoed here. Leslie talked of the organisation that was going on behind the scenes to bring about adequate familiarity and knowledge for new staff there. She talked of Anna being "connected", suggesting to me she and her team were facilitating a two-way transference of information, a fitting between Anna and the new people who would be around her. Leslie also highlighted a perceived need to "protect" Anna from these processes to avoid her becoming anxious about the changes. The impact of a change of this magnitude was mediated by beginning the organisation processes early, with the longer time frames ensuring optimal sharing of knowledge and transferred understandings. Leslie also saw that the impact of the change would be mediated by the presence of children in the new setting who were already familiar with her.

..... the concept of transitioning to high school next, that's huge....what we do is we put in place at an IEP what we should be doing, because we don't want to even allude to the fact that it's important for Anna yet...It shouldn't be on Anna's mind at the moment but we as a team are thinking about how we best do that. You know who's connected with her at the high school.....Well we're just finding out staffing, whose going to support her, hours, looking at um all of the things that should be done now, to make sure that that transition process which starts as early as September...You know do we take colleagues from her room with her... we've talked about the parents being involved, in the interview process with the high school in regards to friendships because that's been a huge part of Anna...I think if she was, aware of all of those conversations now she would be a bit um, bemused, and a little bit stressed by it all (13).

.....her teachers will be all new and her teacher aide will be completely different. Because Joanne K., her core teacher aide has been with her the entire time is not transferring to the high school. But then Joanne will be going over from October onwards just to do the walk over and to see. hopefully the high school can do what we've done before and have a teacher aide that they know is going to be working the following year assigned, and they will be quietly, oh the teacher aide looking at everything we're doing and hopefully meeting and greeting (75-77).

Sharing knowledge between school and home was identified as important, but had been more difficult. At a pragmatic level, this was probably partially limited by Jan's working hours. The therapy team had played an intermediary role through having a key person who communicated with Jan. Changes to Anna's routine posed by medical intervention were also sometimes communicated by Jan directly to Leslie. It is possible that Leslie's longer-standing senior role meant Jan felt a sense of familiarity that facilitated her to share information; when I visited Jan, she encouraged me to contact Leslie about Anna's school participation. It is also likely Leslie was more available around hours which fitted with Jan's own time frames.

Additionally, Leslie's role was specifically concerned with sharing information with other team members.

The Rehabz team. There's one person that leads it and they very much link to home. And often we might get a message saying, you know so and so's happened at home, or you know we've talked to Jan and Anna's going to the *** Rehab Centre. You know it's not that we haven't been told, but sometimes Jan might tell a classroom teacher who hasn't got back, you know that whole link.....the Rehabz team's really happy to pass on...I will pass on everything that Jan tells me. Because Jan comes in and does a big catch up with me. And we might just do it very informally one morning when Jan happens to come in for a reason and she'll sit down and say now, surgery for this, *** Rehab Centre for this ah, ooh, the doctors that day and um, orthotics this day. So I'll get a whole months dates and she's got them in her head. She rattles them off and says next Tuesday Leslie she's you know whatever... So understanding Anna is much easier (49).

Differentness

Leslie was very aware of the causes of Anna's injury, and her circumstances seemed to evoke a heightened emotional response towards Anna. Leslie appeared to view Anna as different to other children under her umbrella primarily in relation to the way her support was provided. I asked Leslie to clarify her perception that Anna had high needs. Her words seemed at odds with the fact that Anna was not accessing Very High Needs or High Needs ORRs funding through the Ministry of Education. From Leslie's perspective, Anna's needs were high in relation to the number of specialists visiting her as part of her rehabilitation programme. This created interruptions to her participation in classroom tasks, when she was required to participate in rehabilitation activities. These were seen as additional "work" and were generally seen as addressing physical concerns "Physicality. Yep, absolutely.....And they Janve the curriculum side very much up to us" (52). The visits created additional demands for teaching staff, and generated a great deal more reporting from those involved. "Last night I looked at it (Anna's file).....And I got her notes and I'm not kidding, it was about this thick" (77). Nonetheless, Leslie felt that having the therapists visit the school was advantageous in terms of sharing information rather than Anna leaving school to visit the therapy centre.

You said before that Anna's probably one of the neediest children, in the school. In so much as the fact, she has possibly up to three visitors a week.....I mean Rehabz head injury people, they would visit, it's fantastic but there's three people.....Anna's speech language therapist, her physiotherapist and her occupational therapy are all done on school site now..... unlike before, taken out to B's physio, where she used to be taken outside of school hours sometimes but you know it was always done at that site.....so needs wise she works with all of those, possibly once a week.....And so as a teacher, the need for that teacher to understand,.....she's got the greatest need in so much as understanding all the people that work with her. It's a huge amount of disruption to her day um. No Anna is not my most needy child when it comes to.....physicality and curriculum adaptation. In fact Anna's curriculum adaptation is pretty much on a par with her classmates on some levels. You know she's working within groups within her class.....they've got to understand that there's going to be a lot of interruption, a lot of demand on their time to speak with those specialists, there will be an element of possibly filling in a bit of paper work. Meeting as an IEP team, transitioning to high school. All of those things, really do impact on your teacher's programme, hmm. (24)

Initially when Anna began school, teaching staff were cautious of their interactions with her, fearing they had inadequate knowledge to support her safe participation in personal, rehabilitation and physical activities. Anna herself was unable to communicate her needs. The therapy team therefore acted as both a facilitator and a barrier. Their involvement heightened

the sense of “specialness” or difference, but did support staff by spurring and facilitating a sharing of knowledge which built confidence as staff helped her to participate.

.....when she entered, I think there was an element of fear that whatever we did, we didn't want to hurt her. Like we had to get to understand that, you know the leg splint, and all of the stretching had to be done correctly, because it was often off site, so we didn't have that modelling. So everything we did here we thought, is this the correct way? So we started photographing, you know specialists with her just to say, you know her back should be against the wall but her foot should be here, her hands should be like this. So initially, everything was geared to not making anything worse for Anna. So there's an element of fear that you're going to damage something. Um and also understanding what her capabilities were, that was really quite interesting. I mean how, how did she get on in the swimming pool. How do we best cater for her, um. But we wanted to do things correctly. And Anna when she arrived of course wasn't able to tell us that hurtbut she wasn't able to say no I don't do my hands like that you know and no that's not how I you know.so we photographed everything we did, everything and we shared those photographs and we had a pool of specialists who spent time and we went off site to ensure that, when Anna was having anything done we had the right way of doing it. So that's improved, that's a whole lot easier.

Participation in therapy activities also made Anna herself feel different. Leslie was very aware that Anna disliked being made to feel different. Participating in different activities, working in different places, and having help from different people all singled her out, emphasised disparities between herself and others, and making her feel apart.

“.....please just let me be like everyone...can my specialists work with me, not take me out of the classroom, but have me out of the classroom possibly in the learning enrichment centre at the high school and then do what you need to do but don't kind of sit in the room and make me feel any different from anyone”. So there's a real balance we've got think about that and that's very important for Anna...we've started to talk about that. You know and we've talked about too um, Anna's more aware that there is now, there is that difference. There is an element of difference.

Leslie played a role in advocating for Anna's participation alongside classmates. Where there were conflicting times between participation in therapy or skill development and participation in school or medical events, she liaised with therapists and shared information to ensure that Anna did not miss out.

I have actually said to the Rehabz team, they always usually email or ring, is it okay for Wednesday and I'll say no, I know Anna's at orthotic... I know that she's unwell she's got a cold today and home with Jan.....But also ...actually said look can we just forgo it this week can we do it the following week because we've had, the neuropsych, you know.....We may have had um, a school trip and they're doing the follow up the next day and I don't want Anna to miss any of the follow up. So I sort of look after that side of her a little...I don't want her to miss school cross country because there's a specialist coming so I'll say to them no, it's school cross country I want her to be part of it. ...Or it might be swimming carnival or it might be the school camp...and they leave... her alone that week, give her a couple of days to settle back and do the things and then I'll see you (50).

Leslie saw Anna's participation as optimal when she was simply a part of the class doing the same things in the same places at the same times.we don't remove her from class as much as we used to. Um there isn't the need for that and I, that's been one of our goals. Sort of in amongst everything is to Janve her with her peer group and that's what she's wanted too. She really hasn't wanted to be withdrawn too much on her own. Because that makes her different (70).

The focus was on doing the activity with others. There was less concern with the way Anna might do the activities. Leslie was encouraging of Anna attempting activities using her own strategies. sitting on a mat and listening and taking on the instructions and then getting back to her desk and thinking in my way I can do that...(68) she's one of, the class. And watch out if you treat her or miss her out of any activity. She, in her own way she does the cross country, in her own way she's involved in every element of school (30).

Where there were risks of other children noticing differences in appearance, such as having a dirty face, Leslie had felt able to facilitate a routine for Anna by drawing her notice to the fact that it was an activity that other children also did.

.....we're working a little bit on you know, looking in the mirror and you know checking yourself. In our subtle way we're just trying to make her aware that checking in a mirror is accepted, everyone does that.

Having a Say

Fitting with her concerns about not being made to feel "different", Anna played an active role in expressing what she wanted to participate in, and how she wanted to participate. Anna was not provided with a formal role in goal planning at her IEP along with other members of her team.

So, our goals are more the teacher and specialists with Anna.....we have goals around surgery, stretching, um raising achievement in reading Now we might share that with Anna but we wouldn't necessarily say Anna should agree to this (11).

At an informal level however, Anna played an important part in dictating what would happen. Her ability to communicate about her wishes and needs had increased over time "It's far...easier, Anna's very much more, I mean she's old enough to talk to us and tell us exactly" (54). Leslie acted as a conduit, relaying Anna's concerns and coordinating action. When expressing her wishes about what she wanted to happen or not happen, Anna could inadvertently be very blunt, and this could be distressing to staff who had her best interests at heart. This may have arisen from her communication difficulties, but may also have reflected frustration at times.

...she's a strong girl, mentally very, very determined..... very black and white in what she likes. And I think she would really dig her toes in and be really antsy if she thought, this teacher, wasn't up to standard in her eyes, for whatever reason (21-22).

...she'll say I don't want you today. I don't need you. I'm okay. In her own way can be, can be quite um...it's been a bit hurtful at odd times (55).

Leslie had responded to Anna's wish to manage without support. Although this had meant a difficult time for staff, Leslie felt that Anna learned from the experience and gained insight into her need for help with some things.

Anna gets, really annoyed. She just wants to be left alone and she's been to my office and said Mrs Pritchard, I don't want to see anyone...last year we tried a week of no teacher aide support, we gave her exactly what she wanted...I rang Rehabz, no visits. No [teacher aide]. And by the end of the week Anna was, exhausted, the teacher Natalie was... tired and aware that oh my goodness, there was an amount of curriculum adaptation... So all of a sudden Anna thought oh maybe I do need some of that help. (24).

I met her afterwards and said well what was it like?...she said...she didn't have anyone to hear her read... It was all just like everyone else you know, independent stuff....no one to talk to, no specialist doing...the software programme with her...it made her very aware that you know we were there for her and we talked about that...she's quite mature about our chats (55).

Fit

The fit between Anna's needs and abilities and the environment was important to facilitating her sense of participation. Sometimes, there was good congruence between Anna's abilities and the demands of tasks available in the curriculum, particularly if there could be flexibility in the way tasks were performed . "...writing has been an issue but then we've discovered Anna is a very gifted poet. And so she can put down ideas in poem form, poetry...I think she's got quite a skill and I think if ever you know there was, a curriculum area we could develop, poetry would be it" (62). When there was not a good fit, help from staff alleviated the discrepancy, although sometimes in Anna's eyes this marked her as different. Sometimes, it was challenging to fit class activities with other activities Anna was participating in such as medical appointments, testing, or therapy. "...she had a go at me once because we were doing something and she missed a swimming session and that was really in my face. Um, and that was just bad management on time tabling..." (54-55). At other times, Leslie had noticed that Anna was able to participate better when a staff member's teaching style was consistent with Anna's needs for quiet and calm.

...although Natalie's a young teacher,.....in her quiet way...she's really quiet, calm. *I think Anna said she's really happy...*Yes she doesn't like um, a lot of, screaming, and she can't stand, um a huge amount of movement and the bustle of you know, a really busy class (22).

Observations at School: Art Class

Context

This observation was completed in the final week of term. It was a time of change or transition, with bustle to complete tasks before the holidays, unsettled routines, physical shifts of equipment and resources, allocation of new classes and teachers, and. departure of some children and staff. As was usual, Anna had teacher aide assistance for the art class. The teacher was familiar with Anna, although was not her regular teacher. Art was held in a small room after morning break, and was attended by the whole class for approximately one hour. The teacher had explained to the children that I would be in the classroom but had not explained the reason for my visit. Anna however was excited that I was coming and had told the class she knew me. On my arrival, she seemed pleased to see me. Other children appeared to interact with me naturally, possibly reflecting that they were accustomed to having visitors in the classroom.

The Activity

The children were completing collaged pirate pictures that they had started last week. The activity was loosely structured, and children worked at their own pace and made their own decisions about materials and composition. Music was put on to listen to. Fabrics, wool, buttons, glitter and other resources such as scissors, glue and pens were scattered in different places around the room. The activity was interrupted several times by children moving into a back room to watch a DVD a small group had made, and also by part of the class being reprimanded for a misdemeanour that had occurred earlier. The group generally felt unsettled, and some of the children expressed that they had been bored.

As lunch approached and the task was nearly complete for most children despite the short time frames, some began play-acting with the wool, using it as fake moustaches and swaggering around, seeking notice from their peers. Two girls talked to me of their responsibilities in minding younger children in the junior classrooms on wet lunch-hours. A small group of children left the room to help their classroom teacher with moving equipment to their next year's classroom. Anna does not appear to contribute to the wider school in this way, and it was not something her teacher talked of.

The Group

Children were constantly changing positions, moving around, and talking between themselves to access materials, comparing their ideas, showing each other their work, giving comment, and sharing items. They talked as they worked and moved around. Noise levels were high in the small room, with varying degrees of focus on the activity itself.

Children were generally working in pairs or in small groups, sitting, or standing at desks. Anna alternately sat and kneeled on the floor on her own at the front of the room, initially with her teacher aide close beside her. Later her teacher aide moved away to assist other students, and Anna remained working on her own, although did ask another child for an item, and was also approached by a different child who was looking for items. At one point she sought assistance from her teacher aide, and on another occasion she endeavoured to use the scissors herself. She managed the gluing on her own, moving across to a desk in high kneeling.

Anna's Involvement

While other children were able to do the task and chat together at the same time, Anna was fully engaged in the task. Perhaps this reflected her need to focus in the noisy environment, but may also have related to her enjoyment of craft type activities which involved glue and glitter.

The physical aspects of the activity presented some challenges to her, with a need to use two hands to cut materials; her teacher aide generally helped her with this. The teacher aide also provided her with choices, and often anticipated her needs for materials. Anna worked slowly, and was given prompts to organise and start different components of her picture. Every time the class suddenly shifted to a new activity, it was effortful for Anna to get

up from the floor and move to the new room, and she followed behind the other children standing at the back of a group. Other children that engaged in talk with me showed some awareness of Anna's disability, and explained to me the physical reasons why she usually sat in a certain place in their normal classroom.

Towards the end of the session, at tidy up time, Anna moved around the room with me, picking up materials and items and returning them to their boxes. After, she went and stood beside a small group of children sitting on the floor who were tossing glitter around; although she enjoyed watching them, clapping her hand and laughing in a spontaneous display of pleasure, they did not respond to her or admit her to their activity.

Observations at School: Reading

Context

These observations were completed in April, relatively early in the new school year, although children would have been in class together approximately ** weeks, and had been on camp at the beach together. Anna's father assisted at the camp. There was a new teacher this year, and I noticed a mix of familiar and new faces in the class. Anna had been having problems with her leg splint, and was having further treatment for a foot infection and was using a temporary splint while the other splint was being adjusted at the hospital about 40 minutes drive away.

The walls and beams within the classroom already displayed children's work labelled with their names. This poster type art-work seemed to be directed at children thinking about and communicating information about themselves to their classmates. Along one wall high up is a long line of "shields", each containing a display of things important to the child. Another beam contains posters showing "What I want to do when I grow up". Anna's poster tells me she wants to be an artist. On the whiteboard are the names of the five different reading groups in the class- Anna is in the Super Sharks with one other child. Another set of class competition groups are named on the board, and recorded beneath them are tallies of points allocated for positive behaviour and achievement. Another wall has photographs of the children on their class camp at a local beach.

Reading Activity

When class begins, the children all sit together on the mat all facing the teacher listening to the day's events and instructions for reading time. I remember Anna telling me how she dislikes missing out on news. She is sitting in the centre of the group. The children get up and move off to their activities at their desks. Anna doesn't join these activities and instead has one on one reading with her teacher aide to develop her skills-the aim is to move her up to Turquoise level. Joanne, the teacher aide helps Anna choose 2-3 reading books and they go out to the small, brightly painted resource room at the back of the main classroom with me and close the door. This muffles the noise from the rest of the class who are doing either individual reading (paperback fiction) or book reports on large, pre-printed sheets of paper. Anna has her own special book browsing box kept in a separate place.

Anna chooses to sit on the floor, and Joanne sits close beside her. It is difficult for Anna to move into a comfortable sitting position with her splint, and she moves into a high kneeling

position halfway through the book. Anna has chosen a book about naughty monkeys- I remember she likes animals. She reads slowly and haltingly but concentrates hard. Joanne repeats the slowest sentences back to her, praising her and cuing her to sound out difficult words. Anna is pleased when she suddenly reads a word for herself. She turns the pages herself. Anna is enjoying her story- she laughs at the cartoon pictures, and especially when she occasionally throws in a random word that is out of context.

Although Anna has choice, Joanne directs what happens. When Anna finishes the book, Joanne instructs her to fetch her reading bag so that some of her reading cards can be discarded. Anna argues with this. "Why?" "Because I asked you to". It is hard for her to get up- her leg is stiff. Joanne tells me they sometimes go for a walk to stretch it out. While Joanne sorts the word cards, Anna tells us about playing 2-ball soccer with a class from another room, and about trying golf. It was a bit tricky for her to hold the golf-club, but she enjoyed it anyway. She says she hit a big ball and it was easy. Everyone got a turn.

Anna explains she doesn't want to throw out the spare cards, because she likes to have enough to make sentences. This makes sense to me- it would seem that she might remember the words better if they are contextualised rather than being rote learned with no meaning. However, Joanne explains that she has done new cards with rhyming families of words in one colour, and double-ups of words are binned. Anna sounds out the words as Joanne sorts them. She knows the words associated with animals or insects, but eventually begins to misbehave, making noises and answering "wah"! She tosses a book and demands all the cards. I wonder if this might be due to my presence. Joanne ignores this, and de-fuses the situation by suggesting they read another book. Anna's reading ability varies, with good days and bad days- today is medium.

Anna works at her Publishing Activity

At 11:45 it is time for Joanne to leave. Anna goes to a corner of the room and begins working on the computer at publishing a story Joanne wrote down for her. The computer is not at an ideal height making it hard for her to sit steady and requiring her to lean forward to see the screen. Each letter on the keyboard is laboriously found, but Anna is focussed in her own world, typing the letters with one hand and checking the spelling against Joanne's writing. At times she looks pensive.

Group Interactions and Time Frames

One other child comes up to look at Anna's story briefly. The other children are working in small groups- 3-4 at a table. There is chatter. Some are off task. They move around tables, borrowing things, looking at each others' work. Miss D. is working at her desk. Sometimes children go to her to get her to check their work. At one point she goes to Anna and checks in with her.

When she returns she calls out "Room 23, packing up! Put your book reports back on the desk!" The children rush around, rapidly putting away work. Anna gets up as quickly as she can and tidies up. Her actions are jerky, rushed. "Those who haven't finished their cards, another 5-10 minutes! All others down on the mat!" Most children move to the mat, sitting by

their buddies and chatting. It is awkward for Anna to get down. When Miss D. sits at the front, there is instant quiet while she explains the story-writing and publishing activity that is next. Things feel fast-paced, short periods of time before changes of activity or demeanour. Quick responses needed. Lots of instructions require careful listening. The children begin writing, and Anna continues at her publishing. When noise levels rise, Miss D. claps and reminds them "writing time is silent time".

Learning about each Other

After reading is finished, the children sit back on the mat. A girl sitting next to Anna stares at Anna's hemiplegic hand. She moves her own hand, and Anna imitates with her affected hand. The girl is interested that she could make Anna's hand do this. She bats at Anna's hand again with Anna trying to imitate. I think the girl is simply curious, but she and Anna are also having fun. Maybe this is acceptable, and reflects the way children Janrn about things, but not if it became taunting. I wonder if the girl is sensitive to how Anna might feel if she were teased? Maybe Anna would tell her....

Needing Help

Boys are told to go and get their lunch first, girls next. They eat sitting on the floor. They are allowed to read or play cards while they eat. All are with buddies or in small groups. Anna is on her own concentrating on her lunch. She is unable to open her tube of juice, despite gnawing at it. After a while I move over, and ask if I can help. Another little girl has been watching. I ask if she could fetch a pair of scissors, and she rushes off to assist.

A Friend from Another Class

After lunch, the children go outside. Anna rushes, but is last. She drops something when she puts away her lunch, struggles with her hat. Her gait is jerky. She lurches down the steps, then back up to check on the adjacent classroom. She waits and waits outside the classroom, peering in through the window, rushing up and down the verandah, up and down the steps again. Eventually Sean come out, and runs off. Anna runs off after him. I see them both running across the field. Anna is behind.

Observations at School: Power Walk, Spelling, Maths

Context

It is May, a little later in the new school year. The marathon training happens first thing, and I arrive early while children are still being dropped off by their parents. Today I think Anna comes with her Dad, but usually she walks with her caregiver. It is a big, busy car-park. Mums are talking with each other about going running, going walking together, some are going to work. A lot seem to know each other. Babies are being put in and taken out of push chairs, some walk over to class with their children. When I arrive in the classroom, Anna is there, and looks pleased to see me. She comes up and talks, even though I have only waved at her discreetly.

When the bell goes, the other children suddenly come in from outside. They hang up their bags, put items in their desks, then move to sit at the front on the mat. Anna sits on an adult sized chair at the back- perhaps this is more comfortable for her, but it seems to single her out. She doesn't seem worried, and the other children take no notice. Miss D. greets Room 23, and the children reply. The teacher goes through the roll, calling out children's names one by one as they respond. Some boys at the back are playing with cards. Anna gives me a shy smile after her name. After class news, there is a reprimand given for a problem with the rubbish bins. Anna puts up her hand to answer a question. The class are prepared for the power walk, and school values are related to it and reinforced.

Power Walk

On the large concreted area between the classrooms, there is all confusion, big groups of children, different adults, milling around. Children are asked to go into a line with either the walkers or the runners. Other children notice what Anna is doing. She has changed and is with the other girls. She has opted to go with the runners. The slower girls stay up with her. We head off at a fast pace. Ahead of me I can see Anna, moving as fast as she can. It is hot, sunny. As we go, other children comment about Anna "what's she doing?" "Why is Anna in the running group?"

As we move around the course, Anna falls behind. She seems very much on her own- no one is making an effort to walk with her- her focus is on getting around the course. Other children are in groups of 2s or 3. We wind around the street that runs parallel with that of the school- along leafy footpaths, up a hill, around the corner. The children are familiar with the course- they have done it before. As we approach the final lap back towards the school, I notice another girl walking beside Anna, and they are chatting together. One of the teachers describes Anna as a "success story". Although she "says what she wants", "the other kids include her".

Spelling

The children change out of their walking clothes and return to Room 23. Anna doesn't have a teacher aide for this activity. The whiteboard is an important way of communicating information about the class, reinforcing group membership and expectations. Spelling groups, and activities are outlined. There are word lists for different groups- Keas, Tuis, and Robins. On another area Room 23 rules are stated – they relate to the school values: "follow teacher directions, treat others and their property with respect, put up your hand to speak, no running or pushing, work hard, and have fun". The board also lists special jobs under a heading "Be a Star Helper". I wonder if Anna has a responsibility? Children's names are called out and spelling books are handed out. They start copying down their lists. The class is very quiet- just occasional subdued giggling.

Maths

The class is given warning to pack up. Shortly after, "we have run out of time. Pack up. Stand behind your desk ready". Anna seems familiar and comfortable with the process. "Get

your pencil, rubber, and ruler, and go to the next room". I follow the group of children Anna is with. She is a little behind the others getting there. They sit on the mat in the new room listening to the teacher. The children are divided into their "shape" groups. After the test, circles will work with the teacher, triangles will work on the laptops on rainforest maths, and rectangles will do the worksheet.

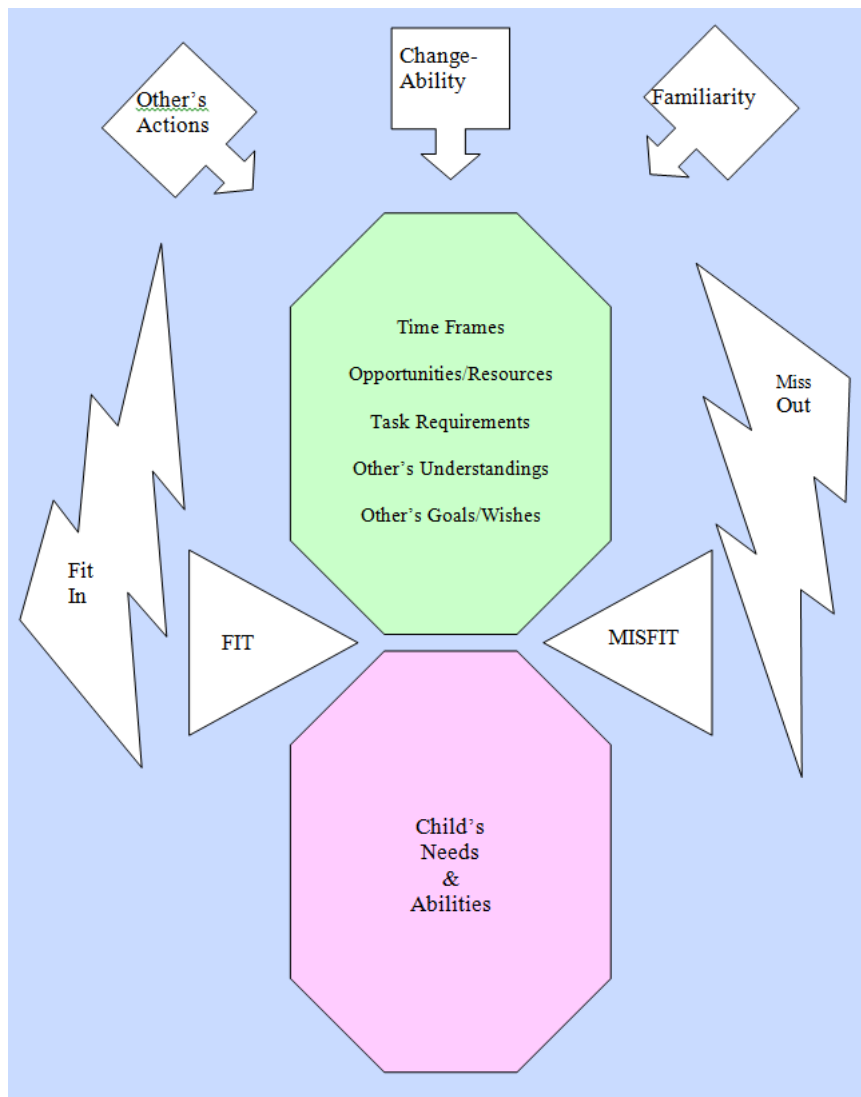
The children are asked how they are going to achieve all the work. Anna tries, but finds it hard to answer questions on the spot. "Work together, help each other, be kind, be quiet, don't distract, don't copy, listen" are suggestions offered. "hands up if you're not good at listening" from the teacher. "there's still time to make amends". This seems to flag an understanding that everyone is not good at everything- instilling the children with an expectation of differences. The test is about times tables. Before beginning, the teacher covers the rules, and Anna is asked a question which she answers correctly. When she is given an opportunity, it is great when she can show her skills. I wonder if the teacher asked her because I am present...

Anna is getting up from the floor. She is asking another child for help. The children begin writing answers. They are all very quiet, concentrating, whispering. "What if it's 1 x 0" someone asks the teacher out loud. "Good thinking Mary". It's OK here to ask, it's OK to get the wrong answers, it seems it's being involved that is important. Quickly the time is up. "Standing up, hand your papers in, and STOP". Children move around shaking their writing hands and sit down with their shape groups.

Anna is in the rectangle group, and sits a group of desks blocked against each other, with 5 other children. There is quite a buzz in the room. The other groups are very aware of what the others are doing. It must be challenging for the teacher to support 3 different lots of Learning activities in the classroom. This group has a worksheet with the 2 and 3 times tables on it. They are also given crayons. Anna has the worksheets, and another child gets the answers.

This is small group work- nice to see Anna being involved with the group. There is some quiet talking, but I feel children assume they really should be working individually. Anna has worked with these children before, they are familiar with other group members. One child asks Anna for help. The children are reaching across each other for crayons, and around Anna. She is resting her hand on the desk. The children begin surreptitiously looking at each others' answers, but Anna is very focused on her own worksheet, getting on with it. Others seek and provide help. One child looks at Anna's work- seems to be helping her. Collaboration between children is co-incidental here, not deliberately part of the activity. Two children are not concentrating.

Anna has completed a very small amount of work. One answer does not seem correct. The children are struggling with this task. The instructions are very small and there are several steps. Shortly the bell goes.



Appendix 4.12: Approaches to Data Analysis for Individual Case Studies

Table of Potential Approaches to Data Analysis for Individual Case Studies

Analysis Source/Name	Description	Pros	Cons
(Stake, 1995) The Art of Case Study Research	Intuitive analysis of individual case studies. Explicates “direct interpretation” of data and “aggregation of instances” (p. 74). Responds to initial understandings of data along with the need to convey understandings to readers. Sense-making, taking material apart, relating parts to each other, putting material back together with new meaning. Work with “episodes or passages” or “portions of observations” (p. 78). May use “pre-established” codes (p. 79) or search for novel codes. Codes are related to research issues or questions. May use tables to identify correspondences.	Emphasizes the individual case, values the particular. Holistic- data is analyzed in context, presented holistically. Flexible- responsive to different types of data, different purposes and questions.	Difficult for novice researcher to understand some of the techniques used due to their intuitive nature. Generates lengthy reports, large volumes of researcher narrative. Difficult to see how this was derived from the raw data. Volume limits accessibility, makes it difficult to gain insight into most important understandings.
(Yin, 2009)	Provides four general strategies: a) use of theoretical propositions; b) describing the case; c) integrating qualitative & quantitative data; and d) exploring differing explanations. Explicates five techniques to aid analysis: a) pattern matching; b) explanation building; c) time-series analysis; d) logic models; e) cross-case synthesis (pp. 136-149). Can incorporate quantitative statistical analyses.	Comprehensive. Explicit. Detailed. Use of diagrams & examples to illustrate. Clear explanations.	Informed by positivist perspective- quantitative, quasi-experimental (p. vii). Intention is to generate empirical assumptions from data and “rule out” alternative explanations (p. 130). Findings are used to replicate, add to, and support existing theory, and/or rule out competing theories. Techniques are complex, not easy for novices, recommends

			prior practice with simple cases.
(Merriam, 2009)	Coding and categorizing, themes Phenomenological analysis/Grounded theory/Ethnographic analysis/Narrative analysis Facilitating the reader to know the case. Refers to Yin- develop a database to draw together and organize the data.	Lacks specific guidance	The study is not informed by phenomenology or ethnography. It does not specifically include narratives.
Qualitative Data Analysis (Miles & Huberman, 1994) (Bates, 2002) (Matrices)	Informed by Transcendental Realism. Aim for a “causal description of forces at work” (p.4). Steps: Data reduction: mining important data from sources : coding, summarizing, arranging Data display: matrices, tables, diagrams Conclusions: identifying patterns, links, assertions : confirming	Organized. Logical Clear to read Can be inductive or deductive Matrix displays aid identification of patterns.	Prescriptive more than intuitive. Doesn’t explain how to support interpretation of meanings from individual/single cases.
(Merriam, 2009; Silverman, 2006; Simons, 2009; Strauss & Corbin, 1998) Grounded Theory	Informed by Symbolic Interactionism Positivist influences Aim is to understand and construct theory that is grounded in the data.	Gives specific processes & techniques.	Emphasises aggregation of data and explanation. Aim-theory-building. Focus on processes. Less valuing of the particular.
Coding & Categorizing (Simons, 2009) (Silverman, 2006)	Taking the data apart Comparing and re-assembling the data Can draw on pre-existing theory to guide analysis	Can reflect theoretical perspectives of researcher	Views the data away from its’ original context- may lose sight of important relationships with context. Use of pre-existing theory may constrain understandings.

