How do people with brain injury reintegrate into their communities on return home from in-patient rehabilitation?

Jonathan Armstrong

A thesis submitted to

Auckland University of Technology

in partial fulfilment of the requirements for the degree of

Doctor of Health Science (DHSc)

2023

Faculty of Health and Environmental Sciences

Abstract

Community integration is widely acknowledged as a primary goal of rehabilitation following acquired brain injury (ABI). Although there are frameworks that help to describe certain components of community integration, these frameworks are not congruent with research that explores lived experience of community integration for those recovering from ABI. Further, literature relating to community integration frameworks and lived experience does not appear to be translating into clinical practice, service organisation, or health policy.

Using Interpretive Descriptive methodology, eight people, who had recently been discharged from in-patient rehabilitation following ABI, were interviewed to explore the question: *How do people with brain injury reintegrate into their communities on return home from in-patient rehabilitation*? Interviews were transcribed and data analysed using a four-stage process of comprehending, synthesising, theorising, and reconceptualising. From this analysis four interconnecting themes were developed: Growing into a new way of community living, Living up to expectations, (Re)Building social connections, and Engaging in meaningful occupations.

Growing into a new way of community living was a four-stage process that offers insights into the dynamic, iterative, and temporal aspects of community integration. Each stage builds on the previous, with a range of practical and emotional experiences reported by participants. Living up to expectations incorporates expectations from a variety of sources: self-expectations; and expectations of significant others, life roles, and those of society in general. These expectations either facilitate or challenge people's reintegration. (Re)Building social connections highlights the importance of various types of social networks providing a range of support through which people with ABI are able to increase their connections and continue to build their community engagement. Engaging in meaningful occupations assists people with ABI to measure their progress, motivate themselves through ongoing achievements, reduce dependence on others, and stay occupied to distract them from negative thoughts and feelings.

These findings have generated a number of recommendations that can be integrated into rehabilitation service delivery to facilitate community integration for people with ABI. Most importantly, rehabilitation programmes should support the person with ABI to engage in meaningful shared occupations that create opportunities for social connection and lead to a sense of belonging in the community. With shared occupation and social connection being significant factors in community integration, the concept of relationship-centred rehabilitation is proposed as an approach that could further promote community integration.

Table of Contents

List of Figures

List of Tables

Attestation of Authorship

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

Jonathan Armstrong

10 June 2023

Acknowledgements

I would like to express my appreciation to the participants of this study who kindly volunteered to be interviewed and shared their experiences. They participated despite interviews being arranged at a time of great upheaval for them - coping with their recovery from brain injury and dealing with the impacts of COVID-19 on their daily lives. They have been generous with welcoming me into their homes, sharing their stories and their time.

I would like to thank my employers, both ABI Rehabilitation NZ Ltd and Te Whatu Ora – Counties Manukau, for their financial support and allowing flexibility in my working hours. They have also allowed recruitment for the study to take place through their services.

Thanks go to a number of friends and colleagues who have continued to support me over the years that this DHSc has taken. Their interest in my progress and outcomes has helped to keep me motivated. I have valued their feedback on my findings as I proceeded through the research and had opportunities to test out any emerging theories through presentation or discussion.

Particular thanks to my two supervisors, Nicola Kayes and Felicity Bright, for assisting me in navigating my way through the research process. Their knowledge of Interpretive Descriptive methodology and brain injury rehabilitation has been invaluable for offering advice, new perspectives, and challenging my thinking. They provided much needed encouragement when progress was stalled on multiple occasions during the pandemic.

Finally, thanks must go to my partner, Graham, who has travelled this research journey with me and supported me through the highs and lows. He has provided multiple cups of tea and fresh baking when my writing sessions have gone on for many hours. He has been patient and understanding when our social life has dwindled due to the commitments of my work and study. I am incredibly lucky to have his listening ear and fortitude when wrestling with my doubts that I could ever reach completion.

Here it is though! A complete thesis that I can feel proud of and will help as I continue to work in the field of brain injury rehabilitation, guiding others in their clinical practice in a range of different ways.

'Ehara taku toa i te toa takitahi, he toa takitini'

My strength is not as an individual, but as a collective.

Chapter 1: Introduction

This qualitative study explores the experiences of adults with acquired brain injury (ABI) as they reintegrate into their communities on return home after an in-patient rehabilitation stay. It is widely acknowledged that community integration is a key goal for people with brain injury (Kent et al., 2014; Parvaneh & Cocks, 2012; Sander et al., 2010; Willer et al., 1993). Since the 1990s, numerous frameworks have been developed to describe components of community integration (Jacobs, 1993; McColl et al., 1998; Parvaneh & Cocks, 2012; Shaikh et al., 2018; Willer et al., 1993), and there is a growing body of qualitative research exploring the barriers and facilitators of aspects of community integration for people with ABI (Batchos et al., 2018; Govendar et al., 2019; Nalder et al., 2018; Sigurdardottir et al., 2020; Walsh et al., 2014). When this body of research is compared and contrasted, it can be seen that incongruencies exist; and there has been limited translation of this literature into clinical practice or service structure.

This study intends to advance current knowledge of community integration after ABI (e.g., traumatic brain injury, hypoxic injury, stroke), by examining the process of integration from the perspectives of those going through it, amplifying the voice of those with brain injury so they may tell their stories of community integration. When embarking on this study, I anticipated that learning from the knowledge, experience, and expertise of the individuals with brain injury would provide new insights that could influence rehabilitation delivery, organisational systems, public health initiatives, and health policy.

This chapter begins with a personal reflection on my motivations for undertaking this study. I then present the current context surrounding community integration for people with ABI from a social, economic, and systems perspective, setting the scene for why this study is important. I then make explicit my personal assumptions as a clinician, manager, and researcher to clearly position myself within the research. The chapter continues with defining some of the key terms that will be used throughout the thesis; and concludes with the research questions, significance of the study, and structure of the thesis.

Professional Interest in Community Integration

Researchers engaging in qualitative research are encouraged to be reflexive about their personal experiences and beliefs that motivate them to undertake a study as it informs the process and findings, and supports the strategies that ensure the trustworthiness of their work (Creswell, 2007). Interpretive Description is the chosen methodology for this study (discussed

further in Chapter 3); and, as a researcher, knowing who you are, what you represent, and what you are trying to accomplish are the first stages of what Thorne (2016) referred to as "scaffolding a study" (p. 59). The professional journey outlined below conveys my own motivations for conducting this study and forms part of the scaffold of the study.

Working clinically as an occupational therapist in a range of brain injury rehabilitation services, both in the United Kingdom and New Zealand, I developed an interest in community integration as it formed a large part of my clinical practice. Interventions, whether based in the in-patient setting or the community, were focused on helping the person with brain injury return to their optimal level of function within the environment that they would need to be performing the function in; whether that be the home, local community, work, or study settings.

While working as part of a brain injury rehabilitation interdisciplinary team, I was asked to facilitate a group of clinicians from various disciplines in establishing what interventions were being used within our service to promote community integration and what the evidence was for these interventions. This work formed a 'Community Re-integration Programme' document that has since been used to describe and explain the interventions used within the service to interested stakeholders (Armstrong et al., 2012). This work was discussed at an international level as part of the American Congress of Rehabilitation Medicine's (ACRM) International Networking Group, of which I later became a member. The ING is comprised of international researchers, clinicians, service leaders and people with lived experience of disability from a range of countries. The purpose of the group includes collaboration across international boundaries to advance rehabilitation research and evidence-based practice. Along with other members in this group, I presented international models of community integration to delegates at ACRM conferences in 2014 and 2017. This led me to deepen my understanding of community integration as a concept, and examine models and frameworks that attempt to structure its multidimensional nature.

Having explored the topic extensively through reading, presentations, and professional discussion, I began to believe that the concept of community integration was gaining momentum within the general rehabilitation field and the dimensions involved were becoming increasingly well-defined and explored. However, I still had unanswered questions in my mind. For example, several ACRM presentations and published papers reporting to be about community integration were solely focused on return to work (or return-to-duty in the case of veteran studies). In February 2018, an entire supplement of the journal *Archives of Physical Medicine and Rehabilitation* was designated to the topic of community integration; yet, seven

of the 11 included articles were predominantly related to return to employment. Is a return to work really what the individual with brain injury considers to be a measure of successful integration into their community, or does rehabilitation funding or what society sees as successful integration drive interest in this outcome? Is this a westernised ideal of what is perceived as community integration?

There were a range of presentations at ACRM in October 2017 that focused on veterans' return to community life after brain injury in the line of duty, and comparisons were drawn to their civilian counterparts. However, returning to the community after military duty, with or without an injury, would involve a range of adjustments that civilian populations would not necessarily encounter. Therefore, it raised questions about whether comparisons could really be drawn between veteran and civilian populations. Many presenters who talked about the practical strategies undertaken to assist people with community integration within their facilities discussed a 'process' or some sort of dynamic interdisciplinary interplay to assist with reintegration into the home and community; but when I examined the literature about community integration, this dynamic element was missing. Instead, there were frameworks with static components to be considered or met. So, where is the process, or the 'how to', of community integration? Through my reflections it also became apparent that most literature tends to focus on working with the individual with brain injury to improve their performance within community-based activities. Surely community integration is not only the responsibility of the individual with the brain injury but also of the community in which they are living and interacting. This made me wonder, what is the role of the community in community integration?

In recent years, having stepped away from direct clinical roles into leadership roles within ABI services, and adult rehabilitation in general, I have recognised the influence leaders in my position have in shaping service delivery that meets the needs of the population. As a leader in rehabilitation, I feel a responsibility to advocate for services that are person-focused, based on sound empirical evidence that includes, not only literature, but also expert opinion, sound clinical outcome, and service user feedback.

When embarking on my doctoral studies in 2018, I decided that exploring community integration for people with ABI seemed an obvious passion to pursue through formal study. The two papers leading up to the research component of the Doctor of Health Science (DHSc) developed my understanding of theoretical issues by completing a scoping review, and a critical analysis of health and disability policy. This expanded my previous knowledge of broader concepts of community integration such as social connection and support for

components of community integration within national and international health policy. After presenting findings from my papers at a variety of rehabilitation forums, feedback from professionals demonstrated that there was a desire for rehabilitation clinicians to expand the focus of their services towards a broader concept of community integration, and not solely focus on the traditional interventions that related to safety at home and basic daily living skills. One community-based rehabilitation service took my recommendations on board. Towards the end of 2019, I attended a regional symposium where members of this team were presenting. They described their journey towards achieving a broader focus on community integration within their service delivery and how this had improved experiences for their clinicians and service users. They referred to my presentation the previous year as a 'catalyst' for this work. This feedback reinforced my desire to undertake the current research and strengthen the evidence available to clinicians, and those responsible for making service delivery decisions relating to community integration after ABI.

Context for the Study

The context for this study includes an increasing incidence of ABI in New Zealand; as a result, there is a growing number of people with ABI living in the community. This has numerous impacts on the health system, broad economic consequences, and significant social implications for the individual with ABI, their family and whānau (a Māori term for kinship networks), and society in general. Reports from disabled people indicate that multiple dimensions of community integration are limited when compared to their non-disabled counterparts, including their ability to access public services and participate in work and leisure activities. For those with ABI, specifically, the process of recovery may take several years and impacts are evident across multiple aspects of community integration. These contextual factors are discussed in greater depth the sections that follow.

The Growing Population of People Living in the Community with ABI

Population based longitudinal studies have captured the incidence and impact of both traumatic brain injury (TBI) and stroke in New Zealand. The Brain Injury Outcomes New Zealand in the Community (BIONIC) study (Feigin et al., 2013), undertaken in New Zealand during 2010-2011, was the first to assess incidence of TBI for all levels of severity in all age groups across rural and urban populations. This study found that the incidence of TBI per 100,000 people per year was 790 cases, with mild TBI accounting for 749 of these cases. This figure was substantially higher than previously estimated, and greater than in other high-income countries.

The Auckland Regional Community Stroke (ARCOS) studies, recently summarised in Krishnamurthi et al. (2014), have explored stroke incidence and mortality in the greater Auckland area over 3-decades and provide the most up-to-date high-quality local data. These studies indicate that overall stroke incidence has decreased by 23% and stroke mortality by 62% from 1981 to 2012. This decrease has been attributed to modern day public health initiatives, improved primary care prevention strategies, and secondary acute care interventions. Despite these advances, stroke volumes per year are projected to increase by 40% from 7,231 in 2015 to 10,112 by 2028 due to population growth and ageing (Ranta, 2018). The evolving ethnic diversity of New Zealand, with fewer older adults of European background and greater numbers of Māori, Pacific, and Asian ethnicity, has also been attributed to determining the number of New Zealanders who will experience a stroke in the future. These ethnic groups tend to be more susceptible to stroke due to a range of social, economic, and health related factors (Weatherall, 2018).

When embarking on the research component of my doctoral study in 2020, the Australasian Rehabilitation Outcomes Centre (AROC, 2020) annual report "The State of Rehabilitation in New Zealand in 2020" had just been released. This report showed that 1,752 episodes of stroke rehabilitation were submitted for analysis by rehabilitation facilities across New Zealand in 2020. Of those, 20% returned home without any formal support being required, a further 48% returned home with formal supports in place, and 26% were discharged to supported living settings within their communities. These figures indicated that 94% of those having been identified as experiencing a stroke and requiring in-patient rehabilitation returned to some form of community living. Of the 423 rehabilitation episodes that were collected by AROC and categorised as brain dysfunction (including TBI), 91% returned home after in-patient rehabilitation, with around one third of those receiving formal supports in the home.

The above information demonstrates the incidence of ABI within New Zealand is high, and the number of episodes of stroke and brain dysfunction have risen year on year according to previous AROC reports. Further, most people experiencing ABI return home following an in-patient rehabilitation stay. Studies predicting future incidence of ABI suggest that numbers will continue to rise (Ranta, 2018; Weatherall, 2018). The growing population of people with ABI now living at home is rising and will continue to increase. It is, therefore, necessary to focus on strategies to promote integration back into the community to assist these individuals to obtain their desired levels of independence, fulfil meaningful life roles, and feel safe and satisfied.

Social, Economic and System Considerations

Recent national surveys and longitudinal research within New Zealand show that community integration is currently limited for many individuals with ABI, and disability in general. Statistics New Zealand (2014) reported on the social and economic outcomes for disabled people in a report released in October 2014. The primary source of data for this report was the 2013 national disability survey that provides detail about how well disabled people are faring in society compared with non-disabled people. The next national disability survey is not due until 2023. Economic-related findings from this report show that fewer disabled people (45%) are employed in comparison to their able-bodied counterparts (72%); thus they also have lower overall income with 64% earning under NZ$30,000 per year. This would impact the degree to which disabled people are supported through disability benefits. From a social perspective, disabled adults feel less safe in their communities and report a greater frequency of discrimination. A greater number report feeling lonely compared to able-bodied people. They are less likely to participate in common leisure activities, such as playing sports or taking a holiday; and they are generally less satisfied with life. Overall, these statistics would imply that multiple dimensions of community integration are being limited for disabled people resulting in a range of social and economic impacts.

Advancing the findings of the BIONIC study (Feigin et al., 2013), Te Ao et al. (2015) aimed to estimate the economic burden of TBI by calculating the incidence, prevalence, and disability-adjusted life years for TBI in New Zealand. They found that approximately 11,300 first-ever incidents of TBI occurred in the year 2010, with 527,000 people (12% of the population) estimated to have experienced a TBI at some point prior to 2010. They calculated 20,300 disability-adjusted life years attributed to TBI, which is reported to account for 27% of total injury-related health loss, demonstrating that the burden of TBI in New Zealand is substantial.

Continuing with TBI as an example, as TBI tends to affect adults in their economically productive years, it has been recommended that a good return to work benchmark for New Zealand would be a minimum return rate of 50% one year after moderate to severe TBI with the use of a vocational rehabilitation programme (Accident Compensation Corporation [ACC], 2012). This would suggest that 50% of those with moderate to severe TBI could be out-of-work for greater than 1-year (if they return at all) and claiming ACC weekly compensation. Although this benchmark was set some time ago, this rate of return to work at 1-year remains aligned with more recent research conducted in Europe that reports a rate of 54.5% (Sigurdardottir et al., 2020).

Considering the increase in projected figures of incidence from a health systems point-of-view, as described in the previous section, an increase in ABI-related health resource will be required to manage the growing needs. Resources will include bed requirements in acute hospital wards, rehabilitation units, and aged care facilities. Staffing levels will need to increase to meet the growing demands of the ABI population and there will also need to be an investment in the training and development of these staff to ensure they have the necessary specialist skills to manage specific interventions. Investing more resources into community-based rehabilitation services will also be necessary to support earlier and more integrated support for people in the community, and help to reduce hospital rehabilitation bed demand. The Australian and New Zealand Clinical Guidelines for Stroke Management (Stroke Foundation, 2017) strongly recommended the use of early supported discharge services that provide rehabilitation within the person's home to reduce length of stay in hospitals; highlighting that the home provides an optimum rehabilitation environment since the goal of rehabilitation is to establish skills that are appropriate to the home and community settings. Investing in home-based rehabilitation programmes has been proven to result in better quality of life outcomes at 3-months post-stroke with no increase in rehabilitation costs when compared to traditional in-patient rehabilitation options (Rasmussen et al., 2016).

As the above examples demonstrate, there is a growing population of people with ABI and the social, economic, and health system impacts will continue to rise. Assisting with the community integration of these individuals through targeted community-based interventions, pitched at the individual, service, and population levels, could assist in addressing some of the burden currently being reported. For example, community-based rehabilitation services focused on broader aspects of community integration, instead of traditional home-based independence goals, may increase opportunities for social connection. In addition, community education and awareness raising interventions may assist with social issues such as accessibility, and economic issues such as expanding return to work options.

The Experience of People with ABI

Although the experience of people with ABI will be addressed in more detail in the literature review presented in Chapter 2, there are particular New Zealand based longitudinal studies that were instrumental in helping me gain a better understanding of the perspectives of those recovering from ABI when I first commenced this doctoral work. These studies provided the foundations for further exploration and influenced my decision to pursue research to better understand some of the recovery processes specific to community integration. Thus, they are briefly introduced here.

Longitudinal studies that have explored the process of adjustment for people with TBI over the initial 2-years after injury have found several inter-related processes help or hinder recovery and adaptation (Fadyl et al., 2017; McPherson et al., 2017). Processes argued to relate to community integration included 'connectedness to others' and 'the self being at risk' (Fadyl et al., 2017). Connectedness to others, refers to the creation of connections to other people in the community that help in recovery and living with TBI long-term. These connections are particularly valued when they are with people who have lived experience of TBI or understanding of similar disruptions to their lives. The self being at risk, relates to the reconstruction of the concept of 'self' within changed social roles, occupations, and relationships. The processes described relate to various dimensions of community integration that will be explained in the following chapter such as acceptance, social connection, and coping with risk and vulnerability.

Theadom et al. (2018) studied the process of adjustment over the first 3-years following stroke in a longitudinal descriptive study. Participants described an ongoing process of shock, disruption, fear, making sense of what happened, needing to fit in with what is offered, finding what works, and evolving a new normal, while managing the ups and downs of life. When considered from the perspective of community integration, the barriers to social connection, fears of risk and vulnerability, difficulties with adjustment, limited occupation, and difficulties with accepting ongoing disability, that are described within this study, are all likely to be important factors in the context of community reintegration.

As discussed, the number of people living with ABI-related disability is increasing despite advances in health promotion, primary and secondary health care. Longitudinal and predictive studies examining stroke and TBI have shown that this is the case for these populations in particular. There is strong evidence that also points to the barriers that people with brain injury, and disability in general, face to participating fully in daily life when compared to their able-bodied counterparts. Many of the limitations faced by people with ABI relate to various dimensions of community integration and, therefore, there needs to be greater focus on interventions that address these barriers to maximise a person's community integration. This may lead to greater social participation and quality of life for those living with brain injury, and could contribute to reducing the economic impact this population has on health and disability services.

Personal Assumptions

As an occupational therapist with over 20 years of clinical experience in the field of brain injury rehabilitation, and having explored the concept of community integration to the degree described above, I cannot complete research such as the current study without the assumptions, values, and principles that form part of my worldview being brought to the study. Thorne (2016) saw this as inherent to Interpretive Descriptive methodology, as described in detail later in Chapter 3 - Methodology. My clinical beliefs, theories, and background form part of what Thorne (2008) described as, the theoretical scaffolding of the study. This analytical framework contributes to reflexivity as it orients the inquiry; provides a rationale for its anticipated boundaries; and makes explicit the assumptions, biases, and preconceptions that will drive the design decisions. At the onset of this study, and through the process of completing my papers for the DHSc, I have identified these assumptions through discussion with peers and written reflections. My assumptions include:

a) The success of a person's community integration is often measured through outcomes like return to work, which is only one component of the broader definition of integration.
b) The more complex aspects of community integration, such as social connection, are not being well addressed through traditional rehabilitation service provision, despite growing evidence for the direct impact this has on health and wellbeing.
c) Rehabilitation services tend to focus interventions on the individual with brain injury and not on the wider support network surrounding the individual, or the community into which they are attempting to integrate.
d) There is a lack of support for community integration within health policy in New Zealand which has resulted in health spending being prioritised elsewhere.
e) In most literature and policy, the voice of the person with brain injury is lacking related to their community integration.

Defining Key Terms

Several terms are used throughout this thesis which have a variety of meanings for different individuals. To avoid ambiguity, these terms will be defined here. The terms include: ABI, community integration, occupation, and social connection.

ABI

For the purpose of this study, ABI is defined as damage caused to living brain tissue occurring after birth (Headway, n.d.). People in the study may have experienced ABI as a result of trauma by an external mechanical force, or medical problems such as stroke or aneurysm.

Community Integration

Early definitions of community integration within ABI literature describe it simply as: something to do, somewhere to live, and someone to love (Jacobs, 1993). Over time, and with increasing examination and review, the concept of community integration has grown and in more recent literature has been described as "a multifaceted, non-linear process that involves being independent and having a sense of belonging within the community; having a place to live; being socially connected and psychologically adjusted into the community; and involved in meaningful occupational activity" (Shaikh et al., 2018, p. 652).

As this is a more contemporary definition, and encompasses a range of dimensions that reflect the complexity of community integration, it is the definition that, at the outset, helped orient my work. I did, however, remain open to the likelihood that this definition may evolve as my study progressed.

Occupation

The Canadian Model of Occupational Performance and Engagement (Townsend & Polatajko, 2007) is one of the most widely used models in occupational therapy education and professional practice (Ashby & Chandler, 2010). According to this model, the term occupation refers to:

> Groups of activities and tasks of everyday life, named, organised, and given value and meaning by individuals and a culture. Occupation is everything people do to occupy themselves, including looking after themselves (self-care), enjoying life (leisure) and contributing to the social and economic fabric of their communities (productivity). (Townsend & Polatajko, 2007, p. 369)

This definition was drawn on within the current study as it extends concerns with human occupation beyond the actual performance of an occupation, to include level of importance that it holds or degree of satisfaction that it brings to an individual, family, or group.

Social Connection

Holt-Lunstad et al. (2017) described social connection as an umbrella term that "represents a multifactorial construct that includes structural, functional, and qualitative aspects of social relationships" (p. 518). Drawing on this definition, for the purpose of the current study, social connection encompasses the variety of ways a person can connect to others (both positively and negatively) through physical, behavioural, social-cognitive, and emotional channels.

Research Questions

This study sought to answer the following research question: How do people with brain injury reintegrate into their communities on return home from in-patient rehabilitation? Associated questions included:

a) What are people's experiences of community integration as they recover from ABI and how do these relate to current literature?
b) What are the barriers and facilitators to community integration?
c) What strategies are people with ABI using to overcome these barriers?
d) What is the role of the community in community integration?
e) What additional support, services, and/or strategies could be put in place to help people with ABI in their community integration?

Significance of the Study

A study examining the experiences of people with ABI as they reintegrate into their communities following in-patient rehabilitation is important from a personal; professional; and economic, social, and health systems perspective. Considering how this study might add to current knowledge and practice has always been a motivator for me undertaking this research. It was a key factor in choosing a clinical doctorate pathway and a methodology that is explicit in its focus on clinical implications of research findings. At the outset of this doctoral work, I had already envisaged what the outcomes and recommendations could potentially be. Hearing reports that presentations of earlier DHSc work resulted in positive outcomes for some community rehabilitation services, I hoped that discussion of these research findings would take place at rehabilitation special interest groups, workshops, and conferences for clinicians working in relevant areas. I anticipated recommendations may contribute to alternative ways of working with individuals or extend the clinical view of community integration to include the networks of people surrounding the person with ABI; rather than focusing solely on the individual themselves. Knowing from experience that there is difficulty for patients and family or whānau during transition phases between services, due to the siloed nature of service

organisation, it was hoped that findings may help to reduce some of these issues. At a community level, I considered my findings may raise awareness and influence attitudes and perceptions of those within the community towards people with brain injury. At a social level, the research outcomes may provide qualitative evidence for understanding the problems faced by disabled people from their perspective; and, if integrated into health policy, could influence government funding for interventions aimed at improving community integration.

Structure of the Thesis

This thesis is comprised of seven chapters. In this first chapter, I have introduced the background to the study, including my own personal reflections and assumptions that have motivated me to undertake this research. In Chapter 2, I present a literature review of the current frameworks of community integration for people with ABI, and explore the components included within these frameworks. Chapter 2 also considers the broader empirical literature relating to barriers and facilitators to community integration and provides a summary of support for community integration within current health policy in New Zealand. In Chapter 3, I focus on the research methodology and describe the research process.

Chapter 4 introduces the study participants to provide context relevant to their personal narratives. This chapter will assist the reader in engaging with the findings described through four themes in Chapter 5. Chapter 6 then focuses on the clinical implications of the findings at the level of service delivery, organisational structure, and public health policy. As the goal of this Interpretive Descriptive study was to establish recommendations that can inform clinical delivery, it was felt that a clinical implications chapter should stand alone from the discussion; this is presented in Chapter 7.

Chapter 2: Literature Review

This chapter begins with a literature review of conceptual frameworks showing the varied dimensions of community integration that have been proposed to date and how these have evolved over time. The empirical research relating to the experience of people with ABI and what they find helps or hinders their community integration is then explored. Comparisons are drawn between the conceptual frameworks and the lived experience literature to identify the areas of community integration that are, or are not, being addressed in practice from the perspectives of those living with ABI. Recommendations to address the practice gaps are then considered. Finally, New Zealand health policy is explored to identify where support for community integration lies at the level of national strategic action plans that guide the delivery of services.

An Integrative Review of Community Integration Frameworks

This integrative literature review was undertaken to establish the current theories relating to community integration for people with ABI, how they developed over time, and how the theories relate to the reality of clinical practice. First, the methods used for undertaking this integrative literature review will be explained. This is followed by a description of the frameworks that were uncovered during the search, an analysis of how they compare, and examination of their evolution since community integration was initially defined in the early 1990s. The frameworks are then critically evaluated in relation to broader community integration literature in the following section, where conceptual frameworks are compared to the literature relating to the lived experience of people with ABI who are attempting to undertake the various aspects of integration referred to within the frameworks.

Literature Review Methods

The guidelines by Torraco (2016) for writing an integrative literature review were used as the basis for this review. According to Toracco, the aim of an integrative literature review is to review, critique, and synthesise representative literature on a topic in an integrated way such that new perspectives on the topic are generated. Integrative reviews are well suited to topics that have experienced rapid growth in the literature but may still include contradictions or discrepancies between literature and practice observations that require further exploration. As such, this was a suitable methodology to follow in reviewing the literature relating to frameworks of community integration for people with ABI, and comparing these frameworks to knowledge gained through clinical practice and professional discussions.

A literature search using EBSCO Health Databases (incorporating CINAHL, MEDLINE, and PsycINFO) was conducted. Keyword searches used the terms: “community integration”, “community re-integration”, and “community participation” as these terms are often used interchangeably within the community integration literature. These were used in combination with the terms “traumatic brain injury”, “acquired brain injury”, “brain injury”, and “stroke”; along with “model” or “framework”. Publication dates were limited to 1993 onwards as this was when community integration was first defined in relatively colloquial terms (Jacobs, 1993), and I wanted to examine how theory had developed since this time. Peer reviewed journal articles were included if they met all the following criteria:

1. Reported a study exploring community integration as a predominant focus;
2. Suggested a model, framework, or structure for community integration;
3. Were presented in English.

Exclusion criteria included:

1. Studies related predominantly to children, as there are likely different models of care between adult and paediatric populations;
2. A sole focus on return to work, as this is not feasible in many cases and the interest was in a more multi-dimensional conceptualisation of community integration;
3. Studies involving populations other than ABI (such as spinal cord injury and psychiatric illness), as the rehabilitation process, pattern of recovery, and long-term outcomes are likely to differ;
4. Descriptions or evaluation of impairment-based interventions not consistent with broader conceptual thinking of community integration described in the introductory chapter.

The initial search yielded 69 potentially relevant studies. The exclusion criteria above was then applied as titles and abstracts were screened for relevance. Full texts of the papers were retrieved and read in entirety to ensure they met all the above criteria. Reference lists were also checked for additional papers that would potentially meet the inclusion criteria. The references and full texts were shared with members of the ACRM International Networking Group via DropBox and discussed during a monthly teleconference. Additional references were gained though group members who used DropBox to add papers from their own collections. From this process, I identified five papers that had a predominant focus on development of frameworks or models conceptualising community integration for people after brain injury.

These were reviewed and summarised chronologically to examine how they had evolved over time. They are described and critically evaluated in the sections below.

A Description of Community Integration Frameworks

In this section, each framework is briefly described and key components are summarised in Figure 1 (p. 17) to give the reader an understanding of the dimensions included in each of the frameworks. Comparisons between, and evaluation of, the models are included in the section that follows.

One of the earliest attempts to define community integration after ABI is based predominantly on expert opinion, with Jacobs (1993) proposing a broad, multifaceted definition of having something to do, somewhere to live, and someone to love. Subsequent frameworks, described below, have further developed this early definition. However, the importance of independence in meaningful occupations, living arrangements that promote social inclusion, and the power of relationships continue to be emphasised in that later work.

Willer et al. (1993) conducted a study consisting of focus groups with 14 rehabilitation professionals, researchers and consumers, during their field testing of the Community Integration Questionnaire. They established three related but separate aspects of community integration. The first is integration into a home-like setting, where the individual is actively participating in the operation of the household. The second is social integration which refers to participation in activities outside of the home including shopping, leisure, and visiting friends. The third is regular performance in productive activities that include employment, educational and volunteer activities.

McColl et al. (1998), one of the most referred to pieces of literature, sought to define community integration for people with brain injury. This qualitative study involved semi-structured interviews with 18 people in the chronic stages of brain injury (average injury duration being 11.5-years) who had recently moved from the United States to supported living environments in Canada. Eight interviews were conducted with each participant over 1-year, exploring factors related to positive and negative community integration over time. Nine themes were developed, which were then grouped into four dimensions. These became the basis for a model of community integration that included: general integration (including conformity, orientation, acceptance); social support (close and diffuse relationships); occupation (leisure and productivity); and independent living (independence and living situation).

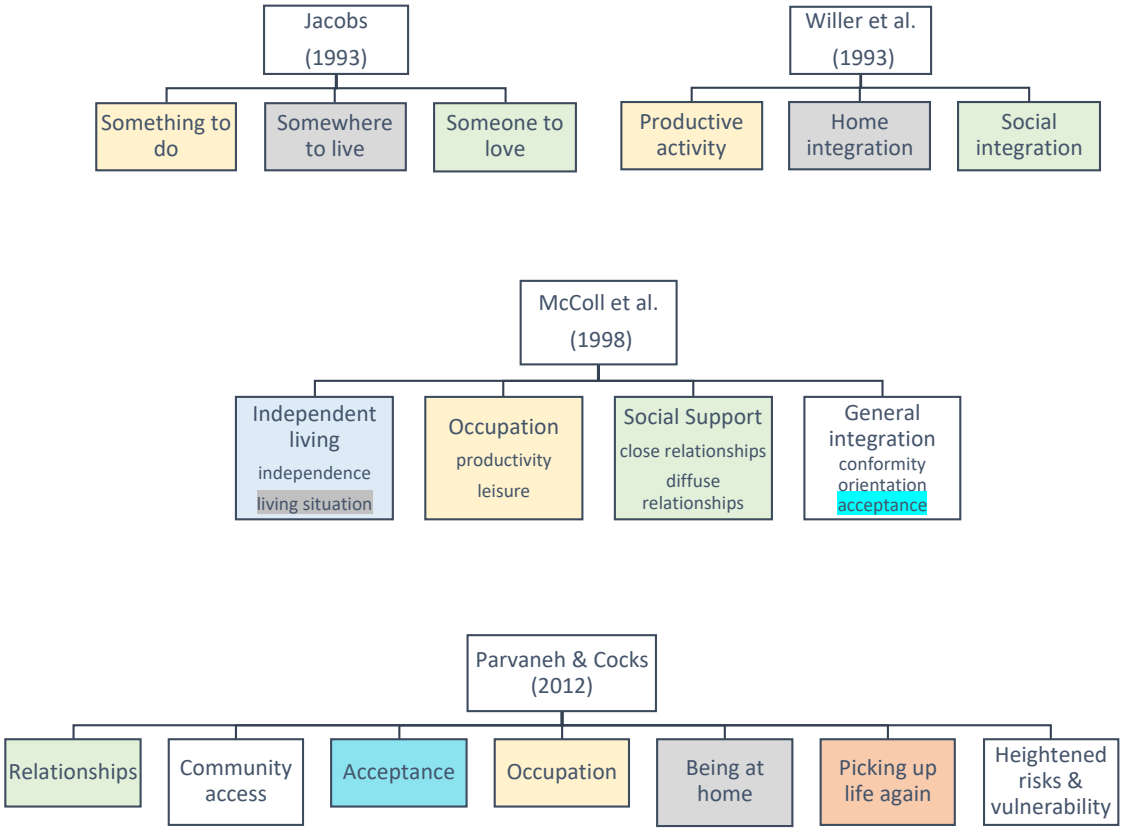
It was another 14-years before any further research was undertaken to refine the concept of community integration for people with ABI. In developing their framework, Parvaneh and Cocks (2012) electronically surveyed a diverse group of stakeholders, practitioners, researchers, and policy makers. They also conducted focus groups with eight people with ABI, arranged through a local advocacy organisation; and carried out individual interviews with 10 family members of people with ABI in their own homes. Participants were requested to respond in as much detail as possible to an open-ended question: "How would you describe and define successful community integration for adults with acquired brain injury?". Data analysis included increasing degrees of descriptive coding, categorising, and reaching coder consensus on the final themes. Member checking was carried out with participants who reviewed the themes and provided comments, from which modifications were made. The final themes were then mapped against existing literature on community integration. This process resulted in a community integration framework consisting of seven elements: relationships, community access, acceptance, occupation, being at home, picking up life again, and heightened risks and vulnerability

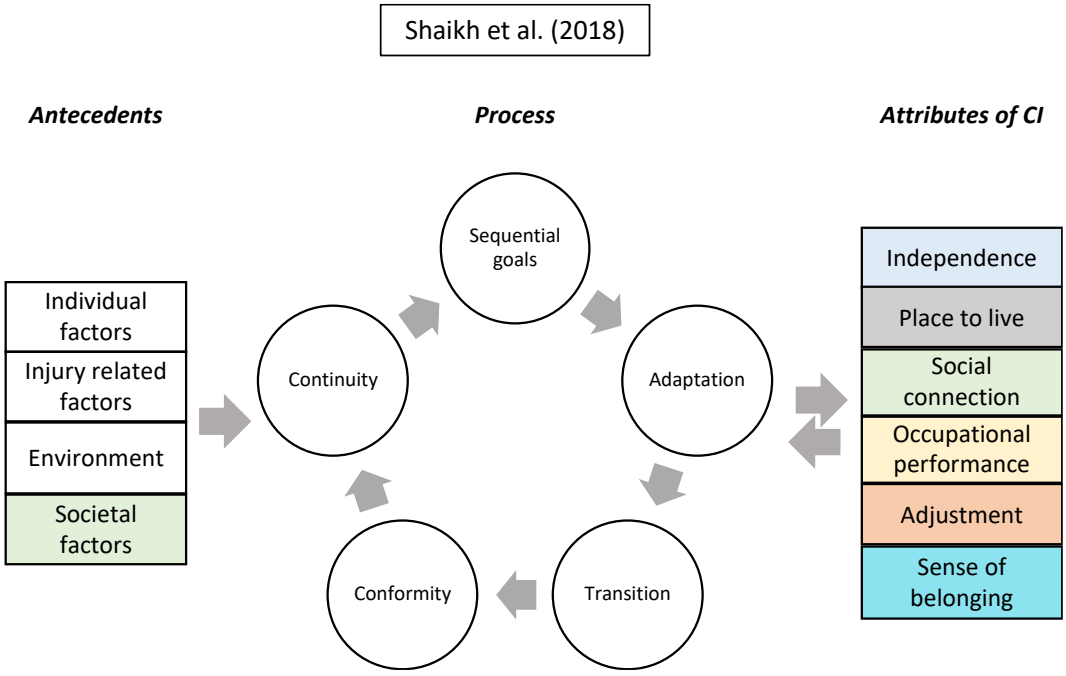
The most recent and comprehensive framework of community integration for people with ABI was published in 2018 by Shaikh and colleagues. They undertook a conceptual analysis, synthesising the available literature on the perspectives of adults with ABI, to accomplish three objectives: 1) clarify the concept of community integration; 2) identify attributes, antecedents, and the process of community integration; and 3) develop a robust conceptual framework. They conceptualised community integration as having six overarching attributes: independence, place to live, social connection, occupational performance, adjustment, and sense of belonging. This framework advanced earlier work in that it considered antecedents of community integration, describing these as phenomena that help clarify its attributes and enhance understanding of the social and environmental context in which community integration is occurring. These antecedents include individual, injury-related, environmental and societal factors. The authors also considered the importance of viewing community integration as a process that includes the transition from rehabilitation to the community, as well as adaptation to new limitations and circumstances.

A visual summary of these five frameworks can be seen Figure 1. The colour-coding indicates where dimensions link to one another and share similar qualities to assist the reader in making comparisons between frameworks at a glance. These similarities and differences are explored further in the following section, along with a critical discussion of the research methodologies employed and, in some cases, the specific targets in mind (e.g., the generation of a measure for community integration).

Figure 1

Visual Summary of Five Frameworks of Community Integration





Comparison and Critical Evaluation of Frameworks

As demonstrated above, conceptual understandings of community integration after ABI have significantly evolved over the last 25-years. The three components of community integration based on Jacob's (1993) expert opinion are mirrored but expanded upon in the three themes described in the same year by Willer et al. (1993), with *something to do* being similar to *productive activity*. *Somewhere to live* is incorporated within Willer et al.'s *home integration* theme which is expanded to include active involvement of the person with ABI within the home setting in activities such as meal preparation and childcare. Jacob's *someone to love* theme is reflected within Willer et al.'s *social integration* but Willer et al. expand on this theme to include more diverse relationships, such as attending social events with friends outside of the home. Willer et al. based their framework on focus groups predominantly consisting of rehabilitation professionals and researchers whose objective was to explore measurable components of community integration for the development of the Community Integration Questionnaire. Therefore, it is probable that priority was given to research and clinical efforts to improve measurable aspects of community integration such as increased household independence and return to employment. Less objective, more multi-faceted, aspects of community integration such as forming and maintaining relationships, feeling emotionally supported, and being accepted, are not apparent in the study by Willer et al. This is despite these factors being clearly identified as an important aspect of community integration for people after ABI in the later frameworks and other literature relating to community integration (Sander et al., 2010).

The three elements of community integration identified by Willer et al. (1993) are evident in the frameworks proposed by McColl et al. (1998) and Parvaneh and Cocks (2012). *Productive activity* is referred to as *occupation* in both these latter frameworks; however, Parvaneh and Cocks are the first to expand this element of community integration to include choice—not only is the person with ABI engaging in meaningful activities at home and in the community but they also have the freedom of choosing how their time is spent. This concept of choice is reflected in other dimensions of the Parvaneh and Cocks' framework, including *community access* (choosing to use goods and services) and *being at home* (choosing to live alone or with others). The *being at home* dimension of their framework is an expansion of Willer et al.'s *home integration*. This aspect of community integration is not a primary dimension of the McColl framework; rather, is included as a component of *independent living.* Finally, Willer et al.'s third theme, *social integration*, is represented in the subsequent two frameworks as *social support* (close and diffuse relationships) by McColl et al.; and *relationships* by Parvaneh and Cocks.

General integration is a dimension in the McColl et al. (1998) model that is not well reflected in any of the other frameworks of community integration. It includes three components: *Conformity*, the idea of knowing how to fit in with other people; *Orientation*, knowing the way around and feeling oriented to the community; and *Acceptance*, feeling comfortable in the community into which the person with ABI was attempting to integrate. It is possible that the dimension *conformity* emerged due to the study sample only including people with chronic moderate to severe brain injury living in supported-living environments. In these environments, people would be living within shared accommodation and trying to fit in with the social rules that were established within these living situations. The need to *conform* in order to be accepted by their peers would be important to integrating successfully into this living situation. Although *conformity* appears in the Shaikh et al. (2018) framework as a component of the central process, there is no explanation of what this term means within the paper itself. It is difficult, therefore, to draw any parallels between these two uses of the same term. Other major themes in the McColl et al. *general integration* dimension included being independent from staff supervision as well as a desire to be autonomous outside of an institution. These themes would seem less likely to be evident in a population of people who return to their own homes and previous living situations rather than living in shared supported living institutions. The third component of McColl et al.'s *general integration* dimension, *acceptance,* is also apparent in the framework proposed by Parvaneh and Cocks (2012) whose sample included people with ABI living in their own homes. Their dimension of *acceptance* has similar properties including: being included, having a sense of belonging, and feeling valued. This would suggest that *acceptance* be considered as a core dimension of community integration regardless of the setting in which the person is living.

Parvaneh and Cocks (2012) based their community integration framework on the views of five groups of stakeholders including: researchers, practitioners, policy makers, people with ABI, and family members; resulting in a more comprehensive framework reflecting a range of views. However, the authors described their participants with ABI as "high functioning" (Parvaneh & Cocks, 2012, p. 133) and so it is possible their participants reflected a different experience of community integration than those with more severe injuries. These individuals were interviewed in focus groups based in a central location so as to overcome the possible barriers relating to electronic surveys. However, people with brain injury may find this type of interview context challenging. Asking interviewees how they would describe and define successful community integration would involve having to make sense of the community integration concept, then relate it to themselves, compare previous function with current function, and reflect on the differences and processes to achieve the level of community

integration they currently have. This requires accurate memory recall and a high level of executive thinking skills including self-awareness, self-reflection, abstraction, and flexibility; all of which are commonly affected cognitive skills following brain injury. Undertaking an interview with a person with ABI within their natural home or community context, and doing so on a one-to-one level or with a trusted support person, may help to reduce the cognitive burden required and may yield a more in-depth narrative.

The theme *heightened risk and vulnerability* established by Parvaneh and Cocks (2012), which acknowledges and addresses risks such as social isolation and exploitation, is not incorporated into any other community integration framework. This appears to be a gap given feelings of discrimination and being unsafe outside of the home were evident in the disability survey findings referred to in Chapter 1. It may be that the 'higher-functioning' individuals in this study identified vulnerability as an issue due to their attempts to return to more complex community-based activities without the support of others. *Picking up life again*, which draws attention to the realities of reintegration into previous roles and having the confidence to take up new roles, was not a dimension incorporated into any of the prior frameworks. This dimension is like the *adjustment* attribute in the final framework by Shaikh et al. (2018).

The concept analysis by Shaikh et al. (2018) drew on 20 studies relating to community integration that included the four prominent brain injury specific frameworks discussed above. These authors incorporate most of the previous dimensions of community integration into the *Attributes* component of their framework. Reflecting the more modern social environment, their attribute *social connection* includes the use of electronic social networking as a facilitator for higher levels of community integration. Where this latest framework particularly adds to the body of work is its incorporation of *Antecedents* and *Process.* The *Antecedents* component emphasises personal, injury-related, environmental and societal factors as contextual conditions that influence integration and can lead to either positive or negative outcomes. Personal factors include self-awareness, coping strategies, and motivation that play an important part in recovery. Injury-related influences include the severity of the brain injury or challenging behaviours that limit a person's ability to successfully integrate into social situations. Environmental conditions that could either limit or promote community integration include the physical environment and wider factors such as the availability of transport, information, finances, and services. Societal factors include interactions with peers and family, being respected, and making a positive contribution to society.

In this more contemporary framework, community integration is also viewed as a *Process*, rather than a static model consisting of set dimensions as in previous frameworks. Previous

authors have identified community integration as a process of adaptation over time (Reisetter & Abreu, 2005; Wood et al., 2010) or a process of transition from in-patient environments to home (Turner et al., 2008). In the case of Shaikh et al.'s (2018) framework, the process involves the transition from in-patient settings to the community as well as accepting changes in functional recovery and adaptation to changing life circumstances. They identified five components of this process, as can be seen in Figure 1: Sequential goals, adaption, transition, conformity, and continuity. Unfortunately, these components are not well explained in their article; therefore, it is unclear how people with ABI move through this process from one stage to the next, or what can be done to facilitate this process. This may also reflect that the process of integration has not been well explored in the previous primary literature on which their concept analysis is based.

Since the World Health Organisation (2001) redefined disability within the International Classification of Functioning, Disability and Health (ICF), the emphasis of outcomes for disabled people has shifted so the focus is no longer on impairments alone but also the interaction between impairments and the environment. Environmental factors such as structural accessibility, social support, societal attitudes, government policies, and family function can serve to be either barriers or facilitators to positive participation outcomes for people with brain injury. Some authors have argued that the ICF concept of participation and community integration are one and the same (Agnithotri et al., 2010; Sander et al., 2010) and suggested that successful community integration can be influenced by "the unique set of restrictions imposed by each brain injury that negatively affect this environment-participation interaction" (Agnithotri et al., 2010, p. 370). To date, the only community integration framework that has taken account of this important aspect of interaction between the person with the brain injury and the social/environmental context is that proposed by Shaikh et al. (2018), who incorporated societal and environmental interactions into the *Antecedents* component of their model.

As this section demonstrates, the different language and terminology adopted by each study to describe similar community integration dimensions can make comparisons between frameworks difficult. To support interpretation, Table 1 overviews the links between similar dimensions across the frameworks. The broad terms of occupation, living at home, social connection, acceptance, independence, and adjustment are provided as the six common dimensions across the different frameworks. The terminology used by each framework is provided under each of these broader labels.

Table 1

Matrix of Similarities Between Community Integration Framework Dimensions

Framework \ Dimension	Occupation	Living at home	Social connection	Acceptance	Independence	Adjustment
Jacobs (1993)	Something to do	Somewhere to live	Someone to love			
Willer et al. (1993)	Productive activity	Home integration	Social integration			
McColl et al. (1998)	Occupation	Being at home	Social support	Acceptance	Independent living	
Parvaneh & Cocks (2012)	Occupation	Living situation	Relationships	Acceptance	-	Picking up life again
Shaikh et al. (2018)	Occupational performance	Place to live	Social connection	Sense of belonging	Independence	Adjustment

Summary of Integrative Review Findings

Although there has been a shift over time to incorporate the ideas of process and person-environment interactions into the concept of community integration, this has not yet been fully developed. Exploring and outlining the process and interactions involved in community integration could be an important part of understanding the experiences of the person with brain injury and how successful integration could be facilitated, either through supporting people at different stages of the process or reducing barriers to their ability to interact with the society and environment.

The perspective of persons with ABI also appears to be under-represented in the frameworks established to date. McColl's (1998) study, which focused solely on people with ABI and their experiences of community integration, is now 20-years old. Society and rehabilitation services serving people with ABI have moved on since that time. Further, the participants in that study were in the chronic stages of recovery and living in supported living settings. As modern rehabilitation services tend to be focused at the more sub-acute stages of recovery, and a higher proportion of people with ABI are now returning to their own homes following in-patient rehabilitation, it would help to have studies that focused more specifically on the earlier stages of recovery and on people returning to their previous living environments.

While other studies, such as Willer et al. (1993), have reported including participants with ABI, these have tended to be people who are functioning at a relatively high level, and not necessarily representative of the wider population of people with ABI who are returning home and attempting to participate in their previous roles and communities. Studies that

incorporate people who are in the more moderate to severe ranges, rather than those who are high-functioning, could shed light on how community integration can be achieved for people across a broad spectrum of functioning.

As Sander and colleagues (2010) pointed out, the meaning of community integration is not necessarily the same for all people with a brain injury. As such, evaluating the degree to which a person has integrated into the community will be different for different groups, including those from different cultures. What might be perceived as a 'good' outcome is likely to vary from one person to the next. To be successful, interventions that address community integration must focus on the priorities of the individual; priorities often partially determined by their cultural beliefs and traditions. Culture as an aspect of community integration is not specifically identified in any previous models despite Corrigan (1994) defining community integration as "the assumption or resumption of culturally and developmentally appropriate social roles" (p. 109). An example from within the New Zealand context would be the role of whānau as a recognised essential aspect of wellbeing for Māori people and, therefore, the role of whānau involvement as a resource for enhancing recovery outcomes after ABI (Elder, 2017). This challenges the concept of *independence* as a key component of community integration, as it is inter-dependence that is important within this cultural context.

Social connection or relationships are, to a varying degree, included in all the community integration frameworks described above. The evidence for social connection as a strong predictor of wellbeing, good health, and lower mortality appears to be growing (Holt-Lunstad, 2018; Holt-Lunstad et al., 2017), in addition to being included as a dimension in all the frameworks. From personal experience, social connection is not well focused on as a goal for traditional rehabilitation programmes where the focus is predominantly on impairment and activity mastery. Douglas (2011) explored social connection from a brain injury perspective and reported "poor social engagement is a convergent finding in much of the severe TBI outcome research" (p. 238). When the specific functions of social support have been explored, "strong-tie" (Douglas, 2011, p. 240) support emerged as being crucial for maintaining the wellbeing of brain injured individuals and their families. People need someone close to them with whom to share their feelings, problems, ideas, and aspirations. In their research, Douglas and Spellacy (2000) identified problems with social involvement and lack of friendship as overriding themes in the day-to-day lives of adults living in the community more than 3.5-years after sustaining a severe brain injury. Lack of social connection had a direct effect on prolonged difficulties with acceptance, adjustment, general wellbeing, and quality of life. This would indicate that improved social connection would have an impact on a range of community integration dimensions including acceptance, sense of belonging, and improved sense of vulnerability.

Having reviewed and analysed the theoretical frameworks that have been proposed in the literature, I was aware that there were contradictions between the dimensions proposed in theory and what was being delivered within clinical practice, such as those outlined above. This led me to further investigate the literature to establish if people with ABI felt supported by rehabilitation teams in all or only some of the domains proposed in the frameworks; or, from the experience of the people with ABI, were there still some aspects of community integration that were not addressed at all?

Experience of Community Integration From the Perspectives of Those with ABI

Following the integrative review of community integration frameworks, I was left with questions such as, to what extent has theory relating to the community integration frameworks been transferred into clinical practice? Are rehabilitation teams engaging people in interventions to increase community integration across all the dimensions proposed? Do these dimensions cover the range of interventions being delivered? What does the evidence from people with lived experience tell us? This section addresses these questions by providing an overview of the literature that explores factors that enable or limit community integration from the perspectives of people with ABI.

This narrative review is not meant to be an exhaustive review of the literature; rather a snapshot of how experience reflects the domains of community integration described in the conceptual frameworks discussed above. A pragmatic search of EBSCO health databases was undertaken using broad search terms including: “community integration” OR “community participation” OR “social integration”, alongside “brain injury” OR “stroke” OR “ABI” and “experience” OR “perceptions” OR “perspectives” OR “barriers” OR “facilitators”. Boundaries of publication year were set for 2010-2020 as it was felt that research older than 10-years would not reflect the current experience of those with ABI. Also, from 2020 onwards, community integration and how it is thought about became a challenge due to COVID-19. This search strategy yielded a total of 224 papers. Qualitative papers were purposefully selected if their title and abstract indicated a predominant focus on the experience of community reintegration from the perspectives of people with ABI, rather than that of carers or health care professionals. Literature was synthesised based on the community integration concepts such as occupation, living situation, social connection, and fears/vulnerability. The following sections are structured by these community integration domains.

Occupation and Living at Home

Walsh et al. (2015) undertook a qualitative meta-synthesis to identify barriers and facilitators to community integration for those in the first year of stroke recovery. This meta-synthesis took data from a variety of cultural and clinical populations, across a range of ages and six countries. The aim was to inform clinical and social interventions to improve community integration. Four themes emerged from this meta-synthesis. A key finding relating to the community integration dimension of *occupation* (that appears in all the theoretical frameworks described earlier in this chapter) was that the meaning attached to activities is an important factor in whether an individual would re-engage in those activities. Meaningful occupations and roles were fundamental to finding fulfilment and enjoying daily life. It was highlighted that activities practiced in the clinical environment did not easily translate to home life. Establishing personal goals related to meaningful occupation was essential in helping resume valued activities in the community; however, this did not always occur in practice. The ability to relate rehabilitation in a clinical setting to meaningful activities in the community was improved when people had an opportunity to practice activities with professionals in the home or community environment. Findings of this review support a need for person-centred goal setting and rehabilitation in a familiar environment; yet indicated that these strategies are not taking place consistently within rehabilitation programmes.

Govender et al. (2019) conducted an explorative qualitative study with stroke survivors to establish if implementation of national South African rehabilitation guidelines, including recommendations for community integration, were being implemented in clinical practice. They also found that stroke survivors reported being unprepared for a return home when discharging from in-patient services. Neither the stroke survivor nor their caregivers felt they were provided with sufficient coping strategies, advice, adaptations, or access to community services that could aid resumption of meaningful occupations within the home. Activity limitations, such as reduced mobility, resulted in a lack of engagement in meaningful occupation and difficulty resuming previous roles. In turn, this led to a loss of autonomy, social isolation, and negative emotions further impacting their ability to regain independence in valued home, work, or social roles. In some cases, the result was role reversal and a feeling of dependence on others, impacting their sense of self. Recommendations from this study indicate that rehabilitation programmes should focus efforts on the resumption of roles and participation in meaningful occupation. It is argued this enables more successful community integration due to improved sense of self, increasing incentives due to observed gains, feelings of pride, and assists with a changing attitude and acceptance.

These studies suggest that the community integration domain of *occupation*, although included in all the frameworks proposed to date*,* is lacking in its broader application within clinical practice from the perspectives of the people with ABI. Although it appears that returning to various occupations are being considered and incorporated into the clinical setting, this is not resulting in actual improvements within the home or community environments. The occupations selected are often not meaningful to the individuals with ABI and the broader implications of occupation on role resumption, sense of achievement, adjustment, and sense of self need to be taken into consideration. A meta-synthesis of qualitative literature undertaken by Reed et al. (2012) found that the home was a place where stroke survivors could best understand what physical and mental adjustments were needed in order to cope with their change in abilities. Home represented a safe and comfortable place where they felt confident; therefore, an ideal place for rehabilitation to take place rather than in clinical settings.

