The Experience of Hospitalisation for People with Intellectual Disabilities; A Qualitative Study of Tāngata Whaiora and Community Stakeholders in Aotearoa

Carrie McColl

A dissertation submission to Auckland University of Technology (AUT) in partial fulfilment of the requirements for the degree of Bachelor in Health Science (Honours) Psychology

2022

School of Clinical Sciences

Department of Psychology and Neuroscience

ABSTRACT

Background: People with intellectual disabilities (ID) have complex health needs, worse health outcomes than the general population, and are at risk of receiving poor care in acute hospital settings. The experiences of hospitalisation for people with ID and the perspectives of ID service providers have been documented in qualitative research internationally, however, little is known about this topic in the context of Aotearoa/New Zealand. Therefore, this study seeks to better understand what the experience of hospitalisation of people with ID in Aotearoa is, what are the things that make the experience easier for people with ID, and what were the things that negatively impact the experience.

Method: For this qualitative study interviews and written surveys were used. Semi-structured interviews were conducted with five adults with ID and nine community stakeholders who work in support of people with ID. Additionally, two anonymous survey responses were received from people with ID and five survey responses were received from community stakeholders. The total number of participants with ID was seven. The total number of community stakeholder participants was 14. The data generated were analysed using reflexive thematic analysis.

Findings: The findings of the study revealed that while for some people with ID, hospitalisation is frightening, most of the participants with ID had positive feelings about hospitalisation. Positive experiences were associated with friendly and communicative doctors and nurses. In contrast, community stakeholder participants perceived the experience of hospitalisation as frightening, traumatic and overwhelming for people with ID. Additionally, participants with ID described challenges with feeling lonely and bored during admission. Community stakeholder participants described significant concerns about failures in the provision of basic care, such as a lack of assistance with eating, toileting, showering and sleeping positions. Instances of patient harm and deterioration of health were attributed to lapses in basic care by nursing staff. Community stakeholders viewed hospital staff as lacking knowledge about ID and how to adjust communication to suit people with ID's needs. Perceived deficits in hospital staff education about ID were attributed as the basis in failures in the provision of individualised patient-centred care and contributed to feelings of mistrust in the hospital system. A lack of knowledge about ID was also attributed to failures in keeping patients safe, as well as disruptions to the continuity of care after discharge.

Conclusion: For people with ID, the experience of hospitalisation may be made easier by making reasonable adjustments that consider individual needs. Participants with ID described preferring being around other people rather than being placed in rooms alone, having shorter wait times in the hospital, having access to activities, music or devices to alleviate boredom, having access to support people and advocates that can communicate their needs and explain things to them, and having compassionate hospital staff who take time with patients, and who are good at identifying and managing pain. Community stakeholders described wanting better discharge planning in order to support continuity of care and patient safety after hospitalisation, and clearer guidelines about the administration of pain medication. For both people with ID and community stakeholders, the development of a uniform system to ensure the effective transfer of information about a person's individual requirements and needs, and a specialist disability liaison nurse or advocacy role in all hospitals were identified as ways that the hospital system could improve to better support people with ID in future.

Table of Contents

LIST OF TABLES

LIST OF ABBREVIATIONS

BIF	Borderline Intellectual Functioning
CRPD	The United Nations Convention on the Rights of Persons with Disabilities (CRPD)
DSM	Diagnostic and Statistical Manual of Mental Disorders
FSIQ	Full Scale Intelligence Quotient
ID	Intellectual Disability
IDLN	Intellectual Disability Liaison Nurse
IQ	Intelligence Quotient
LDLN	Learning Disability Liaison Nurse
NASC	Needs Assessment and Service Coordination

GLOSSARY

Aotearoa	The te reo Māori name for New Zealand
Community stakeholders	Used to describe people who work in support of people with intellectual disabilities and which has been used interchangeably with the terms 'ID service provider'
Tāngata Whaiora	Used to describe people seeking health and which has been used interchangeably with the term 'people with ID' in this study to reference their experience as health-seekers in the hospital system.
Whānau	Used to describe family units

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.

Signature:

Date: 29 November 2022

Acknowledgments

To my supervisor, Dr Liesje Donkin, thank you for the enduring support you have shown me throughout this year, all while managing a head-spinning schedule of your own. Your guidance, patience, generosity and encouragement are greatly appreciated.

To the participants who generously took time out of their day to be a part of this study, thank you. This project would not have been possible without your insights and expertise. This study sits within a larger research project, and it is my hope that your experiences, so generously shared, will lead to positive change for people with intellectual disabilities in hospitals throughout Aotearoa.

CHAPTER ONE: INTRODUCTION

Defining Intellectual Disability

Intellectual Disability (ID) is a common neurodevelopmental disorder described in The Diagnostic and Statistical Manual for Mental Disorders [DSM-5] (American Psychiatric Association [APA] 2013). People with ID are diverse but generally have an Intelligence Quotient (IQ) score of 70 or less (Ministry of Health, 2018), and have marked deficits in adaptive functioning in activities of daily life, such as socialisation, communication, or independent living (APA, 2013). Intellectual deficits in reasoning, planning, problem-solving, abstract thinking, academic learning, learning from experience and judgement also signify an ID (APA, 2013). Intellectual and adaptive deficits often become apparent between the period from birth to age eighteen years (APA, 2013), and diagnosis must be confirmed by both clinical assessment and individualised standardised testing (APA, 2013; Harris & Greenspan, 2016).

ID range from mild to profound (American Psychiatric Association, 2013), and include people with borderline intellectual functioning (BIF) which is defined as having an IQ between 71–84 (Wieland & Zitman, 2016). While individuals with BIF may have an IQ slightly higher than those classified as intellectually disabled, they may also share many of the same vulnerabilities and obstacles that people with lower IQ scores experience (Snell et al., 2009). These challenges include limited academic skills and access to skills training, economic restraints due to underemployment or unemployment, barriers to accessing funding and support services, inadequate housing, and insufficient primary and secondary healthcare services (Grant, 2016; Snell et al., 2009). A lack of inclusion in community, recreational, social, and cultural groups may prevent adults with ID participating in society (Grant, 2016). Such challenges can increase the risk of people with ID experiencing isolation and affect their overall quality of life, which in turn may limit their ability to achieve true empowerment (Grant, 2016). Given this, an IQ score is not the best gauge of ID which has resulted in a shift from using IQ as the primary measure of diagnosis. Indeed, the DSM-5 acknowledges this by no longer including IQ boundaries as part of its classification for ID (Wieland & Zitman, 2016). Instead, the focus is on a person's daily functioning more than a specific IQ score (National Academies of Sciences, Engineering, and Medicine, 2015).

Prevalence of Intellectual Disability in Aotearoa New Zealand

The most recent prevalence data for ID in Aotearoa New Zealand (henceforth referred to as Aotearoa) comes from the 2013 Disability Survey provided by Statistics New Zealand (2014). At that time, two percent of the population self-identified as having an intellectual disability (Statistics New Zealand, 2014). Prevalence rates may be higher, as those with moderate or severe ID may not have completed the survey due to communication issues. For both adults and children, the survey showed that more males (3%) than females (1%) identified as living with ID (Statistics New Zealand, 2014). Higher rates of ID for males may be attributed to a higher prevalence of congenital conditions linked to ID such as Fragile X syndrome that are more common in males. Additionally, behavioural and developmental issues are often more easily and frequently identified in males and brought to the attention of support services, thus leading to a greater likelihood of diagnosis (Ministry of Health, 2018).

Health Outcomes for People with Intellectual Disability

Over the past century, the provision of care and health services for people with ID has changed significantly, both internationally and in Aotearoa. With the closure of the Kimberley Centre (psychopaedic hospital), deinstitutionalisation led to greater inclusion of adults with ID in community care (Brunton, 2003) and in the mainstream private and public healthcare system (McCarthy & Duff, 2019). Today, Aotearoa's government-funded public healthcare system works on a community-focused model, with Te Whatu Ora – Health New Zealand responsible for providing or funding health and disability services in their respective districts (McCarthy & Duff, 2019). Examples of services include the Intellectual Disability Dual Disorder Service (IDDS) in the Waikato region and the Regional Dual Disability Mental Health Service (RDDS) at Te Whatu Ora Counties Manukau which provide support for people with ID who have significant mental health concerns. Continued improvement to the health system and services supporting people with ID is a priority outlined in the Health and Disability System Review (2020). These services are important in providing responsive and specialised community healthcare services which are key to reducing inequities in health outcomes that many people with ID face (World Health Organisation, 2019).

Improvements that consider the needs of tāngata whaiora (henceforth used to refer to service users) in the healthcare system are especially important given that people with ID are high users of health services (Ministry of Health, 2018) and experience more frequent admission to hospitals than those in the general population (Dunn et al., 2018). Higher

service use has been partially attributed to people with ID health needs being more complex than the general population (Landes, 2017) due to higher rates of co-morbid health conditions than the general population and higher rates of early mortality (Landes, 2017; O'Leary et al., 2017).

Morbidities affecting earlier mortality for people with ID range from respiratory illness, circulatory disease, cerebrovascular disease, cardiovascular and ischaemic heart disease, cancer, and congenital defects (Hosking et al., 2016; O'Leary et al., 2017). Adults with ID may also face increased risk of earlier death by accidental poisoning and a higher risk of death by violence (O'Leary et al., 2017). Additionally, children and adults with ID experience higher rates of mental health comorbidities than the general population (Buckley et al., 2020). Therefore, ensuring good access to responsive health services is important for the ID population (Ministry of Health, 2018).

Additional Factors Affecting Wellbeing

Research suggests that some health inequalities people with ID face are likely to be preventable and may be driven by social determinants of poor health (Emerson, 2021). This includes employment inequality, poverty, violence and discrimination, and barriers to accessing appropriate health care services or inadequate service provision catering for the needs of people with ID (Vlot-van Anrooij et al., 2020; Emerson, 2021; McCormick et al., 2021; Ministry of Health, 2013). Under diagnosis and under servicing of mental health care for people with ID is also common, and in some instances, misattribution of symptoms to ID over specific mental illnesses has led some to experience difficulties accessing care (Buckley et al., 2020; Thrum et al., 2019) thus increasing the risk of morbidity and mortality. These increased risks people with ID face may be offset by better access to suitable healthcare services (O'Leary et al., 2017), including consistent and thorough management of health at the primary healthcare level for those with ID (Iacono et al., 2020).

Factors Affecting Negative Hospitalisation Experiences

While people with ID experience more admissions to hospital (Dunn et al., 2018), they are also more likely to endure unsatisfactory hospital experiences than people without ID (Emerson, 2021; Iacono et al., 2014). The existing international literature describes the contributing factors to negative hospital experiences of adults with ID as including poor information sharing and communication between hospitals and patients, and hospitals and whānau (McCormick et al., 2021; Dinsmore, 2012), inadequately trained healthcare staff

(Ministry of Health, 2013), inflexible healthcare systems (Iacono et al., 2014), discriminatory and negative attitudes towards patients with ID (Ali et al., 2013, Iacono et al., 2014), isolation of people with ID from other patients, complex information related to their specific medical conditions, medication requirements or aftercare that are inaccessible for patients with ID (Dinsmore, 2012).

Factors Affecting Positive Hospitalisation Experiences

Existing research also indicates the conditions which facilitate positive hospital experiences for people with ID, such as the importance of accommodating, respectful, and compassionate healthcare professionals (Ali et al., 2013; Brown et al., 2016). Ali and colleagues (2013) found higher levels of satisfaction were described by patients with ID and their carers when health professionals were perceived as going above and beyond their roles to accommodate the patient's needs (Ali et al., 2013). An example of this was nursing staff who took the time to familiarise a patient with ID to the hospital environment prior to being admitted (Ali et al., 2013).

Brown and colleagues (2016) conducted a qualitative study using interviews exploring the impact of a disability liaison nurse role and compassionate, person-centred care from the perspective of patients with ID, whānau, and paid carers. A strong theme that emerged from the data was the importance of having a "stable and compassionate presence in times of great physical and emotional vulnerability" (Brown et al., 2016, p. 975) in the form of a liaison nurse. Participants attributed the liaison nurse role with providing comfort and support during frightening experiences, which ensured consistency and stability in their care journey (Brown et al., 2016). Moreover, participants in Brown and colleagues (2016) study noted that the facilitation of communication and information sharing was improved by the flexibility of the liaison nurse role in the acute care environment (Brown et al., 2016).

Other factors that influence positive hospitalisation experiences are said to include effective communication and information sharing that includes whānau members (Phillips, 2019), roles and responsibilities of hospital staff clearly communicated to patients, whānau and carers to alleviate anxiety and potential gaps in care (Brown et al., 2016), appropriate transition of care to further health services (Ali et al., 2013; Phillips, 2019), and flexible hospital systems that are responsive in meeting the specific needs of the patient (Phillips, 2019).

Equitable Healthcare for People with Intellectual Disabilities

Ensuring equitable healthcare access and a responsive approach to hospital care is expected to be beneficial to the health and wellbeing of people with ID during hospitalisation (McCarthy & Duff, 2019). Research suggests that an essential element in supporting meaningful change in the healthcare of adults with ID includes identifying the needs of people with ID through an understanding of their experiences and perspectives about the healthcare system. However, current research indicates that adults with ID may also face barriers that exclude them from being included as research participants (Rosencrans et al., 2021). This may involve barriers in the form of gatekeeping from service organisations that support people with ID, conditions placed on studies by research ethics committees which result in exclusion of people with intellectual deficits, or inaccessible and complex study designs (Brooker et al., 2015). Brooker and colleagues (2015) argue that research which includes people with intellectual disability as research participants may contribute to reduced health inequities through the generation of evidence that can identity and address barriers faced by adults with ID. This in turn may inform better strategies to support the health and wellbeing of this group (Brooker et al., 2015) therefore highlighting the importance of centring the voice of people with ID in research about their care.

Rationale for the Current Study

In Aotearoa, limited research exists which explores at the experiences adults with ID with regards to the healthcare system. The small number of studies that exist include exploration of access to psychiatric care (Taua et al., 2015), primary health care (Hanlon et al., 2018), and dental care under general anaesthesia (McKelvey et al, 2014). Research that centres on the voices of adults with ID and their experiences of hospitalisation is scarce and there are no studies to date exploring the experience of hospitalisation in Aotearoa. However, it is important to understand such views to better provide services to people with ID when they are hospitalised.

Using a qualitative interpretative description approach as the chosen methodology, this study aims to contribute to the research, and provide data that may guide good practice for the support of adults with ID during hospitalisation in Aotearoa. Thematic analysis was used to identify and organise the data from surveys and semi-structured interviews with participants. This method of analysis enabled the formation of themes and patterns to emerge from the data set (Braun, & Clarke, 2012). Interpretative descriptive methodology has been identified as especially suitable for addressing experiential questions (Hunt, 2009 by capturing themes or patterns from subjective perspectives (Thorne et al., 2004). This

methodology requires the researcher to move beyond a basic description of the data to create an interpretative account of participants' perspectives, which characterise the experience of hospitalisation for tāngata whaiora (Snow et al., 2022; Thorne et al., 2004).

Outline of Dissertation

In summary, Chapter One provided an overview of intellectual disability, its prevalence, and a brief overview of historical and current approaches to the care of adults with ID. It outlined current literature on the hospitalisation experiences of adults with ID, explaining the necessity for further research in the context of Aotearoa. Chapter Two will explore in greater depth the available literature which looks at hospitalisation experiences from the perspective of adults with ID and community stakeholders who support people with ID. This will provide an overview of themes or issues previously identified through qualitative studies. Chapter Three will provide justification and a full description of the chosen methodology, recruitment of participants, methods of participation in the study, the method of data analysis, reflexivity, and ethical considerations. Chapter Four describes the results of the study and details of themes which were produced. Chapter Five discusses the study's major findings, with links to current literature on the topic of how tāngata whaiora (people with ID) experience hospitalisation and what their needs are to ensure good experiences in the public healthcare system. The chapter finishes by discussing the study's implications for future research and recommendations for future research, limitations of the study, and concludes with the researcher's summary of the study's finding

CHAPTER TWO: LITERATURE REVIEW

This chapter examines the existing literature that informed this study. The factors that contribute to inequities in the health of tāngata whaiora ('tāngata whaiora' is a term used to describe people seeking health and which has been used interchangeably with the term 'people with ID' throughout this chapter) are described and the role of caregivers and community stakeholders in the lives of people with ID are outlined. A review of the current literature on the experiences of hospitalisation for people with ID and the perspectives of community stakeholders was undertaken, explaining the purpose of this study.

Working Towards a Non-Disabling Aotearoa

People with disabilities have the right to experience life on an equal basis with others; to be respected and treated with dignity, to live with freedom from discrimination and coercion, to make decisions about their lives as active members of society who achieve their goals, and to have access to appropriate healthcare services that meet their needs.

Entrenched ableist beliefs that purport the quality of life or worth of a person with a disability is inherently less valuable than that of a non-disabled person persist in society (Chicoine et al., 2022). Bogart and Dunn (2019) define ableism as the "stereotyping, prejudice, discrimination, and social oppression toward people with disabilities" (Bogart & Dunn, 2019, p. 650). Ableism occurs at both an individual and a structural level (Chicoine et al., 2022). Structural ableism is embedded in societal and organisational structures or systems, occurring through discriminatory or exclusionary policies, laws or regulations which further marginalise people with disabilities (Chicoine et al., 2022). Unfavourable attitudes toward disability occurring within the context of the healthcare system are especially problematic.

In a systematic review of the literature, Bacherini and colleagues (2021) found that physicians stigmatising attitudes towards people with ID impacted access as well as the quality of healthcare service provided (Bacherini et al., 2021). Prejudicial views of people with disabilities can contribute to further health inequities such as unjust decisions about care for tāngata whaiora (Andrews et al., 2021). This was evidenced during the initial stage of the COVID-19 pandemic, where in some American states, decisions related to Crisis Standards of Care (CSC) included exclusionary 'quality of life' criteria for people with certain disabilities (Ne'eman et al., 2021). Influenced by arguments of bioethics, these early policies effectively deprioritised people with disabilities from accessing intensive care services during times of medical resource scarcity on the grounds of diagnosis and

functional impairment (Chicoine et al., 2022). Thus highlighting the impact of ableism and its intersection with bias and discrimination in healthcare decision-making for people with ID.

Upholding the Rights of People with Disabilities

The New Zealand Disability Strategy was first launched in 2001 (Office for Disability Issues, 2016). The Strategy was a long-term plan for changing Aotearoa from a disabling to a non-disabling society, developed in consultation with disabled people (Office for Disability Issues, 2016). Following this, the New Zealand Government ratified the The United Nations Convention on the Rights of Persons with Disabilities (CRPD) (United Nations, 2006, art. 25) in 2008 (Office for Disability Issues, 2016) which comprehensively outlines the human rights of disabled people globally. The ratification of the CRPD is a demonstration of the New Zealand Government's commitment to ensuring rights for people with disabilities in Aotearoa.

Strengthening this, the New Zealand Disability Strategy 2016-2026 (Office for Disability Issues, 2016) continues to guide the work of government agencies on disability issues. The Strategy outlines eight outcomes; with outcome 3 – Health and Wellbeing being of special relevance to this study. In this outcome, a particular focus is on increasing access to health services and the improvement of health outcomes for people with ID (Office for Disability Issues, 2016). The outcome aims for people with disabilities (including people with ID) to have access to barrier-free, mainstream health services in which tāngata whaiora are treated with respect and dignity by health professionals. Furthermore, the outcome aspires to ensure that all people with disabilities can access both mainstream services and services specific to their disability that provide early diagnosis and take the individuals needs into account. It also aims to ensure people with disabilities are not secluded within services and for whānau and those who support people with disabilities to have access to the correct information when supporting tāngata whaiora (Office for Disability Issues, 2016). Despite the implementation of the New Zealand Disability Strategy 2016-2026 and its subsequent Action Plan, people with disabilities continue to experience disadvantages in society, and little is known about whether improvements specific to the healthcare system have yet yielded any effect.

An Overview of the Health Outcomes Related to Intellectual Disability

Globally, people with ID have poorer health outcomes and are at higher risk of illness, disease and early death compared to the general population (Ailey et al., 2014; Ali et

al., 2013; Hosking et al., 2016; McCarthy & Duff, 2019). Life expectancy is an important indicator of quality of life and often used to gauge the health of a population (Dieckmann et al., 2015; World Health Organisation, 2015). In Aotearoa, the most recent data from the Ministry of Health (2011) showed that for males with ID, the average life expectancy was 59.7 years of age, compared to a life expectancy of 78.4 years of age for any male in Aotearoa's population. For females with ID, life expectancy was 59.5 years of age, compared to a life expectancy of 82.4 years of age for any female in Aotearoa (Ministry of Health, 2011).

For people with ID, this mortality gap is experienced across the world (Dieckmann et al., 2015; Doyle et al., 2021; O'Leary et al., 2017). In England, an inquiry about premature death rates for people with ID revealed that deaths occurred on average 16 years earlier than for people without ID. The inquiry's findings showed that poor healthcare and service provision contributed to this mortality difference and that many early deaths may be avoidable (Hosking et al., 2016).

Avoidable death may be distinguished as either being amenable to treatment through high-quality healthcare such as screening and treatment, or preventable through public health initiatives such as immunisation schedules, or it may be both (Hosking et al., 2016; O'Leary et al., 2017). Avoidable death may be partly due to health professionals who are inexperienced in supporting adults with ID (Sowney & Barr, 2006). Unfamiliarity in effectively supporting the needs of people with ID may create communication barriers resulting in a lack of compassionate and person-centred care (Brown et al., 2016a). These barriers may in turn impact on the provision of appropriate assessments, treatments and interventions that could result in avoidable death.

Additionally, up to half of all adverse events that happen in hospitals are said to be preventable, impacting on patient outcomes and extended hospital stays (Bartlett et al., 2008; Davis et al., 2003). Such events have been found to pose a higher risk for patients with communication barriers (Bartlett et al., 2008) which are commonly experienced by patients with ID. For example, where patients with communication barriers were not able to discuss toileting or showering needs with nurses, soiling of bedding led to some patients developing skin pressure areas (Hemsley et al., 2011). Toileting accidents (Hemsley et al., 2011) and health events like skin ulcers that extend hospital stays (Davis et al., 2003) have also been found to affect hospital staff workloads further impacting resourcing and the quality of care provided.

Inequality and Inequities in Access to Health Care

Health inequality and inequities in access to healthcare remains a pervasive issue for tāngata whaiora (Chicoine et al., 2022; Louch et al., 2021). Previous research indicates that some early and avoidable deaths of people with ID are related to the compounding effects of exposure to social determinants of poor health (Emerson, 2021; O'Leary et al., 2016) as previously indicated. Aside from the social determinants of poor health, other factors found to affect higher use of health services for tāngata whaiora range from inadequate provision of information sharing between health providers and people with ID, variable or inadequate care across the health system, and a lack of access to appropriate health and prevention services (McCormick et al., 2021; Ministry of Health, 2013), as well as complex and comorbid health conditions.

Factors Thought to Improve Care for Tāngata Whaiora

To gain an understanding of the barriers to satisfactory hospital experiences, the following sections explore the existing literature on the hospitalisation experiences of people with ID and the perspectives of community stakeholders who support them.

The Role of Caregivers Supporting Tāngata Whaiora

The end of institutionalisation has meant that people with ID may choose to live at home with their whānau, with a whānau member or members acting as primary caregiver (Riches et al. 2022). People with ID may also reside in the community in supported living facilities designed to meet their needs while promoting independence (Bigby et al., 2015; Zambrino & Hedderich, 2021), or a combination of both.

For people with ID, caregivers provide an important lifeline, and this role is often filled by parents or whānau members who provide daily care and support (Riches et al., 2022). Tāngata whaiora often rely on their caregivers more than people without ID because of communication difficulties (Charles, 2020), and caregivers are often highly attuned to the non-verbal cues of the person they support (Regnard et al., 2007). Even when tāngata whaiora live outside the whānau home, whānau carers maintain a crucial support role (Hakobyan et al., 2020) which has been found to increase wellbeing, social connection, and the functional achievements of adults with ID who live independently (Zambrino & Hedderich, 2021). When adults with ID live outside the whānau home, whānau carers often continue their role as guardians, collaborating with ID service providers on matters of health and wellbeing (Bigby et al., 2015). As such, an effective relationship between carers and ID service providers is important (Bigby et al., 2015; Zambrino & Hedderich, 2021).

Caregivers also play a critical role in support of people with ID during hospitalisation, often acting as the facilitator between patient and hospital staff. As such, effective communication is necessary between caregivers and hospital staff, as this can affect the provision of quality care for people with ID (Charles, 2020). Carers may act as a surrogate communicator and be relied on to provide hospital staff with a person's medical history, specific care needs and information about their level of functioning (Charles, 2020). When barriers to communication exist between carers and hospital staff this may impact on patient safety through insufficient information sharing, reducing satisfaction with the hospital experience (Charles, 2020). Charles (2020) found that when hospital staff communicated with carers it reduced carer anxieties, helped carers to advocate on behalf of their whānau member and improved their ability to support the patient. This highlights the key role that caregivers have in sharing information with community stakeholders. It also highlights the importance of information sharing between people that work in support of tāngata whaiora and their carers to influence better hospital experiences for people with ID (Zambrino & Hedderich, 2021).

The importance of effective communication between carers and hospital staff has been highlighted by findings that poor patient care outcomes were correlated with ineffective communication between caregivers and hospital staff (Charles, 2020). In this qualitative descriptive study, content analysis of semi-structured interviews with caregivers of adults with ID found four main themes: the need for advocacy, the need for better communication, a sense of abandonment and a lack of confidence. Carers described incidences where hospital staff did not address the person with ID on the presumption they would not understand and described staff as unable or unwilling to interpret the patient's cues. This meant that carers became the surrogate communicators for their loved ones. Carers described the need for healthcare workers to include them in information sharing and decision-making and reported miscommunication leading to mistrust in the competence of staff's ability to deliver high quality care to patients with ID (Charles, 2020).

The Role of Community Stakeholders Supporting Tāngata Whaiora

People that work in support of tāngata whaiora, also defined as 'community stakeholders' or 'ID service providers', are a diverse group that assist in the support of people with ID in various ways. Community stakeholders play a crucial role in the lives and wellbeing of people with ID. This group includes agencies and paid professionals who work in support of tāngata whaiora. Community stakeholders offer an assortment of support services from working with people with ID in supported living facilities, in private homes,

assisting with tasks of daily living, providing advocacy on behalf of tāngata whaiora, in allied health services, or in needs assessment and service coordination (NASC). Community stakeholders may also provide support for tāngata whaiora during hospitalisation.

Community Stakeholders Perspectives of Hospitalisation for Tāngata Whaiora

Community stakeholders are significant influencers in the promotion and facilitation of a good life for people with ID, enabling tāngata whaiora to have agency over their lives and wellbeing (Windley & Chapman, 2010). As it has been established that people with ID often experience less satisfaction within the hospital system (Iacono et al., 2014), the insights and expertise of community stakeholders are important as they can provide another perspective about the needs of tāngata whaiora during hospitalisation, and insights regarding how hospital systems might need to adjust.

Several studies have provided insights into the key issues for community stakeholders when supporting adults with ID in hospital (Appelgren et al., 2018; Dinsmore, 2012; Gibbs et al., 2008; Hemsley et al., 2011; Sowney & Barr, 2006; Tuffrey-Wijne et al., 2014; Webber et al., 2010). Key themes identified included a lack of knowledge or training about ID, negative attitudes about people with ID, communication barriers, inadequate care in hospital, and poor discharge and support.