Progressive Focusing (Simons, 2009)	Breaking data down & making sense of it to generate themes and patterns. Refining research questions and foreshadowed issues Develop & confirm explanations & propositions	Acknowledges pre-existing theoretical understandings. Similarities with process described by Stake.	Will not necessarily support continuity of the data with its context.
Computer Software (Hesse-Biber & Leavy, 2011; Maxwell & Miller, 2008; Simons, 2009; Tesch, 1990)	CAQDAS- NVivo 9 and QDA Minder 4.0: Tag Clouds and Cluster Analyses. HyperQual builds concept models/networks, developed inductively, but requires prior categorization, emphasizes conceptual links. Code & retrieve programs Code-based theory-builders Conceptual network builders Textual mapping software (Hesse-Biber, & Leavy, 2011, p. 320)	Clear displays. Clear, structured process. Can embed raw data with analysis. Helpful for managing large amounts of data.	Programs may not be readily available Training may be required Mechanical Tends to depict relationships in hierarchies/linear fashion. Difficult to convey context. Would need to code separately for each case, then a final analysis drawing all the cases together. Harder to tease out and highlight important particularities.
(Silverman, 2006)	Outlines different approaches to use with different types of data: <u>Observational data</u> Computer software Coding & categorizing Progressive focusing Grounded Theory Descriptive	Descriptive- supports integration of context.	Risk of fragmenting the different types of data by treating them differently. Descriptive- Reliance on raw data, lacks interpretation. Anecdotal, lengthy

	Ethnography (traditionally study how people see the world) vs Ethnomethodology (study action in context)		Ethnomethodology- retains context
	<u>Textual data</u> Content analysis- categorize, count	Content analysis: valid, reliable	Content analysis- quantitative in nature. May not generate new insights. Not appropriate to apply with reporting documents- require interpretive approach.
	<u>Narrative structures</u> -Different structures used in stories guide analysis		
	<u>Visual data</u> Quasi-experimental		Quantitative-descriptive in nature
(Neuendorf, 2002) Content Analysis	Quantitative approach to content analysis.		Quantitative- inconsistent with case study approach.
(Krippendorff, 2004) Content Analysis	Analysing textual & other meaningful &/or unstructured data. Involves unitizing, sampling, coding, reducing data, inferring contextual data, & narrating the answer to the research question.	Explicit, detailed processes. Attends to context of data.	Draws on abductive reasoning. Complex for novice researcher. Emphasis is text. May not apply well to or integrate multiple types of data. Less focus on context of <u>case</u> . Quantifies.
(Hsieh & Shannon, 2005) Content analysis	Content analysis: Conventional- descriptive- inductive, coding, categorizing, defining, hierarchical diagrams.	Used where there is little prior knowledge	Divorced from data context

	Directed- using existing framework	Validates/builds on existing theory	May not generate new insights
	Summative	Insights into use of words by different speakers.	Lacks focus on wider meanings & processes.
(Carley, 1993) Content vs Map Analysis	Content analysis- extracting content from texts, describes words used & quantifies them	Engages & remains with text	Doesn't attend to meaning Emphasises frequency
	Vs Mapping- Comparisons of concepts in textual data & interconnections. Uses pre-determined concepts.	Relationships considered for "strength, sign, direction, & meaning" (p.92)	Linear, quantitative focus Restricts open-ness to new insights.
(Wheeldon & Ahlberg, 2012) Argue for flexible application of maps	Concept maps used for data collection. Largely applied to support student learning. Greater structure, non-pictorial. Hierarchical display of relationships. May be non-linear.	Enables measurement & analysis of levels, hierarchies, & relationships.	A means of displaying the data rather than a technique for analysing it. Used in quantitative research.
(Daley, 2002; Daley & Torre, 2010; Davies, 2010; Wheeldon, 2010; Wheeldon & Faubert, 2009)	Mind maps: can be used to gather data, but can also be used to analyse gathered data. Illustrative, non-linear representation of concepts. Brainstorm associations between different notions. Applications in Mixed Methods Research- used to design interviews- & participant generated Mind-maps. Informed by Pragmatism = Abductive approach to reasoning???	More flexible, less formal than concept maps.	Lack of detail on how to implement during analysis.
	Also- Argument Maps		

(Clarke, 2005) Situational Analysis	<p>Grounded theory, informed by post-modernism</p> <p>Situational maps display aspects of the situation and prompt analysis</p> <p>Social words/arenas maps display the different participants & data sources as wells of areas of engagement and interconnection</p> <p>Positional maps explicate the different positions adopted</p> <p>Repeated mappings help organisation of data.</p>	<p>Supplements existing grounded theory data collection and analytical techniques.</p> <p>Situates the research and its data</p> <p>Aids thick description</p> <p>Increased emphasis on meaning, interpretation, relativism</p> <p>Holistic</p>	<p>Emphasizes aggregation of meanings.</p> <p>Pre-specifies aspects of situations to guide inquiry</p> <p>Emphasizes saturation</p> <p>Focus remains on generation of theory rather than understanding a case.</p>
(Saldana, 2013) The Coding Manual for Qualitative Researchers	<p>Recursive & cyclical nature of coding</p> <p>Suggests First and Second Cycle coding strategies.</p> <p>Strategies should be aided by other methods- eg. memo-writing</p>	<p><u>First Cycle</u>: Descriptive Coding: captures the topic of a chunk of qualitative data.</p> <p>Answers general questions such as what is happening in this situation, or what is this information about. Gives a summary of the content of the data. Helpful for analyzing physical environments, artefacts.</p> <p>In Vivo Coding- draws on the words or phrases used by participants.</p> <p>Emphasizes participant's perspectives, especially if marginalized. Useful for action & practice-based research. Helpful for novice researchers.</p>	<p>Generates information at a basic level. Lacks deeper analysis.</p> <p>Can restrict movement into further interpretive and theoretical understandings.</p>
<u>Preparatory Techniques for Second Cycle</u>		Descriptive. Risk of	

	<p>Code Mapping & Code Landscaping- used to arrange and integrate the codes from First Cycle. Iterative cycles in which codes are repeatedly categorized. – Displays of textual data according to frequencies, categories, subcategories.</p>		emphasizing quantities rather than significant data.
	<p>Operational Model Diagramming- another technique to support Second Stage Analysis. CAQDAS programmes aid mapping and diagramming the “sequences & networks” of codes & categories.</p>	<p>Helps researcher to integrate ideas. Assists readers to gain understanding of the findings.</p>	<p>Needs to be supplemented with written descriptions of codes and their relationships.</p>
(Maxwell & Miller, 2008) Categorizing vs connecting strategies for analysis	<p>Present a plausible argument for data analysis based on principle of distinguishing between analysis of similarity vs those which analyse contiguity.</p>		
	<p>Similarity type approaches seek common features, and aim to <u>compare apart from time and place</u>. Data is broken down then re-configured. Connections are between categories not categories and context</p>	<p>Coding & categorizing Thematic analysis</p>	<p>Can lack attention to context Aggregates instances</p>
	<p>Contiguity is concerned with relationships, influences, and connections in context. Use connecting strategies. Networks can be used to provide spatial and causal connection of data from specific events & contexts</p>	<p>E.g. Narrative approaches Microethnographic More holistic Aligns with Stake’s approach.</p>	<p>May not extend past the raw data. Can lack interpretation Drift towards categorization Data for current study is not narrative in nature.</p>
(Hesse-Biber & Leavy, 2011) Data analysis for case studies	<p>Grounded Theory Iterative process Supported by memos, in-vivo coding</p>	<p>Explanation of different phases is helpful.</p>	<p>Lacks detail into specifics of the procedures Explicates grounded theory</p>
Analysis of Qualitative Data	Taking data apart, then reconfiguring it to make		

	<p>sense.</p> <p>Data prep (transcribing)</p> <p>Data exploration & reduction- memos, description, coding</p> <p>Interpretation</p>		
<p>(Daley, 1996)</p> <p>Concept Maps</p>	<p>Ideographic interpretation (individual) rather than nomothetic (generalisations)</p> <p>Maps used to make sense of data from interview</p> <p>Developed through listening to the audio-recordings</p> <p>Comparison and evaluation of the maps</p>	<p>Maps identified differences and gaps in learning. They captured student's progress in learning.</p>	<p>Article blurs the relationship between using maps as a data-analysis strategy and their use to support student learning. Unclear who completed the maps.</p>
<p>(Northcutt & McCoy, 2004)</p> <p>Interactive Qualitative Analysis</p>	<p>Draws on Systems Theory. Data analytic strategies for focus groups. Uses mapping strategies.</p>	<p>Integrates inductive & deductive reasoning- consistent with Deweyan framework.</p>	<p>Primarily for <u>group</u> analytical procedures.</p>
<p>(Kools, McCarthy, Durham, & Robrecht, 1996; Lutz & Bowers, 2005)</p> <p>Dimensional Analysis</p>	<p>Type of grounded theory analysis. Line by line coding. Identification of attributes that comprise the experience, those that are most relevant, and most important influencing conditions. Identifies participants' view of reality.</p>	<p>Useful for analysing between different texts & integrates different forms of text. Could identify facilitators and barriers. More flexible in application than traditional grounded theory.</p>	<p>Breaks data down line by line. Sees influences as occurring one way. Aggregates. Process focused. Explanatory matrix may limit openness to new ways of conceptualizing data.</p>
<p>(Ayres, Kavanaugh, & Knafl, 2003)</p> <p>Compares phenomenological,</p>	<p>Phenomenological: Immersion, compare key statements, reconnect significant statements to data, intuiting, critical reflection, free writing, arrange categories of significant statements into themes, return analysis to participants.</p>		<p>Focus is commonalities, less concern with individual variation.</p>

narrative, and concept development models of analysis	Narrative analysis- storied approach to meaning-making.		May be inconsistent with descriptive focus and multiple types of data (e.g. observations, documents)
	Formal concept analysis. Data from n.200 interviews. Identify themes, define variability in themes, generate a thematic profile for each group, differentiate the different profiles.		Focus on one theme. Less ability to explore and generate new insights, identify transactional relationships.
(Dey, 1993) Qualitative data analysis	Steps include: Reading & annotating; categorizing; linking/associating/connecting; maps/matrices; corroborating; reporting	Maps are used to re-integrate fractured data.	Processes still break data apart from each other and from context, then re-connect it, but in terms of similarities rather than the actual context. Different to contiguous approach (Maxwell & Miller, 2008).
(Tesch, 1990)	Proposes three main avenues to qualitative analysis: “language oriented” “descriptive/interpretive” “theory building”	Useful summary of main approaches, useful conceptualization. Stake’s approach to case study fits best with “descriptive/interpretive.”	Approach to descriptive/interpretive still involves splitting data apart from context for analytic purposes, then re-connecting in terms of similarities rather than contiguous with actual context.
(Northcott, 1996) Cognitive Maps	Single-page visual map of the interview data. Maps drawn directly from repeated listenings of data.	Incorporates meanings and contexts as one. Potential to incorporate context in which data was gathered as well as context as originally experienced.	Draws directly from audio-data rather than transcripts. Uncertain as to its application with observed and textual data.

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Appendix 4.14: Cross-case Analysis Worksheets 2-6

Appendix 4.14: Cross-case Analysis Worksheets 2-6

Worksheet 2. The Research Questions of the Multicase study

Theme 1:

What are the aspects of participation that are important for NZ children aged 9-12 yrs who are in the chronic stages following clinically significant TBI?

Theme 2:

What are the facilitators to participation. for NZ children aged 9-12 yrs who are in the chronic stages following clinically significant TBI?

Theme 3:

What are the barriers to participation. for NZ children aged 9-12 yrs who are in the chronic stages following clinically significant TBI?

Appendix 4.14: Cross-case Analysis Worksheets 2-6 Worksheet 3. Case Summary Notes Case 1 Anna

Worksheet 3. Analyst's Notes while Reading a Case Report
Case ID 1 - Anna

<p>Synopsis: case, sites, activity, information sources, context</p> <ul style="list-style-type: none"> Age 10, NZ European, TBI 9y ago, age by 2m Diets: Vision, dysphasia, hemiplegia. Regular surgery/rehab Lives: mother + sibling, parents separated Likes: poetry, sports - Mother works full time Anna's home, school - Primary ^{Primary} teacher, Mixed class Interests - mother, child, teacher, TAI, SENCO Obs - arts, reading, language, maths, health, home Desc - SRA, T1 Rapid growth - rural town, College next door Situational constraints - No interview with father 	<p>Case Findings:</p> <ol style="list-style-type: none"> I. Fit between child's needs, abilities + preferences + others understandings + actions was <u>important</u> II. Balance between amount ^{time} space ^{places}, people, + occupations involved with was <u>important</u> III. Shared Activity was ^{facilitated} particip ^{particip} by bringing about changes in understandings + actions IV. Changeability in people, their understandings, their actions, the activity ^{place}, time or place could be V. A facilitation of a barrier to participating VI. Anna's ^(P) was characterised by Misfit + Imbalance
<p>Uniqueness of case</p> <ul style="list-style-type: none"> Female, injured as infant - Long term Keen to have a go, but becoming <u>independent</u> independent Rehab + medical, therapy Rapidly growing ^{changing} independent Visits father - weekends Financial pressures for parents 	<ol style="list-style-type: none"> ① Fit - T1 ② Balance - T1 ③ Misfit, Imbalance - T1 ④ Changeability - T2, T3 ⑤ Shared Act - T2
<p>Prominence:</p> <p>Imp Theme 1 <u>Bill</u> 4, 5, 5, 6, 8, 8, 8, 9, 9, 9, 10, 10, 12, 12, 12, 13, 13, 13, 13, 15, 14, 15, 15, 15, 16, 16, 16, 17, 19, 20</p> <p>Facil Theme 2 10, 11, 14, 15, 15, 16, 16, 17, 17, 17, 21</p> <p>Barriers Theme 3 1, 4, 4, 5, 5, 5, 9, 10, 12, 12, 13, 16, 17</p>	<p>Possible excerpts for cross-case report:</p> <p>P. ¹⁵ 15 - Misfit</p> <p>P. ¹⁵ 15 - Shared Occ - Facil</p> <p>P. 16 - Shared Occ</p> <p>P. Scrapping + Scrapping - On my Own MOP</p> <p>P. Striving to help her - T1 p1-2</p>
<p>Utility:</p> <p>Imp Theme 1 - <u>Misfit</u> Imbalance, Change</p> <p>Facil Theme 2 - ? Shared Occ / change b people, → negatives</p> <p>Barriers Theme 3 ✓✓ - other places, ch - Rehab</p>	<p>P. Taking no notice, not built long Obs SU1 P8 = ¹⁵ 15 skills + Powerwalk p3-4 ^{SENCO 20}</p> <p>- Rehab - abnormal pathway, prolonging rehab + leading - SENCO 1A <u>deceiving</u></p> <p>- Feeling diff - Rehab SRA p5</p> <p>- extra-curricular P6 - Balance</p>

Time Frame + change
- short time frames + big change = ↓ P

Worksheet 3 page 2
Case 1 - Anna.

Notes

- Mother - ↓ income, works full time.
- SENCO - an advocate.
- Response to modelled inclusive actions
- Keen to have a go
- Tension betw sppt to my class work + interact w peers

P8 Not understanding

few inclusive actions. Including actions are taught & learned

P10 Child understands an activity or interest - can't do both at once. Emphasis is activity

P10 Being able to have supports (P) by moving around others to share & contribute, " by performing activ.

P13 Potential of rehab to single out - at odds w need for inclusive actions
(see also p. 4 SENCO, p. 5 SENCO)

P16 Parallel participation

X Drawback of CS - not revising earlier CS on basis of new info

Appendix 4.14: Cross-case Analysis Worksheets 2-6

Worksheet 3. Case Summary Notes Case2Tish

Worksheet 3. Analyst's Notes while Reading a Case Report	
<p>Case ID <u>2 Tish</u></p> <p>Synopsis: one, sites, activity, information sources, context</p> <ul style="list-style-type: none"> Age 11. NZ Māori. TBI 2y ago, age 9y Difficulties- attention, fatigue, executive skills, writing lives with father + stepmother + 2 stepisters, parents work full-time - financial challenges after accident Interviews- parents, child, teacher, friend Obs- Classroom, manual training, kapa haka, rugby Docs- RMR, PCR, SRR <p>Situational constraints</p> <p>Unable to interview mother, extended family</p> <p>Uniqueness of case</p> <ul style="list-style-type: none"> School holidays + mother in city NZ Māori Culture of inclusion modeled + enacted Old, well established rural community Short term diagnosis + support pressures <p>Prominence: 14 - interest - Part 16 Key Part</p> <p>Theme 1 3 - pattern 4, connection 1 - conn. Identities from 16</p> <p>Theme 2 3, 3, 3, 4, 4, 5, 9, 9, 10, 10, 10, 12, 12, 13, 13, 15, 15, 16</p> <p>Theme 3 3, 4, 9, 10, 11, 12, 13, 14, 17, 17, 17, 17</p> <p>Utility:</p> <p>Theme 1 ✓✓✓</p> <p>Theme 2 ✓✓✓</p> <p>Theme 3 ✓ Mother / Comm.</p>	<p>Case Findings:</p> <p>I. Connections ^{the} Qualitative ^{aspects} connections between people, place, occupation + time was important</p> <p>II. The pattern of ^{and} between ⁱⁿ people, place, occ + time involved in shared occ was imp</p> <p>III. Shared occupation facilitated changes in others' understandings ^{and} learning ^{about} how to change ^{change} aspects of people, place, occ + time to support participation</p> <p>V. The injury and ^{rehabilitation} disrupted ^{interrupted} + changed the connections ^{connections} + patterns connections ^{connections}</p> <p>VI. Tish's shared occupations, other ^{others} he + others do work ^{work} together ^{together} how to each ^{each} other</p> <p>VII. Initially</p> <p>VIII. The fit between Tish's cap ^{abilities} + needs + aspects of people, place, occupation + time was important</p> <p>Possible excerpts for cross-case report:</p> <p>P. 13 - People chg Shx</p> <p>P. 13 - Maths, burrow</p> <p>P. 4 - Connection - KH</p> <p>P. 14 - Burrows - In vent - family + H/V names</p> <p>P. 16 - Lay to chg proximity</p> <p>P. 16 - Peers helping (+ M.T.)</p> <p>1 - Shared Occ - X Box</p> <p>1 - Skills - Mem - (P3)</p> <p>Culture (3) -</p> <p>Sm Comm (MT) (L)</p> <p>Balanced - (6)</p> <p>Leadership - (3)</p> <p>Misfit (P3)</p> <p>Misfit (14)</p> <p>Time (14)</p> <p>Shared Occ</p>

Appendix 4.14: Cross-case Analysis Worksheets 2-6

Worksheet 3. Case Summary Notes Case3Anton

(annotated) =
highlighting

Worksheet 3. Analyst's Notes while Reading a Case Report

Case ID 3 - Anton

<p>Synopsis: case, sites, activity, information sources, context Age: 11. NZ European, TBI - age 6, 5 yrs ago. Difficulties - tremor, ataxia, seizures, behavior, sleep disturb. - full assist & ADLs Family - Parents, younger brother</p>	<p>Case Findings:</p> <p>I. The presence of connections between events people, place, occupations & time were important.</p> <p>II. The balance in the patterning between of people's shared occupations across place & time was imp.</p> <p>III. Shared occupations define connections with family learning through doing together learned how to perform the occupation & how to work with include each other with other people in the case Anton</p> <p>IV. An absence of shared occupation was a further barrier to forming relationships others learning how to work with Anton</p> <p>VI. Shifts betw aspects of people, place, and aspects of time was a barrier to shared sharing occ</p> <p>VII. The At Queen's intent's connection and aspects of the people, places, occupations of time who also involved in shared occupation was important</p> <p>VIII. being</p>
<p>Situational constraints</p> <p>- Unable to interview child</p>	<p>Possible excerpts for cross-case report:</p> <p>P. Obs - Scout P 7 - skills</p> <p>P. Scouts P 2-4 - context</p> <p>P. Scouts p 7 - following scout's following MI P 26 - following skills</p> <p>P. Soccer T 1 - Incl culture</p> <p>P. TAI p 1 - Leader skills</p> <p>P. Swim P 3 - Shared occ</p> <p>P. TI P 13 - Learning skills</p> <p>P. Soccer p 6 - Connection *</p>
<p>Uniqueness of case</p> <p>- Very severe TBI with partially controlled seizures ongoing - long rehab</p> <p>- Mother not in paid employment - financially secure</p> <p>- Both Parents differing views re value-participation</p> <p>- Involvement - agency caregivers - Special school</p> <p>- Old, well established rural suburb</p>	<p>* Networking of parents → connection → opps ch's (Kathleen) - Spread 3 cam</p> <p>Scout P 9 - leader</p> <p>Incl Skills TAI p 7</p> <p>Sh Du - P Skills MI 32-33</p>
<p>Prominence:</p> <p>Imp Theme 1 - Some - Kathleen, Obs ✓</p> <p>Fair Theme 2 - Some ✓✓✓</p> <p>Poor Theme 3 - ✓ - school Obs</p>	
<p>Utility:</p> <p>Imp Theme 1 ✓✓✓ Misfit other ch's learning</p> <p>Fair Theme 2 ✓✓ Mother, Michael - Obs Modeling</p> <p>Poor Theme 3 ✓ Father teacher</p>	

Appendix 4.14: Cross-case Analysis Worksheets 2-6

Worksheet 3. Case Summary Notes Case4Dana

? adding learning ~~skills~~
- participation skills to Ash's CSdgm

*Inducted following + eg Conn +
Path +
Barrier ++ Change ++
Facil +

Worksheet 3. Analyst's Notes while Reading a Case Report

Case ID 4-Dana

<p>Synopsis: case, sites, activity, information sources, context</p> <p>Age - 10, NZ Māori TB large 8yrm 1y ago</p> <p>Difficulties - fatigue, attention, memory, organize, prob-solving, expressive communication</p> <p>Family - lives w mother, sister, cousin</p> <p>Interviews - Mother, child, cousin, friend, teacher, T/A</p> <p>Observed - classroom, home, class/playground, mass/playground</p> <p>Docs - SNAs, TI</p>	<p>Case Findings:</p> <p>I The presence & quality of connections between people, place, roles, time were imp</p> <p>II The patterning of people's shared occs were important</p> <p>III The pit falls of a child's capabilities & agency of the people, place, occs, time was imp</p> <p>IV People's actions in including, leading, & driving participated Dana's particip.</p> <p>V</p> <p>VI Rights before Dana's capabilities & expanded people, place, occupations & time were barriers to participation</p> <p>VII Dana's participation changed following the accidents (p. 10)</p> <p>VIII Ongoing change - potential & actual was important to participation, leading, driving</p>
<p>Situational constraints</p> <p>No IEP provided</p> <p>Limited # obs</p>	<p>Possible excerpts for cross-case report:</p>
<p>Uniqueness of case</p> <ul style="list-style-type: none"> Family bereavements Catholic school, diverse cultures, inclusive community Limited obs of comm. (p. 10) "gaps" 	<p>P. - discusses & confidence/emotional reactions</p> <p>P. - discusses/emphasizes gaps in (P) due to overly zealous rehab advice re safety needs</p> <p>P. (5) Family/friend connect</p> <p>P. (9) Whānau connections</p> <p>P. (6) Rehab - safety risks / interrupt (11)</p> <p>P. (4) Interrupted (P) (17) - LAST P. ARE including leading driving</p> <p>P. (5) Safety risks = ↓ opp.</p> <p>P. (10) Shared occ & learning *</p> <p>(9) Whānau connect</p> <p>(9) Duration of connect - see also Tish</p> <p>(10) Diversity of patterns & connect heading</p> <p>(12) Leading, Incl. actions</p> <p>(15) Rehab - barrier + (15) + (16) * (16) change after accident</p> <p>(15) Incl. actions. * (15) Diversified</p>
<p>Prominence</p>	
<p>Impr Theme 1</p> <p>Facil Theme 2 - ↓ info re childrens incl. skills ✓ info re leading, driving</p> <p>(Ezzy) Theme 3 - Less diverse - Rehab barrier - v. prominent</p>	
<p>Utility</p>	
<p>Impr Theme 1 ✓ friend, teacher</p>	
<p>Facil Theme 2 ✓ camp</p>	
<p>Rehab Theme 3 ✓ Safety - Mother ↓ Comm Opps - " , inclc</p>	

Appendix 4.14: Cross-case Analysis Worksheets 2-6

Worksheet 3. Case Summary Notes Case5Bob

Worksheet 3. Analyst's Notes while Reading a Case Report	
Case ID <u>5 Bob</u>	
<p>Synopsis: case, sites, activity, information sources, context</p> <ul style="list-style-type: none"> • Age: 12½, NZ European, TBI 1 y 2 m ago, age 10 y 8 m • Difficulties: fatigue, memory, slow info processing • Lives with parents + younger sibling. Parents work, mother part-time. • Likes rugby, water sports, running • Interviews: family, child, teachers x 2 • Obs: class visit, playgroup, swimming • Does: SAH, DC/T/Aide, Peds, Npays <p>Situational constraints</p> <p>Data gathered over shorter time period. Data collection limited to home + school</p> <p>Uniqueness of case</p> <p>Recent injury, good recovery Teacher exp. 2 ch = disability Small, close-knit community Financially secure</p> <p>Prominence:</p> <p>Impr: Theme 1 <u>conn</u></p> <p>Facil: Theme 2 <u>high Mol</u></p> <p>Barriers: Theme 3 <u>less prominent</u></p> <p>Utility:</p> <p>Impr: Theme 1 <u>Monkeys - rugby connect ✓✓✓</u> Pattern: <u>not comm</u></p> <p>Facil: Theme 2 - ✓✓ - <u>adjust - chg new roles</u> - <u>sppt</u></p> <p>Barriers: Theme 3 - <u>rugby / safety ✓</u></p>	<p>Case Findings:</p> <p>I. The quality of the connections created as people shared in occupation in time + place was impl.</p> <p>II. The patterning of shared occupations between people in time + place was important.</p> <p>III. Shared occupation facilitated changes in others knowing + actions. People began to draw on aspects of others, place, occ + time to involve Bob.</p> <p>IV.</p> <p>V. Bob's injury put stop <u>changed</u> the connections + patterns of his occupations. There were insights with his abilities + aspects of people, place, occ + time.</p> <p>VI.</p> <p>VII. The inclusive nature of Bob's community supported the ready use of inclusive actions towards Bob.</p> <p>VIII.</p> <p>Possible excerpts for cross-case report:</p> <p>P. 3 - <u>connector</u></p> <p>P. 3 - <u>Sudden change - path of P</u></p> <p>P. 3 - <u>Teacher - imp role - leading P</u></p> <p>P. 4 - " " "</p> <p>P. 4 - <u>Fitting in - not just TBI?</u></p> <p>P. 6 - <u>P Skills</u></p> <p>P. 11 - <u>Shared occ</u></p> <p>P. 11 - <u>Learn P skills</u></p> <p>P. 11 - <u>Connect - phys envt.</u></p> <p>P. 11 - <u>P skills</u></p> <p>P. 12 - <u>Mustn't restrict + 19</u></p>
<p>Identifying ptns of enrolling existing people who can lead P</p> <p>It out + advocate or flexibility in others, the habits +</p> <p>Presence + valuing of diversity Some communities have a culture that demonstrates + models inclusive actions. Inclusive actions lift skills are more readily</p> <p>Connect created then shared occ Pattern of shared occ</p> <p>values</p>	

Appendix 4.14: Cross-case Analysis Worksheets 2-6
Worksheet 3. Case Summary Notes Case6Ash

Worksheet 3. Analyst's Notes while Reading a Case Report

Case ID Cashe'6, Ash

<p>Synopsis: case, sites, activity, information sources, context</p> <p>Age - 9, NZ Maori / Pacifica. TBI @ 2y age, age 2 1/2</p> <p>Diff. Hearing, fatigue, behavior. Sppt = hearing, self care</p> <p>Sec - lives betw parents 1 x 2 diff parents</p> <p>Lines - dog, drums, drawing, ball (play), help graph</p> <p>Info - IV - Mum, Dad, Gelponey, T, Tiaide, SEAL SEAL SEAL</p> <p>SEAL - class, K4</p> <p>SEAL - SNA, IEP, ESAB</p>	<p>Situational constraints</p> <ul style="list-style-type: none"> community observations no observations - whanau (P) <p>Uniqueness of case</p> <p>Injured as infant - long term - need</p> <p>Multiple changes</p> <p>living betw parents</p> <p>Behavior</p>	<p>Prominence:</p> <p>Theme 1 Med. - connect - family</p> <p>Theme 2 Med. - Timmy</p> <p>Theme 3 High - rehab</p> <ul style="list-style-type: none"> part time school fatigue <p>Utility:</p> <p>Theme 1 Leadership - split bet</p> <p>Theme 2 Leadership - split bet</p> <p>Theme 3 Leadership - split bet</p>	<p>Case Findings:</p> <p>Connections with people, place, time, + occupations</p> <p>I were important</p> <p>II The patterns of peoples occs in place + time were important</p> <p>III The fit between people, their occs, place + time were important</p> <p>IV Shared occupation in the context of an inclusive family culture facilitated Ash's participation through his own + others</p> <p>V Learning</p> <p>VI Ash's injury interrupted + changed patterns of connections, with peers</p> <p>VII</p> <p>VIII</p>
<p>Possible excerpts for cross-case report:</p> <p>P. M1 P 9 - mothers room - child room - time + place + others</p> <p>P. GF1 - p7 - leading - cottoning on</p> <p>P. lack of inclusive culture in class -</p> <p>P. Skills</p> <p>P. Skills</p> <p>P. Skills culture - Obs KH</p> <p>P. Skills culture - Obs KH</p>	<p>Ext Conn - GF1 P 3</p> <p>Learning P Skills TAI P 3</p> <p>Cultural Shared Occ - FI P 13</p> <p>Injury chg Occ GF1 - 13</p>	<p>Ext Conn - GF1 P 3</p> <p>Learning P Skills TAI P 3</p> <p>Cultural Shared Occ - FI P 13</p> <p>Injury chg Occ GF1 - 13</p>	<p>Ext Conn - GF1 P 3</p> <p>Learning P Skills TAI P 3</p> <p>Cultural Shared Occ - FI P 13</p> <p>Injury chg Occ GF1 - 13</p>

Appendix 4.14: Cross-case Analysis Worksheets 2-6

Worksheet 4. Uniqueness And Utility

* Is there overlap between
My questions (Themes?)

(* Diversity is a feature of Patterns)

Worksheet 4. Estimates of Uniqueness of the Situation of Each Case &
Estimates of Utility of Cases to Inform Themes

++ = highly unusual situation, + = somewhat unusual situation, 0 = ordinary situation

UU = high utility, u = some utility, blank = low utility

	Case 1 Anna	Case 2 Tish	Case 3 Anton	Case 4 Dana	Case 5 Bob	Case 6 Ash
Uniqueness of the Case's Situation:	↑ severity split family	recovery ind. comm. split family	↑ severity per school	best placement safety single parent	↑ recovery recent injury ind. comm.	↑ severity - below split family
Utility of Report to Inform Themes	+	0	++	+ +	++	+
Theme 1 What are the aspects of participation that are important to NZ children who have had a clinically significant TBI?	u	uu	u	uu	u	uu
Theme 2 What are the facilitators to their successful participation?	u	uu	uu	u	u	u
Theme 3 What are the barriers to their successful participation?	uu		uu	uu	u	uu
Theme 4						
Theme 5						
Theme 6						
Added Multicase Themes						
Theme 7						
Theme 8						

* Inclusive cultures
nurture a value
participation

Appendix 4.14: Cross-case Analysis Worksheets 2-6

Worksheet 5B. Merged Findings-Case Contributions

Merged Findings		Cases	Themes X Importance		
			1- Importance	2- Facilitate	3- Barriers
1	Aspects of People, Place, Occupation & Time were central to Participation	123456	H	L	L
2	Important aspects of People involved Skills for Driving Shared Occupation Performing a Shared Occupation Including people into a Shared Occupation Leading a Shared Occupation	123456 123456 123456 123456	H	L	L
3	Important aspects of Place involved Resources, Terrain Proximity Space- arrangement, in/outdoor, amount	123456 1 34 6 123456 1 34 6	M	L 25Atype	L 25Atype
4	Important aspects of Occupations included Risks Value Challenge Roles Structure Physicality Product	123456 123456 123456 23456 123456 123456 123456	H	L 1 Atype	L
5	Important aspects of Time included Time frames Schedule Pace	123456 123456 23 56	H	L	L 14Atype
6	Shared Occupation was important to participation. Inherited, parallel, collective, or vicarious in nature. Led to Connections Formed Patterns. A vehicle for Changed Understandings & Learning	123456 123456	H+	M	M
7	Connections formed through experience of Shared Occupation. Connected People, Places, Occupations & Times. Involved sense of engagement, relationship, knowing. Were changing or continuous. Could facilitate further Shared Occupation.	123456	M	M	M
8	Shared Occupation was Patterned across People, Places, Occupations, & Times. Balance, regularity, diversity important to Pattern.	123456	M	M	M
9	Fit between aspects of People, Place, Occupation, & Time was important for Shared Occupation. Peoples actions maintained or changed the Fit	123456	M	M	M
10	Participation Changed over time. The extent to which people, place, occupation, & time could and did Change influenced Fit, Connections, & Patterns of Shared Occupation. Too much Change hampered participation. Too little/lack of change also hampered participation. (Some change was needed for new opportunities).	123456	H	H	H
11	Problematic participation was characterized by Stretched, broken, or confined connections Contained, Irregular & imbalanced (x shared peers) patterns Misfits. Lack of understanding about how to participate.	123456 123(4)(5)6 123456 123 56	L	L	H 45Atype 4Atype
12	Solutions to participation came about through Shared Occupation and Changes in people's Participation Skills. Involved securing and extending connections. Involved establishing, maintaining, adjusting patterns Involved improving Fit	123456 123456 123456 123456	L	H	L
	Noise Weather	1 56 34 6	L	L	M 23Atype 25Atype

*Younger ch
Not apply - older*

Where do understand fit? In 7 shells - all of them?