Kersey et al. (2020) highlighted that traditional rehabilitation approaches tend to focus on interventions targeting specific basic activities such as mobility, personal care, and cognitive performance, with the assumption that this will lead to improvements in community integration. However, these appear to have limited impact on actual improvements in community integration components such as productivity and social participation. Instead, Kersey et al. proposed teaching strategies to overcome barriers to community integration that include problem solving and self-management to address the balance between capabilities, environment, and social situation. They suggested that this approach of promoting client-driven problem solving for management of a wide range of real-world barriers holds potential to generalise into multiple community contexts, and thereby have a greater impact on community integration as a whole.

Fears/Vulnerability and Stigma

Although only highlighted specifically in one of the community integration frameworks (Parvaneh & Cocks, 2012), *fear and vulnerability* have been identified in literature exploring the experiences of people with ABI as a barrier to their reintegration back into community and social lives. In a study by Govender et al. (2019) exploring stroke survivors' experiences of community reintegration in South Africa, participants reported fears of falling, being mugged, and the risk of verbal or physical attack as factors that limited their ability to go places in the community. They felt their resulting impairments left them vulnerable and unsafe to do things; for example, go to the bank or cope with environmental barriers such as steps to access public buildings. They also experienced stigma in the community, and some individuals believed they

were avoided because of a perception that they were 'cursed' in some way; reflecting the particular cultural and spiritual beliefs of the society.

Similar findings are evident in studies from other countries such as the United Kingdom (Hagger & Riley, 2019; Reed et al., 2012) and Ireland (Walsh et al., 2015). Although the findings from Reed et al.'s (2012) meta-synthesis found that stroke survivors perceived home as a safe place to engage in meaningful activity and trial adjustments, there were multiple barriers to being outside the home. One such barrier included negative perceptions of themselves as a disabled person (internalised stigma) and anticipated stigma from those with whom they were interacting in public spaces. Hagger and Riley (2019) explored the social consequences of stigma and self-concealment after ABI with 65 adult participants who were at least 12-months post-injury and engaging with a community-based brain injury support group. They found that participants' anxieties about exposure of their impairments to others lead them to concealment. Preference for concealing their injury was associated with fear of social situations, avoidance of such situations, loneliness, and lower self-esteem, all impacting on community engagement in general. Concealment due to anticipated stigma also prevented some individuals from assuming a social identity as a person with ABI; thereby limiting their access to peer support that could provide them with connection and shared social identity.

Although social relationships may deteriorate as a result of psychosocial impairments following an ABI, the impact of stigma (either internalised, enacted, or anticipated) reported in these studies suggest that community responses to the person with ABI, and the reactions of the person to those responses, may also contribute to deterioration in relationships. Stigmatising behaviour from the community and the expectation of such behaviour leads to negative attitudes towards oneself and difficulties with acceptance of disability post-ABI, which then leads to concealment, anxiety, avoidance, reduced community engagement, loneliness, and, in some cases, a reluctance to adopt a shared identity with others who have experienced ABI (Hagger & Riley, 2019). Evidence would suggest that issues around fear/vulnerability, stigma, and the resulting self-concealment all warrant attention within rehabilitation service delivery. People with ABI need support in addressing these issues so that barriers to community integration can be removed. Govender et al. (2019) and Haggar and Riley (2019) provided suggestions for addressing such issues including the graded practice of social skills to build confidence within a community context, understanding the motivation associated with concealment, support in discriminating between situations where it is to the person's advantage to disclose their ABI and those where it is not, and addressing the psychological obstacles to anticipated stigma that may result in feelings of shame or difficulty with acceptance. Although these suggestions provide some direction as to how community

integration dimensions of *fear/vulnerability* and *acceptance* might be addressed, they are very much targeted at the individual. As the issue of fear and vulnerability appears to relate to the interactions between the individual with ABI and people or objects in their community, there should also be a focus on other people or the context of the community environment. Public misunderstandings of ABI, negative attitudes towards disability, and physical barriers within the environment have all been negatively correlated to social and community functioning (Fleming et al., 2014). The negative relationship between environmental barriers and community integration highlights the importance of considering how the environment (both attitudinal and physical) influences outcomes in rehabilitation.

Social Support, Social Networks and Social Self-efficacy

Social relationships and *social connection* are identified to various degrees in all the previously described frameworks of community integration. The exploration of components of *social connection* such as perceived social support, social network size, and social self-efficacy as factors that influence community integration, quality of life, and wellbeing has grown in recent years. Perceived social support is defined as "the subjective view on available social relationships to provide help in times of need" (Batchos et al., 2018, p. 2063). Social network size is the number of individuals available to provide this social support. Social self-efficacy can be defined as "self-perceptions of interpersonal competency" (Ditchman et al., 2016, p. 1586).

Ditchman et al. (2016) conducted a survey with 103 community-dwelling adults with brain injury with the purpose of investigating factors that impacted on social and community integration. Specifically, they examined the impact of disability (physical, cognitive, communication, behavioural); personal (disability, acceptance, self-efficacy); and environmental (stigma, social support, neighbourhood climate) factors on social integration outcomes. They found that even those living independently with good cognition, communication, and physical recovery still had lower social participation level compared with non-ABI peers. This included fewer friendships and less overall participation in work and leisure. Their findings emphasised that social support, particularly growing social networks, was highly connected with increased community participation. They highlighted that "as people with disabilities overall have less social support and smaller social networks, enhancement of social capital is an important target for rehabilitation" (Ditchman et al., 2016, p. 1586). Their study calls for rehabilitation strategies to take a biopsychosocial approach to help individuals to build social networks and support, in tandem with strategies that address their health and functioning. Ditchman et al. discussed how social self-efficacy may play a significant role in a person's ability to engage in social situations.

In a later study, a similar group of researchers explored the potential route to increasing social networks being through improved self-efficacy (Ditchman et al., 2017). The findings of this later study support a focus on self-efficacy and prosocial behaviours to grow social networks, enhance feelings of sense of community, and navigate potential barriers to community access. The authors called for rehabilitation teams to assist people with ABI to practice social behaviours in personally relevant, real-life situations and provide support to develop social networks, resources, and advocacy skills in order to increase opportunities to access the community.

Batchos et al. (2018) further explored social support and social self-efficacy in a study of social factors predictive of social integration for adults with brain injury. In accordance with other community integration literature, they identified social integration as "a component of the broader construct community integration" (Batchos et al., 2018, p. 2062) and acknowledged the issues of people with ABI experiencing dwindling social networks, declining support, and increasing isolation. To deepen the exploration of social support, their study examined two types of support—instrumental (practical assistance with specific tasks) and emotional. It also divided social self-efficacy into two characteristics—approach-avoidance style and problem-solving confidence. Findings indicated that emotional support and approach-avoidance style appeared to have greater contributions towards social integration than instrumental support and problem-solving confidence. Based on these findings from the lived experience of people with ABI, the authors challenged the primary focus of rehabilitation being on instrumental support and emphasised a need to increase the social skills and relationships that build a foundation for social functioning in addition to more typical cognitive and physical intervention goals.

More specific to stroke recovery, Reed et al. (2012) found that close social support from family and friends provided the stroke survivor with encouragement to persevere, helped with adaptations and a return to social activities. A later survey by Erler et al. (2019) examined the independent contribution of perceived social support to community integration 3-months post discharge in a sample of 422 stroke survivors. Similar to the studies in the populations described above, social support was found to be the strongest predictor of community integration relative to other independently significant predictors including, recovery of motor function and mood; yet, study participants indicated a lack of focus on their social integration or relationships during their rehabilitation. These authors strengthen the argument that focusing stroke rehabilitation on impairment and activity does not necessarily lead to increasing participation in the community. Erler et al., however, are more specific in their practice recommendations and suggested the focus of carer training in preparation for

discharge needs to be extended beyond typical self-care, transfers, and medication management, and address social support in the context of promoting community integration. They acknowledged that this may add to carer burden and, therefore, also recommend that rehabilitation teams explore other people with whom the individual with stroke may have relationships, who can also provide support and include them in interventions. Telehealth and social media are also suggested as potential support mechanisms, providing potential to increase interaction and social networks.

Although Walsh et al. (2015) also found social support as a factor associated with community integration in the first year after stroke, and identified both instrumental (practical) and emotional support from family and friends as important facilitators, they stressed the importance of "maintaining a balance between support and dependency" (p. 1606). Their qualitative meta-synthesis of papers exploring the experiences of people with stroke indicated that support could be associated with feelings of dependency which could lead to tension and the stress of feeling like a burden. They found some participants tried to ease that sense of burden by hiding difficulties or withdrawing from social interactions. Managing family expectation, ensuring family do not set strict restrictions, and providing the person with stroke with the ability to reciprocate by helping others where they could are suggested as potential options to manage this fine balance.

Walsh et al. (2015) also highlighted the broader social support needs of the person with ABI, those that relate to the community as a whole. Lack of public understanding about the invisible consequences of stroke, such as cognitive or communication challenges, was highlighted in several qualitative reviews included in their meta-synthesis, and it could be concluded that this applies to other forms of ABI. This emphasises the wider social implications of increased public awareness. Specifically, these authors suggested that targeting awareness campaigns at staff in transport services and public amenities could facilitate a smoother return to community-based and previously valued activities for people after stroke.

These studies all contribute to the argument that social connection is an essential component when considering how a person with ABI re-integrates into their community; however, the evidence presented regarding the experience of people with ABI demonstrates that rehabilitation is lacking in this area. Instead, the focus of rehabilitation is seen as physical and cognitive recovery, and the return of independence in basic daily living skills such as transfers, mobility, and self-care. Where significant others are involved in rehabilitation it is mostly related to practical skill acquisition to assist in care activities. What this evidence calls for is a biopsychosocial approach that incorporates the individual with ABI, their close friends and

family, and the community as a whole. Building the social self-efficacy of individuals through group interventions has proven beneficial, particularly for those with communication impairments (Raukola-Lindblom et al., 2020). These kinds of interventions help develop verbal and nonverbal communication, practice social interaction, and encourage the individual with ABI to approach rather than avoid social situations. Increasing confidence in social interaction can lead to emotional and instrumental support, and increase social networks. Improving the ability of the social network to provide emotional and instrumental support, and promote awareness of ABI within the broader community, are all strategies that would help facilitate participation in community-based activities but currently appear to be lacking.

Personal Factors

In addition to self-efficacy, literature that explores the lived experience of people with ABI has identified numerous personal attributes that influence a person's journey towards community integration. Acceptance of disability has already been explored in relation to internalised stigma leading to self-concealment, shame, and the likely withdrawal from community and social opportunities. Other personal factors identified include: perseverance, hope, self-identity, adaptability, emotional resilience, and attaching positive meaning to activities. Each of these personal factors is complex and multi-faceted.

Walsh et al. (2015) described perseverance as both optimism and actively working towards goals, and found this to be a facilitator to community integration. Similarly, Bright et al. (2013) explored hope in people with aphasia after stroke and found both a passive sense of hope and an intermittent, future-focused, active form of hope that were important factors to engagement in rehabilitation.

Changes to self-identity will impact on a person's sense of their place within their community. Reconstruction of disrupted self-identity has been found to be an essential part of the recovery process post-ABI with tension between accepting the post-injury situation and striving for pre-injury capacities (Levack et al., 2010; Reed et al., 2012). Based on the findings of Levack et al. (2010), reconstruction of self-identity as it relates to community participation would require experience of how deficits and abilities impact on community activities. Once this impact is realised, an individual needs to learn strategies or retrain community-based skills, redefine what 'successful' community engagement looks like, and revise personal narratives of place and capacity in the community.

Emotional challenges are multiple and varied according to the meta-synthesis of qualitative research by Walsh et al. (2015). They found several emotional barriers to people's ability to

persevere towards community re-integration following a stroke. Findings indicated that people are limited by the fact that they have lost confidence or are uncertain about the control that they have over their bodies. Feelings of fear, anxiety, anger, and frustration were found to be further barriers that, at times, could overwhelm those who were trying to re-engage with their communities.

The meaning that people attribute to activities is also a personal factor that impacts on community integration. This has been described in the 'occupation and living at home' section above, but should be seen as specific to the individual. Meaningful roles, activities, and relationships act as motivators to returning to the community. It should be noted, however, that the meaning behind activities may change post-ABI, particularly if individuals view an aspect of their lifestyle as having caused the brain injury (Walsh et al., 2015).

Although these personal factors have been described in literature as impacting on a person's ability to reintegrate into their communities and re-connect socially, very little attention has been paid to these factors in the frameworks of community integration described earlier in this chapter. Only Shaikh et al.'s (2018) framework incorporates personal factors as a contextual condition (*antecedent*) to community integration that can lead to either positive or negative outcomes. They included self-awareness, attitude towards recovery, life roles, coping skills, motivation, and empowerment within these personal factors.

The influence of personal factors, such as those described above, for ongoing community integration is complex and multi-faceted in nature. Yet, there are common themes through the literature for addressing these factors within rehabilitation programmes. Firstly, literature suggests that rehabilitation clinicians remain cognisant of the impact these personal factors have on engagement and the importance of listening and recognising individual barriers to community integration. Exploring personally meaningful hopes and goals and providing information to help manage any uncertainty is another common recommendation across studies. Improved access to psychological services in the community to help re-construct sense of self is also supported through the literature. The importance of people with ABI feeling empowered in their decision making and facilitating their own participation in the community can be supported through person-centred goal setting, which can also create motivation to progress if goals are reviewed as they are achieved and new goals set. Despite these practical suggestions to addressing the personal factors that impact on community integration, Walsh and colleagues (2015) reported that participants across the studies in their review had low levels of satisfaction with the degree of clinical help available to deal with these social and psychological factors. This would suggest that theory is not translating into clinical practice.

Comparisons Between Lived Experience and Theoretical Frameworks

Examining the literature relating to lived experience of community integration against the community integration frameworks proposed to date reveals there are areas where frameworks and lived experience literature align such as the domains of *occupation,* preparation for *living at home,* and *social connection* that include both close and diffuse relationships. However, the lived experience literature provides greater depth to these domains that is relevant for clinical practice. For example, the meaning attributed to occupation appears to be a fundamental consideration in promoting activity in the community. Establishing ways to engage in meaningful community-based occupations is not simply about promoting independence as the community integration frameworks would imply but also impacts on motivation, pride, improving sense of self, and acceptance of changing abilities.

Fear and vulnerability are more frequently reported in the lived experience of community integration than the community integration frameworks would suggest. This relates to the fear and uncertainty of how capable the body is of functioning in the community context, with multiple barriers to accessing public services, and to stigmatising behaviour from the community, both anticipated and enacted. Internalised stigma that can result from these experiences and can lead to shame and fear, all resulting in withdrawal from social situations and increasing isolation. Personal factors impacting on a person's ability to engage in community integration are also poorly represented across the community integration frameworks. Although these factors are complex and multi-faceted, the literature summarised above clearly indicates that these are essential considerations for successful community integration.

Whether or not aligned with community integration frameworks, the perspectives of people with ABI indicate numerous aspects of community integration are not being considered in clinical practice. The community integration frameworks were published between 1993 and 2018, and the lived experience papers were published between 2010 and 2020. These parallel date lines would indicate that the two bodies of work were taking place simultaneously but in relative isolation from one another, rather than connecting and informing each other. Authors of the lived experience studies explored above frequently identified that traditional rehabilitation focusing on impairment (e.g., cognitive performance) and activity limitations (e.g., mobility) do not translate into improved community integration outcomes. Clinical recommendations made by these authors tended to have three common themes. First, establish personal goals relating to meaningful occupations in order to resume valued community-based activities, and address personal attributes like hope, motivation, and

decision-making empowerment. Second, increase opportunities for graded practice within community environments to assist with skill generalisation, encourage exploration and learning to assist with redefining self-identity, help build confidence, address fears or uncertainty, and address obstacles to anticipated stigma. Third, attend to the person-environment interaction and consider the impact of the community context rather than focusing solely on the individual with ABI. Addressing barriers to community access could include improving awareness of those with whom the person with ABI interacts on a regular basis and will assist with improving social support, social networks, and social self-efficacy, each having an influence on community integration.

Having reviewed community integration literature from both a theoretical framework point-of-view and the perspective of those with ABI personally experiencing community re-integration, it was clear that the evidence had only partly managed to translate into clinical delivery. This being the case, I turned my attention to an alternative means of influencing service delivery—health policy. I had experienced the growth of community stroke rehabilitation services first-hand in the United Kingdom following the first Royal College of Physicians' National Clinical Guidelines for Stroke published in the early 2000s. I witnessed how these guidelines became policy and then policy influenced changes in service delivery. Therefore, I wondered what support there was for community integration within New Zealand health policy, how it may be impacting on service delivery, and, in turn, on the community integration outcomes of people with ABI.

Support for Community Integration Within New Zealand Health Policy

The New Zealand Health Strategy: Future Direction (Ministry of Health, 2016a) governs New Zealand's publicly funded health and disability services. Legislation also requires a strategy for disability support services—The New Zealand Disability Strategy 2016-2026 (Ministry of Social Development, 2016). Taken together, these strategies provide a framework for the full range of services that comprise the wider health and disability system.

Both strategies are underpinned by the United Nations (2006) Convention on the Rights of Persons with Disabilities (UNCRPD) with the overall purpose to "promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity" (p. 4). The UNCRPD defines disability as an evolving concept that results from "the interaction between persons with impairments and attitudinal and environmental barriers that hinders full and effective participation in society on an equal basis with others" (United Nations, 2006, p. 4). This

definition takes into account a range of concepts relating to community integration including: acceptance, risks, social connection, accessibility, and occupation. Many of the principles within the UNCRPD relate to disabled people integrating fully in their communities; these can be mapped on to the dimensions of community integration. For example, living independently and being included in the community (article 19); access to information and communication services (article 21); work and employment (article 27); adequate standard of living and social protection (article 28); participation in political and social life (article 29); and participation in cultural life, recreation, leisure, and sport (article 30).

Bringing these principles into the New Zealand context, the New Zealand Disability Strategy (Ministry of Social Development, 2016) takes a whole-of-life and long-term approach to social investment, and considers a range of community integration dimensions when the Government is making social investment decisions. The approach helps to ensure that those with disability are more independent, have the ability to participate as much as they choose, are recognised for their contribution to the community, and have access to the right supports in order to reach their potential. The eight outcomes that contribute towards achieving the vision of the Disability Strategy include five outcomes that relate to community integration (see Table 2, p. 36). As these comparisons indicate, there is support for a focus on community integration within the New Zealand Disability Strategy.

The New Zealand Health Strategy (Ministry of Health, 2016a) provides limited attention to any aspects of integration into society for people with disability, or the wider wellbeing that can be achieved and maintained through community integration. The priorities in this Strategy, and its Roadmap of Actions (Ministry of Health, 2016b), tend to focus on the structure, provision, and performance of formal health services. Although one of the guiding principles is "thinking beyond narrow definitions of health and collaborating with others to achieve wellbeing" (Ministry of Health, 2016a, p. 14), there is little evidence of thinking that extends beyond issues such as life expectancy, obesity, cost of health services, investing in the health workforce, or the service expectations of an ethnically diverse population.

The population focused health strategies that fall under the New Zealand Health Strategy include: He Korowai Oranga – Maori Health Strategy (Ministry of Health, 2014b) and Ola Manuia – Pacific Health and Wellbeing Action Plan 2020-2025 (Ministry of Health, 2020). Both these documents play a role in managing the service provision for people with brain injury as these specific populations are over represented in the TBI and stroke statistics. As expected, considering their parent strategy has little focus on aspects of community integration, these documents do not specifically target community integration as a health priority. Again, access

to health services and seamless delivery of these services is a predominant priority in these strategies. Some support for community integration, predominantly the dimension of reducing risk and vulnerability, can be found in He Korowai Oranga in the Māori concept of Wai Ora which encapsulates the importance of the environments in which people live and the impact environment has on the health and wellbeing of individuals. “Achieving wai ora will mean that the environment in which Māori, and all New Zealanders, live, work and play is safe” (Ministry of Health, 2014b, p. 6).

Table 2

Links Between the Dimensions of Community Integration and the New Zealand Disability Strategy

Dimensions of community integration	Disability strategy outcome	Description of outcome
Social Connection **Occupation**	Outcome 3: Health and wellbeing	Not being segregated from the community, access to peer support, belonging and participating in the community to reduce social isolation and increase wellbeing: sport, recreation, arts
Risks & Vulnerability	Outcome 4: Right, protection, & justice	Rights are protected, people feel safe, they are understood and treated fairly and equitably
Accessibility	Outcome 5: Accessibility	Getting around, accessing public buildings, public transport, easy to access information and communication, use of technology, participating on an equal basis with non-disabled people
Acceptance	Outcome 6: Attitudes of society	Being treated with dignity and respect
Community access (choice and control)	Outcome 7: Choice and control	Choice about services and supports, access to information, making informed decisions, support to communicate, changing minds, taking risks and learning from mistakes

Ola Manuia – Pacific Health and Wellbeing Action Plan 2020-2025 (Ministry of Health, 2020) recently replaced the previous ‘Ala Mo’ui – Pathways to Pacific Health and Wellbeing (Ministry of Health, 2014a). The updated policy, Ola Manuia, is based on four principles, one of which is “Pacific Wellbeing” (Ministry of Health, 2020, p. 15). This principle stresses the importance of

broader determinants of wellbeing that are central to Pacific worldviews including respect, reciprocity, sense of agency, financial wellbeing, employment, and housing. This plan, therefore, provides synergies with the community integration components of a sense of belonging, acceptance, occupation, and having a place to live. It is an expansion on the 2014 version of the Pacific Health and Wellbeing Plan where broader determinants of health were considered to include only income, education, employment, and housing. The addition of respect, reciprocity, and sense of agency in the 2020 version perhaps demonstrates that over the years, dimensions of community integration (particularly social connection) are being increasingly recognised as important determinants of health and wellbeing.

The Health of Older People Strategy (Ministry of Health, 2016c) also sits under the New Zealand Health Strategy but is informed by the Disability Strategy and, therefore, has a defined focus on 'age-friendly communities' to enable people to age positively. This strategy encompasses the community integration dimensions of occupation, community access, adjustment, and acceptance. The document encourages restorative care services to shift their philosophy away from simply doing things for older people, to helping people retain the highest level of mental and physical function possible, ensuring they enjoy life, and that their communities respect them. Respect includes finding out about their goals, motivations, personal and cultural beliefs in order to develop a personalised plan, while recognising and respecting family involvement, especially when returning home from in-patient stays. Where managing long-term conditions is concerned, the Health of Older People Strategy promotes a workforce that supports older people so they can live well at home with their conditions.

Recognising the importance of social connection is the one community integration domain that these three population-based health strategies all have in common. Te Ara Tuatahi – Pathway One, within the Māori Health Strategy (Ministry of Health, 2014b), supports the removal of barriers for Māori experiencing disability and their whānau to ensure they have access to the services they need and are supported to participate in and contribute to society. Principle 3 of Ola Manuia "Valuing Families" recognises that for most Pacific people, "family is most valued and central to a resilient community and way of life" (Ministry of Health, 2020, p. 15), providing identity, role definition, care and support for this population. The action plan also recognises the importance of respectful relationships and many Pacific families being strong participants in community activities, which creates and reinforces strong social connections and, therefore, resilience. The Health of Older People Strategy applies a "life course approach" (Ministry of Health, 2016c, p. 7) involving initiatives that promote healthy ageing including those that enhance their community participation and social connection.

Despite the recognition of social connection within the guiding principles of the above strategies, the outcomes and action plans that describe the deliverables of the strategies provide little direction or priority towards social connection. Taking an example from Ola Manuia, one of the stated outcomes is "Pacific people lead independent and resilient lives" (Ministry of Health, 2020, p. 18) and the focus areas include cultural, environmental, and social determinants of health. It might be expected that this would be a prime opportunity to measure social participation or community integration as one of these broader determinants. The outcomes here, however, are limited to education, housing, employment, and income. Without any action plans or outcomes that focus on community integration, these population specific health strategies are guiding the design and delivery of services without targeting an important aspect of rehabilitation, health, and wellbeing.

Examining health policy that is more specific to brain injury, New Zealand's ACC (2017a) has the Traumatic Brain Injury Strategy and Action Plan 2017-2021. The Strategy's vision is "to improve the quality of life of New Zealanders by reducing the incidence, severity and impacts of TBI" (ACC, 2017a, p. 4). Although one of the priorities of this document is focused on enabling people to achieve maximum and satisfying participation at home, school, work, and in the community, none of the priorities or action plans directly relate to community integration. The focus tends to be directed towards: prevention, diagnosis, treatment, cultural responsiveness, integration of services, and workforce capability. ACC contracts social rehabilitation services for people after injury, the purpose being to assess injury-related support needs and contribute towards restoring independence in everyday activities to the maximum extent practicable. In its Service Schedule for Social Rehabilitation Needs Assessment Services (2017b), ACC defines the key aspects of social rehabilitation as: "hygiene care, health care, communication, mobility, domestic activities, safety management, parental responsibilities, motivation, cognitive tasks, sexuality and financial management" (p. 14). Although these components relate to some of the basic dimensions of community integration, broader dimensions such as acceptance and social connection are not addressed. If these broader dimensions of community integration are not recognised within the service schedule, then rehabilitation service funding to address determinants of community integration beyond the basic dimensions listed above is unlikely.

Summary

This chapter covered three aspects of the literature relating to community integration. The first was an integrative review of community integration frameworks which outlined and critiqued the theoretical domains that have been proposed to construct the multi-dimensional

concept of community integration. The second was an explorative review of the literature relating to the experiences of those with ABI who are undertaking the process of community integration. This experience literature aligns, in part, with the community integration frameworks; however, evidence from frameworks and lived experience indicate that clinical practice is lacking in its focus on multiple aspects of community integration and, therefore, optimal community integration outcomes are not achieved. The third component of this chapter was a review of New Zealand health policies to establish the extent to which they address and promote community integration, given their influence on shaping rehabilitation services in New Zealand. Although some support for community integration is evident, particularly within the New Zealand Disability Strategy (Ministry of Social Development, 2016), the action plans and priorities of the policies explored fail to focus on broader concepts of community integration and are unlikely to have a formative impact on prioritising community integration as a key outcome in rehabilitation services.

The gaps in community integration theory, the contradictions between frameworks and experience literature, the limited acknowledgement of the importance of community integration in health policy, and the failure of rehabilitation services to deliver evidence-based interventions all strengthened my motivation for carrying out this doctoral research. The strongest driver following this review, however, was that of people with ABI consistently reporting poor experiences of rehabilitation that supported their engagement in the community; and communities that reinforced their fears, vulnerabilities, and internalised stigma. The result being that people with ABI withdrew from communities that had meaning to them and their pre-injury life roles. This occurs despite clear recommendations for how rehabilitation could be structured to address many of these issues.

In addition to the personal reflections and professional journey described in Chapter 1, this review of literature has been key in providing the theoretical scaffolding for the current research. It has helped me to identify conceptual understandings and make methodological decisions that will be described in the next chapter.

Chapter 3: Methodology

This chapter begins with a description of the initial struggle to choose a qualitative research approach that I was comfortable with and which addressed the scope of the study that I wanted to undertake. This exploration leads to an explanation and justification for choosing interpretive description as the best methodology to answer the research question and meet the aims of the study. An overview of Interpretive Descriptive methodology is provided, along with details of how it was applied and how, using the principles of this methodology, a 'theoretical scaffold' was built to inform the initial data gathering phase.

The latter part of the chapter outlines my methods for sampling, recruitment, data collection, and data analysis. Examples will be woven throughout, supporting the description of these methods. The final section of this chapter details how rigour was established and maintained throughout the research process, and ethical considerations that were taken into account.

Qualitative Methodology Conundrums

When initially considering my research question and working through potential methodologies, I was drawn towards my 'comfort zone' of Grounded Theory (Morse et al., 2009). This was the methodology I had used for my Master's research and I related well to the philosophy underpinning the methodology and the structure that came with data collection and analysis. I also considered Action Research (Reason & Bradbury, 2008) as the idea of improving or changing practice throughout the research process was appealing; and the process of implementation, observation, and then evaluation fitted well into the clinical context within which I worked at the time. Interpretive Description was the third methodology I took time to explore. I had no previous experience with this methodology and, therefore, had to learn about its foundational underpinnings and practical application through reading guidance from Sally Thorne, reviewing literature that had used Interpretive Description as a methodology to understand the application of the methods, and discussing the methodology at length with my supervisors. The sections that follow are taken from a table of pros and cons that I created during this methodological exploration and provide reasoning behind the decision to choose Interpretive Description as the methodology for this current study.

Grounded Theory

As mentioned above, I had used grounded theory methodology in my Master's research several years ago and I related to the symbolic interactionist and pragmatist philosophies underpinning it. These philosophies suited me, both as a person and an occupational therapist.

I also appreciated the structure that came with the data collection and analysis described by Corbin and Strauss (2008), with open and axial coding and constant comparative analysis. I found this structure benefited me as a novice researcher and made data collection and analysis methods simple to explain and justify in proposals and ethics applications. Grounded Theory also felt like a good fit with the 'How do...?' question that I was asking, as a process generally tends to emerge from a Grounded Theory study and my ideal outcome was to develop a process that would inform clinical practice. I also considered findings from a Grounded Theory study as being potentially transferrable to a range of practice contexts and have wider influence beyond ABI or New Zealand health services.

When considering the negative aspects of Grounded Theory, I recalled how, after a while, the coding and constant comparative nature of data analysis became exhausting, despite the structure it offered. There was also a need to, ideally, reach theoretical saturation as an end point to data collection and analysis and I had no way of knowing when this might be achieved. As I had a limited timeframe for the current research, there was a concern that theoretical saturation could be difficult due to the broad topic of community integration. Although the end point of the study would be a theory or process that I could then relate to clinical practice to influence change in service delivery, there was more of an appeal with directly influencing service delivery throughout the research process. This idea led me to Action Research as a methodological possibility.

Action Research

I liked the idea of improving practice and learning from improvements in a cyclical way throughout the research process, rather than waiting until the end of the study to influence change. The process of planning, acting (implementing), observing, and reflecting (evaluating) was one that felt comfortable and easily applied to my clinical context. A similar approach had been taken in quality improvement projects in clinical settings in which I had worked and with the teams I worked; therefore, I was, to some degree, familiar with the process. The collaborative nature of Action Research was also appealing as I generally work in a collaborative way and enjoy hearing others' perspectives and having them examine their own practice. I believe that this is a good way to create effective and lasting change, with people as active participants in the change and taking ownership of it, rather than having it forced upon them. Just prior to embarking on the research component of my DHSc, I moved to work in a new organisation. I felt in a good position to perform a critical analysis of systems and clinical practice with a fresh perspective. Action Research was also appealing as I already had an

interest in implementation science and having experience of this methodology was going to be useful for my future career direction.

Although the recent move to a new organisation (Counties Manukau Health) put me in a positive position of having a fresh perspective, it also led to uncertainty as to who the collaborators would be, how motivated my new team would be for change, and whether they had a common goal. With an Action Research approach, I would also be reliant on others in meeting my timelines and, in a large organisation like Counties Manukau Health, I wondered if this was going to be a barrier to meeting deadlines. When looking into the practicalities of this approach, I realised that it was going to be necessary for clinicians to be objectifying their own experiences but thought it was unlikely that already busy clinicians would want to keep journals or record their learnings, in addition to their usual daily administration. Due to my recent change in role and organisation I decided not to proceed with Action Research as, in terms of leadership, I had lost some of my collateral influence. In moving so recently I had yet to build relationships and become familiar with key players or those with influence within the team and broader organisational structure.

Interpretive Description

I knew very little about Interpretive Description when entering into this research journey. It came to my attention during a research methodologies discussion in class during my second paper. Someone talked about Sally Thorne's contemporary approach to research and its key purpose of questioning knowledge that could be applied to people caught in complex and difficult health situations so as to improve their quality of life. This seemed to fit with my research aims and prompted me to look into it in more detail. I liked the fresh perspective of a research methodology that was designed by nurses, and used by other health care disciplines based on the philosophies of their own professional foundations, rather than based on the typical sociological, anthropological, or philosophical disciplines. The fact that Interpretive Description was driven by the knowledge needs of health practice and the outcome tended to focus on knowledge that developed insights for, or changed, this practice for the better rather than theory development or general qualitative description was also appealing. As my intention was to examine community integration from the perspectives of those living through it, Interpretive Description also fitted well with examining a phenomenon in its natural setting. In general, there seemed to be congruence between the objective of my study and the outcomes of Interpretive Description being to produce applied knowledge that would assist clinicians to better support community integration.

My concerns were in relation to the data collection and analysis methods and their potential for being too broad and unstructured. From the reading I had done, Interpretive Description analysis appeared to require more creativity and imagination than anything I had done previously and I was unsure if I had the ability, skill, or time to get that creative. Through discussion with my supervisors, and further reading relating to the use of Interpretive Description in practice, I started to become more comfortable with the idea that I could use some of my previous knowledge of Grounded Theory analysis and yet not be constrained by it. As an example, I could use theoretical sampling to choose rich data sources but not stick to specific sampling schemes as long as I justified my decision making. This less prescriptive approach had the potential to give me more freedom to explore concepts outside of the rules of Grounded Theory and draw on a range of research techniques as needed. Although I had initial nervousness around a lack of specific description of data analysis techniques, and I was unsure how to adequately account for my decision making within the research process to ensure rigour, these were all conundrums that I worked through to create the research process described in the latter sections of this chapter. What follows next is a deeper exploration of the philosophical and theoretical foundations of Interpretive Description and how they relate to this study, and to myself as an occupational therapist.

Interpretive Description – Philosophical and Theoretical Foundations

Thorne et al. (1997) developed Interpretive Description as a research methodology in response to an expressed need from nursing researchers to generate knowledge grounded in the clinical nursing context. Their belief was that qualitative approaches derived from other disciplines, such as sociology, philosophy, and anthropology, had not always met the unique needs of nurse researchers and resulted in misrepresentation of approaches in order to gain legitimacy. Due to nurse researchers leading its development, Interpretive Description was initially a research approach that was derived from nursing's philosophical and theoretical foundations. However, the development of Interpretive Description as a noncategorical approach made it appealing to all applied disciplines resulting in it being taken up more widely (Thorne, 2008). Among its foundations is the recognition that human health and illness experiences are comprised of complex interactions between psychological and biological phenomena. As such, Interpretive Description has been put forward as a useful research approach to employ in studies that involve description and interpretation about a shared health or illness phenomenon from the perspectives of those who are living through it (Thorne, 2016). In the case of this research, the health phenomenon is community integration after in-patient rehabilitation and the perspectives are those of the people with brain injury. This research is also being undertaken as part of a professional practice doctorate; as such, the research

question and aims are practice-based. A core feature of Interpretive Description is the key focus on practice-based questions and findings.

Interpretive Description "acknowledges the constructed and contextual nature of human experience that at the same time allows for shared realities" (Thorne et al., 2004, p. 3). As such, it has a philosophical alignment with interpretive naturalistic orientations. Key principles of naturalistic inquiry provide philosophical underpinnings for research design (Lincoln & Guba, 1985) and include:

1. There are multiple constructed realities that can only be studied holistically. These realities are complex, contextual, constructed, and ultimately subjective;
2. The inquirer and the 'object' of inquiry interact to influence one another;
3. No scientifically deducted theory could possibly encompass the multiple realities that are likely to be encountered; rather, theory must emerge or be grounded in the data.

Drawing from the general tenets of naturalistic inquiry implies a commitment to studying something in its natural state or, as it is, to the extent that this is possible in a research enterprise. The naturalist inquirer uses techniques that allow the target phenomenon to reveal itself as it would if it were not under study (Sandelowski, 2000). As the data collection section below will demonstrate, the aim of this study was to conduct the research in the community environment most meaningful to the individual with the brain injury so as to embed their narrative in the environment in which experiences took place. Constructing data with the participants in their natural environments would also provide those with cognitive or communication deficits cues and strategies to recall specific events, thoughts, or interactions. If the participant was removed from this context, they might have struggled to describe some of their experiences without the ability to point out an object, show an activity, or demonstrate a situation.

Although Interpretive Description was originally developed to address the needs of nurse researchers, the approach has been advocated for use by other applied health disciplines (Thorne, 2008). As an occupational therapist, the philosophical and theoretical foundations of the occupational therapy profession provided a foundation for the inquiry and formed the epistemology and ontology for the study. Ikiugu and Shultz (2005) proposed that philosophy provides a profession with core assumptions, principles related to those assumptions, and values underlying theory; thus clarifying the profession's identity.

Occupational therapy was derived from a humanistic concern for people incarcerated as 'lunatics' in the 18th and 19th centuries. These concerns led to the 'moral treatment'

movement, which sought to replace physical restraint with diversions and work to reduce the effects of boredom and idleness (Ikiugu & Shultz, 2005; Young & Quinn, 1992). Further, the roots of occupational therapy lie in American pragmatism (Brienes, 1986). Ikiugu and Shultz (2005) summarised the strong historical and personal connections between the founders of occupational therapy and the leading pragmatic philosophers such as John Dewey, Herbert Mead, William James, and Emil Gustav Hirsch. They suggested these connections greatly influenced the development of occupational therapy. Both occupational therapy and pragmatism value the subjective experience of the individual as they interact with the environment and share the assumption that humans think and act so as to interact effectively with their environment and, therefore, adapt and survive. Adolf Meyer, a colleague of John Dewey and William James, recognised that the proper use of time in some helpful and purposeful occupation appeared to be a fundamental issue in the treatment of psychiatric patients, and that occupation may be structured, inspected, and, therefore, altered (Young & Quinn, 1992).

Ikiugu and Shultz (2005) compared assumptions, principles, and values of occupational therapy with pragmatism. They found that the themes from occupational therapy literature (e.g., occupation, activity, environment, purposefulness, human development, habit, and adaptation) to be consistent with concepts of pragmatism (e.g., the notion of the human being consisting of the mind and body acting adaptively as a unit interacting with the environment). Translating these philosophical assumptions into theory has led to the values and principles of occupational therapy. Professional values that relate to the above assumptions have been codified by Yerxa (2009) and can be summarised as follows:

1. Acknowledging the essential humanity of the client and their life satisfaction
2. The maintenance and enhancement of health
3. The self-directedness and responsibility of the client
4. A therapeutic relationship of mutual cooperation
5. The client acting on their environment rather than being determined by it
6. Faith in the potential of the client
7. The client as an active participant in treatment
8. Leisure activities are essential components of a balanced life
9. Acknowledging the subjective perspective of the client

Accepting these values as foundations for practice and applying them to rehabilitation and community integration following brain injury, occupational therapists seek the active involvement of clients to become participants in improving their own occupational

performance within their communities. Occupational therapists believe that the person with brain injury has the potential to actively influence their environment to maintain or enhance their own health and wellbeing, and that a person-centred approach to therapy must be employed to address the subjective perspectives of the individual. Leading on from these values, a number of principles for practice have been proposed. These are condensed and clearly stated by Young and Quinn (1992):

1. Intervention is through the use of activity
2. The activity used is determined through functional and task analysis
3. The client is offered opportunities for learning so change in behaviour can occur
4. The expected outcome reflects the goals of the client

Bringing an occupational therapy 'lens' to this research seems congruent with the Interpretive Descriptive view of the constructed and contextual nature of human experience and shared, subjective realities. As an occupational therapist with over 20 years of clinical experience, mostly in the field of brain injury rehabilitation, the assumptions, values, and principles described above are part of a worldview that I bring to this study, along with the philosophical assumptions of the methodology itself. These clinical beliefs, theories, and background form part of the theoretical scaffolding on which this study is based. The construction of this framework is an important starting point for an Interpretive Descriptive study, and is described in more detail in the section below.

Interpretive Description – As It Applies to This Study

Theoretical Scaffolding

In their earlier writings, Thorne et al. (1997) described the 'analytical framework' as a "foundational forestructure to a new inquiry" (p. 173). The analytic framework referred to the background knowledge and disciplinary orientation that the researcher was taking into the study. Recognising that this language could be misleading and convey an impression that data analysis was being explicitly guided by a predetermined conceptual structure, Thorne (2016) changed the language to 'theoretical scaffolding'.

Theoretical scaffolding sets up the initial position from which a study design is built. The term describes the initial building blocks of an Interpretive Descriptive study that include two elements: 1) a review of literature, and 2) locating oneself as a researcher within the field and the theoretical world that surrounds it. The 'personal reflections' and 'personal assumptions' sections of Chapter 1, and the critical review of literature in Chapter 2, formed the basis for

the preliminary theoretical scaffolding which were formative to my sampling, design, and early analytic decisions. In the following sections, I draw reference to this theoretical scaffolding to demonstrate connections between the scaffolding and the decision making that occurred.

Research methods for sampling, recruitment, data collection, and data analysis were chosen for their alignment with Interpretive Descriptive methodology (Hunt, 2009; Thorne, 2016). These methods support the inductive approach taken to this study, with the aim of producing clinically relevant findings, and are described below.

Sampling

This study was concerned with examining the experience of adults as they journey through the process of community integration following their in-patient rehabilitation. People with ABI were eligible to take part if they were aged 18 years or over, had transferred from in-patient rehabilitation to home within the previous 6-months, and lived in the greater Auckland area. The 6-month period was chosen as it was felt that people would still be in the process of community integration at that stage but have enough experience to be able to contribute their stories, while balancing that against challenges in their recall of events. The greater Auckland area was chosen as this is the area in which I reside, and it offers a range of rehabilitation options, ethnic diversity, and living situations (e.g., rural and urban); therefore offering access to a broad range of potential participants from differing backgrounds and social circumstances.

Exclusion criteria included any individuals whom I had worked with in a clinical capacity as it was thought this would affect the interviewer/interviewee dynamic, blur the boundaries between my dual role as clinician and researcher, and risk the person feeling a sense of coercion to participate. At the outset of the study, this criterion was thought to be unlikely as I had been in a leadership role for more than 5-years and was not directly working with patients. However, it was possible that a person could re-present to rehabilitation with recurrent issues.

The initial theoretical scaffolding provided direction for preliminary decisions about purposeful sampling. For example, as the summary of literature relating to previous community integration frameworks demonstrates, independence in personal and household activities is an important aspect of integration after brain injury; therefore, participants were initially sought who identified this as their goal for ongoing rehabilitation. Discussions within the initial few interviews, however, indicated that independence in such tasks was a short-lasting priority for participants and as soon as they were no longer dependent on assistance from others to manage these tasks, they shifted their community integration focus elsewhere. Through the

constant comparative data collection and analysis, a pattern emerged that socialising within the wider community and re-connecting with others was of particular importance. Theoretical sampling was then attempted to develop a more thorough and complex interpretation of the emerging patterns. Theoretical sampling aimed to achieve maximal variation on the emerging concepts and avoid any misinterpretation of the contributions of individual participants. Unfortunately, due to the outbreak of COVID-19, I was unable to fully realise this level of theoretical sampling. As recruitment became increasingly difficult for practitioners working in the community settings, a convenience sampling approach was necessarily adopted. Nevertheless, the participants represented a range of backgrounds and experiences that continued to provide rich data (see Chapter 4 for a detailed overview of participants). Sampling and sample limitations will be further discussed in the strengths and limitations section of Chapter 7.

Sample Size

There is no specific sample size guidance for an Interpretive Description study. However, Thorne (2008) suggested that the best way to determine an appropriate sample size is to generate a rationale consistent with the research question. With this in mind, I used Malterud et al.'s (2016) concept of 'information power' and considered the following five aspects of the study to establish a possible sample size: 1) study aim, 2) sample specificity, 3) theoretical background, 4) potential quality of interview dialogue, and 5) the strategies for analysis. Table 3 below details the information power considerations relating to each of these five study components according to Malterud et al., along with considerations specific to this study.

Taking each of these five aspects into consideration, and informed by my supervisors' experience, it was decided that a target sample of approximately 10 participants with diverse experiences of community integration might provide sufficient information power to generate a clinically relevant thematic analysis. This number was reviewed in an ongoing way as data collection and analysis progressed.

Table 3

Five Considerations of Information Power to Guide Sample Size

Aspect	Description of the information power considerations	Specific considerations relating to this study	Sample size requirement
Study aim	Broad study aims require a larger sample size	Broad study aim	Larger sample
Sample specificity	Information power is related to the specificity of experiences, knowledge, or properties among the participants in the sample	Purposeful then theoretical sampling to seek specific in-depth experiences from people	Smaller sample
Theoretical background	A study supported by limited theoretical perspectives would usually require a larger sample size to offer sufficient information power than a study that applied specific theories for planning and analysis	The theoretical background to this study is somewhat defined but I am employing an iterative methodology, without applying a specific theory at the outset	Medium sample
Quality of interview dialogue	A study with strong and clear communication between researcher and participants requires fewer participants to offer sufficient information power than a study with ambiguous or unfocused dialogues. Difficult to predict in advance	I have a lot of clinical experience in this field. I am capable of building rapport and using communication and cognitive strategies with this population. I am entering the study with knowledge of empirical evidence so can focus the initial dialogue. I have some previous research interview experience.	Smaller sample
Strategies for analysis	An exploratory cross-case analysis requires more participants to offer sufficient power, compared with a project heading for in-depth analysis of narratives	A cross-case analysis required to uncover realistic, clinically relevant findings	Larger sample size to make comparisons

Recruitment Strategies

People with TBI were recruited through ABI Rehabilitation NZ Ltd., the largest provider of rehabilitation services for people with TBI in the upper North Island, providing intensive in-patient and community-based rehabilitation programmes. People with stroke and other brain injury related conditions were recruited via the Counties Manukau Health adult rehabilitation

services. This is the organisation in which I worked, and enabled me access to a diversity of clinicians who could assist with recruitment. Across these two recruiting localities there were a wide range of potential participants with varying degrees of injury severity, ethnicity, and living situations (including urban, suburban, and rural settings). To further extend potential recruitment options, my existing professional networks, such as regional neurological interest groups, were consulted and informed of the research, should they identify any potential participants. Locality approval was sought from each organisation involved in the recruitment process.

Clinicians working in recruiting localities were provided with presentations and clinician guides (see Appendix A) to explain the background and purpose of the research, what would be involved for the participants, and what the research aimed to achieve. They were also provided with the participant information sheets (see Appendices B and C) for use when they identified a potential participant. Two information sheets were available including a simplified version to ensure participants with cognitive or communication difficulties had the best chance to process the information, and one developed in conjunction with Māori advisors to incorporate tikanga. The clinicians were asked to approach potential participants and provide the most suitable information sheet, along with some verbal explanation of the study background and aims. The information sheets included the my contact details, as the researcher, and a Consent to Provide Details form (see Appendix D). These details were used to make initial contact with the potential participants. At this initial contact, the purpose and requirements of the study were discussed to ensure they had a clear understanding of these. If willing to proceed, a convenient time for interview at their home or other community location of their choice was established.

The realities of conducting this research during the COVID-19 pandemic in 2020-2021 meant that there were significant breaks in the recruitment process when clinicians were unable to carry out community visits due to lockdown protocols. Clinicians also had to quickly adapt to new ways of working that took priority over research activities. When initial presentations to clinicians were undertaken at the beginning of 2020, these then had to be repeated later in the year so as to remind the clinicians of the recruitment criteria and continue to encourage identification of potential participants. I did further presentations following the collection and analysis of initial interview data to continue the discussion about the research and demonstrate the potential clinical implications of the findings. Participant information sheets were also adapted, with further ethics committee approval, to include the use of remote interviewing techniques, should these be required or requested by the participants (see Appendix E).

Data Collection

Thorne et al. (1997) stressed the importance of recognising that people will weave their recollections of a subjective experience into their pre-existing life narrative, making it difficult to untangle the shared component of a subjective experience from the narratives that people place them in. In addition, I anticipated at the outset that participants with brain injury were likely to have a range of cognitive impairments that may limit their ability to recall or reflect on an experience outside of the context in which their experience took place. It was, therefore, important for data collection to occur in a context that directly related to the concept of community integration for each individual participant and for the methods to support the participant to reflect on their daily occupations. To address these challenges, three main data collection methods were planned: 1) information from a 7-day structured activity diary, 2) semi-structured face-to-face interviews in the participants' homes, and 3) go-along interviews which would enable me to observe and discuss the participants' experiences as they undertook a community integration activity of importance to them. Although I planned to undertake these three data collection methods, only the semi-structured interviews in the participants' homes actually took place, primarily due to the impact of COVID-19. COVID-19 had an enduring impact on health delivery, on myself as a researcher and clinical leader, and clinicians who experienced reduced face-to-face engagement with their clients. Further, there was a general reduction in community integration that took place across the population as a consequence of Government mandated restrictions over the study period.

It was anticipated that the activity diary would be provided to participants by their clinician prior to the initial interview. It took the form of a single sheet for each day of the week, with five columns in which the participant or a significant other could record the activities completed, the time of day, who was present, where the activity took place, and a brief statement about how it went. An example diary page can be seen in Appendix F. The format of the diaries was informed by previous researchers who utilised structured participant diaries to help facilitate a similar process (Davidson et al., 2008; Orban et al., 2012). The purpose of the diary was two-fold. First, it aimed to encourage participants to record what, when, where, and who they had been interacting with in the 7-days prior to the initial interview taking place. Second, it provided a memory aid and visual cues for the participants with cognitive difficulties, which could be used to guide conversation and prompt recall of specific experiences during the interviews. In reality, the clinicians who recruited participants into the study never provided the diaries despite encouragement to do so at presentations and within the written clinician guides. When the reasons for this were discussed with clinicians, it was

due to their impression that the participant recruited would not require the cognitive support that the diary offered, or that they had simply forgotten about it.

The third component of the planned data collection, 'go-along' interviews, had to be abandoned due to the impact of COVID-19 home isolation requirements and people's anxiety about being out in the community prior to vaccines being available. These go-along interviews were based on Thorne's (2016) description of the "walk around interview" (p. 147) as a popular advancement on conventional participant observation, particularly in community-based research. The work by Emmel and Clark (2011) in relation to visual methodologies in research informed the design of the go-along interviews that I planned to undertake with a purposefully selected number of participants based on findings from face-to-face in-home interviews and concurrent data analysis. I anticipated that go-along interviews would allow data collection to occur in a context that was meaningful to the participant and I could draw on prompts from the individual and observations of the physical and social environment to stimulate their story-telling. The focus of the go-along interviews was to elicit the experience of the participant as they negotiated their environment to achieve a meaningful community integration activity and to develop a more contextually-bound understanding of the person-environment interactions. As this component of data collection was unable to take place, I used some of the techniques within the face-to-face interviews in the participants' homes to stimulate discussion and exploration. Participants were encouraged to show me around and demonstrate the ways that they were doing some of the activities that they described. The strengths and limitations of these changes to data collection will be considered in more depth in the Chapter 7 – Discussion.

A face-to-face interview, lasting approximately one hour, was undertaken with each participant in their home, as COVID-19 restrictions allowed. This meant that at times there were periods of 2-months between recruitment and an interview taking place, due to level 3 and level 4 lockdown rules. This meant I needed to maintain contact with participants over the phone to keep them informed of when interviews could be scheduled. Although ethics amendments had been sought and information sheets had been adapted to offer online/remote interviews, none of the participants preferred this option and, instead, were willing to work around lockdown periods to engage in face-to-face interviews in their homes. The aim of these interviews was to explore how and why certain community integration activities took place, and enable participants to use cues within their home environment to stimulate conversation and allow them the ability to show what they were doing as well as talk about it. Semi-structured interviews explored participants' experiences and process of community integration; the resources required; personal choices; constraints; influence of

social networks; the social, physical, and attitudinal environment; and complexities related to the activities undertaken, to establish a deep understanding of their experiences. The initial interview schedule is located in Appendix G. Following the first four interviews, initial analysis of the data informed further theoretical sampling for subsequent participant interviews.

All interviews were digitally audio recorded using a microphone that could be pinned to the participant's clothing allowing them the freedom to engage in their environment without affecting the quality of the recording. In addition to the interview recording, observations of events and interactions within the home were recorded as field notes. Thorne (2016) advocated for the use of participant observation as it "provides a platform from which to reflect upon behaviour and context as it plays out in its natural context" (p. 144). Collecting both interview and observation data concurrently enhanced the richness of data being gathered as it provided participants with the opportunity to demonstrate what they had been doing in addition to articulating it through the interview alone. One example was a participant who wanted to explain his engagement in carving as a way to return to a meaningful occupation and contribute to his whānau through the carving of gifts for birthdays. This participant took me out to his workshop at the back of his house and showed me the carvings he had been working on and how he had adapted his technique. I could observe how he had redesigned his work space to accommodate his physical limitations. As this gentleman also had communication difficulties, he was able to use gesture and demonstration to support his verbal communication.

I transcribed the initial interview recordings verbatim within 24-72 hours of the interview, providing the opportunity for deeper immersion within the preliminary raw data. Field notes used to record the observations during the interviews took note of barriers, facilitators, and interactions that were evident during the participant's engagement in their home context. As recommended by Hunt (2009), an interview synopsis was also written shortly after completion of each interview to capture initial impressions of the whole of the participant's story. These synopses were useful during the data analysis process as returning to these at various stages helped to ensure the coherence of each narrative was not lost. See Appendix H for some examples of synopses.

Data Analysis

As mentioned earlier, interpretive description allows a degree of methodological freedom. Therefore, I was able to create a more bespoke framework for data analysis to meet the specific needs of this study and deepen my understanding of participants' experiences. Findings were built using a framework adapted from the work of Thorne (2016), Morse (1994),

and incorporating the practical strategies described by Hunt (2009). This framework incorporated four sequential processes of conceptualisation including: comprehending, synthesising, theorising, and reconceptualising. The framework is illustrated in Table 4. Examples of analysis tools and techniques used during each of the four processes are then described with figures to support these explanations.