Stakeholders Views on Knowledge of ID and Training of Hospital Staff

Intellectual disabilities are diverse, and people with ID often have complex and unique health profiles that may be misunderstood by hospital staff (Flood, 2017; Folch-Mas et al., 2017). This may be due to hospital staff having little or no prior experience supporting patients with ID, or due to a lack of specialised training about supporting people with ID (Appelgren et al., 2018; Sowney & Barr, 2006; Webber et al., 2010). A lack of skill or knowledge about ID has consequences for tāngata whaiora, whānau carers, hospital staff and care delivery.

Limited knowledge about ID can impact on healthcare professionals' clinical confidence. For example, to explore experiences of caring for people with ID, Sowney and Barr (2006) conducted a qualitative study involving focus group interviews with 27 Accident and Emergency (A&E) nurses in hospitals throughout Northern Ireland. Of the six themes which emerged, lack of knowledge and dependence on carers were identified as interrelated themes and were the focus of the study (Sowney & Barr, 2006). A perceived lack of knowledge discussed by participants was attributed to a lack of education or practice experience, and this was found to negatively affect confidence in caring for acutely ill

patients with ID (Sowney & Barr, 2006). In turn, a lack of confidence in nursing staffs' abilities to sufficiently support patients with ID was associated with feelings of vulnerability and fear (Sowney & Barr, 2006). Notably, these emotions were said to be a key component in nurses' over-reliance on a patient's caregiver. These findings indicate that education for nursing staff can equip nurses with the skills required to meet the needs of patients with ID. Better education for nurses may also reduce overburdening carers of patients with ID during hospitalisation (Iacono et al., 2014; Sowney & Barr, 2006).

Additionally, hospital care that is attentive to the needs of tāngata whaiora may decrease the prevalence of adverse events and avoidable harm that can impact longer hospital stays and readmissions, which have also been found to impact on increased workloads for hospital staff (Bartlett et al., 2008; Brown et al., 2016a; Davis et al., 2003; Flood, 2017; Hemsley et al., 2011). Appelgren and colleagues (2018) suggested that undergraduate and postgraduate education focusing on patient-centred care may reduce health inequalities for people with ID through quality healthcare provision. Nurses educated in the care of ID and employed in specialised nursing roles, such as the Intellectual Disability Liaison Nurse (IDLN) role, are already in situ across the UK. Studies show the IDLN role plays a pivotal part in the promotion of positive hospital experiences for hospital staff, carers and people with ID (Brown et al., 2012b; Castles et al., 2014).

Furthermore, training hospital staff about the unique needs of people with ID may lead to reductions in 'othering' of tāngata whaiora and lead to reduced stigma (Appelgren et al., 2018). Appelgren and colleagues (2018) suggested that when the person behind the ID is seen by hospital staff, this may impact the quality of care provided with the implication being greater satisfaction for people with ID through the receipt of individualised, person-centred care (Appelgren et al., 2018).

One way of achieving reduced stigma and quality care for people with ID has been proposed by Garland-Thomson (2017). The author suggests embedding disability cultural competence in healthcare settings and healthcare training environments. Garland-Thomson (2017) suggests the tools of competency would be obtained through leadership training and workplace development, presentations and exhibitions, expert patients, certification processes, speakers, and media products (Garland-Thomson, 2017). More broadly, Garland-Thomson (2017) argued that these tools would provide people with a skillset "...to navigate life and to implement the promises and obligations of egalitarian, democratic societies" (Garland-Thomson, 2017, p. 334) beyond the healthcare setting. Shifting broad societal attitudes about disabilities through education may lead to a reduction in ableist and

discriminatory perceptions of ID (Andrews et al., 2021; Bogart & Dunn, 2019). In turn, this may mean greater inclusion and equality for tāngata whaiora; a commitment made by Aotearoa's Government when the United Nations's CRPD was ratified in 2008 (United Nations, 2006).

Stakeholders Views About Hospital Staff's Attitudes Towards People with ID

The presence of negative or discriminatory attitudes towards people with ID can lead to exclusion and inequality in many areas of life (Emerson, 2021; O'Leary et al., 2016; McCormick et al., 2021; Ministry of Health, 2013). Negative attitudes towards people with ID have been found to exist within the healthcare system (Garland-Thomson, 2017; Gibbs et al., 2008; Lewis & Stenfer-Kroese, 2010). These negative views may result in subtle or overt forms of discrimination (Gibbs et al., 2008) which can impact on quality of care.

Lewis and Stenfer-Kroese (2010) study supports this, demonstrating that nursing staff reported significantly fewer positive attitudes and more negative emotions when caring for a patient with an ID compared to a patient with a physical disability. These attitudes were found to adversely impact on the care provided to people with ID and included a high inclination towards segregating patients with ID, avoidance of completing invasive procedures, an overreliance on carers for support with personal care, and less time explaining treatment plans to people with ID or asking if they were in pain (Lewis & Stenfer-Kroese, 2010). Additionally, Lewis and Stenfer-Kroese (2010) found that nurses felt their skills and training were insufficient to cater to the needs of people with ID. This highlights the importance of medical training and education which focuses on ID (Appelgren et al., 2018; Lewis & Stenfer-Kroese, 2010).

Furthermore, negative beliefs about people with ID can lead to discriminatory outcomes. This may occur through medical decision making that is based on skewed perceptions about the quality of a person's life, and ideas about their value as members of society (Bogart & Dunn, 2019; Chicoine et al., 2022; Gibbs et al., 2008). This notion is supported by evidence from a qualitative study by Webber and colleagues (2010) who documented instances where hospital staff questioned whether a treatment should be tried with an adult with ID, which was interpreted as hospital staff seeing people with ID as less worthy of treatment (Webber et al., 2010). Further to this, a participant in Gibbs and colleagues (2008) focus group study shared that a doctor had questioned whether it was worth operating on her son's eyes as he had a severe ID, which consequently led to a more complicated surgery later in life (Gibbs et al., 2008). These findings emphasise how negative

attitudes towards people with ID contribute to the inequities tāngata whaiora experience when accessing healthcare.

Stakeholder Perceptions of Communication Barriers

Communication barriers affecting healthcare for people with ID are a prominent theme within the literature, impacting on the hospital experience for tāngata whaiora and the people who support them (Ali et al., 2013; Appelgren et al., 2018; Bourne et al., 2021; Drozd et al., 2020; Hemsley et al., 2011; Iacono et al., 2014; McCormick et al., 2021; Phillips, 2019; Shady et al., 2022; Webber et al., 2010).

The inability to communicate with hospital staff can increase fear and anxiety for people with ID (Iacono et al., 2013), make people with ID feel invisible and disrespected (McCormick et al., 2021), can contribute to delays in diagnosis and treatment through insufficient information gathering, and lead to hospital staff avoiding people with ID due to the challenges of communication (Drozd et al., 2020; Phillips, 2019). Such barriers to communication have been found to contribute to adverse events occurring, such as the mismanagement of medications (Flood, 2017). When there is a lack of communication between hospital staff and support people, it can lead to insufficient information about medication side effects, correct dosages and how long medications should be administered for (Ali et al., 2013). Additionally, barriers to communication can lead to an overreliance on service providers to act as an interpreter and an advocate (Ali et al., 2013). When tools are available to ensure sufficient communication with patients with ID, hospital staff may be in a stronger position to obtain the information they need to provide appropriate care, and this may in turn reduce reliance on carers (Sowney & Barr, 2006).

Furthermore, communication barriers with people with ID can lead healthcare staff to make assumptions about a patient's level of capability (Smeltzer et al, 2012). This can undermine the autonomy of people with ID. Gibbs and colleagues (2008) found that when hospital staff underestimated a person's capabilities this led to hospital staff doing too much for patients, which carers argued could put tāngata whaiora at risk of losing some skills during their hospital stay (Gibbs et al., 2008). Conversely, Webber and colleagues (2010) found that hospital staff who did not accommodate the needs of patients with ID were perceived as having an indifferent attitude towards those patients. This accentuates the need for hospital staff to be aware of a person's level of functioning by communicating with the person with ID, with their carers, or by reading information provided in patient profiles to ascertain the level of support needed in hospital.

Stakeholders Perceptions of Adequate Care in Hospital

The insufficient provision of basic nursing care for people with ID has been highlighted as an issue in the existing literature by people with ID, their carers and community stakeholders (Tuffrey-Wijne et al., 2014). This may include under-monitoring of a patient and of comfort and distress, not turning a patient enough to avoid pressure areas, insufficient information about eating and drinking routines, or the avoidance of assistance with showering and toileting (Tuffrey-Wijne et al., 2014). Tuffrey-Wijne and colleagues (2014) suggested that insufficient knowledge about ID, avoidance due to perceptions of additional workloads, and an overreliance on carers contribute to these gaps in basic care. The outcome of such omissions may be deteriorated health status or longer stays in hospital.

Additionally, a previous study found that for nurses, the communication of pain and the ability to identify pain in patients with ID is paramount (Hemsley et al., 2011). Insufficient knowledge or aids to assist communication with tāngata whaiora may impact on the timely provision of pain management and comfort in hospital (Hemsley et al., 2011). Using a combination of clinical skills and pain scales suitable to the severity of the ID can help nurses identify a patient's level of pain (Hemsley et al., 2011), but this requires sufficient training and access to communication tools, which not all hospital staff have.

The inability to communicate with people with ID can lead to issues related to hygiene, hunger and thirst (Hemsley et al., 2011). Past research has indicated that when patients with ID cannot sufficiently express their needs or wants, this may lead to agitation or aggressive behaviour, which in turn leads to avoidance by hospital staff (Hemsley et al., 2011). Moreover, the inability to express the need for assistance with menus and meals can lead to people with ID missing meals (Webber et al., 2010). For longer term hospital stays the implication of this may be a deteriorated state of health for tāngata whaiora (Hemsley et al., 2011).

As previously mentioned, studies have found that hospital staff lack of confidence in their ability to support tāngata whaiora due to insufficient knowledge about how to communicate with people with ID (Appelgren et al., 2018; Bell, 2012). There is evidence from past research that communication with patients with ID significantly improved with increased staff training (Shady et al., 2022). A study found that hospital staff who were provided communication tools that utilised the most effective communication method for individuals had a twofold effect. Firstly, effective communication reduced distress in people with ID, which is important as distress can impact on a person's ability to verbally communicate (Shady et al., 2022). Secondly, where healthcare professionals provided

communication assistance, this was said to empower patients and reduce feelings of vulnerability in hospital (Shady et al., 2022).

Discharge Planning

People with ID may live in residential facilities in the community that may or may not include support staff with medical training (Webber et al., 2010). The literature indicates that hospitals may lack an understanding of the level of care that community stakeholders can provide for people recently discharged from hospital (Webber et al., 2010). In one study, group home support staff reported pressure to take residents home despite the facility being unable to provide appropriate and round-the-clock care (Webber and colleagues (2010). Furthermore, community stakeholders described difficulties in gaining the information necessary to provide safe care post-discharge (Webber et al., 2010). This may place an extra burden on community stakeholders and contribute to unsafe care and adverse health outcomes for tāngata whaiora.

The importance of having a person in the role of disability support within the hospital system has been highlighted in several studies (Brown et al., 2012b. Castles et al., 2014). Specialised disability nursing roles such as the Learning Disability Liaison Nurse (LDLN) role offer expertise and support to patients with ID (Brown et al., 2016a). The role comprises the management and administration of person-centered care, liaison work and education, advocacy and mediation between patient, treating teams and whānau or community stakeholders, communication adjusted to the patient's capacity, leading to the promotion of patient autonomy (Bur et al., 2021). Furthermore, this role is said to promote and facilitate effective coordination of care in acute healthcare through reasonable adjustments via the development of policy and procedures (Bur et al, 2021). In addition, disability nurse specialists have been found to effectively link people with ID to specialist ID services, while facilitating the discharge planning process and transfer from hospital and ensuring continuity of care in the community (Brown et al., 2016a; Bur et al., 2021; Castles et al., 2014).

Including the Voices of Tāngata Whaiora in Research

The voices of adults with ID have largely been missing from health research. Historically, people with ID have had limited opportunities to participate in research about topics of which they have direct experience (Drozd et al., 2021; McDonald et al., 2013). This may be related to well-intentioned yet prohibitive ethics approval processes seeking to protect vulnerable people from exploitation or harm in research (Iacono, 2006). Past research

suggests that the inclusion of tāngata whaiora on ethics committees, or people who can represent and advocate for tāngata whaiora may be one way to promote greater inclusion in research (Iacono, 2006).

Additionally, the missing voices of tāngata whaiora may also be due to assumptions about the abilities of people with ID to meaningfully engage or consent to be in the research (Drozd et al., 2021). Iacono (2006) posits that self-determination for tāngata whaiora can be achieved through the practice of obtaining consent to participate in research via the supported decision-making process (Iacono, 2006). This process is said to allow people with ID to canvas the opinions of significant support people, who can in turn outline risks and benefits of research participation in communicable ways, such as plain English or through visual aids (Iacono, 2006). However, gate keeping may still be problematic given the influential role carers play in the life of people with ID. Engaging tāngata whaiora in research is both respectful and vital for addressing inequalities and inequities in health outcomes experienced by people with ID (McDonald et al., 2013).

Existing Literature on the Experiences of Hospitalisation for People with ID

An understanding of the conditions which make hospitalisation either more challenging or easier for people with ID is important for improving health outcomes. Although considerable research has been conducted on the disparities and health outcomes of people with ID, there is a dearth of research that focuses on the voices of tāngata whaiora and their experiences of hospitalisation in Aotearoa. Thus, international literature must be drawn on. A search of the literature identified two systematic reviews and one integrative review which have provided a thorough overview of the experiences of hospitalisation for people with ID. The work of Iacono and colleagues (2014), McCormick and associates (2021), and Drozd and colleagues (2020) form the foundation of this section of the literature review.

Iacono and colleagues (2014) systematic review findings outlined the factors affecting hospital experiences of people with ID. Studies included in their review comprised of past research whose participants included adults with an ID using the hospital system, the views of whānau and paid carers, and the views of hospital staff and primary care professionals providing care for people with ID in hospital settings (Iacono et al., 2014). Iacono and colleagues (2014) study revealed seven overarching themes which included fear of the hospital encounter by people with ID, failure of hospital staff to provide care, hospital staff knowledge and skills, poor or negative attitudes by hospital staff towards people with

ID, staff or system failing to adjust to the needs of people with ID, carer responsibility, and enhancers to appropriate hospital care (Iacono et al., 2014).

Building on Iacono and associates (2014) work, a systematic review of the literature by McCormick and colleagues (2021) focused on international evidence relating to the experiences of adults with ID accessing acute hospital services from 2014 onwards. A benefit of McCormick and colleagues (2021) review was the inclusion criteria, which were limited to adults with intellectual disabilities aged 18 years and above in acute hospital settings. McCormick and associates (2021) findings were consistent with those from Iacono and associates (2014) study, except for the omission of the theme relating to what works to improve the hospital experience for people with ID, identified by Iacono and associates (2014) as 'enhancers to appropriate care'. Three overarching themes from this study included communication, information sharing and compassion and respect (McCormick et al., 2021).

Drozd and colleagues (2020) offered an integrative review of the hospital experiences of people with an intellectual disability, with a specific focus on orthopaedic and trauma hospital experiences. All studies in this review included participants aged 18 years old and over who had ID. The review spanned thirteen years of research, from 2007 through to 2020 (Drozd et al., 2020). From the integrative review (Drozd et al., 2020) four overarching themes emerged; communication issues in hospital, unsafe care, poor relationships with people with ID in hospital, and shoots of person-centred hospital experiences for people with ID (Drozd et al., 2020).

The systematic and integrative literature reviews reviewed have provided a useful summary of the findings from past individual studies on the experience of hospital for people with ID. Themes identified from the work of Iacono and colleagues (2014), McCormick and associates (2021), Drozd and co-authors (2020) and a range of other studies have been explored in the following sections.

The Hospitalisation Experiences of People with ID

Fear of the Hospital Environment

Being in hospital can be overwhelming for people with ID (Phillips, 2019). This may be due to the unfamiliar environment, unfamiliar people, fears associated with pain, or anxieties related to not understanding the situation or the treatment they require (Iacono et al., 2014). Additionally, general fear of doctors, nurses and medical procedures associated

with being in hospital have been noted as prevalent in the reviewed literature (Gibbs et al., 2008; Iacono et al., 2014; McCormick et al., 2021).

Furthermore, inadequate information about diagnoses, procedures or medication regimes (including potential medication side effects) were said to contribute to patients feeling scared (Ali et al., 2013). The literature also identified people with ID feeling pressured to undergo treatment without sufficient information being provided in an effective way (Ali et al., 2013). This shows that fear and anxiety is exacerbated by ambiguous or inadequate communication and systems failing to adequately engage in the informed consent process.

Additionally, abrupt communication between hospital staff and people with ID was found to incite feelings of discomfort and anxiety for some people with ID (Drozd et al., 2020; McCormick et al., 2021). A notable finding from Gibbs et al. (2008) was that several participants with ID felt angry and upset about past hospital experiences, which led to some participants avoiding further health visits. Ensuring a positive hospital experience for people with ID is therefore necessary to promote ongoing proactive involvement in their health and wellbeing (Gibbs et al., 2008).

The support of familiar people such as whānau or paid carers, or the provision of compassionate and individualised care have been found to alleviate fear of the hospital in past studies (Gibbs et al., 2008; Iacono et al., 2014; McCormick et al., 2021). In addition to this, Gibbs and colleagues (2008) found that people with ID experienced reduced anxiety when they knew what to expect from past experiences, or through adequate preparation and explanation before being in hospital.

Communication and Information Sharing in Hospitals

People with ID may experience communication impairments, including the absence of speech, which can have a direct impact on their quality of life (Garcia et al., 2020). Much like people experiencing aphasias or speech impairments due to stroke or head injury, support with being heard and understood is necessary for many people with ID (Garcia et al., 2020). Multiple studies have identified poor communication and information sharing as an issue of significance for tāngata whaiora (Ali et al., 2013; Brown et al., 2016; Iacono et al., 2014; McCormick et al., 2021; Smeltzer et al., 2012). When communication barriers occur for people with ID in the hospital system, this can have significant consequences for their wellbeing.

The inability for tāngata whaiora to communicate with hospital staff may lead to unidentified or untreated pain. Hemsley and colleagues (2011) found that some people with ID who express pain may not be understood or may not have their pain taken seriously. This may also create challenges in the safe positioning of people with ID that impacts feelings of being unsafe (Hemsley et al., 2011). Additionally, tāngata whaiora may exhibit challenging behaviours when unable to communicate their pain or distress sufficiently (Hemsley et al., 2011). This may lead to hospital staff holding unfavourable views about those patients, avoidance of care or the use of restraints (Nijs et al., 2022; Shady et al., 2022).

Studies have shown that communication avoidance was perceived by people with ID as hospital staff displaying a lack of caring and understanding about the importance of their specific needs (Drozd et al., 2020; McCormick et al., 2021; Smeltzer et al., 2012). This relates to issues of compassion and respect (McCormick et al., 2021), and the need for hospital staff to be aware that some adults with ID require individualised support and adaptations to enable them to fully participate in their hospital experience (McCormick et al., 2021). Example of adaptions to communication that work to support people with ID include using simple language for easier comprehension of information, slowing down when talking, asking fewer questions, providing sufficient but not overwhelming amounts information and allowing time for tāngata whaiora to respond (Ali et al., 2013; Drozd et al., 2020; Howieson, 2015; McCormick et al., 2021, Read et al., 2018).

For some, avoidance of communication was manifested as healthcare staff preferring to communicate directly with whānau and carers (Ali et al., 2013; Gibbs et al., 2008; Iacono et al., 2014; McCormick et al., 2021). In contrast to this, Iacono and associates (2014) found a lack of communication by hospital staff was extended to whānau or carers. Some carers reported elevated levels of frustration when they felt that they were not being heard by hospital staff (Charles, 2020). An additional effect of insufficient information sharing between the health system and carers can lead to carers feeling obligated to be present at all important appointments, adding pressure to their role (Ali et al., 2013).

In some studies, communication issues were viewed as the result of discriminatory or negative attitudes by hospital staff towards people with ID (Drozd et al., 2020; Iacono et al., 2014), interlinked with another prevalent theme relating to negative attitudes towards tāngata whaiora. Perceptions of discrimination through negative interactions with healthcare professionals were also found to lead some tāngata whaiora to feel an unwillingness to disclose ID to future healthcare providers (Shady et al., 2022). Ultimately this may maintain health inequities as the needs of people with ID continue to be overlooked and unmet.

Staff or System Failure to Adjust to the Needs of People with ID

An important component of compassionate person-centred care for people with ID is ensuring that they have access to appropriate health service through the provision of reasonable adjustments (Drozd et al., 2020; Read et al., 2018). Reasonable adjustments can include changes to the physical environment through the provision of accessible spaces. Reasonable adjustments also include changes to existing processes such as changing the location, length or time of admission and discharge for people with ID, or providing information in accessible formats (Read et al., 2018).

A lack of reasonable adjustments in the hospital system can lead to delays in treatment and failures of care for tāngata whaiora (Flood, 2017). Several studies identified failures to adjust to the needs of people with ID, and this was interwoven with perceptions that hospital staff lacked understanding of tāngata whaiora needs in hospital (McCormick et al., 2021). Long wait times in waiting rooms, failures in the provision of assistance required for people with ID to eat or go to the toilet (McCormick et al., 2021), failures to consider differences in a person's medicine regimes between home and hospital, and an inability to adapt communication styles to meet the persons needs are signs of staff or the hospital systems failure to reasonably adjust to the needs of tāngata whaiora (Iacono et al., 2014; McCormick et al., 2021).

Making reasonable adjustments to the hospital system can improve the experience of hospitalisation for both tāngata whaiora and the service providers who support them (Bell, 2012; Iacono et al., 2014; McCormick et al., 2021; Tuffrey-Wijne et al., 2014). As an example, the correct use of hospital passports allowed one hospital to identify a patient's unique communication needs, which led to the hospital system adjusting its communication by implementing the use of visual aids to facilitate the hospital experience for that patient (McCormick et al., 2021). Furthermore, having someone who understands the need for individualised support for tāngata whaiora and who can facilitate changes, such as a specialist disability nurse, has been indicated as an important factor in creating positive hospital experiences for people with ID (Iacono et al., 2014; McCormick et al, 2021).

Failure of Hospital Staff to Provide Care

Iacono and co-authors (2014) identified several areas of concern regarding the provision of care by hospital staff. One reason for the insufficient provision of health care is said to be caused by diagnostic overshadowing, where presenting symptoms of mental or physical illness are incorrectly attributed to a person's intellectual disability (Ali & Hassiotis,

2008). For people with ID, diagnostic overshadowing has been associated with barriers to receiving appropriate investigations, screening, and treatment, and it is also attributable to avoidable premature death for people with ID (Ali & Hassiotis, 2008; Ali et al., 2013; Iacono et al., 2014). Diagnostic overshadowing can lead to d**e**lays in treatment, which can have significant ramifications for health and wellbeing. (Ali et al., 2013; Flood, 2017). Tāngata whaiora can experience difficulties communicating pain or distress to hospital staff, or may not have their pain taken seriously (Garcia et al., 2020), thus increasing the risk of delays in receiving timely and effective medical care (Hemsley et al., 2011).

People with ID have been found to be susceptible to late diagnosis and delays in receiving timely healthcare (Yamamoto et al., 2022) which can also be linked to diagnostic overshadowing. Additionally, a population-based study conducted in Taiwan found that the risk of overall complications after major surgery increased for patients with ID and was correlated with a patient's disability severity (Lin et al., 2011). These complications included acute renal failure, pneumonia, septicaemia, and postoperative bleeding (Lin et al., 2011).

Managing pain and distress for people with ID can be challenging for hospital staff (Regnard et al., 2007). Considering that communication barriers pose a problem for some people with ID who cannot verbalise when they feel pain or distress, as well as evidence that hospital staff are not always proficient in identifying distress or pain in people with ID (Doody & Bailey, 2017), delays in diagnosis and treatment that lead to worsening health or invasive surgical procedures are especially serious issues. Verbal pain scales may not be appropriate for use with all tāngata whaiora and may need to be adapted.

Knowledge and Skills of Hospital Staff

A lack of knowledge about how to appropriately care for tāngata whaiora can have dire consequences including death (Sowney & Barr, 2006). The consequences of lack of knowledge can be hospital staff avoiding people with ID, delays to diagnosis and treatment, pain management, inattention to patients needs around meals and basic hygiene, and poor communication and information sharing that contributes to feelings of anxiety for people with ID (McCormick et al., 2021).

Smeltzer and colleagues (2012) conducted focus groups with 35 people with disabilities to explore their experiences with nursing staff during hospitalisation. Participants reported that nursing staff lacked knowledge of specific disabilities and appeared disinterested in learning about them (Smeltzer et al., 2012). Participants in Smeltzer and colleagues (2012) study also perceived some nursing staff as dismissive of their lived

experiences of having a disability, which was linked to a lack of compassion, understanding and respect. A limitation of this study related to the current study is that of the 35 participants, some had a physical disability, while some had a cognitive disability, and others had both physical and cognitive disabilities. While this research explains the prohibitive conditions people with broad disabilities may face in the hospital system, it is not clear whether the issues outlined were applicable to participants with an ID, or to those with physical impairments only. As such, it is unknown whether these findings contribute to understanding the barriers people with ID face specifically.

Medication Management, Patient Safety and Avoidable Harm

Tāngata whaiora often have overlapping health conditions (Ailey et al., 2014; Ali et al., 2013; Brown et al., 2016a; Hosking et al., 2016; McCarthy & Duff, 2019; Skorpen et al., 2016) and a higher prevalence of mental illness than the general population (Hughes-McCormack et al., 2017). Flood (2017) argues that the unique health profile of many people with ID is well known in specialist services but may be less known in primary or secondary healthcare settings leaving a gap in the understanding of needs and how to work with people with ID in non-ID specialist hospital settings. In the literature, a lack of information or understanding about underlying conditions has been connected to tāngata whaiora concerns about hospital staff skills and knowledge (Smeltzer et al., 2012).

Comorbidities can mean managing multiple prescription medications for people with ID (Flood et al., 2017; Hughes-McCormack et al., 2017). Their health may be further compromised by side effects and drug interactions (Flood, 2017). Medication mismanagement can put tāngata whaiora at risk of avoidable harm in hospital (Flood, 2017), connecting back a need for hospital staff to have the knowledge and skills to support tāngata whaiora needs sufficiently. It is argued that medications should be thoroughly accounted for during the admission and discharge process, with this seen as especially important for multiple medication users (Flood, 2017).

Furthermore, the literature suggests that reasonable adjustments related to pharmaceutical care and pharmacy services should include alterations to the built environment through accessible buildings, easy to read information about medications, training for hospital staff to communicate effectively with patients about their treatments and medications, as well as support for people with ID in meetings with personnel overseeing medication management (Flood, 2017). These adjustments can contribute to more equitable healthcare and a safer environment for people with ID.

Negative Attitudes and Stigmatisation

Poor attitudes by hospital staff towards people with ID is a recurring theme in the literature (Bacherini et al., 2021; Drozd et al., 2020; Iacono et al., 2014; Pelleboer-Grunnick et al., 2017; Smeltzer et al., 2012). It has been theorised that non-disabled people may have negative implicit or explicit attitudes about people with disabilities which affect the quality and nature of communication between non-disabled and disabled people (Bogart & Dunn, 2019). In turn, this can reinforce negative perceptions of disability and may lead to the acceptance of inequitable treatment of people with disabilities, as they may be perceived as less deserving than non-disabled people (Bogart & Dunn, 2019). Unfamiliarity of people with ID was found to be a considerable factor in maintaining stigmatising attitudes in healthcare environments (Bogart & Dunn, 2019; Pelleboer-Gunnink et al., 2017).