Worksheet 6: Multicase Assertions for the Final Report

Designator	Assertions	Related to which Themes	Evidence from which Cases
①	Shared Occupation was central to the notion of Participation	1. Anton	Tish - K.4 - Anna - why it's kept
②	Shared Occupation involved people's Participation Skills in areas of Driving, Performing, Including, & Leading	1. Anna - Mum & Dad - Bob - K.4 - Tish - K.4 - Anna - Mum & Dad - Bob - K.4 - Tish - K.4	Tish - K.4 - Anna - why it's kept - Anna - Mum & Dad - Bob - K.4 - Tish - K.4 - Anna - Mum & Dad - Bob - K.4 - Tish - K.4
③	Shared Occupation involved aspects of Place, including Resources, Terrain, Proximity, and Space	1. Anna - terrain - Bob - resources - Tish - proximity - Anna - space	Anna - terrain - Bob - resources - Tish - proximity - Anna - space
④	Shared Occupation involved aspects of Time, including Time Frames, Routines, and Pace	1. Anna - Bob - Tish	Anna - Bob - Tish
⑤	Shared Occupation involved aspects of Occupation, including Value, Risks, Physicality, Challenge, Roles, Structure, and Product	1. Tish - writing - Bob - run - Anna - challenge	Tish - writing - Bob - run - Anna - challenge
⑥	Fit between aspects of people's Participation Skills, Occupation, Place & Time positively or negatively influenced people's ability to Shared Occupations	1. A good fit - Tish - P.R.	Anna - Red cat - Tish - red
⑦	Shared Occupation was Patterned across people, places, occupations and time	1. Bob - bits - Anna - lady - Tish - - Anna -	?
⑧	People who Shared Occupation experienced a sense of Connection between each other, place, occupation and time	1. Anna - - Tish - - Bob -	Anna's Mum - good means Anna's Mum - part of fabric
⑨	The extent to which people's Participation Skills, Place, Occupation, and Time could and did Change, positively or negatively influenced the Fit, Patterns and Connections of participation	1. Anna - school - Tish - - Bob -	Changeability - - Anna - school - Tish - - Bob -
⑩	Shared Occupation was a vehicle for Changes in Participation Skills (learning)	1. Anna - school - Tish - - Bob -	* Anna p. 21

The Connections formed during Sh. or were imp't to quality of Sh. Occ

longest disconn = chg - harder to

** Were some themes missing for cases?*

** How did the assertions vary across cases?*

Appendix 7.1: School Grades and Ages Table

Table Showing School Grades, Ages for those Grades, and Names Used for Different Schooling Levels According to Country

<i>School Grades, Start Ages, and School Type by Country</i>								
<i>Aotearoa New Zealand</i>			<i>Australia (varies by state)</i>			<i>United States</i>		
Year	Start Age	Level	Year	Start Age	Level	Grade	Start Age	Level
Year 1	5	Primary	Kindergarten	5	Primary	Kindergarten	5	Elementary
Year 2	6		Year 1	6		1st	6	
Year 3	7		Year 2	7		2nd	7	
Year 4	8		Year 3	8		3rd	8	
Year 5	9		Year 4	9		4th	9	
Year 6	10		Year 5	10		5th	10	School
Year 7	11	Interm.	Year 6	11	Secondary / High	6th	11	
Year 8	12		Year 7	12		7th	12	
Year 9	13	High	Year 8	13		8th	13	
Year 10	14		Year 9	14		9th	14	High
Year 11	15		Year 10	15		10th	15	
Year 12	16		Year 11	16		11th	16	Higher Ed.
Year 13	17		Year 12	17		12th	17	

Appendix 7.2: Data Extraction Table

Data Extracted from Articles in Review Community-Focused Interventions to Facilitate Participation for Children with TBI

Evidence for each Approach is Located in the Following Order:

High Quality: P1, P2, P3

Medium Quality: P1, P2, P3

Lower Quality: P1, P2, P3

Within these grades, evidence is order with Direct Evidence before Indirect Evidence, then alphabetically.

Note:






N/S=Not Specified

KEY TO STRATEGIES:

Strategies (in the order in which they were interpreted):

- 1 I NTrg=Impairment/Needs Training
- 2 GOTrg=Group Occupation Training – Establishing Rules & Practices
- 3 Prx=Proximity
- 4 PS=Peer Support
- 5 AS=Adult Support
- 6 FCP=Facilitating the Child's Perspective
- 7 C&C=Challenge & Competition
- 8 Recip=Reciprocity
- 9 Adj=Adjustments
- 10 PP=Parent Participation
- 11 S Op=Sourcing Participation Opportunities
- 12 CTP=Collaborative Team Planning
- 13 CPS=Collaborative Problem Solving
- 14 COccProviding Cooperative Occupation
- 15 L Ex Linking Experiences & Contexts

KEY TO COLOURS INDICATING INTERVENTION APPROACHES:

-  Structuring Shared Occupation
-  Creating Opportunities to Experience Occupation with Others
-  Developing Supportive Friendships
-  Fostering Inclusive Communities
-  Rehabilitation Service Provision Models & Modalities for Participation

KEY TO EVIDENCE GRADES

(Turner-Stokes, Harding, Sergeant, Lupton, & McPherson, 2006, p. 97)

E=Expert Opinion

R=Research Evidence

P1=Primary Research—Quantitative

P2=Primary Research—Qualitative

P3=Primary Research—MixedMethods

S1=Secondary Research—MetaAnalysis of Existing Data Analysis

S2=Secondary Research—Analysis of Existing Data

R1=Systematic Review of Existing Research

R2=Descriptive or Summary Reviews of Existing Research

1=High Quality Studies-Score 7-10/10

2=Medium Quality Studies-Score 4-6/10

3=Low Quality Studies-Score 0-3/10

Direct=Evidence involving children with moderate to severe TBI

Indirect=Evidence involving children with other conditions

Citation & Intervention Name	Intervention Process/ Strategies	Strategies															Purpose/Key Outcomes	Intervention Approach	Comments	Context	Population	Time Frames	Evidence for Viability	Evidence Grade
		1 LNTg	2 GOTg	3 Pts	4 PS	5 AS	6 FCP	7 C&C	8 Recip	9 Adj	10 PP	11 S Op	12 CTP	13 CPS	14 COcc	15 LEx								
1-(Werts, Caldwell, & Wolery, 1996) Peer Modeling of Response Chains	Peers were taught how to perform steps of specific tasks, and how to describe the steps for peers. A peer modelled a task for each child daily. Manual guidance, task adaptation, & reinforcers were used in some instances.		2	3	4	5												Structuring Shared Occupation	1 teacher felt the modelling made the child more a "part" of the class. One teacher noted other occasions when children requested to teach the disabled child.	3 Elementary School Classrooms (1 kindergarten, 2 first grade).	Developmental delays, 1 with autistic features, 2 with genetic conditions. Ages 7 ½ -8. Ages of peers not identified.	Modeling took 4min 6 s/day. Duration of intervention is unclear.	✓ Teachers felt they would use the modeling procedure, but were not observed to do so.	P3 High Indirect
2-(Hendrickson, Shokoohi-Yekta, Hamre-Nietupski, & Gable, 1996) Non-disabled students perceptions of strategies that facilitate friendships.	Ordered strategies for teachers & schools: 1. Students working together 2. Information provision 3. Social activities 4. Peer tutoring 5. Circles of support 6. Teaching importance of friends Ordered strategies for parents: 1. Invite students to homes 2. Involvement in support groups 3. Transport disabled students 4. Work with schools & teachers 5. Volunteer in youth groups 6. Friendship with disabled adults	1		4 c o f						1 0				1 4	1 5			Structuring Shared Occupation	Questionnaire may have led to negative perceptions of students with disabilities. No analysis of impact of age. May not reflect actual actions. High number of students already had friends.	School & home	Ages 10-18. Severe disability.	N/A	N/S	P1 Medium Indirect
3-(Jacques, Wilton, & Townsend, 1998) Cooperative Learning	Model by Aronsen et al., 1978 and on Slavin's modification of this unit. Children learn individual tasks, then take turns teaching others in their group. Partnerships formed for helping. Easiest adapted sections delegated to child with disability. Rules posted outlining routine. Group test scores computed each week. Awards for highest scores.		2	3	4			7	8	9					1 4			Structuring Shared Occupation	Limited information regarding all strategies used. May vary from other cooperative learning approach. Based on this approach, a group with a disabled child is likely to have reduced achievement as scoring doesn't recognise group cooperation. Achievement was not assessed. Social acceptance was evaluated based on nominations of who children would invite to a birthday party.	School classroom.	Mild LD Age 9-12 years.	30 mins/day x 4/week x 6 weeks.	N/S	P1 Medium Indirect
4- (Kamps, Barbeta, Leonard, & Delquadri, 1994) CWPT	Classwide Peer Tutoring - Training on procedures - Tutoring teams. - Reading short passages same materials as normal tuition. - Tutor scores points for correct sentences. - Positive & corrective feedback. - Comprehension questions. - Reciprocal roles- roles reversed. - Bonus points for appropriate tutor-learner behaviours. - Public posting of points.		2	3		5	6	7	8						1 4			Structuring Shared Occupation	Study flawed- outcomes not demonstrated. Intervention would not be appropriate for students with more severe learning disabilities.	General Education Classrooms.	8-9 years. ASD High Functioning.	3 x 45 minutes training on CWPT. +25-30 minutes CWPT 3-4 days/week additional to normal tuition in reading.	Not established.	P1 Medium Indirect

Citation & Intervention Name	Intervention Process/ Strategies	Strategies															Purpose/Key Outcomes	Intervention Approach	Comments	Context	Population	Time Frames	Evidence for Viability	Evidence Grade	
		1 LNTg	2 GOTrg	3 Pds	4 PS	5 AS	6 FCP	7 C&C	8 Recip	9 Adj	10 PP	11 S Op	12 CTP	13 CPS	14 COcc	15 LEx									
5- (Lederer, 2000) Reciprocal Teaching	Reciprocal Teaching Structured active discussion of text with small group of peers. Textbook material adapted. Instruction to all students about asking questions about the text, summarizing and predicting. Small groups. Silently read text. Adult/student leader asks questions re content. Discussion by other members. Leader increasingly hands over lead to group.		2	3		5			9					1	4			All students had significant improvement in ability to answer & ask questions & summarise content of text.	Structuring Shared Occupation	Informal observations & teacher feedback suggested that disabled students were working well in a group, were engaged with the task and with other children. Social progress occurred.	School Classroom	4 th , 5 th , 6 th Grade LD	8 weeks Same time frames as typical teaching programme.	Teachers reported they would use Reciprocal Teaching. As staff changes occurred, this was not able to be followed up.	P1Medium Indirect.
6- (Stuart J. Schleen, Mustonen, & Rynders, 1995) Cooperatively Structured Community Arts Prog. Special Friends Prog.	Staff trained in Cooperative goal structuring Special Friends training for Peers- slide show & audio re interacting with children with disabilities, invitation to make friends, interaction strategies. Activities designed to elicit cooperative interaction delivered. Staff training re supervision, reinforcement Adult support from several professionals.	1			5								1	4				Significantly ↑numbers of Social interactions initiated by non-disabled peers. No change in reciprocations from students with disability.	Structuring Shared Occupation	Limited usefulness of outcomes measured. Unknown if increases maintained in other settings. Unclear if changes occurred due to interventions or due to increased familiarity with spending time together. Potential to single disabled children out as different (Misfit).	Art gallery & studio at Museum. Partial inclusive school.	Autism, Age 4-11.	7 mths.		P1 Medium Indirect
7- (Klavina & Block, 2008) Peer tutoring in Inclusive Physical Education	Peer tutoring- At teachers direction -Voluntary Peer training (TIP-TAP Steps). Students with disabilities attended 2 nd & 3 rd sessions. Teachers monitored the tutoring & intervened if behavioural difficulties occurred. Praise for collaboration.	1		3	4	5							1	4				↑ instructional & physical interactions ↑ activity engagement time Social interactions stayed low.	Structuring Shared Occupation	Adequate training needed for peers to ensure safety. No definition provided of "activity engagement time" or how the data informed the construct. No data as to whether interactions were maintained or were generalised outside the classes.	Inclusive General Physical Education	8-9 years Severe & multiple disabilities	Peer training. 30 mins/day x 3 days. Unclear how many sessions of peer tutoring occurred.	Teachers- feasible Peer tutors- 8/9 reported they would like to participate in future.	P1 Lower Indirect

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8- (John E. Rynders, Schleien, & Mustonen, 1990) Intensified Outdoor Education Integration	Camp Context Parents inform peers re children's activity preferences, needs & communication behaviours. Peer instruction through Special Friends Program, including similarities in leisure preferences, how to interact cooperatively, & how to assist. Role as friends not tutors. Adults taught disabled children steps for 2 daily tasks. Daily peer support for craft & outdoor education activity. Reinforcement of appropriate task behaviours & interactions.	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	↑no of task steps performed independently ↑initiations by peers not significant. ↑peer perceptions of friendship. ↑positive attitudes by staff.	Structuring Shared Occupation	Short time frame. No consideration given to disabled children's responses to change of environment & routines. Data does not support changes in Fit of understandings & actions.	Community-Camp	3 children with severe disabilities Ages 9-11	2 weeks	✓ Staff positive about the experience	P1 Lower Indirect
9- (Siperstein, Glick, & Parker, 2009) Inclusive Recreational Sports Programme	Based on principles of unified Sports Programming. -Co-operative -Non-competitive emphasis contribution to team, effort, belonging, & individual improvement. -Instructional -Team building activities -Activities novel for participants -Opportunity to freely socialise during meals, art & craft, field trips, and transport. Sports included swimming, basketball & soccer. Children transported together. Equal ratios of children with and without disabilities in each team. Instruction re sports activities.	2	3		5	6	7	8	9					14			a) 97% & b) 88% of non-disabled children nominated a) at least one disabled child they liked to hang out with and b) at least one disabled child as a new friend. Strong relationship between sports skills & success in building social relationships. All children demonstrated a significant improvement in swimming & soccer skills. No changes in basket ball skills.		Structuring Shared Occupation	Limited generalisability due to sample being all children with mild intellectual disabilities only and teams consisting equal numbers of children with and without disabilities. Children without disabilities may not have even realised peers were disabled. No description of how programme was funded. Extensive supports would have been required, and also physical resources (transport, food, sports equipment, gym, pool)	Community	Mild intellectual disabilities Elementary School. Non-disabled peers.	4 weeks.	Not assessed.
10- (Wilhite, Mushett, Goldenberg, & Trader, 1997) Paralympic Day in the Schools	PDIS Staff & Mentors led Paralympic activities during regularly scheduled PE classes. Students with and without disabilities viewed the Paralympic video, participated, & interacted with staff & mentors. Activities included wheelchair basketball, sitting volleyball, goalball, and wheelchair slalom.	2			5		7		9					14			PDIS helped understanding of difference. No significant changes in attitudes, and some attitudes were less positive.	Structuring Shared Occupation		Very poor quality study.	Physical Education Classes	Ages 11-21. Mobility or visual Impairments.	45-55 minutes. ? # sessions not stated.	N/S

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11- (Hobbs, Bruch, Sanko, & Astolfi, 2001) Structured Computer Play	Local Service Organisation provided Setting & Support Staff. Structured Inclusive Play with Computer Games; Systematic instruction Adaptive equipment & software. Peer Tutoring: Older children with increased skill teach children with disabilities. Assistance also provided by parents and/or older siblings. Staff increased level of Structure for Activities by arranging activities and prompting. Rewarded computer play with praise and attention.																	Increases in inclusive play for both structured & free-play sessions, but increases exceeded 90% for structured condition.	Structuring Shared Occupation	Limited Description of Support Given Limited Data provided constrains ability to understand if Computer play supported P. No control for extraneous variables (eg. familiarity) Includes useful recommendations from staff: Having adequate help Staff need proficiency in eqpt & activities Free play may have been influenced by learning in structured sessions given that same groups were involved. May not be suitable activity if seizure disorder. Suggests Actions changed as a result of sharing in activity that was structured to elicit collaboration.	Recreation Session @ Local Service Organisation	Age 3 ½ -12 6@disab 5 non-dis Cond/Diag not specified	30 mins for structured condition followed by 30 mins free play. Frequency & Duration unclear- ?/week for 2 weeks.	N/S	P3 Lower Indirect	
12- (Tan & Cheung, 2008) Computer Collaborative Group Work	Computer game that aligned with a curriculum topic. Incorporated mystery, adventure, curriculum subjects, and problem solving using clues. Student & 2 peers took 5 minute turns using the mouse. Facilitator reinforced positive behaviours & communication. Debrief on achievements after each session. No assistance provided with game.		3		5		7	8					14					Increases in peer acceptance (not well demonstrated by study)		Structuring Shared Occupation	Some evidence that interactions extended to the playground. Qualitative evidence suggests that increased interactions began to take place.	Classroom.	7 years. ADHD	10x 45 minutes over 2 weeks.	N/S. An education psychologist facilitated all the sessions.	P3 Lower Indirect
13- (Bolich, 2001) Peer Tutoring	Lists multiple types of peer tutoring, including, small groups, same age, and cross age dyads, and situations where the tutoring was delivered by students with disabilities, which promotes reciprocity and a role as a leader. Important features of Peer Tutoring include: minority students should be equal or higher status than majority students; close interactions should be promoted; mutual goals should be established. They should be readily implemented in different contexts and adequate time is required to establish routines.	2	3	4				8					14					Cooperative Behaviours Interactions with peers Peer attitudes & actions Behavioural improvements Skill development			Structuring Shared Occupation	Much of the review is focussed on development of social skills for disabled students, and several items discussed involved preschoolers or teenagers.	School- class and playground. Several items mention participants with disabilities from separate learning units.	Children with disabilities.	N/S	One item mentions teachers were satisfied with the intervention. The authors note that adequate time is needed to deliver the intervention.

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14- (Harper, Maheady, Mallette, & Karnes, 1999) ClassWide Peer Tutoring (CWPT) Classwide Student Tutoring Teams (CSTT)	Weekly competing teams. Random assignment of students to teams. Heterogeneous Groupings. Tutoring pairs assigned. Structured teaching procedure. Set time frames for tasks. Points awarded for pairs & teams. Teacher awards bonus pts for good tutoring behaviours. 2-4x/week, Weekly quiz/test. Role equality Mutual Assistance Shared Goals Interdependency Group Cohesion		2	3	4										1 4																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																							</

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16- (Brookman et al., 2003) Summer Camp Facilitating Social Interactions	<u>Aides trained</u> in behavioural strategies. <u>Participation in activities with peers.</u> <u>Goals-</u> Skills focus: ↑ social interactions - ↑ participation in activities <u>Self Management:</u> ↓ assistance ↑ autonomy <u>Peer Involvement:</u> - Facilitated & encouraged by aides ?& other staff. - Sharing exchanges - Seeking help from each other - Engaging in social conversation - Interacting during activities - Engagement in activities	2								10		12		14					No outcomes stated.	<u>Structuring</u> <u>Shared</u> <u>Occupation</u>		Summer camp on university campus	Autism Ages 4-10	1-3 weeks	N/S	E2 Indirect
17- (Hourigan, 2009) <i>-Expert Opinion</i> Performing Ensembles	Being part of a musical performance group. Sharing information about each other. Planning Events & Activities together with Peers A buddy or mentor is nominated for newcomers. Monitor accountability of buddy. Pair more-skilled students with student with disability. Prepare a joint performance item together, practice together for additional assistance. Teachers Model Inclusive Behavs: Greet students on arrival. Ask about their “activities and interests” (p. 35) Include icebreaker activities. Wear name tags. Share information about each other and about experiences as far as comfortable.	2	3	4	5		7	8				12		14	15				Reports Reduced Invisibility Minority Stdts. Incr Soc Awareness	<u>Structuring</u> <u>Shared</u> <u>Occupation</u>	Although the strategies are advised, examples in the report suggest the child is NOT participating at all. It is possible the examples relate to the child’s participation prior to the strategies being implemented.	Education-Music Junior High Middle School	Age 12-13 Boy TBI	N/S		E2 Direct Case Report
18- (Leach & Duffy, 2009)	<u>Variety of instructional formats for tasks:</u> Small group instruction, peer teaching, cooperative learning, hands-on learning centres, 1x1 instruction, computers, & whole group lessons to create Opportunities for Active Engagement. Groupings & position in classroom. Provide alternative ways for responding to questions/giving information. Compensatory adaptations to support function (eg. memory reminders). Adult Support should be Prompt-Fade in nature. Incorporate child’s preferences & interests into lessons.		3		5	6			9	10			13	14					Successful Inclusion Social Integration Academic engagement	<u>Structuring</u> <u>Shared</u> <u>Occupation</u>	Focus of most strategies is compensatory, & on those directed at the student to improve performance & minimise impact of impairments. - Not included into review.	General Education Classroom				E2 Indirect

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2) (Bernabe & Block, 1994) Modifying Rules of Regular Girls Softball League	Child's wishes explored. Child placed on team with receptive coach. Modifications to game developed by researchers & parents. Presented to coaches for feedback & further ideas. Involvement & Modifications introduced to all teams, attitudes surveyed Minimised focus on disability-focus activity. Team-mates practised skills to support. Child also taught skills.	1	2	4	6	7		9	10	11	12							-Child's batting average in the same range as peers. -On-base ave sig. less than team-mates. -Position safe. -Presence did not chg game for other players.	Creating Opportunities to Experience Occupation with Others	Perceptions of Satisfaction were not formally explored with this Quantitative study, but are outlined in discussion. It was also not explored how realistic this process was. However, the initial work was generated by parents & researchers. Minimal info provided to peers re child & disability-focus was on the activity & changes. Likely this enhanced fit.	Community-Sports Team	12 year girl Mod-Severe Phys & Cog dis, Behav	Unclear-possibly 1 season. Team played 15 games. Child absent for 7	Modifications to the game did not affect the scores of other players. Anecdotal evidence suggested she was well accepted by other players.	P1 Medium Indirect
3) (Bedell, Cohn, & Dumas, 2005) Parent Strategies to Promote Participation	Creating Opportunities -Organising/modify activity or phys/social environment. -Selecting peers to share activities. -Find & access opportunities for Participation. -Involve in family activities -Facilitate decisions & participation -Provide limited choice of activities. -Educate others re strengths & needs.	1		4	6			9	10	11								Social Participation promoted.	Creating Opportunities to Experience Occupation with Others	Strategy delivered concurrently with teaching skills & cognitive/behavioural regulation. Study provides limited information as to what happens when the parents implement the strategies.	Home and Community	School Age Childlren with ABI (7 TBI) ages 5-15 years. 16 mothers, 3 fathers.	Parents describe strategies as being delivered over long time frames.	Some parents also describe having inadequate time to implement the strategies.	P2 Medium Direct
4) (Scholl, Smith, & Davison, 2005) Together we Play- an Inclusion Service Delivery Model	A Service Delivery Agent. Coordinate and link between agencies, referrers, and parents to develop processes, provide assessment and personal support people, information about funding sources and other resources, information & training to support people, and information about resources and availability. Support sharing of resources.	1	2		5	6	7		9	10	11	12		14	15			Ensure opportunities to recreation and after school services. Stakeholders believed provided opportunities for Acceptance, positive benefits for children & peers. Parents had less belief in of benefits for more severely disabled children. Staff felt more training was required.	Creating Opportunities to Experience Occupation with Others	Lacks specific descriptions as to perceived benefits. Unclear which programmes were being attended by parents- problems may lie with particular programme(s). Surveys only completed by 8 parents.	Community Based Recreation Agencies.	Not specified	Not specified Training for Staff is a 1-4 hour workshop.	Parents had decreased belief in viability of adapting activities- felt it interfered with other participants' enjoyment. Coaches had decreased belief in viability of services for more severely disabled children. Instructors & coaches felt a need for more coaching. Fee for Service to Agencies resulted in many agencies withdrawing.	P3 Medium Indirect

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5) (Rosenberg, 2000) Inventory of Community Based Recreation & Leisure Opportunities.	<p>Respondents approached via key informants associated with youth sector, & advertising.</p> <p>Community Resource Inventory for Children with Physical Disabilities.</p> <p>Gathers info re resources incl: Demographics Activity descriptions Availability of activities Age & numbers of participants Staff size, credentials, training needed. Potential to address therapeutic outcomes Factors that might facilitate/limit for children with physical disabilities.</p>										1 1								Increase awareness of leisure resources available in community.	Creating Opportunities to Experience Occupation with Others	Study did not generate information about utility or value of tool.	Community	Children with Physical Disabilities. Age Non-specific.	N/A	N/S	P1 Lower Indirect
6) (Batorowicz, McDougall, & Shepherd, 2006) Community Partnerships based on Life Needs Model	<p>Describes 2 programmes established in collaboration with existing programmes.</p> <p>Storybook Reading Theatre Group</p> <p>Storybook was not run inclusively. A trial of including peers was unsuccessful.</p> <p>Drama was run inclusively.</p> <p>Collaboration and supports involved staff/child actors, clinicians, & for drama, Peer Mentors.</p> <p>Staff & child actors were enskilled in communication strategies by clinicians.</p> <p>Activities were adapted to enable participation.</p> <p>Programmes provided participation opportunities, which included creative activities, interaction, turn-taking, sharing experiences, humour, learning, and choice. Performances, expressing thanks. Take home activities, practice at home.</p>	1	2		4	5	6	7	8	9	10	11	12		14	15			<p>Community Partners, Parents, & Clinicians all gave positive feedback. Partners reported learning & sharing of expertise. Resources were obtained to support extension of programmes.</p> <p>Community awareness of collaboration was raised.</p> <p>Parents reported ↑ awareness of programmes, strategies to increase their children's skills. Particularly benefit from interaction with Peer Mentors.</p>	Creating Opportunities to Experience Occupation with Others	<p>Feedback not gathered from children.</p> <p>Children were not involved in establishing the programmes.</p> <p>Ages of peers/mentors not specified.</p> <p>NB: ** Parents were clear they did not feel comfortable moving on to enrol children in a general Community Drama Programme.</p>	Community: Library & Theatre.	Variety of physical & neurological conditions affecting learning. All children used AAC devices. Ages 3-12.	<p>Drama offered 1/year.</p> <p>Storytime: 5 x 90min sessions over 5 weeks.</p> <p>Drama: 5 x 180 mins over 5 days.</p>	<p>Parents- cost & timing was favourable. Very satisfied with programme.</p> <p>Community Partners- Valued learning from programme. Programme is being continued.</p> <p>*Low response rate for parent feedback.</p>	E1 2 Indirect Case Illustration- data gathered & evaluated.
7) (Becker & Dusing, 2010)	<p>Integration into Community Performing Arts Programme</p> <p>Modifications: rest area, child self-identified need for breaks.</p> <p>Adult supervision & 1x1 assistance faded.</p> <p>Voice recordings for home & practice</p> <p>Peers assistance- guiding, prompting, visual cues.</p> <p>Adult support: Facilitation of peer interactions, skill acquisition, problem solving, task adaptation, manual guidance</p> <p>Activity provided level of challenge and required skill development.</p>				4	5	6	7	8	9				14				Quality of Life- PedsQL (Varni, Seid, & Rode, 1999).	Creating Opportunities to Experience Occupation with Others	<p>Programme involved dancing and singing</p> <p>Participant received speech therapy and special education services.</p> <p>Physiotherapist provided advice re adaptations and supported skill development in child specific to performances.</p>	Community Arts Programme	11 years, Downs Syndrome (peers = 8-14 years)	90m/week Programme ran for 14 weeks	Case Report identifies that the strategies made participation feasible.	E1 2 Indirect	

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8) (Fennick & Royle, 2003) Inclusion in Community Recreation Activities- Swimming, Gym	Partnerships with Community Rec. Agencies Identifying needs, Establishing goals, Solutions to problems with family Information, Adaptation Adult support: Community Instructors require training & time to become familiar with child, build trust with family and learn how to make adaptations. Also needs enough info. Role answering qs from peers. Modeling strategies for Community Instructors. Fading sppt. Partner child @ other chn. Used adaptive eqpt to address sensory & motor issues, as well as adaptation of activity/envt.	1			4	5																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																													</

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10) (Moran & Block, 2010)	Participation in Youth Sports Strategies to eliminate barriers.- <u>problem solving based on the child and the game.</u> Adaptations to games Education and collaboration with coaches Peer tutors Promoting team cooperation Adult volunteers Education Marketing about inclusion of children with disabilities Diversity of programming Combining resources with other communities to create opportunities. Flexibility- different levels of competition Collaboration with parents.	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	Participation in Youth Sports	<u>Creating Opportunities to Experience Occupation with Others</u>	Education to focus on similarities and Abilities as well as Disabilities, and emphasises Collective use of strengths. . Education relates these features back to what to do to enable the child to participate in the sport. Adult leaders should be open with parents about gaps in their knowledge and their willingness to learn. Fliers/marketing should identify that participation of children with disabilities is encouraged. Diverse programming: Facilities should offer recreational programmes as well as providing for skilled levels of participation. Combine resources with other communities. Allow older players to be involved with a younger age level.	Community Sports	N/S- Children with Disabilities	N/A	Cites practical examples from experience.	E2 Indirect
11) (Scholl, Dieser, & Davison, 2005) Ecological Approach to Inclusive Recreation. Together we Play- an Inclusion Service Delivery Model	*Agency provides information about available recreation activities *A Community Coalition was Formed. *Funding gained. *Agency Collaboration.- Social service agencies, general recreation service providers, & parents of disabled children with existing community programs. *Certified Therapeutic Recreation Specialist, Adult Leisure Companions *Team approach to deliver inclusion services. *CTRS Interview child, parents, teacher, assess childrens abilities & progress in conjunction with IEPs. Match programme to abilities. *Information & guidance for agencies to adapt their programmes. *Evaluate programme	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	Y- in part- cites numbers of agencies utilising and providing services, and numbers of children/families accessing the service. Reports on child outcomes for one case. Case Study <u>does not provide data as to parent & stakeholder perceptions of the success of the project.</u>	<u>Creating Opportunities to Experience Occupation with Others</u>	Case Report-	Community leisure agencies	Children & young people aged 3-18 with high incidence disabilities such as cerebral palsy, learning disabilities, cognitive disabilities & autism.	Agency has been running for 4 years at time of publication.	Not discussed. May not be realistic to implement specifically for children with TBI due to scattered locations around the country.	E2 Indirect Report

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Creating Opportunities n = 11																										
1) (Frederickson & Turner, 2003) Circle of Friends	Gain Management Support. Need 30-40 minutes staff time/week 6 weeks. Gain consent from students & Parents. Class Discussion with disabled student absent from room. Ground rules, Identify students strengths and areas of difficulty. Talk about friendships, generate ideas to support friendship for child. Seek volunteers & recruit 6-8 peers. Child helps identify target goals Weekly problem solving meeting to ID goals for the week & solutions.	1		4		6						1 2	1 3					Statistically significant improvements in child's ratings by peers for how much they would like to play with other children in the class for COF intervention but not for control condition. Statistically significant improvement in child's self worth for second group. No changes in child's behaviour.	Developing Supportive Friendships	Common goals for the COF included addressing teasing & bullying, managing and respecting feelings, making new friends, listening to others, sharing/turn-taking, fair play, being assertive, adult interactions, appropriate language, & improved organisation & work production. Study does not inform as to child's involvement in activities with peers. Assessments may not translate to action. Very short term study. Inadequate description of school setting (eg. Inclusive?)	Schools	6-12 year old children Behavioural & emotional difficulties.	6 weeks & 12 weeks.	Not Addressed	P1 Medium Indirect	

Citation & Intervention Name	Intervention Process/ Strategies	Strategies															Purpose/Key Outcomes	Intervention Approach	Comments	Context	Population	Time Frames	Evidence for Viability	Evidence Grade
		1 LNTg	2 GOTg	3 Pds	4 PS	5 AS	6 FCP	7 C&C	8 Recip	9 Adj	10 PP	11 S Op	12 CTP	13 CPS	14 COcc	15 LEX								
2) (Eriks-Brophy et al., 2007)	Parent Support Group Parents Facilitate Friendships- -Home open & welcoming to other children -Transport children to social activities -Hold sleepovers, & parties. Enrolment in Sports & Social Activities Parents take leading roles in sports & community activities (eg. coach, volunteer) leads to opportunities to educate others.	1				5		7	8	9	10	11			14	15				Community	Young Adults Hearing Impairment. Orally taught.	N/S	Parents felt the strategies were demanding but carried them out to support their child.	P2 Medium Indirect
3) (Heyne, Schleen, & McAvoy, 1994) Making Friends Prog. Recreation Activities to Promote Friendship between Children with and without Disabilities. Presents facilitators and barriers coming out of the FP interviews. Barriers incl: ↓s/skills, ↓comm, families not acquainted, need for info re dis, ↓common interests, ↓communicates for family	<u>Structured & Informal Recreational Activities</u> -Adapt activities -Support Partial Participation. -Cooperative Activities. -Collaboration -Non disabled students = prob solving. -Parent Involvement -Recruit non-dis students. Teach interaction skills in Curriculum. -Peer tutoring or Companions. Tutors = Skills Acquisition Companions = social ints. -Prepare other Adults; Integr Facilitators- Other Adults- prompt +ve interaction, reinforce, redirect. -Environmental Analysis -Acquainting other families, invitations on outings & to homes, learning re needs, talking re f/ship at home, encouraging +ve soc interactions, -Knowledge of rec resources, incl soc/rec skills in curriculum, involving families at school, incl friend/rec goals in IEP, offer disab awareness training at school to parents/non disab chn, educate staff, provide co-op activities. -Focus Gps support planning.	1	2		4	5				9	10	11	12	13	14	15				School & Community	K-G6 Elementary School	3 years	N/S Potentially demanding for Staff. Query the long-term viability unless part of a committed school community. TBI children geographically scattered.	P2 Medium Indirect