Table 4

Data Analysis Process – Conceptual Organising Framework

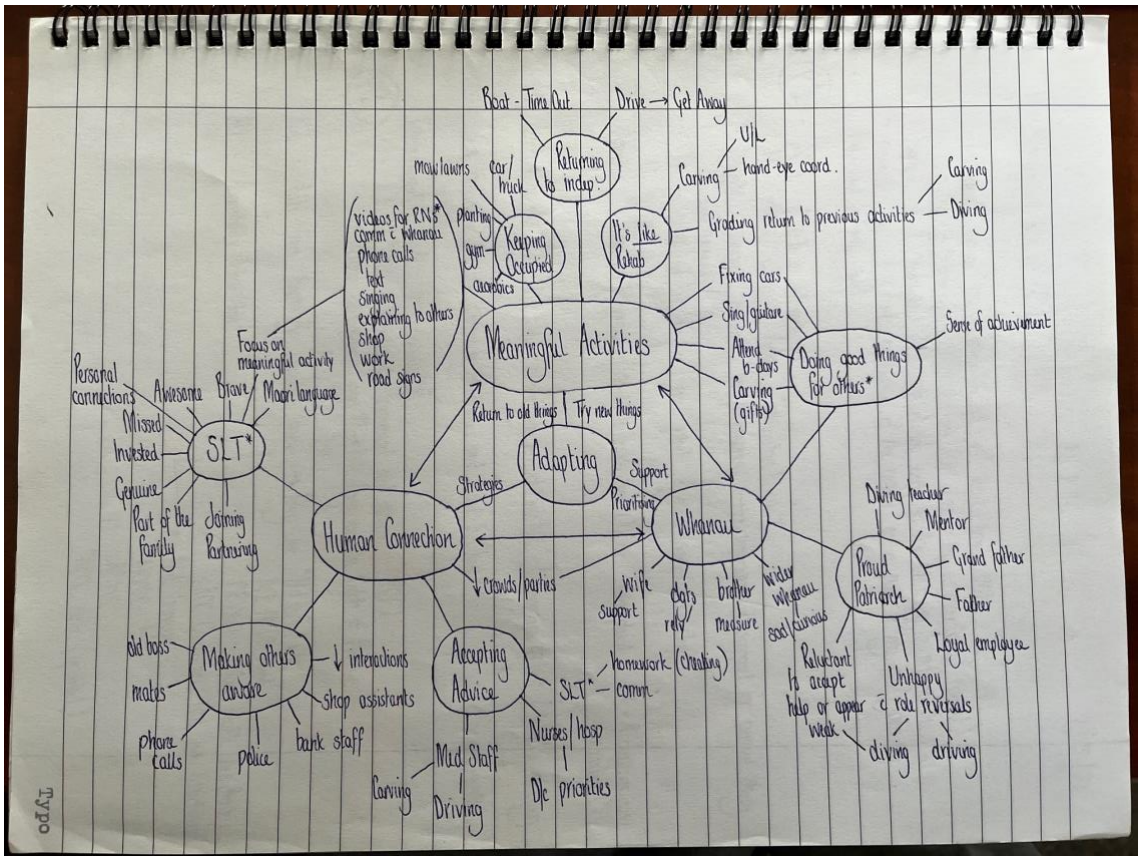
Sequential cognitive processes of conceptualisation	Description of the process	Data analysis strategies
1. Comprehending	• Learning about the setting and experiences • Holding judgements • Absorbing everything relating to the topic • Bringing some form to initial interviews	• Transcription of interviews • Writing an interview synopsis after each interview • Initial examination of data pieces • Note making of initial ideas • Broad questioning • Reflection and memoing • Discussion in supervision of ideas and reflections
2. Synthesising	• Merging instances, experiences, and events that describe typical or shared patterns • Sifting through significant versus insignificant • Examining variations between patterns • Extracting common features • Generate/manipulate • Verify/falsify • Select, revise, discard possibilities	• Memoing • Concept mapping • Generating initial patterns • Collating data pieces relevant to each pattern • Checking and re-checking against new data • Supervision feedback • Repeated reading across interviews
3. Theorising	• Developing considered theories about explanations • Asking additional questions of the data/participants based on insights	• Review/revision of initial interview question schedule • Theoretical sampling • Seeking other empirical data sources • Gathering all the specific data
4. Reconceptualising	• Articulating what has been synthesised into a form applicable to other contexts • Bringing the theory back to practical implications	• Thoughtful clinician test • Relating back to the literature • Writing findings

During the *comprehending* process of data analysis, I immersed myself in the data through transcription of interviews, which allowed me to listen carefully to what was being said and how it was being articulated. Relating the recording back to each interview synopsis immediately after each transcription had been completed and asking broad questions of the

data through memoing allowed me to absorb as much of the situation and experience as possible. Initial form was brought to each interview through coding of data pieces within the transcript and then linking these through memoing and mapping to form sets of data pieces that related to one another. An example of the memoing/mapping that took place can be seen in Figure 2.

Figure 2

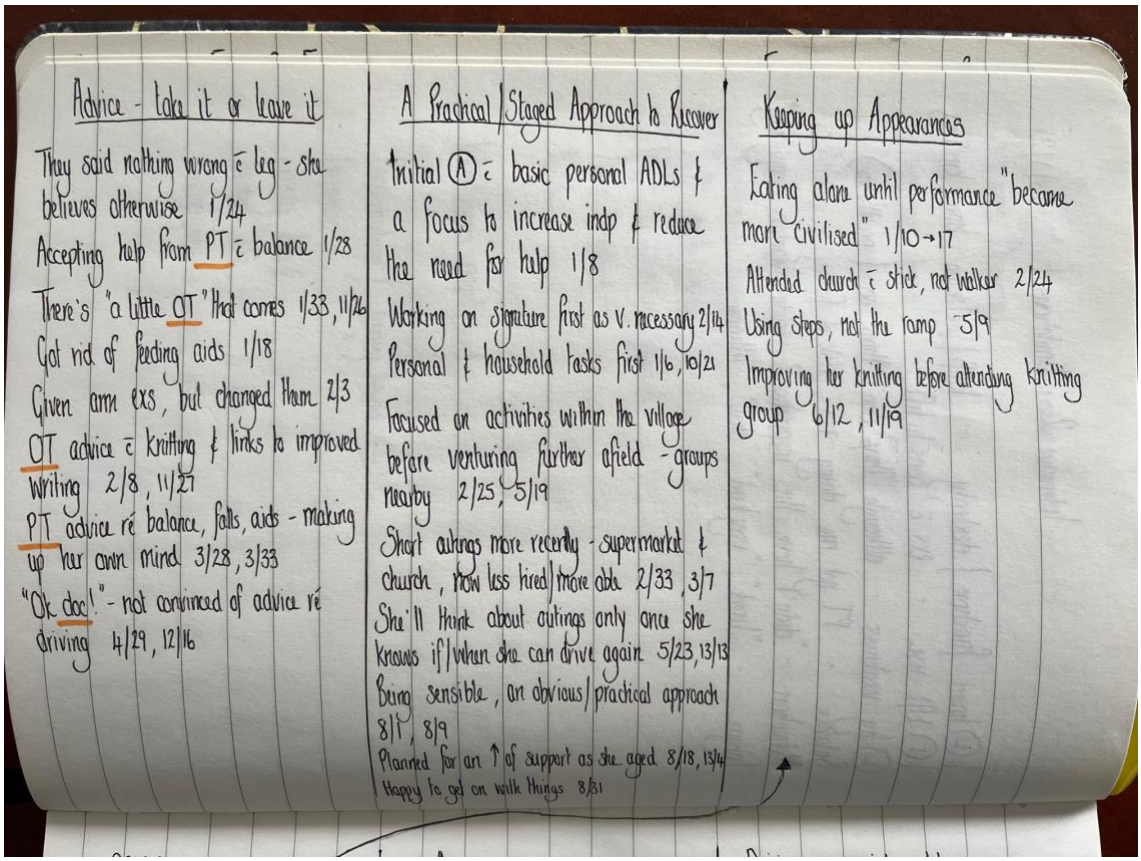
Example of Linking Data Through Memoing and Mapping



This process resulted in between five and 10 sets of data pieces being generated from each interview. Each set was labelled to describe the key idea of the component pieces. Examples of labels included “Keeping up appearances” which grouped together data pieces that related to keeping limitations hidden from others, not being seen performing a task in public until it had been mastered at home, concern over appearing weak or crazy, and hoping people did not notice anything was wrong. Another example of a label was “Support from others” and included data pieces such as help from family, provision of formal support services, advice from medical staff, information from those who had similar experiences, and practical help from friends. An example of how these data sets were formed is provided below in Figure 3. It provides details of three labelled data sets, including “keeping up appearances” as described above.

Figure 3

Example of Data Sets



I then began to move back and forth between the *comprehending* and *synthesising* processes of analysis as the interviews continued. Following the first four interviews, an entire supervision session was dedicated to sorting the labels across the interviews and establishing patterns between the labels within and between the interviews. My supervisors were able to challenge these patterns and suggest alternatives which helped inform the direction of future interviews. This iterative and constant comparative nature of data collection and analysis continued throughout. At the point of completing all interviews, I began to further manipulate the labelled data sets and group these to explore commonalities and variances, sorting and resorting until I became satisfied that the patterns across the interviews reflected participant experiences. Figures 4 and 5 (p. 57) demonstrate the first and final sorting that took place. Each piece of paper represents a label that was assigned to a set of data pieces within an interview, the different coloured text on the labels represents the interview from which that particular label emerged (e.g., all green labels are from the first interview and all purple labels from the second).

Figure 4 *First Sorting of the Labelled Data Sets*

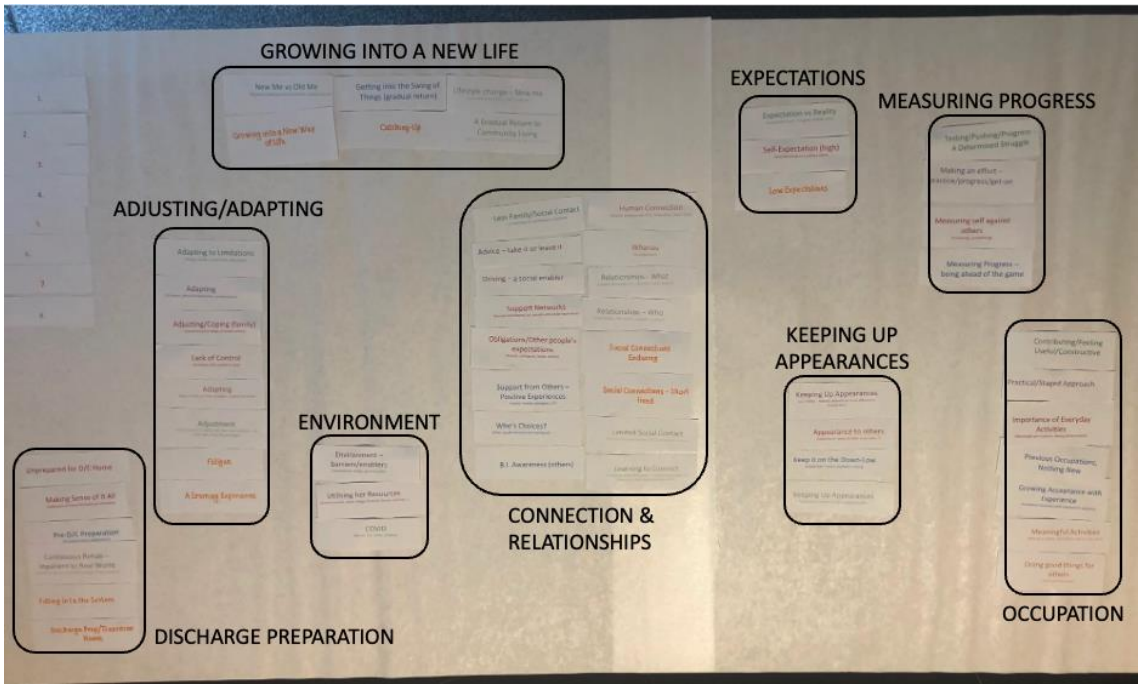
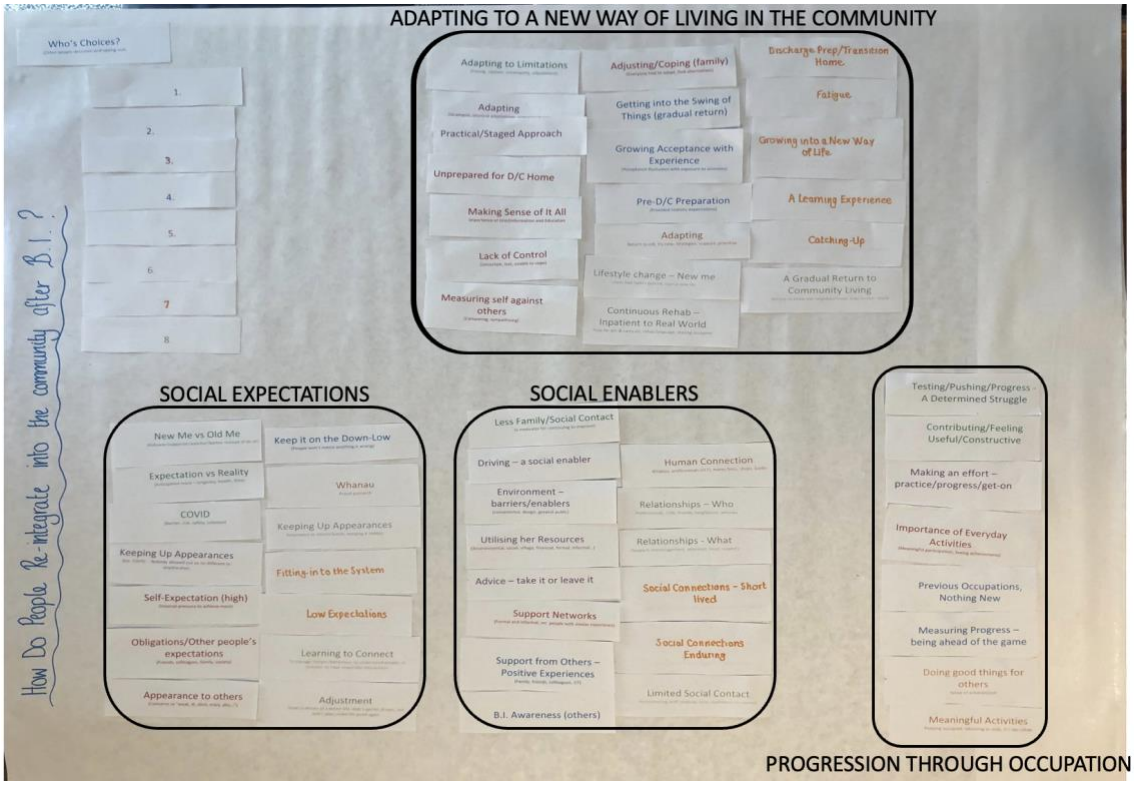


Figure 5 *Final Sorting of the Labelled Data Sets*



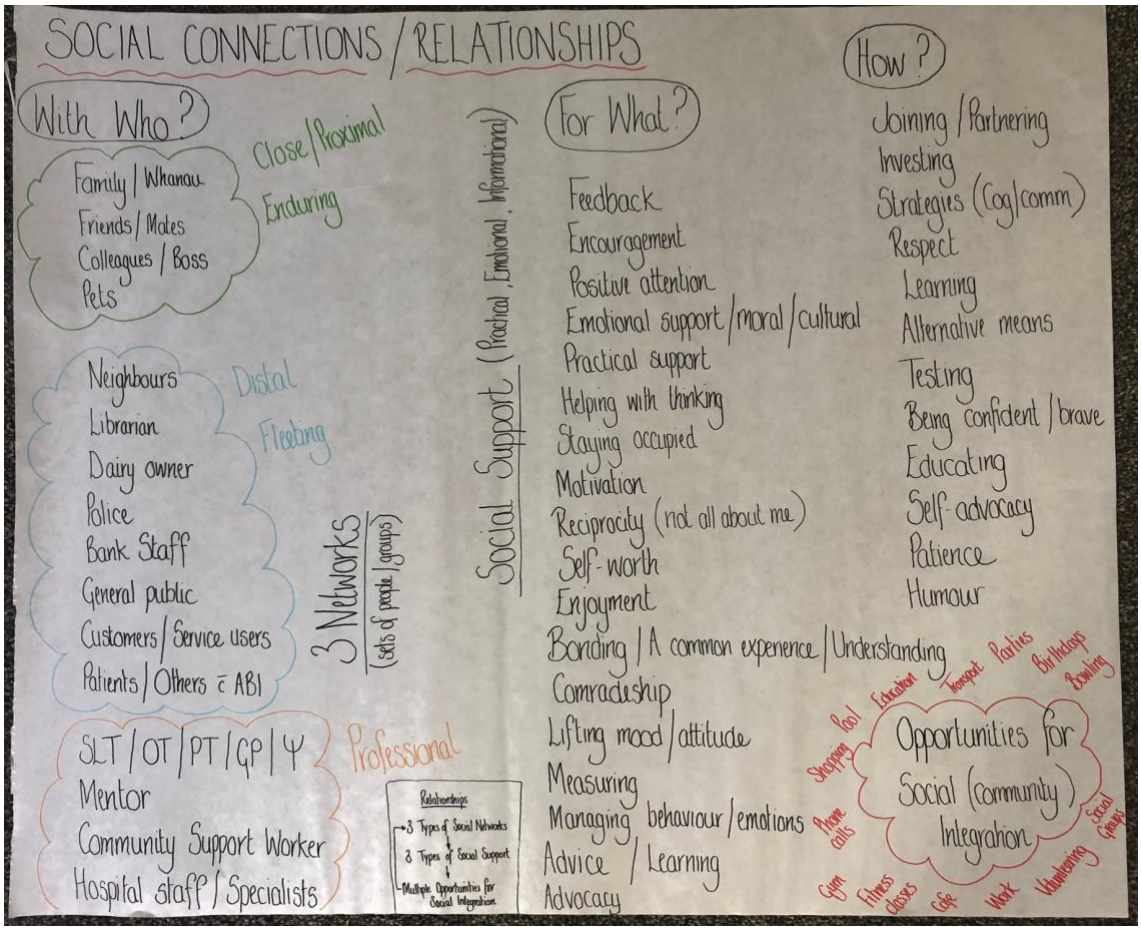
Each instance of the sorting and associations was photographed, added to power point, and shared with my supervisors during Zoom based supervision sessions so that, again, questions could be asked and my reasoning challenged, explored, and extended. As the figures above demonstrate, the associations became more defined through sorting, discarding, and resorting; ultimately reducing the number of initial groupings from nine to four.

Synthesising then began to merge into *theorising* and developing more considered theories about the associations made in the *synthesising* process. Each of the four groups that were established and represented in Figure 5 above were explored in depth, returning to initial interviews and seeking collateral data sources to expand these groups into themes that could then be articulated as findings. Thorne (2016) advocated that appropriate collateral data sources should be sought to expand the scope of an inquiry and broaden the reach of the sample without incurring excessive costs. Collateral data for this study included clinical papers, regional council policies, national clinical guidelines, and national health policies. As an example, a number of participants referred to driving as an enabler and having to seek alternative means to get around in the community. Therefore, Auckland Transport Accessibility Action Plan 2020-2022 was referred to for an understanding of future developments in transport provision for disabled people. These materials helped provide a testing ground for insights that were being developed during the theorising stage of data analysis. Figure 6 (p. 59) below provides an example of how one of the themes (initially called Social Connections/Relationships, and later (Re)Building Social Connections) was developed from the group "Social Enablers" established during the *synthesising* process (represented in the lower centre circle in Figure 5 above).

It was through this process of *theorising* that the theme "(Re)Building Social Connections", described in the findings sections that follow (see Chapter 5), was established, and the three components of this theme including social networks, social support, and social integration were realised.

Figure 6

Developing the Theme Social Connections/Relationships



The final process of data analysis, *reconceptualising*, took place during the process of writing my findings chapter and reviewing my writing through supervision. Some patterns, relationships, and explanations that had appeared clear in concept maps and memos required revision to better articulate them through writing. I also took the opportunity to informally present my four themes to colleagues working in the area of community rehabilitation to get their perspectives on whether the themes resonated with them. Thorne (2016) referred to this process as the 'thoughtful practitioner test', and it is described in more detail in the Ensuring Rigour section. During these discussions I was able to bring the theories I had been working on back to clinical practice and ground them in practical implications within the clinical context, consistent with the intentions of Interpretive Description (Thorne, 2016).

Ensuring Rigour

Attention to rigour and the reporting of that process is critical to an Interpretative Description study. The research process, particularly as it relates to the intersubjective construction of knowledge and the positioning of the researcher, must be transparent in the report; therefore,

the researcher must explicitly account for their influence upon the research findings as much as possible (Thorne, 2008).

Epistemological Integrity

Thorne (2016) described 'epistemological integrity' as "a defensible line of reasoning from the assumptions made about the nature of knowledge through to the methodological rules by which decisions about research process are explained" (p. 233). Through this methodology chapter I have provided details of my research process that demonstrate my epistemological standpoint and how it is consistent with my research question. The decisions for choosing the research approach and the subsequent sequential process of data analysis directly relate to this epistemological position. The interpretative strategies employed have been explained, which lead logically from the research question and result in findings that will be described in the sections that follow.

Interpretive Authority

Thorne (2016) described 'Interpretive authority' as an essential principle in ensuring the credibility of an Interpretive Descriptive study. Interpretive authority has been demonstrated in Chapter 1 where my personal and professional experiences were made transparent. These included my clinical experience as an occupational therapist working with people in various rehabilitation settings and my perspectives on the importance of promoting occupation to improve quality of life. Assumptions inherent in the research to date, such as the importance of independence versus interdependence within frameworks of community integration, were made apparent to the reader in Chapter 2. Creating this transparency has hopefully contributed to the reader's understanding of the potential influence these pre-existing ideas and knowledge may have on the questions asked and the methods sought to answer them. Thorne et al. (2004) highlighted the importance of external guidance to support the kind of disciplined reflexivity required to avoid clinging to assumptions or preventing premature closure of emerging conceptualisations. Throughout the course of the study, guidance was sought through regular sessions with my university supervisors who are experts in the use of qualitative research methods, including Interpretive Description. These supervisors also provided valuable feedback on the content and structure of written documentation as it was produced.

Analytic Logic

The credibility of findings derives largely from the way the specific analytic decisions are presented and contextualised within the larger picture. Thorne (2018) referred to "analytic

logic" (p. 234) as an audit trail that another researcher could follow. The theoretical scaffolding described above was the first stage in accounting for this analytic logic as it oriented the inquiry, provided a rationale for its anticipated boundaries, and made explicit the assumptions and preconceptions that drove the design decisions. The systematic analytical sequence of conceptualisation described in the data analysis section of this chapter provides the framework for the analytic logic that continued and led to the findings presented in the following chapters. The use of interview quotes within the Chapter 5 – Findings provides details of the analytic reasoning process to allow readers to follow the reasoning and judge the degree to which the analysis is grounded in the research data.

Representative Credibility

The theoretical claims made in the chapters that follow are consistent with the manner in which the community integration data collection was undertaken and the sample represented. An introduction to the participants is provided in the chapter that follows for the reader to understand the backgrounds and journeys of the participants, and provide additional context to the four key themes that are reported in the findings chapter. The clinical implications and broader discussion demonstrate that claims being made are not beyond the scope of the study that has been undertaken.

Member Reflections

Some qualitative researchers would advocate for member checking that takes the form of returning to the study participants to have them confirm that they have said what the researcher thinks they have said (Corbin & Strauss, 2008; Creswell, 2007). In contrast, Thorne (2016) believed this can lead to false confidence and potentially derail analytic interpretations. Instead of this traditional form of member checking, alternative options for 'sounding out' and reflecting on developing theories were used in the process of this study. As patterns began to emerge from the data analysis and particular relationships between participant experiences began to be generated, these were brought to research participants in later interviews for their critical consideration, creating opportunities for challenging and refining emergent theories. For example, when synthesising the data across the first four interviews, it became apparent that all participants were monitoring, testing, or measuring their progress towards community integration through the use of familiar daily activities. They were comparing what they were capable of post-ABI to how they performed previously and 'pushing' themselves to improve. This led to the interview schedule being adapted to incorporate additional questions about how participants were keeping track of their progress as they accomplished greater levels of integration back into their communities.

The best Interpretative Descriptions will pass what Thorne (2016) referred to as the "thoughtful practitioner test" (p. 93), in which those who have expert knowledge of the phenomenon find that the claims are plausible and confirmatory of 'clinical hunches', as well as illuminate new relationships and understandings. Bringing concepts that emerged from the study to colleagues and professionals working in the field of brain injury through in-services, workshops, and one-on-one conversations about the findings provided a context in which the findings could be tested and further refined. The additional presentations that were undertaken for clinicians due to the breaks in recruitment enforced by the COVID-19 response actually assisted in this process as the initial grouping of data pieces that had been established through the synthesis of four interviews could be discussed with experienced clinical teams.

Ethical Considerations

Ethical approval for this study was sought through the Auckland University of Technology Ethics Committee (AUTEC) and written approval was received on 11 November 2019 (Appendix I). Due to complications resulting from the COVID-19 restrictions limiting the initial recruitment strategies (as described in the data collection section above) an amendment to the original ethics application was submitted to AUTEC and approved on the 1 December 2020 (see Appendix J). This amendment requested approval to extend the recruitment strategy to include other organisations working with people in the early stages of their return home after in-patient rehabilitation and the use of electronic media for the recruitment and interview process. An amended version of the Participant Information Sheet can be seen in Appendix E. Despite these additional strategies to generate recruitment, no participants were recruited through the non-government organisations or community neuro-rehabilitation providers that were approached. None of the participants chose to utilise the remote electronic interviewing options, preferring to meet face-to-face. The ethical guidelines and procedures as outlined in the AUTEC Ethics Knowledge Base (2020) were followed and those that applied to this study are described below.

Informed and Voluntary Consent

Potential participants were informed of the study through the use of one of two information sheets (Appendices B and C). Clinicians made the decision as to which information sheet best met the needs of the potential participant based on their cultural preferences. As noted above, the study information was explained by the individual's clinician who then sought approval to provide the individual's contact details to the researcher using the Consent to Provide Details form (Appendix D) if they indicated an interest in finding out more. I then followed interested parties up with a phone call (lasting approximately 10-15 minutes) to have a conversation

about the research purpose and process, discuss what was involved, and ensure that the participant had understood and retained enough information about the study to make an informed decision on progressing to an interview. A template for this telephone conversation can be found in Appendix K. Formal consent for the interviews was gained in writing at the face-to-face meeting, prior to beginning any interviews. In anticipation of the nature of certain brain injury related impairments, there was also a plan for verbal consent to be captured through the audio recording prior to the interview commencing. This was never necessary as all participants were comfortable and capable of providing consent in writing.

Privacy and Confidentiality

Participants were informed that their identities and names of any places in the community that they discussed would be protected at all stages through the project. Any identifying information about the participant or the community that they discussed was removed from the transcripts and each participant was allocated a pseudonym. Information relating to the participants has been kept in locked cabinets in my home office or under password protected computer files. Signed permission to share details and consent forms have been stored separately from the data, in a locked cabinet. Audio files of interviews that were shared for the purposes of supervision were done so via password protected MS Teams, only available to my two supervisors and myself. No information that could identify an individual participant has been used within the report writing or in presentations that have been provided in relation to the project findings thus far. In addition, recruiting from two of the largest organisations for people with ABI and covering such a large geographical area assisted in maintaining the confidentiality of the participants and their stories.

Minimisation of Risk

During interviews I used my clinical observation skills to ensure that fatigue (a common symptom after brain injury) was being managed and not exacerbated. Two participants demonstrated these symptoms towards the end of their interview which were then drawn to a close and the participants encouraged to take a break and rest prior to commencing further activities. Some participants had already identified that fatigue may impact their interview so had rested prior to my arrival. For two participants, their brain injury had resulted in some challenging behaviours; therefore, my clinical skills and experience of working in brain injury were helpful and employed to monitor for any risk of escalation and maintain safety. As the data collection took place in the homes of participants there were a number of other safety considerations that needed to be taken into account. The AUT Centre for Person Centred Research (to which my supervisors are affiliated) has a safety protocol that has been accepted

by AUTEC for previous studies. This protocol was amended for the current study's specific circumstances prior to submitting my ethics approval (see Appendix L).

There was a possibility that reflecting on some of their experiences may cause distress to participants. If this issue arose it was to be managed through monitoring for any early signs of distress, and ensuring a support person was present should the participant require support. Although some participants shared intimate and detailed personal experiences of their struggles to progress within their communities, none showed signs of distress in disclosing this information. I was also prepared with my own skills of supporting people from previous clinical experience and with information about counselling and support organisations, these were never required.

As the data collection portion of this research began at a time when New Zealand was fluctuating between COVID-19 alert Levels, necessary precautions in relation to the pandemic were taken. At community alert levels 4 and 3, between 25 March and 13 May 2020, no face-to-face interviews were able to take place due to lockdown precautions, limited travel within the city, and the need for maintaining peoples' 'bubbles'. This was the case when Auckland returned to alert level 3 for a period of 3-weeks in August 2020, and again in February 2021. When Auckland returned to alert level 4 and 3 again from August 2021 through to October 2021, data collection and recruitment had to be drawn to a close. Data collection was able to proceed during alert level 2. On these occasions, precautions were followed consistent with those recommended through District Health Board and AUT procedures. In summary these involved screening an individual for potential risk prior to visiting, maintaining physical distancing, good hand and cough hygiene, mask wearing where physical distancing was unable to take place, and being responsible for my own health and ensuring I was not visiting participants at a time when I, myself, was unwell. There were two instances where I was identified as a close contact to someone who had tested positive and, on these occasions, interviews were postponed until I had clearance to leave home isolation. This unfortunately led to the loss of one participant.

Right to Withdraw

Participants were given the opportunity to withdraw from answering any particular questions during their interview or to withdraw from the study all together at any time. They were offered a choice of whether the data that had been provided up to the point of withdrawal was used or removed from the data pool. None of the participants chose to withdraw at any point.

Te Tiriti o Waitangi

The principles of Te Tiriti o Waitangi, as articulated by the Waitangi Tribunal (2019), provide a framework for how researchers meet their obligations under Te Tiriti in research endeavours. These principles and how they were applied to my study are as follows:

Tino Rangatiratanga: The guarantee of tino raratiratanga provides for Māori self-determination in the design and monitoring of the research process. If people identifying as Māori volunteered to participate in the study, I took steps to respect their values, practices, and beliefs through consultation with identified parties that serve the interests of Māori, including the Kaumatua for Counties Manukau Health and the Kaiārahi Kaupapa Māori for ABI Rehabilitation (the two organisations specifically targeted for the recruitment of participants). As part of these consultations the intended methods of data collection, appropriate materials and resources, appropriate language and description, and potential greetings that assisted in rapport building were discussed. Consultation with Kaumatua and Kaiārahi Kaupapa Māori provided me the opportunity to evaluate the language, description, resources, and materials used during the recruitment and data collection phases of the research and ensure these were inclusive to a range of populations/cultural/social groups. The Participant Information Sheet (Appendix C) is an example of documents that were adapted for Māori following consultation with the above individuals.

Options: Providing participant information designed in a culturally appropriate way (as described above) and observing Māori tikanga when visiting Māori participants in their own homes, recognised and supported the expression of Hauora Māori (Māori wellbeing) during the research process.

Active protection: The identification of participants was protected at all stages through the project. Each participant was allocated an ID number and a pseudonym. Information relating to the participants was kept secure as described earlier. No information that could identify an individual participant was used in report writing. During the COVID-19 response, explicit steps were put in place to minimise risk to participants from infection, as described above.

Partnership: In terms of the partnership perspective of study outcomes, this study provided an opportunity for the participants to tell their story from their perspective within a meaningful context, and do so in a way that limited the challenges of their cognitive or communication impairments. Participants were provided with a koha (gift) to acknowledge their contribution in the research project. The research outcomes have been designed to benefit people with ABI in that the range of potential findings could be used to inform future rehabilitation delivery,

formal and informal community supports, or community-based initiatives such as addressing attitudes and awareness of the general public towards those with ABI. The findings could also contribute to health policy at a national level through the provision of qualitative evidence of the perspectives of disabled people, and, therefore, influence health funding.

Equity: One of the aims of this study was to amplify the voices of those with ABI (including Māori participants) in the design and delivery of health services that promote community integration. The study participants were people with brain injury in the process of community reintegration following return home from an in-patient setting. They came from a range of social and cultural backgrounds, including Māori. Their principal involvement was one of sharing their experience. As this is an Interpretive Descriptive study, the iterative process of data collection and analysis ensured that the emerging themes were grounded in the data provided by the participants. As the concurrent data collection and analysis continued, and patterns began to emerge, these were brought to individual research participants in later interviews for their critical consideration, creating opportunities for challenging and refining findings. As far as research outcomes are concerned, it is anticipated that the findings will be used to add the voice and experiences of people with brain injury to future health service delivery and policy. In this way, study participants will have participated in shaping future service delivery.

Summary

In this chapter I have provided an overview of the Interpretive Descriptive methodology and how it was employed within the current study. An explanation of my initial grappling with qualitative approaches has been described with the rationale for the decision to adopt Interpretive Description as the methodology that best fits this project. The philosophical and theoretical underpinnings of Interpretive Description and how it relates particularly to the study aims have been discussed. The methods employed throughout the study for selecting participants, collecting and analysing data have been described, as well as ways in which rigour was maintained. Finally, the ethical considerations have been discussed.

The findings resulting from the data analysis strategies described above will be presented in the following chapters. An introduction to the participants is provided in the next section (Chapter 4) prior to presenting the findings themselves (Chapter 5). Chapter 4 aims to provide the reader with background for each participant with a short narrative describing their living situations, life roles, support networks, and the types of challenges experienced post-ABI as a result of specific impairments. This will assist the reader in contextualising the themes

presented in the findings chapter itself, and to better understand the experiences and quotes used to strengthen the description of themes and sub-themes.

Chapter 4: Introducing the Participants

In this chapter, I introduce the participants so as to provide additional context prior to presenting the findings in Chapter 5. To maintain confidentiality and avoid the chance of any 'deductive disclosure' (Tolich, 2004), certain participant characteristics have been altered but the context, background, and situation of each individual description continues to provide important insights into the similarities and diversities of experiences that will become evident in the following findings chapter.

Table 5 provides basic demographic details of the participants, including their gender, approximate age, social situation, and employment status prior to their ABI. Also included is the timeframe since discharge from in-patient rehabilitation as an indicator of how long they have been living in the community and attempting to reintegrate. Pseudonyms have been used to further maintain confidentiality. The pseudonyms chosen reflect the ethnicity of the participant with names that are popular for their particular ethnic group. In addition to the information provided in Table 5, a short narrative for each participant is provided. This narrative provides background such as life roles and living situations, and the types of challenges experienced post-ABI as a result of physical, cognitive, communication, sensory, psychological, and behavioural impairments. The formal and informal supports being received in the community are also outlined.

Table 5

Participant Demographics

Gender	Pseudonym	Age	Ethnicity	Social Situation	Location	Employment	Type of ABI	Time since discharge
M	Charles	80s	Euro NZ*	Lived with wife in own home. Children in NZ and Australia. No formal support.	Suburban	Volunteer	Bilateral Stroke	5 months
F	Vera	70s	Euro NZ	Lived in a serviced apartment in a retirement village. No direct family.	Semi-rural	Retired	Stroke	4 months
F	Angela	40s	South African	Lived with husband and sons in own home. Extended family in South Africa.	Suburban	Full-time	Stroke	10 weeks
M	Andrew	20s	Euro NZ	Lived with parents and brother in family home.	Suburban	Student, part-time employment	TBI	3 months
M	Matiu	50s	Māori	Lived with wife, son, and daughter-in-law.	Suburban	Full-time+ (60 hour/wk)	Stroke	6 months
M	Rangi	50s	Māori	Lived in a lodge, no whānau in Auckland.	Suburban	Unemployed	TBI	2 months
M	Patrick	60s	Euro NZ	Lived with wife and daughters in rental home	Suburban	Part-time	Stroke	5 weeks
M	Salesi	50s	Tongan	Lived in shared, supported accommodation.	Urban	Unemployed	TBI	10 weeks

* Euro NZ = European New Zealander

Participant 1: Charles

Charles was an older gentleman who, at the time of his interview, was 5-months post hospital discharge and living back at home with his wife. His wife was still working part-time and had a busy social life; therefore, Charles' initial concern on his return home was to be as independent as he could around the home so he did not have to be a "burden" to his wife and rely on her for assistance with everyday activities. Charles portrayed himself as a man who liked to "contribute" and feel "of value". This was demonstrated through his career in public services and his voluntary work, which had stopped since his stroke. Prior to the stroke he described himself as a fit and healthy man who enjoyed participating in a range of active sports, including skiing; and would travel frequently to visit his family in various parts of New Zealand and Australia.

Following his stroke and return home, Charles had struggled with reduced balance, poor memory and concentration, visual changes, upper limb weakness, mild aphasia, and fatigue. He had found even simple tasks that he would have previously enjoyed, such as reading, difficult on his return home due to trouble with tiring easily, concentrating, and "working out the words". Charles had received support from a community rehabilitation team in the initial weeks at home but no longer received visits from this team. He was managing his own recovery, taking on the recommendations that the team had provided.

Participant 2: Vera

Vera was a retired lady living in a serviced apartment in a retirement village. She had moved there a number of years prior after starting to struggle in her own home. Her decision to move to a retirement village was a pragmatic one as it enabled her the opportunity to live independently in her apartment as long as possible, with the option to move to higher levels of assisted living as needed. She was interviewed 4-months following discharge from in-patient rehabilitation. She described herself as having taken a very "practical" approach to entering back into her everyday life, starting off with mastering small but essential daily activities and then building up to more complex community-based activities. Although Vera did not have family living close by, she had a number of close friends within her retirement village, as well as services available to her such as private buses to take village residents to and from the supermarket. The retirement village also offered organised social groups that she had attended on a frequent basis prior to her stroke,.

On her return home Vera reported she was struggling with her dominant upper limb movement and reduced mobility, resulting in her being reliant on a walking frame. She also

had difficulty with eating and drinking, sometimes spilling her food which she found distressing as taking meals with friends was something she had previously enjoyed but felt unable to participate in until she became "more civilised". Fatigue was also impacting Vera and she described feeling "lethargic" after even the simplest of tasks, although this had been improving over time. Vera had initially received home care support for her personal care but had worked to improve her independence so was no longer reliant on this support. She was continuing to receive input from a physiotherapist and occupational therapist who visited once every couple of weeks.

Participant 3: Angela

Angela spent only 10-days in the in-patient setting, the shortest in-patient duration of all participants. Angela's interview took place 10-weeks following her return home. She was living back at home with her family and had tried to return to her role as a mother, without any modification, as soon as she had been discharged from hospital. Angela reported feeling angry and frustrated with her inability to return to her previous level of function. She had high expectations of herself and viewed others such as family, colleagues, and friends as having similar expectations. She viewed herself as the "helper" not the "helped". Prior to her stroke she led a very active life looking after her family, being a mother, home maker, working full-time hours in a highly stressful environment, and teaching exercise classes at the weekends and in the evenings.

At the time of the interview Angela was coming to terms with her change in function, although continued to expect high achievements over time. Fatigue and generalised weakness were her main concerns. She was grateful for the support she had received from family, friends, and colleagues as she began to adapt her lifestyle to meet her needs. She also praised the intervention she had received from the health professionals who supported her at home post-discharge which included input from a physiotherapist, occupational therapist, and psychologist. These professionals had provided her with education that she felt she had missed out on in the in-patient setting due to her short stay. They also provided practical advice and strategies to manage the daily activities that were important to her, and helped her to find coping strategies to manage her frustration and anger.

Participant 4: Andrew

Andrew was a young man who was soon to turn 20 when he was interviewed at his parents' home, 3-months after leaving the in-patient rehabilitation setting. Andrew had sustained a TBI while riding his motorcycle. His motorcycle was clearly one of his passions and he was planning

to return to riding as soon as he was able. Andrew denied any specific residual impairments as a result of his injury, but through his description of the 3-months prior to the interview, it became apparent that a number of difficulties had arisen on his return home including slowed cognitive processing, visual disturbances, generalised weakness, and reduced balance and self-awareness. Some of Andrew's descriptions of his abilities since returning home seemed inconsistent with his plans for the near future. He was engaging in a return-to-work programme through which he had identified difficulties with cognition that he was finding strategies to manage. However, these strategies did not appear to factor into his plan to return to driving or university study.

Andrew had initially received support from his parents with basic activities of daily living, and had tried to contribute to more complex household tasks such as constructing flat pack furniture, with varying degrees of success. He was receiving formal support from an occupational therapist on a weekly basis to assist him with a graduated return to work.

Participant 5: Matiu

Matiu was interviewed at home surrounded by three generations of his whānau, nearly 6-months after leaving the in-patient setting. His position as the patriarch of an extended whānau was clear in his discussions regarding his previous roles as a father, mentor, brother, support person for close mates, and spokesperson at local hui. He was very proud of his wife and all her achievements, as well as his children and grandchildren. He had engaged himself in meaningful activities since returning home that gave him a sense of purpose. These included carving gifts for members of the whānau; looking after the garden; and maintaining the car, boat, and trailer. He took pride in showing me around his garden and workshop, and demonstrating his progress on various projects.

Matiu's primary challenge on returning home was his communication. He described great difficulty and focused effort over recent months to manage successful communication with bank staff, shop keepers, whānau, mates, police, and multiple others. He received support from a speech language therapist in his initial few months at home and spoke very fondly of the relationship he had built with her. He valued her encouragement to participate in communication tasks that were of importance to him and willingness to participate alongside him when he began to feel "foolish". Although this formal support had come to an end well before the interview took place, Matiu was still utilising strategies that had been recommended and had generalised these into new, more complex situations.

Participant 6: Rangi

Rangi had been living in shared accommodation for a number of years prior to his ABI and had returned to this setting 2-months prior to his interview. He knew his neighbours very well and referred to some of them as his mates. It was while helping one of these elderly neighbours that he sustained his brain injury, falling from a height. He had been unemployed at the time of his injury but spoke at length, and with pride, about previous heavy manual jobs where he had been promoted and earned the trust of his employers through his hard work. Rangi appeared very loyal to his friends and extended whānau, and since his discharge back home he had been trying to help out friends and whānau members who had "got themselves into trouble". The interview had been rescheduled on two occasions as he had been out of the city at short notice to help his whānau. Rangi had a history of heavy drinking and gang affiliation but explained that since his injury and in-patient rehabilitation he was now steering away from that and "beginning a new life".

Following his return home, Rangi continued to experience challenges with his higher-level balance, generalised weakness, cognitive processing speed, and social communication. He was determined to maintain the positive life habits that he had learned during rehabilitation such as healthy eating and abstaining from alcohol. Although he was not receiving any formal rehabilitation services such as physiotherapy, he continued to apply the "protocols" and "regime" that he had learned while in the in-patient setting to his daily routine, incorporating regular walks, exercise, gym workouts, meal planning, and reading into his schedule. Rangi was receiving community support from a Māori support provider, which consisted of an age matched Māori support worker who visited two to three times a week and helped Rangi work towards goals like learning computer skills.

Participant 7: Patrick

Patrick's interview took place at his family home approximately one month after his discharge from in-patient rehabilitation. Both his wife and daughter were out at work at the time. The family were in the process of packing up their house in preparation to move to a new home a few suburbs away. Patrick was a very spiritual man who had strong links to his religious roots. He had recently retired from a part-time role that required a significant amount of communication skills and empathy for others. He had some plans to return to a few elements of his previous role but for now this was "on hold" until he recovered and got the house move over with. Throughout his interview Patrick talked about the isolation and loneliness that he felt following his stroke and the importance of "comradery" to his recovery.

Patrick's stroke had resulted in reduced balance, right sided weakness, sensitivity to light and noise, double vision, dizziness, and fatigue—all of which continued to impact on his ability to function independently on his return home. He initially required supervision while walking around indoors and carrying out his personal care activities. This had now improved and he was "pottering" around the house helping out with some of the packing when everyone was out at work. Patrick had limited experience of being out in the community as he was being cautious not to try and do too much too quickly. He had been out with his family in the car a few times, mostly to visit family, had visited the home that he was moving to, and had met with mates in cafes on a couple of occasions.

Participant 8: Salesi

Salesi was living a transient lifestyle prior to his brain injury, with no fixed abode. He had very little natural support other than a nephew whom he had reconnected with during his time in rehabilitation. Salesi valued his Pacific heritage and described a conservative religious upbringing in Tonga prior to moving to New Zealand when he was young. Salesi was living in a supported transitional housing situation when he was interviewed. This housing was in an area of the city that he was unfamiliar with. He had been exploring the local neighbourhood over the previous weeks and was now beginning to use public transport to venture further afield to local shopping malls.

Although he had recovered well from a physical perspective, Salesi's ongoing behavioural issues were his main concern following his brain injury. He described difficulty managing his temper and being quick to anger when he thought that people were being "ugly" or had a "bad heart". This had been particularly challenging for him in recent community outings where he experienced noisy groups of teenagers on the bus and people being impolite in the shops. Salesi was continuing to receive regular input from occupational therapy and psychology to assist him with his community reintegration, social communication, and behavioural management.

Chapter 5: Findings

Introduction

The aim of this study was to explore the experiences of people with ABI as they returned home and began their integration into their communities. The research question asked, "How do people with brain injury reintegrate into their communities following in-patient rehabilitation?". The findings revealed that reintegration is an ongoing journey that can be reflected in four interconnected themes:

1. Growing into a new way of community living
2. Living up to expectations
3. (Re)Building social connections
4. Engaging in meaningful occupations

In the following sections, these four themes are discussed separately. However, in people's everyday experiences, they do not stand alone. Therefore, a final section will describe the relationships between them. To assist the reader in forming a picture of each theme, a visual representation has been produced and will feature at the beginning of each section (see Figures 7-10).

Theme 1: Growing into a New Way of Community Living

Overview

This theme illustrates a process of growth as participants endeavoured to reintegrate back into their home and community lives. Although the actual term "growing" was only used by one participant (Patrick) in the study, I settled on this framing as the term encapsulated several other expressions used by participants as they discussed their "development", "adaptation", "learning", "progress", and "movement" towards community integration.

Underpinning the process of growth was the sense of temporality, with growth happening as people moved through stages of recovery and integration. People moved from the early phases of taking their first steps into home and community life (e.g., overnight leave prior to hospital discharge, practice trips from the rehabilitation unit to the supermarket), through to the initial period of being back at home and making sense of what they were now able to do (and not do) when compared to pre-ABI. They then moved into a phase of settling back into their home life and managing to tackle day-to-day tasks more confidently, before venturing further afield into their communities only to find them busy, noisy, and tiring. Participants'

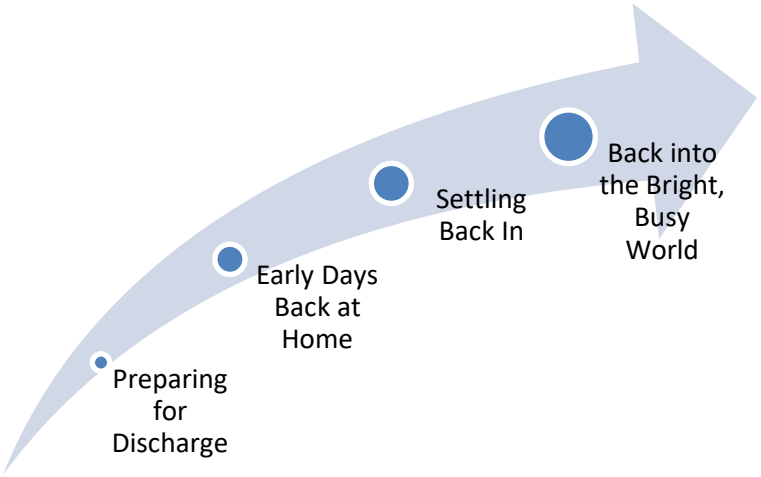
stories conveyed the adjustment and coping that took place during these stages of growth—both for the person with ABI and those around them who also had to adapt to new ways of doing things. Some took this as a practical and staged process of integration, while others saw it as a continuation of their rehabilitation, taking their learning from their formal rehabilitation out into the community with them. Others found the limitations on their abilities frustrating and felt unprepared to deal with the challenges.

Four phases became evident in participants' stories about *Growing into a new way of community living,* as depicted in Figure 7. These four phases were relatively fluid and dynamic but are described separately to help structure this findings section and included:

1. Preparing for discharge
2. Early days back at home
3. Settling back in
4. Back into the bright and busy world

Figure 7

Growing into a New Way of Community Living



Each phase builds on the previous, with the degree of integration increasing, as represented by the blue dots increasing in size and the arrow becoming larger as it curves upwards. Below, I explore each of these phases and explain the practical and emotional experiences of the participants. Participant quotes are used throughout to illustrate particular experiences and feelings. These quotes are referenced by the page and line number from the interview transcript from which they were taken.

Preparing for Discharge

Participants identified that they began their transition back into the community before leaving the in-patient environments where they were receiving rehabilitation. Most participants had activities relating to living in the community and their own homes integrated into their rehabilitation programme, including the trial and practice of functional skills they would need once at home and out in the community. These skills included car transfers, negotiating flights of stairs, practice of self-care tasks in an environment set-up similar to the home environment, and manoeuvring with a walking aid within a confined space as they would do within their home. In some cases, home visits were undertaken to assess their ability to manage within and around the home environment.

> *I would practice going up and down the stairs to make myself stronger. I knew as soon as I could get up and down, I could go home*. [Matiu, 1:20]

> *I went home over night on the Saturday-Sunday. That was, sort of, I was built up to that by the team, by [name of physio], by the OT [occupational therapist], they came into the shower to make sure I could stand in the shower, checked that out, they talked about the pill regime, all that stuff. Then… um, they said take home a wheelchair, [name of physio] showed me how to get in and out of the car, from the wheelchair.* [Patrick, 4:31]

Some participants also took part in more complex community-based tasks relevant to their life roles that were arranged by members of their rehabilitation teams, such as occupational therapists. These activities were aimed at assisting them to prepare for living back in the community by trialling adaptations to task performance or re-learning essential skills. Examples included cooking meals for themselves, undertaking a weekly shopping trip at a local supermarket, taking a walk to the library, and accessing the IT resources. These activities were described by participants as helping them prepare for the "real world".

> *I would go down to the library and I got me a card and I started looking through the book shelves and they [occupational therapist] helped me get all this stuff going, and they would keep encouraging me… I was getting my independence and I was just able to carry it on when I get back into the real world and start my new life.* [Rangi, 13:13]

Where available, and relevant to the discharge destination, trials of living independently in a pre-discharge unit that were set up in a similar way to being at home, were also taken advantage of. This was the case for Andrew who stayed in such a unit in the weeks prior to his discharge. He described becoming independent in all his personal daily living activities so he could be confident he would manage when he returned home.

> *I moved into one of those little self-contained apartment type things… so before I left it was pretty much just me, pretty much the same as it is here [at home] in terms of like washing, bathing, clothing choices and stuff, I've been fine on my own.* [Andrew, 3:1]

Some participants took it upon themselves to arrange their own time outside of the rehabilitation environment, such as asking friends and family to take them out to nearby cafes, so they could get a sense of life outside the in-patient setting.

> *I had a couple of mates that came to see me and we went one day down to a coffee place that is sort of in the middle of the hospital and that was nice.* [Patrick, 3:29]

These experiences of community access, prior to discharge from in-patient rehabilitation, provided some participants with confidence that they were prepared for living back at home and in their community. It also helped to manage expectations of what they would be able to achieve.

> *I was ready to go, yup. They [the rehab team] knew I was ready to go too but it was up to me to discharge myself… I felt prepared.* [Rangi, 10:1]

> *I wasn't thinking like, I'm going to come home and then I'll be straight back into it, back to work, building things. I don't know, I guess I just thought it would be what it was. I was pretty open minded about things so I suppose it met my expectations.* [Andrew, 9:31]

However, when describing the initial steps and experiences of community integration, some participants used descriptive language that indicated a struggle of returning to community life with a change in functional abilities. They detailed a range of emotions that included feeling "crushed", "useless", "frustrated", "frightened", "worthless", "embarrassed", or a "burden" on others. This was particularly the case for participants who used adaptive aids or required assistance to manage their mobility.

> *I didn't marry her [wife] to be a burden. I married her to be contributive and I was feeling that I was a bit of a burden, not that she minds, that is not the issue, but I was feeling like I'd like to be able to be more constructive, be able to contribute.* [Charles, 3:3]

> *That was nice [to be out of the hospital] but I was in the wheelchair again and I was like, urgh, yeah, I don't really like being looked at, it's embarrassing!* [Patrick, 3:31]

> *Walking with other people, I got a bit frustrated, like 'oh god do you have to be there!'. I didn't show it really, but I felt it. I was frightened that I was going to fall so there was that fear too*. [Patrick, 8:3]

Despite these feelings of uncertainty, frustration, low mood, and self-doubt, some participants noted there was little focus on their emotional or spiritual wellbeing in their preparation for discharge. The health care professionals around them seemed far more focused on the practical aspects of managing once they left the structured and supportive environment of the in-patient setting. Participants reported being aware that their health professionals were under pressure to manage their workloads and therefore did not seek support of this nature from them. Rather, they looked to other sources for emotional support such as fellow patients. Patrick described this as "comradeship".

> *The nurses run for the 8-hours that they are on. All they are worried about is getting the pills, getting the care, getting the shit cleaned up, and then they go home and they are exhausted… a place like that needs some pastoral care… I'm not talking about the spiritual stuff, but noticing the loneliness, noticing the tears, noticing someone a bit alone. There is not time for it with the staff.* [Patrick, 16:5]

> *I just got chatting to them [other patients in the room] and we actually established a great little bond. We had a lot of fun, we had a lot of laughs… we would egg each other on, sort of say "good on you".* [Patrick, 2:28]

Not all participants felt prepared for discharge and life in the real world. Angela, who only had a short in-patient stay (about a week), did not get the opportunity to experience community-based activities with the support of the rehabilitation team. She was given some verbal advice and then discharged home. This lack of preparation was clear in her interview. She felt she had no understanding of the impacts her stroke would have on her ability to manage her usual daily tasks.

> *I didn't actually realise the size… or… I don't really know what it's called but the size of the matter. The importance of what actually has happened, the impact the stroke had on me, I didn't realise.* [Angela, 4:21]

Angela returned to living at home and attempted to continue to carry out her daily activities as she would have done pre-ABI. She found that things were difficult, yet had minimal understanding as to why this was, until she was contacted by community rehabilitation professionals a week after returning home.

> *I just didn't understand, no one at hospital explained to me what happened to me. Like [name of community physio] said to me, "you have had a brain injury, things are going to be slower for you, you are going to be tired." Nobody told me that until I actually spoke to them.* [Angela, 4:34]

> *No one said to me, "no exercise, no walking very far, just resting, being at home, doing nothing" but at the same time I wanted to prove to myself that I could do all of those things*. [Angela, 8:33]

Her situation was not helped by receiving information that appeared inaccurate prior to discharge, which caused confusion about what she should and should not be capable of doing when she returned home.