In a systematic review, Pelleboer-Gunnink and colleagues (2017) found that stigmatising attitudes prevalent in some healthcare professionals created barriers to accessing sufficient healthcare for people with ID. Similarly, Bacherini and associates (2021) found that doctors stigmatising attitudes towards people with ID impacted upon access to healthcare as well as the quality of care received. Assumptions that people with ID would be less cooperative, easily distressed, more likely to exhibit challenging behaviours, and likely to have complex health issues that placed a burden on health professionals' time were found to lead to the avoidance of some treatments being offered, and a sample of health professionals acknowledging they would prefer to avoid working with people with ID (Bacherini et al., 2021; Pelleboer-Gunnink et al., 2017).

Additionally, discriminatory attitudes in healthcare may lead to people with ID being denied procedures or treatments. This was evidenced during the COVID-19 pandemic when patients with disabilities were excluded from receiving critical care in hospitals during times of resource scarcity (Andrews et al., 2021; Chicoine et al., 2022; Ne'eman et al., 2021). Another way that negative and stigmatising attitudes of hospital staff contributes to healthcare barriers can be related to a reluctance to communicate with tāngata whaiora, resulting in delays to diagnosis and treatment which may worsen tāngata whaiora health and increase the risk of avoidable death (Ali & Hassiotis, 2008; Flood, 2017; Iacono et al., 2014). A reluctance by health professionals to modify communication was found to contribute to difficulties in assessment and treatment of people with ID (Bourne et al., 2021).

Negative attitudes toward people with ID may lead to indifference toward patients or their carers by hospital staff (Iacono et al., 2014). This indifference was evidenced by Smeltzer and colleagues (2012) whose findings showed that nursing staff sometimes

assumed the role of expert over a person with ID and showed disinterest in learning about disabilities (Smeltzer et al., 2012). Participants reported feeling that nurses ignored the knowledge people with ID attempted to provide about their conditions or needs, and in some instances, avoided tāngata whaiora or exhibited dehumanising and abusive behaviour such as removing dinner trays before a person had finished eating (Smeltzer et al., 20120. When hospital staff dismiss the expertise of people with ID, or make assumptions that overlook an individual's needs, such as assistance with bathing, eating or toileting (Smeltzer et al., 2012), this may lead to compromised care through failures in assessing and addressing the health needs of tāngata whaiora (Smeltzer et al., 2012).

A search of the available literature showed that while health professionals exhibit a preference to communicate with caregivers over people with ID (Iacono et al., 2014), negative attitudes about people with ID may also be transferred to their families or caregivers (Charles, 2020; Iacono et al., 2014). Flood (2017) argued that hospital staff do not always understand the pivotal role of carers and the importance of carer expertise (Ali et al., 2013). Caregivers often have intimate knowledge of the person they care for, with unique skills that help facilitate communication as well as identification of any signs of distress (Ali et al., 2013). Carers can play a crucial role in the management of health and medication adherence (Charles, 2020), and their involvement may improve outcomes for the person with ID (Flood, 2017). As such, dismissal of carer expertise may increase the risk of compromised patient care.

The Role of Carers

Whānau carers and key support people play critically important roles in the care and support of tāngata whaiora, yet healthcare professionals have been perceived as dismissive of carer expertise (Ali et al., 2013). Conversely, the literature also reveals an overreliance on carers and support people by hospital staff (Ali et al., 2013). This is said to place an undue burden on a carers time (Ali et al., 2013). The neglect of basic needs in hospital wards was highlighted in the findings of Ali and colleagues (2013) research. Carers identified concerns about staff not responding to requests for support with toileting, which in one example had long-term implications for a person's continence (Ali et al., 2013). Carers also perceived such instances as discriminatory (Ali et al., 2013). Feelings of discrimination were linked to a lack of respect and dignity for people with ID and their carers (Ali et al., 2013). Participants in Ali and colleagues (2013) study also reported reluctance to return to hospital or engage with GP services and refusal to attend future medical appointments due to

discriminatory and unsatisfactory healthcare experiences (Ali et al., 2013). The effects of failures in the provision of sufficient hospital care and future avoidance in seeking necessary treatment may contribute to preventable deterioration and avoidable death in tāngata whaiora, further contributing to health inequities for people with ID (Brown et al., 2016a; Hemsley et al., 2011; Sowney & Barr, 2006; Tuffrey-Wijne et al., 2014). Caregiver perspectives on the hospitalisation experiences of people with ID are a crucial element in better understanding the needs of tāngata whaiora. However, it is beyond the scope of this project and has been discussed as separate part of this project exploring the caregiver experiences of supporting tāngata whaiora during hospitalisation.

Enhancing the Hospital Experience

To ascertain whether their needs were being accommodated by health services, Ali and colleagues (2013) examined the perspectives of people with mild to moderate ID and their carers. This study was conducted in patient-carer dyads. A strength of Ali and colleagues (2013) study was the inclusion of participants ideas and examples of good practice for supporting the needs of tāngata whaiora. Examples of good practice included staff going the extra mile to accommodate a patient's needs, good communication skills, approachable and friendly staff that made both carer and patient feel respected and flexible and accommodating health systems that worked with the patient's needs (Ali et al., 2013). Furthermore, participants in Ali and colleagues (2013) research felt that improvements to the care of people with ID could include accessible, easy to read information, or the provision of a health passport or communication book. These aids were also suggested to efficiently communicate changes to a person's treatment plan (Ali et al., 2013).

More recently in the literature Phillips (2019) discussed reasonable adjustments in hospitals for people with learning disabilities. Like Ali and colleagues (2013), the author argued that good practice is associated with accommodating, respectful and compassionate health workers, effective communication skills, accessible information sharing, the smooth transition of care to other health providers, and flexibility in the health system's protocols around appointment times (Phillips, 2019).

Conclusion

This literature review synthesises past research providing an understanding of the challenges prevalent for people with ID when hospitalised. An exploration of previous literature makes clear the issues that persist within the hospital system, and which make access to equitable healthcare for people with ID more challenging. Whether the experiences

of hospitalisation for tāngata whaiora are similar in Aotearoa to those in the international literature reviewed is unclear. This study aims to add to understanding community stakeholder and tāngata whaiora perceptions of hospitalisation, the issues which may negatively impact hospital experiences, and the systems or approaches which make the experience more positive for adults with ID in the context of Aotearoa.

CHAPTER THREE: RESEARCH DESIGN

Methodology

As the purpose of this research was to gain insight into the lived experiences of tāngata whaiora with ID and community stakeholders who support tāngata whaiora during hospitalisation, a qualitative research approach was chosen. The selection of the qualitative approach for the research methodology has been informed by international research in this space, and the clinical and theoretical knowledge of the senior researchers and clinicians involved in this project (Dr Liesje Donkin and Dr Marleen Verhoeven).

Qualitative research is described as a useful methodology for obtaining an in-depth understanding of the experiences and perspectives unique to a sample population (Braun & Clarke, 2013). Beail and Williams (2014) have stated that qualitative methods may help bring the unknown about people with ID into the known, playing a valuable role in informing research that centres itself on the lived experiences of people with ID (Beail & Williams, 2014). This method is considered a suitable vehicle for asking questions that explore what an experience of hospitalisation was like for a person, or questions about peoples' views on health services (Beail & Williams, 2014). Thus, making it a good fit for the research question: What are the experiences of hospitalisation for people with intellectual disability and the community stakeholders who support them?

Guided by the need to explore the hospitalisation experiences of people with ID and the perspectives of community stakeholders, an interpretative description methodology was chosen as most suited to answering the study's research question. Epistemologically, interpretative description was born out of research related to the discipline of nursing and has since been used by many other health disciplines such as the medical sciences, occupational therapy and psychology (Hunt, 2009). Interpretative descriptive methodology is aligned with a naturalistic and constructivist orientation to inquiry (Hunt, 2009), and ontologically aligned with relativism which states that reality is subjective and varies from person to person (Hunt, 2009). Epistemologically, interpretative description is positioned within contextualism which believes that a person's words reflect their reality (Thorne, 2016).

As a methodological approach, interpretative description is considered an appropriate choice when a study aims to capture the subjective experience of a population (Thompson et al., 2020). Moreover, interpretative descriptive methodology is suited to research aiming to address complex experiential questions in which the knowledge acquired

intends to inform the practice of health disciplines (Hunt, 2009; Thompson Burdine et al., 2021). To develop this knowledge, the analysis process requires a level of interpretation that reaches beyond a basic description of the data, to one that involves inductive reasoning, the recognition of patterns, and the logical linking of concepts (Snow et al., 2022).

Participant Recruitment

Sampling

Participants were recruited into this study by email invitation, snowballing recruitment, researcher's networks, and through community groups that support people with ID. Snowball recruitment is a popular recruitment technique used in qualitative research, in which research participants assist researchers in identifying other potential participants (Heckathorn, 2011). Participants who agree are asked to recommend other contacts who fit the research criteria and who may also be willing participants. In turn, newly identified participants recommend other potential participants (Hecakthorn, 2011). Researchers may draw from their own networks to establish initial participants, with momentum developing until a sufficient number of participants have been recruited (Heckathorn, 2011). Snowball recruitment has been an established method for recruiting participants from hard-to-reach populations and may be especially useful when the researcher does not have strong links into the research population (Harding, 2021)

A problem with using a snowball sample strategy can occur when the snowball fails to gather pace. This may be caused by a lack of recommendations from participants who initially agreed to recruit, or due to a lack of interest in participating (Heckathorn, 2011).

As the aim of the study was to gain an in-depth understanding of how adults with ID experience hospitalisation, snowballing sampling of adults with ID was considered a useful strategy to identify people who would be eligible to participate in the study. For tāngata whaiora to be included in this study, potential participants were required to be aged 18 years or older with an intellectual disability (typically defined as a full-scale IQ (Intelligence Quotient) score of 70 and below). There were no exclusion criteria as such, but potential participants needed to be able to demonstrate an understanding of the purpose of the study and were required to be able to consent to be interviewed. Criteria also included having a caregiver that was able to attend the interview with them, that tāngata whaiora had sufficient English reading and writing skills to read the Participant Information Sheet (PIS) (Appendix A) and to complete the informed consent process (Appendix B). Tāngata whaiora were required to have the ability to read and write English sufficiently to complete the online

survey if they chose to participate in this way (Appendix C). Inclusion criteria for tāngata whaiora included the ability to engage in conversational English to participate in an interview, and access to the technology required to undertake a teleconference interview if they chose to patriciate in an interview.

As the study aimed to gain an in-depth understanding of how community stakeholders who work in support of tāngata whaiora view their experience of hospitalisation, snowball sampling was chosen for the recruitment of community stakeholder participants as well. For the community stakeholder participants, inclusion criteria consisted of working in a role that supported people with ID in the community. These participants needed to be able to read and write English sufficiently to read the participant information sheet (PIS) (Appendix D) and complete the informed consent process (Appendix E). Written English needed to be sufficient to complete the online survey (Appendix F) if they chose that as their option to participate in the study. Community stakeholders were required to have conversational English skills to participate in interviews if they chose to be interviewed. Finally, community stakeholder participants were required to have access to technology required for a teleconference interview if they wished to participate in an interview.

Recruitment Process

As the study aimed to be accessible to as many people as possible, interviews were offered by Zoom interview as well as focus group interviews on-site, encouraging participation from all regions across Aotearoa. To enable people who did not have time to participate in an interview or did not want to be interviewed, participants were able to complete an online anonymous survey instead (Appendix C and Appendix F).

Recruitment of participants commenced once ethics approval (Appendix G) was obtained on the 21st of July 2022. The recruitment period began on the 22nd of July and was initially scheduled to conclude on the 30th of October 2022. However, due to difficulties with recruitment of both tāngata whaiora and community stakeholders, the recruitment process continued until the 9th of November 2022.

Participants were recruited into this study by email invitation (Appendix H) through the lead researcher's networks and through emails to agencies identified via internet search**.** Other methods of recruitment included social media posts (Appendix I) placed on the social media pages of community stakeholder agencies.

Tāngata whaiora were invited to be interviewed with the support of a caregiver or support person, or by completing an anonymous online survey (Appendix C). Similarly, community stakeholders were invited to be interviewed online, or by completing an online anonymous survey (Appendix F). Additionally, both tāngata whaiora and community

stakeholders were invited to participate in person, via focus group interviews (Appendix J). For both participant groups, the anonymous Qualtrics surveys were open to as many participants who wished to complete the survey without limits.

Rather than providing pre-determined response options for participants to select, the qualitative surveys used open text boxes that encouraged participants to respond by typing responses in their own words. This format may produce rich and complex accounts of a participants' subjective experience, allowing the researcher to capture data that is meaningful to the participant, including their terminology or style of language (Braun et al., 2021).

Participants

Five adults with ID were recruited into this study. Four Qualtrics survey responses from tāngata whaiora were received, but two were omitted due to incomplete information. Nine community stakeholders were recruited in to this study. Additionally, five community stakeholder Qualtrics survey responses were received. The demographic information for the participants who participated in the study are provided in Chapter Four.

Method of Data Collection for Interviews

Tāngata whaiora and community stakeholder participants who were recruited into the study were given the option of participating in an online or face-to-face semi-structured interview. A support person or caregiver was invited to attend alongside tāngata whaiora participants. The online format was considered a good option to reduce barriers to participation. Participants from both groups could also participate via an online anonymous Qualtrics survey. Once an ethics amendment was obtained on the 3rd of October 2022 (Appendix K), community stakeholders contacted from the 4th of October 2022 were given the opportunity to participate in focus group interviews at their premises (Appendix J).

Participants who indicated an interest in completing an interview were contacted by a researcher within two days of signaling their interest to participate. The lead researcher (Liesje Donkin) was the primary point of contact for participants who wished to discuss the study, where participants' understanding of the study was rechecked, along with their consent to participate and their study eligibility. The researcher then contacted the participant to arrange to conduct an interview via Zoom at a time that was suitable for the participant.

A semi-structured interview question format was chosen to allow open-ended responses from participants for the purpose of obtaining more in-depth information than a structured interview format might allow. Using a semi-structured interview format also allowed for flexibility to ask other relevant questions and provide space for the participant to make additional comments. Once the interview was complete, the interviewer transcribed the interview verbatim, removing identifiable information from the transcript.

A recorded consent to participate (Appendix L) was obtained from both tāngata whaiora and their support person. This included rechecking their understanding about the researcher recording the interview for transcription, and the protection of confidentiality of the participants' identity.

The interview included five semi-structured questions about tāngata whaiora experiences of hospitalisation.

1. Can you tell me about the last time you were in hospital and what that was like for you?
2. What were the hardest bits of being in the hospital for you?
3. What were the things that helped you when you were last in hospital?
4. Are there any things you think could help make your next experience in hospital better or easier for you?
5. Are there any other comments or thoughts you would like to share with us?

For the community stakeholder participants, five semi-structured questions were asked which enquired about their views on the experience of hospital stays for tāngata whaiora.

1. Can you please tell me about your views on how people with intellectual disabilities experience being hospitalised.
2. What are the biggest challenges with being in hospital for people with intellectual disabilities?
3. What are the things that make being in hospital easier for people with intellectual disabilities – both for the person with the disability and for their caregiver/support people or treating team?
4. How do systems need to change to better support people with intellectual disabilities when they are hospitalised?
5. Are there any other comments you would like to make?

Online Qualtrics Survey Design

The study was part of a three-part project that included the recruitment of three distinct groups of participants; adults with ID (tāngata whaiora), caregivers of tāngata whaiora, and community stakeholders who work in support of tāngata whaiora. Initially, the researcher was responsible for completing the tāngata whaiora aspect of this study, but later pivoted to include the community stakeholder perspective as well. This was due to difficulties in the recruitment of tāngata whaiora participants and allowed these experiences

to be compared and contrasted. Another researcher undertook the caregiver aspect of this study.

The study's email invitation included three separate links (tāngata whaiora, caregivers, community stakeholders) that led to an online participant information sheet (PIS) for tāngata whaiora (Appendix C) and carer/community stakeholders (Appendix F). After reading the PIS, participants were asked to complete the online consent form indicating they consented to participate in the study. Participants were then asked if they would like to complete a brief online survey (Appendix C and Appendix F) or complete an interview. The electronic survey captured basic demographic information and contained five open text boxes that aligned with the semi-structured interview questions.

When participants chose to complete an interview, they were asked to enter their contact information so a member of the research team could contact them within two working days. Where participants indicated they wished to complete the online anonymous survey only (or online anonymous survey and interview with a researcher), they were directed to a separate Qualtrics page to complete the survey.

Method of Data Analysis

Thematic analysis (TA) was the chosen method of data analysis for the study. TA is a widely used method of analysis in qualitative research and has been used in past research with people with intellectual disabilities. For example, Van Alphen and colleagues (2009) used TA to identify themes of relevance to their research which explored the views of people with ID living in the community and how this group experienced relationships with their neighbours (Van Alphen et al., 2009).

TA is described by Braun and Clarke (2006) as a method that aims to identify themes across a qualitative dataset (Braun & Clarke, 2006). Braun and Clarke (2006) conceptualise themes "as reflecting a pattern of shared meaning, organised around a core concept or idea." (Braun et al., 2019, pg. 845). Themes therefore capture the essence and span of meaning, uniting dissimilar data and capturing implicit ideas not immediately obvious in the data, as well as more explicit and concrete meaning (Braun & Clarke, 2006).

More specifically, the data analysis utilised a reflexive TA approach which is characterised by its focus on the researcher's subjectivity. It demands a recursive and reflexive involvement with the dataset to obtain robust analysis (Braun & Clarke, 2006). Braun and Clarke (2006) outline six steps in the process of conducting reflexive TA. Each step is said to act as a form of scaffolding for the next, yet Braun and Clarke (2006)

emphasise that analysis is a recursive process, and back-and-forth movement between phases is expected. The process of thematic analysis as it has been used in this research is outlined below in a 6-step process as explained by Braun and Clarke (2006).

Step one involves the researcher becoming familiar with the data set (Maguire & Delahunt, 2017). This occurred during revision of the Qualtrics survey data and interview transcription. The transcripts and survey data were read and reread, allowing the researcher to fully immerse herself in the data prior to further analysis. During this step, initial analytic observations about individual data (e.g., a single interview transcript) as well as the entire data set were noted down, as suggested by Braun and Clarke (2006).

The second step involved coding the data. Coding requires the researcher to develop labels or codes that succinctly express important features of the data, which may be key in addressing the research question (Braun Clarke, 2006; Maguire & Delahunt, 2017). Using an inductive style of analysis allowed the researcher to 'open-code' data, rather than using a pre-existing coding framework (Byrne, 2022). Inductive analysis is said to enable a good representation of meaning as communicated by participants (Braun & Clarke, 2013). During this step, the entire dataset was coded at least twice, culminating in the collation of all the codes and relevant data extracts required for further analysis by the researcher.

Once coding was complete, the researcher moved to step three which as Braun and Clarke (2006) explain involves the generation of initial themes (Maguire & Delahunt, 2017). Here, codes and collated data were examined to determine broad patterns of meaning or additional themes. Data relevant to the themes identified were collated to determine the feasibility of each apparent theme (Braun & Clarke, 2006).

In step four, the identified themes were checked against coded data and the whole dataset to establish whether they told a cogent story of the data, which also addressed the research question. Additional themes typically emerge in this phase, and others may be combined or discarded as necessary (Braun & Clarke, 2006; Maguire & Delahunt, 2017). One theme was collapsed into another as a sub-theme. Relevant literature supported emerging themes, which were recorded by highlighting important quotes and noting down codes in the transcripts.

Step five involved developing a detailed analysis about each identified theme (Braun & Clarke, 2006). This included determining both the breadth and focus of each theme, as well as naming the themes (Braun & Clarke, 2006) in ways that captured the essence of a theme.

The sixth and last step involved writing up the results of the analysis. Here, themes and data extracts were weaved together to form the final analysis. At this step, the researcher also situated her findings within the existing literature (Braun & Clarke, 2006; Maguire & Delahunt, 2017). Braun and Clarke (2006) specify that the themes should convey the point the researcher is trying to demonstrate in a simple manner using examples or extracts. By following the six-step method of thematic analysis (Braun & Clarke, 2006) the researcher has aimed to move beyond simply describing the dataset to construct an argument that supports the research question.

Reflexivity

Reflexivity typically refers to the ways that researchers examine their beliefs and biases during the process of research and consider how these may impact their research. It involves questioning ones taken for granted assumptions and puts the researcher in to the research. (Berger, 2015). Reflexivity has been recognised as essential in qualitative research and in the process of interpretation of data to understand how the research may be influenced by the unconscious biases or beliefs of the researcher (Berger, 2015). Reflexivity is also considered one of the ways that qualitative researchers can ensure rigour and trustworthiness in their research (Dodgson, 2019). Because of the potential influence of the researcher in the presentation of data, it is important that individuals who may read the research are provided with an explanation of the positioning of the researcher.

As the researcher, it is important to disclose my limited connection to the community I have researched. I have had little interaction with people with intellectual disabilities, and this may have made it more complicated to recruit tāngata whaiora with limited knowledge or access to this population. During interviews with tāngata whaiora I had assumed that I would be able to convey my interest, openness, and empathy to make a fast connection with the participants. However, in one such interview where the participant had limited verbal language skills and a distrust of strangers, I felt my inexperience in sufficiently communicating with people with ID became evident. This prohibited asking further questions of the participant and led to a reliance on the carer to communicate on her behalf. Here, my personal background, including the way I use language and pose questions may have prohibited the interview, and the inability to simplify language became a point of frustration for me as the researcher. In conversation with the wider research team, this led to a discussion about whether unfamiliarity with effectively communicating with people who have limited language abilities may lead to a subset of health professionals avoiding working with people with an ID, due to its complex and diverse nature. It seems an important

question to ask, as this may impact on the quality-of-care people with intellectual disabilities may have access to in the healthcare system.

Ethical Considerations

Ethics approval was obtained from the Auckland University of Technology Ethics Committee (AUTEC) on the 21st of July 2022, approval number 22/131 (Appendix G).

The study design has reflected the potential vulnerability and need for additional support for tāngata whaiora by offering participant information in both written and video format to increase accessibility, and by providing the opportunity to participate with the support of a caregiver or support person. Each potential participant received a Participant Information Sheet (PIS) to ensure they were fully informed before partaking in the research (Appendix A and Appendix D).

Both oral and written informed consent was obtained before all interviews and surveys. To protect the confidentiality of participants, all names and other identifying information were removed from transcripts. The results of the study are presented anonymously. Access to the data was restricted only to the research team, all recorded oral consent, interviews and transcripts were stored on a secure server within AUT's North Campus, located in the lead researcher's office. The researchers did not obtain contact information from any third party or group to approach participants.

An ethics amendment (Appendix K) was obtained from AUTEC on the 3rd of October 2022 which approved the research team to invite community stakeholder participants recruited from the 4th of October 2022 onwards to participate in focus group interviews at their premises.

Reflecting on the Challenges

The most prominent challenge the researcher experienced was the recruitment of participants. Initially, the study was intended to recruit adults over the age of 18 years old with an intellectual disability (ID) who had been hospitalised during the previous six months. After AUT ethics approval was received on the 21st of July 2022, the recruitment phase commenced on the 22nd of July 2022 and was intended to conclude eight weeks later, on the 30th of September 2022.

Thirty-four organisations were contacted via email and invited to participate in either an online survey or an online interview. Despite the outreach effort, just one tāngata

whaiora participant was successfully recruited into the study by the final week of August 2022. By the second week of September 2022 only two tāngata whaiora participants had been recruited to be interviewed. In consultation with the lead researcher, Dr Liesje Donkin, a decision was made to widen the study to include recruitment of community stakeholder participants so that the views and experiences could be compared and contrasted where possible.

As recruitment of tāngata whaiora continued to be challenging, further ethics approval was sought by the lead researcher to obtain permission to conduct on-site focus group interviews, as an alternative to individual online interviews and surveys. A presentation at the New Zealand Psychological Society's Annual Conference on the 4th of September 2022 yielded two further contacts who indicated a strong interest in participating and disseminating the study invitation to both colleagues and tāngata whaiora they worked in support of. From one contact received at the conference, an extensive collaborative effort to conduct online interviews and the offer of the researchers conducting focus group interviews outside of Auckland were attempted, however these did not proceed.

Six additional organisations were identified and invited by email to participate in focus group interviews, with no responses received. A further six individuals identified as working in both previously contacted organisations or identified through the lead researchers' networks were contacted via email and phone call. This led to the recruitment of four community stakeholder participants. From these stakeholder interviews, an additional three participants were recruited, including two adults with ID.

The primary concern of the researcher was whether the voice of tāngata whaiora may have become lost or inadvertently decentred, given the larger number of community stakeholder participants and the larger volume of information those participants provided. As an example, one tāngata whaiora participant had indicated that he was not scared of being in hospital, but this was contested by his support person who supported him during the interview. The support person perceptions of hospital can be marred by trauma, and this may guide or impact on the person that they support. This interaction highlights the importance of people with ID being included in research, as much as it highlights the potential to overpower responses given by tāngata whaiora, and the two perspectives require equal consideration.

CHAPTER FOUR: FINDINGS

This chapter presents the themes and sub-themes derived from analysis of the data. Using reflexive thematic analysis, eight themes with a total of 12 sub-themes were produced, which are presented in Table 1.

Table 1

A Summary of the Themes and Sub-Themes Produced Through Reflexive Thematic Analysis

Primary Themes	Sub-Themes
Tāngata Whaiora's Perception of the Hospital Environment	Boredom and Loneliness in Hospital
Communication Needs	
Lapses In Basic Care and Patient Safety	Meals and Menus Pain Management Wait Times Discharge Planning Continuity of Care
Mistrust of the Hospital System	Discrimination in Hospital Minimisation of Inequality in Care
Patient-Centered Care	
Training and Education	
Support and Advocacy	Specialised Disability Support Consideration for Community Stakeholders/Carers
Health Passport	Digital Barriers Putting it All Together - Facilitators of Effective Care

Participant Demographics

Five adults with ID were recruited in to the study from across Aotearoa. Three participants with ID were male and two participants were female. There were a broad range of ages in this group, from one participant in their early twenties to one participant in their sixties. Of the two tāngata whaiora participants who completed the online survey, one identified themselves a NZ/European male in his thirties, and the other identified themselves

as a NZ/European female in her forties. Five community stakeholders responded to the Qualtrics survey. All participants identified as female, four identified themselves as NZ/European, with one identifying their ethnicity as Other. Ages ranged from twenty eight to fifty six years old.

Theme One: Tāngata Whaiora's Perception of the Hospital Environment

Understanding how people with ID experience being in hospital was the primary focus of the interviews conducted with tāngata whaiora participants. When asked to explain their last experience of hospitalisation, most tāngata whaiora participants described positive feelings about being in hospital. Feeling safe and supported through the presence of their regular carers, as well as the assistance of pleasant and helpful nursing and surgical staff who showed patience in explaining the situations and procedures were common reasons for this:

> *"It was good. I felt safe and better afterwards. I waited in the hallway but was seen in a room. They gave me a coffee. The hospital staff were nice, I had my support staff to help me when the doctors and nurses were talking about my health"* (TWQ2)

Despite the overall pleasant description of hospital, two tāngata whaiora participants described feeling scared and anxious, with one participant stating that they "hated" being in hospital. The inadequate management of pain and fears associated with surgery were the primary reasons for these feelings. One caregiver offered further explanation; the person they supported was frightened by unfamiliar people and found communicating harder with strangers, which in turn intensified the feeling of being afraid of the hospital. In the case of this participant, having the support of family carers who knew her well, and could explain the situation to her appropriately was considered a crucial aspect of ensuring the requisite treatments were received.