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4) (Glang, Todis, Cooley, Wells, & Voss, 1997) Building Friendships Problem Solving Process	Adult Facilitator- (Teaching Staff) -Attends 1-day workshop- Information re TBI & Social issues, Building Friendships Process, Strategies, Practice & Feedback. -Obtain information about pupils current friendships. -Recruit 4-8 team members -Strategies developed with team- different for each child- included weekly lunch meetings with activities (not cooperative), education about child's experiences, generalised Friendship group that hosted lunch meetings & a dance, teaching a friend about the child's needs, & involvement in community activities.					5	6				10	11	12	13						School	3 males, age 8, 11, 13 with TBI.	10-12 weeks.	Facilitators were paid to take part. Needed to devote 2-3 hours/week over 4 months. Did not involve teachers.	P3 Medium Direct
5) (Nota, Ferrari, & Soresi, 2005) Willingness to help & be Friends	Receiving information regarding disabled classmate's needs for companionship & help	1																		Elementary School.	Down Syndrome vs Child in Wheelchair.	N/A	Not Addressed	P1 Lower Indirect

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6) (Callaway, Sloan, & Winkler, 2005) Practical strategies to facilitate friendships.	Educate friends re TBI sequelae & strategies to support person's engagement, understand risks and implement boundaries. EARLY STAGES Welcome friends to rehabilitation facility. Involve friends in therapy activities Role model practical skills. Work with friends to identify occupations they can share in and support engagement. Support participation in social routines (eg. birthdays) Develop interests in community activities. Restructure communication channels to maintain contact. Collect contact details & update. Send thankyou cards & emails Develop & circulate newsletter	1	2	4				8			1	1		1	4	5					Friendships are maintained and developed.	Developing Supportive Friendships	Many recommendations based on unpublished data. Recommendations derive from clinical experience. Focus is friendships rather than support networks.	Focus is during in-patient rehabilitation.	General-some strategies may not be appropriate for children.	Early stages of rehabilitation.	N/S	E2 Direct	
7) (Salend, 1999) Facilitating Friendships	Teach about Individual Difference- Role Models, Curriculum Activities, sharing information about individual interests, abilities. Teach Meaning of Friendship- Development of Social skills, Depiction of Friendships, Activities & materials directed at/depicting Friendship (music, books, drama, & art) Teach Skills to Communicate with Students with Disabilities. Establish friendly class environment- vary the seating plan, learning centres, accommodations to activities, activities & toys that promote social interactions, activities to help students get to know each other and establish class cohesiveness. Cooperative groupings for activities. Teach games that are non-competitive, easy, and which can be played as a team during recess. Activities that require collaboration. Peer support committees- to ensure all students are valued and accepted. Buddy and Partner systems. Participation in Extra-curricular activities. Involve family members- create opportunities outside school, invite friends home, outings, study groups, games & activities to promote friendship, provide transport, volunteer. Leisure education to be aware of, select and participate in integrated recreation activities.	1		3	4		6		8		1	0	1		1	4	5					Facilitate friendships Acceptance Community	Developing Supportive Friendships	Emphasis is on Content of Activities and Materials rather than the interactions that take place during an activity. Some activities unsuitable for older children. Teaching about individual difference is conflicted- explains to focus on similarities, but also to appreciate the value of individual difference. Limited evidence cited for the effectiveness of the activities.	Class, recess, & community	Not specified.	N/A	N/S	E2 Indirect

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8) (S. J. Schleien, Green, & Stone, 2003) Inclusive Community Recreation Programs	Outlines strategies that can be delivered as adjuncts to Community Recreation Programmes to support development of Friendships. These include: ----- <u>Sociometry</u> . Identify popular peers & those who can serve as "gatekeepers" to groups, re-structure groups & place children in groups who attraction. Popular peers can be recruited to be "companions". ----- Circle Of Friends, ----- Cooperative Peer Companions, ----- <u>Family Involvement</u> ; take opportunities to meet other families, organise & reciprocate visits & outings, provide info to peers, gain list of possible friends from teacher. ----- <u>Family Advocacy Groups</u> . Inform others re benefits of friendships & strategies to develop & maintain them. Presentations, slides, videos, Increase community awareness & support.	1		3	4				8		10	1	1	2	3	4																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																												

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3) (Janney & Snell, 1996) Teachers use Peer Interactions	<p>New Rules about Helping. Peers encouraged to help child with disability in addition to adult supports. Rules around when to help. Helping behaviours modelled by teachers. Peers were not allowed to help each other, only the child with the disability.</p> <p>Just Another Student. Maintain child's physical presence and involvement in routines through adaptations & accommodations. Expectations to follow rules.</p> <p>Age Appropriate Interactions. Normalise appearance, materials. Prompt age appropriate interactions.</p> <p>Backing Off. Peers provided with time and opportunity to interact with child without adult interference.</p>		2	3	4	5				9									Peer Interactions facilitated.	Fostering Inclusive Communities	Unintentional consequence of helping behaviours was that peers developed parent-like/ teacher-role relationships towards child and relationship was no longer reciprocal. Decisions were made for the child.	Elementary classrooms and over recess where students were being integrated into general education.	Age 5-9. CP & MR. Mod-Severe Disability	N/S	N/S	P2 High Indirect
4) (Mortier, Van Hove, & De Schauwer, 2010)	<p><u>Supports for Children with Disabilities in regular classrooms</u>- Flanders</p> <p>Adult Support- ways of working to incr Participation. Help with task Not exclusive focus on child Task adaptation Time adjustment Rest/escape Staying with others Promoting Inclusive actions Flexible planning Parent involvement &communication Sppt from disabled peers Providing info re disability Bridge school & home Communication with Parents Support from Disabled Peers.</p>	1		3		5				9	10		12			15			Inclusion	Fostering Inclusive Communities	<p>Not focussing solely on child with disability.</p> <p>No details provided re type/severity of disability</p> <p>Children appreciate support but like to be as independent as possible.</p> <p>Having a child with supports can complicate the teaching process, but is Satisfactory when a good working relationship is forged/t-aide doesn't interfere with teacher's role.</p> <p>Teaming & communication is important to parents.</p>	School	Age 5-17 ?Disability Parents, teachers	N/A	N/S	P2 High Indirect
5) (Richardson, 2002) Interactive Processes	<p><u>Peer Reciprocity</u>: Provide opportunities to help or contribute Accept child's help Give the child help Respond to requests for help Don't help unnecessarily.</p> <p><u>Adult Support</u>: Not interrupting or removing from play Not treating differently Not constant provision of assistance or praise.</p> <p><u>Play Interactions</u>: Responding to child's initiations Adequate engagement in play supports peer interaction.</p>			3	4	5	6		8			11			14				Social Interactions with peers occur and these interactions are of better quality.	Fostering Inclusive Communities	Does not describe how these behaviours come about or how they can be promoted. However they play a role in increasing involvement in shared activity.	School	Children with Physical Disabilities only Ages 5-8 years.	N/A	Not Addressed	P2 High Indirect

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6) (C. L. Salisbury, Gallucci, Palombaro, & Peck, 1995) Teachers Strategies	Active Facilitation of Interactions Cooperative grouping- desk positions, placement in activity groups with receptive students. Collaborative problem solving with peers. Class meetings, listen to concerns, generate solutions with students. Structuring time & opportunity for choice of activity and peers. Building community in class. Develop attitudes & values. Model acceptance. Multi-age classes, maintaining some peers from previous year to provide continuity of support.			3		5	6							1 3	1 4	1 5				Positive social relationships	Fostering Inclusive Communities	Although question asked in interview, data doesn't inform re which strategies were more effective. Unclear if student is involved in problem solving.	Inclusive School Classrooms	6-12 years. Mod-Severe Disabilities.	N/S	N/S Presumably viable as teachers were using the strategies.	P2 High Indirect
7) (Causton-Theoharis & Malmgren, 2005) Training for Paraprofessional staff	Training included 4 hr 1x1 inservice directed at facilitating interactions between child & peers. Drew from Ghere, York-Barr & Sommerness, 2002. - Enhancing perspective of students' social relationships - Establishing importance of peer interactions - Clarifying PP's role in facilitating interactions. - Teaching strategies to facilitate interactions: Modeling Highlighting similarities Identify strengths Teach interaction skills to peers Interpret behaviours for peers Partner students. ↑ proximity to peers Minimise removal Direct peers queries to student Fade assistance Integrate home experiences into conversations Use interactive technology Use Interactive rewards Give student interactive classroom responsibilities.	1 +		3	4	5	6							1 4	1 5				Frequency of Teacher Aide facilitations ↑ x 2 Frequency of Interactions with peers ↑ x 25	Fostering Inclusive Communities	Not stated if interactions occurred outside the classroom Not stated if task performance was promoted. Informal feedback from 1 teacher & 1 parent supports findings. 1 child was invited to play out of school by peers.	Inclusive elementary school classroom.	Severe Disabilities 2 ASD 2 CP Ages 6-11	Observations over 9 weeks after intervention with teacher aide.	N/S	P1 Medium Indirect	

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8) (Bentley, 2008) Lessons from the 1%.	Other children instinctively used inclusive actions when the child was present for activities in an inclusive setting. Dynamic Assessment of Communication Interpreting Behaviour Ecological Assessment of Support Needs Partial Participation Transition Planning Recognising as a Friend Re-Imagining Disability & normalising stories Sharing Medical Experiences. Circle of Friends (COF) Approach: Peers volunteer to help & interact with child. Peer tutors for schoolwork, play games, cook, do art projects. Adult Supports Provided	1 +		3	4	5	6						1 2		1 4	1 5								
																		Fostering Inclusive Communities	Bentley's study was not clear as to what was resulting in the children's Inclusive Actions. However it was an Inclusive Setting. COF Approach also implemented, as were familiarisation strategies, although these were not clearly reported. Reports lack of inclusive practices by staff & therapists, although these were not clearly described. Others argue that simply "being there" is not enough (Odom, Demchak & Drinkwater, 1992) NB For this item, strategies are those implemented by adults as it is assumed these brought about the peers' actions.	School-Classroom COF- Life Skills Classroom	12 yr old girl Rett Syndrome	N/S how long child had attended school. COF 15-20 mins 1-2x/week at end of school day.	N/S	P2 Medium Indirect
9) (Hemmingsson, Borell, & Gustavsson, 2003) School Assistants.	School Assistants: Proximity to student Availability of Help Type of Help- training skills -Supporting task -Adapting task -Including peers in adapted activity -Including peers in Reaching Solution Student's participation in Decision Making			3		5	6		9					1 3	1 4			Fostering Inclusive Communities	Very few examples of types of help/tasks/skills trained/peers responses. Lacks clear definition of terms. Satisfaction is dependent on style of support- Back up assistance is favoured by teachers who emphasise learning by doing and adjust the curriculum, while stand-in assistance is favoured by teachers who emphasise learning by knowing. Students accepting of support when it facilitates social participation, but rejected it when they perceived it limited inclusion.	School. Class levels not described. 2 Special Ed Classes.	7-15 years. Include 1 child between 10-12 yrs. Phys Dis. (CP, SB)	N/A	N/S	P2 Medium Indirect

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10) (Janney & Snell, 1997) Strategies used by teachers	Posits degrees of participation Teacher role modifications Assign peer helpers, cues. Treat student the same. Adapt materials. Parallel instruction from aide. Class routine & physical environment modifications to keep student near peers in similar seating Includes adults & peers providing help & cues. Timing & location of activities changed. Activity modifications.- Activity, method, materials.																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																								

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12) (Hunt, Alwell, Farron-Davis, & Goetz, 1996) Creating Socially Supportive Environments Designed to Facilitate Social Inclusion. Interactive partnerships between children with and without disabilities. Education provided to Aides by inclusion support teacher 3 times in context of normal daily routines. Education to peers supported by modelling of strategies and "ongoing feedback". Classmates without disabilities were taught by teaching &/or therapy staff about communication signs used by one of the children at a club. Supported by learning "stories, poems and songs" in sign. Another club for a different child used group problem solving to come up with solutions for participation-based issues identified in discussion.	-Instruction to Classmates & Paraprofessionals in Context of Daily Activities & ***Club Meetings. -Support staff provided interactive materials & activities for learning and play sessions. Identifying "media" (interactive activities) that can form the basis for interactive exchanges scheduled throughout the day. Included interactive games, and cooperative educational tasks. -Club Meetings set up. These included a Support Circle for one child, a Sign Club (communication) for another, and a Recess Club (games focused) for another. Children recruited via class announcement. Included initial games/icebreakers. Agenda reviews Discuss concerns for students. Group Problem solving. -Buddy system set up- each child had peer partner for the day who sat next to them in class, and accompanied them at other times and areas of the school (eg. recess, cafeteria). Buddies were communication partners, & joined students in written, meals, art, outings, stories, & maths. -Provision of Adapted Communication Technology. -Peer Problem Solving. -Programme delivered by Teachers, ParaProfessionals, and Therapist. -Positioning to support Social Interactions -Full time Aides & Inclusion support teachers: Prompting & Interpreting Communicative Exchanges, Organizing & Running Clubs, Arranging physical environment to promote participation	1		3	4	5				9				1	3	4								
																	Increases in reciprocal interactions with peers where there was both an "initiation & an acknowledgement" (p.56). ↑initiation of interactions by students with disability No increases in requests or protests.	Fostering Inclusive Communities	Presence of Adults through much of intervention may hinder participation Not focused on all aspects of participation. Not aimed at community. Potentially unrealistic to expect teacher to deliver this instruction throughout the day. Authors acknowledge this. Data re this issue not gathered, and much teacher data not reported. Instruction re child with disability may single the child out/highlighting difference, although could be delivered positively. Could a therapist deliver this instruction? No- unlikely to be funded Very Limited Analysis of Qualitative Data Limited data presented re quality of interactions changes in this quality. Over-focus on Disabled Student may highlight difference, decrease Fit (refer p. 58). Teachers perceptions of long-term viability of intervention not explored/described. Full-time Para-professionals.	Elementary School, \school club, playgrd	N3, 2x7y 1x12 Severe and multiple Disabilities	3 ½ - 7 mths	Extensive programme	P3 Medium Indirect

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13) (Ison et al., 2010)	<u>Just Like You Disability Awareness Programme</u> - based on Cognitive Behavioural Approach 2 sessions of discussions, written activities, equipment demonstrations, & disability simulation activities.	1															Significant improvement in Knowledge, Attitudes, Acceptance	<u>Fostering Inclusive Communities</u>	Training included presentation by person with disability. No information re types of disabilities involved 2 Week Follow-up Only.	School	Age 9-11 y.	2 x 90m sessions	6 Teachers Satisfaction – fit with curriculum	P3 Medium Indirect
14) (Martinez & Carspecken, 2007)	Books re children with various disabilities. Brief Intro to Book 3-5 Facts re Disability Book read aloud to Class Discussion re plot, disab, similarities with typical chn.	1 +															Significant group effect for overall attitudes, defined by acceptance of peers with a disability/special needs & expressed in questionnaire. Over ½ children expressed would be friends with book character, especially if they look fun, are humorous, & they do activities child values.	<u>Fostering Inclusive Communities</u>	Changes in reported attitudes may not equate to Actions. Potential biases in study may have influenced findings.	Urban Elementary School predominatl y Latino children. Age 8-10. ?Not stated whether Inclusive Ed.	Did not involve children with disabilities.	6 times in 5 weeks.	N/S	P3 Medium Indirect
15) (Adibsereshki, Tajrishi, & Mirzamani, 2010)	8 x 45 minute sessions (?over how long) Material presented about differences and disabilities, including movies, stories, equipment, & large pictures. Questions and discussion were facilitated. Information was included about communication problems disabled people have and alternative means of communication were introduced. Information was provided about services used by people with disabilities.	1															Significant increases in acceptance by peers occurred.	<u>Fostering Inclusive Communities</u>	Intervention engenders a “them and us” attitude, and embodies a limitations focus. Although focused on improving attitudes, has the potential to increase sense of difference. Unclear from the study if attitudes might translate to inclusive actions.	Inclusive elementary school	Grades 3-5.	8 x 45 minute sessions	N/S	P1 Lower Indirect
16) (Hutzler, Fliess-Douer, Avraham, Reiter, & Talmor, 2007)	1 hour spent with eyes covered, legs tied together, one arm tied to body, or sitting in a wheelchair etc. Experience of simulated disability.	1															Significant intervention effect-increase in attitudes towards including children with disability.	<u>Fostering Inclusive Communities</u>	Intervention has potential to emphasise that source of difficulty lies with person with disability. Doesn't inform re maintenance or enactment of attitudes. Lack of information re meaning of test scores. *Suggests need to consider development of theory of mind/executive function re ability to empathise with others who might be different.	Center for people with disabilities.	General-suggests people with physical disability.	1 hour + discussion.	N/S	P1 Lower Indirect
17) (Dumas, Bedell, & Hamill, 2003)	<u>Routine, repetition, consistency.</u> Includes preview/Review. <u>Supports & Models</u> Involve peers in therapy. Buddy in class & when leaving classroom. Role models & product models. Liaise with person with similar experience. Promote choices & goal setting. Training for staff.			4		6			9			1 2			1 5		Activity performance and participation.	<u>Fostering Inclusive Communities</u>	Emphasis is on classroom/School Limited focus on peers. Actual outcomes of strategies not explored with research. Rehabilitation stage is important consideration.	General	Acquired Brain Injury. Age not specified, although stated as an important consideration .	N/S	N/S	P2 Lower Direct.

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	<u>Curriculum & Environmental Modifications</u> Collaboration with all team members. Frequent review. Computers. Communication is an important consideration.																								
18) (Mortier, Hunt, Desimpel, & Van Hove, 2009) Parent/Teacher Collaborative Teaming Model, based on Unified Plans of Support model	-Open Process -Regular scheduled team meetings -Include WHOLE team -Problem solving approach to develop supports -Focus on specific daily Classroom Activities -Flexibility to change ineffective supports -Accountability system. <u>Examples of Strategies include:</u> Teacher Support Buddy Support Behavioural Reinforcement Responsibility for tasks Positioning relative to teacher. Repetition Adaptation & Variety Choice Adapt duration of tasks.		3	4	5	6			9		11	12	13					↑Academic progress (?) ↓ Time spent not engaged in activities ↑Reciprocal interactions ↑Student initiated interactions	<u>Fostering Inclusive Communities</u>	Fit with IEP Process. However, meetings are more frequent, and focus on actual classroom activities rather than curriculum areas. Small sample only provided of actual strategies. Inadequate evidence of academic achievement.	General Education Classroom	Ages 5-9 years Downs & DD	25 weeks	Team saw support items as practical Meetings were efficient. Authors suggest time should be made available for meetings.	P3 Lower Indirect
19) (Pavri & Monda-Amaya, 2001) Strategies used by teachers	<u>For all students:</u> <u>In Structured time</u> Schoolwide Programmes 42% Grouping students 37% Acceptance, respect & belonging 28% Collaboration & interaction 22% Group Problem Solving 9% Academic assistance 8% <u>In Unstructured time</u> Encourage interactions 43% Class jobs & games 13% Time with teacher 18% Teacher intervention 14% <u>Peer Directed Strategies</u> Group Problem Solving 42% Grouping 16% Encourage interactions 10%	1	2	3		5					11	13					Students develop social relationships, feel comfortable, feel valued.	<u>Fostering Inclusive Communities</u>	Only qualitative data considered as quantitative data did not incorporate specific strategies. Overlap of strategies Strategies lack explanation, illustration, or expansion of themes, and therefore have limited utility. Study does not inform as to whether strategies were effective, only that teachers were using them. Satisfaction reported by teachers not by students.	General Education classes	Ages 9-12 LD	N/A	N/S- presumably some viability as teachers were using these strategies.	P3 Lower Indirect	
20) (C. Salisbury & Evans, 1993) Collaborative Problem Solving Strategy	Teachers trained in using Collaborative Problem Solving Process with students to include students with disabilities.	1											13					Inclusion in Education Activities	<u>Fostering Inclusive Communities</u>	Poor quality report. Inadequate description of design, methods and inadequate presentation of data. Includes CPS Resource. Unable to be determine relevance to aspects of Participation.	?Elementary Schools, Kindergarten. ?Inclusive	? Severe Handicaps Grades K-4?? Unclear	3 years	N/S	P3 Lower Indirect

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21) (Higgins, MacArthur, & Kelly, 2009) Including Disabled Children at School: As Simple as ACD: Positive Acknowledgement of Diversity	Positive Acknowledgement of Diversity: Mirror a Family: Include children of different ages & abilities Respect everyone Turning what might be considered negative behavior into positive challenges and learning opportunities Providing Opportunities alongside Peers for Children to exercise Agency and Capabilities	1 +	2	3		6					1	1		1	4																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																						

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24) (Harrower & Dunlap, 2001) Review of strategies for including children with Autism in general education classrooms.	<p><u>Antecedent Procedures</u> Altering routines or environments. Priming, prompting (including prompting via peers), & picture schedules.</p> <p>(Behavioural strategies.)</p> <p><u>Self Management</u></p> <p><u>Peer Mediated Interventions</u> Peer Tutoring Peer Supports Cooperative Learning</p> <p><u>Multi-Component Intervention</u> Information to classmates during normal routines & club/class meetings, interactive communication media, rotating buddy system, staff prompts.</p>																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																					</

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	f- Multiple Peer Supports																	e- Improved engagement & increased social interactions. <u>Improvements may not generalise outside class.</u> f- Dramatic increases in numbers & quality of reciprocal interactions (ref Hunt et al 1996; 1997)		cooperative groups than others. e- Social interactions may not generalise into other settings.					
26) (Causton-Theoharis, 2009) The Golden Rule of Providing Support: Support Others as you would wish to be Supported.	Positioning: relative to teacher, relative to other children, of Teacher Aide relative to Child, of Activity. Peer Support Adapt Activities: Modify Materials, Content, Instruction. Eg. enlarged handouts, adaptive paper, a word-bank, making tape to steady paper, reducing no. problems required to answer Environmental Cues Positioning Plan to Fade Support		3	4	5			9										Inclusion	Fostering Inclusive Communities	Recommending strategies in context of providing adult support. Provides a number of specific, practical strategies that are described in detail.	School	N/S Children with Disabilities	N/S	Realistic	E2 Indirect
27) (DeZonia, 2009) <u>Positive Humanising Narratives</u>	Sharing Stories. Things others can relate to. Common interests	1												1 5				Gaining Acceptance Moving towards Community Connections	Fostering Inclusive Communities	-Reduce mystery, unknown, perception of difference. -Promote connections -Help train new caregivers. -Promotes sharing experiences.	All settings	All ages & Disabilities	N/A	N/S	E1,2 Indirect
28) (Meadan & Monda-Amaya, 2008) Social Support Structure	Propose 3-level Social Support Structure: <u>Level One</u> -Structuring a classroom community; <u>Level Two</u> - Strategies & curriculum to promote social competence; <u>Level Three</u> - Individual Interventions. <i>Level One is directed at the Social Community surrounding the child.</i> <i>Accepting Class Environment:</i> - Clear, positive rules & expectations. - Disability awareness & acceptance. Use curriculum & materials that portray a range of diversity. Promote connections with disabled adult role-models. - Culturally responsive classroom. - Welcome collaborating partners. Model collaborative interactions for students. Involve volunteers & support personnel from the community. Train paraprofessionals to promote positive peer interactions. <i>Place/Voice for each Student:</i>	1 +	2	3	4	5	6		9		1 1			1 4	1 5			Maximise academic & social success. <i>- promote a socially accepting environment.</i> <i>- increase social competence in all students</i> <i>- prevent or positively address socially inappropriate behaviours.</i>	Fostering Inclusive Communities	Foster environments that Value Diversity Argues the need to connect between social competence and instructional goals, but fails to build argument adequately. Adequately argues need to take into account classroom & school-wide structures that will affect social interventions. Although not part of the model, the discussion talks about promoting the child's autonomy. Does not provide evidence that these strategies are effective. Limited detail as to how to carry out the strategies.	School-classroom & recess.	Students with Mild Disabilities	N/A, although some strategies need to be conducted early in the school year.	N/S	E2 Indirect

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	<p>- Class jobs & responsibilities.</p> <p>- Promote individual talents/interests.</p> <p>- Promote membership & belonging; acknowledge unique perspective & contributions, share in class decisions. Reinforce respectful dialogue. Stress individuality through curriculum choices & adapted instruction. Share experiences, achievements, work.</p> <p><i>Opportunities for Social Interactions</i></p> <p>- In-class activities such as centres, flexible grouping.</p> <p>- Peer mediated learning such as Co-operative learning & peer tutoring.</p> <p>- Structure out-of-class interactions (eg. group games, recess).</p> <p>- Encourage collaboration (eg. group/pairs projects).</p> <p>*Open communication of differences, concerns.</p> <p>* Mutual linking- students encouraged to know their classmates</p> <p>*Shared goals</p> <p>*Connectedness, trust, safety.</p>																										
29) (Mickel & Griffin, 2007)	3 Day teacher Workshop: Creative Simulation Activities Lectures Reflective Journaling Inclusive Social Gatherings & Discussion Panels- sharing experiences through conversations with people with disabilities. Skits Teacher Resources- includes activities to help class members share similarities & differences with each other.	1 +												1 5				Inclusion- understanding & acceptance by staff & students. Teachers learn how to include children of all abilities in General Education Curricula.	Fostering Inclusive Communities	Limited reporting of Actual Outcomes. Emphasis- children with Sensory and Motor Disabilities.	School	Teachers	3 Day workshop	N/S	E2 Indirect		
30) (Roger, Gorevin, Fellows, & Kelly, 1992)	School Site Integration Task Force Information sessions for parents & staff, emphasize similarities & differences. Peer tutoring Peer Support Networks/Buddies Peer Involvement in Planning Proximity	1 +	2	3				9	1 0		1 2	1 3	1 4				-“Integrate students with mild-severe disabilities into their school sites” -“Team building” & “Collaboration” -Deliver effective programes -“Develop...a belief that everyone has gifts & talents to	Fostering Inclusive Communities	Multiple strategies from other resources included in workshop- very limited details provided re the strategies & minimal discussion of evidence regarding their effectiveness. Some strategies may limit rather than Facilitate Fit by Emphasising Difference.	Education & Community	School Age students Integrated Setting	N/S	N/S	E2 Indirect			

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School Sites.	Modeling Inclusive Behaviors McGill Action Planning System & Friendship Circles Adaptations Grouping for cooperative activities																offer". (p.9).							
31) (Stivers, Francis-Cropper, & Straus, 2008) Month by Month guide to strategies teachers can implement with families and community agencies.	Welcome letter including expression of commitment to Inclusive Education. Regular communication using variety of creative strategies. Present program in collaboration with paraprofessionals. Recruit parent volunteers. Include extended family/supports in conferences. Public performances with opportunities for all students. Promote involvement in extra-curricular activities. Provide books that portray people with disabilities accurately & positively. Share student learning with family. Involve families at picnics/field days & provide adapted games/sports. Awards for persistence & determination	1 +							9	1 0	1 1	1 2		1 4	1 5		Community appreciation of Inclusive Education and their role in its success.	<u>Fostering Inclusive Communities</u>	Provides details & examples of exactly how to implement these strategies and how they will affect families/children.	School & community	Families of children with disabilities, and Community agencies.	N/A	Notes at end of article the extra demands these strategies will entail but argues for the rewards that come with them. Strategies are fitted with tasks that are occurring anyway.	E2 Indirect.
32) (Walker, 1990) Information Package of resources for supporting integration	Support should be individualised & flexible. Avoid over-support. Model interactions for other children. Ascertain the best type of support is likely to take time and needs to respond to changing needs. Adaptation of activities/partial participation. Skills training should be contextualised.	1 +	3	4	5				9					1 4			Integration	<u>Fostering Inclusive Communities</u>	Resource is an Introduction and a compilation of older published material. The Introduction (first item only) was included into the present review.	Recreation & Leisure Activities.	Children with severe disability.	N/S	N/S	E2 Indirect
33) (York & Vandercook, 1990) Principles & strategies for including students with severe disabilities in general education classes & other age-appropriate natural environments.	Involve natural class supports & fade adult supports. Parents & peers problem-solving strategies for inclusion, & on planning teams & task forces. Opportunity for all students to share ideas re-education & their dreams. Integrating in extra-curricular activities. Provide information to other parents. Establish communication networks. Circle of Friends. Documentation of Curriculum-based & Extracurricular activities available through the school.		3	4	5	6				1 0	1 1	1 2	1 3	1 5			Successful shift to inclusive education.	<u>Fostering Inclusive Communities</u>	Aimed at classes shifting to an inclusive model. Very generalised ideas. Introduces idea of developing an inventory of activities.	School	Middle School Students with Severe Disabilities	N/A	NS	E2 Indirect

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		1 INTg	2 GOTg	3 Prg	4 PS	5 AS	6 FCP	7 C&C	8 Recip	9 Adj	10 PP	11 S Op	12 CTP	13 CPS	14 COcc	15 LEx										
Fostering Inclusive Communities n = 33																										
1) (McDougall et al., 2006) PABICOP	Community Outreach Programme. Visits to school to gather & provide information. Clinics 3-6 monthly are a forum for assessment, consultation, planning, problem solving. Child's input is central to planning sessions. Include gradual transition back to school. Modifications. Educational sessions to teachers. Education to peers regarding the condition.	1				6		9	10		12	13						Integration back to family & community. -GCS -ABI Knowledge, & Strategies -Family empowerment -Family functioning & impact -Child behaviour Checklist or Functional Status II. -Parent/carer/teacher satisfaction & perceptions of services.	Rehabilitation Service Provision Models and Modalities for Participation	PABICOP: = significantly greater knowledge re ABI. =significantly greater participation in activities those who had <u>for less than 10 contacts</u> . =no significant difference for empowerment. =no significant difference for behaviour, family function, burden. Data from teachers not examined as inadequate numbers completed questionnaires. Significance levels set at 0.1.	Community, home & school	96 child & youth with ABI- 1 wk - 19 years,	3 weeks post discharge, , 3 months, 1 year FU.	Parents/carers on average: Satisfied with service- supportive staff, communication, & info sharing, individualised. Services mostly useful apart from advocacy skill building. Wait time too long. Staff unavailable.	P1 High Direct Quasi-experimental	
2) (Graham, Rodger, & Ziviani, 2010)	Address parents goals Change parent actions to improve match between child, environment & task.					6 v i a		9				13					Clinically significant increases in parent perceptions of their own & their child's	Rehabilitation Service Provision Models and	Does not ascertain perceptions of performance/satisfaction by child or others such as teachers. Parents may not be adequately aware of participation issues in	Non-specific.	Children ages 5-9. No diagnosis. Occupational	10 weeks.	Parents talked more of the impact of the intervention	P3 High, Indirect		

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Occupational Performance Coaching	10 sessions once/week at centre & 2 assessment sessions. Three Domains: Emotional support Information exchange Structured process Process: Set goal, explore options, Plan action, Carry out plan, Check performance, Generalize. Strategies used include Solution & enablement oriented questioning, Diagramming, Demonstration of Collaborative Problem Solving, Demonstration of Comic Strip Conversations.					p a r e n t s												performance, and parent satisfaction with performance.	Modalities for Participation	settings outside the home (eg. school). Children's goals may differ to those of their parents. Study does not state particular strategies used with parents, and gives limited detail regarding strategies used.		Performance issues.		than of their experience. However, they indicated that it was challenging implementing the changes, especially at the start.		
3) (Wade, Michaud, & Brown, 2006) Family Centered Problem Solving Intervention	Training for families in and application of a problem solving strategy for real-life situations. Education about the effect of TBI on cognitive function and teaching behaviour management strategies.	1	2			6				10			13						80% in intervention group reached targeted goals for problem solving. >90% parents in intervention group reported they knew strategies for handling future problems. All parents in intervention group reported improved parent-child relationships. For parent child interactions, the difference between the changes in the intervention and control group were not significant meaning the intervention had no significant effect on interactions.	Rehabilitation Service Provision Models and Modalities for Participation		Context of problems is not explicit.	Children aged 5-16 with moderate to severe TBI.	Programme ran for 6 months. Involved 7 bi-weekly sessions and up to 4 individual sessions.	Parents and children rated programme as extremely helpful & would recommend it to others. The problem solving process was easy to use.	P1 Medium Direct. Randomised clinical trial.
4) (Wade, Oberjohn, Burkhardt, & Greenberg, 2009) I-InTERACT: a web-based	Online treatment programme for families of school-age children with TBI using PCIT (Parent Child Interaction Therapy). This involves live coaching in parenting over the web with Broadband video-conferencing using parents as therapists. Content involved 10 core sessions and up to 5 supplementary sessions. In context of play parents are taught:	2				6				10									Significant increases in positive parenting behaviour Significant decreases in negative parenting behaviours.	Rehabilitation Service Provision Models and Modalities for Participation		Home.	Children aged 3-8 years, moderate-severe TBI.	10 core sessions (duration not specified). Each sessions followed by a 50 m session with a therapist.	Training and certification for those delivering the PCIT intervention is required. Adequate internet connection needed.	P1 Medium Direct Pilot study- pre-experimental.