> *I asked the doctor, I said "Am I able to drive?" and he said "yes". The Saturday I took my kids to [name of theme park], driving, and I was so tired! I had all of their friends in the car and everything. Then on the Tuesday I get a call from [name of Community Stroke Team contact] who says to me "you are not meant to be driving for 6-weeks". No one told me this, and that was SO bad!* [Angela, 3:16]

In general, those participants who stayed longer in the in-patient setting and were provided with greater exposure and opportunities to practice meaningful community-based activities felt more prepared for their return home. Despite this, they perceived that the focus was predominantly on the practical aspects of coping in the community, not the psychological or social aspects. Those participants who did not have opportunities to experience home and community activities, or were not coached through the changes they may encounter once discharged, were not as prepared and felt confused and abandoned on their return home.

Early Days Back at Home

Participants took two different approaches during their first few days and weeks back at home. One group took a practical graded approach to returning to their previous activities by starting with those tasks they had worked on in rehabilitation and gradually adding additional demands. Conversely, a second group attempted to make sense of what they were capable of achieving by starting with complex or lengthy activities, experiencing challenges, and having to revise what they were capable of.

Participants in the former group described trying to "start simple" and "get back to the basics". They started with whatever activities they had been working on while in the in-patient setting, ensuring they mastered these within their home or local community context, and building on the progress made. They took a practical and staged approach to their return to day-to-day activities, knowing that they would gradually build themselves up to more complex tasks over time. These individuals started with engaging in activities they considered more sedentary or straight forward, activities where they could make a small contribution to others, or tasks that were essential for managing their affairs. Andrew and Salesi described some of the more sedentary activities they started out doing at home.

> *It was just like getting back into the swing of things again I guess around here. Doing pretty much nothing, like doing this [indicating sitting on the sofa and chatting*]. [Andrew, 2:4]

> *I didn't do much, mostly stayed by myself quietly, listened to the radio and watching TV. I felt I am going to get into some trouble going outside then I just stay in my room, listen to my radio. Sometimes I used the phone*. [Salesi, 8:4]

Charles and Matiu provide examples of activities undertaken where they could contribute some assistance to others but were not solely responsible. These individuals discussed assisting family members with their work in the garden as they showed me around and pointed out what they had been doing since their return home.

> *There's a shed there and my compost bins are there. I've got three for the lawn clippings and her [wife's] garden things. We mulch it up and I put it in there and then she spreads it around the garden, so she has got a good garden.* [Charles, 8:11]

> *I do enough around the house to keep myself occupied you know. I do my lawns and my gardens and even fixing the trailer, you know, doing things like that to help out… so, yeah, our garden is looking mint!* [Matiu, 6:14]

Skills that were essential for managing their affairs included managing the finances. Vera had repetitively practiced writing her signature until she felt it had returned to its previous standard and she could sign banking documents.

> *As you can see, I've done a whole pile of writing my signatures there [pointing to pieces of paper with multiple attempts at signing her name] … there were things I needed to get signed*. [Vera, 2:9]

Within this first group who focused on "starting simple", there were those that required support from others with their basic personal or household tasks. These individuals focused on improving their performance in these activities so they could reduce their dependence on others or on adaptive equipment. Vera was receiving home care support services and wanted to reduce her need for these so practiced "things like combing my hair and cleaning my teeth and that sort of thing". Andrew preferred the idea of not having to rely on his parents to help him in the bathroom.

> *My parents, out of precaution I suppose, told me "if you shower, don't lock the bathroom door, if you fall over we need to come and help you". So, I didn't lock the bathroom door but I didn't fall over so it's going well so far*. [Andrew, 2:27]

The second group took a different approach to the participants described above. Instead of a practical staged return to home and community, they attempted to make sense of what they were capable of achieving by undertaking more complex or lengthy activities, including trying to return to work. However, in doing so, they discovered they were unable to perform to the same degree as they had previously or complete the tasks successfully. After experiencing failure to some degree, they then took a step back and returned to more simple activities. Angela was the most prominent example of this, likely due to her lack of experience in undertaking a supported return to community-based tasks while an in-patient, as described in the section above.

> *I took a 5km walk that morning after I came home from the hospital. My husband was like [gesturing using a telephone] "where are you?" and I was like "oh, I'm at the coffee shop up in [name of suburb]". So, he was like "what are you doing?" and I was like "I just came for a walk" and then I told the physio and she was like "What!"* [Angela, 8:28]

> *I felt this urgency to go back to work because, yeah, because I'd been out of work obviously since I went into hospital so I had a week and then thought, ah I should probably go back*. [Angela, 5:10]

Regardless of the approach taken, participants across the two groups felt frustrated by the need to keep things simple and not return directly to their previous roles and responsibilities. During their attempts at daily tasks, participants felt they had to take things slowly and cautiously. When describing their early attempts at practical activities during this phase of community integration, they used language such as "cautious", "patient", "anxious", and "careful".

> *Frustrating that I can't do everything that I used to do, and even moving around is a lot slower, and I get frustrated with that. [Vera, 7:31]*

> *The hardest one was the phone when people would say "ah, you have some bills" and then would want to give my bills over the phone and I couldn't um say what I wanted to say and I'd be getting all anxious*. [Matiu, 4:17]

Emotions at this early stage of community integration were varied, with all participants describing positive feelings of excitement for being home, surprise at what they were able to manage, and viewing their return as an opportunity to "start a new life" (Rangi). Conversely, when expectations of their return to pre-ABI functioning were slower than they anticipated, they described feeling a "lack of control" and the "struggles" that they had to go through. Angela described feeling like a "loser" a number of times as she attempted to take back some control over her ability to function within the home. The following quotes from Charles

demonstrate the complex multiplicity of emotional responses that people held at one time: his determination to get through the early process of recovery and his co-existing fear of being a "nuisance" and a burden to others.

> *I want to be able to say, "ok I've got this problem but I am going to deal to it as much as I can" and I will carry on doing so. I want to get back to as normal a life as I possibly can. It's been a long slow process. It's been longer and slower than I thought it was going to be. This type of thing is demanding, it wasn't easy to do.* [Charles, 12:22]

> *I haven't gone back up there [voluntary job] because I wish I was going there for a reason not just having a cup of coffee and walking away. I've pulled away from that, not because I want to but I think psychologically I feel as though if I was there, I'd likely be a nuisance, I don't want to be a nuisance, you know what I mean*. [Charles, 5:28]

Both these emotional responses had an impact on Charles' ability to move forwards in his community integration.

As they discussed this early phase of integration back into their home and community lives, there was a general sense that participants were having to catch up on life. It appeared to participants that others close to them had moved on and they had not been part of this journey. They felt things had been suspended for them while the rest of the world had kept on moving. As an example, Patrick felt his life had been "on hold" and he felt "like I was fitting back into their lives again, because my life sort of stopped, theirs had moved on".

Participants found multiple ways to cope with this range of emotions, including keeping themselves occupied with activities that were relatively straight forward so they did not dwell on negative thoughts. More on this use of day-to-day occupations to distract from negative emotions is described in the fourth section of this chapter, under the theme *Engaging in meaningful occupations.* Other coping strategies included engaging in a process of learning about their new functional status and adapting tasks to minimise the limitations they experienced as a result of their impairment.

> *The OT made me some little hand grips to go on the knives and forks so I could grip them better but I've discarded those now just because I don't need them anymore, it's just things like peas that get away from me now and soup is not the best either. I'm alright with that as long as I don't fill the spoon too full.* [Vera, 1:15]

> *Finding what works, and how long I have to do it for is just another thing that I have needed to figure out, but we are getting there.* [Angela, 6:30]

> *I do carvings out there… I dropped everything out of this hand. It was useless. Like, I'd be holding on to stuff and it would drop on the ground so I used my mallet with that hand to give it more strength… It was real good. Still a little slow, but way better than before.* [Matiu, 7:5]

Participants found that if they persevered with learning, practice, and adaptation they got to experience a sense of success and achievement.

> *I made lasagne, I made roast potatoes, all sorts of stuff and I felt great. It felt so good getting back into cooking dinner for the family*. [Angela, 20:23]

For the five participants who lived with family members (Charles, Angela, Andrew, Matiu, and Patrick), this need for adaptation was supported by the close family members who helped out or found new ways of managing the daily activities that would normally have been performed by the participants.

> *My son comes up and he splits it [fire wood]. I used to but I don't now, I'm not stupid.* [Charles, 8:29]

> *Because I worked up the road from the train station I would take [two sons] with me in the morning, drop them at the train station and then go to work and that. They have to jump on the bus now, jump on the bus and all those things. That was really good because they understood why it needed to happen and from that point on I realised it's actually working out pretty well.* [Angela, 5:30]

Most participants were receiving community-based rehabilitation during their *early days back at home* from a range of professionals, dependent on their needs. The advice and support provided by these different professionals were perceived to be beneficial in terms of educating them about brain injury recovery in general; managing specific deficits such as fatigue, weakness, and communication; and coaching them through progressions in their functional recovery. Psychosocial support from these professionals, in addition to the practical guidance, was also important to the participants at this early stage of their community integration. The professionals provided motivation, encouragement, and reassurance that they were progressing as expected and would continue to do so. The advice from professionals also assisted participants in adjusting coping strategies they had trialled but found to be unhelpful. This practical, informational and emotional support from the rehabilitation professionals is explored in more detail in the *Professional Networks* section of Theme 3 *(Re)Building Social Connections*.

One participant (Rangi) did not receive formal rehabilitation or support services during this early point in his community integration journey. These services were provided later. He took

the lessons learned from his in-patient rehabilitation stay and maintained these over this time, even going as far as referring to his routine as a "protocol". He continued a daily physical exercise regime which he referred to as his "physio", undertook a weekly shopping trip similar to the one he had learned while on outings with his occupational therapist, and focused on a healthy diet of "brain food" instead of returning to the diet he had prior to his ABI.

> *I hardly get take-aways any more, yeah, I just do with the old protein and the stuff for lunch, like I'll make egg salads, you know, or a good healthy lunch. A healthy lunch and a healthy tea, more vitamins for me, to keep me moving around properly and that, all good brain food.* [Rangi, 14:30]

The early days back at home were a complex time in the integration process for participants. This period involved a combination of determination and struggle. Some participants took a practical and staged view of what they would be capable of achieving and paced their return to more complex community tasks. Others tried to dive straight into the more complex tasks and had to revert back to something simpler when they did not perform well. Regardless of the approach, emotions ran high during this phase as the realisation of what they were now capable of became apparent. Participants began to find a range of coping strategies to help them move forward and continue to progress into the next phase of *Settling back in.*

Settling Back In

As participants continued their journey of community reintegration, they transitioned from the struggles of the *Early days back at home* to a point where they began to feel more settled and natural completing their basic daily tasks around the home and local neighbourhood. They had a better understanding of their limitations, such as when they might become "too wobbly" (Patrick) or "(not) able to concentrate to any great extent" (Charles). They knew what they could achieve and felt things had become less of a conscious effort and more automatic.

> *I sort of feel normal again, I'm sort of with it. I'm not worried about if I am going to fall over or thinking oh god I've got to walk again. That was hard in the beginning, you almost had to will yourself. It's much more natural sort of thing now.* [Patrick, 11:24]

Having experienced a range of activities within the home and community settings over their initial few weeks post-discharge, the participants had gained insights into their capabilities and awareness of what adaptations could work for them. There was a sense of acceptance of their current function, but this was accompanied by trials of adjustments to their current situation and finding additional ways of accommodating their limitations in ways that allowed them to prioritise what is important.

> *I'm limited in my ability to maintain, as I say, continuity of thinking and action, er, for instance I go out and do the gardening for a quarter of an hour and then come back in for a breather for half an hour, three quarters of an hour, and then I go back out again, once I've got my steam back up.* [Charles, 1:21]

> *It's a massive, massive lifestyle change. It's like, I'm not sitting at a cricket game for 4-hours because I have to be there. It's okay to drop him [son] off and then come back home. It is okay to ask someone to pick him up and then go for a massage. It's okay to do that, whereas I would never have done that before, I would have never done it. I would take myself and I would sit there for 4-hours and then bring him back.* [Angela, 13:30]

At this stage, participants often compared pre-ABI abilities and their new level of ability as they mastered more simple household activities and explored more complex community-based activities. A lot of participants used the phrase "used to" and compared to what they "can do now"; and some referred to finding a "new life" or a "new me".

> *You just want to try and do as much as you used to do, but you'll never do as much as you used to do, it's being comfortable with what you can do.* [Matiu, 12:26]

> *So, I was getting my independence and I was just able to carry it on into the real world and start my new life again. Yeah, start my new life.* [Rangi, 13:21]

The section *Occupation to measure progress* in Theme 4, *Engaging in Meaningful Occupation*, explores the participants' perspectives of comparing pre- and post-ABI performance in more depth.

Participants persevered with finding ways to still enjoy previous activities without engaging in them in the same, more effortful, way. Charles, as an example, continued his interest in sports such as cricket and skiing but took a more passive role of socialising with his group of skiing friends and following the cricket on the television rather than going to the club. He described himself now as "a great follower of sports, not a do-er of sports" (Charles). Vera still enjoyed watching the same television programmes but now caught them in the afternoon instead of at night as she was too tired to stay up as late as she had prior to her stroke. Angela, who had previously taught aerobics classes several times a week, began to think of alternative ways to keep herself fit that were less intensive such as yoga or Pilates.

> *I've only got one class a week now and I still can't keep up. So, yeah, I'm not as fit as I used to be. I need to regain my strength and I know I'll need to do it with yoga or Pilates or something. Not high intensity stuff.* [Angela, 9:10]

It was also apparent in participants' descriptions of their progress in community integration that this was the stage where they began to turn the focus away from themselves and more towards others. This was a stage where they began to socialise with some of their close networks again.

> *I'm getting back into it now. I went to news-and-views group this morning, which is reading the newspaper and discussing what is in it*. [Vera, 2:25]

> *[Meeting mates] was very enjoyable. That connection again, and also not just talking about me! I'm tired of me! In the hospital it was all about me, and the doctors looking at me, and even with [daughters at home]. It was about something else than me. It was about them, about their kids, about their lives, what they were up to and so on.* [Patrick, 18:17]

Some participants also felt like they could begin contributing to other people's lives in some way, even just in small ways. Matiu was a good example of this. He integrated his desire to say thanks to the nurses who looked after him in hospital into his community-based therapy programme and was supported by his speech language therapist to record a video that was sent to the ICU staff.

> *[Speech Language Therapist] gave me the idea to make a video for the nurses up at the ICU at the hospital. She said "well do you want to do it?" and I said "well, I'd like to say thanks to them". So, we got a video done and my daughter edited it, then we got the address and sent it to the ICU, for the nurses, that was nice. They thought it was really neat and they could see I was recovering and all, yeah it was cool, because you never get to see them again up there you know…. and they are really nice people.* [Matiu, 16:25]

In the *Early days back at home* stage, participants felt as though life had gone on without them while they were suspended in a period of rehabilitation that focused solely on themselves. Now, in *Settling back in*, participants began talking about "catching up" with others around them and entering back into life alongside others.

> *I'm involved with them again, I know what they are up to, they know what I am up to, I'm not up to much but I'm not up to much with them and that is the important thing.* [Patrick, 18:1]

As the participants grew more confident in their abilities, they began venturing further afield, out of the home and within the immediate neighbourhood. For Vera, she was fortunate there were a number of social activities and groups within the retirement village in which she lived, including bingo afternoons and knitting groups. Having tested her limitations with fatigue

within her household activities, she started attending these easy-to-access and nearby social opportunities before venturing into the wider community.

> *I'm not getting out and about very much because I've just been to lethargic and tired, I've not wanted to get out much so I'm just starting with the activities here.* [Vera, 5:18]

Salesi had moved into temporary supported accommodation following his in-patient stay. He had spent time learning to manage his social behaviour around people he did not know within the immediate accommodation complex.

> *I see when I first come that it is a bit new but when I stay a bit longer it is getting slowly better and better and good. Yeah, I learn a lot and I learn slowly, I learn heaps of new stuff for my life and my brain… How to live with people, sense the people, stay with the people.* [Salesi, 7:12]

Having built up his confidence to manage his behaviour and feelings of agitation towards others within his immediate environment, he felt confident enough to venture out into the local community: "I walk and I go and I can tell on the street, I see the people, lots of people and it's [the agitation] not too bad" (Salesi).

Now feeling more confident about their ability to manage their limitations, having gained some experience and insights into what adaptations worked for them, and having practiced certain tasks to the point that they felt they had mastered these, participants began talking about feeling "stronger" and more "determined" about continuing their progression. Participants expressed a sense of hope at this stage, hope that they would eventually integrate back into their community lives to a similar extent as prior to their ABI.

> *Okay, I have got this problem but I am going to deal with it as much as I can and I will carry on doing so. I want to get back to as normal a life as I possibly can. It's going to be a long slow process. It's been longer and slower than I thought it was going to be. This type of thing is quite demanding, it wasn't easy to do. So, anyway, I'm going to do it*. [Charles, 12:22]

> *It's hard as I learn how to connect with the people. If it is no good then you try to make it good and try to make it better, it depends how strong you are and that is how you learn, how to have contact with the bad people and make it good and just have some respect. I tell myself, you know, the strong people know how to conquer or handle the hard life, and the dirty and ugly people and all that. You don't have to get lost and angry, that is when you lose. If you handle it and go with it then you are the strong one.* [Salesi, 12:26]

The *Settling Back In* phase of the community integration journey was a period where participants began feeling more confident in their abilities, having been through the struggle of experimentation and exploration during the *Early Days Back at Home*. It was a stage where previous effortful activities that had caused anxiety became more natural and automatic. They caught up with the people around them, turning the focus away from themselves and towards other people for the first time since their brain injury. The ongoing progress with broader community-based activities during this period provided them with determination and hope that they would eventually return to full integration within their communities. This is when participants began to venture *Back Into the Bright and Busy World* and found that they faced further challenges that required new learning and growth.

Back Into a Bright and Busy World

Some participants had more experiences to draw upon than others when it came to this phase of community integration. Those that were interviewed earlier on in their return home (e.g., Patrick, interviewed only 5-weeks after returning home) were only just beginning to get out into the "bright and busy" world. Others, interviewed later in their integration journey, had more experience of this phase (e.g., Matiu, interviewed at 6-months).

Participants described attempting a range of activities as they ventured further afield and into their communities. These included productive tasks such as getting small amounts of groceries from the local dairy, or completing the weekly shopping at the supermarket.

> *I just go across the road to Countdown or Pak' n' Save, or the butchers up in [name of suburb]. I'll go up there, yeah. I've got a slab of meat in the fridge because I'll go hard on the shopping.* [Rangi, 14:21]

Community activities included taking advantage of social occasions such as church attendance with friends, visiting the marae with whānau, and attending family birthday parties. These activities built on those undertaken during the *Settling back in* stage, extending them both geographically and relationally. Leisure activities. such as exercise classes, bowling, going to the movies, and going fishing also took place; as well as return to work for those participants who held jobs prior to their ABI (Angela and Andrew). These community-based experiences were, for the most part, enjoyable. However, they were also less predictable and the participants found they had less ability to anticipate challenges or control the environment around them.

> *I love doing it [exercise class]. It is that thing that I have found I really enjoy doing and so I just go if they ask me and I think it was just a little bit too much at the time.* [Angela, 7:16]

> *I have actually been doing this work trial thing for about, well I mean I started last week so I have been in probably twice. So, that's fine. It's just like getting reacquainted with the store. It's changed quite a bit since before I had my accident*. [Andrew, 8:8]

Participants all experienced difficulties with these more complex activities due to the greater degree of physical and cognitive demand involved. The most common challenge, across all participants, was that of fatigue. All participants described the feelings of tiredness, low energy, and the need for extra rest periods during the day to help cope with the additional efforts involved in more unpredictable community activities.

> *Three weeks ago I went to the supermarket. We have a little van that runs down there twice a week. I found that doing extra things like that made me very tired*. [Vera, 2:33]

> *When I go to the marae and that, well that is only just us [whānau] anyway, it's not heaps of people so I just try to do something there, while I am there, and if it is too much for me then I will just go home or go for a sleep.* [Matiu, 6:23]

> *It's the fatigue that I have to adjust to. I don't have any other physical things where I can't do stuff. It's the fatigue, it kills me! I find that it controls you, you have no control over it*. [Angela, 9:15]

In addition to managing their fatigue levels, participants found they had to adapt their activities to suit their capabilities in other ways. For example, prior to her stroke, Vera would have driven herself to church and she had no issues with negotiating access to the building. However, at the time of her interview, she was reliant on her friend to drive and would use the ramp to access the church instead of the steep stairs when she "ran out of steam". Other participants adapted by requesting the assistance of others for aspects of the community task or by altering the physical requirements, even if this was simply sitting down rather than standing during long social gatherings.

> *We were at a football tournament for the weekend and there were lots of mates there and no one knew… I was fine I just sat down a lot. I sat down heaps and just didn't say much.* [Angela, 11:20]

In social environments, a common challenge that participants experienced was being in a crowd and having to exert effort to maintain their attention on the conversation. Those who had been in these situations found they had to leave earlier than they would have liked and return home to rest.

> *If it's like a crowd, I've never been much on anyway, and if it is a birthday or something, I'll probably just have a kai and then I'll go or I'll say 'bring me kai at home'. I'd rather be home if it is like that.* [Matiu, 6:21]

Participants approached these more complex community-based activities with caution. Having learned how to pace themselves during previous phases of growth into community living and recognising the benefit of pacing themselves, they took gradual steps. For example, Matiu was keen to return to diving as this was a leisure activity that he enjoyed with his sons and grandsons. However, he recognised the need to take a gradual approach to returning to the water.

> *First, I went in about this deep [indicating a meter from the floor] so I don't drown... and then a bit further and further and deeper until I'm sure I don't drown*. [Matiu, 11:18]

Other examples of pacing and performing a graduated return was the way participants tested out shorter outings with support in place prior to longer, more demanding outings.

> *I have been for little walks around the block, just up and down here a wee bit, then yesterday I went to my sister-in-law's place down in [name of next suburb] and had a cup of tea there*. [Patrick, 10:29]

> *I walk around and I go around on the streets near here. I see people, lots of people and it's not too bad. Then, yeah, I go out, I use the bus and go to [nearby suburb] to Countdown and do some shopping and come back on the bus, and hop off… somebody took me the first time and then the second time I do it by myself.* [Salesi, 10:28]

A number of participants indicated they were cautious of entering back into community living due to concern that it might aggravate their symptoms, lead to some sort of regression, cause further damage to their brain, or lead to another injury.

> *I want to wait until my head comes right, because I don't want to hit anything. You know, there are a lot of crazy people out there and I want to protect, you know it is going to be hard to protect my head. I have got to protect my head, and I have to protect it hard, because if this happened again then that is it, game over. I don't want that*. [Rangi, 19:16]

> *I probably need to move out a little more but, um, and that will happen with this [moving house], and various things, yeah, that will be okay but I will not be rushing anything. I have got to take it carefully. I don't want another one [stroke]. No thank you!* [Patrick, 21:12]

There were occasions where participants felt overwhelmed and experienced failure in their efforts to reintegrate when they attempted to undertake greater challenges. An example of

this was Salesi who had worked on taking a few bus trips around the local area to gradually increase his tolerance to the noisy behaviour of other people. He then decided to take a trip to a large local shopping mall and found this too much to tolerate, returning home immediately after entering the building.

> *One day I go to [name of shopping mall]. First time I have seen it. I did not know it was so big and high. I was going there but I did not know that, so the first time I go there on the bus I feel like 'oh boy!' this is different for me now… so I didn't walk around a lot there, just by the bus stop, and then I came back. I did not want to go around*. [Salesi, 13:21]

The challenges, and at times the failure, in their community integration provided participants with growing acceptance of their limitations; it also helped them identify the need for ongoing effort into practice and strategies to manage the difficulties. Andrew, as an example, gained emerging insights of his ongoing issues with hand-eye coordination and balance through his experience of bowling and scoring poorly compared to his mother who he would usually beat without difficulty. These insights motivated him to persevere with these aspects of his recovery.

> *I like bowling. My scores have been pretty bad… my vision isn't that good and the whole balance thing. I don't know. It's probably just not as good… the bowling motion is good but it's a bit off-balance… the action looks really good but the result is not that good.* [Andrew, 5:15]

In the previous phases of *Growing into a new way of community living*, participants had predominantly interacted with people who had journeyed alongside them through their recovery or health professionals and formal support people. These individuals either knew the impact of brain injury due to their professional backgrounds or had learned of the impacts and adapted alongside the participants. When discussing their entry back into the wider community, participants described their interactions with the general public and people such as shop staff, who had limited knowledge of the impacts of brain injury, and could not understand the behaviour that some participants were exhibiting. This was a new challenge for them to negotiate.

> *If I go to the bank or somewhere like the shop, go to do something there, it's like it [speech] all goes. When it is all meant to be down-pat, as soon as the man comes along to the bank window, it's gone*. [Matiu, 10:21]

To assist them in managing their interactions with strangers, participants sought support from their formal rehabilitation providers, community support workers (if they had these in place),

family or whānau members, or close friends. Expanding on Matiu's experience at the bank, he discussed how he would take his daughter with him to assist if needed.

> *I get my daughter to do it [the speaking] … because she is on to it, she doesn't get phased by much, she has always got the answers.* [Matiu, 10:25]

Despite recognising the progress they had made in their community integration up to this point, participants reported feeling concerned that they appeared "stupid" and "foolish" to others due to their invisible limitations.

> *When I am talking to someone I would just fade out, drift off, and they would be like 'hey' [gestures giving a prod] and I'd be 'oh yeah!' or words would fumble, yeah, my words would get mixed up and stuff. I hate it when it happens at work because I feel like they think you are a complete idiot.* [Angela, 10:14]

Only a couple of participants felt confident enough to ask for the help of a person in the general public who knew nothing of their history. When this assistance was requested, it did not appear that the individual providing the assistance thought much of it. Participants perceived these people were too busy with their own lives to really bother about why help had been requested. Vera described her experience asking other customers for help in the supermarket when she was unable to reach for items as she required the support of the trolley to assist with her balance.

> *Well mostly they just ignore you don't they. They aren't getting in the way or anything like that. I'm quite good at saying excuse me would you reach that down for me.* [Vera, 10:9]

Andrew described interactions with wait staff in a restaurant when having difficulty with the menu. The staff provided the assistance and then continued focusing on taking orders without any apparent hesitation. The impression was that they had a job to do and they just got on with it.

> *Maybe if they are highly switched on they might think 'this guy is a bit weird', I would be like that, but I think most people are just too busy focusing on what they are having to do for their job to, you know, pass judgement or whatever.* [Andrew, 9:19]

Regardless of the time that interviews took place after discharge, none of the participants felt that their community integration was complete. They all described ongoing hopes for future consolidation and extension of the integration that had taken place to that point. For those in

the earlier stages of their community reintegration, their hopes were relatively simple, mostly aiming to build their confidence in being back out in the world again.

> *I'm not scared of going out but I'm just going to go down, one of the girls is on holiday… there are some lovely Chinese restaurants down the road so we are going to take a walk down there one day… having someone with you is a good idea so I am not doing it by myself.* [Patrick, 11:1]

Others were aspiring to return to driving and looked forward to the opportunity this would provide in getting further afield and back to the activities they enjoyed and where they could contribute something to others.

> *I'd love to drive again. That's really my dream. If I can drive again I just feel as though I could go out and go and do things for other people.* [Charles, 3:7]

> *Drivers' license! That's the next thing!... I've got a very dear friend near to where I used to live and I want to go and see her*. [Vera, 12:13]

For others, a return to paid employment was a future goal considered to indicate successful reintegration; for instance, Angela and Andrew who were already engaging in return-to-work plans for the roles that they had held pre-ABI. Matiu knew he would not be able to return to his previous role as a truck driver so wanted to seek alternative employment.

> *Getting a job that I can do, without going to the, oh, I don't know what to say, urgh, early retirement. Just something that is really nice that you really want to do. If I can find something like that I'll be happy, you know.* [Matiu, 20:4]

Others, such as Rangi, who were not previously employed at the time of their ABI also considered paid employment a future goal.

All participants experienced ongoing challenges as they starting *Getting Back into the Bright and Busy World*. They saw this phase in their community integration as a positive one but one they entered into with caution following their learning in their *Early Days Back at Home*. All had experienced the value of pacing themselves, asking for help when needed, and a graduated return to previous levels of participation. All were willing to adapt tasks to suit their new levels of ability. They took the strategies and advice that had been followed in the earlier stages of reintegration and generalised those to more complex community scenarios, with positive outcomes in the majority of cases. Participants still held hope for continued community reintegration and, although they were cautious in their approach, continued to have confidence that they would eventually achieve their goals.

Theme 2: Living Up To Expectations

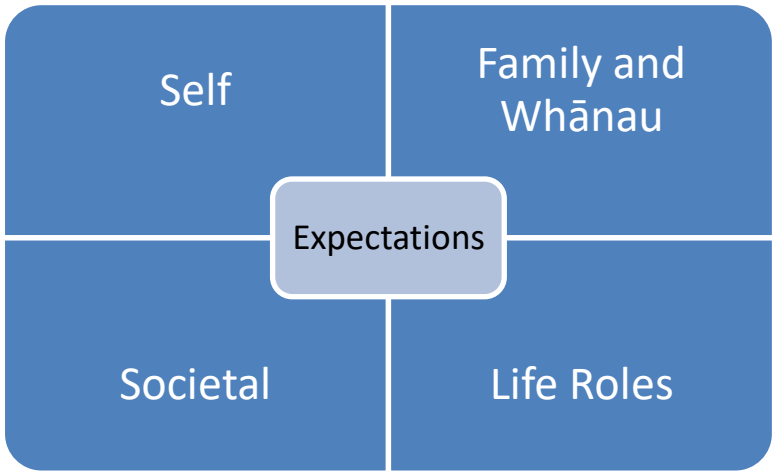
Overview

Every participant talked about *Living up to expectations*. Sometimes these were self-expectations, strongly held beliefs of the persona they had prior to the ABI, how they perceived they were supposed to manage in order to re-establish their roles, and how they wished to convey themselves to the world. Several people described a need to keep their limitations hidden and to convey an outward appearance of coping and control. At other times, these were external expectations associated with a life role such as a voluntary position or a job that required certain responsibilities to be achieved in order to fulfil obligations. Some individuals found that those close to them had varying expectations of how quickly they would recover and manage independently. The expectations of family and others close to participants tended to be based on previous experience of people with ABI and how well they had seen those people return to community living. Based on this experience, family members were either pleasantly surprised by the speed at which the participant recovered or found the speed of return to community living to be much slower than anticipated. Family and whānau played a large part in mediating people's expectations of their return to community living. However, there were other key players such as colleagues, friends, health professionals; and more distant influences such as the general public, social media, and public health information about COVID-19.

Figure 8 represents this theme by dividing the expectations that were discussed during the interviews into four categories: self-expectations, the expectations of significant others such as family and whānau, expectations that came with life roles that participants held, and the expectations from society influencing how a person should live and behave.

Figure 8

Living Up To Expectations



In the sections that follow, each of these four categories is explored in more depth and quotes are used to illustrate the findings.

Self-expectations

Self-expectations frequently came in the form of comparisons between "the old me" and "the new me"; the person they were prior to their ABI versus the person they were following their ABI. Prior to their hospitalisation, several participants described themselves as the person who would help others or the person who would lead others. Now they saw themselves as the ones being helped, more passive participants in life, instead of the active person they had been. "A great follower" instead of a "do-er" is how Charles phrased it. This shift caused internal conflict for participants who were motivated to return to their previous self rather than remain dependent on others.

> *I used to, well I was in charge of 300 people at one stage, you know, in railways. I'm used to standing up and speaking, or I used to be. Now I am very, as I say 'scattergun'.* [Charles, 1:12]

> *I was hard on myself because I don't normally ask people for help, it's normally me offering the help or helping out*. [Angela, 8:16]

Matiu gave a very specific example of how, before his stroke, he preferred to be the man in control in his whānau, to the point that he had nearly drowned on a number of occasions when out diving rather than ask his sons or mokopuna (grandchildren, whom he had taught to dive) to help. He indicated he would rather struggle through than request help from younger members of the family.

> *I didn't want to call out. I didn't want to say like 'oh, I'm drowning' [gesturing waving his hands in the air]. No, I'll drown [laughing], I'll just drown.* [Matiu, 12:17]

Now, he was being closely watched by his grandsons while out diving and was frustrated that he could no longer "smash them" when it came to holding his breath and diving deeper. Other participants also conveyed a desire to return to their previous identities as the people providing help and being someone others could rely on.

> *I loved working for a firm where I was contributing to the community's welfare. That was my biggest aim in life. Now I find I have been truncated by circumstance and I would like dearly to be able to put my feet on the floor and go out and do something where I could help someone else.* [Charles, 2:30]

> *Instead of leaving work early or saying 'no, find someone else to do the class because I can't get there on time', I want to prove to people that I can do it, I want to prove to myself that I can do it.* [Angela, 14:28]

Angela saw herself as a high achiever prior to her stroke. She was the one participant who explicitly identified that she had very high self-expectations. She admitted to putting a great deal of pressure on herself to perform to the best of her abilities in all aspects of her life and talked of her concern of how others might perceive her if she did not. She believed others may see her as "weak", "ill", or "sick"; and this was not the image she wished to portray.

> *I was really hard on myself and I am still hard on myself. I kept saying to [name of OT] and [name of physio] that I felt like a loser, like such a loser because I'm not going to work as I should be. I'm not someone who takes the piss, so to speak, and calls in sick for no reason and that kind of thing. I pride myself on being present.* [Angela, 7:5]

> *I'm putting myself under pressure all the time because, I should not say this, but I do not want to appear weak. I do not want people to see me as weak… It's my own pressure that I put on myself, it's proving it to myself.* [Angela, 14:19]

Although only Angela was explicit about the pressure she put on herself to appear a certain way, other participants also suggested that this internal pressure partly motivated them to continue persevering with their reintegration challenges. Vera gave an example where she preferred eating alone in her apartment rather than with her friends in the social dining space of the retirement village "mostly for politeness sake". As her affected hand caused her to spill some of her food, she had decided not to return to dining in company until she had practiced eating without any mishaps and "became more civilised" (Vera). Patrick also identified feeling "crushed, small and useless" in his wheelchair and described how he disliked "wallowing in self-pity" so continued to focus on his walking and balance until he could abandon the wheelchair all together.

Other internal expectations came from the participants' health beliefs and their history of proactively managing their health to enable a longer, healthier life. These tended to be older participants, such as Charles, who had witnessed his parents suffer through ill health as they had gotten older and, therefore, had tried to be responsible for maintaining good health himself.

> *My father lived to 76 but he had problems with cancer on his back, he got sunburned badly as a kid but he didn't want to do anything about it. He was frightened of hospitals so he delayed it and he finished up being limited and he died… I've made sure to go out and have moles off my back… I've tried to take account, to learn from my predecessors.* [Charles, 2:7]

Having managed his health well prior to his stroke, Charles had expectations of a long and healthy life. Although already in his 80s he claimed, "I haven't finished yet, I've still got 20 years left". Vera was similar in her expectations of a long and healthy life. In her 70s, she still maintained an expectation of continuing with her independence in the community, particularly in regards to returning to driving following her stroke.

Participants' hopes and dreams also drove their self-expectations. Salesi spoke of his dream to make a better life for himself prior to his brain injury.

> *I always had a dream, I always thought my life would get better and I would get a job, a house, and a wife and everything. I didn't know I was going to end up here. I always thought I was going to get my dream. It was a big goal but the thing I see that I stayed strong on the goal.* [Salesi, 15:7]

Although he maintained that he would stick to his dream, there was some indication that he was uncertain the dream was realistic anymore and he had considered adjusting his goals to something less specific, to simply "enjoy life" (Salesi).

> *You can say it, but you don't know what you are going to do, if you are going to get there or not, that means you can't control your life, you just don't know if you can get there… I've tried to enjoy life, so I like the life, because sometimes if you don't enjoy it then it is no good, aye?* [Salesi, 15:30]

As the above section demonstrates, participants placed a number of expectations upon themselves for a variety of reasons. Some of these expectations were related to who they "used to be" and trying to get back to being that person again. Some self-expectations were driven by concern regarding their outward image and wishing to portray independence and control rather than weakness or dependence. Other internal expectations stemmed from previous health behaviour and the belief that they would continue to live a long, productive life. Finally, there were self-expectations that related to long-held life goals.

Family and Whānau Expectations

The expectations of family and whānau, or close family friends, varied depending on their previous experience of ABI and their knowledge of the recovery that was possible. Some family members had low expectations and participants felt the need to prove themselves as surpassing these. Patrick's wife and close friend both expected him to be a "total cripple" following his stroke and Patrick aimed to prove otherwise.

> *[A close friend] wheeled me a couple of times in the chair down to the coffee place and he was very, sort of, concerned and 'god, this is awful, you might end up a cripple'. As time went on he began to see 'hey, you are not like that'… he was surprised… Maybe it is a lack of knowledge, I don't know. Or maybe we don't want to think about it because it is too hard. People think, a stroke – your life is stuffed. Well, it's not and I was not going to let it be, no way!* [Patrick, 19:28]

Some participants described family members or close friends who had either experienced a brain injury themselves or had knowledge of recovery through other acquaintances. When this was the case, these family members or friends were able to relate their expectations to a previous experience and understand certain limitations and recovery patterns. They provided valued guidance and reassurance that further advancement in community integration was possible with time and effort.

> *She is 29 you know, but she [had a stroke]. Now she can tell me, you know 'I understand what has happened, take care of yourself, it's important that you listen to your body'. That is one thing I have been hearing a lot 'listen to your body'.* [Angela, 19:12]

> *[A friend/colleague] also had a brain injury a couple of years back. She like fell down a flight of stairs or something. So, they are very familiar I guess with like the recovery process and I guess how forgetful people are after brain injury. So, it is no surprise for them. They were commenting today that they are impressed with how quick my recovery has been*. [Andrew, 8:28]

Matiu's wife had worked with people who had sustained brain injuries previously. She understood what would be required for recovery and continued to provide him with encouragement when he began to get frustrated with his situation. She assisted in guiding him through his graduated return to the community, encouraging him to undertake activities that were meaningful to him, like carving and diving, while recognising potential risks and minimising these as much as possible.

> *I was always hurting myself, my legs, like I'd drop something and put it in my legs, especially my tools, and they are sharp! So, I make sure I don't do that aye. She [wife] made me put boots on and then made me put gloves on. That's not me, definitely not me. So I had to get up to speed, you know.* [Matiu, 7:19]

> *Diving is good but she knew she had to watch me because my strength wasn't good, so she got my son and my grandson to jump in the water too. Lucky my grandson is a big boy too, well you know, he's tall, but yeah, it's not been a problem.* [Matiu, 12:1]

Some participants had family and whānau who had no experience or knowledge of brain injury or similar health conditions. These participants preferred to keep their condition hidden until they were more able to demonstrate a high level of functioning without any obvious impairment being evident.

> *I tried to keep it hidden, that's what I did, I tried to keep it hidden, until my two baby brothers found out and came up… They wanted me to go back home because I am the only one up here now but I said 'ah, no, I'm not ready to go home just yet'. I wanted to carry on with my procedures [rehabilitation], but I will eventually go back home at some time*. [Rangi, 17:21]

Expectations placed on participants by their family, whānau, or close friends appeared primarily derived from knowledge that had been gained from others who had experienced similar injuries or medical conditions. When participants were asked if their families, or they themselves, had sought information elsewhere, such as through websites or written materials, it seemed these resources were utilised very little. In some cases, participants viewed these kinds of resources (particularly the online information) as unreliable; the preference was for first-hand information from others around them.

> *I could just Google it [brain injury information]. I'm sure there would be like a thousand results for whatever I'm going to Google but whether it will be like applicable knowledge or not, I don't know.* [Andrew, 10:18]

> *I'd never really looked for it [stroke related information]. I've maybe seen it on the TV. I've seen it in doctors' surgeries. God when I am bored, I might pick it up off a thing [gesturing a leaflet rack] but I am going to be honest with you, I think I have been quite, not judgemental, but, what would the word be… I've sort of looked on stroke people like 'oh god, well their life is stuffed isn't it' and dismissed it as not wanting to go down that track. I've seen my cousin and his wife struggling with that. He could hardly walk, and it is a pity sort of thing, but it was something I had never thought about too hard until now*. [Patrick, 19:7]

The expectations of those close to participants played an important part in motivating them to continue their community integration journey. These expectations varied depending on past experiences with similar kinds of injuries or conditions. Some family and whānau had positive and encouraging expectations due to having seen others with similar conditions who had recovered well. Others had low expectations when the past experience had been of poor recovery. Regardless of whether the expectations of these significant others were positive or negative, they had a similar effect in spurring the participants on to greater levels of independence, either through utilising the guidance and assurance of friends and family or through a desire to prove them wrong.

Role Expectations

Through the interviews, participants referred to a range of life roles. They were aware of certain expectations relating to these roles that had to be fulfilled for them to successfully carry out the role again. Four of the participants had a role as a parent and spoke of their responsibilities to their families including providing their meals, tidying up after family members, keeping them safe, and celebrating their birthdays.

> *It felt so good getting back into cooking a dinner for the family because other times I was just too fatigues to do it. It was just bossing someone, telling them what to do or [husband] would cook the dinners or the kids would cook and I'd be like 'urgh!, I don't want them to' but they had to because mum can't do it.* [Angela, 20:24]

> *So now I just want to make sure that my son and my grandkids are safe when they are in the water, so I make sure they do not go too far, you know, they stay nice and safe in the rock pools, you know?* [Matiu, 12:13]

Even those with older children who had moved away from home years earlier, still felt an expectation to meet their parental obligations.

> *[My children] are scattered around, doing their thing, but I have not been able to see them since I had my stroke… I haven't been, for instance, my twins, one of my twins is over in Australia the other is down getting married and I couldn't get to the wedding. I am limited here… So, they come up to see me but I have not been able to get down.* [Charles, 9:8]

For those who were not parents, they still talked of roles within their family or whānau such as being a responsible older brother and uncle.

> *I've always liked to support them [siblings], give them whatever support I can… I come from a big family, a BIG family! There is a lot of drama because they are all in close relationships, you know, close whānau relationships, and all those kids, you know, that is where the drama is coming from. There is all the drama with the innocent one. The innocent one has to go and sort something out that he does not know shit about, poor fella, so I just helped, got in and out, sorted it.* [Rangi, 16:4]

In addition to roles within the family unit, participants held a variety of other roles that all came with a range of responsibilities. These included formal roles such as exercise instructor, employee, colleague, volunteer, and student; and self-identified roles such as mentor, friend, helpful neighbour, carver, and gardener. Each participant spoke of the "obligations" that came with the positions they held and how these needed to be achieved for them to fully return to the role. These expectations provided participants with continued motivation to reintegrate into their community lives.

Charles held a position as a volunteer driver prior to his stroke, a role that he had enjoyed a great deal and one where he felt he was making a valuable contribution to other people. His goal to return to this role provided him with the motivation to work on physical and cognitive deficits so he could return to driving.

> *I'd love to drive again. That's my real dream. If I can drive again I just feel as though I could go out and go and do things for other people… I used to drive for [name of voluntary organisation] I was the main driver for taking people to the hospitals and I used to take them to places like Hampton Downs to the rallies down there, taking them down to community support, do all that.* [Charles, 3:7]

Angela was an exercise instructor and had run exercise classes two or three times a week prior to her stroke. Following her stroke, she found that she could not do as many classes, which increased her determination to improve her physical fitness.

> *I can't exercise as much as I used to. I can't do as many classes as I used to. If I am having a bad week, like I was last week, then I have to call, that Thursday morning I knew I'm not going to be able to take the class tonight… I've got one class a week now and I still can't keep up. So yeah, I'm not as fit as I want to be. I need to regain my strength.* [Angela, 9: 6]

Andrew was beginning to return to his previous employment in a store and spoke of his need to improve his cognitive and physical skills to meet the demands of the role and provide a good service for customers.

> *It's tricky. Like my product knowledge is a bit more hazy than it used to be. My knowledge of where products are, how everything has moved around, it's not great for customers and it's a bit of a trek going to the stock room which is downstairs and then finding something and then bringing it back up and then the customer doesn't want it*. [Andrew, 8:13]

Participants held a range of roles and, therefore, the expectations were varied. However, the common concern to all was that other people were relying on them to return to these roles, and they wanted to make positive contributions in those peoples' lives. Ultimately, it appeared that they wanted to have purpose and contribute something back to their communities.

> *I was filling in for other people because they needed someone and there was no one else.* [Angela, 7:15]

> *I feel I'd like to be able to be more constructive… being able to contribute, as I say, to the family unit.* [Charles, 3:5]

Societal Expectations

The fourth category of expectations that participants discussed were those that came from society in general. At the time of the interviews, New Zealand was going through various levels of lockdown in response to the COVID-19 pandemic and society was being bombarded with public health messages focused on reducing the risk of infection. These messages included the enforcement of home isolation at level 4, or limited movement within the community at level 3. This impacted the degree of community integration that participants could undertake, as everyone in the country had their community-based participation put on hold. Although most participants mentioned COVID-19 home isolation during their interviews, Charles and Vera were interviewed shortly after the first series of lockdowns so the experience was still new and fresh in their minds. Both experienced the same restrictions on their community engagement; yet, each saw the home isolation expectations from a different perspective. Charles saw them as a barrier that was limiting his community integration progress.

> *We belong to the Cossie [Cosmopolitan] Club and we used to go there but we haven't since… well frankly it's the bug, this thing that is in the air. Mixing with the public I feel is less useful to me because, if I get it, it is going to be bad for her [wife]. I'd probably make myself critical pretty quick. So I have actually reduced my activity because of COVID. Those activities are more limited that they were before so I'm feeling isolated to this home and it is because of this difficulty, the health of the country.* [Charles, 4:18]

Vera, in comparison, saw COVID-19 restrictions as an enabler, allowing her to take her time to recover and improve her independence at home first, rather than rush into community-based activities. There was an expectation that everyone should remain at home, so she was no different to anyone else.

> *Of course, we went into lockdown here just after I got home but that served my purposes very well because I didn't want to be doing anything anyway*. [Vera, 2:26]

In addition to the national restrictions relating to the COVID-19 response, participants talked about other ways in which society had expectations of them, such as how they should appear and behave in public. This was particularly challenging for Salesi whose brain injury had caused him difficulties with managing his behaviour, including controlling his anger towards others. He still considered certain people he came across in the community to be "bad" or "ugly" but he was learning to control his anger towards them and remain "strong" as this is what society expected.

> *It's hard as I learn to connect with the people. If it is no good then you can try to make it good and try to make it better, it depends how strong you are and that is how you learn, how to have contact with the bad people and make it good and just have some respect. I tell myself, you know the strong people know how to conquer or handle the hard life and the dirty and ugly people, you don't have to get lost and angry.* [Salesi, 12:26]

Other expectations from society included the idea that people should always be busy and productive. Angela, as a mother of two young children and working two jobs, was very aware of this expectation.

> *It's really hard because on a Saturday morning, like now if I'm fatigued, I can't really do much. I just have to relax, sit back, have a coffee, where as I would normally be at a market or getting out and doing stuff because society dictates that you have to do stuf.f* [Angela, 13:19]

The influence of social media was also mentioned as an additional pressure to be out exploring new places and keeping up with popular events.

> *And there's Instagram you see, 'oh, it's a cute market I might try that next week' or 'nice new donut place, looks good, we'll go there next week'. No! It's going to be there in 4-weeks time, it's going to be there in 6-months time and it's okay if you can't go… nothing is going to happen.* [Angela, 13:23]

As the four sections above reveal, participants discussed a range of expectations that impacted their ability to reintegrate into their communities. Some were internal self-expectations and others were external expectations derived from significant others, perceived role responsibilities, or society. Some of these expectations had a positive impact on the individuals, motivating them to progress. Some were limiting, resulting in a barrier to their progression. The way in which participants responded to these expectations was complex and individualised with, at times, different participants responding in alternative ways to the same expectation.

Theme 3: (Re)Building Social Connections

Overview

All participants discussed building social connections that enabled them to cope and participate in their community. Some of these connections were established pre-ABI, while others were new. When analysing these social connections, it became apparent that participants were engaged in three types of social networks. The first of these networks was made up of close and enduring social relationships (family, close friends, partners, old

colleagues). The second, incorporated more distal and fleeting relationships such as others with ABI and acquaintances in their neighbourhood. The third network consisted of health care professionals who were working with participants to assist in their recovery. Relationships within all three networks were seen as particularly valuable and helpful when individuals had awareness or experience of ABI and could talk realistically about the process of recovery and reintegration.

From these social networks, participants were provided with three types of social support: practical, emotional, and informational. Practical support incorporated assistance to manage daily activities, developing strategies to assist with circumnavigating their limitations, and skills to self-advocate. Emotional support included encouragement to continue with their integration, feedback on the progress they had made so far, and a sense that they were not alone in their struggle. Informational support came in the form of advice, assistance to navigate services, and learning about brain injury in general. The social networks into which the participants integrated, and the social support that they received from within these networks, led to increasing opportunities to continue with their social and community integration. Continued integration then created further expansion of social networks and the cycle continued. Figure 9 illustrates these diverse social connections.

Figure 9

(Re)Building Social Connections

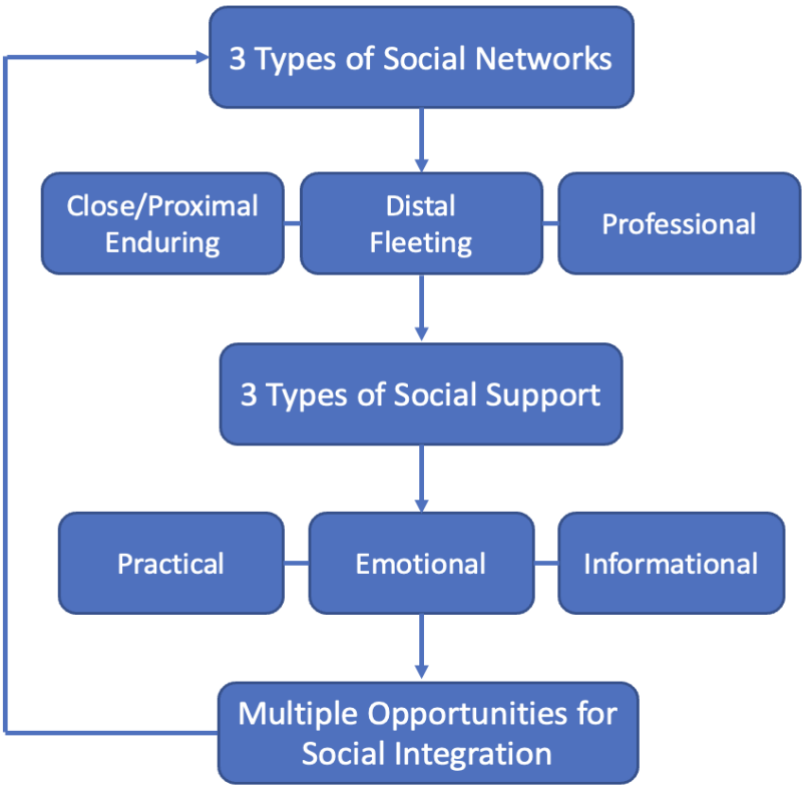


Table 6 provides a matrix of the types of social support (practical, emotional, informational) that were received by each participant from the three social networks. Each of these social networks and associated patterns of support will be outlined in the sections that follow, with reference to this matrix. The wide range of opportunities for community integration that these social connections facilitated will also be described.

Table 6

Types of Social Support Provided From the Three Social Networks

	Close/enduring	Distal/fleeting	Professional
Charles	P, E	N/D	P, I
Vera	P, E	P	P, I
Angela	P, E	P, E, I	P, E, I
Andrew	P, E	P, I	P, I
Matiu	P, E	P	P, E, I
Rangi	E	P, E	P, E, I
Patrick	P, E	E	P, E, I
Salesi	P, E	P, E	P, E, I

*P=practical, E=emotional, I=informational, N/D=not discussed

Close and Enduring Networks

The *close and enduring networks* that participants discussed were predominantly family or whānau. This network also included good friends and employers or colleagues with whom they had close relationships over long periods of time. In the case of participants who had pets, these were also included in their *close and enduring network*.

Family members within the *close and enduring networks* provided both practical and emotional support to the participants in all but one case. Rangi's whānau lived a considerable distance from Auckland and, therefore, he did not receive any day-to-day practical support from them. As discussed in the previous section, *Living up to expectations*, he was also reluctant to inform his whānau of his injury and ongoing symptoms, preferring to keep these hidden until he had recovered to a greater extent.

The types of practical support provided by family and whānau varied considerably but frequently included assisting with transport as the participants themselves were unable to drive for periods directly following their ABI. They still wanted to get themselves to a range of community places and events and so had to rely on members of their family to assist.

> *They wouldn't let me drive until I went to the doctors and he said 'yes'… They would hide the keys and the grandchildren would come running out every time I went out back saying 'shift over pop, we'll take you'. Yeah, they'd put me in the truck and then they would drive me around.* [Matiu, 13:16]

For those who were parents, support with transport applied to themselves and other family members they would have usually driven places. Angela, for example, would usually drive her children to school or their weekend sports activities but now relied on her husband to do this task, or the children had to catch the bus. Although this was a change to her children's routine, they appeared to be accepting of it and aware of their need to support their mother with her recovery in this way.

> *They [children] have to jump on the bus now, jump on the bus and all those things. It's been really good because they understood why it needed to happen and from that point on, I realised it's actually working out pretty well.* [Angela, 5:32]

Practical support from family and whānau also came in the form of supervision or hands-on assistance with daily activities ranging from personal care tasks to more complex domestic activities such as cooking meals, gardening, splitting firewood, or banking.

> *They [husband and children] cooked their own dinners and stuff and all of that stuff. So, they had to fend for themselves when I came home from hospital.* [Angela, 8:24]

> *All this wood here is ready to split, that is fresh wood. We'll use the stuff from last year first and then that will go in the shed for next year. My son comes up and he splits it. I used to but I don't now, I'm not stupid!* [Charles, 8:25]

Within the *close and enduring network*, good friends also provided practical support with a range of daily activities ranging from simple favours to supporting participants' ability to get out of the house and participate in social or leisure activities.

> *I had one friend who did things like peeling an apple, that was one thing that I couldn't do. She used to come down straight after her lunch and peel an apple for me.* [Vera, 8:14]

> *My mates drive me… I mean I could always get, if I wanted to, I could always get an Uber or whatever, like we go to the bowling alley… I went to Denny's with mates… went out on that movie night… I went to the theatre.* [Andrew, 3:23]

For those participants who were engaging in return-to-work programmes, colleagues and managers were included in their *close and enduring network.* They described the practical support that these individuals were able to offer. Andrew particularly valued the practical support he received from his colleague who had experienced a brain injury herself and could understand his limitations to a greater degree than others.