Community stakeholder participants had mixed views on how they perceived the experience of hospitalisation for tāngata whaiora, "*Some people actually love to go to hospital because they get attention 'Am I going to go to hospital?' And other people, it's really bewildering for them"* (CSH08)

One stakeholder described the people they support as generally enjoying the experience. The perception seemed to be that these participants enjoyed the one-on-one time for being in hospital and were able to see the benefits of being there:

> *"I would say overall, the guys enjoy being in a hospital. Surprisingly enough, I have one person who doesn't like to have a blood test done anywhere else. If you give the*

> *option of hospital, they're like 'oh my gosh, yes, I want to go back to the hospital. Yes, yes, yes, please'. So generally, I would say very favourable experiences of being in the hospital"* (CSH05)

Many community stakeholder participants opinions contrasted with the positive feelings that most participants with ID expressed about hospitalisation, highlighted by the following statement:

> *"I think there's a lot of individual circumstances. However, if you would want to cluster them, I think they feel quite bewildered. They're outside of their normal environment, their normal routines, their normal activities, their normal food. So, they can only be expected to be highly anxious because it's so bewildering. Sometimes they have somebody with them from the care agency who can translate, as it were, to ensure that they understand as much as possible of what's happening"* (CSH04)

> *"They're frightened. They're scared. If they've got a mild intellectual disability, they know they're going to be labeled. They don't want to come. I think for people with a more moderate to severe disability, it is very frightening, very scary"* (CSH09)

Additionally, community stakeholders described hospitalisation as daunting and traumatic because "*It's just so unfamiliar that they actually don't want to be there"* (CSH02). Furthermore, if people with ID were perceived as unable to understand why they are in hospital and why they are receiving treatment, community stakeholders felt these exacerbated feelings of distress. These experiences likely impact on the distress that support people experience as well. As an example, one tāngata whaiora participant stated that they did not mind being in hospital, but this was contested by the participant's mother; "*You're not scared? Well, I think you are scared at times. Depends how sick you are. Mum was scared that time you went to hospital. Yeah, mum was. Mum still has traumas from it"* (CG03).

Boredom and Loneliness in Hospital

Participants with ID described struggling with boredom when in hospital. Being situated within a ward was noted by some participants with ID as helpful for alleviating boredom and feelings of loneliness. Being near other patients offered the opportunity to feel connected and supported when their traditional support people were not able to be with them. The environment in the Accident and Emergency (A&E) department was singled out by some participants as being more interesting than being on a ward or alone due to the level of activity:

> *"It's better cause' you can see other people moving around and that. In the ward you just had yourself. In the ward if you were with another person you can easily talk to them, but I was in the ward by myself. Like that for a couple of days"* (TW05)

Having friends visit and not being in a room or ward on their own were indicated by several tāngata whaiora participants as ways to make their time in hospital feel easier. Additionally, having activities to do or having access to devices or music were given as examples of things that could ensure more positive experiences of hospitalisation in the future. Furthermore, a comment from a participant admitted for emergency surgery demonstrates the importance of having access to both people to connect to, and tools to alleviate boredom:

> *"I would say I didn't get really bored per se. I was more interested in my iPad. But I did have lots of questions to ask while I was there, like "does the hospital get any people who have had car accidents?"* (TW04)

Despite tāngata whaiora participants indicating a strong preference for being placed on a ward with other patients, several community stakeholder participants indicated a preference for people with ID being placed in rooms alone. Some described having more privacy as one of the ways that hospitalisation could be improved for people with ID. The rationale for this varied from consideration for other patients on the ward, which was framed as being beneficial for tāngata whaiora, and perceptions that tāngata whaiora would not cope with being around strangers, as indicated in the following statement:

> *"Being removed from their usual environments and having to stay somewhere new if they can have their own room, that I would think is ideal. But if it's not possible, that would be even worse because they have to be together with strangers. So that would be a bit of a struggle"* (CSH03)

Tāngata whaiora were described by community stakeholders as *"not your average consumer of healthcare"* (CSH02). People with ID were indicated as likely to struggle with being confined to a bed, room, or ward. Without access to their typical coping strategies people with ID were perceived by some community stakeholders as more likely to experience increased feelings of distress and irritation. As one community stakeholder explained:

> *"I would also think just the confinement of being on a ward or in a room, that they would probably struggle with that too, just because they don't understand that they have to stay there. And many of them would really struggle to stay in such a small place in relation to being confined. Knowing what the person finds calming or what are their rituals, what are the things they like to do, is it music, watching certain TV shows or using fidget toys? What do they usually do? Is it going for a walk?"* (CSH03)

Additionally, behavioural challenges were mentioned as likely to occur when tāngata whaiora feel lonely or unable to cope with their new surroundings. Incorporating coping strategies that people with ID find helpful was indicated as a way to reduce

behavioural incidents during hospitalisation by community stakeholders and noted by participants with ID as strategies for coping with boredom.

Theme Two: Communication Needs

Effective communication was indicated as a pivotal element of healthcare access and the provision of appropriate health service for people with ID. The ways in which barriers to effective communication impacted both tāngata whaiora and community stakeholder participants were inter-related with every theme produced from the dataset.

Community stakeholder participants described a variety of issues with communication in hospital and indicated that *"Hospital staff don't know to communicate with a person with ID"* (CSH08), and that *"Their style of communication is poorly understood by the hospital*" (CSH04). When tāngata whaiora struggled with verbal communication this was described as influencing the amount of time and support community stakeholders need to provide in hospital. Verbal communication issues were also noted as impacting on hospital staff, as described in one community stakeholder's response; "*Some are unable to verbally express themselves well and this seems unfair on the patient as well as the hospital staff"* (SHQ2). Additionally, when hospital staff cannot communicate with people with ID this can lead to a lack of basic care, as described by one ID service provider "*People are left alone, unable to use the call bell, unable to verbalise how they feel, unable to feed themselves, unable to reposition themselves"* (SHQ4).

There was a strong sense of concern that communication barriers created avoidable issues related to patient safety and wellbeing, as highlighted by one community stakeholder:

> *"Our support workers must attend in order for proper and safe care to be delivered. Fractures and falls have occurred by not understanding moving and handling. As have choking episodes, not understanding safe eating and drinking for the people we support. We use health passports and ensure that hospital staff receive a full handover"* (SHQ1)

Some service providers found that even when they provided detailed information about a patient's specific requirements or preferences, hospital staff did not always read the information provided:

> *"At our service we have a sheet about the person, 'the things I like'... I dislike this' ... And you might send it along with the person, but staff don't read it. It's a profile we can supply that and do, but things get lost in translation. You might give information to one person, and it doesn't get passed on. And people don't go back. Staff don't go back and read"* (CSH08)

These remarks may reflect frustration at the effort that community stakeholders make to ensure the needs of the people they support are known to hospital staff, and that when their efforts are overlooked this may cause additional work for ID service providers.

The difficulties associated with communication for tāngata whaiora are often overlooked or misunderstood by hospital staff. The following quote reflects the fear of being unable to communicate a person's needs in an already overwhelming situation:

> *"I found those sorts of things quite distressing, and it must be distressing for the person because if they can't even communicate what sort of diet they want, which is their foods, what are they able to communicate in a hospital setting? Are they able to communicate pain? Are they able to communicate who they want next to the bed? Whether they want the parent involved or you know yeah communication is a big one and I think people often don't consider their communication style"* (CSH04)

Community stakeholders also empathised with the hospital about the impact of communication difficulties and being equipped to provide effective care for people with ID. They recognised that working with people with ID can be challenging, and that the diversity of presentations of people with ID can be challenging to adapt to:

> *"People with intellectual disabilities have a wide range of communication skills and needs I think it is a challenge for both sides to ensure communication needs are met-both sides meaning how that person with a disability can or cannot explain their needs, if a hospital staff is provided with some quick information about the persons communication needs from a caregiver/whanau member how is that documented, what support is that hospital staff member given to effectively communicate with the person"* (SHQ2)

Furthermore, poor communication was indicated a missed opportunity to understand the person with ID, and this was related as a lack of person-centred care during hospitalisation. Communication was indicated as a contributor to discriminatory attitudes towards people with ID and feelings of mistrust towards the hospital system. The following comment reflects a sense of justification about why the hospital cannot accommodate reasonable adaptations to ensure better hospital experiences for tāngata whaiora:

> *"I suppose the system is too task orientated and too busy to take the time for this group of people to explain it in their own language or by pictures or diagrams or any other means that they may be able to understand"* (CSH01)

Effective communication was a significant influence on whether people with ID described positive or negative past experiences of being hospitalised, with participants describing this as either "very good" or "scary". One participant with ID described the pain that they experienced as creating anxiety, and that this was alleviated by the ability to talk to his mother and the hospital staff when he needed to. Without the ability to communicate these anxiet:

> *"It was a bit scary at first. There were things that when I felt like I was in pain quite a bit of the time, and I was under a lot of anxiety. Accordingly, the medical team...plus on the bright side, my mum and I, we did a lot of talking"* (TW04)

One participant described feeling pleased with hospital staff because they explained the surgical procedure that they were having; "*It was good, the staff were nice. They told me what was going to go on about the operation, how they were going to put the things in my naval to get the camera in"* (TW02). The person who supported this participant in their interview agreed that communication from hospital staff was good but indicated that her presence may have influenced the time doctors took to explain things to the patient. Conversely, the tāngata whairoa participant also described how communication barriers affected how they felt about communicating with healthcare professionals without support people present. This participant echoed her support persons thoughts, reflecting that effective hospital care might only be given when someone is there to communicate on her behalf:

> *"Sometimes they don't understand my speech, because I've got a bit of a speaking disorder and they don't understand, especially on telephones and that. Some doctors don't understand people with intellectual disability and if you're by yourself if you have a disability; it would be hard. You need a special person, I think if my sister or family wasn't with me, I wouldn't be treated the same"* (TW02)

Theme Three: Lapses in Basic Care and Patient Safety

Community stakeholder participants described people with ID as being overlooked in the hospital system. This perception was influenced by instances of neglect of basic care for tāngata whaiora that had been witnessed by support people. Examples included hospital staff overlooking assistance that a patient might need with eating and drinking, not asking the person which way they needed to lay in bed, and not turning the patient sufficiently to prevent pressure injuries. Community stakeholder participants related these lapses in basic care to deterioration in the wellbeing of the people they support "*I have seen many people discharged from hospital with pressure injuries because they have not been positioned regularly or correctly"* (SHQ2). Insufficient basic care was also indicated by some community stakeholders as the reason for further complications in the health of the people they support which could be avoided, with one noting that "*People leave hospital with pressure injuries or don't leave because they acquire hospital pneumonia"* (SHQ4).

Lapses in basic care can mean that community stakeholders were required to take on additional responsibilities in the care of the people they support; often filling in roles and

responsibilities that hospital staff may take with other patients. Without support people, it was implied that these tasks would not be completed:

> *"People from our service will go into hospital without a pressure area and come home with them. And* so, *at the hospital, you know going in, and it'll be one of the things that I'll do, a check of the body. But it might even be before that, I'll say 'this person will need a pressure relieving mattress.' Like, telling them what it is that they're going to need and then following up to make sure that it has been ordered"* (CSH08)

Hospital staff were perceived as assuming that people with ID were released into facilities with a medical staff, when often community providers employ non-medical support workers who they described as ill-equipped to care for unwell residents. This was indicated as creating additional pressure for community providers, some of whom were facing industry-wide staff shortages and barriers to receiving funding to provide additional staff when someone was hospitalised. This practice is meant that these was poor continuity of care, and this could increase readmission.

Meals and Menus

Issues related to being able to read menus along with a lack of assistance with meals was a recurring issue for both participants with ID and community stakeholders. One tāngata whaiora participant mentioned how long he had to wait to receive a meal specific to his health condition:

> *"They brought me a meal like that. Yeah, like that. I had to wait ages for a meal because I'm a diabetic. And then I was waiting for ages for a meal, but they gave me a meal and they were very good like that. Yes, yes, yes. Yeah, I asked the staff rang the button and ask the staff for some breakfast and some lunch, like tea like that"* (TW05)

In this study, community stakeholders described concerns around the hospital not setting up the environment correctly for people with ID to eat or drink. This was related to hospital staff not reading information provided about their residents, not asking patient's what assistance they needed and not considering the unique needs of people with ID in general:

> *"They would put the meal in front of them, but they don't feed people and so the person isn't fed. So, the meal is still sitting there, you can go in later and the meal is still sitting there, so no one's actually fed the person"* (CSH06)

This comment reflects a gap in basic nursing care and may reflect that people with ID can be invisible to hospital staff. Additionally, when eating or drinking needs were not attended to properly, community stakeholders described how this could contribute to instances of avoidable harm:

> *"So, they bought two cups of coffee with milk and three sugars, and they tipped them over themselves and ended up with burns. But what this person would normally have is half a cup of warm coffee, right? And so they took the person at face value that they had two cups of coffee and it was hot coffee and it was full to the brim. Okay. And even though they went into hospital and they had their own cup and it had a lid on it and a straw, they just ignored it"* (CSH08)

One community stakeholder described issues with literacy and numeracy and how menus can overwhelm people with ID. The current process for ordering meals is not set-up for people with learning disabilities or intellectual disabilities that often require support to read menus and order food:

> *"But actually, the people we support really struggle with the selecting of the foods. So, picking which one they want and understanding how to do it, because they may not be literate and numerate, and they might not understand...quite the quantity of what they're ordering"* (CSH05)

Pain Management

One tāngata whairoa participant described the importance of having good pain management during hospitalisation and that his main wish for future hospital visits was "*A better team to understand when people are in a lot of pain*" (TW04). This participant had been seen by ambulance and cleared to return home but later that evening was rushed to hospital for emergency surgery. The community stakeholder present during this interview indicated disbelief about the situation, "*Yeah. Interesting scenario. Here we've got a very well-spoken person, but yeah, it's a very complex one. They just didn't see that you were in pain?"* (CSH05). The tāngata whaiora participant also explained that he had little access to the call bell which was placed out of reach after his bowel surgery, which made asking for pain relief challenging and contributed to his anxiety. The inaccessibility of the call bell may indicate that the individual's needs were invisible to hospital staff, including the pain he was in. It may also be that the call bell was placed out of reach to prevent overuse by the patient who described enjoying asking the doctors and nurses lots of questions. If that were the case, making the call bell inaccessible might also indicate the hospital staff's lack of knowledge about the needs of tāngta whaiora, many of whom described feeling better when they had some company in hospital.

Community stakeholders described the difficulties in identifying pain in some people with ID, which they related to a persons' capacity to verbalise their pain or due to the way that pain presents in some people:

> "*There have been cases where people were labelled as having behavioural issues and so of course people with ID can present differently than normally developing people and I would think that when hospital doesn't understand and when they're*

> *very busy like these winters, when they had so many people waiting...it can be hard to make time to understand what the presenting issue is"* (CSH03)

Community stakeholders expressed concern about how to manage pain in people with ID outside of hospital. One community stakeholder described her frustration around a lack of information and guidance about pain relief, stating that clearer instructions would be beneficial. The lack of clear instructions can lead to confusion in appropriate medication use which carries significant risk:

> *"And so, it's really...you want almost like guidelines from the hospital in terms of instead of going "hey, here's some pain medication", going "hey, we're expecting that the person would most likely have a pain at level eight for like one day, then it goes down to six. So, give the medication this amount" rather than saying, here's the medication that's given as needed, because that person doesn't have the ability to tell me when it's needed"* (CSH05)

Confusion around medication management was reiterated by another community stakeholder who described the confusion for people with ID who were only given a sheet of paper post-operation about what medications to collect from a pharmacy, with an instruction to call their GP if they needed to. Providing accessible information about medications in easy-read format or through the support of a disability liaison service person in hospital would be one step towards ensuring Aotearoa was reducing barriers and moving towards an enabling society. Another community stakeholder with many decades of nursing experience and specialised knowledge of ID echoed the confusion around pain management for people with ID, and outlined her position on how to best manage pain relief for people with ID:

> *"I would say if you give a medication PRN as required, pain relief after a surgery, what is the normal acuity of people taking that? And then you don't give it PRN for a disability. You give it three times a day or four times a day. Because if someone can't express pain and know what pain is, how can they ask for pain medications? So, it's better to give them the pain medication" (CSH09)*

As many community service providers are not medically trained, having the hospital or pharmacy provide clearer information on how best to manage pain after hospitalisation would benefit many service providers. Moreover, the inability to communicate pain and distress were seen as a risk of being overlooked by hospital staff, who may interpret distress as challenging behaviours, which one community stakeholder attributed to earlier discharge.

Wait Times

Having shorter wait times in hospital was mentioned as a way to make hospitalisation easier for people with ID. Tāngata whaiora participants recalled instances of long wait times or having to wait for assistance during hospitalisation, as described by one

tāngata whairoa, "*They were very good. I was waiting for ages and ages and ages. And then later on that night, early in the morning, they shipped me to a ward"* (TW05).

The challenges of long wait times in hospitals were echoed by community stakeholders. Whilst wait-times are not exclusive to people with intellectual disabilities, long waits can be problematic for managing stress, anxiety and sometimes the manifestation of behavioural issues:

> "*The amount of time that you're spending in ED, especially if they have aggression or emotionally are just distraught by the fact that they're in hospital...Most people love hospital,but some people don't want to sit still, some people want to walk around, some people want to, you know, and it's very, very hard when you're sitting here waiting for 8 hours to have someone sitting nicely down there. That's very much a challenge. And of course we supply staff to them"* (CSH05)

Additionally, community stakeholders described the challenges of waiting for surgical procedures, and the stress of having to try to communicate to the people they support that they cannot eat or drink before a procedure. One community stakeholder described the difficulties of waiting to be seen in hospital, suggesting that a priority pathway or priority screening with reasonable adjustments could benefit patients with ID:

> *"And if it was possible then for them once seen maybe to leave and come back in a couple of hours and they can be seen so they don't have to sit in the waiting room. But I don't see how someone with an intellectual disability, especially with behaviour problems, could be contained in a seat for hours. It's just pretty impossible if they don't have any help"* (CSH03)

When asked if flexible admissions could be beneficial to people with ID, one community stakeholder expressed agreement, and described the ways that one hospital in Aotearoa had changed their surgical procedures to support people with ID:

> *"Oh, gosh yes. In theaters, it's still stayed in theaters for over ten years now. We've had it that if you've got an intellectual disability or if you've got any other specific needs and its dental surgery, you don't have to get changed to go to theater. You can come just half an hour before your appointment. So, if you're third on the list you don't come in at seven, you come in at eleven and family members can walk into theaters with you up until you're sedated"* (CSH09)

Creating more flexible processes for tāngata whaiora was also indicated as a way of reducing the potential for escalating behavioural issues, which was seen as beneficial to the patient and to the treating team but indicates that this would reduce pressure for community stakeholders as well.

Discharge Planning

People with ID may live in residential facilities in the community that may or may not include support staff with medical training (Webber et al., 2010). The literature indicates that hospitals may lack an understanding of the level of care that community stakeholders can provide for people recently discharged from hospital (Webber et al., 2010). Furthermore, community stakeholders described difficulties in gaining the information necessary to provide safe care post-discharge (Webber et al., 2010). This may place an extra burden on community stakeholders and contribute to unsafe care and adverse health outcomes for tāngata whaiora.

Several issues were raised in relation to discharge planning. Community stakeholder participants described the pressure they felt from hospitals to take tāngata whaiora home earlier than the support people felt was appropriate. Similar findings were reported in Webber and colleagues (2010) study, where group home support staff reported pressure to take residents home despite the facility being unable to provide appropriate and 24-hour care. Most community stakeholder participants with nursing qualifications mentioned that they had more power to stop an early discharge than support workers without seniority or medical training:

> *"In some cases, they want to send people home and it's too early. Like, they want to send people home when they haven't got back to the baseline that they were at when they entered hospital. So we might not have the resources we need then to care for them when they get home. So you have to be really quite strong in those circumstances and say, actually, I'm not taking them back home at the moment"* (CSH01)

Hospitals may lack an understanding of the level of care that community stakeholders can provide for people recently discharged from hospital (Webber et al., 2010). Participants in this study also felt that hospitals lacked an understanding of where people with ID lived in the community, stating that hospitals make assumptions about patients being released to an aged care facility with medical staff, as described by one participant "*So, the biggest issue we come across is that people are discharged too early. They want to get them out of the hospital, but they don't have a good understanding of where they're going"* (CSH06).

One community stakeholder described feeling anxious about how to best support people released from hospital without sufficient information provided about their condition. This highlights the tenuous position that service providers find themselves in when hospitals assume there are medical staff at a person's residence. Additionally, this participant

described having to ask 'really good questions' before discharge, which indicates the pivotal role that support people play in the wellbeing of tāngata whaiora:

> *"Biggest challenges? I would say the biggest challenges would be discharging. So probably for us, discharging when there's not really a conclusion to what's going on for a person. And I understand why hospitals need to discharge at that point because the person is stable. But it's a real concern where someone has this big event and it's kind of a bit uncertain as to how to support someone going forward"* (CSH05)

Community stakeholders described the stress and unsafety of hospitals discharging tāngata whaiora early during a time of industry wide staff shortages. Many providers described situations where there were not enough staff in a house to ensure a safe discharge or ongoing care of the medical needs of tāngata whaiora. Community stakeholder participants mentioned concerns around a lack of planning after people with ID left hospital. The stress of supporting unwell people without sufficient staff numbers was indicated as increasing the risk of avoidable harm for residents:

> *"There was one man recently who got admitted to hospital, and they wanted to send him back home, but he actually couldn't walk. And there was nothing in the house. We had, like we didn't have a high low bed, we didn't have a standing hoist, we didn't have a walker. All those sorts of things that we needed to be in place before he was allowed to come back home, and they wanted to release him prior to us having all those things"* (CSH01)

Two community stakeholders reported strong feelings about discharges that regularly occur late on Friday afternoon. Issues of patient safety, and disruptions to the continuity of care and to other residents were primary areas of concern and a discharge at this time with little warning prevented planning and organisation around this:

> *"We don't like discharges late in the afternoon because there are several reasons...One time equipment came at 10.30 at night. So, waking the household up when the equipment has been set up, whatever and getting...if there's been a change in prescription, making sure that whatever change is there because it has to go through the chemist and then the chemist has to deliver. So, we want the continuity of care...have they been started on a medication regime? We want that to continue with prescriptions"* (CSH08)

This highlights the amount of planning and consideration required to ensure people with ID are safe after leaving hospital, and the degree of responsibility placed on community stakeholders to reduce gaps in the ongoing care of tāngata whaiora.

Continuity of Care

A participant with ID described examples of quality care received from community support services, such as organisations that provided support with meals after

hospitalisation. Additionally, two tāngata whaiora participants described the important role their GP played in their health. There was also an indication in the findings of this study that female doctors listen to people with ID more than male doctors.

> *"Yes. It was lockdown and we went and CG02 took me to my doctor because we had different doctors and it was a lady doctor. She did more to get me into the hospital than what my other doctor did because it was hurting. I couldn't eat a lot of food and I was sick all the time"* (TW02)

Continuity of care was identified as an issue by community stakeholder participants. In some instances, a lack of information sharing from hospitals to service providers meant that information crucial to continued care was missed, such as medication requirements. For others, a lack of consideration about the ongoing needs of tāngata whaiora outside of hospital was indicated as problematic and burdensome for service providers. Support agencies indicated having to go above and beyond to coordinate the many needs of the people they support, often under significant time constraints.

Additionally, community stakeholders indicated that Needs Assessment Service Coordination Agencies (NASC) were not doing enough to provide support for people with ID, and that there was a lack of cohesion between hospital and NASC services:

> *"They don't see they need to step up care. When somebody has a medical procedure, they see it as part of the hospital system. They don't see it as part of the disability because it's an event. The two systems, with the best of intentions, just don't get it right"* (CSH04)

A community stakeholder participant related a story of a person with ID having a knee brace with a dial she could not stop touching. This was said to lead to an 'undoing of the good' that the operation had initially provided. This was seen as a failure by a NASC agency who did not provide sufficient support to manage the patient's situation to ensure a better outcome. NASC agencies were indicated as being inflexible in responding to the needs of people with ID after hospitalisation, but were also identified as the solution to managing better health outcomes for people with ID.

Theme Four: Mistrust of the Hospital System

This study found that a sense of mistrust about hospitals and the care that people with ID received in hospitals across Aotearoa was a prominent issue:

> *"Well, I think being in hospital is a vulnerable place for all people, not just people with disabilities, but for people with learning disabilities it's probably doubly, triply vulnerable. And I would suggest that you never leave a loved one alone in hospital. That's the one thing we're saying"* (CSH07)

Concerns ranged from a perceived lack of basic care such as turning a patient regularly, concerns of important information being missed or overlooked due to barriers to communication or staff not reading the information provided about tāngata whaiora, inconsistencies between departments and wards, medication drop out, perceptions that hospital staff had insufficient knowledge of ID to provide adequate care, along with instances of insufficient care or neglect:

> *"Just that for me it's always a concern when somebody's in hospital, the people that I work with, whenever they're in hospital, because I feel sometimes that they can be neglected. And I'm thinking about one man who had COVID and, you know, people weren't allowed to visit. And so I was, and he was on his own and he was dying, and he was on his own. Staff were doing whatever on the wards, and nobody ever came. So that's sad. Yes. I have seen some quite awful things about people, with just the care of people"* (CSH08)

> *"And I thought to myself, all you people who did nothing! And I thought, is that why you didn't want to turn her? I don't know, I don't know. She obviously hadn't been turned in a very long time. With the amount of fluid that came through her nose, I guess experiences like that kind of make me feel that it's unsafe"* (CSH08)

For service providers, that sense of mistrust in the hospital system manifested in feelings of protectiveness about the people they support. Some participants mentioned wanting to get a 'lay of the land' and to find out who the Charge Nurse was when people they supported were hospitalised. Additionally, community stakeholders mistrust meant that they felt an obligation to provide extra support staff to ensure their residents remained safe in hospital placing burden on their services. Another community stakeholder described feeling exhausted at the additional work they had to do to ensure hospital staff were taking care of their residents sufficiently and not them causing harm.

> *"People with an intellectual disability need to have an able-bodied person checking in on them to make sure they don't come to harm while hospitalised. I never knew how awful or unsafe hospitals can be when a person can't speak up for themselves"* (SHQ3)

> *"It's exhausting for me when someone's in hospital - having to cultivate staff to make sure they do take care of the person (and don't do them harm), checking and making sure things are done"* (SHQ4)

Discrimination in Hospital

Four community stakeholder participants and one carer described instances of perceived discrimination against tāngata whaiora in hospitals throughout Aotearoa. Labelling, stimgatisimg and bias were present throughout:

> *"I think they're labeled, I can't think of the word...stigmatized. People were still.. I've been here 20 years, I've been in this role 14 years...And people would tell me on the phone of all different senior levels as well as healthcare systems, "we've got one of your people on the ward"....As soon as they get on the ward, 90% of them are put in a continence brief unless they can fight to not have it because they're presumed to be incontinent. So, yeah, very negative"* (CSH09)

In this study, there was a concern that discriminatory attitudes about people with ID had led to tāngta whaiora missing out on medical procedures as they were presumed as being unable to cope with the outcome of a treatment:

> *"So, I've heard many a time that a person with a disability does not get a procedure because they are assumed not to be able to cope with the result of the procedure, and I think that is to me.... That is really, really painful"* (CSH04)

An example of discriminatory decision making in hospital treatment was described by a community stakeholder whose then adolescent child with ID had his neck damaged during an ear operation. There was a strong sense of the hospital minimising the family's concerns which appeared to manifest as a sense of mistrust in the hospital system:

> *"And then it took me months to get listened to. Finally, he was 15 at the time, finally ended up and got corrective surgery. But even the doctor at that stage was saying to me that it was my choice. Now I just totally believe that that was total discrimination, because would you let any other child walk around with your head, like with this angle, spinal cord exposed the rest of their life?"* (CSH07)

Additionally, one community stakeholder who supported her son with ID during an interview described a recent incident in which her son presented with chest pains and was left to wait in the Emergency Department (ED), against hospital protocol for people presenting with chest pains:

> *"TW03's fortunate that I know the process. Other families don't. Other families would have sat there waiting. So, it ended up in digestion, which is fine. And then he had it another time. But this time I phoned the Charge Nurse because I had a relationship. I said, "oh, TW03's on his way". Well, he got royal treatment straight through how it should have been. Because I actually put in a complaint after that. The first time I put in the complaint, I thought, that's not good enough. No, that's not good enough. It was discrimination at its height. Yeah. And I think that's what we're up against is the discrimination"* (CG03)

Other community stakeholder participants made clear that to get the right service in hospital people with ID needed to be assertive, but often this can be seen as difficult behaviour which may be dismissed by hospital staff as a function of the ID rather than valid frustration with their lack of care. Moreover, every community stakeholder and the majority of tāngta whaiora participants described the necessity of having an advocate or support people present through the hospital experience to ensure people received appropriate service

delivery. The implication was that without this, the tāngata whaiora would not be listened to or included in their care.