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parenting skill programme	Providing praise Reflecting a child's verbalisation Narrating the child's behaviour Supporting a child to lead by not asking questions, giving commands or criticising. Making instructions specific Following instructions with praise or time out.																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																	

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OT Service Provision	<p>Advises use of MAPS, COACH, and PATH systems to aid “lifespan educational planning” (p. 8).</p> <p>Inclusive education- ie. “student belongs and is supported in the general education environment” (p. 10).</p> <p>Using natural environmental cues and fading instructional prompts from others.</p> <p>Coordinating service delivery- collaboration between professionals, personnel, & parents.</p> <p>Assessment and intervention should focus on & be provided while student is participating with peers in naturally occurring routines and environments.</p> <p>Provides an example of a Matrix Method to integrate goals into daily schedules/activities /environments.</p> <p>?Skill Development in Context</p>																success in school environment.	Provision Models and Modalities for Participation	participation. Although argues for use of Inclusive Education, few strategies are provided to ensure that participation occurs in this setting.	settings	Disabilities		“Role Release” (p. 15) to enable information to be shared across teaching & therapy disciplines.		
8) (Forsyth, Kelly, Wicks, & Walker, 2005) Family Empowerment Intervention: Information Provision	<p>Free video & booklet provided to parents for use with new teachers. Video: 4 families after ABI & medical staff illustrate late emergence of cognitive & behaviour problems, and the need to seek specialist assessment.</p> <p>Booklet provides “remedial” advice for classroom challenges & contacts.</p>	1							10						15			Aim is to empower parents in interactions with teachers & other professionals. Aid in monitoring educational progress & meet children’s special education needs.	Rehabilitation Service Provision Models and Modalities for Participation	Lacks specifics as to booklet content. Lacks specifics as to outcomes. Focus appears to be on educational task performance.	School classroom.	Acquired brain injury- included 3 children with TBI in video. Age not stated.	N/S	N/S- although informal feedback from clinicians, support groups & families has been positive.	E2 Direct.
9) (Glang, Tyler, Pearson, Todis, & Morvant, 2004) Statewide TBI Consulting Teams	<p>Provide educational consultation & training to schools. On-site situation specific help. Team members based in schools.</p> <p>Training Topics for the Consulting Team include: Communication strategies between parent & school Student involvement in planning Building Friendships Compensatory memory & organisation systems Collaboration & consultation. Conducting training sessions.</p>	1		4		6		9	10		12	13						Effective Educational Experiences Support educators of students with TBI. Capacity building. Make available to schools a group of well-trained peer consultants who can provide in-service training & ongoing consultation to prevent problems.	Rehabilitation Service Provision Models and Modalities for Participation	Approach to Service Delivery. Provides support for some strategies. Does NOT Demonstrate outcomes. Focus of report is Training of Consulting Team members Adaptations (in the case of this model) include aids to compensate for impairments (eg. memory changes) or in the case of other models/strategies include contextualised adaptations to the task/environment/time etc. Pilot surveys and focus groups guided the content and nature of the training. Includes illustrative case study.	School	TBI Children, Age N/S	N/A	N/A	E2 Direct
10) (Scaletti, 1999) Occupation	<p>Community Development Establish mutual support groups & take part in skill development/learning activities. Access support groups to form coalitions</p>			4				8		11					15			Empowers clients to take control of events that influence their health and lives.	Rehabilitation Service Provision Models and	Model proposed draws on theoretical understandings. Provides fictive examples to illustrate strategies.	Community	Mental Health Age N/S	N/S	N/S	E2 Indirect

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Specific Community Development Model	to identify needed community resources, develop play, implement & evaluate. Support those involved to take control and build their skills. Social commitment. Focus- working with & empowering clients.																?Use change to develop and expand occupational roles.	Modalities for Participation						
11) (Sutter, Ditto, & Peterson, 2008) Chalkboards & Wheelchairs: School Re-entry Program	Initiate contact early. Engage the patient: use videos, photographs & descriptions. Normalise return. Prepare classmates Offer accommodations Work collaboratively to develop programme for patient and classmates. Begin IEP process. Visit school to work with peers.	1							9			1 2			1 5		Emotional adjustment for patient & classmates. ↑ sense of inclusion ↑ acceptance ↑ understanding of TBI	Rehabilitation Service Provision Models and Modalities for Participation	Children also receiving special education services. Abstract of presentation at NABIS conference.	School	Children with newly acquired ABI States programme should be development ally appropriate for child & peers.	Focus is at point of return to school from hospital or rehabilitation facility.	N/S	E2 Direct
Rehabilitation Service Provision Models and Modalities n = 11																								

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Appendix 7.3: Example of Qualitative Appraisal

Critical Review Form - Qualitative Studies (Version 2.0)

© Letts, L., Wilkins, S., Law, M., Stewart, D., Bosch, J., & Westmorland, M., 2007
McMaster University

CITATION:

Hutchison, Mecke & Sharpe 2008
Partners in Inclusion at a Residential Summer Camp: A Case Study

	Comments
STUDY PURPOSE: Was the purpose and/or research question stated clearly? <input checked="" type="radio"/> yes <input type="radio"/> no	Outline the purpose of the study and/or research question. Examine attempt to foster inclusion • How was i. process strx • what were incl. goals • what facil incl? • How could incl be imprd
LITERATURE: Was relevant background literature reviewed? <input checked="" type="radio"/> yes <input type="radio"/> no	Describe the justification of the need for this study. Was it clear and compelling? Rationale emphasises need for camp rather than study, but states need to examine camps critically
	How does the study apply to your practice and/or to your research question? Is it worth continuing this review?
STUDY DESIGN: What was the design? <input type="radio"/> phenomenology <input type="radio"/> ethnography <input type="radio"/> grounded theory <input type="radio"/> participatory action research <input checked="" type="radio"/> other <u>Case Study</u>	Was the design appropriate for the study question? (i.e., rationale) Explain. - Qualitative methodol - Stake - Good rationale (relatively!) - ability of methodology & design to "illustrate issues," give "broad undstg" & generate "insight." = congruent with aim & questions ✓

1 When doing critical reviews, there are strategic points in the process at which you may decide the research is not applicable to your practice and question. You may decide then that it is not worthwhile to continue with the review.

<p>Was a theoretical perspective identified?</p> <p><input type="radio"/> yes</p> <p><input type="radio"/> no</p>	<p>Describe the theoretical or philosophical perspective for this study e.g., researcher's perspective.</p> <p>✓ Little interpretation of involvement of researcher & influence on findings</p> <p>— case = proximity to (R) - team → ? influences should be described</p>
<p>Method(s) used:</p> <p><input type="radio"/> participant observation</p> <p><input type="radio"/> interviews</p> <p><input type="radio"/> document review</p> <p><input type="radio"/> focus groups</p> <p><input type="radio"/> other</p>	<p>Describe the method(s) used to answer the research question. Are the methods congruent with the philosophical underpinnings and purpose?</p> <p>* Limited descripⁿ of doc. analysis & interview - no examples</p>
<p>SAMPLING:</p> <p>Was the process of purposeful selection described?</p> <p><input type="radio"/> yes</p> <p><input type="radio"/> no</p>	<p>Describe sampling methods used. Was the sampling method appropriate to the study purpose or research question?</p> <p>Yes - ? best able to inform? } lack of detail</p> <p>? These campers</p>
<p>Was sampling done until redundancy in data was reached?²</p> <p><input type="radio"/> yes</p> <p><input type="radio"/> no</p> <p><input type="radio"/> not addressed</p>	<p>Are the participants described in adequate detail? How is the sample applicable to your practice or research question? Is it worth continuing?</p> <p>3 chⁿ D.Dis. 10, 0x/9, 0x/11 0x (P185)</p> <p>✓ limited detail re types of disabilities = ↓ transferability</p>
<p>Was informed consent obtained?</p> <p><input type="radio"/> yes</p> <p><input type="radio"/> no</p> <p><input checked="" type="radio"/> not addressed</p>	<p>?</p>
<p>DATA COLLECTION:</p> <p>Descriptive Clarity</p> <p>Clear & complete description of site: <input checked="" type="radio"/> yes <input type="radio"/> no</p> <p>participants: <input type="radio"/> yes <input checked="" type="radio"/> no</p> <p>Role of researcher & relationship with participants: <input type="radio"/> yes <input checked="" type="radio"/> no</p> <p>Identification of assumptions and biases of researcher: <input type="radio"/> yes <input checked="" type="radio"/> no</p>	<p>Describe the context of the study. Was it sufficient for understanding of the "whole" picture?</p> <p>✓ Good descrip Context - very detailed → transferability</p> <p>✓ Excellent descrip of camp & activities & responses!</p> <p>What was missing and how does that influence your understanding of the research?</p> <p>lacks descripⁿ of participants & their views</p> <p>No interview with child participants</p> <p>XX</p>

² Throughout the form, "no" means the authors explicitly state reasons for not doing it; "not addressed" should be ticked if there is no mention of the issue.

Procedural Rigour Procedural rigor was used in data collection strategies? <input type="radio"/> yes <input type="radio"/> no <input type="radio"/> not addressed	Do the researchers provide adequate information about data collection procedures e.g., gaining access to the site, field notes, training data gatherers? Describe any flexibility in the design & data collection methods. <i>No</i> <i>& limited descripⁿ</i>
DATA ANALYSES: Analytical Rigour Data analyses were inductive? <input type="radio"/> yes <input type="radio"/> no <input type="radio"/> not addressed Findings were consistent with & reflective of data? <input type="radio"/> yes <input type="radio"/> no	Describe method(s) of data analysis. Were the methods appropriate? What were the findings? <i>Open coding - N Vivo</i> <i>Memo generation</i> <i>Constant comparison</i> <i>Not consistent with Stake</i> <i>Focus is constant comparison => categories</i> <i>x Write up is narrative & descriptive - mts</i>
Auditability Decision trail developed? <input type="radio"/> yes <input checked="" type="radio"/> no <input type="radio"/> not addressed Process of analyzing the data was described adequately? <input type="radio"/> yes <input checked="" type="radio"/> no <input type="radio"/> not addressed	Describe the decisions of the researcher re: transformation of data to codes/themes. Outline the rationale given for development of themes. <i>Lacks interpretⁿ - literature</i> <i>Decisions not explained</i> <i>No examples</i> <i>- inadequate description of coding decisions</i>
Theoretical Connections Did a meaningful picture of the phenomenon under study emerge? <input type="radio"/> yes <input type="radio"/> no	How were concepts under study clarified & refined, and relationships made clear? Describe any conceptual frameworks that emerged. <i>✓ Notion of P/Incl. is defined.</i>

OVERALL RIGOUR Was there evidence of the four components of trustworthiness? Credibility <input type="radio"/> yes <input type="radio"/> no Transferability <input type="radio"/> yes <input type="radio"/> no Dependability <input type="radio"/> yes <input type="radio"/> no Confirmability <input type="radio"/> yes <input type="radio"/> no X No reflection on strengths & limitations of study	For each of the components of trustworthiness, identify what the researcher used to ensure each. $\frac{1}{2}$ - triangulation of data sources ✓ - excerpts of data provided ✓ - inadeq. descript ⁿ of children - good description of context. What meaning and relevance does this study have for your practice or research question?
CONCLUSIONS & IMPLICATIONS Conclusions were appropriate given the study findings? <input type="radio"/> yes <input type="radio"/> no The findings contributed to theory development & future OT practice/ research? <input type="radio"/> yes <input type="radio"/> no	What did the study conclude? What were the implications of the findings for occupational therapy (practice & research)? What were the main limitations in the study? No interview w/ ch ⁿ Placement w/ other ch ⁿ same age non-dis. Only provide sppt for task perf if need demonstr ^d match of Considered local ⁿ (opp), facilities, interests, needs Allow time for prep

- Ad:
- ✓ Staff training - vstd. Extra time (respite)
 - ✓ adaptive eqpt
 - ✓ Ensure opp to "try out" all activ.
 - ✓ Improve phys. accessibility
 - ✓ Staff help
 - ✓ adapt acti.
 - ✓ "scheduler"
 - ✓ Help other chⁿ w/ std dis
 - ✓ Teach how to interact. - modelling incl
 - ✓ Keep w/ the group - guidance
 - ✓ Time away fr group vs Pulling Out.
 - overwhelmed
 - (- Strx opps for socializⁿ into Prog)
- ✓ Floutⁿ Staffing
 (Team?)
 (Intracdisc?)
 - Communicatⁿ, Info Sh,
 Sppt w/ Prob solvⁿ.

© Letts et al., 2007

Qualitative Review Form

4.

RESEARCH TYPOLOGY EVALUATION OF STUDIES: Details: *Hutchison, Meade & Shape 2008*

R: Research Based Evidence

E: Expert Opinion

E1: Parents/Children
E2: Professionals
E1 & E2: Both

RESEARCH

DESIGN CLASSIFICATION

PRIMARY RESEARCH-BASED EVIDENCE
SECONDARY RESEARCH-BASED EVIDENCE
REVIEW-BASED RESEARCH EVIDENCE

P1 Quant
S1 Meta-Analysis
R1 Systematic Rev

P2 Qual

P3 Mixed
S2 Secondary Analysis
R2 Descriptive Rev

QUALITY Yes=2, In Part=1, No=0.

a) Are Research Questions/Aims & Design clearly stated? **(2)**

b) Is Research Design appropriate for Aims and Objectives of Research? **(2)**

c) Are Methods clearly described? **(1)**

d) Is data adequate to support author's interpretations/conclusions? **(1)**

e) Are results generalisable? **(1)**

TOTAL: /10

QUALITY: High=7+/10
Med=4-6/10
Poor=3-/10

APPLICABILITY

DIRECT: Children School Age, Traumatic Brain Injury
INDIRECT: Other Conditions.

CLASSIFICATION: **P2 High Indirect**

OUTCOMES: ☐

*Inclusion in gp by others / peer interacⁿ.
Participⁿ in activities*

☐

☐

☐

CONTEXT:

Education

Home

Community

TIME FRAMES:

RELEVANCE OF STRATEGIES TO NOTIONS OF PARTICIPATION COMING FROM CASE STUDIES									
Provides Opportunities for new Experiences "Have a go"	Child is Facilitated to "Have a Say"	Child is Facilitated to Engage in Meaningful Activities	Participation is shared with Peers	Satisfaction • Child • Parent • Other	Achievement	Strategy/ Approach Improves Fit of: • Understandability • Activity • Others' Actions • Time • Environment	Collaborative	Realistic	Supports Participation across Contexts
✓			✓			TEAUA		✓	

DESCRIPTION OF APPROACH/STRATEGIES:

Additional trained staff to support managers

Appendix 7.4: Example of Quantitative Appraisal

Critical Review Form - Quantitative Studies

© Law, M., Stewart, D., Pollock, N., Letts, L., Bosch, J., & Westmorland, M., 1998
McMaster University

CITATION:

Godeau et al., 2010	
Improving attitudes towards children & disabilities in a school context:	
Q: How effective are interventions aimed at improving children's attitudes towards peers & disabilities?	
STUDY PURPOSE: Was the purpose stated clearly? <input checked="" type="radio"/> Yes <input type="radio"/> No	Outline the purpose of the study. How does the study apply to occupational therapy and/or your research question? Comments: <i>Intended to assess effectiveness of intervention prog. to improve attitudes in 7th graders towards peers & disabilities - French school</i> <i>2 Determine personal / env't factors assoc. & attitudes & potential improvement. - this doesn't clarify range / type of factors under focus.</i>
LITERATURE: Was relevant background literature reviewed? <input checked="" type="radio"/> Yes <input type="radio"/> No	Describe the justification of the need for this study. <i>Negative peer attitudes = barrier to full social inclusion of disabled students. - Few large-scale intervention studies.</i>
DESIGN: <input checked="" type="radio"/> Randomized (RCT) <input type="radio"/> cohort <input type="radio"/> single case design <input type="radio"/> before and after <input type="radio"/> case-control <input type="radio"/> cross-sectional <input type="radio"/> case study	Describe the study design. Was the design appropriate for the study question? (e.g., for knowledge level about this issue, outcomes, ethical issues, etc.) <i>Cluster randomized intervention study. 6 schools & SEUs matched to schools without SEUs randomly selected fr schools in similar location. 6 pairs - 3 randomly allocated to intn, 3 to control</i> Specify any biases that may have been operating and the direction of their influence on the results. <i>RCT - appropriate to investigate effectiveness of intn. - less approp. to address 2nd question.</i> <i>- Randomiz. process not explained.</i> <i>- Description of demographic locations lacking - potential for bias - eg could be diff betw schools in intn gr vs control grs</i>

Comments

<p>SAMPLE: N =</p> <p>Was the sample described in detail? <input checked="" type="radio"/> Yes <input type="radio"/> No</p> <p>Was sample size justified? <input checked="" type="radio"/> Yes <input type="radio"/> No <input type="radio"/> N/A</p>	<p>Sampling (who; characteristics; how many; how was sampling done?) If more than one group, was there similarity between the groups? large sample, but less than figure calculated for power (1500) → possible Type 2 error.</p> <p>Sample described - multi-level regression models allowed to adjust covariates</p> <p>Describe ethics procedures. Was informed consent obtained? ages not described * no types of disab. not described Students not blind to intv → may infl. responses More studts in intv groups than control groups - not addressed in analysis - different means * No details re teachers delivering intv → extraneous v.</p>
<p>OUTCOMES:</p> <p>Were the outcome measures reliable? <input checked="" type="radio"/> Yes - Lit cited <input type="radio"/> No <input type="radio"/> Not addressed</p> <p>Were the outcome measures valid? <input checked="" type="radio"/> Yes " " <input type="radio"/> No <input type="radio"/> Not addressed</p>	<p>Specify the frequency of outcome measurement (i.e., pre, post, follow-up) Pre + 8 mth post-test → longer-term outc. but unable to control for confounders over this time</p> <p>Outcome areas (e.g., self-care, productivity, leisure). List measures used.</p> <p>Attitude towards ch'z handicap * Only 1 qst used for this variable? bias a second would have spt reliability of findings * Unclear - assts may have been administered by same teaching staff who delivered intervention → bias Translated version of CATCH used - psychometric properties not established</p> <p>CATCH - self report * may not equate to actual behaviors * may endeavor to give "correct" answers at post-test (training effect) → bias</p>
<p>INTERVENTION: Intervention was described in detail? <input type="radio"/> Yes <input checked="" type="radio"/> No <input type="radio"/> Not addressed</p> <p>Contamination was avoided? <input checked="" type="radio"/> Yes <input checked="" type="radio"/> No <input type="radio"/> Not addressed <input type="radio"/> N/A</p> <p>Cointervention was avoided? <input type="radio"/> Yes <input type="radio"/> No <input checked="" type="radio"/> Not addressed <input type="radio"/> N/A</p>	<p>Provide a short description of the intervention (focus, who delivered it, how often, setting). Could the intervention be replicated in occupational therapy practice?</p> <p>Inadequate description - teachers educ. re study - taught re social model - disability * content of lessons / materials not described - provided lessons re disability & inclusive in humanities classes, students watched a film, debated re differences & disab. → indiv or group actions Focus of description is on material / process with teachers = teacher training ↓ generaliz - prog. = mis-match with Q & Aim. potential = Hawthorne effect?</p>

Comments

<p>RESULTS:</p> <p>Results were reported in terms of statistical significance?</p> <p><input checked="" type="radio"/> Yes NE</p> <p><input type="radio"/> No</p> <p><input type="radio"/> N/A</p> <p><input type="radio"/> Not addressed</p> <p>Were the analysis method(s) appropriate?</p> <p><input checked="" type="radio"/> Yes</p> <p><input type="radio"/> No</p> <p><input type="radio"/> Not addressed</p> <p>Clinical importance was reported?</p> <p><input type="radio"/> Yes</p> <p><input type="radio"/> No</p> <p><input type="radio"/> Not addressed</p>	<p>What were the results? Were they statistically significant (i.e., $p < 0.05$)? If not statistically significant, was study big enough to show an important difference if it should occur? If there were multiple outcomes, was that taken into account for the statistical analysis?</p> <p>No signif diff betw intuⁿ + control post-test</p> <p>Significant improvements for both intuⁿ + control ($p < 0.001$, 0.009)</p> <p>- ie) improvements due to variables other than intuⁿ.</p> <p>Use of multi-level variable regression - rules out several possible confounders. Improvements had sign. -ve correlatⁿ base line scores</p> <p>CATCH = 5 pt rating scale - Likert type. ? use of parametric analysis & Likert scales</p> <p>What was the clinical importance of the results? Were differences between groups clinically meaningful? (if applicable)</p> <p>* Not reported. Impact of project explored qualitatively. → Qs re satisfaction. → 40.7 were positive, 28.6% reported improved relatⁿ.</p>
<p>Drop-outs were reported?</p> <p><input type="radio"/> Yes</p> <p><input type="radio"/> No</p>	<p>Did any participants drop out from the study? Why? (Were reasons given and were drop-outs handled appropriately?)</p> <p>- Several students didn't take part - [? why - no analysis of demogs] X</p> <p>- Lots absent at both pts, several lost to follow-up</p> <p>- Number failed to complete parts of pre/post, and many completed No tests - CONSORT diag.</p>
<p>CONCLUSIONS AND CLINICAL IMPLICATIONS:</p> <p>Conclusions were appropriate given study methods and results</p> <p><input type="radio"/> Yes</p> <p><input type="radio"/> No</p>	<p>What did the study conclude? What are the implications of these results for occupational therapy practice? What were the main limitations or biases in the study?</p> <p>Concluded - no effect</p> <p>- potential effect of assts.</p>

RESEARCH TYPOLOGY EVALUATION OF STUDIES: Details: Leclercq et al. 2010

(R): Research Based Evidence

E: Expert Opinion

E1: Parents/Children
E2: Professionals
E1 & E2: Both

RESEARCH DESIGN CLASSIFICATION

PRIMARY RESEARCH-BASED EVIDENCE
SECONDARY RESEARCH-BASED EVIDENCE
REVIEW-BASED RESEARCH EVIDENCE

P1 Quant
S1 Meta-Analysis
R1 Systematic Rev

P2 Qual

P3 Mixed
S2 Secondary Analysis
R2 Descriptive Rev

QUALITY Yes=2, In Part=1, No=0.

- a) Are Research Questions/Aims & Design clearly stated? (2)
- b) Is Research Design appropriate for Aims and Objectives of Research? (1)
- c) Are Methods clearly described? (2)
- d) Is data adequate to support author's interpretations/conclusions? (2)
- e) Are results generalisable? (0) — little to no info re teaching content for children

TOTAL: 7 /10

QUALITY: High= 7+/10
Med=4-6/10
Poor=3-/10

APPLICABILITY

DIRECT: Children School Age, Traumatic Brain Injury
INDIRECT: Other Conditions

— Peers aged 12-15 y.

CLASSIFICATION: P1 High Indirect

- OUTCOMES: ☐ No significant differences between intervention & control at post test for attitudes towards children & handicap.
☐ Significant improvements for both groups.
☐

CONTEXT: Education

Home

Community

TIME FRAMES:

N/A

RELEVANCE OF STRATEGIES TO NOTIONS OF PARTICIPATION COMING FROM CASE STUDIES									
Provides Opportunities for new Experiences "Have a go"	Child is Facilitated to "Have a Say"	Child is Facilitated to Engage in Meaningful Activities	Participation is shared with Peers	Satisfaction • Child • Parent • Other	Achievement	Strategy/ Approach Improves Fit of: • Understanding • Activity • Others' Actions • Time • Environment	Collaborative	Realistic	Supports Participation across Contexts
						<u>Understands</u>			

DESCRIPTION OF APPROACH/STRATEGIES:

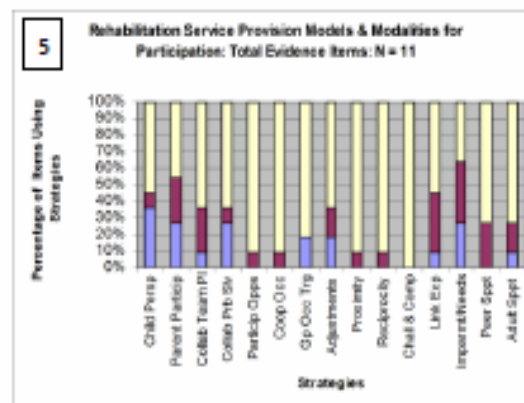
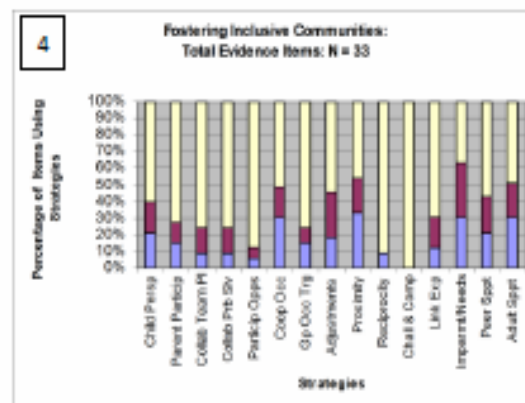
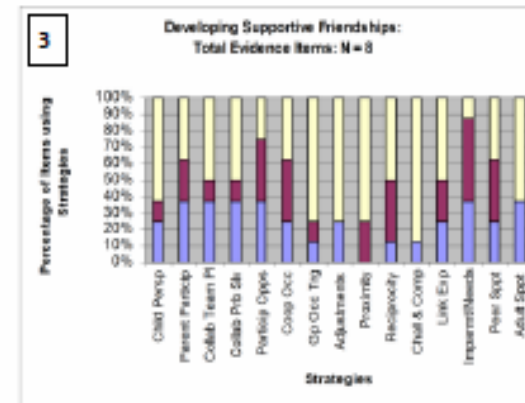
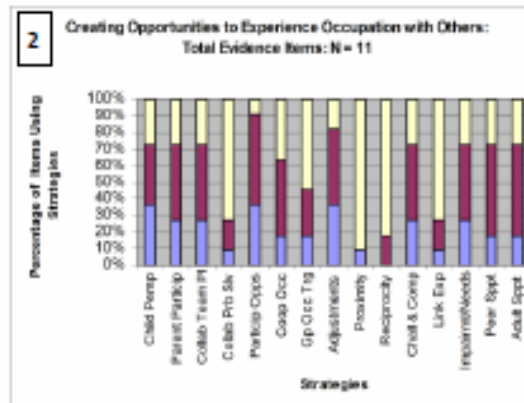
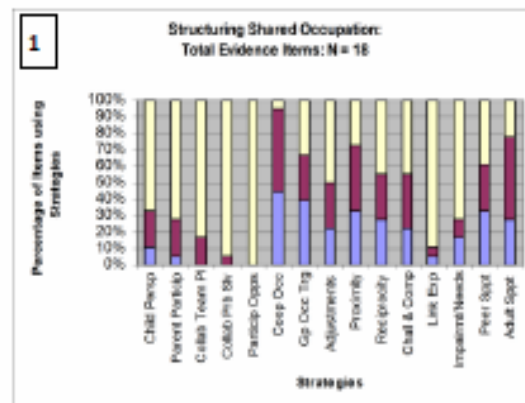
Information provided to teachers
little to no description of intervention provided to ~~teacher~~ children by teachers. — lessons/class prog.
social model of disabilities, legislations
Film — schooling children & physical disabilities

* No effect from intervention

Appendix 8.1: Analysis of Frequency of Strategy Use across the Five Intervention Approaches

Further analysis was undertaken to the frequency to which of the strategies shown earlier in Tables 8.8–8.11 were used by particular intervention approaches. The percentages of articles using each strategy for lower quality/expert-opinion evidence, and for medium/high quality evidence out of the total articles included into each intervention approach were graphed. This supported some overall conclusions about the strategies used by the different intervention approaches which are summarized next.

The graphed percentages of evidence items using each strategy for lower quality/expert-opinion evidence, and for medium/high quality evidence out of the total of evidence items included into each intervention approach are displayed in Figure 8 below. For reference, a copy of Table 8.7 is included, which provides an overall depiction of the therapeutic groupings and strategies identified within each. The results of this analysis are discussed.



KEY: Not Using Strategy
 Lower Quality & Expert-Opinion Evidence
 Medium & High Quality Evidence

Therapeutic Groupings	Strategies Interpreted from Articles
Promoting Client Perspectives	Facilitating Child's Perspective Parent Participation Collaborative Team Planning Collaborative Problem Solving
Making Shared Occupation Available	Sourcing Participation Opportunities Providing Cooperative Occupation Group Occupation Training
Addressing Fit of Child's Needs & Abilities, Occupation, & Context	Adjustments Proximity Reciprocity Challenge & Competition Linking Experiences
Addressing Disability Related Support Needs	Impairment/Needs Training Peer Support Adult Support

Percentages of evidence items using strategies were calculated for Lower quality/Expert-opinion evidence, and for Medium/High quality evidence, out of the total number of evidence items included into each approach.

Figure 8: Frequency of Strategy use for the Five Intervention Approaches Note: Child Persp=Facilitating Child's Perspective. Parent Particip=Parent Participation. Collab Team Pl=Collaborative Team Planning. Collab Prb Sol=Collaborative Problem Solving. Particip Opps=Sourcing Participation Opportunities. Coop Occ=Providing Cooperative Occupation. Gp Occ Trg=Group Occupation Training. Chall & Comp=Challenge & Competition. Link Exp=Linking Experiences. Impairmt/Needs=Impairment Needs Training. Peer Sppt=Peer Support. Adult Sppt=Adult Support.

The graphs in Figure 8.3 suggest some patterns, and indicate emphases in the use of strategies for each broad intervention approach. The patterns and emphases are described and discussed below. In keeping with the formatting convention used earlier, names of the strategies, therapeutic groupings, important aspects of participation, and intervention approaches are formatted as follows:

- 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);
- Intervention approaches are in bold font (e.g. **Structuring Shared Occupation**).

Quality of the evidence using the strategies in the five intervention approaches.

It can be seen that all strategies have some medium/high quality evidence which supports their use. Lower quality/expert-opinion evidence contributes a similar, although slightly higher percentage of articles using each strategy. Because percentages for each strategy were calculated for the two different quality grades based on the total of articles included in each approach, rather than the percentages for the total of each quality grade, this trend likely reflects a similar, if not slightly greater number of lower quality/expert-opinion evidence items compared to the high/medium quality evidence, rather than any significant differences between the two different quality grades in the use of strategies. More noticeable exceptions to this appear to be in Graph 3, the **Developing Supportive Friendships** approach, where *Adjustments* and *Adult Support* strategies were noted in high/medium quality evidence, but not in lower quality/expert opinion evidence. Another exception is in Graph 5, in the **Rehabilitation Service Provision** approach, where, for the *Facilitating Child's Perspective* strategy, the percentage of high/medium quality evidence is greater than the lower quality/expert opinion evidence.

Diversity of strategies used by the evidence in the five intervention approaches.

The graphs give an indication that the intervention approaches (and thereby the articles comprising these approaches) adopt a variety of strategies. This provides some weight for using a multi-faceted intervention to facilitate participation, whatever the situation. However, there are some differences between the five broad intervention approaches in the diversity of their strategy use. For Graph 4, the **Fostering Inclusive Communities** approach, and Graph 5, the **Rehabilitation Service Provision Models and Modalities for Participation** approach, as with most of the other approaches, almost every strategy gains mention at some point in each of the two groups of articles. However, the percentages for each strategy are relatively low in these two graphs, particularly for Graph 5, suggesting diversity across the articles for the strategies used, but for each article, employment of relatively few strategies. It may be that existing **Rehabilitation Service Provision Models and Modalities** tend to address particular aspects of participation, but do not comprehensively address all the aspects that are important. Likewise, in **Fostering Inclusive Communities**, there may be an emphasis on addressing participation in the education environment, but diverse strategies are not used because a range of participation environments are not addressed (this can be seen in the Data Extraction Table on Disc One, Appendix 7.2, where 27 out of a total of 33 articles for this approach were solely focused on the school setting). In contrast, in Graph 2, the **Creating Opportunities for Participation** approach, whilst there was still diversity of strategies across the articles, the percentages using each strategy are relatively high, suggesting that for each article, a greater number of strategies were being employed. Relating to this, a requirement to draw on multiple strategies may be the reason parents in Phase One of this study found it particularly challenging to successfully Drive participation opportunities for their children.

Strategies used in the intervention approach “Structuring Shared Occupation”.