> *If it's like the work advice stuff, like the write it down if you are going to forget, that idea, the other colleague of mine that had a brain injury, you know, she has been like checking up on me and making sure that everything is all good and that I don't have any trouble dealing with customers or whatever.* [Andrew, 10:5]

As Table 6 shows, all participants discussed receiving emotional support from their *close and enduring networks*. Although other networks also provided emotional support to some extent, it was *close and enduring network* that provided this kind of support to the greatest degree. Whether it was family, whānau, close friends, old colleagues, or their pets, each participant described the "support", "understanding", and "encouragement" that had been received and how grateful they had been. Some of the emotional support came with simple gestures such as the delivery of flowers on their return home.

> *I was hard on myself because I don't normally need people's help… so that made me feel a little bit [frowns], yeah, but I was really grateful everybody helped out. Flowers came and I was quite overwhelmed with all the support*. [Angela, 8:16]

Some of the emotional support came from just being able to chat things through with friends and family, either on the phone or in person, and receiving positive reinforcement about their progress. Vera missed her good friend whom she could no longer visit as she lived a distance away, so they now caught up on the phone to have a "gossip" on a regular occasion. Patrick caught up regularly with his sister who knew a lot about stroke due to her nursing background, and was able to provide him with encouragement.

> *Family is the main thing, and the fact that they are so very, very caring. My sister, who lives in Wellington, her husband died a few years ago. She is a retired nurse so she knows a lot about it. We are in touch all the time. She is just amazed… She said the advances are amazing… She is so delighted.* [Patrick, 22:6]

Salesi had very few close and enduring social connections due to his transient lifestyle pre-ABI and was, therefore, building some of these from scratch. He had started with his nephew who lived close by and found simple telephone conversations provided him with the motivation to

learn new things, such as how to operate a new phone. They also allowed him to experience how his nephew was living a life that he himself would like one day.

> *I just buy a new mobile phone and I try to learn to use the phone and try to phone around for my nephew so we can start to talk about stuff… because my phone is like $19, it is hard to use. My nephew said to me 'buy a cheaper one, learn how to use the thing, then buy a good one'. I think I am going to try to do that.* [Salesi, 8:6]

> *I have got his number and sometimes I try to phone him but I haven't now for a few days. He is good. I think he is better than me. He is a policeman and he has got a wife and two kids… last time I tried to phone him he said 'I can't talk we are on the road, we are on the way to the mountains' and I was like 'aye!'… It was a holiday and I say 'wow boy!'* [Salesi, 9:10]

Participants also mentioned how small comments or reactions from people around them, such as friends and long-standing neighbours, had provided them with positive feedback and boosted their motivation. These may have seemed inconsequential to those making the comment, but they appeared significant, positive, and reassuring for participants. Rangi, as an example, had a close relationship with his neighbours as he had lived in a hostel situation with shared facilities for a number of years. When he got home from rehabilitation, he described how he "went up and down to see people. Everyone was happy to see me" (Rangi). Matiu also found support through his mates, particularly when he was getting fed up with being at home around his whānau all day long. Even when he insisted on going out for a drink for the first time since his ABI, his mates made sure he was well looked after.

> *I was only allowed to have one beer can. Intake wasn't the same and I would have got drunk off any little thing but my mates, they always make sure I am all good… They are really good… and they are always making sure that I am alright, and that is good mates, eh?* [Matiu, 14:9]

Spending time with or doing things for the people they cared about within their *close and enduring networks* provided great motivation for all participants. Sometimes it was as simple as having people they loved to come home to.

> *The other great thing I think, I was thinking about that this morning, is having love in your life… I've come home to love and acceptance, to the most wonderful family. We are not perfect, we have our moments, we are all under stress but we are actually doing quite well, but if I didn't have that to come home to, I wouldn't bother, I'd just give up!* [Patrick, 7:10]

Sometimes it was the sense of achievement that they felt after completing a task for somebody else including getting the gardening done (Charles and Matiu), singing a song (Matiu), cooking a meal (Angela), or fixing their car.

> *Mum's car had a bust plug and they don't have to replace them that much but this one, this was mum's car, there was a need to get another new one. It is only a $2 part but it was in a kind of a place and it took me about 5, 6 days to fix it… I was like 'urgh!' but I ended up doing it myself and just got it fixed and I've never had a car that couldn't be fixed*. [Matiu, 18:12]

Pets also provided positive support for participants' mood. Charles talked about losing a number of his friends as he had been very active previously and could no longer join them in their physical pursuits. He still had a group of friends visit now and again but he described them as "more my wife's friends than mine" as they were "her work-related friendships" (Charles). He described his cat as his "mate" on several occasions during the interview.

The *close and enduring networks* provided both practical and emotional support. The practical support ranged from simple favours from a friend, to families that completely adjusted their daily schedules to help assist participants with previous roles and responsibilities. This was the network that provided the bulk of the emotional support to participants. Some of this support came in the form of simple gestures or one-off comments about their appearance or recovery. The participants also found motivation and sense of achievement from those in their close network who offered a listening ear, or through activity that involved spending time with or doing things for significant others.

Distal/Fleeting Networks

The *distal/fleeting networks* that participants discussed consisted of a wide range of individuals whom they only had brief connections with yet were formative to their community integration. This network of people predominantly provided practical support; although four participants (Angela, Rangi, Patrick, Salesi) also identified people within this network who provided emotional support. In the two cases where informational support was provided, it was due to the individual within this network having previous knowledge and experience of brain injury or a condition with similar symptoms.

The practical support received from the *distal/fleeting network* included that from shop assistants, neighbours, and the general public. There were some specific cases where people within their *distal/fleeting networks* made contributions to progressing participants towards their individual community integration goals. In Angela's case, some of the other exercise instructors whom she knew assisted her in managing her successful return to teaching the evening classes by accompanying her to the class or sharing her original schedule of classes between them and allowing her to make a gradual return at her own pace.

> *I said 'can I have another class because everyone is asking when the Monday classes are restarting and I've said I can take it?' and the girls have said 'no, you need to recover and get better and we'll see if we can put another class on'. So again, and even there, they are like, if I am feeling tired or something, they are like, 'don't worry about it someone is going to fill in for you'. They have been amazing.* [Angela, 15:13]

Matiu was interested in returning to physical exercise when he initially returned home and his daughter suggested that he try out the gym that she attended regularly. This is where he met an aqua-aerobics instructor who knew about stroke as her husband had experienced one. She was able to support Matiu to try out the aqua-aerobics, something he never would have considered before.

> *The lady who runs over at the gym, her partner was a stroke, you know, they are good. Some people who are around it, they know. Some people who are not around it, well they don't really know eh. Unless you tell them or you have got a card or something like that, otherwise you are blind to it really, yeah. But the lady at the gym, she was really good and I went to try and do the aerobics but it wasn't really my thing, I'd go, I go under the water, you know!* [Matiu, 6:2]

Rangi had a goal to return to some form of employment as he had always valued being an employee and having a work schedule. He was aware that manual labour was not ideal following his brain injury so had been encouraged to try learning to use a computer during his in-patient rehabilitation. This was something he was continuing at his local library and was grateful for the assistance of the librarians.

> *These computers, well, I'm a bit afraid of those things. They say it's only pushing buttons but where? Where do have to push them? I might delete a load of files all something! [laughs] Oh, I don't know, I'll still try anyway. It's just something, just something, well at least someone is there, you know the librarians, they come up and give you a hand and, you know, just show you this and that.* [Rangi, 14:3]

Angela, Rangi, Patrick, and Salesi also received emotional support from their *distal/fleeting network.* For both Angela and Rangi, this emotional support came in the form of positive feedback from people they had loose connections with but who were aware of their struggles and provided encouragement. For Angela, it was feedback from those attending her exercise class the first time she ran it. For Rangi, it was positive comments made by his landlord about how well he looked.

> *It was a really hard class. I didn't move as much. So I would show them and then I would tone it back a bit I was worried that, I didn't know what to expect, if I was to get really tired or anything like that, um, it was okay… but I felt good at the end because there was good feedback, they gave feedback as they always do, so there was good feedback on the class and lots of 'welcome back' and stuff like that, so that felt good.* [Angela, 12:29]

Patrick talked at length about the importance of "comradeship" that he felt with other patients in the rehabilitation unit and how their encouragement as he was transitioning home motivated and supported his progress. He also found these relationships, although short-lived, helped to reduce his feelings of "self-pity" and "isolation".

> *The two characters opposite, one was nearly going home and the other was an old, old bloke… I just got chatting to them and we actually established a great little bond. We had a lot of fun, we had a lot of laughs, we sort of egged each other on. The younger of the two, he went home about half way through my time, he was really struggling but, you know, we would egg each other on and say 'good on you!'* [Patrick, 2:26]

> *Even the major, major strokes, they seem to be able to work with it and do things, yeah. That was an eye opener for me and it stopped me, along with the socialising, staring at my navel and feeling self-pity. It really helped… I hate this bloody place [hospital] but it-is-what-it-is and I'll go with it, and I saw little bits of light and life here and there and I took them.* [Patrick, 8:22]

Patrick only maintained one of these relationships following his return home. He remained in telephone contact with a lady who he still shared "comradery" with as a result of their shared common experience.

For Salesi, who was managing behavioural changes following his ABI, emotional support came from his positive interactions with the general public. Each positive interaction appeared to reinforce his belief that he could learn to control his anger and aggression when out in public.

> *It's hard as I learn to connect with people. If it is no good then you can try to make it good and try to make it better, it depends how strong you are and that is how you learn, how you have contact with the bad people and make it good and just have some respect.* [Salesi, 12:26]

Only Angela and Andrew received informational support from their *distal/fleeting networks* and this was due to people in their network having previous experience of similar symptoms and limitations to their own. Angela had a colleague, with whom she had had little to do with in the past, but who had multiple sclerosis and was able to discuss fatigue management strategies with her. She felt this person was "on the same level" and could "open up to them and talk to them more about it" (Angela). Andrew had enrolled in a peer mentoring

programme and had a mentor who had also experienced ABI and was able to offer advice when managing his social outings and accompany him on some of these outings. Although Andrew reported that "he hasn't imparted special knowledge on me but it's cool having him there".

Professional Networks

As indicated in Table 6, and in contrast to the *close and enduring* and *distal/fleeting* networks, the *professional network* contributed the majority of the informational support received by participants. Much of the informational support was provided through face-to-face or telephone discussions with health care professionals. Only one participant (Angela) talked of written material that was provided for her to refer to at a later date. None of the participants were provided with websites or reliable on-line information sources by their professional networks. All participants referred to medical professionals, such as their general practitioners (GPs) or specialists providing advice and information mainly to do with test results that might impact their ability to return to daily activities within the community. For many, this information related to returning to driving but also included other medical information such as precautions to take while on blood thinners or eye test results that impacted their general abilities.

> *I haven't got my driver's license back yet. I had it before the stroke but when I went to see the doctor the week after she said 'well don't be in a hurry because if you are having trouble you might not get it'… Okay doc!* [Vera, 4:27]

> *What I am interested in is what the stroke person who is going to operate on my eyes is going to do. He says he can probably be able to provide abilities with what he is going to do and I'm interested to know what that is, I'm trying to find out this week. So it is going to be good if that is going to give me a chance to get myself back on my feet again*. [Charles, 1:32]

In addition to medical professionals, a lot of information came from the allied health providers working in community settings which is where a lot of the participants received their general advice and explanations about brain function, why they were experiencing limitations, and how these related to their individual brain injury. Vera received advice from both occupational therapists and physiotherapists on her use of mobility aids indoors and outdoors which helped to advance her community mobility. Angela found advice from her physiotherapist was helpful in improving her understanding of fatigue, which to her was an "invisible" limitation unlike a "droopy face". She appreciated how the physiotherapist explained this in terms she was familiar with such as "road works" and "traffic jams" within the brain.

> *I was really drained for the first week after I came out of hospital but not realising until I spoke with the rehab team why this is happening and (name of PT) explained 'you have had a brain injury and this is what has happened now, there is road works now when you are trying to go in the traffic, it's pulling you back and it is slowing you down because it needs to fix itself now, yeah, the wires need to fix themselves' and only then did I understand the impact of it all.* [Angela, 6:16]

Just as Vera and Angela found the information provided by health professionals helpful in managing their physical and fatigue issues, Matiu found advice and information from his speech language therapist important for helping understand and manage his communication impairment. This information was provided during his face-to-face intervention with the speech language therapist, but he carried it forward as he continued to practice his speech in daily life, aware this was the best kind of practice he could do after all the formal "homework".

> *And then as soon as I got home, yeah, I um had to do all my homework for [name of SLT] so, because everything she was helping me with was good for um so I could communicate with everyone.* [Matiu, 2:9]

Informational support from the *professional network* also provided participants with the confidence to advocate for themselves, with a better understanding of their impairments.

> *If I did not have them [community rehabilitation team] to explain to me what happened I would have just been lost, I don't think I would have coped very well because as soon as I had the team coming in, I could explain to my husband what was going on, the fatigue as well, because he would say "oh, you are just tired" and I could say "well it is actually different you know", (name of PT) says this and (name of OT) says that, and I could just explain to other people what fatigue is too.* [Angela, 17:12]

> *I'm learning to say 'no' a lot now, I say 'no' a lot more… like if my husband asks me to do stuff I just say 'no, I'm tired, no' or can I take another class at another pool outside of the area, I'm like 'no, I can't'. So, saying no, even if it is just little things, like the kids 'can you pick us up from the barber's shop?' – 'No!'. I feel like all those extra little things will add to me being fatigued.* [Angela, 11,7]

Practical support was also received from the *professional network*. A common objective of the professional network was to improve the participants' functional performance in activities that would lead to improved independence within the home or community. The participants also described how this improvement in functional performance often led to increases in social connection, although this was not perhaps the primary intention of the professional. Vera's occupational therapist worked with her to adapt her cutlery with the aim to improve her ability to feed herself independently.

> *The OT made me some little hand grips to go on the knives and forks so I could grip them better but I have discarded those now, just because I don't need them anymore, it's just things like peas that get away from me now [laughs] and soup is not great either.* [Vera, 1:15]

Once Vera mastered her eating, she then felt confident enough to return to eating with others and going out for meals with her friends in her retirement village. Matiu's speech language therapist practiced his use of his mobile phone so he could maintain contact with friends either via a phone call or text message, something he initially struggled with on his return home.

> *I couldn't even text, it took, trying to put a message in there [gesturing using his phone] it was a real headache you know, and even if I ring them it would be harder too. Ah, I just couldn't do it… and then like, [name of SLT] gave me some tips on how to message them, and even like, she would get me on the phone, she would record me.* [Matiu, 15:3]

Healthcare professionals assisted participants to adapt their entire daily routines, not only individual tasks, to allow for successful completion of prioritised tasks to take place across the day or week. This was particularly the case for those returning to work and those who were having to manage their fatigue levels within other community activities.

> *I went back full-time but coming home in the afternoons and having a sleep and stuff, that was after I had spoken to (name of OT) and (name of PT) and they told me you have to find this type of pattern, you need to know what works for you and if you are tired you have to take the break, all of these things, but at the hospital when I left no one told me, I wasn't given the tools to work through what has happened to me.* [Angela, 5:13]

Five participants also received emotional support from the *professional network.* For Angela and Salesi, this was formal support received through a psychologist who assisted with managing their adjustment; and in Salesi's case his behaviour.

> *I was making jest of my situation a little while ago and one of the ladies [at work] said, 'no, you should not do that'. I do it to mask what has happened. I'm working through that with [name of psychologist] as well, so yeah, I do that quite a bit. I would go, 'I've had a stroke guys, come on help me out!' [in a joking voice] and I shouldn't do that because I make light of what happened so I can mask the seriousness*. [Angela, 10:27]

> *I've been trying to relax and just do some appointments, you know, like with the psychologist… it's hard as I learn to connect with people. If it is no good then we try to make it good.* [Salesi, 12:18]

For the other three participants (Matiu, Rangi, Patrick) the emotional support received was due to the close therapeutic relationships established between them and the people within their professional network. Matiu, in particular, built a strong bond with his speech language therapist, going as far as to describe her as "part of the family" and mentioned on a number of occasions that he "missed her" and was "sad to see her go". It appeared this strong emotional bond was established through the speech language therapist's ability to focus on activities within her therapy that were of value and importance to Matiu, such as his Māori language and singing.

> *I practiced a lot of Māori on her, you know, greetings and um, er, Six Sixty I think. They have a song and she knew the Māori version of it and she would sing it on her phone and I would say, 'Hey, you are bloody too much, alright!' [laughing] because she had more vocab, more Māori vocab that I did!* [Matiu, 15:20]

The speech language therapist had worked alongside him, joining him in some of the tasks where he felt uncertain and partnering with him throughout their rehabilitation period, thus contributing to a strong therapeutic relationship.

> *She's not faking it, she's genuine you know, and even though she is from [name of country] she doesn't really care aye. She just wants to be in it with you, you know.* [Matiu, 15:31]

Both Patrick and Rangi had similar experiences with their health care professionals. For Patrick, it was his physiotherapist and for Rangi, it was his occupational therapist. Similar to Matiu, they both stated in their interviews that they had "bonded" with these people, had benefited from their "positive attitudes" and "encouragement", and they missed them now they were no longer in their lives.

Opportunities for Social (Community) Integration

Across all participants, the experience of being involved in the three social networks and receiving the three types of social support led to opportunities for ongoing social and community integration. This integration was across a variety of areas but particularly leisure activities. In some cases, these were relatively simple leisure activities such as having a meal with friends (Vera) or being able to maintain contact with friends and family by mobile phone (Matiu and Salesi). Other leisure activities that were enabled through these social connections were undertaken with immediate family such as visiting the marae (Matiu) and attending birthday parties (Matiu and Angela). Some participants were also able to venture further afield through the support of their social networks to undertake community-based activities such as

bowling and pool (Andrew) or visiting local cafes and restaurants (Angela, Andrew, Patrick, Salesi). Those participants who were eager to improve their physical wellbeing through group exercise, including attending the gym or fitness classes (Angela, Matiu, Rangi, Salesi), were enabled to do so through their support networks. In addition to facilitating leisure pursuits, social supports also created opportunities for vocational endeavours such as learning new skills in preparation for work (Rangi), returning to voluntary positions (Charles), and returning to previous employment (Andrew, Angela).

With additional opportunities for social and community integration came possibilities of expanding social networks, particularly within the *close and enduring* and *distal/fleeting networks.* This was important over time as the *professional network* shrank with services withdrawing as participants recovered and gained independence. The impacts of a shrinking network could be seen through the reports from some participants who "missed" their professional support people.

Theme 4: Engaging in Meaningful Occupations

Overview

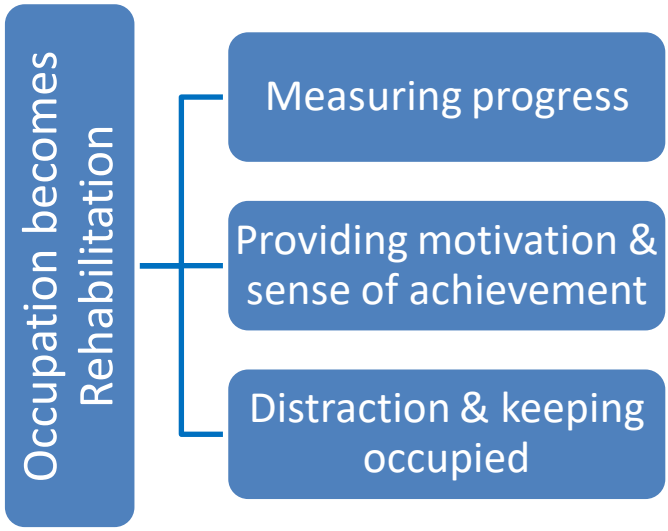
People tended to describe their progress with community integration through their engagement in occupations that had meaning for them. They started with relatively simple daily tasks and, once those were mastered, moved on to more complex activities. They tested themselves by trying out previous occupations and comparing how well they were doing based on pre-ABI performance. In this way, occupation became their new rehabilitation. Some described their attempts at enjoyable occupations such as carving or fishing as "like rehabilitation". This signalled they were aware that engaging in these activities provided them with an opportunity to practice a variety of skills ranging from communication to behaviour management to hand dexterity. Others described their ongoing progression in their occupations as keeping up with the rehabilitation "plans" and "protocols" they had been taught in the in-patient setting.

Achievement in daily occupations and establishing greater levels of independence gave people motivation to make an effort and continue practicing and pushing for progress. Occupations that gave them a sense of contributing or doing good for others were particularly motivating and important for some people. Daily occupations also served a purpose of keeping participants busy and distracted from thinking about more negative aspects of their lives or lifestyles they felt had been "sacrificed" following their ABI.

Figure 10 summarises participants' experiences as they described their efforts to engage in meaningful occupation and progress their community integration through actions of "trying", "pushing", "testing", "practicing", and "giving it a go". Their descriptions demonstrated how they viewed their daily occupations as a new kind of rehabilitation, less formal than that they had experienced in the in-patient environment. Engaging in meaningful occupations helped the participants to measure their progress, motivated them through achievement and increasing independence, and kept them occupied and distracted from negative thoughts and feelings.

Figure 10

Engaging in Meaningful Occupations



The sections that follow are divided to reflect the four portions of Figure 10. The first section comprises of the actions participants undertook that created ongoing informal rehabilitation opportunities, *occupation becomes rehabilitation*. The subsequent three sections describe the results of these actions including *occupation to measure progress, occupation providing a sense of motivation and achievement,* and *keeping occupied and distracted.*

Occupation Becomes Rehabilitation

Participants described how they purposefully chose or adapted daily activities within a variety of domains including self-care, domestic, leisure, and productivity to incorporate aspects of their ongoing rehabilitation. They then "pushed" themselves, "practiced" or graded the complexity of tasks, and "gave it a go" to progress their independence in daily activities that would lead to increased community integration. For some, this was physically based

progressions with skills like strength, endurance, coordination, balance, and dexterity. For others, it was cognitive or communication skills or developing behaviour management abilities. Most participants were cognisant of making progression and talked about how it was "like my rehab" (Matiu) or a continuation of the "plan", "carrying on my physio" and "sticking to the protocols" (Rangi).

Most participants had experienced or continued to experience impacts on their physical abilities, particularly using their arms and hands. Vera's left (dominant) hand was affected by her stroke and she was having difficulty with managing a range of tasks due to the lack of dexterity. She began with practicing some personal and essential activities within the home to help rehabilitate her hand, including using her hand to comb her hair and practice writing her signature. She also used her weaker left hand in some of her social activities, such as playing bingo, as she was aware this would help her to regain further function. She adapted the way she picked up counters from the table so that she incorporated her left hand into the activity as much as she could, while also keeping up with the game.

> *I've done a whole pile of writing my signatures… It's bit unfortunate because I've got arthritis in both hands and the worst is the right one and of course the stroke affected the left one didn't it… the hand got in the way. Things like combing my hair and cleaning my teeth and that sort of thing was difficult. It's not entirely better now, but a lot better than it was.* [Vera, 2:9]

> *Bingo, that was the other thing that I have done. I found that… well it was difficult picking up the counters off the table… I had to pick them up with the other hand, used my brain, then put them into this hand so I could put it on [the bingo card]. I'm normally a left hander you see so it's easier to put it in that hand [indicating left, weaker hand] but I can't get it off the table so I pick it up with that one [right hand] and put it in to this one.* [Vera, 10:27]

Andrew and Matiu chose a variety of leisure occupations to practice their upper limb recovery. These ranged from playing pool to help with reach, to carving complex wood carvings as gifts for whānau to help with hand-eye coordination.

> *My reaching for pool is not that good but it's actually improved quite a lot considering how quick it has been. Like, the physio is quite impressed with how much arm movement I have.* [Andrew, 3:9]

> *I dropped everything out of this hand. It was useless. Like I'd be holding on to stuff and it would drop on the ground so I used my mallet with that hand to give me more strength… it was really good. It's still a little bit slow, but way better than before. Yeah, and for my hand, what's it called, my eye, what's it called, my eye-hand, my hand-eye, you know?* [Matiu, 7:7]

Other participants, such as Charles and Rangi, had physical limitations due to a lack of general strength and endurance so they chose to practice activities that assisted them in building up their stamina such as composting, stacking wood, and taking long walks.

> *That's why I'm carrying that wood around because I'm trying to build up. Before I was trying to get my legs, trying to get those strong but my upper body wasn't strong so now, you know, I'm half cocked, you know, I'm not operating properly so I thought I'd do the composting, lifting and strengthen up my arms.* [Charles, 12:12]

> *It's been slower, you know, the body, it's been slower to go through the process, but when you do it [long walks] all the time, you start getting faster and faster and you start getting back to the real world.* [Rangi, 20:1]

Some participants integrated the management of their cognitive and communication impairments into everyday activities. Fatigue was described as impacting on most participants' cognition, causing a deterioration in performance. They had to monitor this cognitive deterioration and arrange their participation in daily activities in order to manage the impact.

> *But the main thing is the fatigue because I get distracted, can't concentrate. There just feels like there is this wall and I can't push through it and I get grumpy [laughs], I get really grumpy!* [Angela, 10:4]

> *Today I have heaps of energy because I've been sleeping every [afternoon] since last Wednesday and I was going for it at work today, my brain was firing, and I was full pistons and everything but, if I don't have a nap this afternoon, tomorrow I will just start going downhill again.* [Angela, 9:27]

Matiu was the only participant who had significant communication impairment. He described how his speech language therapist had encouraged him to incorporate his practice into his daily occupations as she concluded her formal community rehabilitation with him, rather than continuing with his "homework" tasks, which mainly consisted of drills, pen and paper tasks, and exercise sheets.

> *That's pretty much what [name of SLT] said, after you get um, it's your daily actions that get you sort of like um, that is your practice, daily practice. And I haven't went back to… [name of SLT]'s homework box, and like I haven't been back to that since she finished with me*. [Matiu, 17:21]

Both Rangi and Salesi had issues relating to behaviour management following their ABI; although these issues were only in the initial stages of recovery for Rangi. For Salesi, managing his behaviour during interactions with people in the community, such as on the bus and in the shops, became his rehabilitation which he referred to as his "learning".

> *I tell my psychologist, it is a good education I think. I learn every day from the people that I see every day. I do a bad thing and I begin to slowly stop it and go the other way and make it good. That was the best education I learned. I learn from all the people.* [Salesi, 6:31]

By incorporating their ongoing rehabilitation and progression towards community integration into their daily occupations, participants identified that these actions provided them with a range of outcomes. These outcomes are described in the following sections and include: the ability to measure their progress, a sense of motivation and achievement, and keeping themselves occupied and productive.

Occupation to Measure Progress

Through their efforts to progress in their meaningful occupations, participants were able to monitor and measure their success. They did this in a variety of ways. Some started with simple tasks, such as walking, and measured improvements in stamina by paying attention to the distance walked or the time spent out walking. In Vera's case, her reduced dependence on walking aids as she stopped using her walking frame and "progressed to using a walking stick sometimes outside" was a marker of progress.

> *I go walking for instance, my walk is down the road and I do the block and then… that is the little block… and then two, no a week ago, when I went out I went the whole block all the way down and it was half an hour's full walk and I felt 'that's good'. I wanted, before I was only doing a quarter of an hour but I pushed myself to half an hour just a week ago*. [Charles, 5:5]

For Charles, measuring this progress was more than just about walking. He had a greater purpose in trying to improve the distance walked. By increasing his tolerance, he would be able to get to a number of locations that he enjoyed such as the botanical gardens, the local café, or the hospice where he knew people.

> *I am keen to go and get a cup of coffee down at the, at the, gardens… Then we can walk through the gardens. And the hospice is up through the other side and it's a similar distance so you can go that way or that way*. [Charles, 5:22]

Those who had cognitive or communication impairments took a similar approach to measuring progress. Matiu, for example, measured his improvement in daily conversation by the number of words he was able to say in one response.

> *I was still in about like two or three word conversations, you know, and now it's a little bit more better and it is only going to be more better as time goes on I suppose, aye? I hope so! And that is the only reason why I can tell, you know, before I couldn't really um, it takes ages to get it out, what I want to say, you now, until now, I can't shut up now!* [Matiu, 17:14]

Participants also went about measuring their progress in terms of getting back to "normal" or having things feel more "natural". They reported attempting to return to their previous ways of engaging in activities whilst also being pragmatic about their limitations. Patrick described, "the desire to be normal has to be tempered with, you have to go slowly".

> *I want to get back to as normal a life as I possibly can. It's been a long, slow process. It's been longer and slower than I thought it was going to be. This type of thing is quite demanding it wasn't easy to do. So, anyway, I'm going to do it.* [Charles, 12:23]

> *The last few mornings I have started to feel really good. I sort of feel normal again, I'm sort of with it. I'm not worried about if I'm going to fall over or thinking 'oh god, I've got to walk again'. That was hard in the beginning… It's a much more natural sort of thing now.* [Patrick, 11:24]

Measuring their progress was also achieved through their reduced dependency on others and getting back to performing their previous life roles more autonomously. For Angela this was cooking dinners for the family and what this meant to her in terms of her role as a mother.

> *It felt so good getting back into cooking the dinner for the family because other times I was just too fatigued to do it. It was just bossing someone, telling them what to do or [husband] would cook the dinners or the kids would cook and be like 'urgh, I don't want to' but they had to because mum can't do it… getting into that made me feel so good.* [Angela, 20:24]

Feeling more capable and confident carrying out their daily occupations was also a sign that they had made progress.

> *I feel capable, confident, I don't even have to think about them [daily tasks] anymore to be honest… I don't think about it, I just do them.* [Patrick, 17:21]

Engagement in occupation was used to measure and monitor progress through objective measures, such as changes in distance or time; and reductions in dependence on others, such as the removal of home care support. It was also measured through more subjective changes, like progress towards "normality" or feeling more confident.

Occupation Providing a Sense of Motivation and Achievement

Engaging in meaningful occupations and seeing their progression provided participants with a sense of motivation. When activities were completed successfully or an additional milestone accomplished in their progression, there was a sense of achievement. Angela described the first time she was able to run her exercise group without the assistance of another trainer and how much she "loved" the feeling of returning to this level of ability again.

> *I teach the class but at the same time I give it my all and I know when I am there it is just me, the people in the water and there is nothing else happening. I have to deliver and they have come to train so I really enjoy that part of it and I love being there so I just loved getting back into it.* [Angela, 20:17]

For others, the motivation behind their engagement in an occupation and their sense of achievement came from doing things for others. This was a significant motivator for Charles who felt a need to "contribute" to his community and feel "useful" and "constructive". Matiu had similar motivations when engaging in his carving as his creations were to be gifts for members of the whānau. Patrick also felt motivated to help out when he saw his daughters struggling with some of the daily chores.

> *I like to help more around the house. I see the girls struggling with stuff. I've been putting the rubbish out and doing the bins and, God, it all sounds so very, very basic. There is a lot to running a house, all sorts of stuff. The essential stuff, I've been doing a little bit more of that for them.* [Patrick, 12:8]

Participants were determined to carry on their rehabilitation and progress towards community integration so as to not disappoint those who had invested time and effort supporting them to recover. Rangi did not receive any formal rehabilitation input on his initial discharge; this came later in the form of cultural support services. Instead, during his first few weeks back at home, he managed his own progress and rehabilitated himself, enjoying the development that he saw in himself, but also wanting to ensure he did not let anyone down who had helped him to that point.

> *What I've really enjoyed the most since I got out [of in-patient rehabilitation] was carrying on my rehab… doing all my rehab and carrying on with my plan, anything like that, that is what I enjoy the most now, just getting up and starting on my protocols… that is what I have loved the most… I just want to, just want to carry on the work from [name of rehabilitation unit]. It is all about trying to be happy and I have come a long way.* [Rangi, 20:11]

> *I have got to protect my head because if this happened again then that is it, game over. I don't want that, and I don't want any sad faces back in the place where they helped me. So, I am doing this for them too, aye, all those good supporters.* [Rangi, 19:19]

Future aspirations included a range of occupations that would allow greater degrees of community integration and continue to keep participants motivated to progress. As mentioned previously, for several participants, one of these occupations was driving. Not just simply the act of driving, but what driving would make possible which included being able to return to their voluntary role (Charles), being able to visit old friends (Vera), or being able to look after her children to a greater extent (Angela). Andrew provided another example in the task of building his desk on return home. This activity led to the ability to use his new computer and flight simulator. His hope was that practice on his flight simulator would be a step towards his pre-ABI goal of qualifying as a pilot.

> *I've only just put [the desk] in my room, I don't know, maybe a week ago. I've only just finished it and I bought that PC to go on it, so I guess we will see. I was planning on being a pilot before, so I was buying a PC to use with the new flight simulator but I probably can't be a commercial pilot just yet. Well, I mean, never say never.* [Andrew, 7:25]

Patrick also discussed hopes and aspirations for future occupations such as returning to his previous job, which gave him the drive to keep "pushing" himself. He reflected on new productive aspirations with the potential to use his experience of recovery to help others.

> *Perhaps next year I could even mentor people who had strokes, because of my background and dealing with people and stuff in all sorts of situations. I would be quite interested in that, and it's not coming from a 'God, I know everything!'. No! But there is a common human experience here. It's not out of a book. We are all in the same boat.* [Patrick, 14:28]

In addition to measuring their progress and providing participants with motivation and a sense of achievement, *engaging in meaningful occupation* also provided the simple outcome of staying occupied. Participating in meaningful daily occupation kept participants' minds off their ongoing "struggles" and helped avoid any deterioration in their mood.

Keeping Occupied and Distracted

Staying busy and keeping themselves occupied to prevent boredom was one of the reasons that participants continued to *engage in meaningful occupations*. They felt it was "good to keep busy" (Matiu) and chose productive but relatively straight forward activities in order to keep themselves "out of mischief" (Matiu).

> *I do enough around the house to keep myself occupied you know. I do my lawns and my gardens and even fixing my trailer, you know, do all the things like that. I can pretty much do all that so that is enough… I'd get bored otherwise.* [Matiu, 6:14]

> *I moved my room around, chucked some of the shit out and moved things around a bit, just to keep me occupied. Once I had moved it around and felt I'd stabilised things, that's when I started hitting the basin, going up and moving around every day… Four or five hours I am out, and then I come back and I'll start doing stuff around here, you know, I couldn't just sit.* [Rangi, 11:28]

Staying focused and participating in their daily occupations was noted by some participants (Charles, Angela, Patrick, Rangi, Salesi) to prevent a deterioration in their mood, or "wallowing in self-pity" as Patrick phrased it. The focus on the tasks, noting their progression, and keeping their eye on their ultimate community integration goals were all strategies that the participants appeared to utilise to remain optimistic. Charles reflected on how walking around his neighbourhood, increasing his distance and speed, and focusing on his goal of making it far enough to the local café and botanical gardens, kept him from becoming despondent.

> *I can go for walks and develop, because my legs are strong and upper body is getting stronger. So I am trying to work my way, a bit at a time and work my way to it. I'm not saying, 'oh, woe is me' I certainly do not want to do that*. [Charles, 12:19]

Certain participants (Rangi and Salesi) had made significant lifestyle changes since their ABI with the support of their in-patient rehabilitation teams. They seemed determined to maintain these positive changes. Now they were back living in the community and external support was less frequent, engaging in their newly found productive occupations enabled them to maintain their positive lifestyle changes and prevent them regressing to previous lifestyle choices, such as heavy alcohol use.

> *It's [learning to use the computer] something anyway, to help me get my mind off my sacrifices, that's all I'm trying to do, that's all I want to do. Keep me occupied and keep away from, well stay away from my dark side. It's all good anyway because it is working, it is definitely working.* [Rangi, 14:13]

Engaging in meaningful occupations was the fourth and final theme generated from the synthesising and theorising stages of data analysis. This theme encompassed the actions that participants took to incorporate their ongoing rehabilitation into daily occupation, including "pushing", "trying", "giving it a go", and "a whole pile of practice". Engagement in daily occupation also provided participants with a range of outcomes including measuring progress, providing motivation and evidence of achievement, and keeping busy.

In the following section, the patterns and relationships between the four themes: *Growing into a new way of community living, Living up to expectations, (Re)Building social connections*, and *Engaging in meaningful occupations* are explored.

Relationships Between Themes

Overview

The purpose of this fifth and final section of the findings chapter is to illustrate the interconnections between participant experiences across the four themes. When working through the synthesising and theorising stages of analysis (described previously in Chapter 3 – Methodology) multiple interconnections were found across all four themes. In keeping with the structure of this findings chapter, a visual representation of the themes and their interconnectedness is provided (see Figure 11) and brings together all four themes, and associated sub-themes, into one figure. Each of the themes represents an aspect of community integration made visible through the research process. Analysis suggests that these must be pieced together and work alongside each other for a successful experience of community integration as a whole for those with ABI. As such, the four themes are represented as interconnecting loops. If all four are not present then the journey towards community integration is interrupted. All four aspects of community integration are required to work in unison for continued progress in community integration.

Figure 11

Relationships Between Themes

In the following section, some of the more dominant interconnections are discussed as examples of how the four themes overlap and need to work in tandem for community integration to progress.

Interconnections

Within *Growing into a new way of community living,* the sub-theme *early days back at home* included the participants' experiences of support from their rehabilitation team to assist them in finding practical ways to overcome some of their limitations. Rehabilitation professionals also provided psychosocial support and advice to facilitate progression through this stage of "growing". This connects to sub-theme of *professional networks* within *(Re)Building social connections,* where the professional network is identified as providing three types of social support—practical, emotional, and informational. *Growing into a new way of community living* is further connected to the theme of *(Re)Building social connections* through the *close and enduring networks* sub-theme. This network provided practical support to participants, particularly evident during the *back into the bright and busy world* phase of *Growing into a new way of community living*. In this phase, participants relied on their family to assist them in managing interactions with others in the community who had little knowledge of the impacts of ABI, such as bank staff.

Growing into a new way of community living links to the theme *Engaging in meaningful occupation.* In the *settling back in* phase, participants began to feel day-to-day household activities were more "natural" following the adjustments and accommodations they had made to achieve success in these activities. This is when they started making comparisons between pre- and post-ABI abilities as they mastered simple activities and began to attempt more complex ones. An outcome of *Engaging in meaningful occupation* was the participants' ability to use *occupation to measure progress*, monitoring and measuring success towards community integration through both objective and subjective measures. One of the more subjective measures was the feeling of "getting back to normal" or performing more like their pre-ABI self. *Engaging in meaningful occupations* also linked strongly to the *role expectations* sub-theme within *Living up to expectations*. The meaningful occupations that participants tended to choose to engage in were closely linked to the responsibilities that came with their roles in life such as a mother choosing to make meals for her family, and a carver choosing to create carvings as gifts.

A further prominent connection is that between the *close and enduring networks* sub-theme within *(Re)Building social connections* and *expectations of family and whānau* sub-theme within the theme *Living up to expectations.* Where close and enduring networks were found to

provide practical and emotional support to participants, this support was based on expectations of progression and recovery held by family or whānau members.

Many other interconnections exist between the four themes and some existed between multiple themes. Those described above are some examples of the more predominant themes that have been mentioned in the body of the previous four sections of this chapter.

Summary

This chapter has explored the four interconnected themes that were derived from the data analysis process described in Chapter 3. *Growing into a new way of community living* demonstrates the four-stage process that participants described as they worked towards increasing levels of community integration. The theme *Living up to expectations*, whether those were internal or external, illustrates the range of expectations that participants felt impacted on their community integration journey. *(Re)Building social connections* demonstrates how the participants used three types of social networks to establish three types of social support which assisted in their social integration and led to further opportunities to build their networks. The fourth theme, *Engaging in meaningful occupation,* highlights how participants began to consider their daily occupations as a type of rehabilitation, as formal rehabilitation services withdrew. From engagement in their chosen occupations, they found a means of measuring their progress, a sense of motivation and achievement, and a way to establish a routine that kept them occupied. The final section of this chapter demonstrated how these themes were interconnected and provided examples of how relationships between themes supported the progression of community integration.

The findings reported in this chapter have several implications for clinical practice. These will be the focus of the following Chapter 6 as the ultimate purpose of an Interpretive Descriptive enquiry is to apply findings to the real world and create useful clinical practice insights. In the final Chapter 7, the findings will be more broadly discussed to demonstrate the contribution this work has made in relation to expanding the knowledge about community integration following brain injury.

Chapter 6: Clinical Implications

Introduction

Developing insights that can inform improvements in clinical delivery is a key aim for Interpretive Descriptive studies, and was a primary reason for using this methodology. As noted in Chapter 1, a key question for this study was "what additional support, services, or strategies could be put in place to help support community integration for people with ABI?". This chapter, therefore, focuses on discussing the clinical implications of the findings for rehabilitation services, health organisations, and public health policy. The chapter is structured using the four themes discussed in Chapter 5. Within each theme, there is a focus on key points relevant to potential improvements to practice, organisation, or policy that would create a positive impact on the aspects of community integration related to that theme.

Growing Into a New Way of Community Living

There are two areas of clinical improvement that arise from the theme *Growing into a new way of community living.* They are mainly relevant to the earlier phases of *preparing for discharge* and *early days back at home.* The first, relates to the benefits of integrating community re-entry activities into pre-discharge planning as people prepare to leave the structured and supported in-patient environment. The second, involves consideration of consistent emotional and psychosocial support from across the rehabilitation team to assist the person with ABI to manage the range of emotions that accompany their efforts to reintegrate back into their community lives.

Community Integration Within Discharge Preparation

Some participants identified that they had begun their transition into the community before leaving the in-patient setting. However, rehabilitation activities were mostly focused on preparing them to live within their own homes by creating opportunities within the in-patient environment to mirror the home setting and practice practical skills that would be required to participate in basic daily living activities such as self-care. While national clinical guidelines recommend that a pre-discharge home visit occurs "to ensure safety and provision of appropriate aids, support and community services" (Stroke Foundation - InformMe, n.d.), fewer than half of the participants were given the opportunity to visit their homes to trial practical skills within their real-world context. Even fewer participants were provided with an opportunity to experience more complex community-based activities and establish strategies to manage these before leaving the in-patient environment. Those who did have this

opportunity felt more prepared for life in the community, established an awareness of what challenges might face them as they continued their community integration journey, and had more developed coping strategies for managing setbacks in their progression.

Those participants that received formal community-based rehabilitation services on their transition home described these as focusing predominantly on activities based within their own home or garden, rather than anything further afield. In the later phases of community integration, when venturing beyond their home and *getting back into the bright and busy world,* participants (other than those engaged in return-to-work programmes) did so without support from rehabilitation providers, utilising strategies that they had put into practice in other areas to establish if these would suffice.

People with ABI have previously reported that the practical support to deal with managing functional independence has been important to them on their transition home (Stiekema et al., 2020). However, as highlighted in Chapter 2, they have also reported feeling ill prepared for community living on their transition out of in-patient services and in the early stages of re-settling at home (Govender et al., 2019; Stiekema et al., 2020; Turner et al., 2008, 2011). Over 10 years ago, Turner et al. (2011) emphasised the importance of people with ABI testing and getting a sense of their level of autonomy within contextually appropriate community environments, suggesting this provided a foundation for successful early community integration. They found that preparation for the real world is an essential component of person-centred rehabilitation for people navigating life after ABI. My findings suggest that this component remains inconsistent across the services, as experienced by my participants. Incorporating community-based rehabilitation activities into the discharge preparation would likely facilitate an increase in participation in rehabilitation beyond everyday self-care tasks, and support progression towards confident community integration.

Early involvement in community integration prior to and in the early stages of return home, when formal rehabilitation supports were still in place, provided participants with awareness of how they were able to perform valued or essential occupations within a community context. They were then able to work with their rehabilitation professionals to establish strategies to manage these activities and build self-management skills to prepare them for formal supports being withdrawn. An example of where other specialist services have recognised the importance of bridging this gap between supported in-patient services and returning to the community is that of the Transitional Rehabilitation Programme based at the Burwood Spinal Unit in Christchurch (Te Whatu Ora – Waitaha Canterbury, n.d.). This programme is located within a home-like environment, adjacent to the spinal rehabilitation

unit, with each client having their own bedroom and shared kitchen and living facilities. Learning sessions are facilitated by independent living coaches who are people with spinal cord injury who have experience of living in the community. The programme usually lasts 4-weeks prior to discharge and focuses on the skills important to the client's return to their community. Research has also demonstrated how transitions can be improved. In an attempt to improve the transition home experiences of people with stroke, Gustafsson, Hodson, Fleming, and Hoyle (2014) implemented a novel inpatient outreach program - STRENGTH (Stroke Rehabilitation Enhancing and Guiding Transition Home) and conducted a qualitative study to investigate expectations and experiences of participants. STRENGTH increased opportunities to practice activities and test abilities in the home and community during the week prior to discharge. It was found that this promoted realistic expectations, adaptation and confidence, and provided the ability to better plan for return home. Despite the positive outcomes of this study the STRENGTH program does not appear to have received funding anywhere outside of the original study site. These two examples, one from New Zealand, the other from Australia, may serve as an example on which similar services could be based for people with ABI.

The early community integration phase is considered pivotal to enhancing awareness in functional abilities, roles, relationships, and routines in previous studies exploring the perceptions of people with ABI (Nalder et al. 2012; Turner et al., 2011). The interplay between community integration, developing awareness, and emotional adjustment was apparent in the theme *Growing into a new way of community living*. As participants experienced more complex community-based activities, their awareness of their brain injury and its impact grew. Emotional responses varied with positive and negative experiences, and when mastery of certain skills co-existed with the struggle to progress in other areas. Services need to support people through successful community integration by providing opportunities for experiencing community-based activities, building awareness, and navigating the emotional response. Provision of psychosocial support may be a key component and is discussed next.

Access to Psychosocial Support to Progress Community Integration

Participants used emotive language—"crushed", "useless", "frustrated", "frightened", "worthless", "embarrassed", "a burden"—to describe their struggle of returning to the community and discovering differences in their functional independence. They also discussed uncertainty, frustration, low mood, and self-doubt. The same emotive language has been used by participants with ABI in previous research exploring their perspectives of transition from hospital to home (Turner et al., 2011). My participants indicated there was little focus on their

emotional or spiritual wellbeing in readiness to integrate back into their home and communities. Participants perceived that health professionals were more focused on the practical and safety aspects of managing once back at home, rather than anything broader. In exploring rehabilitation delivery from the perspectives of the health professionals, similar findings have been reported where value is placed on physical improvement and achieving optimum safety in basic daily activities such as transfers (Bradley et al., 2021). This finding is also reflective of findings in a longitudinal qualitative study of stroke recovery which referred to a theme of "needing to fit in with what's offered" (Theadom et al., 2018, p. 6). Participants in that study reported that rehabilitation focused predominantly on managing the physical effects of their stroke and that psychological impacts were less well addressed. As mentioned above, supporting the development of self-awareness through real-life experience may have a positive influence in progressing community integration; yet can lead to emotional distress. The fluctuations in emotional state have the potential to impact on psychosocial wellbeing and the capacity to persevere with ongoing integration. Nalder et al. (2013) have highlighted the significance of the transition phase in the process of adjustment. These authors identified how adapting to a new normal involves the individual with brain injury fluctuating between perceived freedom along with frustration over the loss of former independence.

Only two participants in my study discussed receiving formal psychological support to manage their emotional responses to the challenges and frustrations described above. One of these participants was also managing severe behavioural issues, this being the main focus of his psychological support. Formal psychological support is a scarce resource within health services in New Zealand (Czuba et al., 2017). Such scarcity is not unusual and reported in countries with similar health systems including the United Kingdom and Australia (Gilham & Clarke, 2011; National Stroke Foundation, 2014). In New Zealand, people experiencing stroke have reported the emotional, spiritual, and social challenges they experience and have described limited resources available to them to cope with these difficulties (National Stroke Network – Psychosocial Working Group, 2022). A proposed solution to these limited resources is a stepped care model for supporting psychosocial wellbeing that incorporates a proactive approach from a wide range of formal and informal services that support the person with ABI. Although the evidence for this kind of stepped care model is only recently emerging for use with the ABI population, there are promising indications that implementation of such a process results in improved outcomes in terms of emotional distress, mood, satisfaction, physical function, and quality of life without significant cost implications (Baker et al., 2018; Kneebone, 2016; Meuldijk & Wuthrich, 2019; National Stroke Network – Psychosocial Working Group, 2022).

Kneebone (2016) elaborated on the stepped care model that was originally proposed by the Department of Health in the United Kingdom for psychological support after stroke (Gilham & Clarke, 2011). Level 1 of the model considers sub-threshold problems that are common to many stroke survivors who are having general difficulties with coping with the consequences of their stroke on their lifestyle. Level 2 considers those with mild to moderate levels of impaired mood. Interventions at Levels 1 and 2 include support groups, befriending, active listening, normalisation, advice and information for adjustment, goal setting, problem solving, motivational interviewing, relaxation techniques, and peer support that could be delivered by members of a multi-disciplinary rehabilitation team or voluntary support networks with some additional training. At Levels 3 and 4 of the stepped care model, people exhibit more severe psychological issues including suicidal ideas, risk of self-harm, and challenging behaviours. At these steps, interventions are more specialised and include cognitive behavioural therapy and behavioural management strategies that are best delivered by trained psychologists. Kneebone suggested that the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983) should be used for assessment and to guide decisions about what level of support is needed. Validated psychosocial screening and any indicated risk assessment at least once during an individual's episode of care is similarly recommended in the recent New Zealand National Stroke Network's guidelines for supporting psychosocial wellbeing (National Stroke Network – Psychosocial Wellbeing Group, 2022).

The use of the stepped care model described above has been investigated for people with communication disorders and adaptations introduced to optimise communication within the interventions for people with aphasia, particularly at levels 1 and 2 (Baker et al., 2018). The stepped care model has also been proposed as a solution to address service gaps in the provision of support for people in hard-to-reach populations, including those in remote or rural areas and those with transport or mobility issues (Meuldyk & Wuthrich, 2019).

My findings reflect the ongoing need for psychosocial support to address emotional distress during all four phases of community integration reflected in the process of *Growing into a new way of community living.* It is recommended that multi-disciplinary psychosocial screening be administered at designated intervals in the rehabilitation journey (e.g., on entry to in-patient rehabilitation, during the discharge planning phase, after the initial phase of re-entry to the community). Dependent on the outcome of the screening the appropriate step level of support could be established and interventions delivered to prevent, minimise, or address the emotional distress. The majority of these interventions could be delivered by multi-disciplinary members of a rehabilitation team or through community-based organisations such as peer support services (these will be discussed in detail later in this chapter) to prevent or minimise

emotional distress. Only those with severe difficulties would require formal psychological support but would be identified early to prevent further deterioration in mood.

With community-based rehabilitation being limited in some areas of New Zealand due to the remote rural demographics of some locations, interventions at the lower levels of the stepped care model, such as goal setting, motivational interviewing, and relaxation have been proven to be effective when delivered remotely via telephone or web-based solutions (Meuldyk & Wuthrich, 2019). This could also meet the needs of a population with ABI who have limited access to transport options, are unable to drive, or have ongoing mobility issues. Adaptations to the interventions would be required for those with communication and cognitive impairment. Some advice in this regard exists although further work is warranted in this area (Baker et al., 2018).

Routine screening and the use of a stepped care model are ways to distinguish between those who are having difficulties with what would be considered a natural emotional response to their altered abilities and those who have more serious clinical needs. It provides rehabilitation teams with strategies that could be considered to address the psychosocial issues that are identified through routine screening at regular intervals. The role of the therapeutic alliance between clinicians and people with ABI, as a form of general emotional support relevant to levels 1 and 2 of this model, is discussed within the *(Re)Building Social Connections* section later in this chapter.

Living Up to Expectations

My participants described a range of (perceived) expectations that impacted on their ability to reintegrate into their communities. There were internal self-expectations along with external expectations from significant others (family, whānau, friends), or derived from role responsibilities, or society. Some of these expectations had a positive impact on individuals, motivating them to progress. However, some were limiting, resulting in a barrier to their progression. There is potential to address the limiting self-expectations through interventions incorporated in the stepped care model described above. However, the significant impact of external expectations demonstrates the need for rehabilitation services to focus both on the needs of the individual with the brain injury and extend support towards those with whom the individual interacts when returning to the community.

Involvement of Significant Others in Community Integration

Family and whānau expectations were found to be particularly pivotal in influencing community integration. Therefore, their involvement in rehabilitation and information sharing

should be prioritised alongside the individual with ABI. The involvement of family in the brain injury rehabilitation process has been well documented with various authors encouraging rehabilitation professionals to help families learn about brain injury recovery, and address family perceptions of patient function to facilitate favourable outcomes (Evans et al., 2008; Foster et al., 2012; Kreutzer et al., 2010; Sherer et al., 2007). Less has been documented about specific family-centric interventions to facilitate community integration once an individual with ABI returns home. My findings indicate that it would be wise to incorporate family members, who are likely to be the primary support for the individual with ABI as they progress into community living, to equip them with the skills required to undertake this support role and address any limiting expectations they may have.

Participants' stories indicated that their family or whānau members were strongly motivated to support their return to greater levels of independence in community living. However, family and whānau had varying expectations of the rate and extent to which this could be achieved, creating challenges to progression. As previously mentioned, while there are recommendations to enhance family involvement in the general rehabilitation process, there is limited understanding of family members' needs in facilitating community reintegration. Recognising this gap, Gagnon et al. (2016) focused on gaining an in-depth understanding of the roles that family members take, challenges they encounter, and potential supports they require to facilitate ongoing community integration for a person with ABI. They identified six key support roles that family members frequently engaged in: researcher, advocate, case manager, coach, ADL [activities of daily living] supporter, and emotional supporter. They also identified key challenges associated with these roles including difficulties with navigating the health/support systems and advocating for the person with ABI. The authors made recommendations for supporting family members' continued engagement in the community integration process through comprehensive interprofessional programmes that incorporate educational information, advocacy, and coaching skills; health care orientation packages; and summaries of relevant legislative policies. They also suggested connecting families to appropriate community-based resources (vocational services, peer support groups, brain injury associations) at varying stages of recovery to minimise the time they spend on researching suitable services and allow them to prioritise other aspects of support. Although not mentioned by Gagnon et al., perhaps connecting families with these kinds of longer-term support agencies would also reduce time spent in researching, advocating, and coordinating roles, allowing more time to maintain their original relationship as a mother, father, husband, wife, son, or daughter. As noted by Fadyl et al. (2017), many families and whānau feel an

expectation from professionals to be readily available to provide support for their loved ones, without consideration of other pressures and commitments that may restrict their ability .