Minimisation of Inequality in Care

The majority of tāngata whaiora participants described feeling positive about their last experience of hospitalisation. On further exploration of the challenges of being hospitalised, some participants with ID described the staff as "lovely" while simultaneously describing long wait times or a lack of assistance with basic care. One participant who had been profuse in her praise of doctors and nurses concluded the interview by saying that she did not feel she would get good support in hospital without the presence of her family members.

Additionally, concern about the state of the hospital system was expressed by carers who supported tāngata whaiora in their interviews, with one family member stating "*I think it's an overall picture of that our whole health system is actually decaying at the moment and somebody needs to stop it. Step in"* (CG02). The participant with ID involved in that interview described her concern for how little nurses were paid and expressed concerns about needing more nurses in the hospital system.

On top of feelings of mistrust, community stakeholders also held conflicting views about the provision of sufficient hospital care for people with ID. Often community stakeholder participants would give an example of inadequate care, but in the same sentence appeared to excuse this as the symptom of a system that is stretched as described by one participant "*I don't think they have the time. I don't think it's the professional's fault. I think it's the system around them and I think it would depend on individuals as well"* (CSH02).

There was an indication that poor outcomes for tāngata whaiora were the by-product of both discrimination and a stretched system, and that these conditions combined to invalidate and disrespect people with ID. Additionally, one community stakeholder highlighted how the system under pressure impacted on the provision of quality care for people with ID:

> *"But from my perspective, I've been a nurse for over 30 years. That whole connecting with people and having the time to do that and understand where they come from, what these supports look like, where they're going to go when they're discharged, all of that connection is not there anymore because nurses are so busy and so task orientated and well aware of their time schedule, the paperwork that's needed at the end of the day. So, I think that ability to connect and understand the person has been impacted because of that"* (CSH02)

Additionally, COVID-19 was perceived as adding pressure to the hospital system and community stakeholder participants empathised with the impact of this on hospital staff, as noted by one community stakeholder "*It's got way worse after COVID. Everything's got worse. It seems to me that everybody's now in... systems are in survival mode after COVID, just kind of trying to get through their day"* (CSH02).

Conversely, one community stakeholder and one tāngata whaiora/carer dyad described hospital care during COVID-19 as better and more supportive, as described by the support worker "*I did find that the hospitals were very, very supportive and understanding towards people with intellectual disabilities and allowing a support person through that time"* (CSH05). These feelings may reflect the support persons relief at being given special dispensation to access the people she supports during a time when hospitals were off limits to most people. Without this access, there likely would have been higher anxiety about the quality of care and the treatment that the tāngata whaiora was receiving. Support during COVID-19 was indicated as an example of good care in hospital for this participant, and for another participant:

> *"When she was in hospital, they had an outbreak of COVID in her ward. So, she was restricted who could go in. But I was told I could go up and see after the operation and wore the heavier mask and…you know. And I have to say that five days after she came home, they rang us to see if either of us had got COVID-19, which I thought was really positive"* (CG02)

The additional care that was received during COVID-19 was perceived as a positive, however, this is likely a level of care that all people would have received if they had been on a ward during a COVID-19 outbreak.

Further to this, community stakeholders acknowledged the pressure hospitals were under, while also identifying small but significant ways that the system could better support people with ID. One participant captures this sentiment, "*I know that the hospital is really stretched as well. I can understand where they come from. They need to rely on the people that know the ID person well"* (CSH02). Additionally, focusing on the person was identified as a way to make things easier for patients, support workers, and for the treating team:

> *"Staff don't go back and read 'my name is such and such and I like this, that and the other'...I think the hospital is under pressure and staff are under pressure, but sometimes just reading just to get a little bit of a picture of the person could make life easier"* (CSH08)

Theme Five: Patient-Centred Care

Ensuring individualised, compassionate and patient-centred care was a prominent theme that was interwoven with all other themes in this study's findings. People with ID have unique needs and when hospital care is individualised to those needs, participants indicated this can lead to better outcomes for people with ID, their support people and the treating team. Patient-centred care was described by one participant; "*It needs to be client centered. Client driven. If it's client centred, it's client-driven, then everything else should fit in place"* (CSH09).

Seeing the human behind the ID and familiarisation about people with ID may work to reduce feelings of fear which could increase the quality of care provided to people with ID, and set the conditions necessary to deliver individualised, patient-centred care that all people can benefit from. For one community stakeholder with specialist knowledge of ID, person-centred care was described as beginning with knowing a patient's name before naming their condition, and considering the whole picture:

> *"And then it's looking at how that person needs it. So, some people will need sensory stuff, some people will need not to wait for an appointment. Some people will need this or that. So, it should be actually if you know someone's coming to hospital, whatever, the relatives, if you've got a liaison there, that's good. If not, then someone from whatever department is checking in with that person and all their care and support people to see what specific needs that person needs" (CSH09)*

Individualised care was indicated as the "basics of care" and was related to simply taking the time to get to know the person and ask questions about their preferences. At its core, the provision of patient-centered care was indicated as respectful, compassionate, considerate and responsive to people's needs:

> *"People aren't got out of bed for a shower. It's all ReadyBath. The bathing team comes in and they have a big bath. I probably sound like really old, old school; water on the body, chat in the shower. You learn such a lot about a person, but just people like to feel clean and fresh"(CSH08)*

Community stakeholder participants in this study described similar reasonable adjustments that could alleviate distress, boredom and challenging behaviours in tāngata whaiora. These were framed as ways to make hospitalisation better for the people they support, but also indicate that reasonable adjustments could take the pressure off community stakeholders having to fill time, entertain or manage behaviours. Suggestions included adaptations to lighting, adjustments to waiting times, the ability to play music or the incorporation of physical movement.

Theme Six: Training and Education

Training hospital staff about the unique needs of people with ID has been suggested as a way to reduce the stigmatisation of tāngata whaiora. When asked what the biggest challenges are for people with ID in hospital, one community stakeholder participant, a nurse with many decades of experience explained:

> *"Staff. Yeah, staff. I do get concerned when people from our service have to go to hospital, and I do worry about them. And I make a point of getting up as often as I can to visit, just to get a lie of the land and see what the staff are like and see what the charge nurse is like and that kind of thing. But generally, I don't think hospitals are prepared to care for a person with a disability. They try, but somebody with a disability actually needs somebody there looking out for them"* (CSH08)

Additionally, a nurse with specialised training in ID described the lack of knowledge that medical students have about developmental disorders, and her frustration at the limited training provided to medical students generally: "*I find medical students come in in their first year as House Officer medical students who have no knowledge of disability and they're working with them in the hospital. They couldn't even tell you a disability"* (CSH09).

Some community stakeholder participants expressed their dismay at the lack of specialised training in ID within Aotearoa. The need for better training of hospital staff in undergraduate, postgraduate and continued education were highlighted as an essential element to changes to the hospital system which could lead to better health outcomes for tāngata whaiora. This was also indicated as a way to reduce fear that hospital staff might have about supporting people with ID, as noted in past studies (Iacono et al., 2014; Sowney & Barr, 2006).

Theme Seven: Support and Advocacy

The vital role that support people play was a recurring theme. Stakeholders suggested that when carers can be present at the hospital "*those types of admissions can be more successful"* **(**CSH08) as they can provide familiarity and advocacy for people with ID, as well as expertise on the patient that can be useful to hospital staff. One community stakeholder related the impact of tāngata whaiora "*having a carer with them at the bedside; it makes a huge difference in terms of the anxiety and in terms of the communication. To me, that is the solution to it"* (CSH04). Additionally, community stakeholders indicated that hospitals often work quickly to assess and discharge patients, and this can disadvantage people with ID if they do not have a support person to advocate in these situations, which may indicate a sense of empathising with the hospital system and reflect a sense of

justification for why the needs of a vulnerable group may get overlooked without the presence of a strong advocate ensuring that their needs are met:

> *"I guess what is happening in the hospital is that they have to do these assessments quickly and they need the beds, and there are not that many beds so people have to move through quickly, so they definitely have a disadvantage, especially if theres no one there to support them and advocate them"* (CSH03)

This was echoed by tāngata whaiora participants who described the importance of "*Having someone there to answer questions*" and the crucial role of support people in liaising medical staff on their behalf:

> *"You need somebody. If she wasn't there, or my nieces…There are people who haven't got family they need somebody that will help them to understand and there are a lot of people around that don't understand. And they get upset and confused. You need a special person to help you" (TW02)*

A participant with ID and their carer expressed the essential nature of having a "special" person to provide for people with disabilities, noting that simply having a supportive person was not enough, and that advocates needed to have familiarity with disability and the hospital system. The importance of advocacy was captured by one community stakeholder participant who stated that "*Advocacy is actually a huge part of having a better experience, it's huge"* (CSH02).

Participants from both groups described the role of advocacy as something that family carers and support workers can and do provide but this was also described as a 'special person' that exists outside of tāngata whaiora immediate networks.

Specialised Disability Support

Several community stakeholders described the utility of having a specialist disability role within the hospital system. It was a point of frustration for some that Aotearoa does not have a pathway to specialised ID training like other countries do; "*I come from the UK and in every hospital there is a Clinical Nurse who is trained in ID and she is called a Liaison Nurse. She trains staff and co-ordinates outpatients and inpatients*" (SHQ3). In other countries, a formal disability liaison nursing role comprises the management and administration of person-cantered care, liaison and education, advocacy and facilitate effective communication between patient, treating teams and family or community stakeholders (Bur et al., 2021)

Community stakeholders often described their wish for a nurse with knowledge of ID, as noted by one ID service provider "*I really like the idea of the Hospital... of the having*

a nurse who...I think a nurse with a background in disability being available to oversee people with disabilities, oversee them while they are in the hospital's care (CSH08).

There were indications that some hospitals across Aotearoa had started to employ a type of disability support person, but this did not appear to be consistent across hospitals:

> *"Absolutely every hospital should have a disability equity lead that is informed when someone with a disability is admitted to support them on their journey and to navigate consent issues. They should adopt the flower lanyard used in some DHBs to identify people with disabilities that may need extra support"* (SHQ1)

Stakeholders did describe the significant impact of healthcare assistants (HCA) and 'watch' people who had previously worked in the disability sector as fulfilling a very useful role in supporting tāngata whaiora. The implementation of a formal disability liaison nurse role across hospitals was indicated as an especially helpful way to improve the hospital system for people with ID. However, this was contested by one carer with a nursing qualification (supporting an adult with ID during the interview):

> *"I would not trust anybody from the hospital doing that role at all. Okay. I want somebody who knows [TW03] doing that. Okay. I don't want a stranger doing that. I don't see the role as advocacy. I see the role of support, but not advocacy"* (CG03)

Other carers and community stakeholders described their desire to see a formal advocacy or specialist role rolled out in hospitals, in case they were ever unable to be there and to ensure continued care: "*Hospitals would benefit from Disability Liaison Nurses to work with ward staff and the community supports to ensure good treatment outcomes for the person and safe transition back to community"* (SHQ4).

Importantly, tāngata whaiora participants expressed their desire for "special" people who could support them during hospitalisation and beyond. One participant described wanting a person similar to a lay advocate who supports children in family court and who can support all people with disabilities, *"I just want somebody to help, for all disability people. Just somebody to help us"* (TW02).

Consideration for Community Stakeholders/Carers

Community stakeholders often spend long hours at hospital supporting tāngata whaiora and can feel neglected, overlooked and taken advantage of. Community stakeholders and a caregiver who supported a person with ID during their interview described a lack of consideration for their needs while carrying out their supporting role. Their needs ranged from wanting a comfortable chair while spending time at someone's bedside, a place to rest, to less restrictive visiting hours, as described by one participant:

> *"So, where's a camper bed? You can sleep on a Lay-Z Boy chair or just something. I remember in ICU, there were these benches that you had to sit on in the waiting room. And I ended up on this hard bench trying to sleep with the kids and dozing off while the kids were awake. There was nothing. And that's a really high area, you know, and you think they'd be making it more pleasant for people, and, you know, you have to go, you have to go at ten or whatever time you had to get out. And I don't see why we had to get out if we're only allowed there doing during daylight hours at certain times. Why was that so restrictive?"* (CG03)

Similarly, one community stakeholder described simple considerations that would benefit their comfort and assist the people that they support:

> *"But what I found with that is that there's not really much of a set up in terms of...I would really, really appreciate just a cup of coffee or something like that. I feel like it's valid, sorry to say, but I feel like that's valid because I think it's hard to drop of food and stuff like that. But again, you're not meant to have food within the wards. I'm not meant to bring anything in"* (TW05)

One stakeholder described two different hospitals in their region where access to non-patient toilet facilities was difficult and greater access to toilets on the wards "*would make it just a little bit easier. Just that little bit easier"* (CSH05). This may reflect a tension between community stakeholders having the responsibility of hospital staff when caring for tāngata whaiora, without having the same considerations or benefits that hospital staff receive. Additionally, having to leave the ward to use the facilities was indicated as problematic time away from a patient's bedside which put pressure on nursing staff, and ran the risk of stakeholders missing ward rounds and information from doctors:

> *"You really want to make it like the shortest amount of time for me to go to the bathroom, but at the same time, I'm going to need to go to the bathroom. But yeah, the toilets are very inaccessible, so I honestly just stopped drinking when I arrive, and I just hold on as long as I possibly can. You get used to it aye!"* (CSH05)

Theme Eight: Health Passport

People with ID described the importance of having someone to communicate their needs or health history with medical staff. Additionally, Health Passports were noted as a useful tool for sharing information about the needs of people with ID in the healthcare system, described by one tāngata whaiora participant:

> *"Yeah, the health passport. That's very good. So, the support people can put the things in health passports so the doctors and the nurses can read the passport. It's very good. There's a lot of people with learning disabilities, or people with like autism, like that. It's very hard to understand them like that, and it's very good like that"* (TW05)

The Health Passport or similar concepts such as a patient checklist was mentioned by several community stakeholders as an important factor in effective communication and information sharing. Knowing what a person with ID can do for themselves or what assistance may be needed for meals and personal care was indicated as a way to reduce lapses in basic care, noted by one community stakeholder "*Be patient, learn a bit more about them, because that's what the intention of the health passport was - so you don't have to rely on the person who's unwell or someone around them"* (CSH04).

The creation of a health profile for people was noted by one stakeholder as something that Aotearoa as not good at developing. While the Health Passport was an item that was well known by community stakeholder participants across the country, there appeared to be no cohesive use of the Health Passport throughout Aotearoa. This can lead ot frustration when information is provided and not used.

Digital Barriers

Three community stakeholder participants discussed the possibility of the Health Passport being moved to an online format. While one was supportive of the idea of digital health passports, the others had concerns about whether digitising the passport would make any difference if it was not read by hospital staff, and one was concerned about digital barriers for people with ID:

> *"Yes, but to my mind, that's even worse. People, a lot of people can't afford anything digital and it's their living document. It's not our living document, it's their living document. I work with a lot of clients who could never use anything digital and it's about them - for them. So, I'm pretty anti that"* (CSH09)

Digital barriers were also mentioned by one tāngata whaiora who described her frustration at being told to look up information online: "*They say, 'go online' and a lot of people with disabilities don't understand going online"* (TW02). These remarks indicate the importance of providing accessible information without barriers for people with ID that are made in consultation with tāngata whaiora and their support networks.

Putting it All Together - Facilitators to Effective Care

There were several ways that participants felt hospitals could better support people with ID. The most prominent request was a specialist ID nurse role, advocate or liaison person in hospitals. This role was described as needing to be filled by a person with experience and knowledge of how to work with tāngata whaiora and their families. People that have previously worked in disability support but who do not necessarily have medical training were seen as especially useful:

“I had the recent experience of meeting a "Behaviour Support Nurse" at one of the hospitals. She was brilliant and the 'watch' had been a community support worker with a disability support organisation and had experience in the area. Together they made a great team and I could see they knew what they were doing, the person was being well cared for (and cooperative!). This experience is one of the best examples of care I have seen and I hope it can be extended to other hospitals/areas” (SHQ4)

CHAPTER FIVE: DISCUSSION

There is little known about the hospitalisation experiences of people with ID in Aotearoa. Given this, the aim of this research was to gain insight into what the experience of hospitalisation for tāngata whaiora and community stakeholders who support tāngata whaiora in Aotearoa is, to better understand what are the things that make the experience easier for people with ID, and what were the things that negatively impact the experience. Using thematic analysis of interviews with tāngata whaiora and with community stakeholders, eight main themes of tāngata whaiora's perspectives of the hospital environment, communication needs, lapses in basic care and patient safety, mistrust of the hospital system, patient-centered care, training and education, support and advocacy, and health passports were produced.

Tāngata Whaiora Perception of the Hospital Environment

While two tāngata whaiora participants described feeling anxious or scared about being in hospital, most participants felt positive about being in the hospital environment. These views may reflect a desire to please people or say the right thing. For tāngata whaiora in this study, supportive, friendly and communicative hospital staff and support people were cited as primary reasons for feeling positive about prior hospital admissions. There is a possibility that positive experiences of hospitalisation may relate to tāngata whaiora having one to one time and attention with hospital staff or their support people. Additionally, having someone to talk to was indicated as helpful for reducing anxiety. In contrast, community stakeholders perceived tāngata whaiora experiences of hospitalisation as traumatising, bewildering and overwhelming. The community stakeholder participants cited the stress of an unfamiliar environment, unfamiliar people, and a person's inability communicate or to understand what was happening to them as the main reasons for perceiving hospitalisation for tāngata whaiora in this way. This complements previous research with people with ID which found that fear and anxiety during hospitalisation have been noted as common issues (Iacono et al., 2014; Phillips, 2019; Tuffrey-Wijne et al., 2014) and these feelings are likely exacerbated by the things highlighted by stakeholders.

Participants with ID indicated a preference for not being placed in a hospital room alone and wanting the support and connection of others. These findings are similar to those of Gibbs and colleagues (2008), whose participants with ID described feeling bored when there was nobody to talk to and feeling better when able to talk to others.

However, in contrast to the wishes of tāngata whaiora, the findings of this study revealed that community stakeholder participants preferred private rooms for patients with ID. Reasons for this included concern that people with ID would not cope being around strangers, and a desire to manage potentially disruptive behaviour of the tāngata whaiora in privacy. This contrasts with the community stakeholders from the same study by Gibbs and colleagues (2008) felt most of their residents could be in the main ward with other patients.

Communication Needs

There is a significant body of research that focuses on the communication challenges of people with ID, and the barriers to communication between hospital staff and patients with ID (Iacono et al., 2014; McCormick et al., 2021). When medical staff lack an understanding about how to communicate with people with ID it affects every aspect of the hospital experience from how a person with ID is understood by hospital staff, how patients with ID understand information from hospital staff, the treatment received, the risk of incidents related to patient safety, the level of support required from carers and ID service providers, through to how pain is managed.

ID service providers and carers are crucial to facilitating communication on behalf of tāngata whaiora in hospital. Previous studies have described nurses' frustration at patients with ID presenting in hospital without sufficient documentation (Lewis et al., 2017). This was said to hinder communication, the process of diagnosis and the timely receipt of treatment Lewis et al., 2017; Sowney & Barr, 2006). The findings from this study indicated the lengths that community stakeholders go to in providing information about the needs of tāngata whaiora, through the creation and provision of ‘patient profiles’. When these simple checklists are not read or considered by hospital staff, this can lead to injury or additional illness due to omissions in the provision of basic care, such as eating or turning requirements and exacerbate the frustrations that are felt.

Past studies have revealed that hospital staff may overlook communicating with people with ID directly, often on the presumption they would not understand (Charles, 2020). Hospital staff were seen as unable or unwilling to interpret the patient’s cues, which led to an overreliance on support people as surrogate communicators for people with ID (Charles, 2020). The tāngata whaiora, participants in this study felt that they were well-spoken to by doctors and nurses. Some support people involved in this study felt that the time hospital staff took to talk to tāngata whaiora may have been influenced by their presence, and one participant with ID described needing a person at hospital so that they did receive the correct information about their health.

Lapses In Basic Care and Patient Safety

Community stakeholder participants described many instances of a perceived lack of basic nursing care by hospital staff. Several participants connected a lack of care to incidents where the people they supported developed pressure injuries. Similar to the findings of a study by Davis and colleagues (2003), community stakeholders in this study attributed oversights and omissions in the provision of basic nursing care to extended hospital stays due to injuries, or the development of pneumonia caused by a patient not being turned regularly. Similar incidents have been noted in the existing literature as causing a patient avoidable harm (Hemsley et al., 2011), which can occur through under-monitoring patients and of their comfort and distress, not turning a patient enough to avoid pressure areas, having insufficient information about eating and drinking routines, and the avoidance of assistance with showering and toileting (Tuffrey-Wijne et al., 2014). The community stakeholders in this study described the lengths they went to in ensuring that hospital staff had information about the patient's needs and described frustration that patient information and basic environmental cues about a patients' needs were ignored by hospital staff. That frustration may also extend to the additional work that lapses in basic nursing care may add to community stakeholders, who described their industry as currently experiencing staffing shortages. Thes shortages were also said to affect their ability to provide staff when residents were hospitalised.

Meals and Menus

Having to wait for a meal or having no assistance with drinking were identified as issues by participants with ID. Additionally, community stakeholders perceived many issues with menus in hospitals; primarily that people with ID often have difficulties with numeracy and literacy, and menus can be confusing to understand. An easier menu format was identified as one way the hospital could adjust to support people with ID who need to stay in hospital overnight.

Furthermore, community stakeholders described instances where meals were left in front of patients who could not eat without the support of nursing staff. This was related to a lack of communication with tāngata whaiora about their specific needs, and hospital staff not reading information provided by ID service providers about such requirements. Past research has found that people with ID are at risk of experiencing deterioration to their health when meals are missed, especially in longer term hospital stays (Hemsley et al., 2011; Webber et al., 2010). The study's findings support this, with one community stakeholder describing an

inattention to ensuring patients were able to eat meals as leading to the deterioration of health in the people she supports.

Aside from potential malnutrition, food is an important factor in the safe use of pharmaceuticals (Flood, 2017) and a lack of food intake can impact safe use of medicines. One community stakeholder recalled medication being put in yoghurt which was not eaten, as no assistance was provided to the patient to do so. Additional issues related to meals included an instance of avoidable harm, as in one example where hospital staff brought a patient hot coffee which led to burns. The community stakeholder perceived this as a lack of care on the part of nursing staff, who had ignored the coffee mug with a safety lid they had provided for the patient. Additionally, ignoring the environmental cues in this patient's room shows a lack of adaptability of care and a disregard for the individual's needs that could have been avoided by asking the person about any requirements they needed to drink coffee safely.

Pain Management

People with ID often have trouble communicating their symptoms, pain or feelings of distress. Research has previously identified that despite nurses placing high importance on the ability to communicate about pain and the ability to identify pain in patients with ID, insufficient knowledge or aids to assist communication with tāngata whaiora may impact on their ability to do both (Hemsley et al., 2011). This can affect the timely provision of pain management and comfort in hospital.

Confusion around how to best manage pain relief was indicated as problematic in this study's findings, with some community stakeholders describing anxiety over how to best provide sufficient pain relief and medications without any clear guidance. Such concerns were especially prominent for community stakeholders working in residential homes who did not have medical training.

More specific guidelines on how to provide pain relief to people who cannot communicate their pain was indicated as one way to make future hospitalisations easier for community stakeholders and people with ID. Additionally, Taylor and colleagues (2014) found that the DISDAT (Disability Distress Assessment Tool) can be a successful measuring tool for pain and distress for people with a Learning Disability, who are cared for in residential homes by people with a range of skills, qualifications, training and experience. Therefore, the DISDAT may be a useful tool to identify pain in people with ID which could be utilised by community stakeholders who are not medically trained.

Wait Times

This study found that long wait times in hospital was challenging for tāngata whaiora, which has been cited as problematic for people with ID in previous studies (Gibbs et al., 2008). Additionally, community stakeholders described issues with long wait times, especially in the Emergency Department (ED), and this was indicated as problematic for some tāngata whaiora who struggle with sitting still. This may also reflect challenges for caregivers and community stakeholders, who are concerned about managing the potential of tāngata whaiora becoming distressed or exhibiting behavioural outbursts. Past studies have found that community stakeholders did not find waiting in hospital to be problematic (Gibbs et al., 2008), which supports the majority view of this study's tāngata whaiora participants, but contradicts the majority of community stakeholder perspectives in this study who described long wait times as potentially increasing distressed states in some residents.

Moreover, community stakeholders described the challenges of waiting before surgery. One community stakeholder described their desire for a priority pathway which would allow quicker admissions and greater flexibility for people with ID, and which they felt could alleviate potentially challenging behaviours. This is an example of reasonable adjustments to the hospital system, as described by Read and colleagues (2018), where changes to a hospital's existing process can benefit the person with ID and the people who support them (Read et al., 2018). Making reasonable adjustments to the hospital process is also said to be a crucial element of patient-centered care (Drozd et al., 2020) and can improve the hospital experience for tāngata whaiora.

Discharge Planning

Community stakeholders can feel unprepared to care for people with ID after discharge from hospital. The findings from this study indicate that people with ID often live in residential facilities in the community where they are supported by staff without medical training. Additionally, ID service providers described a sense of frustration that hospitals did not seem to understand the level of support residential facilities were able to provide patients after being discharged. These sentiments are consistent with the findings of an earlier study, which found that poor discharge planning placed significant burdens on community stakeholders to provide sufficient care to patients recently discharged and elevated the risk of patient harm due to having limited time and resources available to support an unwell person's needs at short notice (Webber et al., 2010). Additional concerns from the findings of this study related to hospitals discharging patients on Friday afternoons, which meant that equipment, medications and needs assessments were unable to be arranged in time to

support the continuity of care for a person with ID, concerns that were consistent with the findings of Ali et al (2013).

Continuity of Care

Community stakeholders in this study described frustration at the lack of continuity between the hospital and NASC. Additionally, this study found that NASC agencies were perceived as inflexible in responding to the needs of people with ID after hospitalisation, and were viewed as passing responsibility on supporting people with ID when their needs were related to a medical event. This echoes findings abroad which found a need for better information sharing between primary, secondary and ID service providers to improve morbidity and mortality rates and quality of life for people with ID (Ali & Hassiotis, 2008). Reducing disruptions to the continuity of care for people with ID was of special concern to many community stakeholders in this study. Prior research has found that specialist disability liaison services in hospitals can effectively facilitate the discharge process through facilitating and planning equipment needs and by linking people with ID to additional support services to ensure continuity of care in the community (Brown et al., 2016a; Bur et al., 2021; Castles et al., 2014).

Mistrust of the Hospital System

In this study, most community stakeholders shared a strong sense of mistrust in the hospital system due to perceptions of omissions in basic nursing care that had a detrimental effect on patients' health. The implications of this are that ID service providers feel obligated to spend additional hours at hospital when residents are admitted ensuring that the patients' needs are being met and to keep them safe from harm.