Strategies addressing therapeutic groupings which center on the *Availability of Shared Occupation*, and the *Fit of Children’s Needs & Abilities, Occupation, and Context* are most frequently used; these include *Providing Cooperative Occupation, Group Occupation Training, Adjustments, Proximity, Reciprocity, and Challenge & Competition*. Likewise, for this approach, *Addressing Children’s Disability Support Needs* is important, and *Adult and Peer Support* is typically provided.

Few articles use *Collaborative Problem Solving*, although this may be an unarticulated component of *Group Occupation Training*. None of the articles in this approach use the *Sourcing Participation Opportunities* or the *Linking Experiences* strategies, suggesting the focus is occupations that are readily available in a single setting.

Strategies used in the intervention approach “Creating Opportunities to Experience Occupation with Others”.

Evidence items in this approach tend to use multiple strategies. As might be expected, *Sourcing Participation Opportunities* is the most frequently used strategy. There is a pattern of frequently used strategies in the therapeutic grouping of *Promoting Client Perspectives*, and in *Addressing Children’s Disability Support Needs*, highlighting that this approach is typically collaborative in nature, in order that the opportunities are appropriate to children’s needs, and that they need to be adequately supported to take part. *Collaborative Problem Solving, Proximity, Reciprocity*, and *Linking Experiences* are infrequently used.

Strategies used in the intervention approach “Developing Supportive Friendships”.

The most frequently used strategies are those which are included in the therapeutic grouping of *Making Shared Occupation Available* (*Sourcing Participation Opportunities, and Providing Cooperative Occupation*), and *Addressing Disability Support Needs* (*Impairment/Needs Training,*

and Peer Support). Differing from approaches One, Two, and Four, there is some use of the *Linking Experiences* strategies: given the intent of this strategy, it may be for this intervention approach that experiences with friends in the school setting are used to establish linkages with contexts and times outside of school.

Apart from the strategy of *Reciprocity*, strategies included in the therapeutic grouping for *Addressing the Fit of Children's Needs & Abilities, Occupation and Context* are seldom used; low percentages of items involve *Adjustments*, *Proximity*, and *Challenge & Competition*. This pattern in conjunction with the emphasis on *Addressing Disability Support Needs* risks a focus on the individual child and their disability, portraying them to their peers as reliant on them to create opportunities, and as needing of support.

Strategies used in the intervention approach "Fostering Inclusive Communities".

For this broad intervention approach there is an emphasis on strategies in the therapeutic grouping of *Addressing Disability Support Needs*, including *Impairment/Needs Training*, *Peer Support*, and *Adult Support*. The strategies of providing *Cooperative Occupation*, *Adjustments*, and *Proximity* are also highlighted in the graphs. Surprisingly few articles make reference to strategies in the therapeutic grouping of *Promoting Client Perspectives*; although some *Facilitate the Child's Perspective*, there is limited mention of *Parent Participation*, *Collaborative Team Planning*, or *Collaborative Problem Solving*.

Although there is some use of *Providing Cooperative Occupation*, few articles refer to *Sourcing Participation Opportunities*. This perhaps reflects that many of the articles in this approach are concerned with school settings, where opportunities are available, but where an occupation needs to be selected and planned by the teacher to encourage cooperation. Of note, there is little use of *Group Occupation Training*, perhaps indicative of an assumption within this approach that if the correct occupation is selected and set up, children will learn how to work

cooperatively on their own. This was not always observed to be the case in Phase One of this study. *Reciprocity*, and *Challenge & Competition* strategies are likewise rarely used in this approach. .

Strategies used in the intervention approach “Rehabilitation Service Provision Models and Modalities for Participation”.

For this intervention approach strategies contained in the therapeutic grouping of ***Promoting Client Perspectives*** are emphasized, including *Facilitating the Child’s Perspective*, *Parent Participation*, *Collaborative Team Planning*, and *Collaborative Problem Solving*. *Impairment/Needs Training* is the most frequently used strategy. This perhaps points to rehabilitation providers seeing one of their important roles as educating others about children’s impairments and how to manage them, although the analysis in Table 8.6 shows this strategy facilitated relatively few of the important aspects of participation. It is noted that for this approach, *Impairment/Needs Training* is directed towards enskilling adults rather than peers. As seen in the **Developing Supportive Friendships** intervention approach above, *Linking Experiences* is also a frequently used strategy, this suggesting a possible role for rehabilitation providers in assisting the child and others to make connections across settings to support participation.

Apart from *Adjustments*, there is little emphasis on strategies that address the therapeutic groupings of *Making Shared Occupation Available*, or *Addressing the Fit of Children’s Needs & Abilities, Occupation, and Context*. No articles discuss provision of *Challenge & Competition*.

Overall trends in the use of strategies across the intervention approaches.

Impairment/Needs Training stands out as one of the more frequently used strategies across all the graphs except for intervention approach one, **Structuring Shared Occupation**. This potentially means that those involved in most intervention approaches feel that an understanding of children’s impairments is necessary to adequately support them to participate with others. However, as found in answering Question Five, this strategy facilitates relatively few of the important aspects of

participation. Further, an important dimension of this strategy is that of Stigmatization: When disability and difference are emphasized, participation is hampered. Therefore, in order to facilitate participation, any intervention that delivers *Impairment/Needs Training* needs to do so in a way that minimizes drawing attention to the child's differences and limitations. Other strategies would be needed to address the range of important aspects of participation.

In the **Structuring Shared Occupation** intervention approach, fewer articles make reference to the *Impairment/Needs Training* strategy. Instead, almost every article makes reference to *Providing Cooperative Occupation*, and *Group Occupation Training*. This pattern potentially opens up an alternative avenue to learning how to work together where, by directly training a group of people with diverse skills to how work together in the context of an occupation that requires them to collaborate, stigmatization is avoided, and others learn through experience how to include one another into the occupation. However, the potential of these two alternative strategies do not seem to be well recognized in the other intervention approaches.

It is concerning that the strategy of *Facilitating the Child's Perspective* is not given a lot of weight in any of the approaches, especially as seen in Table 8.7 that this strategy had the potential to address five of the important aspects of participation. The exception is the intervention approach of **Creating Opportunities to Experience Occupation with Others**. In this approach, there is a specific focus on seeking out occupations that match with the skills and preferences of the child, hence a particular need to gain their perspective.

Another strategy that gains little mention in three of the intervention approaches is that of *Linking Experiences*. It is possible this reflects the fact the approaches of **Structuring Shared Occupation**, **Creating Opportunities to Experience Occupation with Others**, and **Fostering Inclusive Communities** have a focus on a single setting (refer to the Data Extraction Table on Disc One, Appendix 8.1). The *Linking Experiences* strategy is directly concerned with enabling

connections between a child and other people and other occupations in different contexts. Given that Connection was found to be an important aspect of participation in Phase One of this study, and that the *Linking Experiences* strategy directly addresses this important aspect (refer to Table 8.7), this is perhaps a gap that could be addressed.

Appendix 9.2: Ethical Approval District Health Board April 2010



12 April 2010

Research Office
Level 14, Support Bldg
Auckland City Hospital
PB 92024, Grafton, Auckland
Phone: 64 9 307 4849 Extn. 23834
Fax: 64 9 307 8931
Email: SamanthaJ@adhb.govt.nz
Website: www.adhb.govt.nz/ResearchOffice

Institutional Approval

Margaret Jones
Lecturer, Occupational Therapist, PhD
Dep't of Occupational Science & Therapy
Auckland University of Technology PB 92006
Auckland, NZ

Dear Margaret

RE: Research project A+4683 (Ethics # NTY/10/01/003) - Action Research to Develop a Community Focussed Intervention that Facilitates Social Participation for New Zealand Children who have had a Traumatic Brain Injury

The Auckland DHB Research Review Committee (ADHB-RRC) would like to thank you for the opportunity to review your study and has given approval for your research project.

Your Institutional approval is dependant on the Research Office having up-to-date information and documentation relating to your research and being kept informed of any changes to your study. It is your responsibility to ensure you have kept Ethics and the Research Office up to date and have the appropriate approvals. ADHB approval may be withdrawn for your study if you do not keep the Research Office informed of the following:

- Any communication from Ethics Committees, including confirmation of annual ethics renewal
- Any amendment to study documentation
- Study completion, suspension or cancellation

More detailed information is included on the following page. If you have any questions please do not hesitate to contact the Research Office.

Yours sincerely

On behalf of the Research Review Committee
Dr Samantha Jones
Manager, Research Office
Auckland DHB

c.c. Vipul Upadhyay

Andrew Law

Danah Cadman

.../continued next page

MAINTAINING YOUR RESEARCH APPROVAL

Your Ethical and Institutional approval is dependant on the Research Office having up-to-date information and documentation relating to your research and being kept informed of any changes to your study. While the RO endeavours to send reminders for annual approvals and missing documents, it is your responsibility to ensure you have kept Ethics and the Research office up to date and have the appropriate approvals.

Please note, when missing or updated document reminders are sent, if the RO receives no response from you after 3 reminders it will be assumed that your research has been completed and we will notify the relevant Department CD, the RRC and Ethics Committee that your Locality Assessment Approval has been withdrawn. This will not be reinstated until all issues have been resolved.

All documents / communications must be referenced with the ADHB project number. For simplicity when sending information to the Ethics Committees, please cc the RO. When receiving letters from Ethics, please copy and send to RO for our records.

TOPIC	REQUIREMENT	ACTION
ETHICS		
All Ethics Correspondence	All formal Ethics Committee communications to you	<ul style="list-style-type: none"> o send a copy to RO immediately
Annual Ethics Renewal	Use Ethics form, complete and submit BEFORE anniversary date of original research approval	<ul style="list-style-type: none"> o copy to Ethics o copy to RO (e-copy) o send copy of Ethics approval letter to RO when received
Changes to Research (design, PI, protocol etc)	Write letter detailing changes, Mark up changes in relevant documents. Ethics approval must be received BEFORE implementing	<ul style="list-style-type: none"> o copy of changes to Ethics o copy changes to RO o send copy of Ethics approval letter to RO when received
Stopping Study or Study Complete	If the study is stopped for any reason or study is complete	<ul style="list-style-type: none"> o notify Ethics and attach relevant documents (final report etc) o notify RO and attach relevant documents
Final Report	Complete Ethics template for final report	<ul style="list-style-type: none"> o Send to Ethics and RO o Inform RO if all finance elements also complete
LEGAL		
Contracts, Indemnities, Agreements, insurance certificates	All legal must be reviewed and approved before signing	<ul style="list-style-type: none"> o Send all legal documents to RO
Amendments – Non-financial	As above	<ul style="list-style-type: none"> o Send all legal documents to RO
Amendments - financial	As above and revise Budget	<ul style="list-style-type: none"> o Send all legal documents to RO o Send revised budget using template to RO
FINANCIAL		
Budget Changes i.e. change in visits or tests or proposed income	Liaise with accountant and adjust budget accordingly	<ul style="list-style-type: none"> o Send revised budget using template to RO
Budget maintenance	It is recommended that you review and update budgets at least quarterly	<ul style="list-style-type: none"> o Liaise with accountant and forward update to RO

All documents must be referenced with the ADHB project number and can be sent via email to: jennym@adhb.govt.nz. All paper copies can be faxed to, Attention: Jenny Ma, internal # 23789, external # 09 630 9978 or sent by post, Attention: Jenny Ma, Research Office, Level 14, Support Building, Auckland City Hospital, Private Bag 92024, Auckland, New Zealand.

For further information go to www.adhb.govt.nz/researchoffice/

Appendix 9.3: Ethical Approval District Health Board Maori Research Review March 2010



9 March 2010

Miss Margaret Jones
Lecturer, Occupational Therapist, PhD
Dep of Occupational Science & Therapy
AUT PB 92006
Auckland, NZ

Research Office
Level 14, Support Bldg
Auckland City Hospital
PB 92024, Grafton, Auckland
Phone: 64 9 307 4949 Extn. 23854
Fax: 64 9 307 8931
Email: SamanthaJ@adhb.govt.nz
Website: www.adhb.govt.nz/ResearchOffice

This support letter is issued by the Maori Research Review Committee and does not represent the Ethics approval or the ADHB management approval. Investigators are advised to seek other approvals separately.

Tena koe Miss Jones

RE: Research project A+4683 - Action Research to Develop a Community Focussed Intervention that Facilitates Social Participation for New Zealand Children who have had a Traumatic Brain Injury

The Maori Research Review Committee (MRRC) would like to thank you for the opportunity to review your research.

ADHB MRRC would welcome being involved in any consultation that may be beneficial in improving patient rehabilitation following Traumatic Brain Injury.

The MRRC is happy to support your research study, however, they would like you to please include a statement in the consent form: "I have had sufficient time to discuss with Whānau/Family or a friend prior to signing the consent."

Please send a copy of the final report that includes ethnicity data to the Maori Research Review Committee (c/o Jenny Ma, Research Office, Level 14, Support Bldg, Auckland City Hospital, PB 92024 Grafton, Auckland) at the conclusion of the study.

We wish you the very best in your research.

If you are forwarding a copy of this letter to the Ethics Committee please ensure you add the EC number to the document (if not already listed). This will ensure there are no delays in processing your application at the Ethics Committee.

Noho ora mai,

On behalf of the ADHB Maori Research Review Committee
Dr Samantha Jones
Manager, Research Office
Auckland DHB

c.c. Mats Forbes, MRRC

Appendix 9.4: Northern Y Regional Ethics Committee Approval April 2010



21 April 2010

Ms Margaret Jones
Dept of Occupational Science & Therapy
AUT University
Private Bag 92 006
Auckland 1142

Northern Y Regional Ethics Committee

Ministry of Health
3rd Floor, BNZ Building
354 Victoria Street
PO Box 1031
Hamilton
Phone (07) 858 7021
Fax (07) 858 7070

Dear Margaret

Ethics ref: NTY/10/01/003 (please quote this reference in all correspondence)
Study title: Action Research To Develop A Community Focussed Intervention That Facilitates Social Participation For New Zealand Children Who Have Had A Traumatic Brain Injury.
Investigator: Ms Margaret Jones Supervisor: Dr Clare Hocking
Localities: Starship Children's Health

The above study has been given ethical approval by the Northern Y Regional Ethics Committee.

Approved Documents

- Workshop question guide version 1, 3/Dec/2009
- Advert version 1, 3/Dec/2009
- Reply form –family/whanau version 1, 3/Dec/2009
- Reply form –professionals/community support person version 1, 3/Dec/2009
- PIS and CF –parent/whanau version 1, 3/Dec/2009
- PIS and CF –professionals/community support person version 1, 3/Dec/2009

Accreditation

The Committee involved in the approval of this study is accredited by the Health Research Council and is constituted and operates in accordance with the Operational Standard for Ethics Committees, April 2006.

Final Report

The study is approved until **21 April 2011**. A final report is required at the end of the study and a form to assist with this is available at <http://www.ethicscommittees.health.govt.nz>. If the study will not be completed as advised, please forward a progress report and an application for extension of ethical approval one month before the above date.

Amendments

It is also a condition of approval that the Committee is advised of any adverse events, if the study does not commence, or the study is altered in any way, including all documentation eg advertisements, letters to prospective participants.

Please quote the above ethics committee reference number in all correspondence.

It should be noted that Ethics Committee approval does not imply any resource commitment or administrative facilitation by any healthcare provider within whose facility the research is to be carried out. Where applicable, authority for this must be obtained separately from the appropriate manager within the organisation.

We wish you well with your study.

Yours sincerely

Amrita Kuruvilla
Administrator
Northern Y Ethics Committee

Email: amrita_kuruvilla@moh.govt.nz

Appendix 9.5: Advertisement

People Helping Children Participate in their Communities after Brain Injury

“.....every game, what the girls play, they say I can’t play because it’s too tricky for you, like that” (Cassie, 2008)

After children have a Brain Injury, joining in with activities at school and in the community can be challenging! My PhD studies have given me a unique opportunity to listen to stories from children, parents, community support people, and teachers about those challenges. Often, it appears the best solutions lie with others who are living in the community around the children. For the next phase of the study, you are invited to come to a workshop to hear some of those stories, my thoughts about how to help these children to participate, and to contribute your own thoughts and experiences about things you have found useful.

With your help, I would like to develop these ideas into a resource that can be shared with other people who face these situations.

- ✦ Are you the parent of a child aged 8-18 years who has a traumatic brain injury **and**
- ✦ Did the injury occur before they were 14 years old? **or**
- ✦ Have you taught, trained, assessed, case-managed, or supported such a child?

If this describes you, you are invited to take part in this Workshop, which is part of a study at AUT University.

Do you know someone else who might like to participate?

Date & Time: **Tuesday 13 July 2010: 8:45-1:30**

Venue: **AUT University Akoranga Campus, 90 Akoranga Drive, Northcote, Auckland.** (Map & parking will be provided)



What are the Costs? - The workshop is free, but numbers are limited to 18 people
- Support with travel costs is available
- Morning tea and Lunch will be provided
- You will be provided with a certificate of attendance
- Remuneration of \$100 is available to all participants to cover costs such as childcare or time off work.

Margaret Jones (Occupational Therapist)

Free Phone: 0800 WE PARTICIPATE (0800 93 72784)

Email: margjone@aut.ac.nz



* Version 1: This version was last edited on 3 December 2009

Appendix 9.6a: Reply Form Whanau-Parent



People Helping Children Participate in their Communities after Brain Injury

Reply Form- Family/Whānau

Name: -----

Address: -----

Phone: -----

Please Tick:

- ☐ Yes I would like to attend the workshop and take part in the study
- ☐ I am interested and would like to hear more about the workshop and study
- ☐ No. I do not wish to take part in the workshop and study. I do not want any more information and do not wish to hear further.

Please return the completed form in the envelope provided.

Alternatively, you may wish to ring Starship Children's Health to advise your decision or to ask any questions: 09 307 4949 ext 22413

Or, phone me on 0800 WE PARTICIPATE (0800 93 72784).

Thank you for your reply.

Yours sincerely,

Margaret Jones (Researcher, Occupational Therapist)



Appendix 9.6b: Reply Form Professional-Community Support



People Helping Children Participate in their Communities after Brain Injury

Reply Form- Professional/Community Support Person

Name: -----

Address:-----

Phone: -----

Please Tick:

- ☐ Yes I would like to attend the workshop and take part in the study
- ☐ I am interested and would like to hear more about the workshop and study
- ☐ No. I do not wish to take part in the workshop and study. I do not want any more information and do not wish to hear further.

Please return the completed form to:

Margaret Jones (NZROT)
School of Rehabilitation and Occupation Studies
Faculty of Health and Environmental Sciences
AUT University
Pte Bag 92 006
Auckland 1142,

or email to margjone@aut.ac.nz

Alternatively, you may wish to phone me on 0800 WE PARTICIPATE (0800 93 72784).

Thank you for your reply.

Yours sincerely,

Margaret Jones (Researcher, Occupational Therapist)



Appendix 9.7: Recruitment Table

Helping Children to Participate after TBI

Recruitment Table

Inclusion Criteria: Whānau/parents and professionals who have experience in supporting social participation for a child who **a)** is currently aged 8-18 years **b)** sustained a Moderate – Severe TBI before the age of 14, and **c)** has been discharged from acute hospital care at least 12 months.

Exclusion Criteria: Not a Current Patient of Researcher

Not Birth Injuries

Not Non-Accidental TBI

i.e. *Injury occurring any point between DOB & Turning 14 years*

Can be up to Age 18 years in 2010

Cannot be younger than 8 years in 2010

All hospital d/cs must have occurred before April 2009 to allow 1 year to

Pass- this will mean they are very unlikely to be a current patient of researcher at Wilson Centre

Recruitment Band	DOB (year)	Latest Date of Injury <ul style="list-style-type: none"> (Up to but no more than Month turning 14, years from DOB) (Up to Birth Month in Year turned 14 if older than 14) (to be d/c from hospital 1+ years) 	Current Age-yrs-Mar/Apr 2010
A	1992	2006	18
B	1993	2007	17
C	1994	2008	16
D	1995	2009- March April	15
D	1996	2009 -“	14
D	1997	2009 -“	13
D	1998	2009 -“	12
D	1999	2009 -“	11
D	2000	2009 -“	10
D	2001	2009 -“	09
D	2002	2009 -“	08

Band One: DOB 1992, Injury 1992-2006
Band Two: DOB 1993, Injury 1993-2007
Band Three: DOB 1994, Injury 1994-2008
Band Four: DOB 1995 - 2002, Injury 1995- March/April 2009

Appendix 9.8: Whanau-Parent Information Sheet

Parent/Whānau Participant Information Sheet



People Helping Children Participate in their Communities after Brain Injury

An Invitation

Dear Parent(s)/Whānau,

My name is Margaret Jones. I would like to invite you to take part in a workshop which is a study drawing together people's ideas and experiences to develop a resource that can be used to help children join in their communities after a brain injury.

I am an occupational therapist who works at the Waitemata District Health Board Child Rehabilitation Service at Wilson Centre in Takapuna, with children who have experienced brain injuries. I am undertaking this research project for my PhD studies at AUT University.

Taking part in the research is voluntary (your choice).

This Information Sheet explains the study. However, if you have any questions about anything, please feel free to contact me on

0800 WE PARTICIPATE (0800 93 72784)

What is the purpose of this research?

The study aims to build and put together useful ways to enable people in the community to support the social participation of children who have had a traumatic brain injury. Ideas developed at the workshop will be made into a resource that will be available to parents/whānau, professionals, and community support people. I will write about the findings of the study for publication in a health journal, and hope to present the findings in New Zealand and also overseas.

How was I chosen for this invitation?

- This Information Sheet has been sent to you on my behalf by Starship Children's Health.
- You have been sent the invitation because, as the parent(s)/whānau of a child aged 8-18, who sustained a brain injury before the age of 14, I believe you will have ideas and experiences that will be useful for helping such children take part in community activities.

What will happen in this research?

If you decide to take part, it will involve coming along to a ½ day workshop at a central location. Other parents/whānau, professionals, and community support people will be invited to attend the workshop as well, but numbers are limited to 18 people.

At the workshop I will present what I have learned from families who have a child with a brain injury, about things that help them participate in their home, school and wider communities. I will ask you to join a small discussion group to talk about those ideas, and to give me your ideas about a strategy I have designed to support participation. You will also hear what other groups think, and have a chance to respond to their ideas.

The discussions will be audio-taped, and notes will be made of key points. If your group makes any notes or diagrams to explain what you think, I will ask you to give me those. After the workshop I will analyse the audio-recordings, and written material, and formulate people's ideas into a draft resource. A copy will be sent to you, and if you wish, you will be able to provide me with any further feedback over the phone or by email.

What are the discomforts and risks and how will these be addressed?

Some people can feel stressed or sad talking about these sorts of things, and may find it hard to talk in a group.

You will be able to let me know, and you can stop or withdraw from the workshop or study at any time. If you felt uncomfortable with any questions, you would not have to answer them. Your part in the discussions could be deleted as far as possible from the information if you decided you no longer wanted to take part.

However, you may find support in having other parents/whānau around who have shared similar experiences. You can bring along a support person, and an interpreter can be provided.

What are the benefits?

You will learn more about NZ children's participation after they have had a brain injury. You might find that sharing your experiences with others at the workshop is supportive and informative.

Your contribution will help other parents/whānau, professionals, and community support people know more about what can be done to support children to participate.

If you wish you will be given a brief report about the findings and will also be invited to attend a presentation. You will get a free copy of the resource the group develops.

How will my privacy be protected?

The workshop itself does not intend to gather information about specific people or children. People will sign on the consent form to keep the identity of children, other people at the workshop, and the details of discussion at the workshop confidential. You will not have to discuss information you do not wish to share.

After the workshop, any notes, charts, & computer discs/memory sticks will be stored securely in the researcher's office.

No material which could identify you will be used in any resources or reports on the study.

What are the costs of participating in this research?

The workshop will take 4 ½ hours of your time, and you will need to arrange to travel there.

Parking will be free. Morning tea & lunch will be provided, and you will be given a certificate of attendance.

To cover reasonable travel costs, you will be offered petrol vouchers.

If you need remuneration for your time or other expenses to attend the workshop, up to \$100.00 is available to cover loss of income or childcare costs. This can be in the form of vouchers of your choice, or can be paid on submission of a tax invoice. I will ask you if you will need to be reimbursed when the workshop details are finalised.

What opportunity do I have to consider this invitation?

You will have an opportunity to think about this invitation and to talk it over with family/whanau or friend before you choose whether or not you would like to take part. An interpreter can be provided to assist you if you wish.

- Please write your name & contact details on the Reply Form. Tick a box to indicate your decision, and return the form in the envelope.
- Alternately, you can phone the following Starship number to advise your decision or to ask any questions: 09 307 4949 ext 22413, or phone me on 0800 93 72784.
- If we haven't heard from you in 2 weeks time, Starship Children's Health will pass on your name & telephone number, so that I can phone you to follow up whether you would like to take part, confirm arrangements, and answer any questions. This will take about 5 minutes of your time.

Taking part in the study is entirely voluntary. If you decide you prefer not to take part, or if you withdraw, this will not affect your child's rehabilitation in any way and there will be no adverse consequences for you or your child.

How do I agree to participate in this research?

If you wish to take part and send back the Reply Form indicating you would like to attend, you will be given a Consent Form to sign when you arrive on the day of the workshop. If you bring a support person, they will also be asked to sign a Consent Form.

Do you know of Other People Who Might Like to Participate?

You are welcome to forward this information to other people who you think have supported your child's participation and may be interested in taking part. Some additional copies of the information have been provided in case you wish to do this.

Will I receive feedback on the results of this research?

You will be given a copy of the final resource manual when it is completed and, if you wish, a brief report. You will receive an invitation to a presentation about the research findings and the resource. Please note there is usually a delay between collecting information and letting people know the results.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, Clare Hocking, Associate Professor, AUT University. Email: clare.hocking@aut.ac.nz Phone 09 921 9162.

Concerns regarding the conduct of the research should be notified to the Executive Secretary, AUTECH, Madeline Banda, Madeline.banda@aut.ac.nz, 921 9999 ext 8044.

If you have any queries or concerns regarding your rights as a participant in this study you may wish to contact an independent Health and Disability Advocate: Free phone: 0800 555 05. Free fax: 0800 2 SUPPORT (0800 2787 7678). Email: advocacy@hdc.org.nz

Whom do I contact for further information about this research?

▪ Researcher:

Margaret Anne Jones, Occupational Therapist. margjone@aut.ac.nz . Phone 09 921 9999 ext 7781 or 0800(number to be advised). AUT University, Private Bag 92 006, Auckland 1142.

▪ Project Supervisors:

Dr Clare Hocking, Associate Professor. clare.hocking@aut.ac.nz 09 921 9999 x 7120

Professor Kathryn McPherson. kathryn.mcpherson@aut.ac.nz 09 921 9999 ext 7110

▪ For Cultural Support or Advice

Mo Wai Te Ora, Waitemata District Health Board. 09 486 8324 ext 2324.

▪ If you would like to Contact Starship Children's Health about the study call: 09 307 4949 ext 22413.

This study has received ethical approval from the Northern Y Regional Ethics Committee on 21/04/10; Reference number NTY 10/01/003.

Appendix 9.9: Professional Community Support Information Sheet

Professionals & Community Support Participant Information Sheet



People Helping Children Participate in their Communities after Brain Injury

An Invitation

Dear Therapist/Teacher/Case Coordinator/Support Person,

My name is Margaret Jones. I would like to invite you to take part in a workshop which is a study drawing together people's ideas and experiences to develop a resource that can be used to help children join in their communities after a brain injury.

I am an occupational therapist who works at the Waitemata District Health Board Child Rehabilitation Service at Wilson Centre in Takapuna, with children who have experienced brain injuries. I am undertaking this research project for my PhD studies at AUT University.

Taking part in the research is voluntary (your choice).

This Information Sheet explains the study. However, if you have any questions about anything, please feel free to contact me on

0800 WE PARTICIPATE (0800 93 72784)

What is the purpose of this research?

The study aims to build and put together useful ways to enable people in the community to support the social participation of children who have had a traumatic brain injury. Ideas developed at the workshop will be made into a resource that will be available to parents/whānau, professionals, and community support people. I will write about the findings of the study for publication in a health journal, and hope to present the findings in New Zealand and also overseas.

How was I chosen for this invitation?

- This Information Sheet has been sent to your workplace, or it may have been forwarded on to you by another person who has been approached about the study.
- You have been sent this invitation because, as a person who has provided therapy services, case coordination, education, or supported a child aged 8-18 who sustained a brain injury before the age of 14, I believe you will have ideas and experiences that will be useful for helping such children take part in community activities.

What will happen in this research?

If you decide to take part, it will involve coming along to a ½ day workshop at a central location. Other professionals, community support people, and parents/whānau will also be invited to attend, but numbers are limited to 18 people.

At the workshop I will present what I have learned from families who have a child with a brain injury, about things that help them participate in their home, school and wider communities. I will ask you to join a small discussion group to talk about those ideas, and to give me your ideas about a strategy I have designed to support participation. You will also hear what other groups think, and have a chance to respond to their ideas.

The discussions will be audio-taped, and notes will be made of key points. If your group makes any notes or diagrams to explain what you think, I will ask you to give me those. After the workshop I will analyse the audio-recordings and written material, and formulate people's ideas into a draft resource. A copy will be sent to you, and if you wish, you will be able to provide me with any further feedback over the phone or by email.

What are the discomforts and risks and how will these be addressed?

You may find it hard to share your ideas in a group situation.

You will be able to let me know, and you can stop or withdraw from the workshop or study at any time. If you felt uncomfortable with any questions, you would not have to answer them. Your part in the discussions could be deleted as far as possible from the information if you decided you no longer wanted to take part.

What are the benefits?

You will learn more about NZ children's participation after they have had a brain injury. You might find that sharing your experiences with others at the workshop is informative.

Your contribution will help other parents/whānau, professionals, and community support people know more about what can be done to support children to participate.

If you wish you will be given a brief report about the findings and will also be invited to attend a presentation. You will get a free copy of the resource the group develops.

How will my privacy be protected?

The workshop itself does not intend to gather information about specific people or children. People will sign on the consent form to keep the identity of children, other people at the workshop, and the details of discussion at the workshop confidential. You will not have to discuss information you do not wish to share.

After the workshop, any notes, charts, & computer discs/memory sticks will be stored securely in the researcher's office.

No material which could identify you will be used in any resources or reports on the study.

What are the costs of participating in this research?

The workshop will take 4 ½ hours of your time, and you will need to arrange to travel there.

Parking will be free. Morning tea & lunch will be provided, and you will be given a certificate of attendance.

To cover reasonable travel costs you will be offered petrol vouchers.

If you need remuneration for your time or other expenses to attend the workshop, up to \$100.00 is available to cover loss of income or childcare costs. This can be in the form of vouchers of your choice, or can be paid on submission of a tax invoice. I will ask you if you will need to be reimbursed when the workshop details are finalised.

What opportunity do I have to consider this invitation?

You will have opportunity to think about this invitation and to talk it over with a colleague or friend before you choose whether or not you would like to take part.

- Please write your name & contact details on the Reply Form. Tick a box to indicate your decision, and return the form in the envelope.
- Alternately, you can phone me on 0800 93 72784.
- If I haven't heard from you in 2 weeks time, I will phone you to follow up whether you would like to take part, confirm any arrangements, and answer any questions. This will take about 5 minutes of your time.

Taking part in the study is entirely voluntary. If you decide you prefer not to take part, or if you withdraw you will not be disadvantaged in any way. Your employment will not be affected.

How do I agree to participate in this research?

If you wish to take part and send back the Form indicating you would like to attend, you will be given a Consent Form to sign when you arrive on the day of the workshop.

Do you know of Other People Who Might Like to Participate?

You are welcome to forward this information to other people who you think have supported such a child's participation and may be interested in taking part. Some additional copies of the information have been provided in case you wish to do this.

Will I receive feedback on the results of this research?

You will be given a copy of the final resource manual when it is completed and, if you wish, a brief report. You will receive an invitation to a presentation about the research findings and the resource. Please note there is usually a delay between collecting information and letting people know the results.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, Clare Hocking, Associate Professor, AUT University. Email: clare.hocking@aut.ac.nz Phone 09 921 9162.

Concerns regarding the conduct of the research should be notified to the Executive Secretary, AUTECH, Madeline Banda, madeline.banda@aut.ac.nz, 921 9999 ext 8044.

If you have any queries or concerns regarding your rights as a participant in this study you may wish to contact an independent Health and Disability Advocate: Free phone: 0800 555 05. Free fax: 0800 2 SUPPORT (0800 2787 7678). Email: advocacy@hdc.org.nz

Whom do I contact for further information about this research?

- Researcher:

- Margaret Anne Jones, Occupational Therapist. margjone@aut.ac.nz . Phone 09 921 9999 ext 7781 or 0800 93 72784. AUT University, Private Bag 92 006, Auckland 1142.
- Project Supervisors:
Dr Clare Hocking, Associate Professor. clare.hocking@aut.ac.nz 09 921 9999 ext 9162
Professor Kathryn McPherson. kathryn.mcperson@aut.ac.nz 09 921 9999 ext 7110
- For Cultural Support or Advice
Mo Wai Te Ora, Waitemata District Health Board. 09 486 8324 ext 2324.

This study has received ethical approval from the Northern Y Regional Ethics Committee on 21/04/10; Reference number NTY 10/01/003.