A practical example of how some family-inclusive interventions can be put into practice can be seen in Winter et al.'s (2016) description of their Veteran's In-home Program (VIP). The VIP is described as "an innovative programme for veterans with TBI, delivered in veterans' homes, involving a family member and targeting the environment (social and physical) to promote community re-integration" (Winter et al., 2016, p. 373). The aim of the VIP is to focus on the veteran and their family member together, by bringing the family member into the intervention as much as possible, including the family in the process to reinforce intervention strategies, keeping them informed, and addressing their needs in addition to the needs of the veteran. The programme includes six in-home sessions, with both the veteran and family member present, and includes activities such as discussing expectations of the family member, reviewing the routines of both family member and veteran, providing both with information and education materials, helping family better understand the experience of recovery, addressing family concerns, observing communication and interactions, introducing and practicing stress and emotional management techniques with family, and discussing coping strategies. These are in addition to the practical activities of joint goal setting and practical problem solving to address impacts of ABI on daily living activities. In their randomised controlled trial, comparing the VIP to usual out-patient clinic interventions, Winter et al. demonstrated how veterans receiving VIP had significantly higher community reintegration scores on the Community Re-integration for Service Members Scale (Resnik et al., 2009) at follow up than the control group. They attribute this positive outcome, in part, to the involvement of the family member in the intervention along with the veteran, and thus establishing similar expectations of progression in both parties. In the absence of being able to integrate the full VIP programme, as described above, community-based services could still integrate aspects of the programme into clinical delivery such as providing education materials aimed at family members, taking account of the family routine in addition to the routine of the individual with ABI when establishing goals, and taking opportunities wherever able to engage the family members in joint problem solving alongside the person with ABI.

The expectations of close friends were also found to have an influence on participants' community integration, with participants in the current study describing both low expectations, such as the likelihood of them remaining "crippled"; and high expectations, such as looking good and therefore functioning fine. Similar to participants in my study, those in the study by Stiekema et al. (2020) also identified that relatives and friends did not empathise with the impact of their brain injury, and they were tired of continuously defending themselves for

not engaging to a greater degree in social activities as they “look so good” (p. 424). In my study, only one participant mentioned engaging with friends during their in-patient rehabilitation stay, and that was a single visit. Most participants re-engaged with their pre-injury friendships once they left the in-patient setting and were settling back into their lives at home. Therefore, the expectations of friends as they re-engaged with the person with ABI were based on knowledge and experience of others who had gone through similar conditions, rather than the reality of the current situation. It was difficult, by this time, for friends to engage with formal rehabilitation professionals who could support their understanding and expectations, and the person with ABI was left to advocate for themselves.

Being misunderstood by friends is a common experience reported by people with brain injury in previous mixed method studies (Douglas, 2019); with this lack of understanding preventing a sense of belonging and resulting in people being dismissive or detached. It is noted in previous literature that traditional approaches to maintaining friendships after ABI have focused on interventions targeting the social and communication skills of the individual with brain injury rather than targeting the reciprocal relationship that is friendship (Callaway et al., 2005). Callaway et al. (2005) advocated for early intervention to maintain existing friendships. They suggested a range of occupational therapy interventions to encourage active involvement of friends within the earlier stages of rehabilitation, including getting consent to include the friendship network in comprehensive education so they develop realistic expectations and understanding of the cognitive, behavioural, physical, and communication difficulties and help identify strategies to address these. They also suggested restructuring communication channels to ensure friendships are not lost over time, and incorporating shared occupations that enable opportunities to interact with friends into goal planning.

Although the evidence for selected interventions that support the integration of family, whānau, or friends into the community re-entry of people with ABI remains somewhat sparse, there are practical recommendations in recent literature to assist in this matter. By incorporating family and friends as active participants in joint education sessions, goal setting, and problem solving, it is anticipated that their expectations may be better addressed and lead to positive impacts on facilitating community integration for those with ABI. Addressing the expectations of this group of individuals is likely, in turn, to impact the expectations of the wider community. As indicated by Gagnon et al. (2016), once family members are empowered with a greater depth of knowledge, they feel better able to educate the wider community about ABI survivors’ needs, address misinformation about the abilities of people with ABI, and dispel stigma and discrimination within the general public.

Building Awareness of the Implications of ABI Within Society to Enhance Community Integration

Societal expectations had an impact on the participants' community integration in a range of ways. First, the COVID-19 response across New Zealand (including being restricted to the home, limits on gatherings, social distancing, closure of public venues) placed expectations on the public to behave in a way that limited everyone's community engagement. Second, there were societal expectations around the ways in which people were to behave and appear that impacted on participants such as polite behaviour in public, and the assumption that people should appear busy and productive in order to make a valued contribution to society. Public preconceptions and societal attitudes are factors that have been found to influence community and social integration of people with ABI in studies dating back over 20 years (Conneeley, 2002; Turner et al., 2011). Links have been drawn between recovery from ABI and societal expectations as people with brain injury have been found to create their definition of a return to normal life according to certain social stereotypes (Nalder et al., 2013).

The broad brain injury related knowledge of the general public has been explored through a series of studies spanning 25 years (Merz et al., 2017). In their most recent survey Merz et al. (2017) found that misconceptions regarding ABI continue to be prevalent and may be explained by inefficiencies in education practices, scientific literature, and misleading media reports. A seemingly contradictory finding was that those who had received education regarding ABI, such as people who had experienced concussion, those who reported formal training, or those who participated in contact sports, actually exhibited lower accuracy rates in their responses than participants who had not received this exposure to ABI information. The unfortunate reality being that education received by these groups was either miscommunicated or misinterpreted leading to continued misconceptions despite the formal training or information sharing. This would suggest that formal educational sessions to improve awareness regarding the experience of those with ABI in their communities are not the optimum approach to take. Alternatives to formal education sessions should be explored to build public awareness of the experience of those with ABI as they attempt to reintegrate into their community and the ways that people in society could help facilitate this process.

Participants in the current study faced limited participation in community and social occupations as a result of COVID-19 restrictions. This was not isolated to New Zealand as there has been a global experience of occupational deprivation and community restriction due to the pandemic. Suddenly, people who had previously been living full lives were restricted in their ability to move around and participate in their communities, much like those who suffer

sudden disability due to injury or illness. This experience could be put to use to emphasise the impact of ABI on community participation.

Studies exploring the impact of unexpected COVID-19 restrictions and occupational deprivation on the general public are only just emerging. However, what has been published to date is rich with examples that reflect the experience of those who have encountered sudden deteriorations in their health and functional status through disease or injury. Studies that have explored the experience of older people in Sweden (Fristedt et al., 2022) and students in the United States (Vanpuymbrouck & Olson, 2021) demonstrated the disruption to habits, roles, and routines that were experienced by both groups as the conditions of day-to-day life changed abruptly. The older population that partook in Fristedt et al.'s (2022) study struggled to manage the sudden cancellations to regular activities such as choir rehearsals, outdoor exercise, social and community groups, visits to the cinema, concerts and restaurants. Some were unable to continue with their part-time jobs or voluntary work, and social contact became minimal. Days and weeks lost structure due to limited activity to engage in and, for some, life became boring and meaningless. Multiple adaptations had to be made to find meaningful activities in which to engage and carry out safely. These experiences closely mirror those of people with ABI and similar reports were provided by participants in my study. In addition, the emotions that participants with ABI described and those of people who experienced COVID-19 restrictions were also similar. Fristedt et al.'s study participants explained "how they dreamt about getting on the local train or just shopping for themselves" and "were frustrated from no longer being independent, but having to rely on support from others such as children" (p. 518).

It would seem that there is potential to use the occurrences of community restriction and occupational deprivation that have been widely experienced by societies across the globe to help people resonate with the experience of people who are experiencing disability who cannot participate fully in daily life. Particular parallels could be drawn to those who experience a sudden change to functioning, such as those who have a stroke or TBI, and go from living a full life one day to limited function the next. Perhaps challenging individuals by having them reflect upon their own experience of limited community integration would assist them in empathising with the situations of those with ABI and transform existing perspectives.

A second alternative to traditional didactic teaching is an approach that has been recommended by the Commission on Accreditation of Rehabilitation Facilities (CARF). CARF is an international, non-profit organisation that surveys rehabilitation facilities with a mission "to promote the quality, value and optimal outcomes of services through a consultative

accreditation process and continuous improvement services that centre on enhancing the lives of the persons served" (CARF International, 2021, p. 1). In their programme of survey standards, CARF recommended that rehabilitation services offering a brain injury specialty programme demonstrate efforts to educate the community about prevention of brain injury, impact of acquired brain injury, the need for rehabilitation, accessibility and reasonable accommodation, and inclusion. It offers suggestions for meeting these standards that go beyond traditional community education workshops and include participating in community events such as festivals or charity runs, entering collaborations with local governments to enhance services, promoting inclusive community events such as integrated theatre and dance or community meals, and speaking to philanthropic/foundation organisations about the needs of those with ABI.

Building awareness and understanding of ABI in the community has the potential to contribute to the development of a more enabling social and cultural environment for people with ABI as they attempt to re-join community living. Two suggestions for building awareness and understanding of ABI in the community include a broad approach that would need public health engagement to enact, and an organisational approach where rehabilitation services could partner with non-government organisations and other disability services. These approaches extend beyond what rehabilitation services would traditionally see as in their scope. Yet, they hold exciting potential for addressing the expectations of society that impact on those with ABI.

(Re)Building Social Connections

My participants engaged with three types of social networks to facilitate their community integration. These included the *close and enduring network,* the *distal/fleeting network*, and the *professional network.* From these social networks, participants received three types of social support that included *practical*, *emotional*, and *informational* support. This variety of support provided a wide range of opportunities to progress their community and social integration, thereby increasing opportunities to continue building social networks. Generally, loss of social connection including friendship, close relationships, and social isolation have emerged as consistent findings in research exploring outcomes for people with ABI (Callaway et al.,2005; Conneeley, 2022; Douglas, 2019; Exell et al., 2022; Salas et al., 2018). As social networks and the support they provide appear to be a significant facilitator of community integration, it is imperative to protect and develop good quality social networks.

Holt-Lunstad et al. (2017) defined social connection as an organising construct encompassing "the variety of ways one can connect to others socially – through physical, behavioural, social-cognitive and emotional channels" (p. 518). They identified three factors that contribute to the construct of social connectedness including structural (e.g., network size, marital status, living arrangements), functional (e.g. received or perceived support, perceived loneliness), and qualitative (e.g. positive or negative qualities of a relationship). Based on this definition, social connection results from a range of interpersonal, behavioural, and environmental factors, a portion of which are modifiable and could be targeted through rehabilitation interventions. However, as an intervention target, social relationships may seem too complex and abstract to incorporate into the typical rehabilitation process of assessment, creating a rehabilitation plan, designing interventions, and measuring outcomes. A focus on physical and functional improvements appears more tangible with rehabilitation providing a direct, observable, and measurable impact. As illustrated in Chapter 2, the previous literature relating to lived experience suggests that assisting people to practice social behaviours in relevant, real-life situations and providing support to develop social networks, resources, and advocacy skills should be seen as community integration focused goals of rehabilitation (Ditchman et al., 2017). Traditional rehabilitation approaches still, however, tend to focus on interventions targeting specific basic activities such as mobility, personal care, and cognitive performance with the assumption that this will lead to improvements in community integration (Kersey et al., 2020). My findings suggest this remains the case in New Zealand rehabilitation settings.

Social connection to improve the health, wellness, and outcomes of people with ABI will be discussed in greater detail in Chapter 7. In the section below, I make a number of recommendations to enhance *(Re)Building social connections* into rehabilitation service delivery or health policy to help facilitate community integration. The first of these recommendations considers how improved social connection could be incorporated within rehabilitation programmes. The second highlights the need for improved use of a range of informational support available that appears poorly accessed at present. The third recommendation is the development of peer support as an additional social network to be made available to people with ABI. The fourth proposal emphasises the role that professionals have in emotional support of the person with ABI and how this can be better realised and addressed. Finally, prioritising social connection as a health priority at a national health policy level, as has been seen in other countries, is considered within the New Zealand context.

Incorporating Social Connection Within Rehabilitation Programmes

The general process of rehabilitation routinely incorporates components including assessment, goal setting, treatment planning, delivering intervention based on the plan, review and adjusting interventions, and evaluating to establish if improvements have been made. This process, ingrained into the culture of many rehabilitation services in which I have worked both nationally and internationally, does not need to change drastically to enable a focus on social connection as a primary outcome. My findings suggest that three types of social supports (practical, emotional, informational) are provided by three types of networks, the close and enduring, distal/fleeting and professional networks. Participants experienced the professional network reduced over time as formal supports were withdrawn. Through the rehabilitation process, rehabilitation professionals could aim to increase the close and enduring and distal/fleeting social networks, which could then offer ongoing practical, emotional, and informational support. This would compensate for the reduction of professional support as the person with ABI recovers and is discharged from formal services.

Should a community rehabilitation service choose to focus on social connection as a priority and perform a thorough assessment of social relationships, it would need to factor in the three variables described by Holt-Lunstad et al. (2017)—structural, functional, and qualitative. Size of the social network, the social support perceived and received, and satisfaction with relationships could be considered within the assessment process. Assessment and final evaluation could be carried out through standardised measures that encompass these variables of social connection and have been used in previous research with ABI populations (Excell et al., 2022). Functional aspects, such as the perceived frequency of problems within companionship, could be assessed using subscales of the Instrumental Expressive Social Support Scale (Ensel & Woelfel, 1986). Qualitative aspects of social connection could be evaluated using the Revised Dyadic Adjustment Scale (Busby et al., 1995) that measures the stability, distress, and satisfaction within relationships. These scales could then be reviewed and completed at the end of the rehabilitation programme to evaluate if changes have been made to the structure, function, or quality of social relationships. This would encourage a focus on social connection from a clinical perspective and provide services with an evaluation of whether the strategies they were using to improve social integration were having an impact or if they needed to revise and try alternative strategies.

For rehabilitation programmes that wish to incorporate aspects of social connection into their assessment, but do not wish to undertake lengthy, specific measures such as those above, this evaluation could take a less formal approach. During the initial assessment, questions about

activities the person with ABI would like to engage in could be expanded to include “who do you do these activities with?”, “who would you like to do these activities with?”, “are there activities that involve other people that you would like to (re)engage in?”, “who are the people that you like to spend your time with?”. This would help identify those within the person’s social network with whom they may wish to reconnect; for example, a choir, bowling club, quiz team, members of an exercise group. These questions may also reveal options to create new relationships. Incorporating questions such as these into initial assessments would assist rehabilitation teams to avoid the assumptions described by Conneeley (2002) who highlighted the number and extent of social networks in people’s lives naturally change over the lifespan. It should not be assumed that everyone has an extended network of friends and acquaintances.

Through assessment, the rehabilitation team can identify limitations to be addressed or facilitators and strengths that can be utilised in the development or maintenance of social networks. Factors contributing to a loss of social connection could be targeted in goal setting and treatment planning. These may be brain injury related factors such as a loss of skill, a lack of initiation, inability to initiate social behaviours, or personality changes. However, as identified by Callaway et al. (2005), factors leading to a reduction in social connection can also be related to personal choice. People with ABI may choose to take time to rest and recuperate following their return home, or choose to limit social visits to reduce the impact of fatigue. Such choices have the potential to limit social connection and the balance between benefits and drawbacks should be evaluated.

Person-centred goal setting is widely accepted as a key component of treatment planning in the early phase of a rehabilitation programme, following an initial period of assessment (Cameron et al., 2017). Based on participants’ reports within this study, rehabilitation goals tended to focus on household, mobility, and self-care activities. Setting rehabilitation goals around increasing presence in the community would be a first step towards integration. However, this alone does not always lead to community inclusion or expansion of social networks (Callaway et al., 2005). For example, setting a goal that relates to walking to and from the local café places the person with ABI in the community to a greater extent, but does not in itself create an opportunity to develop social relationships. Considering a trip to the local café as a shared occupation with others within their close and enduring network (e.g., to meet a close friend) or an opportunity to develop distal/fleeting connections (e.g., with the barista who may remember the person with ABI the next time they arrive to order their coffee) will assist in maintaining or expanding the social network. A reduction in the range of shared occupations will lead to a reduction in close and distal connections. It is, therefore,

important for rehabilitation teams to set goals with the person with ABI that identify suitable shared occupations in which to participate that increase social contact and develop the skills to participate to a greater extent.

Targeting important relationships within goal setting may include changing the language of the goals. Typically, rehabilitation teams are encouraged to set "SMART goals" that focus multi-disciplinary teamwork on discrete areas of functional change that can be evaluated and measured (Playford et al., 2009). SMART goals generally read along the lines of "Mobilise outdoors 500m with a stick in the next 3-weeks". Teams could include aspects of social connection by reframing such goals to include other people, "Be able to walk my grandchildren to school at the end of the road when the term re-starts in 3-weeks". Asking the question "Who with?" when a person with ABI identifies a goal they would like to work on would help incorporate *(Re)Building social connection* into rehabilitation goals and the treatment process.

Following an assessment that takes social connection into account, and establishing goals for rehabilitation that include the relational aspect of shared occupations, intervention can then target impairments of social cognition that are common after ABI. These impairments may include disinhibition, inappropriate behaviour, inability to interpret another's emotions, difficulties with communication, or poor divided attention. Interventions may also target physical impairments that restrict access to certain community environments. Ideally, these interventions should include the individuals with whom the person with ABI interacts and take place in the community context, where it is safe and practical to do so. In their recent systematic review of interventions that support adults with ABI in dating and romantic relationships, Excell et al. (2022) found a lack of agreement or evidence relating to specific content of clinical delivery that supports the development or maintenance of these close relationships. However, as illustrated in the *Living up to expectations* section, integrating significant others into intervention plans has the potential to positively impact community integration. I would also argue that incorporating the concept of social connection into assessment and goal setting stages of the rehabilitation process will keep rehabilitation teams more cognisant of the importance of social connectivity. A review of goal progression at regular team meetings would be a reminder to the clinical team to continue to incorporate valued relationships into their rehabilitation interventions.

Sustainable Sources of Informational Support

Participants in my study regularly identified people in their close and enduring network and the professional network as those who provided informational support. When asked about where else they or their family members looked for informational support about ABI, recovery,

or impacts on daily living, none could identify resources outside of conversations with these social networks. Their reliance on the professional network is of concern as this network withdraws over time and is then absent when information is required at a later date. The reliance on the close and enduring social network, although mostly maintained longitudinally, is also of concern if this network does not provide accurate information and expectations due to being ill-informed themselves.

Similar to the participants in my study, those interviewed in the study by Stiekema et al. (2020) found that information was limited other than general advice received in the acute stages of their recovery. However, information received in the acute stage was not perceived as helpful at that time. Some found this information difficult to read or were not open to information about long-lasting problems. Participants in both my study and that by Stiekema et al. found that repeated, simple, and individualised information from a professional over prolonged periods was more useful. However, information from peers was also considered valuable as those with similar lived experience could understand the struggles, accept the behaviour, and provide practical information that people with ABI were more inclined to use than advice from professionals.

Clinical implications of these findings include the need for rehabilitation clinicians to familiarise themselves with a range of reliable information sources available on-line and in print, recognise when these resources might be suitable to address the individual needs of their clients, and provide access to these sources of information. The person with ABI and their close and enduring network then has continued access to this information and some ability to self-manage their information needs after the professionals withdraw. This is also a more reliable way for people to receive credible information that has been evaluated by clinicians rather than "just Googling it" as Andrew (study participant) suggested he would do.

Peer Support

Although participants in my study identified those with similar experiences of recovery being a useful source of information, none received any type of formal peer support. Peer support, when provided in a formal way, is more than simply informational support and has a range of positive outcomes including "a unique sense of community, the opportunity to be accepted, the opportunity to gain information from others, as well as to socialise and broaden social networks" (Hughes et al., 2020, p. 847). Through their systematic review of peer support Hughes et al. (2020) evaluated participant experience and found four common themes: obtaining friendship, expression of feelings, sharing of coping strategies, and gaining information. These themes resonate with the three types of social support that participants in

my study identified as receiving from their networks “expression of feelings” relating to emotional support, “sharing of coping strategies” relating to practical support, and “gaining information” relating to informational support. This suggests that peer support could be a useful addition to the social network of a person with ABI in order to expand the network and provide all three types of social support.

Being connected to other people who have a concept of living with brain injury that is aligned with a person’s own experience has been found to be a key component in developing a concept of recovery after TBI (Fadyl et al., 2017). These kinds of peers were identified within the distal/fleeting social network of some participants in my study as those with similar experiences and those that understood first-hand some of the challenges of community re-integration. The peers referred to were those that participants happened to already have within their distal/fleeting social networks. A recent scoping review of brain injury rehabilitation interventions has acknowledged the lack of attention peer support has received in the ABI population, despite ABI survivors themselves recognising the benefits of peer-to-peer forums (Sveen et al., 2022). Examples of peer support as an additional social network to help facilitate community integration can, however, be found in the Spinal Cord Injury (SCI) and amputee populations. Peer support services are provided for those with SCI through the New Zealand Spinal Trust and Spinal Support New Zealand. These organisations provide peer support through face-to-face interactions and through their websites and Facebook community pages. The SCI peer services have been based on a theoretical model, developed through research, aligned with self-determination theory, and nationally implemented in 2018 (Martin & Nunnerley, 2018). The peer supporters provide informational support and act as role models providing practical and emotional support. In their discussion paper providing evidence for the provision of peer support to people with newly acquired spinal injuries, Martin and Nunnerley (2018) described how the addition of a peer into the social network of those with spinal injury can contribute to all the three types of social support identified within my study (practical, emotional, informational).

> SCI peers are rich sources of information, providing a sense of understanding, assistance with problem-solving, accessing information and goal setting. Peer support can be a valuable resource for people with newly acquired SCI as they can help with both practical and functional tasks. Peer supporters can give credibility to the practical advice, and information that health care professionals cannot. Peer support addresses unmet emotional needs during SCI rehabilitation and helps with encouragement and motivation to participate in rehabilitation. (Martin & Nunnerley, 2018, p. 5)

Peke Waihanga, the Artificial Limb Service, in collaboration with the Amputees Federation of New Zealand, also provide a similar type of peer support for their clients through Te Pou Aropa Takitoru – Peer Support Service. Through enlarging social networks Te Pou Aropa Takitoru aims to address emotional support needs such as managing fears and coping with feelings of vulnerability. It also provides practical support such as helping to adjust and re-engage in community activities, and informational support such as sharing information about other support services (Peke Waihanga – Peer Support Service, n.d.).

As these examples demonstrate, models of peer support have been developed for other populations who have experienced similar life-altering events. These models could be adapted to help expand the social networks of those with ABI who are beginning their community integration journey and currently relying on professional networks to provide support that could be offered by peers. The Traumatic Brain Injury Strategy and Action Plan (2017-2021) published by the ACC (2017a), identifies the need to "develop a professionalised peer support programme" (p. 31) in order for people with TBI and their whānau to experience good outcomes. It lays out a broad implementation plan including supporting current research, reviewing international research, and working with interested parties to develop a programme. Although this plan is yet to be fully realised, work that has been undertaken in New Zealand so far, in this regard, includes a feasibility study exploring the acceptability of peer mentoring from the perspectives of both the mentee and mentor (Kersten et al., 2018). The study identified that peer support was acceptable to mentors and mentees, with a number of perceived benefits, particularly supporting mentees to make sense of recovery through the sharing of experiences and stories. This type of support seemed highly valued and different to that provided by clinicians, family, or whānau. Based on this feasibility study, a randomised control trial is now underway with the primary objective of testing the effectiveness of the peer support intervention for improving health, wellbeing, and participation (Kayes et al., 2023). Results of this study will produce outcomes, economic data, and process recommendations that health funders and providers can then use to determine the utility of peer support for optimal impact.

Therapeutic Relationships as a Form of Emotional Support

Within the theme of *(Re)Building Social Connections* it was found that participants relied more heavily than I would have anticipated on their professional network for emotional support during their community integration journey. Many participants reported how they had built significant emotional bonds with members of their rehabilitation team and missed them when their services were withdrawn. This emotional support helped to facilitate meaningful

community engagement as the participants felt there was someone to “be in it with you” which provided confidence and motivation.

In the *Growing into a new way of community living* section of this chapter, there is a recommendation for a stepped care model of psychosocial support to be integrated into service provision which covers some specific interventions that could be offered to individuals at various levels of the model. In this current section, the concept of the therapeutic alliance is discussed as a way that professionals can provide emotional support. It is argued that professionals need to be more cognisant of their role in this alliance.

The therapeutic alliance can be broadly defined as “the collaboration over goals and tasks of therapy, and the interpersonal bond between client and therapist” (Stagg et al., 2019, p. 490). Other related terms include working alliance, therapeutic relationship, professional-patient relationship, and helping alliance. Occupational therapy literature also refers to “therapeutic use of self” as a parallel term that encompasses many similar concepts (Holmqvist et al., 2013).

In their recent scoping review of therapeutic alliance in ABI rehabilitation, Stagg et al. (2019) found a significant correlation between a strong alliance and a range of community integration outcomes including return to employment, positive views of future employment prospects, return to study, return to driving, utilisation of cognitive strategies in daily living, and greater levels of household independence. The findings support the concept that active participation and engagement, driven by strong therapeutic alliance, contribute to progress in community integration. In order to establish this therapeutic alliance, Stagg et al. recommended allowing time for the development of the relationship and consideration of factors such as therapist skill to strengthen alliances, particularly in people with ABI experiencing cognitive impairment.

In their study of client-centred practice, from the perspectives of people with TBI, D’Cruz et al. (2016) argued that therapeutic alliance is a foundation of client-centred practice from the perspective of the client. Participants in their study identified therapeutic alliance as “critical to client-centred practice” and “spoke of valuing a relationship in which they were appreciated as a person, not just a client, observing that the quality of the relationship with their therapist enabled or constrained their participation in therapy” (D’Cruz et al., 2016, p. 32). The results of D’Cruz et al.’s study affirm the importance of the therapeutic alliance and insights from their participants provide practical examples of how this alliance can be established and maintained. In summary, some of the practical strategies that rehabilitation professionals could take on board, based on the themes that emerged from this study, include:

- Acknowledge the trauma and be sensitive to the emotional impact of the trauma

- Get to know the client as the person they were before their ABI
- Getting along with the person: listening, showing interest, conversing about topics other than rehabilitation
- Identify positives, translate these into goals, show belief in abilities, provide positive feedback and spur them on
- Work together in a partnership that evolved through building rapport and personal connection
- Reasoning together and the client being central in choosing the direction of rehabilitation
- Collaboration that includes the wider social network (family, whānau, friends)
- Clients value qualities like honesty, confidentiality, keeping promises, being an advocate, explaining the purpose of therapy, respecting them as individuals with unique perspectives, and trust

Along with the above strategies, professionals considered use of self-disclosure to reduce any power imbalance, build trust, and reduce vulnerabilities as key in fostering a therapeutic alliance that supports the person's emotional needs and promotes engagement in therapy. This emotional understanding and engagement supports the person with ABI with acceptance and adaptation to life back in their community after ABI. However, there can be tension between a personal connection and the need for professional boundaries. Professionals need to consider in advance what personal details they feel comfortable sharing and in what situations (Bishop et al., 2021).

Emotional support through the therapeutic alliance did not appear to be considered a primary focus of clinician delivery according to the participants in my study; instead, they believed clinicians' focus was on practical and informational interventions. Some described "pastoral" care as "lacking". Other participants emphasised how emotional support from their professional network was helpful in supporting them to continue their journey into community living. Clinicians need to understand how this alliance contributes to positive outcomes for people with ABI and build their skills in developing therapeutic relationships, taking into account the strategies described above, so as to offer emotional support within a professional context.

Social Connection as a Priority in Health Policy

The recommendations above have predominantly focused on addressing the *(Re)Building social connections* component of community integration within current rehabilitation service

delivery or through expansion of service delivery. An alternative to addressing *(Re)building social connection* at this clinical/organisational level is to target national health policy and incorporate elements of social connection into the priorities and action plans. This is likely to lead to increasing initiatives that support the engagement people with disability in social networks, recognising the health benefits that this promotes. As illustrated through the exploration of New Zealand Health Policy in Chapter 2, such initiatives have not been accomplished to date. However, there are examples in other countries where this has been particularly successful.

In 2010, the United Kingdom's Minister of Health established loneliness as a health priority and announced funding for initiatives to help people at risk of longer-term social isolation remain active, independent, and positively engaged with their communities (Department for Work and Pensions, n.d.). This led to an increase in "social prescribing" initiatives within health and social care. Social prescribing is defined as "a catch-all term for non-medical services that aim to prevent worsening health for people with long-term health conditions" (Sheffield Hallam University Centre for Regional Economic and Social Research, 2016, p. 1) and includes community groups, volunteering, benefits support, and physical activity groups as examples.

One such service that has been progressively and systematically evaluated is the Rotherham Social Prescribing Service for People with Long-term Conditions. The Service was first commissioned as a 2-year pilot in 2012. After a proven track record of improving wellbeing outcomes through non-medical strategies, the service is now permanently funded as part of GP-led integrated case management. A team of voluntary and community sector advisors receive referrals from GPs and assess potential support needs before referring on to appropriate voluntary and community services. Ongoing evaluation has found that people with long-term conditions who were referred to the Social Prescribing Service had a reduction in GP visits, fewer non-elective episodes of care and emergency department admissions, and made progress towards better self-management of their conditions. Therefore, a number of cost-benefits have been identified and it is calculated that, over the first 3-years, the reduction in access to other NHS services equated to approximately half a million pounds of avoided costs. There is also evidence that people receive an immediate boost to their wellbeing and that these benefits are sustainable. Social prescribing appears to be particularly effective at reducing social isolation and loneliness for people with long-term conditions, such as stroke and TBI, enabling them to become more independent and engaged in the community (Sheffield Hallam University Centre for Regional Economic and Social Research, 2016). The service is now one of the largest and highest profiled of its kind in the United Kingdom, and has provided a model of service delivery that is being replicated in other parts of the country.

It seems that due to key policy changes in the United Kingdom, over 10 years ago, researchers and service providers were able to overcome obstacles that impeded large scale funding for social connection interventions. In New Zealand, the obstacle of health policy priorities and funding that focuses on specific mental and physical health problems, rather than broader health risk factors like social connection, still exists. Despite recent system reforms within the New Zealand public health services, the strategic intentions recently outlined by the Ministry of Health (2021) remain focused on safe and sustainable service delivery, investing in technology, building the capability of clinicians, and building an integrated system. Despite the overarching goal of "Pae Ora: Healthy futures" there remains very little evidence of considering broader health determinants such as social connection within the Strategic Intentions 2021 to 2025 (Ministry of Health, 2021). Community-based organisations that support people with ABI, such as the Stroke Foundation, are an alternative option to publicly funded health services for supporting people with social and community integration. As an example, the goals of the Stroke Foundation NZ (2022) include "supporting people in the community, enabling them to have the best life possible after their stoke" (p. 4) . However, funding to sustain and grow services delivered by organisations, such as the Stroke Foundation, are lacking and they struggle to provide evidence-based approaches to improving the lives of people after ABI (Stroke Foundation NZ, 2022). If publicly funded health services are predominantly focused on systematic reforms and integration of services, better funding needs to be provided to those organisations that have potential to address some of the broader determinants of healthcare.

Engaging in Meaningful Occupation

My participants referred to the daily occupations in which they were engaging as "like rehabilitation". They recognised that they were making a variety of gains through engagement in occupation which, in turn, led to increased levels of independence generally. The use of meaningful occupation both as an outcome to intervention and a therapeutic medium in itself is the foundation of occupational therapy. As defined by the World Federation of Occupational Therapists (2018), "Occupational therapy is a client-centred health profession concerned with promoting health and wellbeing through occupation" (p. 4). Participants identified that rehabilitation teams focused on ensuring they had the practical skills to manage their basic daily tasks such as self-care, household mobility, and some productive activities such as meal preparation. Participants' perceptions of the professionals were that they aimed to increase independence in the tasks identified; but for the participants, engagement in particular activities held much more meaning than simply the ability to independently undertake each step to successful completion.

Consider What Occupation Signifies, Beyond the Doing

It is important for rehabilitation professionals to not only focus on independence as an end goal, but also be cognisant of what occupational independence signifies beyond gaining task-specific mastery. In this study, participants described their progress in community activities as providing motivation and a sense of achievement, acting as a distraction and helping them to stay occupied. It also gave them a feeling of belonging within their communities, and provided them with a sense of contributing back to the community. Examples of belonging and contribution included returning to a voluntary role, visiting old friends, looking after children, assisting colleagues, creating gifts for others, and continuing progress towards a chosen profession.

Other qualitative studies exploring the experience of recovery after ABI have identified that people commonly express feelings of satisfaction, pride, and joy and want to celebrate their functional achievements, such as walking around the block, managing a household chore, or engaging in a hobby (Turner et al., 2011). Although participants in my study discussed their sense of achievement, there were only a few that indicated this was celebrated in any way with their rehabilitation professionals. Those that did receive this feedback from their health professionals felt encouraged and motivated to continue their efforts. Kayes et al. (2022) identified the interaction between professional and client as a collaborative process of investing and reciprocating, and an essential component of developing connections for engagement in rehabilitation. Evidence suggests that rehabilitation team members should be aware of the impact their encouragement has and celebrate the achievement of certain milestones with people as they progress through their rehabilitation toward greater levels of community integration. Viewing these events as opportunities for those with ABI to regain components of a life that had been lost, and reflecting on their progression towards their principal goals, may provide them with a sense of ongoing motivation and pride in their efforts. As Turner et al. (2011) reported, “smaller achievements were often perceived by participants as merely appendages to the pursuit of more salient targets to goals they sought to return a sense of normality to their lives” (p.79).

Distraction, creating structure, and occupying their time were other common reasons for participants to engage in meaningful occupations. They reported that “it felt good to keep busy” and it kept them “out of mischief”, prevented their moods from deteriorating, or from becoming despondent. This finding is reflected in previous qualitative studies examining the longitudinal recovery of people after brain injury who identified that engaging in familiar social environments and activities prevented them from getting depressed (Fadyl et al., 2017). For

some participants in my study, establishing a routine was difficult as they transitioned from the highly routine in-patient rehabilitation environment back to their communities. For some, this change of environment and loss of structure initially led to a relatively unproductive daily schedule that included watching daytime television or sitting around on the sofa. The impact was addressed by creating a routine and ensuring that they had something to occupy their time, whether this was home-based DIY or taking a daily walk around the local neighbourhood. The routine was sometimes supported by family members who could assist and supervise as necessary. Turner et al. (2009) found similar participant experiences regarding the importance of establishing a structure in order to stay occupied when transitioning home from hospital after ABI.

Engaging in meaningful occupations also gave my participants a sense that they were contributing back to their communities. They talked about a need to feel useful and described occasions where they had engaged in occupations as a kind of reciprocity, or doing good for others who had done good for them. In turn, such actions seemed to lead to a sense of self-worth and a link to their pre-ABI sense of identity. Reciprocity and the need to help others, as well as being helped by others, was also a finding in the longitudinal study by Fadyl et al. (2017) whose study participants identified engaging in these sorts of occupations at their 12- and 24-month post-TBI interviews. The participants in my study (<6-months post-ABI) were already beginning to identify areas where they were "paying back" to others in small ways, such as creating gifts or videoing and sending their thanks to the ICU team. Feeling useful and contributing are viewed as important elements of the transition back to community living and are necessary for adjustment and integral to the transition process from in-patient environment to home. This should be considered by community rehabilitation clinicians as they design their programmes and engage people with ABI in truly meaningful occupations that involve the potential for a sense of reciprocity, particularly during the *Settling back in* stage of *Growing into a new way of community living.*

The meaning that participants placed on their chosen occupations was also related to a sense of belonging, connecting, or contributing. There appeared to be some tension between participants' concept of "meaningful" versus the rehabilitation professionals' idea of what meaningful occupation meant. Professionals predominantly focused on the *doing* of the activity in order to establish a greater level of independence, whereas participants tended to talk about what engagement in the occupation achieved from a broader perspective. Dominant occupational therapy models emphasise *doing* self-care, productivity, and leisure occupations; thereby ignoring occupations that contribute to the wellbeing of others, occupations that foster connections, collaborative occupations, and those valued for their

social context and potential to strengthen social roles (Hammell, 2014). Hammell (2014) highlighted the research evidence that shows the ability to contribute to others is associated with increased feelings of belonging, a sense of both wellbeing and competence, and a sense of value and worth. Therefore, a shift in the clinician's concept of what "meaningful occupation" is may be required and might be more usefully understood by focusing on the meaning that people with ABI attribute to their occupations, including the need to belong and connect.

The American Occupational Therapy Association (1995) defined occupation as "the ordinary and extraordinary things people do in their day-to-day lives to occupy time, maintain wellbeing and contribute to society, and it includes active participation in self-maintenance, work, leisure and play" (Christiansen et al, 1995; p.1016). It would appear from the accounts of participants within this study that the focus of clinicians was on the second aspect of this definition (participation in self-maintenance, work, leisure, and play). Perhaps more attention needs to be paid to the former aspects of occupying time, maintaining wellbeing, and contributing to society. These are the drivers identified by participants and if rehabilitation professionals are to truly focus on what is "meaningful" then this is where they should begin their exploration with the person with ABI. When the person is home and has the ability to engage in a range of community-based activities (as opposed to being restricted by an in-patient environment), interventions should offer the scope to think more broadly and develop therapeutic goals around social inclusion, belonging, and contribution.

Consideration of what is meaningful to the person with ABI early on in their community integration by clinicians will assist in preparing for the withdrawal of formal rehabilitation services at a later stage. By setting a course and establishing future meaningful tasks, that their clients are motivated to continue to progress, clinicians can encourage ongoing engagement in "rehabilitation-like" activities that will continue to promote community integration while meeting the higher-level desires of the individual. Clinicians should be cognisant that participation in truly meaningful occupations is more than promoting independence in daily living activities but also about celebrating achievements, creating a routine to stay occupied, contribution, sense of self, and feelings of belonging.

Summary

This chapter has considered the clinical implications of the findings from this study and has explored these in relation to other literature that explores similar concepts either within the

ABI population or wider. Recommendations have been structured within the four themes introduced in Chapter 5 and are summarised in Table 7 at the end of this chapter.

In relation to the process *Growing into a new way of community living,* recommendations for improving preparation for discharge home and the provision of psychosocial support within the community have been suggested for addressing the difficulties expressed by participants at various stages of the process. Within the *Living up to expectations* theme, strategies have been provided for increasing incorporation of family and significant others in the community integration rehabilitation programmes. Potential opportunities for raising awareness of ABI within society in general have also been outlined. Numerous recommendations to address the community integration component of *(Re)building social connections* have been made. These involve strategies ranging from adaptations of clinical delivery to incorporate social connection as a therapeutic goal, identifying and providing reliable information resources to both the person with ABI and their family and whānau, promoting peer support as a valued support network, and prioritising social connection within national health policy and funding. Finally, it has been recommended that rehabilitation professionals consider the significance of meaningful occupation in broader terms. *Engaging in meaningful occupation* should incorporate more than a focus on independence in task completion, and consider connection, reciprocity, and belonging from the perspectives of the person with ABI.

Table 7

Summary of Clinical Implications and Recommendations

Theme	Clinical implication	Summary of recommendations
Growing into a new way of community living	Community integration within discharge preparation	Provide people with ABI early opportunities to experience community-based activities that prepare them for the real world and help them navigate the emotional response
	Access to psychosocial support to progress community integration	Consider implementation of screening and a stepped care model to embed psychosocial support into routine practice
Living up to expectations	Involvement of significant others in community integration	Incorporate interventions that involve family, whānau, and friends as active participants into the community re-entry efforts
	Building awareness of ABI within society	Consider a range of strategies to raise awareness of ABI in local communities and contribute to the development of a more enabling social environment
(Re)Building social connections	Incorporating social connection within rehabilitation programmes	Assess aspects of social connection at the outset of rehabilitation and incorporate social connection into therapeutic goals and intervention
	Sustainable sources of informational support	Become familiar with a range of reliable on-line and in-print resources and provide the appropriate ones to address the informational needs of the person with ABI
	Peer support	Adapt models of peer support that have been established for other populations to expand the social networks of those with ABI
	Therapeutic relationships as a form of emotional support	Establish a sound therapeutic alliance to offer emotional support throughout the stages of community integration
	Social connection as a priority in health policy	Influence New Zealand health policy reforms to consider broader determinants of health such as social connection
Engaging in meaningful occupation	Consider what occupation signifies beyond the *doing*	Consider broader components of occupation such as motivation and achievement, routine and structure, maintaining wellbeing and a sense of belonging

Chapter 7: Discussion

Introduction

When embarking on this research journey, a key motivator was that the findings would contribute to alternative ways of working with individuals with ABI, and would extend the view of community integration to include the networks of people surrounding the individual, rather than focusing solely on the individual themselves. I hoped to address gaps in evidence and knowledge translation that related to the difficulties reported by people with ABI and their family or whānau, particularly during the transition phases between services. I also wanted to explore ways to influence attitudes and awareness of those within the community towards people with brain injury. At a societal level, I hoped that the research outcomes would provide evidence for understanding the barriers faced by those with ABI and suggest ways to influence health policy aimed at improving community integration for those with disabilities.

This study sought to answer the following research question: How do people with brain injury reintegrate into their communities on return home from in-patient rehabilitation? Associated questions included:

a) What are people's experiences of community integration as they recover from ABI and how do these relate to current literature?
b) What are the barriers and facilitators to community integration?
c) What strategies are people with ABI already using to overcome these barriers?
d) What is the role of the community in community integration?
e) What additional support, services, and/or strategies could be put in place to help people with ABI in their community integration?

I begin this chapter by comparing the community integration experiences of participants that were identified in this study to the frameworks and literature that were explored in Chapter 2. Dimensions of previous community integration frameworks will be discussed in relation to the four themes uncovered in the study; and attention will be drawn to the similarities, differences, and new perspectives that have been generated. I argue that engaging in meaningful occupations has a higher purpose than just successful performance of activities, in that it creates a sense of belonging in the community by helping people with ABI to (re)build social connections. These social connections provide opportunities for people with ABI to grow into a new way of community living and develop a sense of belonging, reciprocation, and contributing back to their communities. Considering the importance that building social

connections has on the community integration for a person with ABI, I argue that rehabilitation service providers need to look beyond the common models of person-centred practice and, instead, consider approaching rehabilitation from a relationship-centred perspective. Strengths and limitations of this study will be discussed, as well as recommendations for further research into community integration for people with ABI. I conclude with a summary of the findings from the study and key messages.

Extending the Conceptual Understanding of Community Integration

Previous frameworks of community integration for people with ABI have been multidimensional, reflecting the complexity of community integration as a construct. As demonstrated in Chapter 2, there are some dimensions common across all previous frameworks and supported by studies of lived experience such as *occupation* and elements of *social relationships.* Other dimensions, although evident in lived experience literature, are unique to particular frameworks, such as *risk and vulnerability* (Parvaneh & Cocks, 2012). Some of my findings resonate with these existing frameworks with the common dimensions of occupation, living at home, social connection, acceptance, independence, and adjustment all apparent in my study. However, my findings have extended the understanding of these dimensions in a number of ways including adding a temporal, progressive element to living at home as described in the theme *Growing into a new way of community living*. My findings have also extended the concepts of occupation and independence to include the need to consider the meaning of the occupations beyond their successful achievement. The importance of social connection also emerged as a predominant theme within my study. The links between occupation and social connection, and the need for shared occupation to encourage this connection, are not demonstrated in previous frameworks (to be discussed in detail later in this chapter). The expectations of others within the social networks surrounding the individual with ABI is also a finding that has not been previously highlighted in published literature. These findings provide important considerations for clinical practice, service organisation, and health policy to underpin rehabilitation programmes and support services that address barriers to community integration for people with ABI.

A Progressive Process of "Growing"

The theme *Growing into a new way of community living* incorporated four stages of growing: *preparing for discharge, early days back at home, settling back in,* and *back into the bright and busy world*. *Preparing for discharge* involved exposure and opportunities to practice the practical (mostly physical) aspects of community-based activities, with the support of rehabilitation teams, prior to leaving the in-patient environment. *Early days back at home* was

an emotional stage for participants as they undertook a determined struggle to establish what they were capable of within the home environment and began to adapt or find coping strategies to help them progress. *Settling back in* was a stage where participants became more comfortable and confident in their abilities and they began to catch-up with the people around them after feeling that their own lives had been placed on-hold. This was a stage where participants began turning their focus away from themselves and towards others. Their ongoing progress with broader community-based activities during this period provided them with the motivation to get *Back into the bright and busy world.* In this final stage, participants took a cautious approach and tried to generalise the strategies learned in earlier stages to more complex community scenarios, with both positive and negative results.

Growing into a new way of community living highlights that community integration is a dynamic and iterative process where people with ABI gradually extend their reach into the community, grappling with a range of social, emotional, cognitive, and physical complexities as they proceed. This sits in contrast to early frameworks of community integration which tended to focus on static dimensions rather than the dynamic processes of "growing", "developing", "adapting", or "progressing" that were described by the participants in this study. Willer et al. (1993) was primarily concerned with developing a measure of community integration and therefore focused on discrete measurable outcomes. The concern was about whether or not people with ABI participated in certain activities and the frequency of participation, rather than how people came to engage in these activities or whether the experience was more successful, enjoyable, or felt more natural with repeated attempts. Progression towards community integration is somewhat reflected in McColl et al.'s (1998) framework of community integration in the *Independent* dimension. McColl's participants expressed a need to become self-determining in terms of their own abilities, not to have to ask permission or rely on others. This was evident in my participants' experiences within the *Early days back at home* where they spoke of a desire to be free from the supervision of others and to manage daily activities around the home by themselves. The concept of a temporal process of trial, adaptation, and growth becomes somewhat more apparent in the framework proposed by Pavaneh and Cocks (2012) who revealed two more dynamic, dimensions of community integration than had been proposed in other frameworks. Although not divided into discrete or progressive stages, their *Being at home* dimension included a range of components that can be related to the later three stages of *Growing into a new way of community living.* "Doing ordinary things people do at home, e.g. cooking and eating food you like, watching tv, read the newspaper" (Pavaneh & Cocks, 2012, p. 135) can be linked to the types of tasks that participants in my study were attempting to master in their *Early days back at home*. "Feeling

and being in your own home" (Pavaneh & Cocks, 2012, p. 135) is very closely related to the idea of *Settling back in* and "from the home base, participating in chosen important outside activities" (Pavaneh & Cocks, 2012, p. 135) is similar to the *Back into the bright and busy world* phase described by participants in my study. Parvaneh and Cocks (2012) also included a dimension of *Picking up life again* in their community integration framework. To date, this dimension is not reflected in any other community integration frameworks but suggests an active process of adaptation*. Picking up life* again can be summarised as returning to old roles at home or in society, gaining confidence, having new experiences, and taking up new roles, resembling the stages of growth that were uncovered in my study.

Shaikh et al. (2018) referred to Parvaneh and Cocks' (2012) *Being at home* concepts (as described above) within their *Place to live* attribute of community integration but do not add anything new. Although they have an *Adjustment* attribute, the description is focused on cognitive and behavioural functioning that facilitates performance in vocation and emotional bonding. When my participants described "adjustment", they referred to the adaptations they made in the practical aspects of living at home and developing strategies to manage everyday activities. Therefore, "adjustment" across the two studies appears to refer to two very different ideas and stages of the community integration journey. Although Shaikh et al.'s conceptual analysis includes a component of community integration that is a process, this is only briefly referred to in their published paper. From the sparse information available, the process appears to have some elements that reflect the more progressive and dynamic nature of community integration, similar to my study. These include transitions from hospital to home (similar to *Preparing for discharge*), adapting to limitations and changed circumstances (*Early days back at home*), and regaining normality (*Settling back in*).

Table 8, on the following page, summarises the dimensions from each previous framework and how they link to the process of community integration that emerged from this study. As can be seen, while parts of the process are addressed by some frameworks, the whole process is not well captured in its entirety by existing frameworks. In comparison to the frameworks and descriptions that have gone before it, this study has made visible a more dynamic concept of growing and progression towards community integration as opposed to descriptors of static dimensions. I have attempted to provide a detailed account of the four stages of this process in terms of what people with ABI are thinking, feeling, doing, and what appeared to facilitate (or hinder) their growth. Distinguishing four phases to this process, and providing a comprehensive account of each phase, builds upon previous lived experience work and strengthens understanding of how the process unfolds and is uniquely experienced by people.

This helps to identify opportunities where supports could be put in place to help people navigate the complexities of the community integration process.

Table 8

Summary of Community Integration Framework Dimensions and How They Apply to a Progressive Process

	Preparing for discharge	Early days back at home	Settling back in	Back into the bright and busy world
Willer et al. (1993)				
McColl et al. (1998)		Independent		
Parvaneh & Cocks (2012)		Doing ordinary things people do at home	Feeling and being in your own home	Participating in chosen important outside activities
Shaikh et al. (2018)	Transitions from hospital to home	Adapting to limitations and circumstances	Regaining normality	

Considering the Expectations of Others

Highlighting that the expectations of other people have a role in the process of community integration is the second way that my findings contribute to the overall conceptual understanding of community integration after ABI. Participants perceived that they were required to live up to a range of expectations when they returned home from in-patient rehabilitation. These included their own expectations of how they should be performing and conveying themselves outwardly. In addition, the expectations of others were found to be highly influential in either supporting or hindering their integration back into the community. Participants identified family and whānau as having both realistic and unrealistic expectations. They also identified the need to live up to the expectations of their roles in life (e.g., mother, husband, uncle, friend, faith-based, employee, student), and societal expectations. Some of the societal expectations were concrete and clearly apparent, such as the isolation rules during the national COVID-19 response; others were more abstract, such as the value society places on people seeming to be busy and productive.

Living up to expectations is not readily evident in other frameworks of community integration. In McColl at al.'s (1998) study there is an element of expectation in the *Conformity* component of their *General integration* dimension. *Conformity* here related to the need to "fit in" with other residents in shared supported accommodation and the expectations of conforming to the rules of the residential setting. Although the participants in the McColl et al. study were

living in supported residential settings, rather than their own homes, there is synergy with the idea of "rules" that need to be lived by. However, the concept of *Living up to expectations* is not otherwise apparent in community integration literature. This is despite other more multifaceted models, such as that by Parvaneh and Cocks (2012), including expansive consideration of interactions with others in the components of their community integration framework. They identified a range of interactions with what is termed *close and enduring* and *distal/fleeting* networks within my study; yet, their framework focuses completely on the individual with the brain injury without considering how the expectations of those with whom they interact impacts their ability to progress in their integration. It could be that personal expectations are implicit in *Individual factors* included as an antecedent of community integration in Shaikh et al. (2018).

Environmental factors are also referred to as an antecedent. Although only physical structure, availability of transport, finances, and access to services and information are provided as examples of these environmental factors, the ICF Disability and Health (World Health Organization, 2001) would consider attitudes of others and social policy (examples of societal expectations) as other environmental factors that impact participation. Attitudes of others has been seen as a barrier to community integration within the small body of literature that explores the social consequences of stigma on people with ABI (Govender et al., 2019; Hagger & Riley, 2019). Participants in these studies reported expectations of society that negatively impacted their ability to re-integrate into their communities, including beliefs as extreme as the person with ABI being cursed and, therefore, to be avoided.

Overall, the concept of *Living up to expectations* is not included as a key component of community integration for people with ABI in existing frameworks. This is despite participants in my study clearly defining it as an issue for them, and the broader ABI literature (Chapter 6, p. 134) identifying the importance of actively involving significant others in rehabilitation programmes to address their expectations and help facilitate favourable outcomes. This appears to be a significant gap in previous literature relating to the concept of community integration and an important addition to the knowledge base for facilitating community integration at clinical, organisational, and societal levels.

Poorly Defined but Commonly Occurring Dimensions of Community Integration

Other key aspects of community integration identified in my findings, such as social connection and meaningful occupation, are reflected in existing frameworks. However, in some cases, the aspects have not been well defined or they have been spread across multiple dimensions thereby diluting the focus on these two important areas.

Social connections have been identified as a factor in community integration since the very first definition by Jacobs (1993), who identified *Someone to love* as one of three dimensions of community integration. The term *Someone to love* would assume, in this instance, that the social connection was one of a *close and enduring* nature rather than *distal/fleeting* or *professional*. Willer et al. (1993) took a broader view and identified *Social integration* as the second dimension of their framework, referring to participation in a variety of activities outside of the home and reflecting aspects of interpersonal relationships such as having a best friend. Again, due to the motivation behind Willer et al.'s study being to create measurable outcomes, the focus on this social integration tends to be what Holt-Lunstad et al. (2017) referred to as the structural aspects of social relationships, such as the network size or arrangement. There is little acknowledgement of the qualitative aspects of these social connections or the function they serve.

Although Jacobs (1993) and Willer et al. (1993) tended to focus on family and friends within the social connection aspects of their frameworks, McColl et al. (1998) identified that there were also diffuse relationships that were an important component of social connection. McColl et al. identified *Social Support* as the second dimension of their framework and acknowledged two networks from which this support is received—close relationships (spouse, parent) and diffuse relationships that include people their participants came into contact with on a daily basis such as shop keepers. Despite McColl et al.'s participants living in supported residential settings and referring to staff presence, the identification of a professional or staff network is missing from the social support aspect of their framework. It seems unlikely that this network did not provide some sort of social support or influence the progression towards greater integration. Similar to the current study, the participants in the McColl et al. study recognised the importance of meeting new people and making new friends to expand their social networks and continue to promote their community inclusion. They also identified that peers with similar experiences were important for social comparison, learning, and a sense of shared history. These peers were included in the diffuse relationships, as is the case in my study. This further affirms the recommendation discussed in Chapter 6 to introduce formal peer support into rehabilitation so peers can become more than diffuse relationships and readily provide a range of practical, emotional, and informational support.

Parvaneh and Cocks (1998) also identified a *Relationships* dimension to their community integration framework and within this recognise the importance of both a close/intimate network alongside a distal network. Peer or professional networks are not included in their framework. The importance of social connection is spread across a number of other dimensions within Parvaneh and Cocks' framework thereby diluting it somewhat. There is

evidence of the need for the involvement of social networks in their *Community access* dimension which includes the descriptor "obtaining necessary practical and social support" (Parvaneh & Cocks, 1998, p. 135), and also within their theme of *Heightened risks and vulnerability* which includes social isolation as a potential risk. Similarly, Shaikh et al. (2018) spread components of social connection across a range of dimensions within their conceptual model of community integration. Interactions with peers, family, and caregivers are used as an example of the *Societal factors* in their antecedents impacting on community integration and *Social connection* is an attribute of their model that acknowledges forming and maintaining relationships both from within and external to family. Within Shaikh et al.'s definition of the attribute *Social connection*, they use the term social integration in a similar context to Willer et al. (1993) and refer to social support and a social network. Combining these terms, that have been used independently across other studies, blurs the understanding of these concepts.

Where previous studies of the dimensions of community integration have blurred the terms social connection, social support, social networks, relationships and so on, it is hoped that my findings offer insights that help better define these in a way that serves to be of clinical relevance. The concept *(Re)Building social connections* requires the consideration of three different social networks and the provision of three types of social support, all of which build opportunities for further social and community integration and thereby continue to increase or deepen social networks. This study has also focused attention relating to *(Re)Building Social Connections* as a key component of community integration in its own right rather than having various components of social connection dispersed across multiple dimensions. This highlights its primacy and importance as a key component of community integration that needs explicit attention in practice.