Previous studies indicate that discrimination in medical decision making may occur due to negative perceptions about the quality of a person's life and personal beliefs about the value of the lives of tāngata whaiora (Bogart & Dunn, 2019; Chicoine et al., 2022; Gibbs et al., 2008). In this study, prior experiences of hospital where community stakeholders had perceived discrimination in relation to access to treatments for people with ID appeared to contribute to the mistrust they felt. Participants recalled medical decisions being made about people with ID that they felt would never have been a question for people without a disability. Participants in this study related negative perceptions of ID to a lack of knowledge and inadequate training during and after university.

While the findings of this study revealed many issues of trust about the hospital system, these feelings often sat parallel to acknowledgments of a system that community stakeholders and participants with ID see as stressed and overwhelmed. A review of the literature did not find a similar theme in which consideration for the people that work in hospitals were interwoven with feelings of being let down by the system. Participants in this study signalled that they felt that inadequate care was a significant issue for people with ID, while acknowledging that individuals in the hospital were trying hard under incredibly intense circumstances. This may be a reflection of this study taking place after three years of the COVID-19 pandemic. It may also be that many of the community stakeholder participants were qualified nurses with many decades of experience and familiarity of the role of nursing staff especially.

Patient-Centered Care

At the heart of the findings of this study lies the concept of patient-centered care. This is said to involve seeing a person before seeing their condition, and compassionately and flexibly responding to the needs of the individual. Making reasonable adjustments to the hospital system can improve the experience of hospitalisation for both tāngata whaiora and the ID service providers who support them (Bell, 2012; Iacono et al., 2014; McCormick et al., 2021; Tuffrey-Wijne et al., 2014). In addition, hospital care that is attentive to the needs of tāngata whaiora is suggested in prior research as a way to decrease the prevalence of adverse events and avoidable harm which can lead to long hospital stays and readmissions (Bartlett et al., 2008; Brown et al., 2016a; Davis et al., 2003; Flood, 2017; Hemsley et al., 2011).

A lack of patient-centered care and a desire for this was prominent in this study's findings and interweaves with all other themes produced. In this study, the participants with ID identified simple ways that they could feel better about being in hospital. This included shorter wait times in hospital, having their support people able to stay or visit, having access to people to talk to, having the time to ask and respond to questions, having access to the call bell, and coping strategies that helped pass the time such as music, activities or devices. Additionally, tāngata whaiora in this study identified the desire for an advocate who can assist their needs within the hospital system.

Past studies have argued that long wait times, inflexible admission and discharge processes, inadequate nursing care, and deficits in adapting communication to meet the needs of people with ID are signs of staff or the hospital systems failing to reasonably adjust to the needs of tāngata whaiora (Iacono et al., 2014; McCormick et al., 2021). Community

stakeholders in this study also identified the many ways in which the hospital system could adapt their processes or environment to ensure the delivery of patient-centred care. Like the participants with ID, community stakeholders described the necessity for priority screening to reduce long wait times for people with ID and ensuring that patients had access to the support people they were familiar with, along with some home comforts that made them feel less anxious.

Additionally, community stakeholders indicated that people with ID can be invisible to hospital staff and felt that hospital staff could be more aware of the person they were treating and ask the patient about their individual needs. Moreover, having a system for sharing information about people with ID and their requirements so that the delivery of patient-centred care could occur was significant in the study's findings. Previous studies have indicated that a health passport can communicate a patient's preferences and allow the hospital to make reasonable adjustments to facilitate a better experience for tāngata whaiora (McCormick et al., 2021). The findings of this study ed that some community stakeholders did not trust hospital staff to read information provided and felt that hospital passports were only useful if everyone in the hospital system used them adequately.

Training and Education

Knowledge about the complex and diverse nature of ID and hospital staff having a lack of specialised training have been noted as impacting on good health outcomes for people with ID in previous studies (Appelgren et al., 2018; Flood, 2017; Folch-Mas et al., 2017). Moreover, insufficient education about ID has been found to impact on the confidence of nursing staff, leading to an overreliance on carers (Sowney & Barr, 2006). Concern about a perceived lack of specialist education about ID in Aotearoa was a recurring theme in this study's findings. For community stakeholders in this study, there was concern that training about ID was virtually non-existent in Aotearoa's education institutions, and that medical students were lacking basic knowledge about disabilities in general. It was suggested by participants that sufficient training about ID begin at undergraduate level and continue through to ongoing education in the hospital system.

How much education Aotearoa's universities provide medical students about ID is unclear. This may be an important avenue for research, as a lack of inclusion about ID in medical training may suggest that discrimination against tāngata whaiora begins with omissions in the training and education of hospital staff at university, which works to make people with ID invisible in healthcare.

Furthermore, research has shown that educating hospital staff about the unique needs of people with ID may lead to reduced stigma about ID (Appelgren et al., 2018). Studies show that expressions of explicit bias are evaluations that are accessible in a person's mind and able to be controlled, and therefore able to be changed over time (Wilson & Scior, 2015). Changing discriminatory perceptions of ID may occur through training and education about ID (Garland-Thomson, 2017; Wilson & Scior, 2015). Therefore, undergraduate and postgraduate education focusing on patient-centred care in relation to ID is suggested as a way to reduce health inequalities for people with ID, by promoting hospital environments in which individualised, patient-centred care can flourish (Appelgren et al., 2018).

Support and Advocacy

The study's findings reveal the importance of tāngata whaiora having access to familiar support people during hospitalisation. Support people can offer company, comfort and often play a crucial role in communicating on behalf of people with ID and hospital staff. They may also act as advocates for tāngata whaiora in getting their health needs met. This role may be filled by a whānau member, or an ID service provider situated in community living residences. The study's findings showed the lengths that community stakeholders often go to, to ensure that the people they support are safe in hospital and supported correctly after discharge.

Specialist Disability Support

In this study, participants with ID described wanting a 'special person' to help them understand information in hospital, and to help them communicate their needs in the hospital system. One participant acknowledged that this person needs to be more than just a 'supportive' friend, they needed to have knowledge of the hospital system and an ability to communicate what is being said. Community stakeholder participants agreed, all of whom described a need for a specialist liaison role within the hospital system to facilitate and advocate for people with ID. Some community stakeholders were able to identify one or two instances of this type of role being offered in hospitals across Aotearoa, where nurses had been placed in the role of disability liaison with good effect.

Nurses with knowledge and clinical expertise in the care of people with ID have been established within acute hospitals in the UK (Brown et al., 2016a) in specialised nursing roles, such as the Intellectual Disability Liaison Nurse (IDLN) role or the Learning Disability Liaison Nurse (LDLN) role. This role offers additional expertise and support to patients with learning or intellectual disabilities (Brown et al., 2016a). The role comprises

the management and administration of person-centered care, liaison, education, advocacy and mediation between patients, treating teams and carers, and ensures communication is adjusted to the patient's capacity (Bur et al., 2021). Studies show the IDLN role plays a pivotal part in the promotion of positive hospital experiences for hospital staff, carers and people with ID (Brown et al., 2012b; Castles et al., 2014; Iacono et al., 2014; McCormick et al, 2021; Phillips, 2019).

There was overwhelming agreement that a IDLN role should exist across all hospitals in Aotearoa, as it would be hugely beneficial to supporting tāngata whaiora during hospitalisation. Many of this study's participants described small adjustments to the hospital environment that would be beneficial to people with ID, such as activities or people to talk to for support or company. In past research, patients and carers perceived the IDLN/LDLN role as promoting positive experiences, supporting patients in making choices, and facilitating adjustments to the hospital environment (Brown et al., 2012b). Additionally, patients and carers in previous studies found the IDLN/LDLN facilitated access to services, with the provision of preadmission planning that ensured care needs were identified and ensured appropriate services were put into place prior to hospitalisation (Brown et al., 2012b).

The IDLN/LDLN role has been found to facilitate reasonable adjustments during hospitalisation, and effectively facilitate the discharge planning process through to transfer from hospital, which has been found to increase continuity of care for patients with ID (Brown et al., 2016a; Bur et al., 2021; Castles et al., 2014). Community stakeholders in this study identified the need for more cohesive discharge planning and better support from NASC agencies for tāngata whaiora after hospitalisation, and the IDLN/LDLN role could arguably fill some of those gaps.

Finally, previous studies have shown that through their role, liaison nurses have contact with a wide variety of clinicians, from doctors through to general practitioners (GP's). Their expertise and the facilitative nature of the role were seen as opportune for delivering education to hospital staff and students on clinical placements (Brown et al., 2012b). Having IDLN/LDLN's available to support tāngata whaiora could in turn support hospital staff and encourage confidence in working with tāngata whaiora in Aotearoa.

Health Passports

For people with ID, barriers in communicating impacts all aspects of the hospital experience. The ability to identify the needs of people with ID can also be challenging for

hospital staff with limited knowledge of their unique communication style, and this can lead to an overreliance on carers to communicate and provide advocacy (Ali et al., 2013). Additionally, communication barriers can lead to instances of avoidable harm when communication cues are missed or misinterpreted. Moreover, the transfer of information about tāngata whaiora individual needs is important for the provision of individualised, patient-centred care. The Health Passport is one tool that can provide information about a person with ID to health professionals. As an example, the correct use of a Health Passport allowed one hospital to quickly identify a patient's unique communication needs, which led to the hospital system adjusting its communication by implementing the use of visual aids to facilitate a positive and safe hospital experience for that patient (McCormick et al., 2021).

Health Passports for people with ID are primarily designed to be read by healthcare professionals in hospitals and clinics (Heifetz & Lunsky, 2018). They provide brief but substantial information about the person that can include a photograph of how the person looks when they are in optimal health, the persons communication style (including whether they are verbal or nonverbal), medical history, likes or dislikes, current medications, eating and drinking schedules, and notes on the individuals capacity to cope with medical procedures (Heifetz & Lunsky, 2018). Health Passports are living documents that can be easily modified, providing consistency for tāngata whaiora in the health system (Heifetz & Lunsky, 2018). Descriptive studies on the efficacy of Health Passports found that their use improved hospital stays for people with ID, however, for the passports to work, all healthcare staff needed to be aware of their existence (Heifetz & Lunsky, 2018). Dinsmore (2011) also viewed Hospital Passports as an effective way to improve the hospital experience but noted that this only work when staff use them, and not all staff did. In this study community stakeholder participants had mixed feelings about the Health Passport. For some there was a sense of mistrust that hospital staff did not take the time to read the information provided in patient profiles or Health Passports. A solution to this may be having the Health Passport visible in the room with the patient.

For others, the Health Passport was indicated as a useful tool but one that was inconsistently used across hospitals in Aotearoa. Additionally, there were some concerns that the Health Passport may become digitalised, which was identified as a barrier for many tāngata whaiora who do not have access to digital devices which may prevent them accessing their living document. Changes to Health Passports should therefore, be made in consultation with people with ID, or be accessible in all formats.

Limitations of the Study

The current study included the perspectives of both adults with ID and community stakeholders who support tāngata whaiora, and participants were recruited from across Aotearoa. Demographically the study's participants were primarily NZ/European and mostly female. The study aimed to recruit 6 – 10 tāngata whaiora participants and 6 –10 community stakeholder participants. The final sample size for tāngata whaiora included five participants. Additionally, four online survey responses were received from people with ID, but two responses only included demographic information and no responses to questions were provided and so were unable to be included in the analysis. The final sample size for community stakeholders included nine participants. Five survey responses were received from community stakeholders. A limitation of this study may be the imbalance of tāngata whaiora participant numbers, whose views may be decentered or overwhelmed by the perspectives of the larger group of community stakeholders involved in the study.

It has been indicated in the literature that carers or community stakeholders may seek to protect the people they support, and this may lead to adults with ID being excluded from the opportunity to participate in research (Brooker et al., 2015; Nicholson et al., 2013; Rosencrans et al., 2021). Building relationships with carers and other stakeholders has been indicated as one way to resolve this. On reflection, the recruitment of tāngata whaiora may have been easier if connections were made with community stakeholders first. In this study, three of the community stakeholder participants became proactively involved in recruiting on the researcher's behalf, and this led to snowball recruitment of four tāngata whaiora participants in November 2022, although only three participants with ID continued through to an interview. Had the recruitment of community stakeholder participants been the initial focus, recruitment of adults with ID may have occurred much earlier in the study.

The criteria for the study may have been too specific or stringent, as the study asked for participants who had been hospitalised overnight and within the past six months. A common remark in interviews with tāngata whaiora was that they were more likely to access Emergency Department (ED) services, and outpatient services such as audiology or diabetes support. While this does not fit the study's criteria, the experiences of obtaining support in the hospital system are still pertinent to understanding barriers tāngata whaiora may experience when accessing healthcare services. The study may have benefited from widening the timeframe criteria for tāngata whaiora being hospitalised, as well as the inclusion of day stay experiences.

Another limitation of the study may be its design. The study was designed to be accessible to tāngata whaiora through easy read Participant Information Sheets (PIS), easy read surveys, and an online interview option intended to reduce barriers to participation. However, the study may have reached more adults with ID had the information been further simplified, as suggested by a community stakeholder participant who was knowledgeable about easy read formatting. However, producing such documents may be costly and would require preplanning to reduce delays to recruitment (Tuffrey-Wijne & Butler, 2010) and were beynod the scope of this project as an Honors dissertation. It was also highlighted by community stakeholders that many of the people they support do not have access to the internet or their own devices, and this may have prohibited people from participating in this study. Furthermore, as one tāngata whaiora participant discussed, not everybody understands what going "online" means, and depending on the severity of a person's ID this may also have prohibited their inclusion in this study.

Implications and Recommendations for Future Research

The small number of tāngata whaiora participants necessitate further research which involves people with ID. This would provide a deeper understanding of the challenges they face in accessing healthcare services and may provide additional information about how to better serve their needs in the healthcare system.

Additionally, this study did not seek to recruit any participants who were trained and employed by hospitals as doctors or nursing staff. It would be beneficial to understand the perspectives of doctors and nurses in treating people with ID, as this may reveal challenges or barriers to effective change in the hospital system. Previous studies identified that a lack of familiarity or knowledge about ID can impact on healthcare professionals' clinical confidence (Sowney & Barr, 2006). This may have ramifications for the quality of care provided to people with ID. Understanding the perspectives of medical staff would therefore be useful to consider in future research in Aotearoa.

Additionally, the study identified that community stakeholders perceived Aotearoa's universities and training institutions as not providing sufficient training about ID to medical students. Participants also described a lack of professional development about ID in the healthcare sector more broadly. Recruiting participants from medical training facilities may provide new insight into the state of training and education about ID, and whether changes to training and education could be made.

Further studies would benefit from focusing on the recruitment of tāngata whaikaha (Māori with ID) and other ethnicities to explore additional inequalities non-European people with ID may face in accessing healthcare services. Recruiting tāngata whaikaha may provide an understanding about what culturally appropriate services would look like for tāngata whaikaha. Additionally, if changes are to be made to documents such as menus or Health Passports, participation in the planning, design and implementation should include tāngata whaikaha, and include consultation about translations to te reo Māori as well.

Conclusion

There is a scarcity of published research exploring the hospitalisation experiences of tāngata whaiora with ID in Aotearoa. The current study has contributed to this subject, shedding light on how people with ID experience hospitalisation. The findings of this study were consistent with previous research, suggesting that better hospital experiences and health outcomes for people with ID are possible when care is centred on the individual and not the disorder. People with ID respond to kind and communicative hospital staff that take the time to explain things to them. Additionally, reasonable adjustments to the hospital system, such as reduced waiting times, activities or strategies that help people with ID cope with boredom, ensuring that people with ID are not segregated in hospital, and adjusting to the person's communication capabilities, are all indicated as ways to ensure positive hospital experiences for tāngata whaiora.

This study included the perspectives of community stakeholders who work in support of people with ID, which added another layer of understanding about the barriers and facilitators to the provision of appropriate medical care, as well as an understanding about how to create more positive experiences for people with ID during hospitalisation. Community stakeholders indicated that communication barriers are contributing to challenges to hospitalisation for tāngata whaiora. For these participants, ensuring the safety of the people they support during hospitalisation was paramount. The findings from this study revealed that community stakeholders felt a sense of mistrust in the hospital system due to experiences where people they support had received insufficient care in hospital which led to injury or further illness. In addition, there was a strong desire to see reasonable adjustments to the hospital process enacted to support people with ID. Suggestions about how to improve the hospital system included considering the individual's needs to ensure the provision of basic nursing care, priority screening and shorter waiting times, the addition of a IDLN and adjustments to the environment which may include a person's coping strategies, such as going for a short walk. This study found that changes to the education and training

of hospital staff about the unique and diverse nature of ID was important, and that better education about ID may encourage patient-centered care that is respectful of the person's individual needs.

People with ID experience many complex challenges with their health and are a diverse group with unique needs. This study has explored the hospitalisation experience of people with ID, including the challenges and enhancers to better hospital experiences from the perspectives of people with ID, and the community stakeholders who support them, and has provided further understanding to this area of research.

References

Ailey, S. H., Johnson, T., Fogg, L., & Friese, T. R. (2014). Hospitalizations of Adults with Intellectual Disability in Academic Medical Centers. *Intellectual and Developmental Disabilities, 52*(3), 187–192. https://doi-org.ezproxy.aut.ac.nz/10.1352/1934-9556-52.3.187

Ali, A., Scior, K., Ratti, V., Strydom, A., King, M., & Hassiotis, A. (2013). Discrimination and Other Barriers to Accessing Health Care: Perspectives of Patients with Mild and Moderate Intellectual Disability and Their Carers. *PLOS ONE, 8*(8), e70855. https://doi.org/10.1371/journal.pone.0070855

Ali, A., & Hassiotis, A. (2008). Illness in people with intellectual disabilities. *BMJ (Clinical Research Ed.), 336*(7644), 570–571. https://doi.org/10.1136/bmj.39490.543137.80

Andrews, E. E., Ayers, K. B., Brown, K. S., Dunn, D. S., & Pilarski, C. R. (2021). No body is expendable: Medical rationing and disability justice during the COVID-19 pandemic. *American Psychologist, 76*, 451–461. https://doi.org/10.1037/amp0000709

Appelgren, M., Bahtsevani, C., Persson, K., & Borglin, G. (2018). Nurses' experiences of caring for patients with intellectual developmental disorders: A systematic review using a meta-ethnographic approach. *BMC Nursing, 17*(1), 51. https://doi.org/10.1186/s12912-018-0316-9

Bacherini, A., Havercamp, S. M., & Balboni, G. (2021). Physicians' Attitudes about Individuals with Intellectual Disability and Health Care Practices Toward Them: A Systematic Review. *Psychiatria Danubina, 33*(Suppl 11), 79–90. https://pubmed.ncbi.nlm.nih.gov/34862898/

Barrett, A., Kajamaa, A., & Johnston, J. (2020). How to… be reflexive when conducting qualitative research. *The clinical teacher, 17*(1), 9-12. https://doi.org/10.1111/tct.13133

Bartlett, G., Blais, R., Tamblyn, R., Clermont, R. J., & MacGibbon, B. (2008). Impact of patient communication problems on the risk of preventable adverse events in acute care settings. *CMAJ, 178*(12), 1555–1562. https://doi.org/10.1503/cmaj.070690

Beail, N., & Williams, K. (2014). Using qualitative methods in research with people who have intellectual disabilities. *Journal of applied research in intellectual disabilities: JARID, 27*(2), 85–96. https://doi.org/10.1111/jar.12088

Bell, R. (2012). Does he have sugar in his tea? Communication between people with learning disabilities, their carers and hospital staff. *Tizard Learning Disability Review, 17*(2), 57–63. https://doi.org/10.1108/13595471211218712

Berger, R. (2015). Now I see it, now I don't: researcher's position and reflexivity in qualitative research. *Qualitative Research, 15*(2), 219–234. https://doi.org/10.1177/1468794112468475

Bigby, C., Webber, R., & Bowers, B. (2015). Sibling roles in the lives of older group home residents with intellectual disability: Working with staff to safeguard wellbeing. *Australian Social Work, 68*(4), 453-468. https://doi.org/10.1080/0312407X.2014.950678

Bogart, K. R., & Dunn, D. S. (2019). Ableism Special Issue Introduction. *Journal of Social Issues, 75*(3), 650–664. https://doi.org/10.1111/josi.12354

Bourne, M. J., Smeltzer, S. C., & Kelly, M. M. (2021). Healthcare inequities among adults with developmental disability: An integrative review with implications for nursing education. *Nurse Education in Practice*, *57*, 103225. https://doi.org/10.1016/j.nepr.2021.103225

Bradbury-Jones, C., Rattray, J., Jones, M., & MacGillivray, S. (2013). Promoting the health, safety and welfare of adults with learning disabilities in acute care settings: a structured literature review. *Journal of Clinical Nursing*, *22*(11-12), 1497-1509. https://doi.org/10.1111/jocn.12109

Braun, V., Clarke, V., Boulton, E., Davey, L., & McEvoy, C. (2021). The online survey as a qualitative research tool. *International Journal of Social Research Methodology*, *24*(6), 641-654. https://

Braun, V., Clarke, V., Hayfield, N., Terry, G. (2019). Thematic Analysis. In: Liamputtong, P. (eds) Handbook of Research Methods in Health Social Sciences. Springer, Singapore. **h**ttps://doi.org/10.1007/978-981-10-5251-4_103

Braun, V., Clarke, V. (2013). Successful Qualitative Research: A Practical Guide for Beginners. Sage Publications, Thousand Oaks

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, *3*(2), 77-101.

Brooker, K., van Dooren, K., Tseng, C.-H., McPherson, L., Lennox, N., & Ware, R. (2015). Out of sight, out of mind? The inclusion and identification of people with intellectual disability in public health research. *Perspectives in Public Health*, *135*(4), 204–211. https://doi.org/10.1177/1757913914552583

Brown, M., Chouliara, Z., MacArthur, J., McKechanie, A., Mack, S., Hayes, M., & Fletcher, J. (2016a). The perspectives of stakeholders of intellectual disability liaison nurses: A model of compassionate, person-centred care. *Journal of Clinical Nursing*, *25*(7–8), 972–982. https://doi.org/10.1111/jocn.13142

Brown, M., MacArthur, J., McKechanie, A., Mack, S., Hayes, M., & Fletcher, J. (2012b). Learning Disability Liaison Nursing Services in south-east Scotland: a mixed-methods impact and outcome study. *Journal of intellectual disability research : JIDR*, *56*(12), 1161–1174. https://doi.org/10.1111/j.1365-2788.2011.01511.x

Brunton, W. (2003). The origins of deinstitutionalisation in New Zealand. *Health and History*, *5*(2), 75-103. Retrieved June 17, 2022, from https://www-jstor-org.ezproxy.aut.ac.nz/stable/40111454?seq=1

Buckley, N., Glasson, E. J., Chen, W., Epstein, A., Leonard, H., Skoss, R., ... & Downs, J. (2020). Prevalence estimates of mental health problems in children and adolescents with intellectual disability: A systematic review and meta-analysis. *Australian & New Zealand Journal of Psychiatry*, *54*(10), 970-984. https://journals.sagepub.com/doi/10.1177/0004867420924101

Bur, J., Missen, K., & Cooper, S. (2021). The impact of intellectual disability nurse specialists in the United Kingdom and Eire Ireland: An integrative review. *Nursing open*, *8*(5), 2018-2024. https://doi.org/10.1002/nop2.690

Byrne, D. (2022) A worked example of Braun and Clarke's approach to reflexive thematic analysis. *Qual Quant* **56**, 1391–1412 . https://doi.org/10.1007/s11135-021-01182-y

Caldwell, K. (2014). Dyadic interviewing: A technique valuing interdependence in interviews with individuals with intellectual disabilities. *Qualitative Research*, *14*(4), 488–507. https://doi.org/10.1177/1468794113490718

Castles, A., Bailey, C., Gates, B., & Sooben, R. (2014). Experiences of the implementation of a learning disability nursing liaison service within an acute hospital setting: A service evaluation. *British Journal of Learning Disabilities*, *42*(4), 272–281. https://doi.org/10.1111/bld.12070

Charles, M.L. (2020). Communication experiences of family caregivers of hospitalized adults with intellectual and developmental disabilities—A qualitative study. *Nursing Open*; 7: 1725– 1734. https://doi-org.ezproxy.aut.ac.nz/10.1002/nop2.557

Chicoine, C., Hickey, E. E., Kirschner, K. L., & Chicoine, B. A. (2022). Ableism at the Bedside: People with Intellectual Disabilities and COVID-19. *The Journal of the American Board of Family Medicine*, *35*(2), 390–393. https://doi.org/10.3122/jabfm.2022.02.210371

Crotty, M. J. (1998). The foundations of social research: Meaning and perspective in the research process. *Taylor & Francis Group*, 1-256. http://ebookcentral.proquest.com/lib/aut/detail.action?docID=5161332

Davis, P., Lay-Yee, R., Briant, R., Ali, W., Scott, A., & Schug, S. (2003). Adverse events in New Zealand public hospitals II: Preventability and clinical context. *The New Zealand Medical Journal*, *116*(1183), U624.

Dieckmann, F., Giovis, C., & Offergeld, J. (2015). The Life Expectancy of People with Intellectual Disabilities in Germany. *Journal of Applied Research in Intellectual Disabilities*, *28*(5), 373–382. https://doi.org/10.1111/jar.12193

Dinsmore, A. P. (2012). A small-scale investigation of hospital experiences among people with a learning disability on Merseyside: Speaking with patients and their carers. *British Journal of Learning Disabilities*, *40*(3), 201–212. https://doi.org/10.1111/j.1468-3156.2011.00694.x

Dodgson, J. E. (2019). Reflexivity in qualitative research. *Journal of Human Lactation*, *35*(2), 220-222.

Doody, O., & E. Bailey, M. (2017). Pain and pain assessment in people with intellectual disability: issues and challenges in practice. *British Journal of Learning Disabilities*, *45*(3), 157-165. https://doi.org/10.1111/bld.12189

Drozd, M., Chadwick, D. and Jester, R. (2021) Successful strategies for including adults with an intellectual disability into a research study using interpretative phenomenological analysis (IPA). Nurse Researcher, 29 (3), pp.34-41. https://doi.org/10.7748/nr.2021.e1778

Drozd, M., Chadwick, D., & Jester, R. (2020). An integrative review of the hospital experiences of people with an intellectual disability: Lack of orthopaedic and trauma perspectives. *International Journal of Orthopaedic and Trauma Nursing*, *39*, 100795. https://doi.org/10.1016/j.ijotn.2020.100795

Dunn, K., Hughes-McCormack, L., & Cooper, S. A. (2018). Hospital admissions for physical health conditions for people with intellectual disabilities: Systematic review. *Journal of Applied Research in Intellectual Disabilities, 31*, 1-10.

Emerson, E. (2021). Inequalities and inequities in the health of people with intellectual disabilities. In *Oxford Research Encyclopedia of Global Public Health*. https://doi.org/10.1093/acrefore/9780190632366.013.326

Flood, B. (2017). Safety of People with Intellectual Disabilities in Hospital. What Can the Hospital Pharmacist Do to Improve Quality of Care? *Pharmacy*. 2017; 5(3):44. https://doi.org/10.3390/pharmacy5030044

Folch-Mas, A., Cortés-Ruiz, M. J., Vicens Calderón, P., & Martínez-Leal, R. (2017). Health profiles in people with intellectual developmental disorders. *Salud Pública de México*, *59*, 400–407. https://doi.org/10.21149/8199

García, J. C., Díez, E., Wojcik, D. Z., & Santamaría, M. (2020). Communication Support Needs in Adults with Intellectual Disabilities and Its Relation to Quality of Life. *International journal of environmental research and public health*, *17*(20), 7370. https://doi.org/10.3390/ijerph17207370

Garland-Thomson, R. (2017). *Disability Bioethics: From Theory to Practice. Kennedy Institute of Ethics Journal, 27(2), 323–339.* https://doi:10.1353/ken.2017.0020

Gibbs, S. M., Brown, M. J., & Muir, W. J. (2008). The experiences of adults with intellectual disabilities and their carers in general hospitals: A focus group study. *Journal of Intellectual Disability Research*, *52*(12), 1061–1077. https://doi.org/10.1111/j.1365-2788.2008.01057.x

Grant, T. (2016). IHC feedback: New Zealand Disability Strategy Revision–First phase public consultation.