Appendix 9.10: Correspondence with ACC Ethics

From: "Grant Pittams" <Grant.Pittams@acc.co.nz> Wednesday - February 17, 2010 3:31 PM To: "Margaret Jones" <margaret.jones@aut.ac.nz> Subject: RE: RE: PhD Study re Children's Participation after TBI Attachments: Mime.822 (8753 bytes) [\[View\]](#) [\[Save As\]](#)

Good afternoon Margaret - I have looked at your Application and it is my opinion that it will not be necessary for you to apply to the ACC Ethics Committee. ACC Ethics is mainly concerned with ACC client information, and as this Application involves the:

- 1/ Recruitment of ACC Staff
- 2/ Clients will not be identified in any way
- 3/ Clients will not be involved in the study

Then I consider that not ethics application is necessary

However - you will need to discuss with me about how you intend to recruit the ACC staff. I suggest that you should work with the ACC Research Team to gain the necessary ACC Management approvals.

Regards - Grant Pittams - Research Manager

-----Original Message-----

From: Margaret Jones [mailto:margaret.jones@aut.ac.nz]
Sent: Wednesday, 17 February 2010 09:24
To: Fiona Conlon
Cc: Grant Pittams
Subject: RE: RE: PhD Study re Children's Participation after TBI

Dear Grant, I am sending you a copy of my ACC ethics application- I had sent it to Fiona Conlon earlier this morning with an aim of having it to her before the 10:00 AM deadline today, but received an out-of-office reply. Kind regards, Margaret Jones.

Dear Fiona, following from this email correspondence and our telephone conversation, please find attached my ACC Ethics Application and accompanying documentation.

The study was verbally approved at the Northern Y Ethics Committee meeting on 26-01-10. I am awaiting written notification of the approval, which will be conditional on a favourable Locality Assessment through Auckland District Health Board Research Review Committee. I will forward

these items of documentation on to the ACC Ethics Committee as they become available.

Please feel free to contact me should you have any queries- I am available via my cell-phone 027 274 2671. I trust that emailed documents are acceptable- please let me know if hard copy is required. Kind regards, Margaret.

Margaret Jones
(MHSc), NZROT
Lecturer
School of Occupational Therapy
Auckland University of Technology
Private Bag 92006
Auckland 1020
Telephone (9) 921 9999 extn 7781

>>> "Fiona Conlon" <Fiona.Conlon@acc.co.nz> 02/08/10 2:11 PM >>>
Hi Margaret

I have discussed your proposed workshops with my manager and our understanding of this study is that a few ACC staff may be approached to discuss a particular case in which they are involved. It is not about provision of services in general. They would therefore be in the situation of discussing a client's health record.

I think this would require approval from ACC Ethics after approval had been obtained from the Auckland Ethics Comm. In theory approval would also be required from ACC management if the case manager required time of work to attend the discussion.

The next committee meeting is scheduled for Wednesday 3 March. Therefore your application would need to reach me by Wednesday 17 February to be considered at the meeting. I have attached the ethics application form and accompanying instructions.

Please let me know if you have any further questions.

Regards
Fiona

Fiona Conlon, Research Advisor, Research, ACC Tel 04 918 3987 /
Fax 04 918 7402

ACC cares about the environment - please don't print this email unless it is really necessary. Thank you.

Appendix 9.11: Ethics Approval Rehabilitation Service Recruitment February 2010

WDHB Approval of Research



0980711310 **Action Research to Develop a Community Focused Intervention that Facilitates Social Participation for New Zealand Children who have had a Traumatic Brain Injury (TBI)**

Project Personnel

WDHB Contact Megan Jones

Type of Project	Audit or evaluation (clinical, service)	Title Abbrevn	
Multi-site?	Single site (WDHB only)	External Ref #	
Dept	Child Health Service Level Mgt	Status	PENDING
Service	Child Health Services	Project duration	01/03/2010 to 01/12/2010

Project description: The study aims to collaborate with key stakeholders, including whānau/parents and professionals, to participate in developing a resource describing a community focussed intervention strategy, that can be used to facilitate the social participation of children who have a TBI. Participants will attend a half-day workshop at an Auckland setting. Invitation will be extended to WDHB Child Rehabilitation Service staff (eg. therapists, cultural supports) to take part in the workshop and study. It is also proposed to approach teaching staff with experience of working with children with TBI through names of relevant schools provided by the WDHB Child Rehabilitation Service.

Client information is not sought as part of the study although it is proposed that whānau/parents will be approached from a list of contacts provided through Auckland District Health Board (ADHB); participant names &/or any identifying information will be excluded from the analysis and any reports.

The study is part of the principal researcher's PhD studies at AUT University. Primary supervisor is Dr Clare Hocking.

Management Sign-offs

CROSS OUT ANY SIGN-OFFS NOT APPLICABLE TO THIS PROJECT

Our signatures below indicate that the project is feasible and appropriate, and is able to be conducted with the staff, facility and resource availability in the relevant unit.

Order	Dept/Service/Org	Role	Name (print clearly)	Signature	Date Signed
1	Child Health Service Level Mgt	Manager	Ann Smith		
<i>(Cross out if this item is not applicable to your project)</i>					
2	Child Health Services	Clinical Director	Tim Jelleyman		

(Cross out if this item is not applicable to your project)

Please note that Service-level General Manager (or CEO) signatures will also be required for the Locality Assessment Form sent in with the corresponding ethics application.

Please forward this completed form to the Knowledge Centre and ensure all sign-offs are recorded in ResearchMaster.



Waitemata
District Health Board
Te Wai Awhina

NORTH SHORE HOSPITAL
Shakespeare Road
Private Bag 93-503, Takapuna
Auckland 9
Telephone: (09) 486 1491
Facsimile: (09) 486 8908

05 February 2010

Margaret Ann Jones
Department of Occupational Science & Therapy
AUT University
Private Bag 92 006
Auckland 1142
New Zealand

Tena koe Margaret,

People Helping Children Participate in their local Communities after Brain Injury

This letter is to advise that your application was discussed at the last meeting of the Nga Kai Tataki Maori Research Review Committee. We are pleased to advise that your application was approved.

This approval is subject to the condition that the researchers must advise any Maori participants in this proposed health research programme, that before proceeding they should seek support from their own whanau, Kaumatua or Kuia or their local Maori Health Services.

Please send us a copy of the report once your research is completed.

Noho ora mai ra

PP

Tanekaha Rosieur
Chairperson
Nga Kai Tataki

Te Aniwa Tutara
General Manager
Maori Health

Appendix 9.12: Whanau-Parent Consent Form

Parent/Whānau Consent Form



People Helping Children Participate in their Communities after Brain Injury

Project Supervisors: Dr Clare Hocking, Associate Professor. clare.hocking@aut.ac.nz 09 921 9999 ext 9162

Professor Kathryn McPherson. kathryn.mcpherson@aut.ac.nz 09 921 9999 ext 7110

Researcher: Margaret Anne Jones, Occupational Therapist. margjone@aut.ac.nz AUT University, Private Bag 92 006, Auckland 1142. 09 921 9999 ext 7781 **0800 Free Phone to be advised.

- ☐ I have read and understood the information provided about this research project in the Information Sheet dated 03/12/09.
- ☐ I have had time to consider whether to take part in the study.
- ☐ I have had an opportunity to ask questions and to have them answered.
- ☐ I have had sufficient time to discuss the project with whānau/family or a friend prior to signing this consent form.
- ☐ I understand that taking part is entirely voluntary (my choice).
- ☐ I understand that details about my child(ren) are confidential, and I agree to keep this information confidential from the group.
- ☐ I understand that the identity of my fellow participants and details of our discussions in the workshop group are confidential to the group, and I agree to keep this information confidential.
- ☐ I understand that no material which could identify me will be used in any reports on this study.
- ☐ I understand that notes will be taken during the workshop group, that information may be charted, and that discussions will be audio-taped.
- ☐ I understand that I may withdraw myself or any information that I have provided for this project at any time prior to completion of data collection, without being disadvantaged in any way.

English	I wish to have an interpreter	Yes	No
Deaf	I wish to have a NZ sign language interpreter	Yes	No
Māori	E hiahia ana ahau ki tetahi kaiwhaka Māori/kaiwhaka pakeha korero	Ae	Kao
Cook Island Māori	Ka inangaro au i tetahi tangata uri reo	Ae	Kare
Fijian	Au gadreva me dua e vakadewa vosa vei au	Io	Sega

- If I withdraw, I understand that while it may not be possible to destroy all records of the workshop group discussion
Niuean Fia manako 'au ke fakaaoga e tana tagata fakano'ono'ono E Naka
- I agree to take part in this research: Yes ○ No ○
-
- | | | | |
|----------|--|-----|------|
| Sāmoan | Ou te mana'o ia i ai se fa'amatala upu | loe | Leai |
| Tokelaun | Ko au e fofou ki he tino ke fakaliliu te gagana Peletania ki na gagana o na motu o te Pahefika | loe | Leai |
| Tongan | Oku ou fiema'u ha fakatonulea | lo | Ikai |
- I wish for a support person to attend with me: Yes ○ No ○
- I wish to receive a copy of the report from the research: Yes ○ No ○

Request for interpreter

Participant's signature:

Participant's name:

Date:

This study has received ethical approval from the Northern Y Regional Ethics Committee on 21/04/10; Reference number NTY 10/01/003.

Note: The Participant should retain a copy of this form.

Appendix 9.13: Professional-Community Support Consent Form

Professionals/Community Support Person Consent Form



People Helping Children Participate in their Communities after Brain Injury

Project Supervisors: Dr Clare Hocking, Associate Professor. clare.hocking@aut.ac.nz 09 921 9999 ext 7120

Professor Kathryn McPherson. kathryn.mcpherson@aut.ac.nz 09 921 9999 ext 7110

Researcher: Margaret Anne Jones, Occupational Therapist. margjone@aut.ac.nz AUT University, Private Bag 92 006, Auckland 1142. 09 921 9999 ext 7781 or 0800 WE PARTICIPATE

- ☐ I have read and understood the information provided about this research project in the Information Sheet dated 03/12/09.
- ☐ I have had time to consider whether to take part in the study.
- ☐ I have had an opportunity to ask questions and to have them answered.
- ☐ I have had sufficient time to discuss the project with a colleague or friend prior to signing this consent form.
- ☐ I understand that taking part is entirely voluntary (my choice).
- ☐ I understand that details about child(ren)/people I have worked with are confidential, and I agree to keep this information confidential from the group.
- ☐ I understand that the identity of my fellow participants and details of our discussions in the workshop group are confidential to the group, and I agree to keep this information confidential.
- ☐ I understand that no material which could identify me will be used in any reports on this study.
- ☐ I understand that notes will be taken during the workshop group, that information may be charted, and that discussions will be audio-taped.
- ☐ I understand that I may withdraw myself or any information that I have provided for this project at any time prior to completion of data collection, without being disadvantaged in any way.

English	I wish to have an interpreter	Yes	No
Deaf	I wish to have a NZ sign language interpreter	Yes	No
Māori	E hiahia ana ahau ki tetahi kaiwhaka Māori/kaiwhaka pakeha korero	Ae	Kao
Cook Island Māori	Ka inangaro au i tetai tangata uri reo	Ae	Kare
Fijian	Au gadreva me dua e vakadewa vosa vei au	Io	Sega

○ If I withdraw, I understand that while it may not be possible to destroy all records of the workshop group discussion	Niuean Fia manako au ke fakaaoga e taha tagata	Yes <input type="radio"/>	No <input type="radio"/>	Nakai
○ I agree to take part in this research	Sāmoan Ou te mana'o ia i ai se fa'amatala upu	Yes <input type="radio"/>	No <input type="radio"/>	Leai
○ I wish to receive a copy of the report from the research:	Tokelaun Ko'au e loto'u ki he tino ke fakaili te gagana Peletania ki na gagana o na motu o te Pahefika	Yes <input type="radio"/>	No <input type="radio"/>	Leai
	Tongan Oku ou fiema'u ha fakatonulea	Yes <input type="radio"/>	No <input type="radio"/>	Ikai

Request for interpreter

Participant's signature:

Participant's name:

Date:

This study has received ethical approval from the Northern Y Regional Ethics Committee on 21/04/10; Reference number NTY 10/01/003.

Note: The Participant should retain a copy of this form.

Appendix 9.14: Facilitator Guidelines



09/07/10

People Helping Children Participate in their Communities after Brain Injury

FACILITATOR GUIDELINES

Arrival & Registration: 8:45-9:15

Carolyn & Margaret: Warm welcome, Tick off Registration, Provide

- Sticky Label with Name
- Consent Form & Pen
- Workshop Outline
- Power Point Handout
- Draft Resource
- Question Guide
- Invitation for tea/coffee etc located next door, Directions to toilets.
- Check re Parking Label OK
- Explain to find a seat, then Read & Fill in Consent Form, then take to Janet or Clare. Check if assistance/explanation needed. Approach Janet or Clare if assistance needed.

Janet & Clare: Facilitating introductions & Conversation, Seating, Assist with Consent Forms as needed. Location of tea/coffee, Refer to draft resource as appropriate, Be available to answer queries, Monitor time frames and ready group for Welcome & start.

****Collect Consent Forms into Purple Sleeve, and Janet tick them off on List as signed. Check up any on list not signed.**

All: Tidy up arrival tea/coffees as needed ready for Welcome at 9:15.

Presentation 9:30-10:00.

Include outline of day, emergency procedures. Explain there will be time for questions at the end.

Following Presentation: 10:00-10:15

Clare: Switch Recorders on
Request people to either state their name or introduce themselves as a parent when they ask a question. Facilitate people to ask questions and to provide comment.

Janet: Capture ideas onto Whiteboard

Carolyn: Setting up morning tea

Margaret: Fielding Questions. Just before Morning Tea, prompt people that after Morning tea, they will be moving into different rooms with Facilitators. Have a list of names and groups on wall beside Whiteboard for people to check who they are with. Facilitators will each be provided with a list.

Morning Tea: 10:15-10:30

Put Name Lists on board at start of morning tea.

Morning tea will be in room next door- AE114, but can bring drinks etc & move back through. All assist as needed, facilitate conversation, answer questions.

Small Group Discussion: 10:30-11:30

Margaret (Non-Pacific Families) AE119 (Code CY2701 I think)

Clare (Professionals) AE120 (around corner) (CY2701 I think) or AE114 depending on noise

Janet (Pacific Families) stay in AE115.

**** **SECURITY = 9997.**

- Poster Sheets, & Felts will be already set up in room with desks arranged in Horseshoe shape.

- Take Tape Recorders, Question Guides, Outline.
- Facilitate Seating.
- DISCRETELY remind re Tape Recorders and Switch them On at start and Off after.
- Quick round of Introductions
- Monitor and reminders re Time Frames
- Inform people they can write comments on their draft resources if they wish.
- Take notes of discussion on Poster Sheets to help group members to see what is being written. Facilitate group to delegate someone to do this as appropriate, or facilitator may record onto Poster Sheets. Keep all Poster Sheets.
- Have Question Guides ready. Facilitate discussion and opportunity to speak. Prompt people to Question Guide. Keep discussion on track (with discretion).
- Draw discussion to close, at 11:22 and Pull Comments Together, recording Key Points onto a New Poster Sheet for Presenting back. If appropriate, delegate 2-3 people to feed back to rest of group with you assisting them, or Facilitator can do feedback with support from small group members.
- Guide People back to Main Room (AE115).

Carolyn: Assisting with Clear Up Morning Tea, Re-fill Urn & switch on. Support with children, Responding to queries, Problem-solving.

Small Group Feedback: 11:30-12:15

Margaret: Facilitate Feedback from Small Groups, Respond to Questions, Facilitate Questions/Clarification from Other Groups. 15m x 3. 10 mins to explain key points, 5 mins for questions.

Clare: Switch Recorders On (and Off after!)
Support with Feedback and Discussion

Janet: Assist with Sticking Posters to Whiteboard
Record Comments/Thread of Discussion onto Whiteboard.

Carolyn: Assist with Set Up lunch & Brief Tidy up after.

Small Groups Reconvene:12:45-1:20

Switch Recorders on/off. Reflect on and Record Responses to other groups' feedback on Poster Sheets. **NB: Over lunch, key points will need to be noted down and copied for the other groups to refer to.** Keep all Poster sheets.

Thank you and Formal Close: 1:20

Feedback will be drawn together and the Resource Modified. The changed resource will be posted to the Participants. If they have other thoughts they can contact Margaret via email, via FreePhone or by post.

Appendix 9.16: Workshop Question Guide

People Helping Children Participate in their Communities after Brain Injury

Workshop Question Guide

Responses to Suggested Strategy

Thinking back over your own experiences, how well do you think the suggested community focused intervention strategy will work?

Think about 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?

Would it work better with some children than with others (ages, severity of injury, type of impairments)? Please explain.

What do you think a) other children's responses to the strategy might be?
 b) other adult's responses to the strategy might be?

How acceptable do you think the strategy might be to a child who has had a TBI?

When would be the best time to implement the strategy? Over what time frames?

What resources might be needed to implement the strategy?

After Hearing the other Groups' Ideas

Having heard from the other groups, are there things you want to change or add to your earlier feedback?

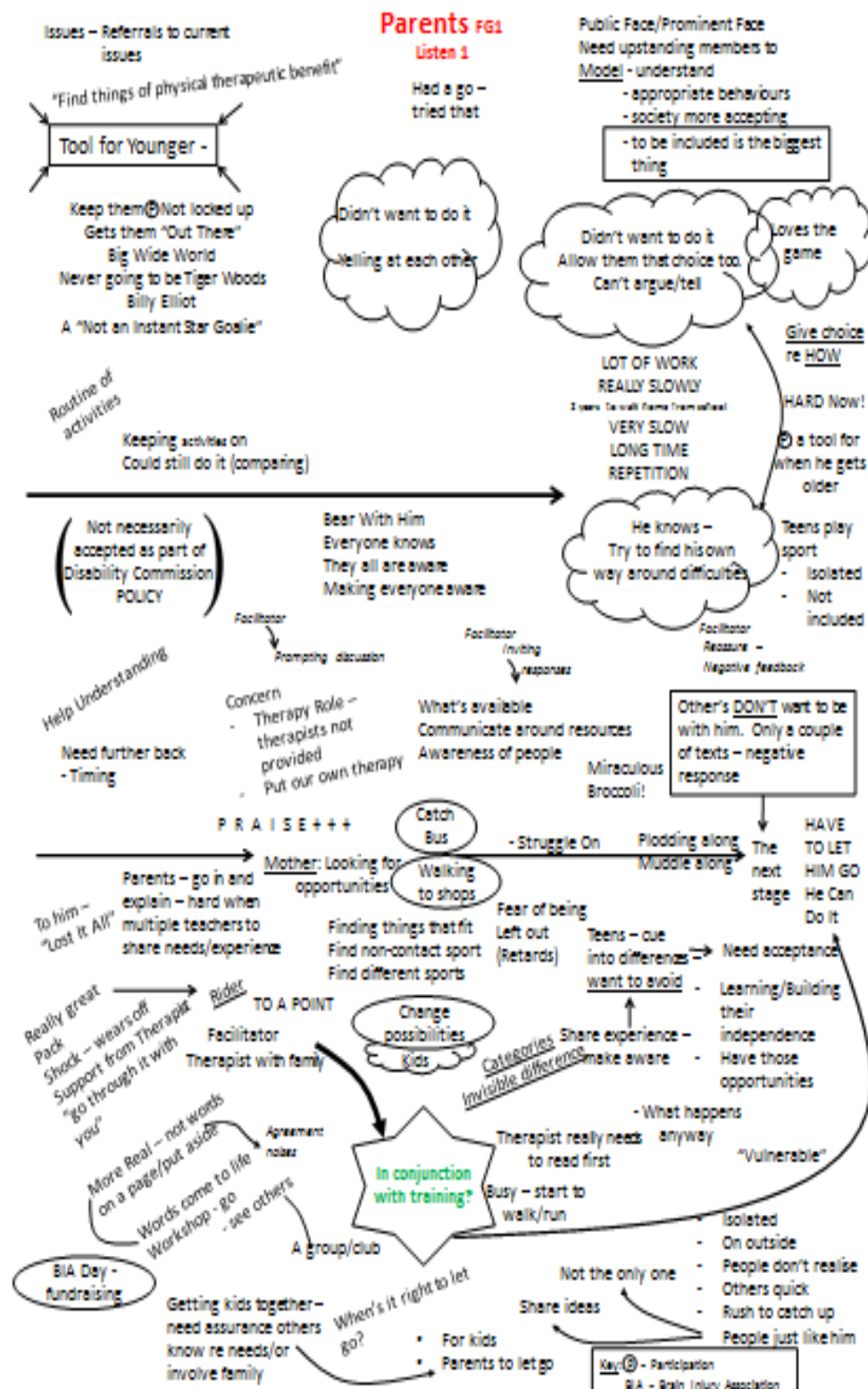
Are there other things you think I need to consider?

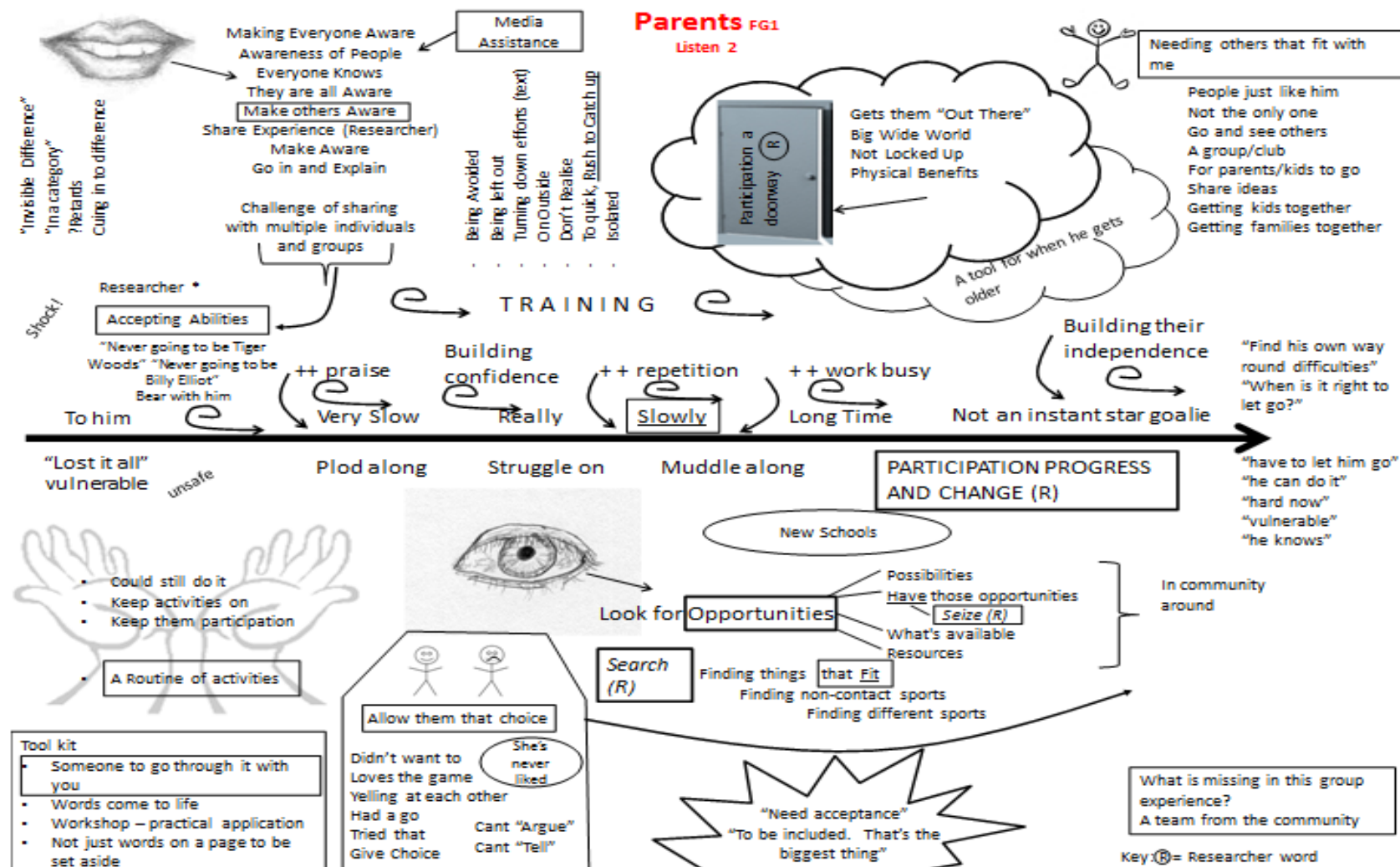
How can the strategy be made available to parents, teachers, and community support people?

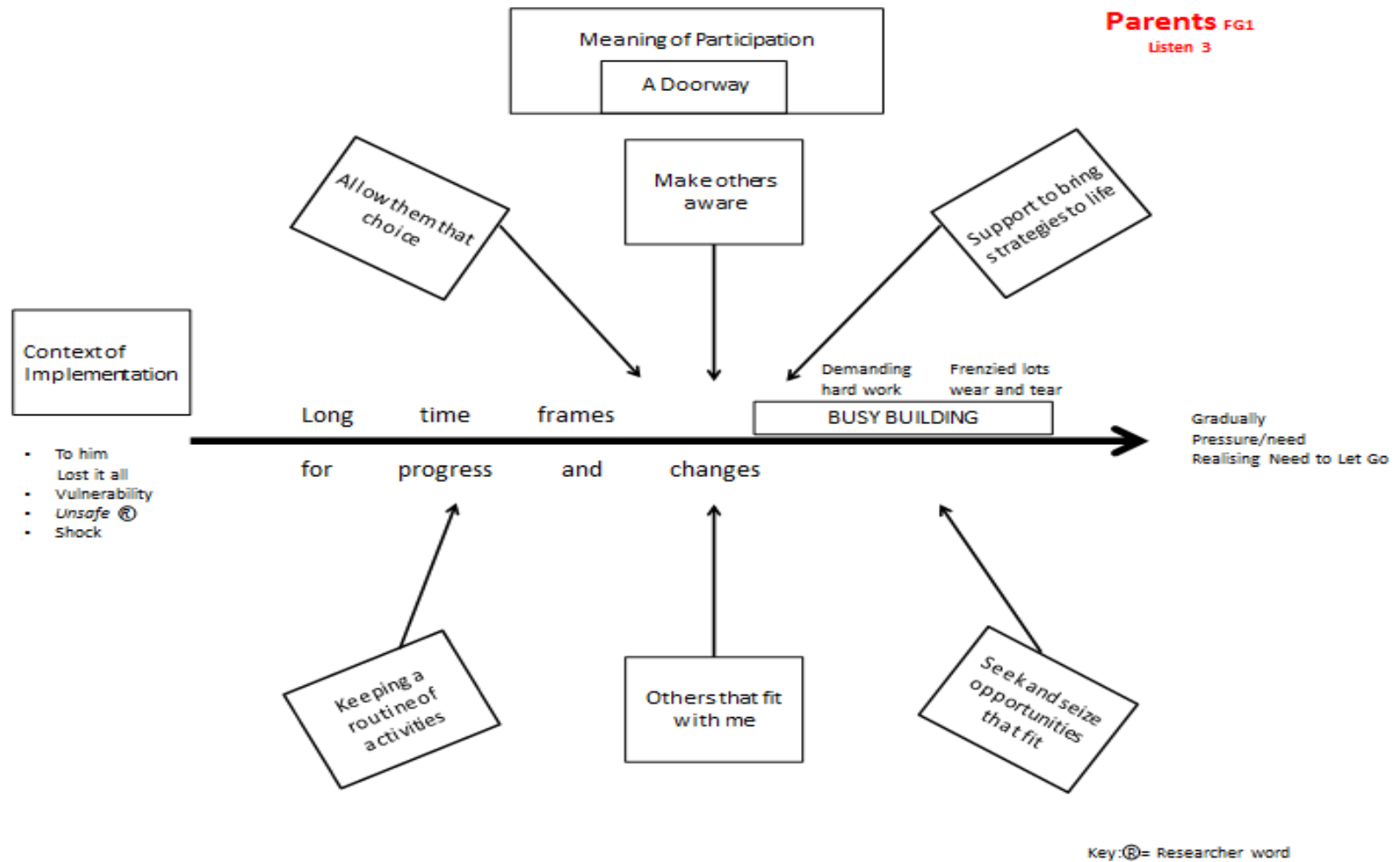
What would you have found useful?

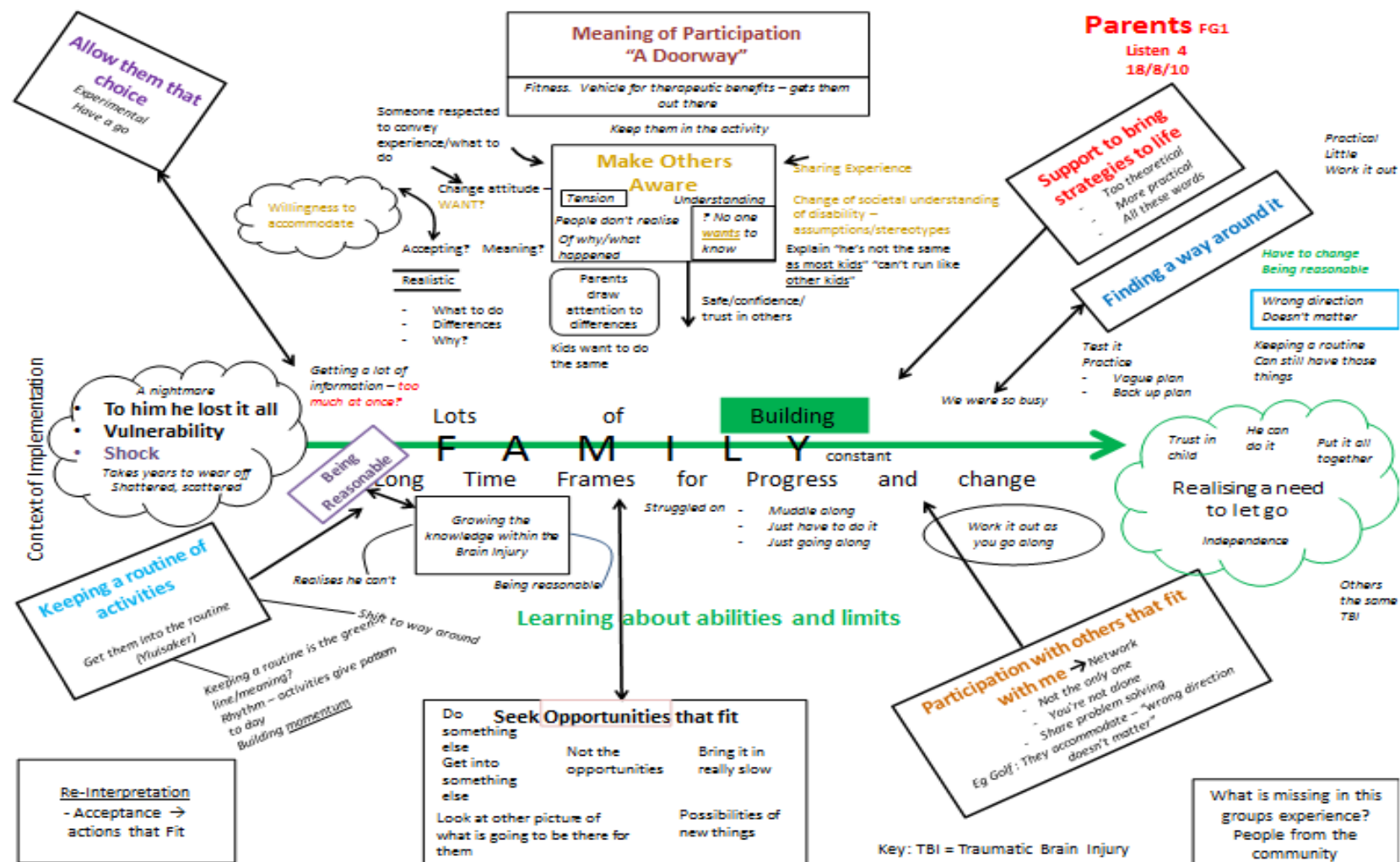
How should the strategy look?