Aspects of the theme *Engaging in meaningful occupations* are also evident in existing community integration frameworks, starting with *Something to do* included in the earliest framework proposed by Jacobs (1993). However, similar to social connection, the concept of engagement in meaningful occupation has been dispersed across a variety of dimensions within different frameworks. As an example, Willer et al. (1993) discussed engagement in daily occupations within the *Home integration* and *Productive activities* dimensions of their framework. The former focuses on "active participation of the individual in the operation of the home, e.g. grocery shopping, preparing meals, housework, planning social gatherings in the home" (Willer et al., 1993, p. 78). The latter focuses on the employment, educational, and volunteer activities in which the individual participates and is explicit in the notion that "society places highest value on competitive employment" (Willer et al., 1993, p. 78).

Data analysis within my study conceptualised *Engaging in meaningful occupation* as a continuum of activities across personal, household, leisure, social, and vocational domains, with different people placing importance on different areas. In contrast, Willer et al. are explicit in their focus on *productive activity* being the pursuit of paid employment (or similar) as a primary dimension of community integration. This view of return to employment being the emphasis of community integration, and seen as a measure of successful integration, is not uncommon, multiple papers that refer to community integration as their subject are predominantly concerned with returning to employment or returning to active service in the case of veterans (Carlson et al., 2018; Dillahunt-Aspillaga & Powell-Cope, 2018; Mortera et al., 2018; Pogoda et al., 2018). This appears to be a western-centric view of successful integration and it may not be a realistic outcome for many individuals with ABI, depending on the severity of their impairment. Social ideals of what constitutes as valued occupations may contribute to the sense of having to live up to societal expectations as discussed in the previous section. As a comparison, Māori culture and models of health, explored towards the end of this chapter, demonstrate an alternative cultural expectation of successful community integration that prioritises the depth and breadth of relationships and connection as opposed to measuring success through return to work or productive activity.

Despite McColl et al.'s (1998) participants being those who were living in supported settings, they also considered returning to paid employment as highly influential in terms of perceived successful integration and discussed employment preparation as an important component of their progression. However, the importance of productive occupations in McColl et al.'s study also included additional motivations such as making a contribution, providing a sense of purpose, adding structure to the day, and receiving respect from others. This is similar to my findings where the meaning of the occupation went beyond that of successful task completion or independence. This was not, however, only relevant to employment as an occupation, but applied to household, leisure, and social occupations.

My findings align more closely with Parvaneh and Cocks' (2012) themes. They identified *Occupation* as one of the dimensions contributing to community integration and described this as "Being engaged and satisfied in useful and meaningful activities in the home and community, e.g. having a job, being involved in social, productive, leisure and recreational activities" (p. 135). This relates to the mastering and independent participation in activities of their choosing. In a separate dimension, *Acceptance,* Parvaneh and Cocks then described the importance of being included in the community, having a sense of belonging, and feeling valued. There is, however, no link in the framework proposed between these two dimensions. Participants in my study linked their engagement in meaningful occupations both with

becoming more independent and providing motivation, a sense of achievement, connection, contribution, and reciprocation. This builds on the idea that occupation needs to be meaningful at a level greater than immediate day-to-day usefulness, or reducing dependence on others, for people with ABI to feel truly integrated into their communities. This is better reflected by Shaikh et al. (2018) who conceptualised their *Occupational performance* attribute of community integration as more than merely doing an activity. They acknowledged that being involved in productive and recreational activities allows people with ABI to contribute back to society, express their identity, and build their confidence. Unfortunately, the whole story of the importance of *Engaging in meaningful occupations* is separated out across three dimensions of Shaikh et al.'s framework of community integration. The successful achievement of occupations is part of their *Independence* dimension, the sense of contribution and confidence these occupations bring is part of their *Occupational performance* dimension, and achieving a sense of being a part if the community is included in their *Sense of Belonging* dimension. Again, it appears to dilute the focus on the importance of occupation as a whole. *Engagement in meaningful occupation* requires a view beyond the successful completion of a specific task, toward the meaning of the occupation as it contributes to a sense of community involvement.

(Re)Building social connection and *Engaging in meaningful occupations,* are incorporated into all previous community integration frameworks; yet have been diluted in their primacy by spreading them across various dimensions or through poorly developed definitions and variable use of terminology. In my findings, it is evident that these two themes are closely linked in that one leads to the other: engagement in occupation leads to increased opportunities to build social connections, which in turn leads to an improved sense of belonging and value within the community. Despite engagement in occupation having broader meaning beyond the "doing", all the participants in my study found that the rehabilitation professionals they worked with were very much focused on the practical, and mostly physical, aspects of carrying out their occupations. From the participants' perspective, it appeared that the focus of these clinicians was predominantly on strategies to improve their occupational performance rather than looking beyond the occupation and exploring what meaning it held. There was also a lack of emphasis on the idea that most occupations to which the participants wished to return involved other people, and were, therefore, shared occupations that required interaction between the person with ABI and others.

In the sections that follow, I argue that rehabilitation professionals must look beyond the successful performance of individual occupations as the goal of their programmes to explore the meaning of these occupations in more depth. I argue that consideration be given to the

many occupations that people wish to undertake as shared occupations versus undertaken in isolation. By considering occupations as shared occupations, more attention can be given to the incorporation of social connection. With social connection comes opportunity to influence societal expectations, and create a sense of belonging, contribution, and reciprocation within a community. Taking the perspective that shared occupation and building social connection enhances community integration for the person with ABI, I highlight how existing person-centred approaches to rehabilitation may impede community integration by encouraging clinicians to attend to the person independently of those around them. A shift away from person-centred rehabilitation towards relationship-centred rehabilitation is proposed as a potential option to address this situation.

Shared Occupations and Social Connection

My participants perceived their clinicians predominantly focused on occupations of a practical nature and emphasised independence in daily living activities such as mobility, self-care, household domestic activities, and daily communication. However, engaging in meaningful occupations meant more to participants than simply *doing* these types of activities to their successful completion. The meaning of the occupation for participants incorporated feelings of progression, achievement, success, recognition, connection and contribution, as well as providing structure and keeping them occupied.

The use of occupation as a therapeutic tool and the engagement in meaningful occupation as a means of promoting health and wellbeing is the foundation of occupational therapy practice (Hagedorn, 1997). As such, it would be anticipated that occupational therapy practice, research, and literature would lead the way in driving rehabilitation based on the broader aspects of meaningful occupation. Although occupational therapy and occupational science literature place some emphasis on the meaning of occupation beyond the *doing,* this does not appear to be translating into clinical practice (Hammell, 2008, 2014; Kennedy-Behr & Hatchett, 2017; Roberts & Bannigan, 2018). An overview of the definitions of occupation, as cited in occupational therapy literature and summarised by Leclair (2010), demonstrated that occupation is experienced by the individual and is subjective, that value and meaning are derived from the cultural context, and that participation in occupation benefits both the individual and communities in which they live, work, and play. However, the dominant models of occupational therapy on which clinical practice is based, such as the Model of Human Occupation (MOHO; Kielhofner, 2008), Person-Environment-Occupation Model (PEO; Law et al., 1996), and Canadian Model of Occupational Performance and Engagement (CMOP-E; Polatajko et al., 2007), divide occupations into three specific categories: self-care,

productivity/work, and leisure/play. These classifications focus primarily on the individual and fail to support broader meanings of occupation that incorporate contribution to community, social interaction, or the importance of shared occupations. These categorisations have also been criticised for focusing on the cognitive, affective, and physical components of activity performance without addressing occupation at the level of community participation (Leclair, 2010; Hammell, 2014). Translation of these models into practice may contribute to clinicians' tendency to target the individual in their interventions rather than examine the wider "who" of occupation. Does the occupation occur in isolation or is it shared as part of a pair, group, or community?

The term "shared occupations" has not been well defined in the literature but includes the concept of "doing with others" (Hammell, 2014, p. 43), "engaging in occupations with others who share a common experience, interest, value or goal" (Leclair, 2010, p. 17), or occupations that "create emotional ties, a group identity and stories of things we did together" (Hocking, 2020, p. 5). All these definitions indicate that people derive a sense of social connection from shared occupations. In their exploration of wellbeing and engagement in occupation for people with Parkinson's disease, Kennedy-Behr and Hatchett (2017) discovered that the occupations that people with Parkinson's disease engaged in served two main purposes that potentially affected their wellbeing. One was developing their sense of identity; the other was building and maintaining relationships. As with the participants in my study, Kennedy-Behr and Hatchett's participants perceived occupation to be important for social interaction and to facilitate or maintain relationships. These relationships gave them a sense of belonging and contribution to their communities and were considered part of wellbeing. The authors argued that occupational therapy literature considers social connection, belonging, and a sense of contribution to be important to wellbeing and quality of life. However, few studies have explored this idea and it does not seem to have translated well into clinical practice. Both mine and Kennedy-Behr and Hatchett's studies suggest that instead of solely focusing on what assistance the person needs, clinicians should also explore ways in which the individual could continue to engage in occupations that promote social connection, and thus progress their community integration.

Roberts and Bannigan (2018) systematically reviewed literature on the subject of personal meaning of engagement in occupation, distilling similarities until they revealed four dynamically interlinked themes. These four dimensions of personal meaning included: a sense of fulfilment; a sense of restoration; social, cultural, and intergenerational connection; and identity shaping. A number of the themes' components resonate with the four themes that were discovered in my study, particularly *Engaging in meaningful occupation* and *(Re)Building*

social connection themes. Their Sense of Fulfilment theme included sub-themes of "achieving mastery and establishing future goals", "pride and satisfaction", and "making a contribution to community and others" (Roberts & Bannigan, 2018, p. 389). These closely relate to the outcomes of *Engaging in meaningful occupation* including providing a sense of achievement, motivation towards future aspirations, measuring progress, and contributing to others. In Roberts and Bannigan's theme, Sense of Restoration, there was a sub-theme relating to keeping the mind active and structuring the day to help relieve stress, which relates to the outcome of *keeping occupied and distracted* that participants in my study identified as a reason to *Engage in meaningful occupation.* Finally, Roberts and Bannigan's metasynthesis revealed that occupations provide a social, cultural, and intergenerational connection. Similar to my study, they referred to a number of networks with which connections are made through occupation including family, friends, and other people in the community. They also identified the importance that social support, derived from connecting with others through occupation, provides in terms of community integration, stating "the sense of support and connection to friends and groups of people contributed to a strong sense of belonging to a community" (Roberts & Bannigan, 2018, p. 391). The similarities between the two studies demonstrate how personal meaning of engagement in occupation is linked to social connection and to community integration.

It is clear from my findings, and from broader evidence in this field, that engagement in occupation brings about a sense of social connection and support from family, friends, and the community. Meaning is attributed to and derived from occupations that foster social connections and further opportunities for contribution, collaboration, and strengthening social roles. These all serve to further community integration for a person with ABI.

Influencing Components of Social Connection to Promote Community Integration

The benefits of social connection on health and wellbeing, and conversely the association of social isolation or loneliness with poor health and increased mortality, have been studied across a range of populations, resulting in a number of recent systematic reviews. These reviews have examined the association of social connections on the physical health of long-term care residents (Lem et al., 2021), the cognitive function of older adults (Kelly et al., 2017), wellbeing in people with physical disability (Tough et al., 2017), and mental disorders such as depression (Santini et al., 2015). While these reviews are potentially useful, given that those living with ABI are impacted by physical, cognitive, and affective limitations, the systematic review by Tough et al. (2017) is perhaps the most significant. Their review included studies

spanning from 1995 to 2016, specific to ABI or similar long-term neurological conditions, and across a wide age range (21-76 years). They focused on three aspects of social connection that relate to the three factors outlined by Holt-Lunstad et al. (2017) as discussed in Chapter 6; structural, functional, and qualitative. Although their aim was to summarise the empirical research on the association of these different constructs with the wellbeing of those with physical disability and highlight conceptual deficiencies in the field of research, their findings also serve to provide clinically relevant information.

Similar to my study, Tough et al. (2017) found social connection to encompass a variety of aspects relating to structure/networks, function/support, and quality/satisfaction. They explored the impact of the size, density, frequency, and duration of social networks (i.e., structural aspects of social connection), the functional significance of social support in terms of providing practical, emotional, or informational resources, and the perceived quality and satisfaction of the support received. This provides some guidance as to where clinicians might best focus their efforts across these three aspects in order to positively influence social connection and promote community inclusion. It is more complex than trying to increase networks on the assumption that this will increase support and lead to better outcomes. Extensive social networks may not necessarily be supportive and members of these networks may instead be a source of conflict. Unwanted social support can lead to negative consequences such as feelings of reduced autonomy, as was the case with one of the younger participants in my study whose parents were insistent on him keeping the bathroom door open so they could check he was safe while he showered, despite him feeling capable of showering without their supervision. The systematic review by Tough et al. found inconclusive evidence of the association between social networks/structure and wellbeing. They argued networks are important in their provision of social support; therefore, perhaps exert indirect rather than direct effect on wellbeing. Social support, particularly the qualitative aspects of support, appeared to be a more significant indicator of wellbeing. Tough et al. concluded:

> Integrating persons with disabilities into social networks is an important endeavour, however, it is of equal importance to strengthen the quality of their relationships and to tailor the level and kind of support to their needs… rehabilitation professionals should support persons with disabilities and their significant others to ensure high quality relationships are established and maintained, and that adequate support is available. (p. 15)

These findings are congruent with studies presented in Chapter 2 that reinforce the development of social self-efficacy to promote the quality of social connections (Batchos et al.,

2018), and optimising social support from family and friends to provide encouragement to persevere with the return to social activities (Erler et al., 2019; Reed et al., 2012). The findings of all these studies suggest that it is not the number or variety of social networks that are most important for successful community integration, but the quality of support being received from these networks.

The discussion, so far, has demonstrated that engaging in meaningful occupation helps to build social connection; thereby facilitating reintegration back to the community for those with disability, including those recovering from ABI. For social connection to occur, the occupations in which participants engage need to be shared occupations (i.e., they need to occur with others). The people with whom these occupations are shared need to provide valued support to the individual with ABI for them to feel satisfied with their social connections and continue in their journey towards greater levels of integration. Therefore, rehabilitation professionals aiming to promote community integration need to consider the importance of shared occupations and the quality of relationships that are being maintained or established through these occupations. To achieve this, the following section considers whether existing person-centred approaches to rehabilitation need to be expanded to incorporate a relationship-centred approach. A relationship-centred approach would consider the importance of incorporating the individual with ABI as a partner in rehabilitation, as well as those around them with whom high quality social connections can be established.

Proposing a Relationship-Centred Approach to ABI Rehabilitation

The term patient-centred care was developed in the 1980s as a model of care that "sought to articulate the doctors' and patients' agendas, to find and explore common ground, and to explore both disease and illness experience" (Beach et al., 2006). More recently, the concept of person-centred care has become more popular, with research and clinical evidence supporting the expansion of the traditional patient-centred care concept to a more co-constructed process between clinician and patient (Kayes et al., 2022). Person-centred rehabilitation has been proposed as "a way of thinking about and providing rehabilitation services 'with' the person" (Jesus et al., 2022, p.109). The term relationship-centred care has been used in the literature previously to emphasise the importance of relationships from the clinician's perspective. These relationships are usually considered as four components: relationship with the patient (the importance of therapeutic alliance), colleagues (the need for interdisciplinary working), communities (incorporating the knowledge of community demographics and multiple determinants of health), and relationship with self (reflective practice) (Beach et al., 2006; Weiss & Swede, 2019).

Here, I am proposing a different definition of a relationship-centred approach to rehabilitation. This approach moves beyond the definitions outlined above which, when used in the ABI rehabilitation context, propose individualised approaches focused on the person with ABI and their needs and preferences. The relationship-centred approach I propose is one that focuses on the individual with ABI as a relational being; connecting and collaborating with a range of social networks through shared occupations to give and receive support, (re)build social connections, and develop a sense of belonging within their community. Although this may appear to be a new way of defining relationship-centred rehabilitation, there is growing evidence that this approach is being considered within contemporary models of rehabilitation and recent research evidence in ABI to support its use.

When Douglas et al. (2015) proposed rethinking social-relational perspectives in TBI rehabilitation, they emphasised the importance of social relationships and interconnection in rehabilitation. They encouraged the use of these constructs to guide practice and develop novel approaches to assessment and intervention. They illustrated the importance of attending to the social-relational aspects of an individual's life in the rehabilitation process and provided evidence to support a greater focus on the relational-self in how clinicians work with people after TBI. Their work reinforces the finding from my study that interactions between those with brain injury and the people around them at home and in the community are crucial to their long-term wellbeing and quality of life. Douglas and colleagues also considered social connection as important for constructing self-concept and argued that rehabilitation clinicians need to consider the implications of the constructs of self-concept and social connection to assist those with brain injury to live well in their communities. Douglas et al. highlighted the intervention potential of social relationships and described intervention strategies targeting six factors that facilitate a sense of social connection: family, friends, carers, pets, concrete reminders of social connection, and self-narratives. These six areas were all identified by my participants as important facilitators guiding community integration. Participants talked of the importance of significant others (including pets) for providing social support. They discussed the concrete reminders of pre-ABI social connection, such as times reminiscing with family members around the dinner table, and described self-expectations that were influenced by the way that others might perceive them (e.g., weak, ill, or sick). These areas all played a part in hindering or enabling their progression with community integration.

Although a person-centred approach is widely recommended for guiding rehabilitation services, conceptual models that support the practice of person-centred rehabilitation have been absent until very recently. A paper in 2022 by Jesus et al. aimed to explain what person-centred rehabilitation means in both concept and practice. They conducted a scoping review

of person-centred literature followed by a thematic analysis that gave rise to a Person-Centred Rehabilitation Model that could be applied within adult physical rehabilitation settings. This model demonstrates that person-centred rehabilitation is embedded in rehabilitation practices and structures over three levels: the person-professional dyad, the microsystem level (including the interdisciplinary team and significant others), and the macrosystem level (the organisation or structure within which rehabilitation is delivered). It is the microsystem level that provides support for the concept of rehabilitation extending beyond the person to encompass the context of relationships. At this microsystem level, engagement of significant others is seen as an essential attribute with significant others playing a key role in the rehabilitation planning and being agents of care. At this level, it is important to establish who the person would like to be most involved in the rehabilitation process. Jesus et al. may have been focusing on the social connections between the person and their social network as a component of their Person-Centred Rehabilitation Model but also support the concept of expanding this approach beyond the person saying "with appropriate safeguards, significant others should be an integral part of PCR [person-centred rehabilitation] approaches, beyond mere bystanders, adding a relational, systemic approach to PCR practices" (Jesus et al., 2022, p. 113). Person-centred rehabilitation also embeds therapeutic alliance (as described in Chapter 6) into the model's attributes at the level of person-professional dyad recommending that clinicians tailor interventions to the needs of the whole person; that they nurture a supportive relationship that is compassionate, trustful, and caring; and they empower the person enabling co-constructed rehabilitation. Although the model supports the concept of rehabilitation beyond the person and the inclusion of relationships as a factor in rehabilitation, it does not appear to be evident in clinical practice based on the reports of participants within my study or other studies of lived experience from the perspectives of the individual with ABI or the clinicians working with them (Bradley et al., 2021; Theadom et al., 2018).

Again, in recent research within ABI, the concept of therapeutic alliance appears to have undergone an expansion to include the traditional person-professional dyad and incorporate relationships beyond this dyad that include family and others in the person's close social network. Bishop et al. (2021) undertook a study that aimed to explore the core components of therapeutic alliance from the perspectives of those who had experienced stroke and their rehabilitation clinicians. They discovered three overlapping core components: personal connection, professional collaboration, and family/whānau collaboration. From the perspective of family/whānau collaboration, participants highlighted the central roles that loved ones played in the person's life. These roles included decision makers, rehabilitation partners who could assist with skill development and provide enduring support, and

advocates. Identifying and involving relatives within these roles was perceived to be an essential component of the therapeutic relationships. Bishop et al. draw attention to family/whānau collaboration being absent from previous theories of therapeutic alliance that tend to categorise the family system as an extra-therapeutic factor, as opposed to a core component. They proposed that these different conceptualisations may be due to the unique context of ABI rehabilitation, such as the need to support cognitive and communication deficits, leading to the need for greater family connection; a need which may be less crucial in other health delivery settings.

Specific to supporting the need for a relationship-centred rehabilitation approach for people with ABI undertaking community integration, Nalder et al. (2022) undertook a scoping review to synthesise the qualitative literature relating to indicators of life success after TBI. They found that positive life experiences were organised within four domains: understanding of oneself and one's life, social relationships and interaction, engagement in activities with a sense of control and accomplishment, and hope for the future. These domains relate closely to the themes established from my own community integration research, and highlight the importance of social relationships as a central positive factor in life success including community integration. Understanding of oneself is similar to the self-concept described earlier by Douglas (2015) and is reported to evolve through social connection. The domain of social relationships and interaction in Nalder et al.'s study incorporates all the components found within my study, namely having people in one's life that one feels connected to (social networks), the feeling of being supported (social support), and having opportunities to engage with others (shared occupations).

One of the limitations of Nalder et al.'s (2022) qualitative synthesis is that the majority of the 76 articles included came from Australia, United States, Canada, United Kingdom, or Western Europe. None were published in Asian or South American countries or low-middle income countries. Therefore, it is likely that the indicators of life success that were synthesised from this scoping review carried a heavy westernised ideology of life success. With this in mind, I explored the New Zealand context, particularly Māori models of health, to identify concepts in relation to social connection and relationship-centred approaches.

Wilson et al. (2021) conducted a qualitative literature review of Māori models of health and wellbeing in order to identify key concepts, principles and values embedded within them. Nine models were then used to inform a Māori-centred relational model of care. The four themes that emerged from this study all incorporate the concept of relationship-centred approach, as defined at the beginning of this section, within a culturally relevant context.

Components of the Māori-centred relational model of care that mirror the concept of a relationship-centred approach include the dimension of whānau within the "Dimensions of health and wellbeing" theme that exemplifies the collective way in which Māori operate and highlights how Māori exist as part of a collective whānau and community. The theme "Whanaungatanga" (connectedness) also demonstrates how Māori models of health are grounded in relationships and connectedness, particularly whakapapa (tracing connections through generations of whānau) which provides unity between individuals, whānau, and hapū (clan).

More specific to Māori experience of rehabilitation following ABI, Wilson et al. (2022) explored Māori experiences of meaningful connection in neuro-rehabilitation. Although their study set out to explore therapeutic connection as related to earlier discussion regarding therapeutic alliance, they found that connection for Māori went beyond the therapeutic relationship. Of the three layers of connection that they discovered, core features include "hononga" (building connection); "whānau" – being valued as an interconnected member of whānau and wider community, with pre-established networks of support that could be drawn upon; and "whanaungatanga" – knowing the person in the context of care. These features demonstrate the need for clinicians to have insight into the home context, personal roles, and relationships that exist within whānau, including the influence that whānau play in recovery and healing. Participants also reported how appreciating the impact of ABI beyond the individual and on the whānau gives clinicians opportunities to extend the benefits of rehabilitation to the collective group. Taking this approach provides the social network with whom the individual with ABI interacts with the knowledge, expectations, and skills to continue supporting the person when the clinicians withdraw their finite services. Whanaungatanga provides a depth and breadth to whānau relationships that extends beyond the understanding of injury or illness and impacts on the person with ABI's engagement in rehabilitation. Wilson et al. concluded that "the whānau context is crucial within neuro-rehabilitation and connection is enhanced when the individual, as well as their whānau, are meaningfully engaged in the care relationship and health environment" (p. 18). These findings move the concept of relationship-centred rehabilitation beyond the western-centric understandings that have been summarised in studies such as the one by Nalder et al. (2022) and incorporate indigenous perspectives that demonstrate the potential this approach could have on rehabilitation outcomes for those with ABI.

These papers, alongside my study, present a useful picture of what relationship-centred practice could look like and how this way of working makes more explicit the active engagement of others as part of the rehabilitation process. Where my study has provided

additional support to the concept of relationship-centred rehabilitation is its mechanism in supporting engagement in meaningful shared occupations, the (re)building of social relationships through increased networks and support, the potential these relationships have on influencing societal expectations, and the sense of belonging and contribution to the community a person with ABI can experience when sound, supportive relationships are established. All these areas impact on a person with ABI's ability to reintegrate into their community on return home from the in-patient setting.

Summary

The aim of this study was to explore how people with brain injury reintegrate into their communities on return home from in-patient rehabilitation. This discussion chapter has examined theory and evidence relating to community integration after ABI and identified where this study has added to that body of knowledge. It has been argued that engaging in meaningful occupations has a higher purpose than just successful performance of activities. There needs to be a shift from occupations promoting a person's independence to shared occupations that help people with ABI to maintain or establish social connections. Social connections lead to opportunities for people to develop a sense of belonging, reciprocation, and contributing back to their communities. Considering the importance of building social connections to support community re-integration, it is argued that rehabilitation service providers look beyond models of person-centred practice and consider approaching rehabilitation from a relationship-centred perspective. Supporting people with ABI to re-integrate into their communities requires rehabilitation professionals to view the individual as a relational being; connecting and collaborating with a range of social networks through shared occupations, in order to give and receive support, (re)build social connections, and develop a sense of belonging within their community.

Study Strengths and Limitations

The use of Interpretive Descriptive methodology ensured a process of recognising my own personal and professional experiences and how they have influenced my epistemological beliefs. Interpretive Description has allowed a sequential conceptualisation of comprehending and learning about experiences, integrating and synthesising instances and events to establish patterns, develop theories, and articulate what has been synthesised. This has led to findings that have clinical relevance and can inform rehabilitation practice at various levels. The strengths and limitations of this research are discussed in the following sections.

Rigour Within the Interpretive Descriptive Approach

My research process has drawn heavily on key aspects of rigour identified as important in an interpretive descriptive study, as detailed in Chapter 3. My own epistemological standpoint has been made clear throughout the research process and during the write up. The principle of interpretive authority has been demonstrated in Chapter 1, where my personal and professional experiences were made transparent and hopefully contributed to the reader's understanding of the potential influence these pre-existing ideas may have had on questions asked and methods sought to answer them. The analytic logic of the research process has been defined, initially through the theoretical scaffolding, and then through a detailed description of the four stages of systematic conceptualisation described in the data analysis section of Chapter 3. Interview quotes used throughout the findings chapter also provide details of the analytic reasoning that demonstrate the degree to which analysis is grounded in the research data. Thorne (2016) advocated for researchers to utilise the expert knowledge of those around them to sound out some of their emerging concepts in order to examine and refine these using the "thoughtful practitioner test" (p. 93). This was done throughout the research process through formal presentations and informal discussions with clinicians working in the field of ABI rehabilitation.

Sample

An introduction to the participants was given in Chapter 4 to provide context to each individual and their recovery journey; as well as the findings and related interview quotes from each participant to their individual experiences. The sample of participants was smaller than planned at the outset. When deciding on a sample size at the beginning of this study, five aspects were considered: the study aim, sample specificity, theoretical background, potential quality of interview dialogue, and strategies for analysis (Malterud et al., 2016). The details of these components are presented in Chapter 3, Table 3 (p. 60). Using these five components as a guide it was predicted that 10 participants would be required to provide sufficient information power to generate a clinically relevant thematic analysis. Although 11 candidates were referred by clinicians during the data collection phase of the study, two were found to not meet criteria as one was discharged to an area outside of Auckland and another to a residential home. A third candidate was lost to follow-up due to COVID-19 lockdowns and restrictions. Despite there only being eight participants, the diversity of participants was broad with representation across genders, ethnicities, ages, social situations, employment status, type of ABI, and time since discharge from in-patient setting. There were, unfortunately no participants of Asian descent, who are increasingly represented within the ABI statistics.

Contextual Data Gathering

One of the strengths intended through the data gathering approach was undertaking interviews within the participants' own homes and community settings. This was purposefully planned to limit the impact that cognitive or communication impairments may have on participants being able to recount their experiences. It proved to be effective as participants were able to support their cognition and communication by taking me to the places where they undertook the activities that they were describing, such as the garden, garage, and work shed. Once in these locations, their cognition and communication could be supported through the use of objects, gesture, and visual prompts to tell their stories. This would not have been the case if interviews had been conducted in a location that was separate to where these experiences had actually taken place. This approach helped to compensate for the inability to acquire the 7-day structured diaries prior to interview. The purpose of these diaries was to generate supportive prompts for participants with cognitive and communication difficulties, instead this was done through environmental cues.

Time Since Participants Acquired Their Brain Injury

During the data analysis phases there were a number of conversations between my supervisors and myself in regards to participants in the study continuing to refer to their "new self" (the person living with the ABI) and their "old self" (how they were prior to their ABI). These terms became confused with the concepts of re-construction of self and developing a concept of living with ABI as being the "new self" for people who were further on in their recovery journey compared to those that I interviewed. The participants in this study were less than 6-months post-discharge following their ABI; therefore, there is little evidence of re-construction of self-identity or place in the world, changing priorities, or developing a concept of living with ABI as has been identified in previous qualitative longitudinal studies (Fadyl et al., 2019; Levack et al., 2010; Nalder et al., 2012; Theadom et al., 2018). Although these ideas were raised in supervision and I returned on a number of occasions to the interview data to look for these concepts, they were not present in the experiences of the individuals in my study. These participants were still determined that they would return to their previous lives and ways of functioning and had not yet developed a concept of living with an ABI or reconstructing their identities in line with living with an ABI. I put this down to the time since injury and perhaps the processes described above in terms of reconstructing their self-identities would occur at a later time.

The Impact of COVID-19

As with all community-based research that was attempted during 2020 and 2021, multiple limitations were caused by the COVID-19 pandemic. This was particularly the case for me as I held a position as Clinical Director for Allied Health within Counties Manukau District Health Board (CMDHB) at that time. CMDHB serves the South Auckland region that was the epicentre of the pandemic in the initial COVID outbreaks. The services for which I was responsible had to be significantly reconfigured and remain agile in order to meet the needs of the impacted population over the initial 2-years. In March of 2020, the 160 plus allied health clinicians for whom I held a responsibility had to completely change the way in which they delivered their clinical intervention and reprioritise their client caseloads. My attention had to focus exclusively on rebuilding services and supporting clinicians to manage their day-to-day service delivery. The pandemic and resulting "lockdowns", isolation requirements, social distancing, contact tracing, and "traffic light system" that evolved over time had numerous other impacts on my study:

a) Due to lockdown and limited travel, I was unable to meet face to face with participants
b) Recruitment was reliant on clinical teams making the initial contact with potential participants. During long periods in both 2020 and 2021 community clinicians were unable to visit their clients for anything other than "essential" interventions; therefore, they were unable to recruit study participants
c) Reduced public confidence in face to face contact with unknown people meant potential study participants were less willing to have strangers in their homes
d) People were unable or unwilling to participate in their usual community-based activities due to the COVID-19 risk; therefore, had less opportunities to experience community integration and fewer experiences to draw on in interviews
e) COVID restrictions became the most obvious barrier to community integration and were discussed in initial interviews to a greater extent than other barriers
f) My own time, resource, and energy had to be directed towards the COVID-19 response within my role as Clinical Director for Allied Health
g) There were occasions where research participants were lost following arrangements to interview due to my own contact with COVID-19 cases and need to test and self-isolate
h) Becoming ill with COVID-19 myself caused delays to data analysis

The pandemic and delays that were brought about by the obstacles listed above resulted in my inability to undertake a second round of data collection that had been planned at the outset of the research endeavour, and included purposefully selecting some participants to interview and observe within community locations and activities of their choice. It was hypothesised that this second round of data collection would further strengthen the findings of the study by observing the interactions between the participant and their surroundings, including other people in the community.

Irrespective of these limitations, study findings have shed light on the experience of community integration following ABI, generating new perspectives that add to previous knowledge in this area. This study has also generated a range of clinically relevant recommendations that could be implemented by rehabilitation service providers in order to improve the experience of people with ABI who are attempting to integrate into their communities following their return home.

Directions for Future Research

As the second aspect of this study was unable to be undertaken, my first suggestion for future research would be an ethnographic study of people with ABI in their communities and interacting with the physical and social environment. This would add depth to the knowledge of people's experience as they reintegrate into their communities by observing and recording the interactions rather than relying solely on the retrospective reports of participants. Participants could be asked about what was happening to them in the present and why they were behaving the way they were in response to the community setting. This approach would provide additional information regarding the role and impact of the community within community integration rather than the focus being on the individual with brain injury.

As one of the primary theoretical findings from this study was the link between meaningful occupation, shared occupation, and social connection to successful community integration, further research should seek to include the perspectives of those with whom the individuals with ABI interact and share their experiences. This may provide insights into the development of shared occupations within clinical practice and how it can be supported through relationship-centred approaches.

A range of clinical implications were discussed in Chapter 6 and included intervention specific recommendations, such as the use of a stepped care model for psychosocial support and strategies to incorporate family and whānau into community-based rehabilitation programmes. Recommendations at an organisation/service level have also been made such as

targeting social connection in community rehabilitation service delivery through assessment and goal setting procedures, and growing clinicians' capacity to build therapeutic relationships. There have also been broader societal recommendations such as building awareness of ABI within communities through participation in community functions, collaborating with local government agencies, and promoting inclusive community events. Any of these recommendations, if adopted by a service or organisation, could be measured and compared to previous practice in order to establish if positive outcomes had resulted from the change in practice or additional resource. These could all prove to be clinical research studies in their own right, that may inform clinical practice beyond an individual service to a wider group of similar rehabilitation providers.

Finally, identified in this research and reported in previous studies of the experience of both people with ABI and clinicians is the perpetuating focus on the individual, physical impairments, and safety concerns in rehabilitation programmes. Exploring why this is the case from a clinical and systems point-of-view could inform changes to expand this focus toward broader components of rehabilitation that have been identified to influence successful community integration, including cultural, psychosocial, spiritual, and relational components.

Conclusion

When commencing this study, I wanted to answer the question "how do people with brain injury reintegrate into their communities on return home from in-patient rehabilitation?". The experiences of the eight participants with ABI who agreed to be involved in the study contributed to the construction of four themes relating to community integration: *Growing into a new way of community living, living up to expectations, (re)building social connections,* and *engaging in meaningful occupations*. These themes did not stand alone but overlapped and interacted with one another. My findings extend the previous theoretical knowledge of community integration frameworks by offering insights into the dynamic, iterative, and temporal aspects of the *process* of community integration through the theme *growing into a new way of community living.* The findings add the concept of *living up to expectations* to community integration that has been missing from previous literature, and provide alternative perspectives to the dimensions of social connection and meaningful occupation.

I have offered a number of recommendations for provoking a shift in future rehabilitation services to better support community integration. These have included a range of alternative ways of working with individuals with ABI, and extending the view of community integration to include the networks of people surrounding the person with ABI. Clinical implications that

resulted from the study findings, and described in detail in Chapter 6, can be considered as those at the level of the individual clinician, at an organisational or service level, a public health level, or a societal level.

I have argued that the meaning people with ABI attribute to the occupations they undertake is an essential consideration for those supporting their community integration. These meanings extend beyond the *doing* and towards greater social connection, leading to a sense of contribution, reciprocation, and belonging within their communities. There is a need for rehabilitation services to consider the role of shared occupations and the positive impact these have on social connection when supporting those with ABI to reintegrate into the community. Rehabilitation professionals should shift their focus from the traditional concept of person-centred rehabilitation, that tends to focus on the individual, to a more relationship-centred approach. A new conceptualisation of a relationship-centred approach has been proposed that considers the range of relationships that can be brokered within the individual's social networks to offer additional support, connection, and ongoing opportunities for community integration.

References

Accident Compensation Corporation. (2012). *Pragmatic evidence-based review: Employment participation in moderate to severe TBI*. Author.

Accident Compensation Corporation. (2017a). *Traumatic brain injury strategy and action plan 2017–2021*. Author.

Accident Compensation Corporation. (2017b). *Service schedule – Social rehabilitation needs assessment service*. Author.

Agnihotri, S., Keightley, M. L., Colantonio, A., Cameron, D., & Polatajko, H. (2010). Community integration interventions for youth with acquired brain injuries: A review. *Developmental Neurorehabilitation, 13*(5), 369-382. https://doi.org/10.3109/17518423.2010.499409

Armstrong, J., Cridge, S., Weeks, E., Sissingh, J., & Foster, A. (2012). *A community re-integration programme: Inpatient rehabilitation pathways, management, and treatment descriptions for clients preparing to transition into the community following moderate to severe traumatic brain injury*. ABI Rehabilitation NZ Ltd.

Ashby, S., & Chandler, B. (2010). An exploratory study of the occupation-focused models included in occupational therapy professional education programmes. *British Journal of Occupational Therapy, 73*(12), 616-624. https://doi.org/10.4276/030802210X12918167234325

Australasian Rehabilitation Outcomes Centre. (2020). *The AROC annual report: The state of rehabilitation in New Zealand in 2020*. Australian Health Services Research Institute.

Baker, C., Worrall, L., Rose, M., Hudson, K., Ryan, B., & O'Byrne, L. (2018). A systematic review of rehabilitation interventions to prevent and treat depression in post-stroke aphasia. *Disability and Rehabilitation, 40*(16), 1870-1892. https://doi.org/10.1080/09638288.2017.1315181

Batchos, E., Easton, A., Haak, C., & Ditchman, N. (2018). Social factors predictive of social integration for adults with brain injury. *Disability and Rehabilitation, 40*(17), 2062-2069. https://doi.org/10.1080/09638288.2017.1326175

Beach, M. C., Inui, T., & the Relationship-Centred Care Research Network. (2006). Relationship-centred care: A constructive reframing. *Journal of General Internal Medicine, 21*(Suppl 1), S3-8. https://doi.org/10.1111/j.1525-1497.2006.00302.x

Bishop, M., Kayes, N., & McPherson, K. (2021). Understanding the therapeutic alliance in stroke rehabilitation. *Disability and Rehabilitation, 43*(8), 1074-1083. https://doi.org/10.1080/09638288.2019.1651909

Bradley, G., Baker, K., & Bailey, C. (2021). The meaning of rehabilitation: A qualitative study exploring perspectives of occupational therapists and physiotherapists working with older people in acute care. *Disability and Rehabilitation, 43*(16), 2295-2303. https://doi.org/10.1080/09638288.2019.1697762

Breines, E. (1986). *Origins and adaptations: A philosophy of practice*. Geri-Rehab.

Bright, F. A. S., Kayes, N. M., McCann, C. M., & McPherson, K. M. (2013). Hope in people with aphasia. *Aphasiology, 27*(1), 41-58. https://doi.org/10.1080/02687038.2012.718069

Busby, D. M., Christensen, C., Crane, D. R., & Larson, J. H. (1995). A revision of the dyadic adjustment scale for use with distressed and non- distressed couples: Construct hierarchy and multidimensional scales. *Journal of Marital Family Therapy,21*(3), 289-308. https://doi.org/10.1111/j.1752-0606.1995.tb00163.x

CARF International. (2021). *Medical rehabilitation standards manual*. CARF International, Tucson.

Callaway, L., Sloan, S., & Winkler, D. (2005). Maintaining and developing friendships following severe traumatic brain injury: Principles of occupational therapy practice. *Australian Occupational Therapy Journal, 52*(3), 257-260. https://doi.org/10.1111/j.1440-1630.2005.00492.x

Cameron, L. J., Somerville, L. M., Naismith, C. E., Watterson, D., Maric, V., & Lannin, N. (2017). A qualitative investigation into the patient-centred goal-setting practices of allied health clinicians working in rehabilitation. *Clinical Rehabilitation, 32*(6), 827-840. https://doi.org/10.1177/0269215517752488

Carlson, K. F., Pogoda, T. K., Gilbert, T. A., Resnick, S. G., Twamley, E. W., O'Neil, M. E., & Sayer, N. A. (2018). Supported employment for veterans with traumatic brain injury: Patient perspectives. *Archives of Physical Medicine and Rehabilitation, 99*(2S), S4-S13. https://doi.org/0.1016/j.apmr.2017.06.027

Christiansen, C., Clark, F., Kielhofner, G., & Rogers, J. (1995). Position Paper: Occupation. American Journal of Occupational Therapy, 49(10), 1015-1018. https://doi-org.ezproxy.aut.ac.nz/10.5014/ajot.49.10.1015

Conneeley, A. L. (2002). Social integration following traumatic brain injury and rehabilitation. *British Journal of Occupational Therapy, 65*(8), 356-362. https://doi.org/10.1177/030802260206500802

Corbin, J., & Strauss, A. (2008). *Basics of qualitative research: Techniques and procedures for grounded theory* (3rd ed.). SAGE.

Corrigan, J. (1994). Community integration following traumatic brain injury. *Neurorehabilitation, 4*(2), 109-121. https://doi.org/10.3233/NRE-1994-4207

Cresswell, J. W. (2007). *Qualitative inquiry and research design: Choosing among five approaches* (2nd ed.). SAGE.

Czuba, K., Anstiss, D., Kersten, P., Rohan, M., Terry, G., Kayes, N., Smith, G., & Siegert, R. (2017). *Outcomes after trauma: A 12 month follow up report for ACC*. Wellington: Accident Compensation Corporation.

D'Cruz, K., Howie, L., & Lentin, P. (2016). Client-centred practice: Perspectives of persons with a traumatic brain injury. *Scandinavian Journal of Occupational Therapy, 23*(1), 30-38. https://doi.org/10.3109/11038128.2015.1057521

Davidson, B., Worrall, L., & Hickson, L. (2008). Exploring the interactional dimension of social communication: A collective case study of older people with aphasia. *Aphasiology, 22*(3), 235-257. https://doi.org/10.1080/02687030701268024

Department for Work & Pensions. (n.d.). *2010 to 2015 government policy: older people*. *https://www.gov.uk/government/publications/2010-to-2015-government-policy-older-people/2010-to-2015-government-policy-older-people#appendix-1-helping-older-people-most-at-risk-of-longer-term-loneliness-and-social-isolation-to-remain-active*

Dillahunt-Aspillaga, C., & Powell-Cope, G. (2018). Community reintegration, participation and employment issues in veterans and service members with traumatic brain injury. *Archives of Physical Medicine and Rehabilitation*, 99(2), S1-S3. https://doi.org/10.1016/j.apmr.2017.04.013

Ditchman, N., Chan, F., Haak, C., & Easton, A. B. (2017). Factors impacting sense of community among adults with brain injury. *Rehabilitation Psychology, 62*(2), 130-142. https://doi.org/10.1037/rep0000139

Ditchman, N., Sheehan, L., Rafajko, S., Haak, C., & Kazukauskas, K. (2016). Predictors of social integration for individuals with brain injury: An application of the ICF model. *Brain Injury, 30*(13-14), 1581-1589. https://doi.org/10.1080/02699052.2016.1199900

Douglas, J. (2011). Social linkage, self-concept, and well-being after severe traumatic brain injury. In Jetten, J., Haslam, C., & Haslam, A. S. (Eds), *The social cure: Identity, health and well-being*. Taylor Francis Group.

Douglas, J. (2015). Elizabeth Usher Memorial Lecture: Placing therapy in the context of the self and social connection. *International Journal of Speech-Language Pathology, 17*(3), 199-210. https://doi.org/10.3109/17549507.2015.1016113

Douglas, J. (2019). Loss of friendship following traumatic brain injury: A model grounded in the experience of adults with severe injury. *Neuropsychological Rehabilitation, 30*(7), 1277-1302. https://doi.org/10.1080/09602011.2019.1574589

Douglas, J., Drummond, M., Knox, L., & Mealings, M. (2015). Rethinking social-relational perspectives in rehabilitation: Traumatic brain injury as a case study. In K. McPherson, B.

E. Gibson, & A. Leplege (Eds.), *Rethinking rehabilitation: Theory and practice* (pp. 137-161). CRC Press.

Douglas, J. M., & Spellacy, F. J. (2000). Correlates of depression in adults with severe traumatic brain injury ad their carers. *Brain Injury, 14*(1), 71-88. https://doi.org/10.1080/026990500120943

Elder, H. (2017). Te Waka Kuaka and Te Waka Oranga. Working with whanau to improve outcomes. *Australian & New Zealand Journal of Family Therapy, 38*(1), 27-42. https://doi.org/10.1002/anzf.1206

Emmel, N., & Clarke, A. (2011). Learning to use visual methodologies in our research: A dialogue between two researchers. *Forum: Qualitative Social Research, 12*(1), 36-44. https://doi.org/10.17169/fqs-12.1.1508

Ensel, W., & Woelfel, M. (1986). Measuring the instrumental and expressive functions of social support. In N. Lin, A. Dean, & W. Ensel (Eds.), *Social support, life events, and depression* (pp. 129-152). Academic Press.

Erler, K. S., Sullivan, V., McKinnon, S., & Inzana, R. (2019). Social support as a predictor of community participation after stroke. *Frontiers in Neurology, 10*, 1013-1020. https://doi.org/10.3389/fneur.2019.01013

Evans, C. C., Sherer, M., Nakase-Richardson, R., Mani, T., & Irby, J. W. (2008). Evaluation of an interdisciplinary team intervention to improve therapeutic alliance in post-acute brain injury rehabilitation. *Journal of Head Trauma Rehabilitation, 23*(5), 329-338. https://doi.org/10.1097/01.HTR.0000336845.06704.bc

Exell, R., Hilari, K. & Behn, N. (2022). Interventions that support adults with brain injuries, learning disabilities and autistic spectrum disorders in dating or romantic relationships: A systematic review. Disability and Rehabilitation, 44(12), 2567-2580. https://doi.org/10.1080/09638288.2020.1845824

Fadyl, J. K., Theadon, A., Channon, A., & McPherson, K. M. (2017). Recovery and adaptation after traumatic brain injury in New Zealand: Longitudinal qualitative findings over the first two years. *Neuropsychological Rehabilitation, 29*(7), 1095-1112. https://doi.org/10.1080/09602011.2017.1364653

Feigin, V. L., Theadom, A., Barker-Collo, S., Starkey, N. J., McPherson, K., Kahan, M., Dowell, A., Brown, P., Parag, V., Kydd, R., Jones, K., Jones, A., Ameratunga, S., & BIONIC Study Group. (2013). Incidence of traumatic brain injury in New Zealand: A population-based study. *Lancet Neurology, 12*(1), 53-64. https://doi.org/10.1016/S1474-4422(12)70262-4

Fleming, J., Nalder, E., Alves-Stein, S., & Cornwell, P. (2014). The effect of environmental barriers on community integration for individuals with moderate to severe traumatic

brain injury. *Journal of Head Trauma Rehabilitation, 29*(2), 125-135. https://doi.org/10.1097/htr.0b013e318286545d

Foster, A. M., Armstrong, J., Buckley, A., Sherry, J., Young, T., Foliaki, S., James-Hohaia, T., Theadom, A., & McPherson, K. M. (2012). Encouraging family engagement in the rehabilitation process: A rehabilitation provider's development of support strategies for family members of people with traumatic brain injury. *Disability and Rehabilitation, 34*(22), 1855-1862. https://doi.org/10.3109/09638288.2012.670028

Fristedt, S., Carlsson, G., Kylen, M., Jonsson, O., & Granbom, M. (2022). Changes in daily life and wellbeing in adults, 70 years and older, in the beginning of the COVID-19 pandemic. *Scandinavian Journal of Occupational Therapy, 29*(6), 511-521. https://doi.org/10.1080/11038128.2021.1933171

Gagnon, A., Lin, J., & Stergiou-Kita, M. (2016). Family members facilitating community re-integration and return to productivity following traumatic brain injury – motivations, roles and challenges. *Disability and Rehabilitation, 38*(5), 433-441. https://doi.org/0.3109/09638288.2015.1044035

Gillham, S., & Clarke, L. (2011). *Psychological care after stroke: Improving stroke services for people with cognitive and mood disorders.* NHS Improvement.

Govender, P., Naidoo, D., Bricknell, K., Ayob, Z., Message, H., & Njoko, S. (2019). 'No one prepared me to go home': Cerebrovascular accident survivors' experiences of community reintegration in a peri-urban context. *African Journal of Primary Health Care and Family Medicine, 11*(1), e1-e8. https://doi.org/10.4102/phcfm.v11i1.1806

Gustafsson, L. A., Hodson, T. L., Fleming, J. M., & Hoyle, M. F. (2014). The impact of STRENGTH on the expected and actual transition to home experience. *Disability and Rehabilitation, 36*(26), 2244-2251. https://doi.org/10.3109/09638288.2014.904937

Hagger, B. F., & Riley, G. A. (2019). The social consequences of stigma-related self-concealment after acquired brain injury. *Neuropsychological Rehabilitation, 29*(7), 1129-1148. https://doi.org/10.1080/09602011.2017.1375416

Hagedorn, R. (1997). *Foundations for practice in occupational therapy* (2nd ed.). Churchill Livingstone.

Hammell, K. W. (2008). Reflections on wellbeing and occupational rights. *Canadian Journal of Occupational Therapy, 75*(1), 61-64. https://doi.org/10.2182/cjot.07.007

Hammell, K. M. (2014). Belonging, occupation, and human wellbeing: An exploration. *Canadian Journal of Occupational Therapy, 81*(1), 39-50. https://doi.org/10.1177/0008417413520489

Headway: Brain Injury Auckland. (n.d.). Brain injury in brief. https://www.headway.org.nz/about-brain-injury

Holmqvist, K., Holmefur, M., & Ivarsson, A. (2013). Therapeutic use of self as defined by Swedish occupational therapists working with clients with cognitive impairments following acquired brain injury: A Delphi study. *Australian Occupational Therapy Journal, 60*(1), 48-55. https://doi.org/10.1111/1440-1630.12001

Holt-Lunstad, J. (2018). Why social relationships are important for physical health: A systems approach to understanding and modifying risk and protection. *Annual Review of Psychology, 69*, 437-458. https://doi.org/10.1146/annurev-psych-122216-011902

Holt-Lunstad, J., Robles, T. F., & Sbarra, D. A. (2017). Advancing social connection as a public health priority in the United States. *American Psychologist, 72*(6), 517-530. https://doi.org/10.1037/amp0000103

Hughes, R., Fleming, P., & Henshall, L. (2020). Peer support groups after acquired brain injury: a systematic review. *Brain Injury, 34*(7), 847-856. https://doi.org/10.1080/02699052.2020.1762002

Hunt, M. R. (2009). Strengths and challenges in the use of interpretive description: Reflections arising from a study of the moral experience of health professionals in humanitarian work. *Qualitative Health Research, 19*(9), 1284-1292. https://doi.org/10.1177/1049732309344612

Ikiugu, M. N., & Shultz, S. (2005). An argument for pragmatism as a foundational philosophy for occupational therapy. *Canadian Journal of Occupational Therapy, 2*(73), 86-97. https://doi.org/10.2182/cjot.05.0009

Jacobs, H. E. (Ed.). (1993). *Behavior analysis guidelines and brain injury rehabilitation: People, principles, and programs*. Aspen Publishers.

Jesus, T. S., Papadimitriou, C., Bright, F. A., Kayes, N. M., Pinho, C. S., & Cott, C. A. (2022). Person-centred rehabilitation model: Framing the concept and practice of person-centred adult physical rehabilitation based on a scoping review and thematic analysis of the literature. *Archives of Physical and Rehabilitation Medicine, 103*(1), 106-120. https://doi.org/10.1016/j.apmr.2021.05.005

Kayes, N., Cummins, C., Weatherall, M., Smith, G., Te Ao, B., Elder, H., Fadyl, J., Howard-Brown, C., Foster, A., & Kersten, P. (2023). Randomised pragmatic waitlist trial with process evaluation investigating the effectiveness of peer support after brain injury: Protocol. *BMJ Open, 13*, e069167. https://doi.org/10.1136/bmjopen-2022-069167

Kayes, N. M., Cummins, C., McPherson, K. M., Worrall, L., & Bright, F. A. S. (2022). Developing connections for engagement in stroke rehabilitation. *Brain Injury, 23*, 42-59. https://doi.org/10.1017/BrImp.2021.27

Kelly, M. E., Duff, H., Kelly, S., McHugh Power, J. E., Brennan, S., Lawlor, B. A., & Loughrey, D. G. (2017). The impact of social activities, social networks, social support and social

relationships on the cognitive functioning of healthy older adults: A systematic review. *Systematic Reviews, 6*(259), 1-18. https://doi.org/10.1186/s13643-017-0632-2

Kennedy-Behr, A., & Hatchett, M. (2017). Wellbeing and engagement in occupation for people with Parkinson's disease. *British Journal of Occupational Therapy, 80*(12), 745-751. https://doi.org/10.1177/0308022617728645

Kent, J., Wright-St Clair, V. A., & Kersten, P. (2014). Older adults' experiences of community integration following traumatic brain injury. *New Zealand Journal of Physiotherapy, 42(*2), 148-153.

Kersey, J., McCue, M., & Skidmore, E. (2020). Domains and dimensions of community participation following traumatic brain injury. *Brain Injury, 34*(6), 708-712. https://doi.org/10.1080/02699052.2020.1757153

Kersten, P., Cummins, C., Kayes, N., Babbage, D., Elder, H., Foster, A., Weatherall, M., Siegert, R., Smith, G., & McPherson, K. (2018). Making sense of recovery after traumatic brain injury through a peer mentoring intervention: a qualitative exploration. *BMJ Open, 8*, e020672. https://doi.org/10.1136/bmjopen-2017-020672

Kielhofner, G. (Ed.). (2008). Introduction to the model of human occupation. In *A model of human occupation: Theory and application* (4th ed.). Williams & Wilkins.

Kneebone, I. I. (2016). Stepped psychological care after stroke. *Disability and Rehabilitation, 38*(18), 1836-1843. https://doi.org/10.3109/09638288.2015.1107764

Kreutzer, J. S., Marwitz, J. H., Godwin, E. E., & Arango-Lasprilla, J. C. (2010). Practical approaches to effective family intervention after brain injury. *Journal of Head Trauma Rehabilitation, 25(*2), 113-120. https://doi.org/10.1097/HTR.0b013e3181cf0712

Krishnamurthi, R., Jones, A., Barber, P. A., Barker-Collo, S., McPherson, K., Bennett, D., Rush, E., Suh, F., Starkey, N., Theadom, A., Parag, V., Rathnasabapathy, Y., Feigin, V. L., & ARCOS IV Programme Group. (2014). Methodology of a population-based stroke and TIA incidence and outcomes study: The Auckland regional community stroke study (ARCOS IV) 2011–2012. *International Journal of Stroke, 9*(1), 140–147. https://doi.org/10.1111/ijs.12108

Law, M., Cooper, B., Strong, S., Stewart, D., Rigby, P., & Letts, L. (1996). The person-environment-occupation model: A transactive approach to occupational performance. *Canadian Journal of Occupational Therapy, 63*(1), 9-23. https://doi.org/10.1177/000841749606300103

Leclair, L. L. (2010). Re-examining concepts of occupation and occupation-based models: Occupational therapy and community development. *Canadian Journal of Occupational Therapy, 77*(1), 15-21. https://doi.org/10.2182/cjot.2010.77.1.3

Levack, W. M., Kayes, N. M., & Fadyl, J. K. (2010). Experience of recovery and outcome following traumatic brain injury: A metasynthesis of qualitative research. *Disability and Rehabilitation, 32*(12), 986-999. https://doi.org/0.3109/09638281003775394

Lem, K. Mcgilton, K. S., Aelick, K., Iaboni, A., Babineau, J., Colborne, D. H., Edwards, C., Bretzlaff, M., Lender, D., Gibson, J., & Bethell. (2021). Social connection and physical health outcomes among long-term care home residents: A scoping review. *BMC Geriatrics, 21*(1), 722. https://doi.org/10.1186/s12877-021-02638-4

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. SAGE.