Hakobyan, L., Nieboer, A. P., Finkenflügel, H., & Cramm, J. M. (2020). The Significance of Person-Centered Care for Satisfaction With Care and Well-Being Among Informal Caregivers of Persons With Severe Intellectual Disability. *Journal of Policy and Practice in Intellectual Disabilities*, *17*(1), 31–42. https://doi.org/10.1111/jppi.12297

Harding, R. Doing research with intellectually disabled participants: reflections on the challenges of capacity and consent in socio-legal research. *J Law Soc*. 2021; 48(Suppl. 1): S28– S43. https://doi.org/10.1111/jols.12331

Harris, J.C., Greenspan, S. (2016). Definition and Nature of Intellectual Disability. In: Singh, N. (eds) Handbook of Evidence-Based Practices in Intellectual and Developmental Disabilities. Evidence-Based Practices in Behavioral Health. Springer, Cham. https://doi.org/10.1007/978-3-319-26583-4_2

Hanlon, P., MacDonald, S., Wood, K., Allan, L., & Cooper, S. A. (2018). Long-term condition management in adults with intellectual disability in primary care: a systematic review. *BJGP open*, *2*(1). https://doi.org/10.3399/bjgpopen18X101445

Health and Disability System Review. (2020). *Health and Disability System Review – Final Report – Pūrongo Whakamutunga*. Wellington: HDSR.

Heifetz, M., & Lunsky, Y. (2018). Implementation and evaluation of health passport communication tools in emergency departments. *Research in Developmental Disabilities*, *72*, 23–32. https://doi.org/10.1016/j.ridd.2017.10.010

Hemsley, B., Balandin, S., & Worrall, L. (2011). The "Big 5" and beyond: Nurses, paid carers, and adults with developmental disability discuss communication needs in hospital. *Applied Nursing Research*, *24*(4), e51–e58. https://doi.org/10.1016/j.apnr.2010.09.001

Hennink, M., & Kaiser, B. N. (2021). Sample sizes for saturation in qualitative research: A systematic review of empirical tests. *Social Science & Medicine*, 114523.

Hosking, F. J., Carey, I. M., Shah, S. M., Harris, T., DeWilde, S., Beighton, C., & Cook, D. G. (2016). Mortality among adults with intellectual disability in England: comparisons with the general population. *American Journal of Public Health*, *106*(8), 1483-1490. https://doi.org/10.2105/AJPH.2016.303240

Howieson, J. (2015). Experiences of acute hospital services among people with mild to moderate learning disabilities. Learning Disability Practice, 18(9), 34–38. https://d**oi:**10.7748/ldp.18.9.34.s27

Hughes-McCormack, L., Rydzewska, E., Henderson, A., MacIntyre, C., Rintoul, J., & Cooper, S. (2017). Prevalence of mental health conditions and relationship with general health in a whole-country population of people with intellectual disabilities compared with the general population. *BJPsych Open*, *3*(5), 243-248. https://doi:10.1192/bjpo.bp.117.005462

Iacono, T., Bigby, C., Unsworth, C., Douglas, J., & Fitzpatrick, P. (2014). A systematic review of hospital experiences of people with intellectual disability. *BMC Health Services Research*, *14*(1), 505. https://doi.org/10.1186/s12913-014-0505-5

Iacono, T. (2006). Ethical challenges and complexities of including people with intellectual disability as participants in research. *Journal of Intellectual & Developmental Disability*, *31*(3), 173–179. https://doi.org/10.1080/13668250600876392

Kalengayi, F.K.N., Hurtig, AK., Ahlm, C. et al. (2012). "It is a challenge to do it the right way": an interpretive description of caregivers' experiences in caring for migrant patients in Northern Sweden. *BMC Health Serv Res* 12, 433 https://doi.org/10.1186/1472-6963-12-433

Landes, S. D. (2017). The intellectual disability mortality disadvantage: diminishing with age?. *American journal on intellectual and developmental disabilities*, *122*(2), 192-207. https://doi.org/10.1352/1944-7558-122.2.192

Lewis, P., Gaffney, R. J., & Wilson, N. J. (2017). A narrative review of acute care nurses' experiences nursing patients with intellectual disability: Underprepared, communication barriers and ambiguity about the role of caregivers. *Journal of Clinical Nursing*, *26*(11–12), 1473–1484. https://doi.org/10.1111/jocn.13512

Lewis, S., & Stenfert-Kroese, B. (2010). An investigation of nursing staff attitudes and emotional reactions towards patients with intellectual disability in a general hospital setting. *Journal of Applied Research in Intellectual Disabilities*, *23*(4), 355-365. https://doi.org/10.1111/j.1468-3148.2009.00542.x

Lin, J.-A., Liao, C.-C., Chang, C.-C., Chang, H., & Chen, T.-L. (2011). Postoperative Adverse Outcomes in Intellectually Disabled Surgical Patients: A Nationwide Population-Based Study. *PLOS ONE*, *6*(10), e26977. https://doi.org/10.1371/journal.pone.0026977

Louch, G., Albutt, A., Harlow-Trigg, J., Moore, S., Smyth, K., Ramsey, L., & O'Hara, J. K. (2021). Exploring patient safety outcomes for people with learning disabilities in acute hospital settings: A scoping review. *BMJ Open*, *11*(5), e047102. https://doi.org/10.1136/bmjopen-2020-047102

Maguire, M., & Delahunt, B. (2017). Doing a thematic analysis: A practical, step-by-step guide for learning and teaching scholars. *All Ireland Journal of Higher Education*, *9*(3)

McCarthy, J., & Duff, M. (2019). Services for adults with intellectual disability in Aotearoa New Zealand. *BJPsych international*, *16*(3), 71–73. https://doi.org/10.1192/bji.2018.37

McCormick, F., Marsh, L., Taggart, L., & Brown, M. (2021). Experiences of adults with intellectual disabilities accessing acute hospital services: A systematic review of the international evidence. *Health & Social Care in the Community*, *29*(5), 1222–1232. https://doi.org/10.1111/hsc.13253

McDonald, K. E., Kidney, C. A., & Patka, M. (2013). "You need to let your voice be heard": Research participants' views on research. *Journal of Intellectual Disability Research: JIDR*, *57*(3), 216–225. https://doi.org/10.1111/j.1365-2788.2011.01527.x

McKelvey, V. A., Morgaine, K. C., & Thomson, W. M. (2014). Adults with intellectual disability: a mixed-methods investigation of their experiences of dental treatment under general anaesthetic. *New Zealand Dental Journal*, *110*(2).

Ministry of Health. (2018). *Health and Independence Report 2017: The Director-General of Health's Annual Report on the State of Public Health*. Wellington: Ministry of Health.

Ministry of Health. (2013). *Providing Health Services for People with Intellectual Disability in New Zealand: Literature review and case studies*. Ministry of Health NZ. https://www.health.govt.nz/publication/providing-health-services-people-intellectual-disability-new-zealand-literature-review-and-case

Ministry of *Health. (2013). Innovative Methods of Providing Health Services for People with Intellectual Disability: Case Studies of programmes and tools used in New*

Zealand.
Wellington: Ministry of Health.

Ministry of Health. (2011). *Health Indicators for New Zealanders with Intellectual Disability*. Ministry of Health. https://www.health.govt.nz/publication/health-indicators-new-zealanders-intellectual-disability

Ministry of Health (2003). *Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003*. Ministry of Health. https://www.stats.govt.nz/assets/Uploads/Disability-survey/Disability-survey-2013/Disability-survey-2013-additional-documents/Disability-Survey-2013.pdf

Mirfin-Veitch, B., Paris, A. & Milner, P. (2013). *Improving access to primary care for disabled people.* Auckland: Te Pou o Te Whakaaro Nui. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6646840/

National Academies of Sciences, Engineering, and Medicine. (2015). M*ental Disorders and Disabilities Among Low-Income Children*. Washington, DC: The National Academies Press. https://doi.org/10.17226/21780

Ne'eman, A., Stein, M. A., Berger, Z. D., & Dorfman, D. (2021). The Treatment of Disability under Crisis Standards of Care: An Empirical and Normative Analysis of Change over Time during COVID-19. *Journal of Health Politics, Policy and Law*, *46*(5), 831–860. https://doi.org/10.1215/03616878-9156005

Nicholson, L., Colyer, M., & Cooper, S. A. (2013). Recruitment to intellectual disability research: a qualitative study. *Journal of Intellectual Disability Research*, *57*(7), 647-656. https://doi.org/10.1111/j.1365-2788.2012.01573.x

Nijs, S., Taminiau, E. F., Frielink, N., & Embregts, P. J. C. M. (2022). Stakeholders' perspectives on how to improve the support for persons with an intellectual disability and challenging behaviors: A concept mapping study. *International Journal of Developmental Disabilities*, *68*(1), 25–34. https://doi.org/10.1080/20473869.2019.1690859

Office for Disability Issues. (2016). *New Zealand Disability Strategy 2016–2026.* Wellington: Ministry of Social Development. Retrieved from https://www.odi.govt.nz/nz-disability-strategy/about-the-strategy/new-zealand-disability-strategy-2016-2026/ [Google Scholar]

O'Leary, L., Cooper, S. A., & Hughes-McCormack, L. (2018). Early death and causes of death of people with intellectual disabilities: a systematic review. *Journal of Applied Research in Intellectual Disabilities*, *31*(3), 325-342. https://doi.org/10.1111/jar.12417

Patel, D. R., Apple, R., Kanungo, S., & Akkal, A. (2018). Intellectual disability: Definitions, evaluation and principles of treatment. *Pediatric Medicine*, *1*, 11–11. https://doi.org/10.21037/pm.2018.12.02

Pelleboer-Gunnink, H. A., Van Oorsouw, W. M. W. J., Van Weeghel, J., and Embregts, P. J. C. M. (2017) Mainstream health professionals' stigmatising attitudes towards people with intellectual disabilities: a systematic review. *Journal of Intellectual Disability Research*, 61: 411– 434. https://doi:10.1111/jir.12353

Phillips, L. (2019). Learning disabilities: making reasonable adjustments in hospital. *Nurs Times*, *115*, 38-42.

Read, S., Heslop, P., Turner, S. *et al.* (2018). Disabled people's experiences of accessing reasonable adjustments in hospitals: a qualitative study. *BMC Health Serv Res* **18**, 931. https://doi.org/10.1186/s12913-018-3757-7

Regnard, C., Reynolds, J., Watson, B., Matthews, D., Gibson, L., & Clarke, C. (2007). Understanding distress in people with severe communication difficulties: developing and assessing the Disability Distress Assessment Tool (DisDAT). *Journal of intellectual disability research : JIDR*, *51*(Pt 4), 277–292. https://doi.org/10.1111/j.1365-2788.2006.00875.x

Riches, V. C., O'Brien, P., Manokara, V., & Mueller, A. (2022). A study of caregiver support services: Perspectives of family caregivers of persons with intellectual disabilities in Singapore. *Journal of Policy and Practice in Intellectual Disabilities*, *n/a*(n/a). https://doi.org/10.1111/jppi.12441

Rosencrans, M., Tassé, M. J., Kim, M., Krahn, G. L., Bonardi, A., Rabidoux, P., Bourne, M. L., & Havercamp, S. M. (2021). Invisible populations: Who is missing from research in intellectual disability? *Research in Developmental Disabilities*, *119*, 104117. https://doi.org/10.1016/j.ridd.2021.104117

Shady, K., Phillips, S. & Newman, S. (2022). Barriers and Facilitators to Healthcare Access in Adults with Intellectual and Developmental Disorders and Communication Difficulties: an Integrative Review. *Rev J Autism Dev Disord*. https://doi-org.ezproxy.aut.ac.nz/10.1007/s40489-022-00324-8

Skorpen, S., Nicolaisen, M., & Langballe, E. M. (2016). Hospitalisation in adults with intellectual disabilities compared with the general population in Norway. *Journal of Intellectual Disability Research, 60(4*), 365–377. https://doi-org.ezproxy.aut.ac.nz/10.1111/jir.12255

Smeltzer, S. C., Avery, C., & Haynor, P. (2012). Interactions of people with disabilities and nursing staff during hospitalization. *The American journal of nursing*, *112*(4), 30–52. https://doi.org/10.1097/01.NAJ.0000413454.07369.e3

Snow, S. L., Smith, I. M., Latimer, M., Stirling Cameron, E., Fox, J., & Chorney, J. (2022). A balancing act: An interpretive description of healthcare providers' and families' perspective on the surgical experiences of children with autism spectrum disorder. Autism, 26(4), 839–848. https://doi-org.ezproxy.aut.ac.nz/10.1177/13623613211034057

Sowney, M., & Barr, O. G. (2006). Caring for adults with intellectual disabilities: perceived challenges for nurses in accident and emergency units. *Journal of Advanced Nursing*, *55*(1), 36-45. https://doi.org/10.1111/j.1365-2648.2006.03881.x

Statistics New Zealand. (2014). *Disability Survey: 2013*. Wellington.

https://doi.org/978-0-478- 42934-3

Taua, C., Neville, C., & Scott, T. (2015). Mental health inpatient experiences of adults with intellectual disability. *International Journal of Mental Health Nursing*, *24*(6), 507-518. https://doi.org/10.1111/inm.12148

Taylor, I., Conway, V., & Knight, A. (2014). Measuring and addressing pain in people with limited communication skills: The "I hurt help me" pain management project. *Journal of Pain Management*, *9*(3), 129-136.

Thompson Burdine, J., Thorne, S., & Sandhu, G. (2021). Interpretive description: a flexible qualitative methodology for medical education research. *Medical Education*, *55*(3), 336-343. doi:10.1111/medu.1438010.1111/medu.14380

Thorne, S. (2016). Interpretive description: Qualitative research for applied practice, Second edition. 10.4324/9781315545196.

Thorne, S., Kirkham, S. R., & O'Flynn-Magee, K. (2004). The Analytic Challenge in Interpretive Description. *International Journal of Qualitative Methods*, *3*(1), 1–11. https://doi-org.ezproxy.aut.ac.nz/10.1177/160940690400300101

Thurm, A., Farmer, C., Salzman, E., Lord, C., & Bishop, S. (2019). State of the Field: Differentiating Intellectual Disability From Autism Spectrum Disorder. *Frontiers in psychiatry*, *10*, 526. https://doi.org/10.3389/fpsyt.2019.00526

Trainor, L. R., & Bundon, A. (2021). Developing the craft: Reflexive accounts of doing reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health*, *13*(5), 705-726.

Tuffrey-Wijne, I., Goulding, L., Gordon, V., Abraham, E., Giatras, N., Edwards, C., Gillard, S., & Hollins, S. (2014). The challenges in monitoring and preventing patient safety incidents for people with intellectual disabilities in NHS acute hospitals: Evidence from a mixed-methods study. *BMC Health Services Research*, *14*(1), 432. https://doi.org/10.1186/1472-6963-14-432

Tuffrey-Wijne, I. and Butler, G. (2010). Co-researching with people with learning disabilities: an experience of involvement in qualitative data analysis. Health Expectations, 13: 174-184. https://doi.org/10.1111/j.1369-7625.2009.00576.x

United Nations. (2006). Convention on the Rights of Persons with Disabilities. *Treaty Series*, *2515*, 3.

Van Alphen, L. M., Dijker, A. J. M., Van Den Borne, H. H. W., & Curfs, L. M. G. (2009). The significance of neighbours: views and experiences of people with intellectual disability on neighbouring. *Journal of Intellectual Disability Research*, *53*(8), 745-757.

Vlot-van Anrooij, K., Naaldenberg, J., Hilgenkamp, T. I. M., Vaandrager, L., Van Der Velden, K., & Leusink, G. L. (2020). Towards healthy settings for people with intellectual disabilities. *Health Promotion International*, *35*(4), 661-670. https://doi.org/10.1093/heapro/daz054

Webber, R., Bowers, B., & Bigby, C. (2010). Hospital experiences of older people with intellectual disability: Responses of group home staff and family members. *Journal of*

Intellectual & Developmental Disability, *35*(3), 155–164. https://doi.org/10.3109/13668250.2010.491071

Wieland, J., & Zitman, F. G. (2016). It is time to bring borderline intellectual functioning back into the main fold of classification systems. *BJPsych Bulletin*, *40*(4), 204–206. https://doi.org/10.1192/pb.bp.115.051490

Wilson, M. C., & Scior, K. (2015). Implicit Attitudes towards People with Intellectual Disabilities: Their Relationship with Explicit Attitudes, Social Distance, Emotions and Contact. *PloS one*, *10*(9), e0137902. https://doi.org/10.1371/journal.pone.0137902

Windley, D., & Chapman, M. (2010). Support workers within learning/intellectual disability services perception of their role, training and support needs. *British Journal of Learning Disabilities*, *38*(4), 310–318. https://doi.org/10.1111/j.1468-3156.2010.00610.x

World Health Organization. (2019). Driving forward health equity: the role of accountability, policy coherence, social participation and empowerment. World Health Organization. Regional Office for Europe.

World Health Organization. (2015). *World health statistics 2015*. World Health Organization.

Yamamoto, S., Nashi, M., Maeda, K., Taniike, N., & Takenobu, T. (2022). Postoperative dysphagia caused by a delay in mandibular fracture treatment in a patient with severe intellectual disability: A case report. *Journal of Medical Case Reports*, *16*(1), 6. https://doi.org/10.1186/s13256-021-03116-6

Zambrino, N., & Hedderich, I. (2021). Family Members of Adults with Intellectual Disability Living in Residential Settings: Roles and Collaboration with Professionals. A Review of the Literature. *INQUIRY: The Journal of Health Care Organization, Provision, and Financing*, *58*, 0046958021991301. https://doi.org/10.1177/0046958021991301

APPENDIX A: Tāngata Whaiora Participant Information Sheet

Tangata Whaiora Participant Information Sheet

This information sheet is for adults with an intellectual disability who want to be part of a research study about what being in hospital is like. A second participant information sheet is available for use by caregivers of adults with intellectual disability.

Date Information Sheet Produced:

4th July, 2022

Study Title

A Study of People with Intellectual Disability and Their Experiences of Hospitalisation

An Invitation

Kia ora, my name is Carrie.

You are invited to be part in a study about how people with an intellectual disability experience being in hospital.

Being part in this study may help to make things better for people with intellectual disabilities when they are in hospital.

The study may make things better for people when in hospital by helping us learn about what is helpful, what support is needed, and how things could be changed to be better.

By being part of this study you will also be helping me with my studies for a Bachelor of Health Science (Honours) Psychology Degree from Auckland University of Technology (AUT).

What is the purpose of this study?

The study is trying to learn how people with intellectual disabilities find being in hospital. What are the not so good parts and what are the good parts of being in hospital, and how we can make it better.

We think that this is important to find out because we know that being in hospital can be scary, or stressful, and can make some people worry.

We hope that by doing this study, we can help hospitals support people with intellectual disabilities better.

To do this study, we would like you to take part in talk with other people with intellectual disabilities.

The interview will be you talking with me and other people with intellectual disabilities about being in hospital and how it could be made better.

The interview will take about 60 minutes so that everyone has a chance to talk

When we finish the study, we will use the information we found to write an article for healthcare professionals (like doctors and nurses), and for presentations.

How was I identified and why am I being invited to participate in this study?

You may have heard about the study through an email or through social media, or from someone you trust.

You're seeing this participant information sheet because you might have clicked on a link on the email or on the social media advertisement about this study. Or because someone you trust gave you it.

To be in this study, you will need to:

- have an intellectual disability
- have been in hospitalised in the last six months
- be able to tell us about what the study is about and why we are doing it
- to be able to tell us that you want to do the study
- have a caregiver that can support you doing the study
- I have access to a computer or phone that would let you do the study

Page Break

How do I tell people that I want to do this study?

Doing the study is your choice.
You should only do the study if you want to.
No one will be upset if you don't want to do the study.
You can stop doing the study at any time.

If you stop doing the study, you can ask to have any information that can be linked to you removed.

Completing the consent form or telling the interviewer that you agree to be part of the study means that you have said that you have understood what the study is about and want to take part in the study.

We think it is helpful to your family/whānau or a person you trust you before you sign the consent form.
Even if you agree to being in the study, you can stop doing the study at any time.
If you want to stop doing the study, you just have to tell us you want to stop. You don't have to tell us why.

What will happen in this research?

The study involves working with adults who have an intellectual disability to have been in hospital.
Being in the study will involve:

- Talking with me (Carrie), my supervisor (Liesje Donkin) and other people that have intellectual disabilities in a group
- We will do this at a place that you know (the place that gave you this information)
-

The interview will be recorded and seen by only me so that I can look at what you have said after we've finished talking.

We would like you to talk to someone you trust before being part of the study.
This is because it might be upsetting to talk about being in hospital and so we think it would be good to have support if you need it.

I will ask you questions about what it was like being in hospital, what were the bits that were hard for you, and what were the things that made it better.
I will also ask what you want or need to help you if you are in hospital again. The group interview will take about 60minutes.

After we talk, I will type out what we have said and will take out all the bits in it that would mean someone would know that it was you I had been talking to.
We do this to keep your information confidential (which means no one will know what you have said) so that you can be honest and not worry about people talking to you about your thoughts, unless you tell them.

What are the discomforts and risks?
We don't think being in the study to make you upset. But it is okay if you do get upset

How will these discomforts and risks be alleviated?
If you do feel upset by the interview, you can access three free counselling sessions at the AUT student counselling service.

This is available to support for adult participants in an AUT research project.

These sessions are only available for issues that come from being in the research only.

To get help this way, you will need to:
• go to our centre at WB203 City Campus, or,
• email counselling@aut.ac.nz, or • call 921 9998.

Let the receptionist know that you are a research participant, and provide the title of my research and my name (Liesje Donkin) and contact details as given at the end of this Information Sheet.

You can find out more information about AUT counsellors and counselling on https://www.aut.ac.nz/student-life/student-support/counselling-and-mental-health

What are the benefits?
If want to be in this study, the things you share with us will be used to help provide better support adults with intellectual disabilities when they are in hospital.
Being in the study will also help me (Carrie) to write academic publications and presentations which will help other health professionals (like doctors, nurses and psychologists) to better support people with intellectual disabilities when they are in hospital.
The study will also count towards my qualification in a Bachelor of Health Science (Honours) degree.

How will my privacy be protected?
To protect your privacy, information that you share with us will be stored safety in a secure computer system at AUT.

When we look at the information that we have collected, we will take out any information that would let someone know that you have done the study.

When we are finished with the information that we are given and no longer need it, we will delete it.

What are the costs of participating in this research?
If you want to do the study, it will use some of your time.
If you want to take part in the group interview, this will take about 60 minutes of your time.

How long do I have to think about if I want to do the study?
You can think about doing the study until the end of September 2022.
We are happy to talk to you about the study and answer any questions that you might have.
If you would like to know more or would like to be involved in the study, you or your support person can call or email us on the details at the end of this information sheet.
Doing this study is your choice.
You can stop doing this study at any time and people won't be upset with you.

Will I be told about out what the study finds?
If want to know about what the study finds, we come and do a talk to the place that you did the interview.
We will also make a video about what we found out, and what we think needs to change and put it on https://academics.aut.ac.nz/liesje.donkin .

What do I do if I have worries about this study?
If you have any worries about this study, you can let Dr Liesje Donkin know. She is in charge of the study. You can let her know on liesje.donkin@aut.ac.nz or 021 847 886.

You could also ask someone you trust to contact Liesje Donkin for you.

If you have any concerns about how the study is being done, you should talk to the Executive Secretary of AUTEC ethics. They can be contacted on *ethics@aut.ac.nz* or (+649) 921 9999 ext 6038.
You can also ask a support person to do this for you too.

Who can I talk to if I want to know more about the study?
Keep this information sheet so that you can read it again if you need to as it includes all the important information about the study.

You can also contact me (Carrie) to ask questions. The ways you can contact me are below:

Researcher Contact Details:

Carrie McColl
srg5707@autuni.ac.nz
(021) 059 4270

You can also contact my supervisor who is in charge of this study too on

Study Supervisor Contact Details:

Dr Liesje Donkin (BSc, MSc(Hons), PGDipHlthPsych, PGDipArts(Dist), PGDipClinPsych, PhD)
liesje.donkin@aut.ac.nz
(021) 847 886

Approved by the Auckland University of Technology Ethics Committee on 21 July 2022, AUTEC Reference number *22/131*.

APPENDIX B: Consent to Participate - Tāngata Whaiora

Consent Form

For use when interviews are involved.

Project title: The Experience of Hospitalisation of People with Intellectual Disabilities; a Mixed-Methods Study of the experiences of people with intellectual disabilities, their caregivers and support people, and stakeholders

Project Supervisor: ***Dr Liesje Donkin***

Researcher: ***Carrie McColl***

¡ I have read and understood the information provided about this research project in the Information Sheet dated 04th July 2022.

¡ I have had an opportunity to ask questions and to have them answered.

¡ I understand that notes will be taken during the interviews and that they will also be audio-taped and transcribed.

¡ I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without being disadvantaged in any way.

¡ I understand that if I withdraw from the study then I will be offered the choice between having any data that is identifiable as belonging to me removed or allowing it to continue to be used. However, once the findings have been produced, removal of my data may not be possible.

¡ I agree to take part in this research.

¡ I wish to receive a summary of the research findings (please tick one): Yes¡ No¡

Participant's signature:

.....……
……

Participant's name:

.....……
……

Participant's Contact Details (if appropriate):

……..

……..

……..

Date:

Approved by the Auckland University of Technology Ethics Committee on 21 July 2022 AUTEC Reference number 22/131

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

APPENDIX C: Online Qualtrics Survey - Tāngata Whaiora

Information sheet

Tangata Whaiora Participant Information Sheet

This information sheet is for adults with an intellectual disability who want to be part of a research study about what being in hospital is like.

A second participant information sheet is available for use by caregivers of adults with intellectual disability.

Date Information Sheet Produced: 7th July 2022
Project Title: A Study of People with Intellectual Disability and Their Experiences of Hospitalisation

An Invitation
Kia ora, my name is Carrie.

You are invited to be part of a research project about how people with an intellectual disability experience being in hospital.

Being part in this research project may help to make things better for people with intellectual disabilities when they are in hospital.

The study may make things better for people when in hospital by helping us learn about what is helpful, what support is needed, and how things could be changed to be better.

By being part you will also be helping me with my studies for a Bachelor of Health Science (Honours) Psychology Degree from Auckland University of Technology (AUT).

Tangata Whaiora Participant Information Sheet - continued

What is the purpose of this study?
The study is trying to learn how people with intellectual disabilities find being in hospital.

We want to know about what are the not so good parts and what are the good parts of being in hospital, and how we can make it better.

We think that this is important to find out because we know that being in hospital can be scary, or stressful, and can make some people worry.

We hope that by doing this study, we can help hospitals support people with intellectual disabilities better.

Tangata Whaiora Participant Information Sheet - continued

You can be part of this study in two different ways.

You can choose which one you want to do.

Survey
The online survey will take 20 to 30 minutes to do.

The survey will ask you about your experience of being in hospital and your ideas about how we could make it better.

To do the survey you will need to be able to type (or get someone to type for you) into the survey which is online.

Interview
If you want to talk about your experiences in hospital, you can do an interview with a researcher. If you would like to talk about your experiences, please contact Dr Liesje Donkin on liesje.donkin@aut.ac.nz or (021) 847 886 and she will arrange for someone to contact you to make a time to do the interview.

It is your choice
You can choose to do the online writing survey or the interview but do not need to do both.

When we finish the study, we will use the information we found to write an article for healthcare professionals (like doctors and nurses), and for presentations.