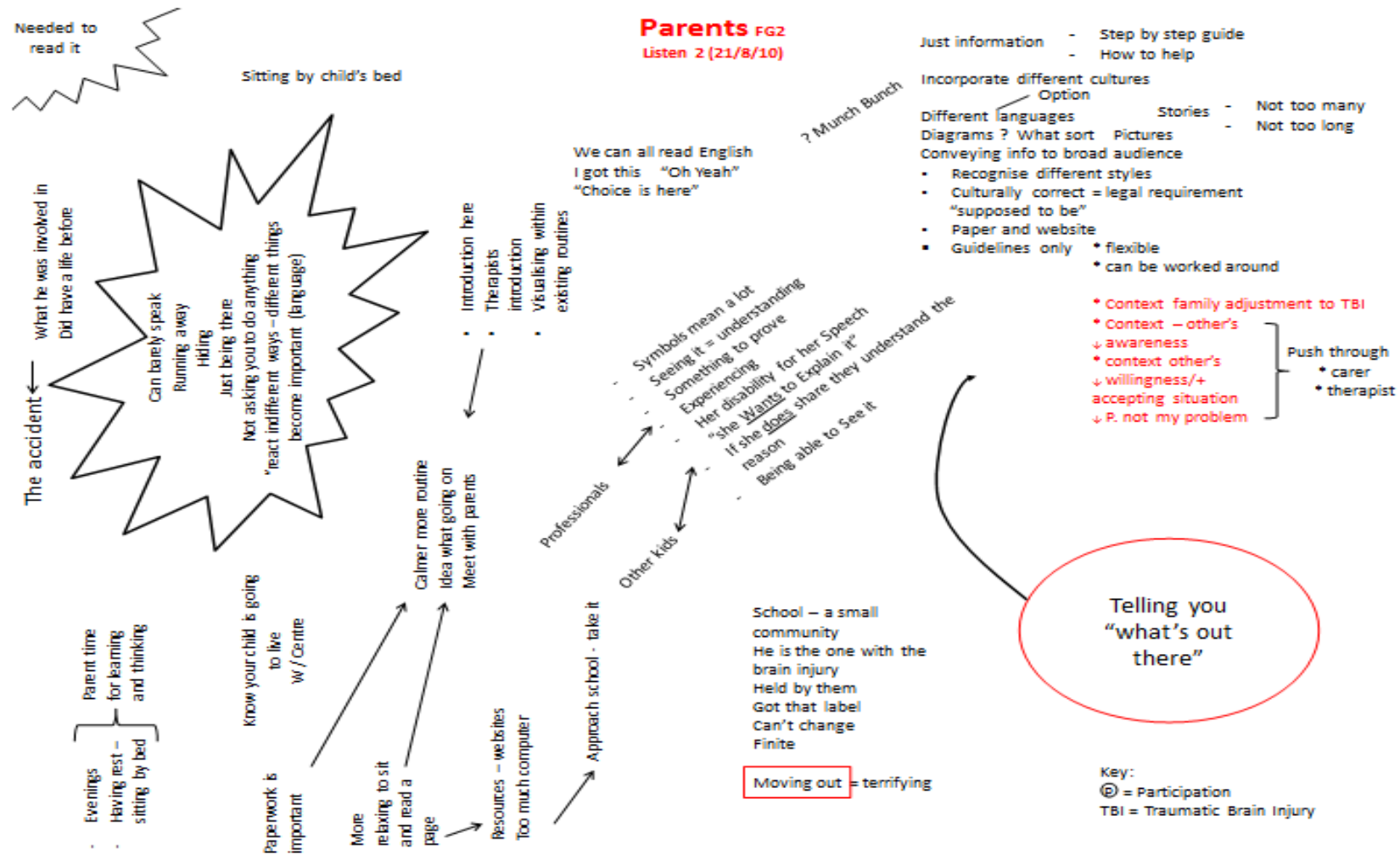
Appendix 9.17a: Cognitive Maps Whanau-Parents



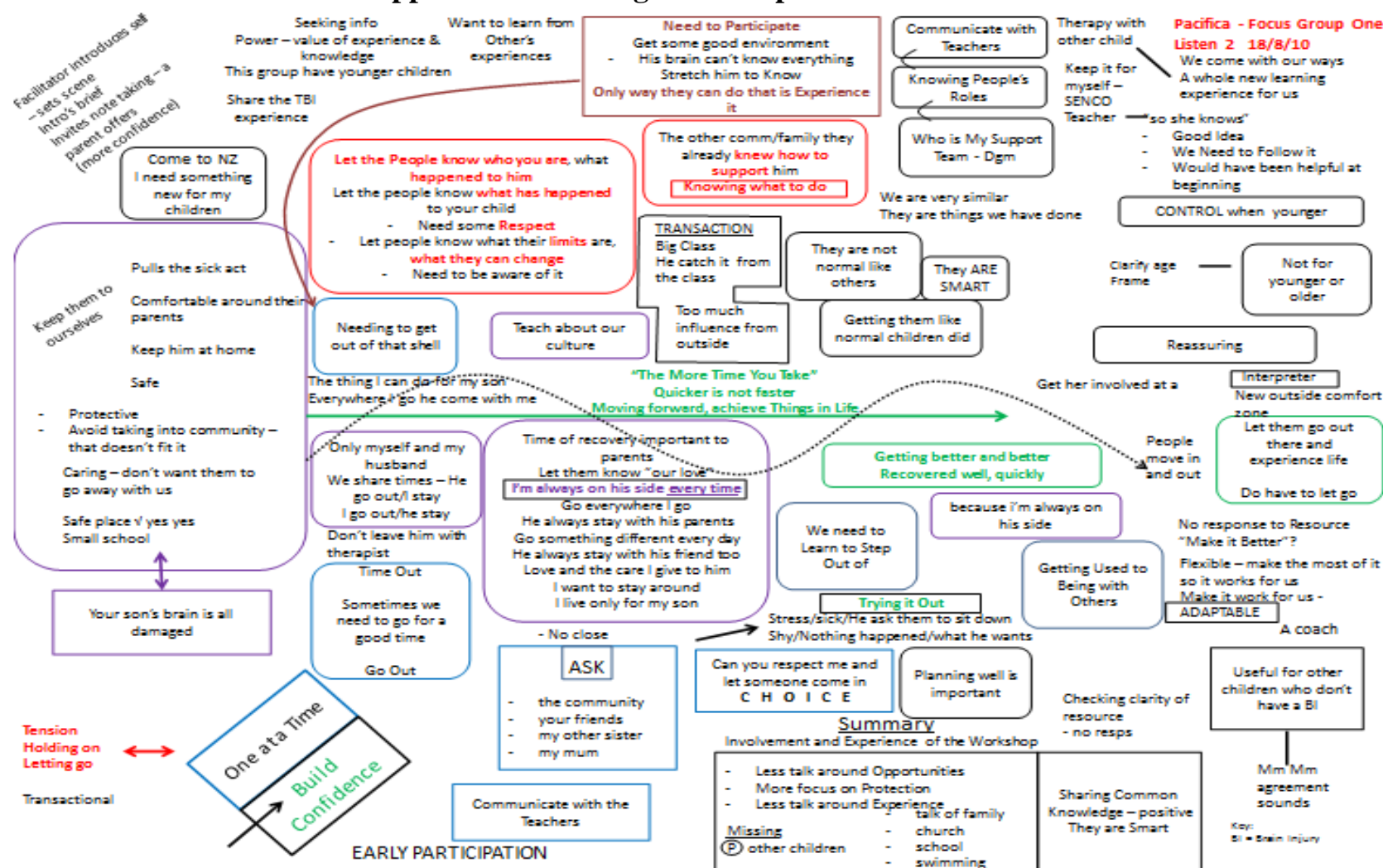




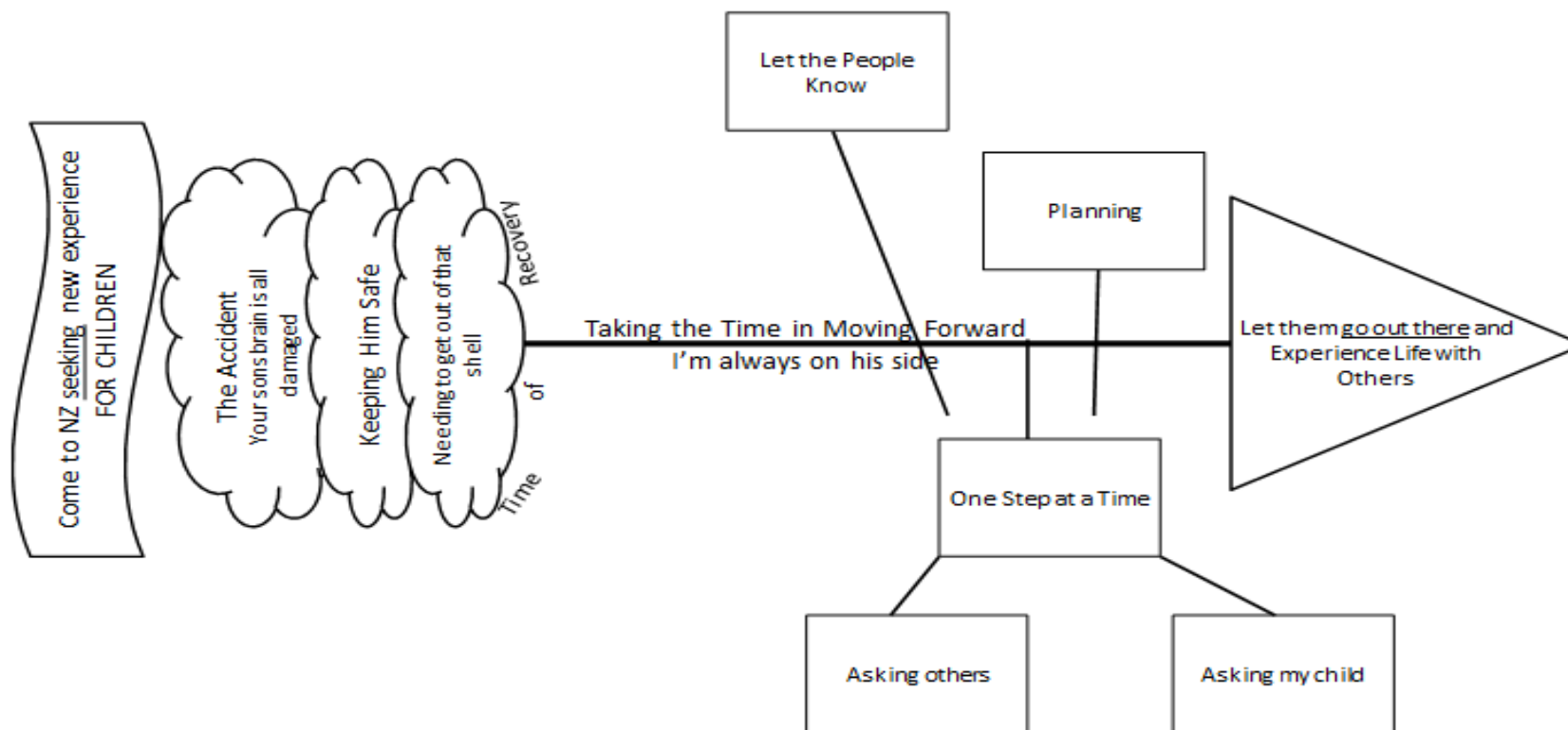


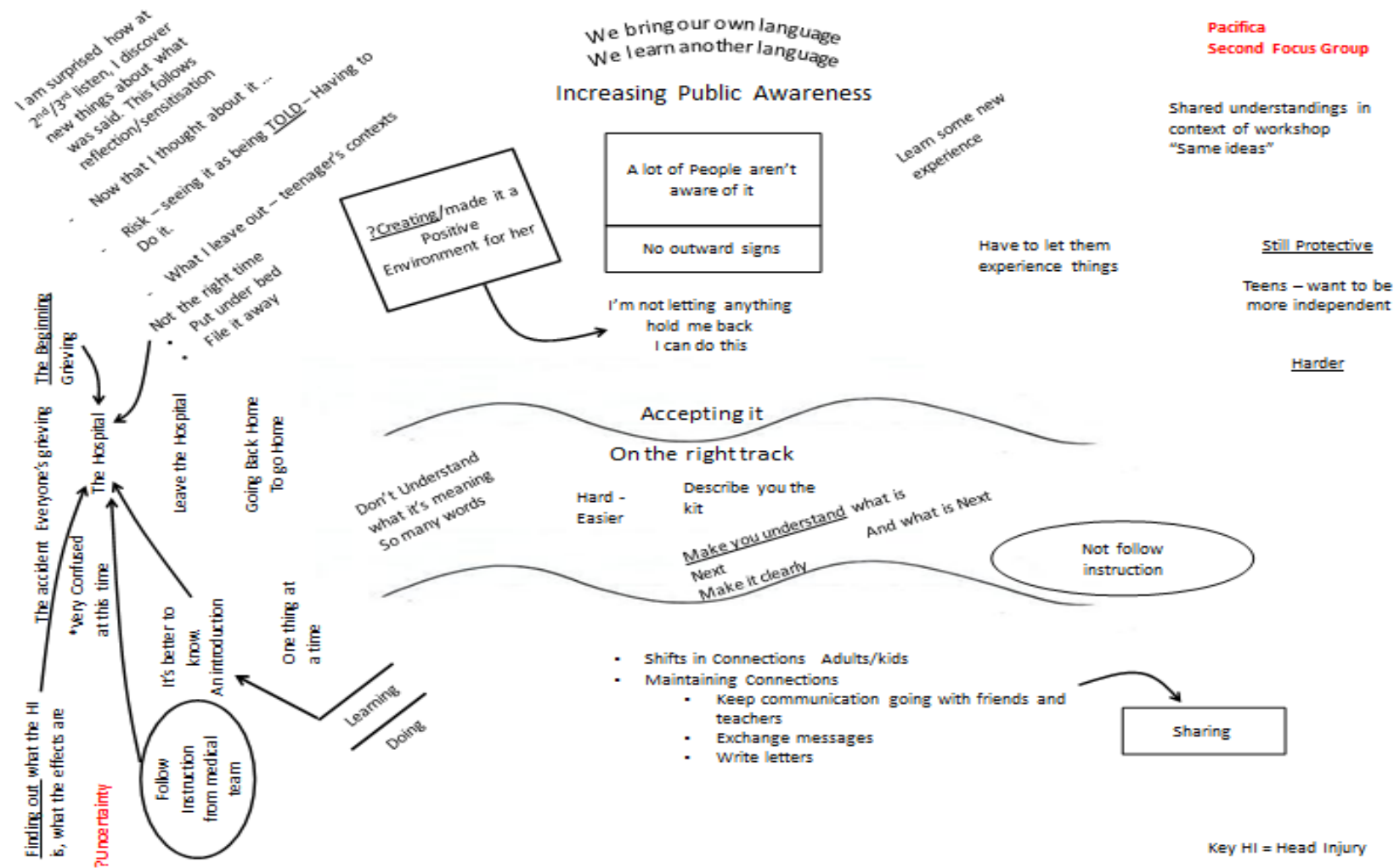


Appendix 9.17b: Cognitive Maps Pacifica Parents

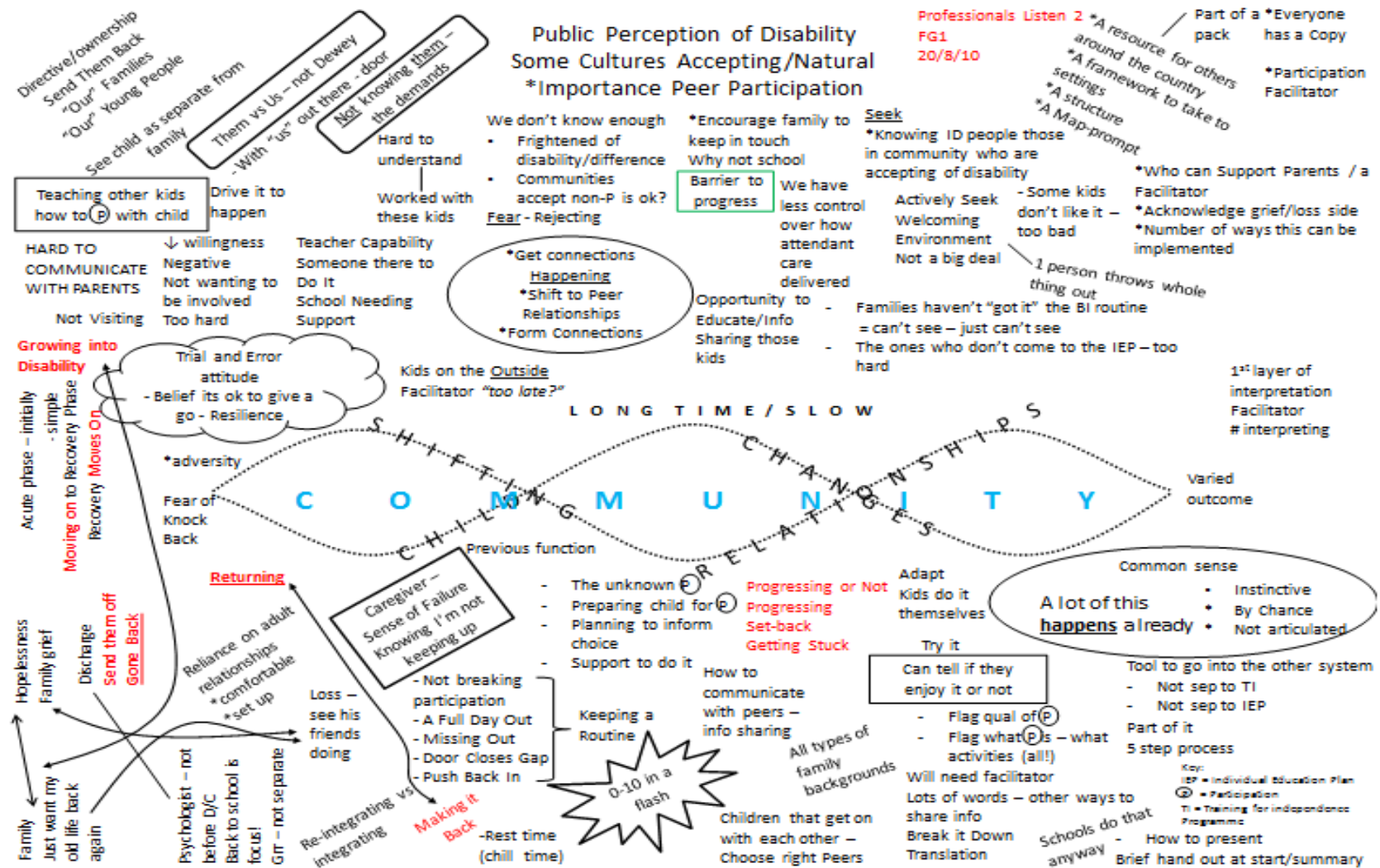


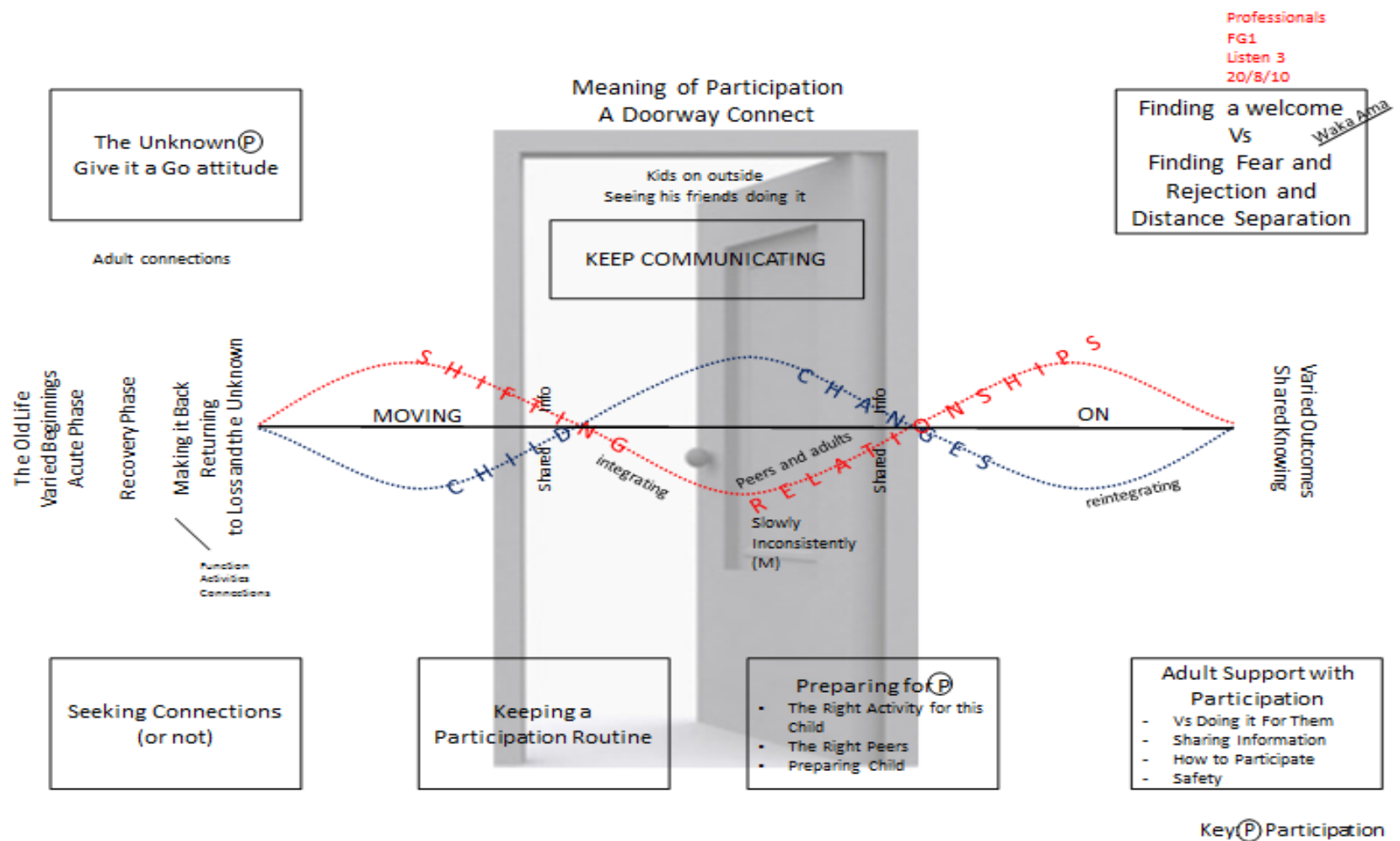
Meaning of Participation A Doorway for Experience

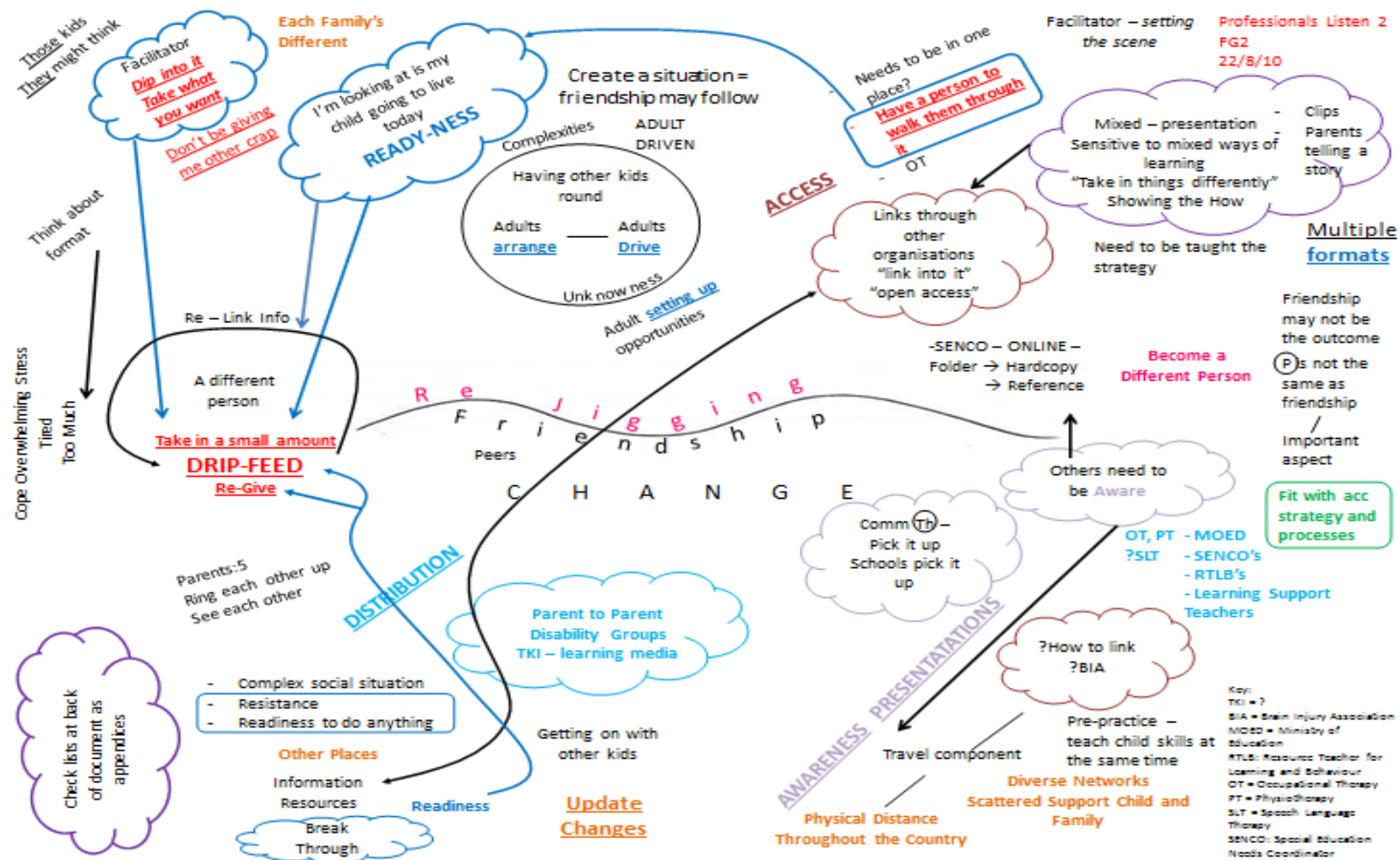




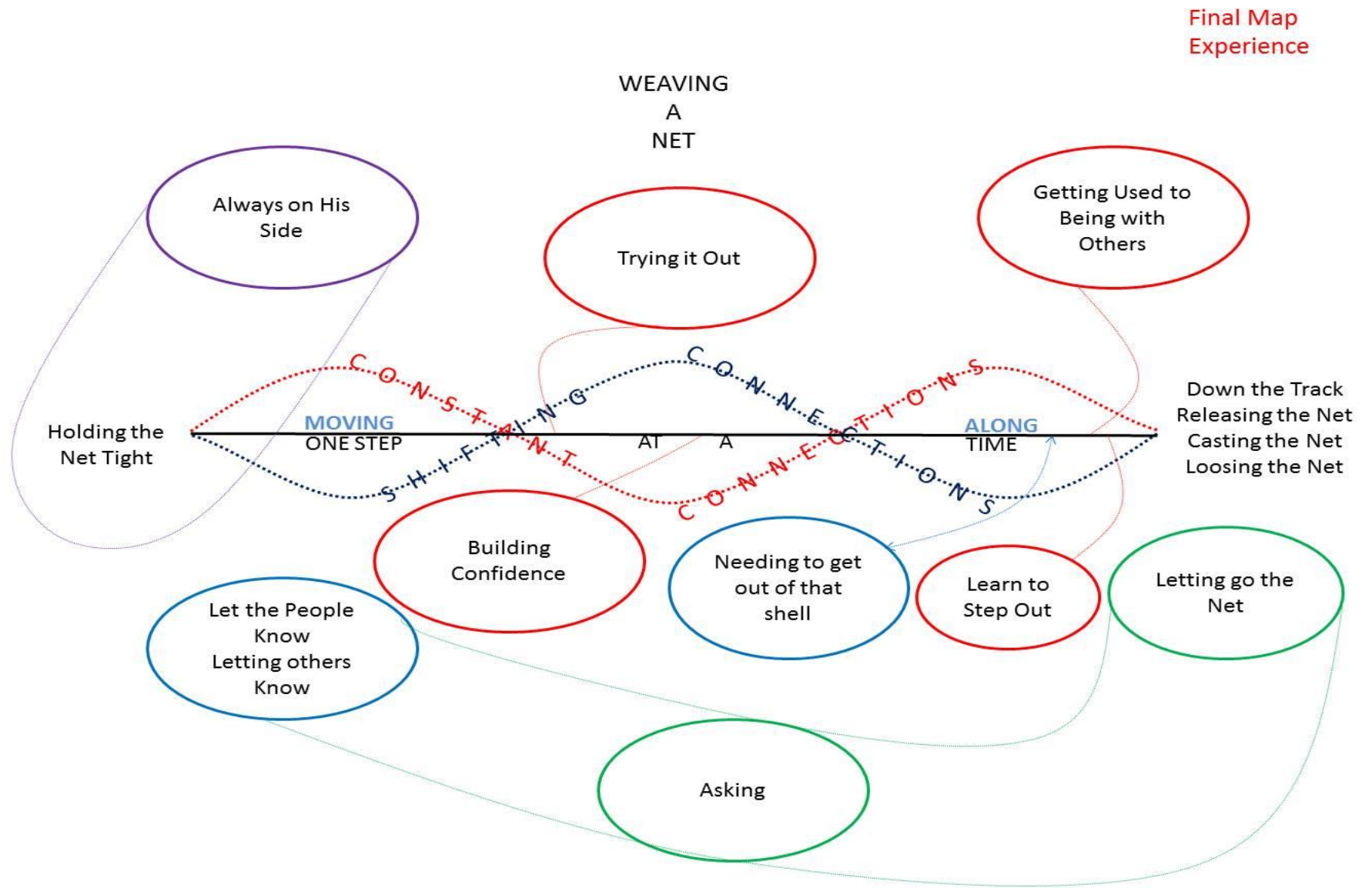
Appendix 9.17c: Cognitive Maps Professionals

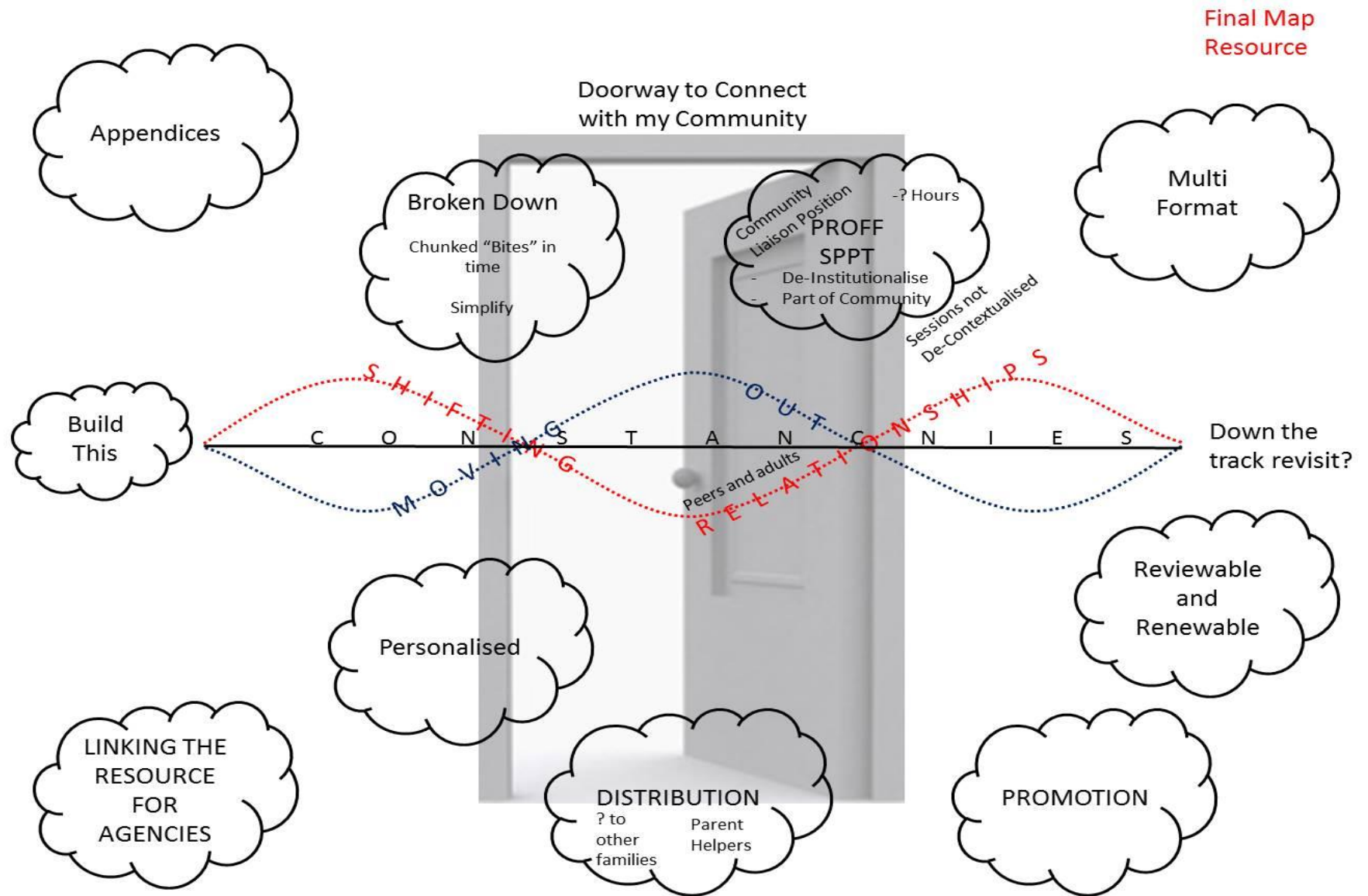






Appendix 9.17d: Cognitive Maps 1 and 2 Final





Appendix 9.19: Scanned Receipt for Copyright to use Photo

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