Malterud, K., Siersma, V. D., & Guassora, A. D. (2016). Sample size in qualitative interview studies: Guided by information power. *Qualitative Health Research, 26*(13), 1753-1760. https://doi.org/10.1177/1049732315617444

Martin, R. A., & Nunnerly, J. (2018). *Peer support for people with spinal cord injury in New Zealand*. Burwood Academy of Independent Living (BAIL). Retrieved from http://hdl.handle.net/10523/12648

McColl, M., Carlson, P., Johnstone, J., Minnes, P., Shue, K., Davies, D., & Karlovits, T. (1998). The definition of community integration: Perspectives of people with brain injuries. *Brain Injury*, *12*(1), 15-30. https://doi.org/10.1080/026990598122827

McPherson, K., Fadyl, J., Theadom, A., Channon, A., Levack, W., Starkey, N., Wilkinson-Meyers, L., & Kayes, N. (2017). Living life after traumatic brain injury: Phase 1 of a longitudinal qualitative study. Journal of Head Trauma Rehabilitation, 33(1), 44-52. http://dx.doi.org/10.1097/HTR.0000000000000321

Merz, Z. C., Van Patten, R., & Lace, J. (2017). Current public knowledge pertaining to traumatic brain injury: Influence of demographic factors, social trends, and sport concussion experience on the understanding of traumatic brain injury sequelae. *Archives of Clinical Neuropsychology, 32*(2), 155-167. https://doi.org/10.1093/arclin/acw092

Meuldijk, D., & Wuthrich, V. M. (2019). Stepped-care treatment of anxiety and depression in older adults: A narrative review. *Australian Journal of Rural Health, 27*(4), 275-280. https://doi.org/10.1111/ajr.12524

Ministry of Health (2014a). *'Ala Mo'ui: Pathways to Pacific health and wellbeing 2014–2018.* Author.

Ministry of Health. (2014b). *The guide to he korowai oranga: Māori health strategy 2014*. Author.

Ministry of Health. (2016a). *New Zealand health strategy: Future direction*. Author.

Ministry of Health. (2016b). *New Zealand health strategy: Roadmap of actions 2016*. Author.

Ministry of Health. (2016c). *Health of older people strategy: Consultation draft*. Author.

Ministry of Health. (2020). *'Ola Manuia: Pacific health and wellbeing action plan 2020-2025*. Author.

Ministry of Health. (2021). *Strategic intentions 2021 to 2025*. Author.

Ministry of Social Development. (2016). *New Zealand disability strategy 2016-2026*. Author.

Morse, J. M. (1994). *Critical issues in qualitative research methods.* SAGE.

Morse, J. M., Stern, P. N., Corbin, J., Bowers, B., Charmaz, K., & Clarke, A. E. (2009). *Developing grounded theory: The second generation*. Left Coast Press.

Mortera, M. H., Kinirons, S. A., Simantov, J., & Klingbeil, H. (2018). Long-term neurobehavioural symptoms and return to productivity in Operation Enduring Freedom/Operation Iraqi Freedom veterans with and without traumatic brain injury. *Archives of Physical Medicine and Rehabilitation, 99*(2), S50-S57. https://doi.org/10.1016/j.apmr.2016.11.026

Nalder, E., Fleming, J., Cornwell, P., Foster, M., Ownsworth, T., Shields, C., & Haines, T. (2012). Recording sentinel events in the life course of individuals with acquired brain injury: A preliminary study. *Brain Injury, 26*(11), 1381-1396. https://doi.org/10.3109/02699052.2012.676225

Nalder, E., Fleming, J., Cornwell, P., Shields, C., & Foster, M. (2013). Reflections on life: Experiences of individuals with brain injury during the transition from hospital to home. *Brain Injury, 27*(11), 1294-1303. https://doi.org/10.3109/02699052.2013.823560

Nalder, E. J., Zabjek, K., Dawson, D. R., Bottari, C. L., Gagnon, I., McFadyen, B. J., Hunt, A. W., McKenna, S., Ouellet, M., Giroux, S., Cullen, N., Niechwiej-Szwedo, E., & ONF-REPAR ABI Team. (2018). Research priorities for optimising long-term community integration after brain injury. *Canadian Journal of Neurological Sciences, 45*(6), 643-651. https://doi.org/10.1111/1440-1630.12611

National Stroke Foundation. (2014). National stroke audit rehabilitation services clinical audit report. Author. https://www.strokefoundation.com.au

National Stroke Network – Psychosocial Working Group. (2022). *Supporting psychosocial well-being after stroke*. National Stroke Network.

Orban, K., Edberg, A., & Erlandsson, L. (2012). Using a time-geographical diary method in order to facilitate reflections on changes in patterns of daily occupations. *Scandinavian Journal of Occupational Therapy, 19*(3), 249-259. https://doi.org/10.3109/11038128.2011.620981

Parvaneh, S., & Cocks, E. (2012). Framework for describing community integration for people with acquired brain injury. *Australian Occupational Therapy Journal*, *59*(2), 131-137. https://doi.org/10.1111/j.1440-1630.2012.01001.x

Peke Waihanga – Peer Support Service. (n.d.). *Peer support te pou aropa takitoru fact sheet*. https://peersupport.nz/files/Peer%20Support%20Fact%20Sheet.pdf

Playford, E. D., Seigert, R., Levack, W., & Freeman, J. (2009). Areas of consensus and controversy about goal setting in rehabilitation: A conference report. *Clinical Rehabilitation, 23*(4), 334-344. https://doi.org/10.1177/0269215509103506

Pogoda, T. K., Carlson, K. F., Gormley, K. E., & Resnick, S. G. (2018). Supported employment for veterans with traumatic brain injury: Provider perspectives. *Archives of Physical Medicine and Rehabilitation, 99*(2), S14-S22. https://doi.org/10.1016/j.apmr.2017.06.029

Polatajko, H. J., Townsend, E. A., & Craik, J. (2007). The Canadian model of occupational performance and engagement (CMOP-E). In E. A. Townsend & H. J. Polatajko (Eds.), *Enabling occupation II: Advancing an occupational therapy vision for health, well-being, & justice through occupation* (pp. 23). CAOT Publications ACE.

Ranta, A. (2018). Projected stroke volumes to provide a 10-year direction for New Zealand stroke services. *New Zealand Medical Journal, 131*(1477), 15-28.

Rasmussen, R. S., Ostergaard, A., Kjaer, P., Skerris, A., Skou, C., Christoffersen, J., Seest, L. S., Poulsen, M. B., Ronholt, F. & Overgaard, K. (2016). Stroke rehabilitation at home before and after discharge reduced disability and improved quality of life: A randomised controlled trial. *Clinical Rehabilitation, 30*(3), 225-236. https://doi.org/10.1177/0269215515575165

Raukola-Lindblom, M., Vuorinen, E., & Vartiainen, R. (2020). Recovering social participation – experience with a relational group intervention for traumatic brain injury patients. NeuroRehabilitation, 47(1), 55-64. https://www-doi-org.ezproxy.aut.ac.nz/10.3233/NRE-203083

Reason, P., & Bradbury, H. (2008). *The SAGE handbook of action research*. SAGE.

Reed, M. C., Wood, V., Harrington, R., & Paterson, J. (2012). Developing stroke rehabilitation and community services: A meta-synthesis of qualitative literature. *Disability and Rehabilitation 34*(7), 553-563. https://doi.org/10.3109/09638288.2011.613511

Reistetter, T. A., & Abreu, B. C. (2005). Appraising evidence on community integration following brain injury: A systematic review. *Occupational Therapy International, 12*(4), 196-217. https://doi.org/10.1002/oti.8

Resnik, L., Plow, M., & Jette, A. (2009). Development of CRIS: Measure of community reintegration of injured service members. *Journal of Rehabilitation Research and Development, 46*(4), 469-480. https://doi.org/10.1682/jrrd.2008.07.0082

Roberts, A. E. K., Bannigan, K. (2018). Dimensions of personal meaning from engagement in occupations: A metasynthesis. *Canadian Journal of Occupational Therapy, 85*(5), 386-396. https://doi.org/10.1177/0008417418820358

Salas, C., Casassus, M., Rowlands, L., Pimm, S., & Flanagan, D. (2018). Relating through same-ness: A qualitative study of friendship and social isolation in chronic traumatic brain injury. *Neuropsychological Rehabilitation, 28*(7), 1161-1178. https://doi.org/10.1080/09602011.2016.1247730

Sandelowski, M. (2000). Whatever happened to qualitative description? Research in Nursing & Health, 23(4), 334-340. https://doi.org/10.1002/1098-240X(200008)23:4%3C334::AID-NUR9%3E3.0.CO;2-G

Sander, A. M., Clark, A., & Pappadis, M. R. (2010). What is community integration anyway?: Defining meaning following traumatic brain injury. *Journal of Head Trauma Rehabilitation, 25*(2), 121-127. https://doi.org/10.1097/HTR.0b013e3181cd1635

Santini, Z. I., Koyanagi, A., Tyrovolas, S., Mason, C., & Haro, J. M. (2015). The association between social relationships and depression: A systematic review. *Journal of Affective Disorders, 175*, 53-65. https://doi.org/10.1016/j.jad.2014.12.049

Shaikh, N. M., Kersten, P., Siegert, R. J., & Theadom, A. (2018). Developing a comprehensive framework of community integration for people with acquired brain injury: A conceptual analysis. *Disability and Rehabilitation*, 41(14), 1615-1631. https://doi.org/10.1080/096388288.2018.1443163

Sheffield Hallam University Centre for Regional Economic and Social Research. (2016). *The Rotherham social prescribing service for people with long-term health conditions: Summary report*. Rotherham Clinical Commissioning Group

Sherer, M., Evans, C. C., Leverenz, J., Stouter, J., Irby, J. W., Lee, L. E., & Yablon, S. A. (2007). Therapeutic alliance in post-acute brain injury rehabilitation: Predictors of strength of alliance and impact of alliance on outcome. *Brain Injury, 21*(7), 663-672. https://doi.org/10.1080/02699050701481589

Sigurdardottir, S., Andelic, N., Wehling, E., Anke, A., Skandsen, T., Holthe, O. O. Manskow, U. S., & Roe, C. (2020). Return to work after severe traumatic brain injury: A national study with a one-year follow-up of neurocognitive and behavioural outcomes. *Neuropsychological Rehabilitation, 30*(2), 281-297. https://doi.org/10.1080/09602011.2018.1462719

Stagg, K., Douglas, J., & Iacono, T. (2019). A scoping review of the working alliance in acquired brain injury rehabilitation. *Disability and Rehabilitation, 41*(4), 489-497. https://doi.org/10.1080/09638288.2017.1396366

Statistics New Zealand. (2014). *Social and economic outcomes for disabled people: Findings from the 2013 disability survey*. Author.

Stiekema, A. P. M., Winkens, I., Ponds, R., De Vugt, M. E., & Van Heugten, C. M. (2020). Finding a new balance in life: A qualitative study on perceived long-term needs of people with acquired brain injury. *Brain Injury, 34*(3), 421-429. https://doi.org/0.1080/02699052.2020.1725125

Stroke Foundation - InformMe. (n.d.). *Living Clinical guidelines for stroke management*. https://informme.org.au/guidelines/living-clinical-guidelines-for-stroke-management

Stroke Foundation NZ. (2022). *Bracing for the stroke tsunami.* Author.

Sveen, U., Guldager, R., Soberh, H. L., Andreassen, T. A., Egerod, I., & Poulsen, I. (2022). Rehabilitation interventions after traumatic brain injury: A scoping review. *Disability and Rehabilitation, 44*(4), 653-660. https://doi.org/10.1080/09638288.2020.1773940

Te Ao, B., Tobias, M., Ameratunga, A., McPherson, K., Theadom, A., Dowell, A., Starkey, N., Jones, K., Barker-Collo, S., Brown, P., Feigin, V., & BIONIC Study Group. (2015). Burden of traumatic brain injury in New Zealand: Incidence, prevalence and disability-adjusted life years. *Neuroepidemiology, 44*(4), 255-261. https://doi.org/10.1159/000431043

Te Whatu Ora – Waitaha Canterbury. (n.d.). Spinal injury – treatment and care. https://www.cdhb.health.nz/health-services/spinal-injury/

Theadom, A., Rutherford, S., Kent, B., & McPherson, K. The process of adjustment over time following stroke: A longitudinal qualitative study. *Neuropsychological Rehabilitation*, *29*(9), 1464-1474. https://doi.org/10.1080/09602011.2018.1440609

Thorne, S., Reimer Kirkham, S., & MacDonald-Emes, J. (1997). Interpretive description: A noncategorical qualitative alternative for developing nursing knowledge. *Research in Nursing and Health, 20*(2), 169-177. https://doi.org/10.1002/(sici)1098-240x(199704)20:2<169::aid-nur9>3.0.co;2-i

Thorne, S., Reimer Kirkham, S., & O'Flynn-Magee, K. (2004). The analytic challenge in interpretive description. *International Journal of Qualitative Methods, 3*(1), 1-11. https://doi.org/10.1177/160940690400300101

Thorne, S. (2008). *Interpretive description.* Left Coast Press.

Thorne, S. (2016). *Interpretive description: Qualitative research for applied practice* (2nd ed.). Routledge.

Tolich, M. (2004). Internal confidentiality: When confidentiality assurances fail relational informants. *Qualitative Sociology, 27*(1), 101-106. https://doi.org/10.1023/B:QUAS.0000015546.20441.4a

Torraco, R. J. (2016). Writing integrative literature reviews: Using the past and present to explore the future. *Human Resource Development Review, 15*(4), 404-428. https://doi.org/10.1177/1534484316671606

Tough, H., Siegrist, J., & Fekete, C. (2017). Social relationships, mental health and wellbeing in physical disability: A systematic review. *BMC Public Health, 17*(414), 1-18. https://doi.org/10.1186/s12889-017-4308-6

Townsend, E. A., & Polatajko, H. J. (2007). *Enabling occupation II: Advancing an occupational therapy vision for health, well-being, & justice through occupation*. CAOT Publications ACE.

Turner, B., Fleming, J., Ownsworth, T., & Cornwell, P. (2008). The transition from hospital to home for individuals with acquired brain injury: A literature review and research recommendations. *Disability and Rehabilitation, 30*(16), 1153-1176. https://doi.org/10.1080/09638280701532854

Turner, B., Fleming, J., Ownsworth, T., & Cornwell, P. (2011). Perceptions of recovery during the early transition phase from hospital to home following acquired brain injury: A journey of discovery. *Neuropsychological Rehabilitation, 21*(1), 64-91. https://doi.org/10.1080/09602011.2010.527747

United Nations. (2006). *Convention on the rights of persons with disabilities and optional protocol.* Author.

Vanpuymbrouck, L., & Olson, L. (2021). I realise I'm part of a greater whole experiencing occupational deprivation: OT students use of practice models in the wake of COVID-19. *American Journal of Occupational Therapy, 75*(Suppl2). 7512505089p1. https://doi.org/10.5014/ajot.2021.75S2-PO89

Waitangi Tribunal. (2019). *Hauora: Report on stage one of the health services and outcomes kaupapa inquiry.* Author.

Walsh, M. E., Galvin, R., Loughnane, C., Macey, C., & Horgan, N. F. (2014). Factors associated with community integration in the first year after stroke: A qualitative meta-synthesis. *Disability and Rehabilitation, 37*(18), 1599-1608. https://doi.org/10.3109/09638288.2014.974834

Walsh, M. E., Galvin, R., Loughnane, C., Macey, C., & Horgan, N. F. (2015). Community re-integration and long-term need in the first five years after stroke: Results from a national survey. *Disability and Rehabilitation, 37*(20), 1834-1838. https://doi.org/10.3109/09638288.2014.981302

Weatherall, M. (2018). Organised stroke care to improve survival and independence: New Zealand perspectives. *New Zealand Medical Journal, 131*(1477), 12-14.

Weiss, T., & Swede, M. J. (2019). Transforming preprofessional health education through relationship-centered care and narrative medicine. *Teaching and Learning in Medicine, 31*(2), 222-233. https://doi.org/10.1080/10401334.2016.1159566

Willer, B. S., Rosenthal, M., Kreutzer, J., Gordon, W., & Rempel, R. (1993). Assessment of the community integration following rehabilitation for traumatic brain injury. *Journal of Head Trauma Rehabilitation*, *8*(2), 75-87. https://doi.org/10.1097/00001199-199308020-00009

Winter, L., Moriarty, H. J., Robinson, K., Piersol, C. V., Vause-Earland, T., Newhart, B., Iacovone, D. B., Hodgson, N., & Gitlin, L. N. (2016) Efficacy and acceptability of a home-based, family-inclusive intervention for veterans with TBI: A randomized controlled trial. *Brain Injury, 30*(4), 373-387. https://doi.org/10.3109/02699052.2016.1144080

Wilson, B., Bright, F. A. S., Cummins, C., Elder, H., & Kayes, N. M. (2022). 'The wairua first brings you together': Māori experiences of meaningful connection in neurorehabilitation. *Brain Impairment, 23*, 9-23. https://doi.org/10.1017/BrImp.2021.29

Wilson, D., Moloney, E., Parr, J. M., Aspinall, C., & Slark, J. (2021). Creating an Indigenous Māori-centred model of relational health: A literature review of Māori models of health. *Journal of Clinical Nursing, 30*(23-24), 3539-3555. https://doi.org/10.1111/jocn.15859

Wood, J., Connelly, D., & Maly M. (2010). Getting back to real living: A qualitative study of the process of community integration after stroke. *Clinical Rehabilitation, 24*(11), 1045-1056. https://doi.org/10.1177/0269215510375901

World Federation of Occupational Therapists. (2018). *Definitions of occupational therapy from member organisations*. Author.

World Health Organization. (2001). *International classification of functioning, disability and health*. Author.

Yerxa, E. (2009). An introduction to occupational science, a foundation for occupational therapy in the 21st century. *Occupational Therapy in Health Care, 6*(4), 1-17. https://doi.org/10.1080/J003v06n04_04

Young, M. E., & Quinn, E. (1992). *Theories and principles of occupational therapy.* Churchill Livingstone.

Zigmond, A. S., & Snaith, R. P. (1983). The hospital anxiety and depression scale. *Acta Psychiatrica Scandinavica, 67*(6), 61-70. https://doi.org/0.1111/j.1600-0447.1983.tb09716.x

Appendices

Appendix A: Clinician Guide

How do people with brain injury re-integrate into their communities on return from in-patient rehabilitation?

Clinician Guide to the Project and Participant Selection

Purpose

To amplify the voice of those living with the ongoing consequences of brain injury so they can share their experiences of community integration efforts. These experiences will be analysed using a qualitative methodology and findings will be used to inform:

- Future rehabilitation/support service delivery
- Public health initiatives
- Health policy relating to community integration for people with disability

How you can help

You can help by identifying potential participants from your client group who meet the following criteria:

- 18 years or over
- Living with the ongoing effects of brain injury (including stroke)
- Have recently returned home (within the last 6 months)
- Live in the greater Auckland area
- Have the cognitive/communication abilities to provide consent (with supported strategies)

Once identified, you can share the Patient Information Sheet with your client and support them to understand the project details. If your client gives you permission to pass on their details to the research team, then ask them to complete the "consent to provide details" form and keep a copy of this for your own records.

What your client will have to do

Your client can take two weeks to decide if they want to take part in the project. They can contact the researcher (Jonathan) using the information on the Participant Information Sheet and Jonathan will answer any questions that they have. Once they have consented to the research, there are three stages to the project:

1. A simple 7-day diary, where they record their community based activities
2. A diary-led interview where Jonathan will chat to them about the activities they have recorded in their diary and find out more about their experiences of these
3. A go-along interview where Jonathan will conduct an interview with your client in a community based setting, and they can describe what they are experiencing "in the moment" while Jonathan makes observations of other contextual factors (e.g. environmental barriers)

Stage 3 of the project may not apply to all participants, as these will be selected depending on the themes that emerge from the analysis.

Your assistance with participant recruitment is greatly appreciated and findings of this research will be shared with you and your team.

Jonathan Armstrong, DHSc Student, AUT & Clinical Director Allied Health, CM Health.

Appendix B: Participant Information Sheet

AUT
TE WĀNANGA ARONUI O TĀMAKI MAKAU RAU

Participant Information Sheet

Date Information Sheet Produced:

11 September 2019

Project Title

How do people with brain injury re-integrate into their communities on return home from in-patient rehabilitation?

We are interested in finding out how people with brain injury settle back into life when they return home after an in-patient stay.

What is the purpose of this research and how is it funded?

Exploring the process that people go through is an important part of understanding how this could be better facilitated, either through supporting people, or reducing barriers to their ability to interact with the environment. Findings may be used for publications and presentations that aim to improve services and policies relating to community integration for people with brain injury. Funding for this research has been received through an AUT Doctoral Scholarship and a small contribution from Occupational Therapy New Zealand, the national association for occupational therapists.

How was I identified and why am I being invited to participate?

We have asked the rehabilitation staff to invite you because you are:

- 18 years or over
- Living with effects of brain injury (including stroke)
- At home within the last 6 months
- Living in Auckland

How do I agree to participate in this research?

- The project will be introduced by one of your rehabilitation team.
- Provide your preferred contact details to your therapist who will pass them on or you can contact Jonathan directly using the details on the last page.
- Jonathan will get in touch and ensure the research is suitable for you.
- We will ask you to sign and return a consent form before starting any interviews.
- Your participation is your choice and you can withdraw at any time.

What will happen in this research?

You complete a simple diary; recording details about activities you carry out over a week.

Jonathan will meet you at home or at a location of your choice

You will be interviewed about activities you have recorded in the diary, or others that come to mind, for about 45 minutes.

You may be contacted within a few months for another interview during which you will take part in one of the community activities that you identified as being meaningful to you.

What are the discomforts and how will they be dealt with?

You do not have to talk about anything you are not willing to share. We can accommodate your cognitive or communication needs and you can take breaks during the interview if you need to. You can decline from answering any questions, or stop altogether if you need to.

AUT Health Counselling and Wellbeing is able to offer three free sessions of confidential counselling support. These sessions are available for issues that have arisen as a result of participation in the research. To access these:

- Drop into our centres at WB219 or AS104 or phone 921 9992 (City or South Campus), 921 9998 (North Shore campus) to make an appointment.
- Let the receptionist know that you are a research participant, and provide the research title and my name and details as given in this Information Sheet

You can find out more counselling information on http://www.aut.ac.nz/being-a-student/current-postgraduates/your-health-and-wellbeing/counselling.

What are the benefits?

This research is the final portion of a Doctor of Health Science degree and findings may help rehabilitation teams to improve services, be used to help promote seamless service delivery to people with brain injury, used to inform public health initiatives like education in schools, or help to inform health policies by providing a better understanding of what is important to people with brain injury

How will my privacy be protected?

Information will be kept in locked cabinets or password protected computer files and only linked by ID numbers. Your signed consent form will be stored in a secure location, separate to the data. No information identifying you will be used in written work or presentations.

What are the costs of participating in this research?

There are no costs, except for your time.

How long do I have to consider this invitation?

You can take up to two weeks

Will I receive feedback on the results of this research?

You will receive a summary of findings on completion of the work. We will keep you updated on any publications and conferences where the findings are being presented.

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, Nicola Kayes, nkayes@aut.ac.nz, 09 921 9999 ext 7309.

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTEC, Kate O'Connor, *ethics@aut.ac.nz* , 921 9999 ext 6038.

Whom do I contact for further information about this research?

Researcher Contact Details:

Jonathan Armstrong, Clinical Director for Allied Health at Counties Manukau Health, jonathan.armstrong@middlemore.co.nz, 09 276 0044 ext 58285, or 021 569676

Project Supervisor Contact Details:

Nicola Kayes, Director of the Centre for Person Centred Research, AUT, nkayes@aut.ac.nz, 09 921 9999 ext 7309

Appendix C: Participant Information Sheet (Māori)

Wharangi patai (Participant Information Sheet)

Date Information Sheet Produced:

11 September 2019

Project Title

Pehea te hoki ki te hapori muri i te whakaoranga wairoro whara.

How do people with brain injury re-integrate into their communities on return home from in-patient rehabilitation?

We are interested in finding out how people with brain injury settle back into life when they return home after an in-patient stay.

He aha te take o tenei rangahau? (What is the purpose of this research?)

This research aims to hear the voices of those with brain injury and help them explore the process that they go through when they are settling back into their community life. This knowledge will then be used to raise awareness and help provide a better future for people with brain injury. Hearing your stories is an important part of understanding how community integration could be better facilitated, either through supporting people, or reducing barriers to their ability to interact with the environment. Findings may be used for publications and presentations that aim to improve services and policies relating to community integration for people with brain injury. Funding for this research has been received through an AUT Doctoral Scholarship and a small contribution from Occupational Therapy New Zealand, the national association for occupational therapists.

Pehea au i tohua, he aha au I powhiritia ai ki tenei kaupapa? (How was I identified and why am I being invited to participate?)

We have asked the rehabilitation staff to invite you because you are:

- 18 years or over
- Living with effects of brain injury (including stroke)
- At home for the last 6 months
- Living in Auckland

Pehea taku whakaae ki tenei rangahau? (How do I agree to participate in this research?)

- The project will be introduced by one of your rehabilitation team.
- Provide your preferred contact details to your therapist who will pass them on or you can contact Jonathan directly using the details on the last page.
- Jonathan will get in touch and ensure the research is suitable for you.
- We will ask you to sign and return a consent form.
- Your participation is your choice and you can withdraw at any time.

He aha nga mahi mo tenei rangahau? (What will happen in this research?)

You complete a simple diary; recording details about activities you carry out over a week.

Jonathan will meet you at home or at a location of your choice

You will be interviewed about activities you have recorded in the diary, or others that come to mind, for about 45 minutes.

You may be contacted within a few months for another interview during which you will take part in one of the community activities that you identified as being meaningful to you.

The interviews will be audio recorded so they can be transcribed by one of the research team.

Pehea te awhina i ahau mehemea he awangawanga? (What are the discomforts and how will they be dealt with?)

You do not have to talk about anything you are not willing to share. We can accommodate your cognitive or communication needs and you can take breaks during the interview if you need to. You can decline from answering any questions, or stop altogether if you need to.

AUT Health Counselling and Wellbeing is able to offer three free sessions of confidential counselling support. These sessions are available for issues that have arisen as a result of participation in the research. To access these:

- Drop into our centres at WB219 or AS104 or phone 921 9992 (City or South Campus), 921 9998 (North Shore campus) to make an appointment.
- Let the receptionist know that you are a research participant, and provide the research title and my name and details as given in this Information Sheet

You can find out more counselling information on http://www.aut.ac.nz/being-a-student/current-postgraduates/your-health-and-wellbeing/counselling.

He aha nga hua? (What are the benefits?)

This research recognises the importance of knowledge flowing into the future and being used to help future generations of your whānau, iwi and hapū. Findings may help rehabilitation teams to improve services, used to help promote seamless service delivery to people with brain injury, used to inform public health initiatives like as education in schools, or help to inform health policies by providing a better understanding of what is important to people with brain injury. The research is the final portion of a Doctor of Health Science degree.

Pehea te noho tapu o aku korero? (How will my privacy be protected?)

Information will be kept in locked cabinets or password protected computer files and only linked by ID numbers. Your signed consent form will be stored in a secure location, separate to the data. No information identifying you will be used in written work or presentations.

He aha te utu o tenei rangahau? (What are the costs of participating in this research?)

No costs, just your time.

Pehea te roa moku ki te whakaaro? (How long do I have to consider this invitation?)

You can take up to two weeks

Ka hoki mai he korero ki ahau mo tenei rangahau? (Will I receive feedback on the results of this research?)

You will receive a summary of findings on completion of the work. We will keep you updated on any publications and conferences where the findings are being presented.

He aha maaku mehemea he awangawanga oku mo tenei rangahau? (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, Nicola Kayes, nkayes@aut.ac.nz, 09 921 9999 ext 7309.

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTEC, Kate O'Connor, *ethics@aut.ac.nz* , 921 9999 ext 6038.

Me pa atu ahau ki a wai me he patai aku? (Whom do I contact for further information about this research?)

Kairangahau: ***Researcher Contact Details:***

Jonathan Armstrong, Clinical Director for Allied Health at Counties Manukau Health, jonathan.armstrong@middlemore.co.nz, 09 276 0044 ext 58285, or 021 569676

Kaiaarahi: ***Project Supervisor Contact Details:***

Nicola Kayes, Director of the Centre for Person Centred Research, AUT nkayes@aut.ac.nz, 09 921 9999 ext 7309

Approved by the Auckland University of Technology Ethics Committee on *18 November 2019*, AUTEC Reference number 19/352.

Appendix D: Consent to Provide Details

Consent To Provide Details

Project title:	***How do people with brain injury re-integrate into their community on return home from in-patient rehabilitation?***
Project Supervisor:	***Nicola Kayes***
Researcher:	***Jonathan Armstrong***

I **have been given information about the study** of community integration after brain injury.

I am **interested in knowing more** about the study.

I agree that my therapist (name).....can **give my name and contact details to the researcher** named above.

Participant's signature:.....

Participant's name:.....

Participant's Contact Details (telephone or email):

.....

.....

.....

.....

Date:.....

Approved by the Auckland University of Technology Ethics Committee on 18 November 2019. AUTEC Reference number 19/352.

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

Appendix E: Updated Participant Information Sheet (COVID-19)

Participant Information Sheet

Date Information Sheet Produced:

11 September 2019 (Updated 23 November 2020)

Project Title

How do people with brain injury re-integrate into their communities on return home from in-patient rehabilitation?

We are interested in finding out how people with brain injury settle back into life when they return home after an in-patient stay.

What is the purpose of this research and how is it funded?

Exploring the process that people go through is an important part of understanding how this could be better facilitated, either through supporting people, or reducing barriers to their ability to interact with the environment. Findings may be used for publications and presentations that aim to improve services and policies relating to community integration for people with brain injury. Funding for this research has been received through an AUT Doctoral Scholarship and a small contribution from Occupational Therapy New Zealand, the national association for occupational therapists.

How was I identified and why am I being invited to participate?

We have asked the rehabilitation staff to invite you because you are:

- 18 years or over
- Living with effects of brain injury (including stroke)
- At home within the last 6 months
- Living in Auckland

How do I agree to participate in this research?

- The project will be introduced by one of your rehabilitation team.
- Provide your preferred contact details to your therapist who will pass them on or you can contact Jonathan directly using the details on the last page.
- Jonathan will get in touch and ensure the research is suitable for you.
- We will ask you to sign and return a consent form before starting any interviews.
- If COVID-19 alert levels mean that we can't get your consent in person then you can provide consent verbally over the phone or via "video chat" and we will record this for our records. Alternatively you can sign, scan or photograph the consent form and return it; or copy the content of the consent form into an email and send this to us from your personal email with a sentence agreeing to participate.
- Your participation is your choice and you can withdraw at any time.

What will happen in this research?

You complete a simple diary; recording details about activities you carry out over a week.

Jonathan will meet you at home or at a location of your choice

Jonathan can phone you or use "video chat" on your phone or computer if COVID-19 alert levels mean we can't meet in person or if that would be your preference

You will be interviewed about activities you have recorded in the diary, or others that come to mind, for about 45 minutes.

You may be contacted within a few months for another interview during which you will take part in one of the community activities that you identified as being meaningful to you.

The interviews will be audio recorded so they can be transcribed by one of the research team.

What are the discomforts and how will they be dealt with?

You do not have to talk about anything you are not willing to share. We can accommodate your cognitive or communication needs and you can take breaks during the interview if you need to. You can decline from answering any questions, or stop altogether if you need to.

Video chat may be necessary due to COVID-19 restrictions. Talking over a video link may not familiar to you but you will be given written instructions on how to connect to the video chat and, once connected, Jonathan will talk you through any technical needs.

AUT Health Counselling and Wellbeing is able to offer three free sessions of confidential counselling support. These sessions are available for issues that have arisen as a result of participation in the research. To access these:

- Drop into our centres at WB219 or AS104 or phone 921 9992 (City or South Campus), 921 9998 (North Shore campus) to make an appointment.
- Let the receptionist know that you are a research participant, and provide the research title and my name and details as given in this Information Sheet

You can find out more counselling information on http://www.aut.ac.nz/being-a-student/current-postgraduates/your-health-and-wellbeing/counselling.

What are the benefits?

This research is the final portion of a Doctor of Health Science degree and findings may help rehabilitation teams to improve services, be used to help promote seamless service delivery to people with brain injury, used to inform public health initiatives like education in schools, or help to inform health policies by providing a better understanding of what is important to people with brain injury

How will my privacy be protected?

Information will be kept in locked cabinets or password protected computer files and only linked by ID numbers. Your signed consent form will be stored in a secure location, separate to the data. No information identifying you will be used in written work or presentations. No video recording will take place.

What are the costs of participating in this research?

There are no costs, except for your time.

How long do I have to consider this invitation?

You can take up to two weeks

Will I receive feedback on the results of this research?

You will receive a summary of findings on completion of the work. We will keep you updated on any publications and conferences where the findings are being presented.

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, Nicola Kayes, nkayes@aut.ac.nz, 09 921 9999 ext 7309.

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTEC, Carina Meares, *ethics@aut.ac.nz* , 921 9999 ext 6038.

Whom do I contact for further information about this research?

Researcher Contact Details:

Jonathan Armstrong, Clinical Director for Allied Health at Counties Manukau Health, jonathan.armstrong@middlemore.co.nz, 09 276 0044 ext 58285, or 021 569676

Project Supervisor Contact Details:

Nicola Kayes, Director of the Centre for Person Centred Research, AUT, nkayes@aut.ac.nz, 09 921 9999 ext 7309

Approved by the Auckland University of Technology Ethics Committee on *4 December 2020*, AUTEC Reference number *19/352*.

7-DAY ACTIVITY DIARY (TEMPLATE)

DAY 1

Briefly write down what activities you did, when you did them, where you were and who you were with. Make a note of how the activity went so that when we meet it will prompt you to tell me anything you feel is important. See the example below.

Time (When?)	Activity (What?)	Place (Where?)	Other people (Who was with me?)	Observations (How was it?)
Example 8-11am	Housework, shopping, walking children to school, making dinner….	Home, Church, Supermarket, School…	Alone, husband, wife, son, friend, grandchildren…	Difficult to get into the building, I got tired quickly, it's the first time I managed to do this, I felt a sense of achievement…

Appendix G: Initial Interview Schedule

Initial "Diary Led" Interview Schedule

This is the schedule that will be used in the initial few interviews. As themes emerge from the data collection and analysis, other questions will be added to later interview schedules in order to explore these emerging themes in more detail.

Before Commencing the Interview:

- Review the participant understands the research, the interview process, and the data use once the interview is complete.
- Ensure consent form is completed
- Engage in general conversation to build rapport
- Ask the participant if there is anything that we need to take into account over the next 45 minutes or make allowances for to ensure they are as comfortable as possible (e.g. toilet use if issues with continence, signs of fatigue…)
- Ask participant to share the 7-day diary

Initial Broad Opening Questions:

Tell me about your experience of transitioning home from the hospital, what went well, what did not go so well?

Since being home, which activities have you been most involved in around the house?

What were some of the first attempts you made to get out into the community like?

Exploring the 7-day diary:

Can we take a look over your diary and can you explain some of the entries for me?

I'd like to find out more about this particular activity that you have added to the diary and learn a bit more about that.

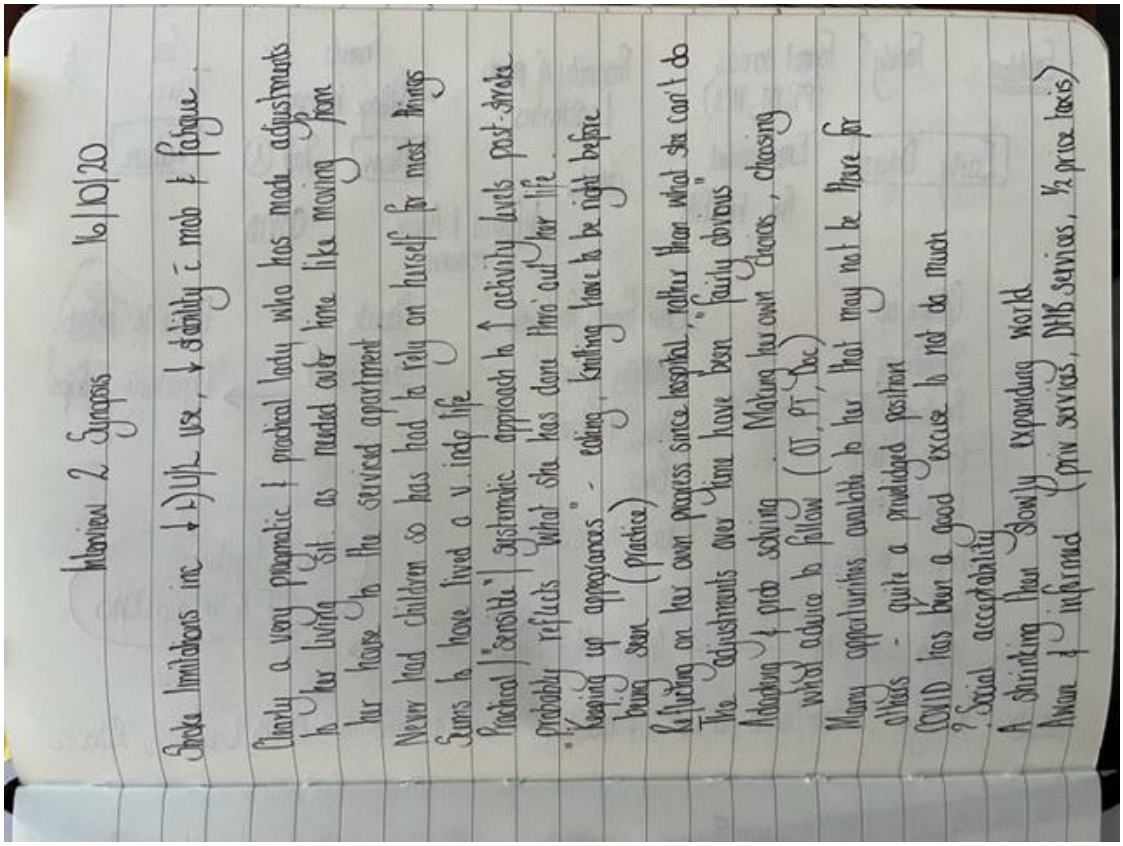
Pick out the activity that you enjoyed the most, what was it about this one that made it so enjoyable?

Which activity did you find most difficult? What was it that made it so hard?

Prompts based on theoretical scaffolding of literature review and clinical experience:

- *Relationships:* It looks like you do a lot of activities with…. Are there other people that you get opportunities to connect with?
- *Acceptance:* Do you feel comfortable out in the community/in that setting?
- *Independence:* What were the limitations resulting from the brain injury? What resources were required? Were these your own personal choices?
- *Access:* The social, physical and attitudinal environment.
- *Risk:* Do you feel safe doing these things?

Appendix H: Examples of Initial Interview Synopses



Interview 2 Synopsis 16/10/20

Stroke limitations inc ↓ L) U/L use, ↓ stability c mob & fatigue.

Clearly a very pragmatic & practical lady who has made adjustments to her living sit as needed after home like moving from her house to the serviced apartment.

Never had children so has had to rely on herself for most things Seems to have lived a v. indep life

Practical / "sensible" / systematic approach to & activity limits post-stroke probably reflects what she has done throughout her life.

"Keeping up appearances" - editing, knitting have to be right before being seen (practice)

Reflecting on her own progress since hospital, rather than what she can't do

The adjustments over time have been "fairly obvious"

Adapting & prob solving Making her own choices, choosing what advice to follow (OT, PT, Dec)

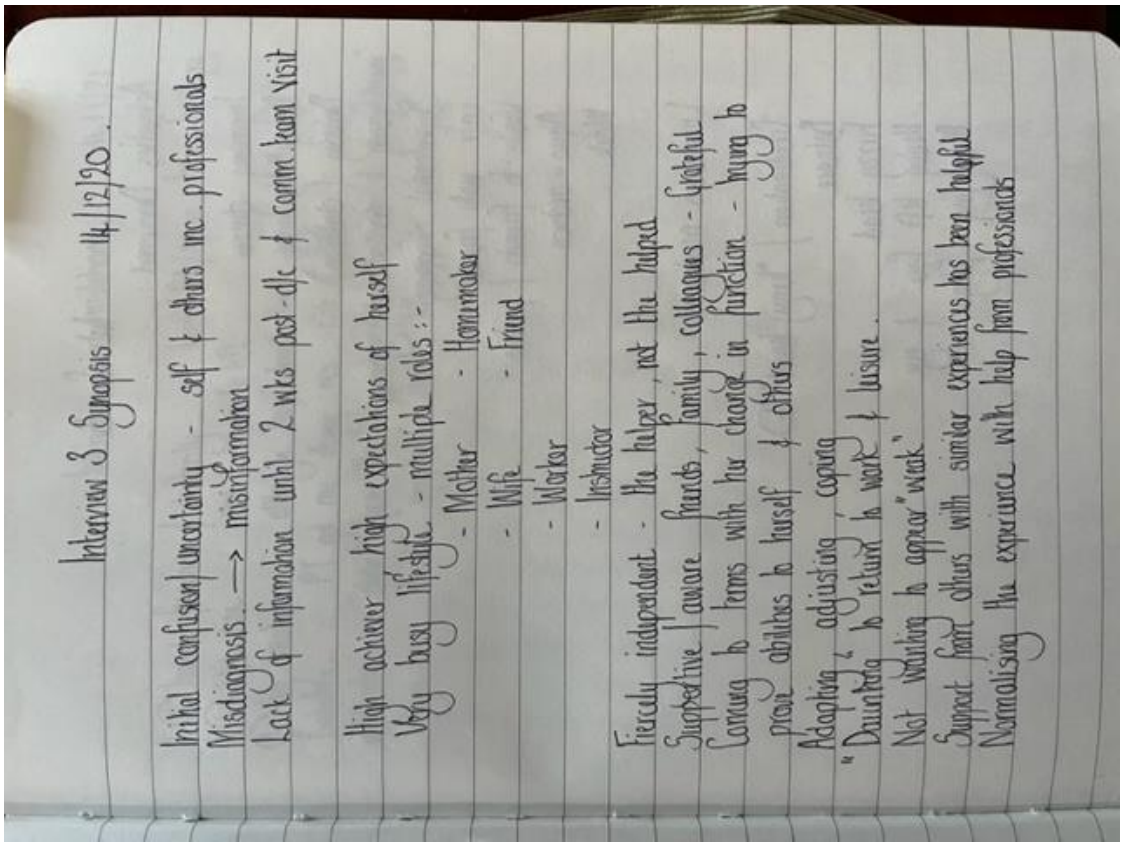
Many opportunities available to her that may not be there for others - quite a privileged position

COVID has been a good excuse & not do much

? Social acceptability

A shrinking then slowly expanding world

Aware & informed (priv services, DHS services, ½ price taxis)



Interview 3 Synopsis 14/12/20

Initial confusion/uncertainty - self & others inc. professionals
Misdiagnosis → misinformation
Lack of information until 2 wks post-dc & comm team visit

High achiever high expectations of herself
Very busy lifestyle - multiple roles ::-
- Mother - Homemaker
- Wife - Friend
- Worker
- Instructor

Fiercely independent - the helper, not the helped
Supportive / aware friends, family, colleagues - Grateful
Learning to frame with her change in function - having to prove abilities to herself & others
Adapting & adjusting, coping
"Downtime" to refuel & work & leisure.
Not wanting to appear "weak"
Support from others with similar experiences has been helpful
Normalising the experience with help from professionals

Appendix I: Ethics Approval (November 2019)

Auckland University of Technology Ethics Committee (AUTEC)

Auckland University of Technology
D-88, Private Bag 92006, Auckland 1142, NZ
T: +64 9 921 9999 ext. 8316
E: ethics@aut.ac.nz
www.aut.ac.nz/researchethics

11 November 2019

Nicola Kayes
Faculty of Health and Environmental Sciences

Dear Nicola

Re Ethics Application: **19/352 How do people with brain injury reintegrate into their communities on return home from in-patient rehabilitation**

Thank you for providing evidence as requested, which satisfies the points raised by the Auckland University of Technology Ethics Committee (AUTEC).

Your ethics application has been approved for three years until 11 November 2022.

Standard Conditions of Approval

1. The research is to be undertaken in accordance with the Auckland University of Technology Code of Conduct for Research and as approved by AUTEC in this application.
2. A progress report is due annually on the anniversary of the approval date, using the EA2 form.
3. A final report is due at the expiration of the approval period, or, upon completion of project, using the EA3 form.
4. Any amendments to the project must be approved by AUTEC prior to being implemented. Amendments can be requested using the EA2 form.
5. Any serious or unexpected adverse events must be reported to AUTEC Secretariat as a matter of priority.
6. Any unforeseen events that might affect continued ethical acceptability of the project should also be reported to the AUTEC Secretariat as a matter of priority.
7. It is your responsibility to ensure that the spelling and grammar of documents being provided to participants or external organisations is of a high standard.

AUTEC grants ethical approval only. You are responsible for obtaining management approval for access for your research from any institution or organisation at which your research is being conducted. When the research is undertaken outside New Zealand, you need to meet all ethical, legal, and locality obligations or requirements for those jurisdictions.

Please quote the application number and title on all future correspondence related to this project.

For any enquiries please contact ethics@aut.ac.nz. The forms mentioned above are available online through http://www.aut.ac.nz/research/researchethics

Yours sincerely,

Kate O'Connor
Executive Manager
Auckland University of Technology Ethics Committee

Cc: Jonathan.armstrong@middlemore.co.nz; felicity.bright@aut.ac.nz

Appendix J: Ethics Approval (December 2020)

Auckland University of Technology Ethics Committee (AUTEC)

Auckland University of Technology
D-88, Private Bag 92006, Auckland 1142, NZ
T: +64 9 921 9999 ext. 8316
E: ethics@aut.ac.nz
www.aut.ac.nz/researchethics

1 December 2020

Nicola Kayes
Faculty of Health and Environmental Sciences

Dear Nicola

Re Ethics Application: **19/352 How do people with brain injury reintegrate into their communities on return home from in-patient rehabilitation**

Thank you for providing evidence as requested, which satisfies the points raised.

The amendment to the recruitment strategy to include other organisations working with people in the early stages of their return home after in-patient rehabilitation, including non-government organisations and community neuro-rehabilitation providers and the use of electronic media for the recruitment and interview process has been approved

Standard Conditions of Approval

1. The research is to be undertaken in accordance with the Auckland University of Technology Code of Conduct for Research and as approved by AUTEC in this application.
2. A progress report is due annually on the anniversary of the approval date, using the EA2 form.
3. A final report is due at the expiration of the approval period, or, upon completion of project, using the EA3 form.
4. Any amendments to the project must be approved by AUTEC prior to being implemented. Amendments can be requested using the EA2 form.
5. Any serious or unexpected adverse events must be reported to AUTEC Secretariat as a matter of priority.
6. Any unforeseen events that might affect continued ethical acceptability of the project should also be reported to the AUTEC Secretariat as a matter of priority.
7. It is your responsibility to ensure that the spelling and grammar of documents being provided to participants or external organisations is of a high standard and that all the dates on the documents are updated.

AUTEC grants ethical approval only. You are responsible for obtaining management approval for access for your research from any institution or organisation at which your research is being conducted and you need to meet all ethical, legal, public health, and locality obligations or requirements for the jurisdictions in which the research is being undertaken.

Please quote the application number and title on all future correspondence related to this project.

For any enquiries please contact ethics@aut.ac.nz. The forms mentioned above are available online through http://www.aut.ac.nz/research/researchethics

(This is a computer-generated letter for which no signature is required)

The AUTEC Secretariat
Auckland University of Technology Ethics Committee

Cc: Jonathan.armstrong@middlemore.co.nz; felicity.bright@aut.ac.nz

Appendix K: Telephone Conversation Template

Script for phone calls

Intros:

Hi ……. my name is Jonathan Armstrong, I'm contacting you because your OT/PT/SLT/… (Name) recommended you as someone who would be interested in contributing to the research that I am undertaking with AUT University.

Do you remember (name of therapist) discussing a research study with you about exploring peoples' experiences of returning home after inpatient rehab following a stroke/brain injury?

Purpose:

We are interested in finding out how people with brain injury/stroke settle back into life when they return home after an in-patient stay.

What we are trying to do is explore the process that people go through and understand how this could be better facilitated, either through particular types of support, or reducing barriers in the environment.

Our findings will help rehabilitation teams to improve services, they could be used to help services work better together to achieve better outcomes, or be used to inform public health initiatives like education in schools

Would you be happy to contribute your point of view?

What's Involved:

I'll visit you at home and we'll have a chat for about 45 mins about how things are going for you and what you have experienced so far in terms of shifting from the hospital back home and getting out-and-about and on with day-to-day life. I'll have a few questions that will kick us off but it will generally be a conversation and you can tell me whatever you think is most important to you or whatever you are comfortable with telling me.

I'll audio record the conversation so I can write it all out and combine it with other interviews to analyse the information.

All your personal information will be anonomised so you can't be identified.

Confirming plans:

- If you are happy to go ahead with an interview then lets confirm a date, time that works for you
- Confirm address, best contact number + safety questions (e.g. dogs, construction)
- Confirm that I will text the day before to check everything is still ok

Appendix L: Keeping Safe in the Community Protocol

BEFORE community visit

Conduct or review risk assessment	• If a risk assessment has not been completed, then conduct a full risk assessment using the risk assessment form • If a risk assessment has already been completed, then review the risk assessment so that you can be aware of any known risks and have a clear plan for maintaining your safety during the visit.
Plan your journey	**Know where you are going and how to get back. Plan:** • How are you getting there? Bus or private car? • Check directions, ask participant for landmark tips • Work out how long the journey will take you
Notify others about visit	• Let your study coordinator (or another agreed buddy) know where you are going and when. • If your visit is in the weekend or evening you may want to tell someone else (such as your partner or family member) - let them know: o Interview address & contact number o Estimated time frame for travel and visit
Confirm visit	• Prior to visit, call or text to confirm – check they are still available and expecting you • Confirm your plans with your study coordinator • If plans change or become delayed, provide clear details of change to your buddy including: o Expected time of return o New destination
Be prepared	• **Always carry charged cell phone** • **Ensure you have enough petrol in your car and that your car is working well** • Pre-programme your phone with emergency contact numbers (including study coordinator and other important contact numbers) • Carry list of useful contact numbers

ON ARRIVAL

Be prepared	• Park facing the direction you wish to leave • Keep your keys on you • Keep mobile on (e.g. on silent)
Assess environment	• Be vigilant regarding the environment both outside and within the home. • Look for evidence of dogs, drug use, isolation, no cell phone coverage, poor access to house/car, gang addresses, etc. • If dogs or other dangerous animals are present, call your participant from outside the property and ask that they be tied up or locked away before you enter. If that is not possible, leave and reschedule the visit.
Assess situation	• If your participant or any person present is under the influence of drugs or alcohol, leave the premises and reschedule the visit. • If you hear raised voices or observe violence, leave the premises and reschedule the visit.
Entering the home	• Do not go first into a room – have the participant ahead of you • Always attempt to place yourself closer to an exit point • Consider home environment o Who else is present? o Atmosphere (interpersonal dynamics) o Position of others in relation to yourself o Dogs or other safety environmental issues • Trust your instincts – if something you see or hear causes you concern or makes you feel ill at ease, thank the participant and advise that the session will be short and excuse yourself.

DURING the visit

Event	Examples	Possible immediate action
Thinks are going off track	Visit interrupted 'mates show up'	• If the visit has been interrupted or derailed, then suggest that you can leave and reschedule the visit.
	Others present take over or ask for information	• Remind others present that you are there to visiting with the participant. If family members want to ask your advice you can make another time to follow up with them.
Feeling uncomfortable or ill at ease	Generally, feeling ill at ease Observing or learning about illegal activity Weapons are on display Participant getting too friendly or close	• Trust your instincts. • If you consider that your safety or that of the participant is potentially compromised during the visit, if possible, leave immediately. • Thank the participant and advise that the session will be short and excuse yourself.
Perceived or actual threats to your safety (or that of others)	Inappropriate language or gestures directed at you Verbal, physical or sexual abuse directed at you or others present	• Trust your instincts. • If you consider that your safety or that of the participant is potentially compromised during the visit, if possible, leave immediately. • If necessary, use de-escalation strategies (e.g. don't answer emotion with emotion; watch your tone and volume; respond calmly with "I" messages; keep statements matter of fact, simple and direct; keep a physical distance; don't reach out and touch the person; don't get up from the chair while the person is sitting; don't leave too abruptly). • If you are in a dangerous position or feel unsafe to exit, dial 111 to seek assistance.
Concern for your participants health and well-being	Concerns about your participant's general health Concerns about your participant's welfare	• Discuss with your participant. • Check they have access to relevant supports (informal and formal). • Suggest they contact their health professional. • Give them information about relevant services they could access. • Seek their permission to discuss your concerns with your study coordinator.
	Your participant is displaying signs of emotional distress	• Check in with your participant and ask if they need a break or wish to cease the session. • Check they have access of relevant supports or if not, if they would like you to share information about services they could access.

	Suicide talk – hints or talks about self-harm or 'no future'	• Use language such as "when people say … they are often thinking about suicide, are you thinking about suicide?". • Ask if they have expressed this to others (e.g. their health professional) and if they are getting the support they need. • Seek permission to contact their health professional • Ask if they would like information about other support services. • If you think they are in imminent danger (e.g. have expressed intent and have means) and you are concerned about leaving them, call the crisis team and seek further advice on next steps.

Immediately FOLLOWING the visit

Notify your buddy when you have completed your visit and left the property	If your buddy has not returned/called in as expected, the following procedure will be implemented: • Call the buddy's work mobile phone • Call the home of the last visit • Call the buddy's personal work/home number/NOK or emergency contact • If you cannot locate your buddy via any of the above means, contact the police