Tangata Whaiora Participant Information Sheet - continued

Why am I being invited to participate in this research?

You may have heard about the study through an email or through social media, or from someone you trust.

You're seeing this participant information sheet because you might have clicked on a link on the email or on the social media advertisement about this study. Or because someone you trust gave you it.

To be in this study, you will need to:

- have an intellectual disability
- have been in hospitalised in the last six months
- be able to tell us about what the study is about and why we are doing it
- To be able to tell us that you want to do the study
- Have a caregiver that can support you doing the study
- I have access to a computer or phone that would let you do the study

Tangata Whaiora Participant Information Sheet - continued

How do I tell people that I want to do this study?

Doing the study is your choice.

You should only do the study if you want to.

No one will be upset if you don't want to do the study.

You can stop doing the study at any time.

If you stop doing the study, we are not able to remove any information that you have written because the survey is anonymous - this means that we won't know what is your information and so can't delete this information.

If you want to be part of this study, you can use the link at the end of this page to do the survey.

Doing the survey means that you agree to be part of this study.

We think it is helpful to your family/whānau or a person you trust you before you do the survey.

Even if you start the study, you are can stop doing the study at any time.

If you want to stop doing the study, you just have close down the study on the device that you are using.

You don't have to tell us why.

Tangata Whaiora Participant Information Sheet - continued

What will happen in this research?

The study involves working with adults who have an intellectual disability who have been in hospital.

If you want to be part of this study, there are two ways that you can do this.

One way is by writing (or typing) about your experiences.

This can be done online in an online form that will be sent to the research team when you are finished.

The online form will ask you questions about what it was like being in hospital, what were the bits that were hard for you, and what were the things that made it better.

It will also ask what you want or need to help you if you are in hospital again.

Tangata Whaiora Participant Information Sheet - continued

What are the discomforts and risks?
We don't think being in the study to make you upset.

But it is okay if you do get upset

How will these discomforts and risks be helped?

If you do feel upset by the interview, AUT Student Counselling and Mental Health is able to offer you three free sessions of confidential counselling.

This is available to support for adult participants in an AUT research project.

These sessions are only available for issues that come from being in the research only.

To get help this way, you will need to:
• go to our centre at WB203 City Campus, or,
• email counselling@aut.ac.nz, or • call 921 9998.

Let the receptionist know that you are a research participant, and provide the title of my research and my name (Liesje Donkin) and contact details as given at the end of this Information Sheet.

You can find out more information about AUT counsellors and counselling on https://www.aut.ac.nz/student-life/student-support/counselling-and-mental-health

What are the benefits?

If want to be in this study, the things you share with us will be used to help support adults with intellectual disabilities when they are in hospital.

Being in the study will also help me (Carrie) to write academic articles and presentations.

The study will also count towards my qualification in a Bachelor of Health Science (Honours) degree.

Tangata Whaiora Participant Information Sheet - continued

How will my privacy be protected?

To protect your privacy, information that you share with us will be stored safety in a secure computer system at AUT.

When we look at the information that we have collected, we will take out any information that would let someone know that you have done the study.

When we are finished with the information and no longer need it, we will delete it.

What are the costs of participating in this study?

If you want to do the study, it will use some of your time.

If you want to do the online survey it will take about 20 - 30 minutes to do.

Tangata Whaiora Participant Information Sheet - continued

How long do I have to think about if I want to do the study?

You can think about doing the study until the end of August 2022.

We are happy to talk to you about the study and answer any questions that you might have.

It is also helpful to talk to someone your trust about the study.

If you would like to know more or would like to be involved in the study, you or your support person can call or email us on the details at the end of this information sheet.

You can also speak to us and we can arrange for a pen-and-paper survey so that you can write your answers if that is better for you.

Doing this study is your choice.

You can stop doing this study at any time and people won't be upset with you.

Tangata Whaiora Participant Information Sheet - continued

Will I be told about out what the study finds?

If you want to know about what the study finds, we will share this online once we have finished the study.

If you would like to know what we find out you will be able to find this next year at https://academics.aut.ac.nz/liesjedonkin

Tangata Whaiora Participant Information Sheet - continued

What do I do if I have worries about this study?

If you have any worries about this study, you can let Dr Liesje Donkin know.

She is in charge of the study.

You can let her know on liesje.donkin@aut.ac.nz or 021 847 886.

You could also ask someone you trust to contact Liesje Donkin for you.

If you have any concerns about how the study is being done, you should talk to the Executive Secretary of AUTEC ethics.

They can be contacted on ethics@aut.ac.nz or (+649) 921 9999 ext 6038.

You can also ask a support person to do this for you too.

Tangata Whaiora Participant Information Sheet - continued

Who can I talk to if I want to know more about the study?

Keep this information sheet so that you can read it again if you need to as it includes all the important information about the study.

You can also contact me (Carrie) to ask questions.

The ways you can contact me are below:
Carrie McColl
srg5707@autuni.ac.nz
(021) 059 4270

You can also contact my supervisor who is in charge of this project on
Dr Liesje Donkin (BSc, MSc(Hons), PGDipHlthPsych, PGDipArts(Dist), PGDipClinPsych, PhD)
liesje.donkin@aut.ac.nz
(021) 847 886

Approved by the Auckland University of Technology Ethics Committee on 04/07/202 final ethics approval was granted, AUTEC Reference number 22/131

Completion of this survey indicates you agree to be part in the research

We will have the study completed and the results available by March 2023.

A summary will be able to be found https://academics.aut.ac.nz/liesjedonkin.

If you wish to read a summary of the results, please make note of this as this information will not be available after you finish the survey.

What is your gender?

- ○ Male
- ○ Female
- ○ Non-binary / third gender
- ○ Gender fluid

- ○ Other
- ○ Prefer not to say

What is your ethnicity?

- ○ Māori/tangata whenua
- ○ Pākeha/New Zealand European
- ○ Pacific Peoples
- ○ South-East Asian
- ○ Asian
- ○ Other

How old are you?

Were are interested in hearing you perspectives on the experiences of hospitalisation for people with intellectual disabilities. You can write as little or as much as you like. We will remove any information that may identify you or other people from your writing when we do the analysis to protect your confidentiality.

Can you please tell us about your what was being in hospital was like for you. You can write as little or as much as you like

What was the hardest bit of being in hospital for you? You can write as little or as much as you like.

What are the things that make being in hospital easier for you? You can write as little or as much as you like.

How could things be changed to make things better for you, if you had to got to hospital again? You can write as little or as much as you like.

Are there any other comments you would like to make?

Thank-you for taking the time to participate in our study. We anticipate that we will have the study completed and will be able to send out the summary of the results to those participants that would like them by March 2023.

APPENDIX D: Carer and Community Stakeholder Participant Information Sheet

Participant Information Sheet

Date Information Sheet Produced:

4th July, 2022

Project Title

The Experience of Hospitalisation of People with Intellectual Disabilities; a mixed-methods study of the experiences of people with intellectual disabilities, their caregivers and support people, and stakeholders

An Invitation

Kia ora, we are a team of researchers and psychologists working together to better understand the experience of hospitalisation of people with intellectual disabilities in Aotearoa. As a caregiver or support person of someone with an intellectual disability, or as a community stakeholder, you are invited to take part in our study. Taking part in this research study may help to improve support for people with intellectual disabilities when receiving hospital care.

What is the purpose of this research?

The purpose of this research is to try to better understand how adults with intellectual disabilities experience being in the hospital, to find out what things make the hospital experience easier, and to discover the things that might make hospital experiences more difficult. We are interested in hearing your perspective of hospitalisation as someone who supports someone with intellectual disability, or a stakeholder that is involved with providing services to some-one with intellectual disabilities. It is hoped that by having a good understanding of these challenges, new resources can be developed that will assist people with intellectual disabilities who are hospitalised in future.

The findings of this research may be used for academic publications and presentations, will be feedback to interested organisations, and will contribute towards my qualification in a Bachelor of Health Science (Honours) degree.

How was I identified and why am I being invited to participate in this research?

You may have heard about the study through an email advertisement that was sent to community agencies that support people with intellectual disabilities, through social media advertising this study on Facebook or through your networks.

To be considered for inclusion in this study, you will need to meet all the following criteria:

- ❑ You are a support person or caregiver for someone with an intellectual disability that has been hospitalised in the last 12-months OR are involved in an organisation (such as an NGO, charity of medical service) that provides services to people with an intellectual disability.
- ❑ You have access to the technology required to complete the online (teleconference) interview if I decide to participate in the interview

How do I agree to participate in this research?

Your participation in this research is voluntary (it is your choice) and whether you do or do not choose to participate will not advantage or disadvantage you. You are able to withdraw from the study at any time. If you choose to withdraw from the study, then you will be offered the choice between having any data that is identifiable as belonging to you removed or allowing it to continue to be used. However, once the data has been de-identified, removal of your data may not be possible.

What will happen in this research?

There are two ways that you can participate in this study. You can complete an online survey where you are asked to share your views on hospitalisation, or in an interview with one of the members of the research team (the link for the survey was in the email invitation and can be re-emailed to you if you wish to do the survey).

If you are interested and you agree to be interviewed, email Liesje Donkin on liesje.donkin@aut.ac.nz. Once you email, a researcher will contact you within 48 hours to book a time to be interviewed. The interview will involve talking to the researcher by video conference call (eg Zoom or Teams Meetings) about your past experiences of supporting or providing services to someone with intellectually disabilities who was hospitalised.

The researcher will ask you questions about things that made hospitalisation easier, and about things that that may have made your experience more difficult. With your consent, the interview will be recorded and accessed by the researcher (the person that interviewed you), so that they can transcribe the data for further analysis. Transcriptions of interviews will be analysed to determine the main themes and findings of the interview. It is hoped that the research findings will inform recommendations about how to better support people with intellectual disabilities during hospitalisation.

What are the discomforts and risks?

We don't expect the interview to cause any harm to you; however, you could become upset when reflecting on your experiences of supporting or treating someone when they were hospital.

How will these discomforts and risks be alleviated?

If you do feel distressed by the interview process, please contact AUT Student Counselling and Mental Health to access three free sessions of confidential counselling support for adult participants in an AUT research project. These sessions are only available for issues that have arisen directly as a result of participation in the research and are not for other general counselling needs. To access these services, you will need to:

- drop into our centre at WB203 City Campus, email counselling@aut.ac.nz or call 921 9998.
- let the receptionist know that you are a research participant, and provide the title of my research and my name and contact details as given in this Information Sheet.

You can find out more information about AUT counsellors and counselling on https://www.aut.ac.nz/student-life/student-support/counselling-and-mental-health

What are the benefits?

If you agree to participate in this research, your insight and experiences may influence the support offered to people with intellectual disabilities who are hospitalised in the future. Finds from the study will also be used to generate new resources that will better support adults with intellectual disabilities during periods of hospitalisation.

A benefit to the researchers is that the research findings will be used in academic publications and presentations and will count towards the students' qualification in a Bachelor of Health Science (Honours) degree.

How will my privacy be protected?

To protect your privacy, data from the recorded interview will be stored in a digital file folder protected by password on a secure server at AUT.

The privacy of you as a participant will be protected by coding all data and removing all identifiable information to ensure that any data published or otherwise disseminated can in no way identify you. Although identifiable data will be collected (eg., name and contact details), only the primary researchers will have access to the raw data files and following transcription, original recordings will be deleted.

What are the costs of participating in this research?

There will be a cost of your time if you choose to participate in the study. We believe that the interview will take between 30 – 60 minutes of your time.

What opportunity do I have to consider this invitation?

You will be able to consider the invitation for 6-8 weeks while recruitment is open. You are able to directly contact the research team to discuss the study before deciding to participate. Your participation in this study is completely voluntary (meaning you can choose if you want to be involved). You can withdraw from the study at any point and for any reason, with no explanation needed. If you wish to withdraw from the study and to have your information removed, please let one of the researchers know.

Will I receive feedback on the results of this research?

A summary of the findings of the research will be sent to you if you wish to receive them. When you complete the consent form, you have the option to indicate if you would like to receive a copy of the findings.

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, Dr Liesje Donkin, liesje.donkin@aut.ac.nz, 021 847 886.

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTEC, *ethics@aut.ac.nz* , (+649) 921 9999 ext 6038.

Whom do I contact for further information about this research?

Please keep this Information Sheet and a copy of the Consent Form for your future reference. You are also able to contact the research team as follows:

Researcher Contact details:

Dr Liesje Donkin (BSc, MSc(Hons), PGDipHlthPsych, PGDipArts(Dist), PGDipClinPsych, PhD)
liesje.donkin@aut.ac.nz
(021) 847 886

Emma Fuller (BSHc)
Vpc0907@autuni.ac.nz
02102976683

Approved by the Auckland University of Technology Ethics Committee on *04/07/2022*, AUTEC Reference number *22/131*.

APPENDIX E: Consent to Participate – Community Stakeholder

Consent Form

Project title: *The Experience of Hospitalisation of People with Intellectual Disabilities; a Mixed-Methods Study of the experiences of people with intellectual disabilities, their caregivers and support people, and stakeholders*

Project Supervisor: *Dr Liesje Donkin*

Researchers: *Dr Marleen Verhoeven, Dr Helen Buckland-Writght, Carrie McColl & Emma Fuller*

- I have read and understood the information provided about this research project in the Information Sheet dated 4th May 2022.
- I have had an opportunity to ask questions and to have them answered.
- I understand that notes will be taken during the interviews and that they will also be audio-taped and transcribed.
- I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without being disadvantaged in any way.
- I understand that if I withdraw from the study then I will be offered the choice between having any data that is identifiable as belonging to me removed or allowing it to continue to be used. However, once the findings have been produced, removal of my data may not be possible.
- I agree to take part in this research.
- I wish to receive a summary of the research findings (please tick one): Yes¡ No¡

Participant's signature:
.....
……

Participant's name:
.....
……

Participant's Contact Details (if appropriate):

……..

……..

……..

……..

Date:

Approved by the Auckland University of Technology Ethics Committee on 21 July 2022 AUTEC Reference number 22/131

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

APPENDIX F: Qualtrics Survey – Carers and Community Stakeholders

Stakeholder

Community Stakeholder Participant Information Sheet

Date Information Sheet Produced: 7th July, 2022

Project Title: *The Experience of Hospitalisation of People with Intellectual Disabilities; a mixed-methods study of the experiences of people with intellectual disabilities, their caregivers and support people, and stakeholders*

An Invitation
Kia ora, we are a team of researchers and psychologists working together to better understand the experience of hospitalisation of people with intellectual disabilities in Aotearoa. As a community stakeholder who works with people with intellectual disabilities when they are hospitalised, you are invited to take part in our study. Taking part in this research study may help to improve support for people with intellectual disabilities when receiving hospital care.

This project is led by Dr Liesje Donkin (Clinical Psychologist and Senior Lecturer at AUT) and Dr Marleen Verhoeven (Clinical Psychologist). Both Liesje and Marleen will be conducting the collection of data for this study.

What is the purpose of this research? The purpose of this research is to try to better understand how adults with intellectual disabilities experience being in the hospital, to find out what things make the hospital experience easier, and to discover the things that might make hospital experiences more difficult. We are interested in hearing your perspective of hospitalisation as a stakeholder that is involved with providing services to someone with intellectual disabilities when they are hospitalised. It is hoped that by having a good understanding of these challenges, new resources can be developed that will assist people with intellectual disabilities who are hospitalised in future.

The findings of this research may be used for academic publications and presentations and will be feedback to interested organisations.

How was I identified and why am I being invited to participate in this research?

You may have heard about this study through an email advertisement that was sent to community agencies that support people with intellectual disabilities, through social media advertising this study on Facebook, or through your networks.

To be considered for inclusion in this study, you will need to meet all the following criteria:

- You are involved in or work for an organisation (such as an NGO, charity, or medical service) that provides services to people with an intellectual disability.
- You have access to the technology required to complete the online survey or for an online (teleconference) interview if you decide to participate in the interview

How do I agree to participate in this research?
Your participation in this research is voluntary (it is your choice) and whether you do or do not choose to participate will not advantage or disadvantage you.

You are able to withdraw from the study at any time by closing your browser window. If you choose to withdraw from the study, we will not be able to remove your data as the study is an anonymous survey and we will not be able to determine which is your data.

If you wish to participate in the anonymous online survey, click on the link at the end of this information sheet to access the survey. Completing the online survey indicates your consent to participate in this research.

What will happen in this research?
There are two ways that you can participate in this study. This information sheet is about the online anonymous survey. If you wish to participate in an interview, you can contact Dr Liesje Donkin directly on liesje.donkin@aut.ac.nz or (021) 847 886.

If you wish to complete the online anonymous survey, you can access this at the end of this information sheet. The survey will ask to share your views on hospitalisation and how this could be improved for people with intellectual disabilities. You can write as little or as much as you want.

It is hoped that the research findings will inform recommendations about how to better support people with intellectual disabilities during hospitalisation.

What are the discomforts and risks?
We don’t expect the anonymous online survey to cause any harm to you; however, you could become upset when reflecting on your experiences of supporting or treating someone when they were hospital.

How will these discomforts and risks be alleviated?
If you do feel distressed by the interview process, AUT Student Counselling and Mental Health is able to offer three free sessions of confidential counselling support. This is for adult participants in an AUT research project. These sessions are only available for issues

that have arisen directly as a result of participation in the research and are not for other general counselling needs.

To access these services, you will need to:

- drop into our centre at WB203 City Campus, or,
- email counselling@aut.ac.nz, orm
- call 921 9998.

Let the receptionist know that you are a research participant, and provide the title of my research and my name (Liesje Donkin) and contact details as given at the end of this Information Sheet.

You can find out more information about AUT counsellors and counselling on https://www.aut.ac.nz/student-life/student-support/counselling-and-mental-health

What are the benefits?
If you agree to participate in this research, your insight and experiences may influence the support offered to people with intellectual disabilities who are hospitalised in the future. Findings from the study will also be used to generate new resources that will better support adults with intellectual disabilities during periods of hospitalisation.

A benefit to the researchers is that the research findings will be used in academic publications and presentations.

How will my privacy be protected?
The survey is anonymous and we will not be asking you for any information that might identify you. To protect your privacy, data from the anonymous online survey will be stored in a digital file folder protected by password on a secure server at AUT. The privacy of you as a participant will be protected by removing all identifiable information to ensure that any data published or otherwise disseminated can in no way identify you.

What are the costs of participating in this research?
There will be a cost of your time if you choose to participate in the study. The online survey is expected to take about 10 - 15 minutes to complete.

What opportunity do I have to consider this invitation?
You will be able to consider the invitation for 6-8 weeks while recruitment is open. You are able to directly contact the research team to discuss the study before deciding to participate. Your participation in this study is completely voluntary (meaning you can choose if you want to be involved).

Will I receive feedback on the results of this research?
A summary of the findings of the research will be available once the research is completed. If you would like to read a summary of these results, they will be posted online next year. You

can review these once posted at https://academics.aut.ac.nz/liesjedonkin

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

Dr Liesje Donkin
liesje.donkin@aut.ac.nz
021 847 886.

Concerns regarding the conduct of the research should be notified to
The Executive Secretary of AUTEC
ethics@aut.ac.nz
(+649) 921 9999 ext 6038.

Whom do I contact for further information about this research?
Please keep this Information Sheet.

You are also able to contact the research team as follows:
Researcher Contact details:
Dr Liesje Donkin (BSc, MSc(Hons), PGDipHlthPsych, PGDipArts(Dist), PGDipClinPsych, PhD) liesje.donkin@aut.ac.nz
(021) 847 886

Approved by the Auckland University of Technology Ethics Committee on 04/07/202 final ethics approval was granted, AUTEC Reference number 22/131

Completion of this survey indicates your consent to take part in the research

We anticipate that we will have the study completed and the results available by March 2023. A summary will be able to be found https://academics.aut.ac.nz/liesjedonkin. If you wish to read a summary of the results, please make note of this as this information will not be available after you finish the survey.

What is your gender?

- ○ Male
- ○ Female
- ○ Non-binary / third gender
- ○ Gender fluid
- ○ Other
- ○ Prefer not to say

What is your ethnicity?

- ○ Māori/tangata whenua
- ○ Pākeha/New Zealand European
- ○ Pacific Peoples
- ○ South-East Asian
- ○ Asian
- ○ Other

How old are you?

In what role do you support people with intellectual disabilities

- ○ Doctor/physician
- ○ Psychologist
- ○ Occupational therapist
- ○ Physiotherapist
- ○ Counsellor
- ○ Community support worker
- ○ Nurse
- ○ Pharmacist
- ○ Other

Were are interested in hearing you perspectives on the experiences of hospitalisation for people with intellectual disabilities. You can write as little or as much as you like. We will remove any information that may identify you or other people from your writing when we do the analysis to protect your confidentiality.

Can you please tell us about your views on how people with intellectual disabilities experience being hospitalised. You can write as little or as much as you like

What are the biggest challenges with being in hospital for people with disabilities. You can write as little or as much as you like.

What are the things that make being in hospital easier for people with intellectual disabilities – both for the person with the disability and for their caregivers/support people/treating team. You can write as little or as much as you like.

How do systems need to change to better support people with intellectual disabilities when they are hospitalised? You can write as little or as much as you like.

Are there any other comments you would like to make

Thank-you for taking the time to participate in our study. We anticipate that we will have the study completed and will be able to send out the summary of the results to those participants that would like them by March 2023.

APPENDIX G: AUTEC Ethics Approval

21 July 2022
Liesje Donkin
Faculty of Health and Environmental Sciences

Dear Liesje

Re Ethics Application: **22/131 The experience of hospitalisation for people with intellectual disabilities; a qualitative study of tangata whaiora, their caregivers, and stakeholders.**

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 21 July 2025.

Non-Standard Conditions of Approval

1. Re word the statement at the end of the survey to say ' We anticipate that we will have the study completed and the results available by March 2023, a summary can be found https://academics.aut.ac.nz/liesjedonkin. Perhaps suggest they make a note of it, as once the survey has been submitted they will not have access to the details.
2. Please review and edit 'The Support Person and Caregiver Participant Information Sheet ' as it makes reference to 'stake holder' involved in providing services'.

Non-standard conditions must be completed before commencing your study. Non-standard conditions do not need to be submitted to or reviewed by AUTEC before commencing your study.

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.
8. 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

APPENDIX H: Study Recruitment Email

Invitation to participate in a research study: The experience of hospitalisation for people with intellectual disabilities, their caregivers, and community stakeholders.

Kia ora,

We are writing to you to tell you about a research project that we are currently undertaking where we are seeking to understand the experience of hospitalisation for people with intellectual disabilities, their support people and caregivers, and community stakeholders.

We are interested in hearing about your views and experiences of being hospitalised or supporting someone while they are in hospital and how this could be improved.

There are two ways that people can participate in the study – by an interview or by doing an online, anonymous survey.

If you would like to participate in an interview or would like to know more about the study, please contact Dr Liesje Donkin (Lead Researcher) on liesje.donkin@aut.ac.nz or (021) 847 886.

If you would like to do the online survey, please click on the link below that best describes you. Appendix I: Ethics Approval

For the study for **people with intellectual disabilities**

ADULTS WITH AN INTELLECTUAL DISABILITY STUDY LINK

For the study for **community stakeholders who support people with intellectual disabilities**

STAKEHOLDERS STUDY LINK

For the study for **caregivers or support people of people with intellectual disabilities**

CAREGIVERS STUDY LINK

Please feel free to forward this invitation to anyone that may be interested in participating so that they can read about the study and make a decision about participating. Please do not forward their contact details to us directly as we require them to make contact with us themselves.

Ngā mihi,

Dr Liesje Donkin, Dr Marleen Verhoeven, Emma Fuller, & Carrie McColl

APPENDIX I: Social Media Recruitment Message

Do you care for someone with an intellectual disability or do you support someone with an intellectual disability? We are researchers through AUT exploring the experience of hospitalisation for people with intellectual disabilities and want to hear your view. We are hoping that this study will help to better support people with intellectual disabilities when they are in hospital.

You can participate by being interviewed by a member of the research team or by completing an online survey. To do an interview, please email liesje.donkin@aut.ac.nz to arrange.

To complete the online survey:
If you are someone with an intellectual disability click here for the survey https://tinyurl.com/whaiora

If you are someone who is a caregiver or whānau member of someone with an intellectual disability click here for the survey https://tinyurl.com/IDCaregivers

If you are a community stakeholder, support worker, or clinician supporting someone with an intellectual click on this link for the survey https://tinyurl.com/IDStakeholders

APPENDIX J: Focus Group Invitation Email

Kia ora,

We are writing to you to tell you about a research project that we are currently undertaking where we are seeking to understand the experience of hospitalisation for people with intellectual disabilities, their support people and caregivers, and community stakeholders. We are interested in hearing about your views and experiences of being hospitalised or supporting someone while they are in hospital and how this could be improved.

We are looking to run focus groups as sites that may be interested in participating. Focus groups usually consist of 3-6 people and take 30-60 minutes to complete. We will also provide morning or afternoon tea as a thank-you for your time.

If you would like to host a focus group or would like to know more about the study, please contact Dr Liesje Donkin (Lead Researcher) on liesje.donkin@aut.ac.nz or (021) 847 886.

Please feel free to forward to this invitation to anyone that may be interested in participating so that they can read about the study and make a decision about participating. Please do not forward their contact details to us directly as we require them to make contact with us themselves.

Ngā mihi,

Dr Liesje Donkin, Dr Marleen Verhoeven, Emma Fuller, & Carrie McColl

APPENDIX K: Ethics Approval Amendment – Focus Groups

18 November 2022

Liesje Donkin
Faculty of Health and Environmental Sciences
Dear Liesje

Re: Ethics Application: **22/131 The experience of hospitalisation for people with intellectual disabilities; a qualitative study of tangata whaiora, their caregivers, and stakeholders.**

Thank you for your responses to the conditions for the amendment to your ethics application.

The amendment to the data collection (to conduct focus groups) and recruitment (social media) protocols 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.
8. 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

(This is a computer-generated letter for which no signature is required)

The AUTEC Secretariat
Auckland University of Technology Ethics Committee

APPENDIX L: Oral Consent for Tāngata whaiora/Community Stakeholders – Videoconference

Oral Consent Protocol – Tāngata whairoa / Community Stakeholders

For use when interviews are being conducted by videoconference.

Project title: *The experience of hospitalisation for people with intellectual disabilities; a qualitative study of tāngata whairoa, their caregivers, and stakeholders.*

Project Supervisor: *Dr Liesje Donkin*

Researcher: *Carrie McColl*

The participant joins the videoconference

¡ Thank participant and support person for joining. Re explain the purpose of the study. Ask both tāngata whairoa and support person individually "Do you agree to me recording your agreement to participate?"

If they agree, then the record function will be activated and they will be asked the following:

¡ Have you read and understood the information provided or watched the video about this research project in the Information Sheet dated 4th July 2022?

¡ Do you have any questions about the research?

¡ Do you understand that notes will be taken during the interviews and that the in interview will also be audio-recorded and transcribed?

¡ Do you understand that taking part in this study is voluntary (your choice) and that you may withdraw from the study at any time without being disadvantaged in any way.?

¡ Do you understand that if you withdraw from the study then you will be offered the choice between having any data that is identifiable as belonging to you removed or allowing it to continue to be used? However, once the findings have been produced, removal of your data may not be possible.

¡ Do you agree to take part in this research?

¡ Do you wish to receive a summary of the research findings? (please tick one): Yes¡ No¡

¡ Do you want me to send you a copy of the audio recording for this consent? Yes¡ No¡

¡ Please confirm you name and contact details

Participant's name:

.....……

Participant's Contact Details (if appropriate):

……..

……..

I will now turn off the recording of the Consent and then will start a separate recording for the interview.

Approved by the Auckland University of Technology Ethics Committee on 21 July 2022 AUTEC Reference number 22/131 *Note: The Participant should retain a copy of this f*