Responses to Abuse, Neglect, and Trauma of Children with Intellectual Disability: Experiences from Social Workers and Health Practitioners in Aotearoa New Zealand

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Kim Simpson

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Abstract

A growing concern in child protection is the higher rates of disabled children being involved. Research has found that children with intellectual disabilities are three to four times more likely to be abused and neglected than their ordinary peers. Though Oranga Tamariki (Ministry of Children) has a legislative obligation to investigate and report on the numbers of child maltreatment among disabled children, this area remains under-developed. The current research focused on exploring the perspectives and experiences of practitioners, such as social workers, and their responses to abuse, neglect, and trauma among children with intellectual disabilities. Using a qualitative approach, eight practitioners were first involved in a focus group to provide a wider perspective of practice and policy issues of abuse, neglect, and trauma among children with intellectual disability. This was followed by a more in-depth exploration and investigation with four experienced social workers to understand issues and challenges to support this cohort of children and their families and whaanau and examine what best practices are needed to strengthen service provisions. Results indicated that practitioners require more skill development to strengthen knowledge about intellectual disabilities and understand disability-related needs to better inform their practice. Fostering and sustaining a strong relationship among disabled children, their families and whaanau and practitioners was a priority to ensure safety, reduce harm and implement support interventions. Addressing barriers, such as poverty and discrimination at structural and system levels, was identified as a key area to strengthen. This research has demonstrated that the abuse, neglect, and trauma of children with intellectual disability need to be urgently addressed to influence positive and transformative change. The importance of relational practice in advocating safety and reduction of harm among this cohort and supporting capacity development among families and whaanau is affirmed.

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Chapter 1 - Introduction

1.1 Background of the study

Child abuse and maltreatment is a substantial problem with wide-ranging negative impacts on health and wellbeing. Existing research has clearly shown that children with intellectual disabilities are three to four times more likely to be abused and neglected than their ordinary peers (Jones et al., 2012; Sullivan & Knutson, 2000). Influential factors to increased vulnerability of this cohort of children have been reported to be the lack of understanding of what abuse is (Lightfoot, 2014; Robinson et al., 2017) and increasing chronic physical, developmental, and behavioural challenges in the caregiving environment for many whaanau and families (Hibbard & Desch, 2007). Social workers and health practitioners have also been criticised for their lack of understanding and ability to assess abuse when working with children with development disabilities (Algood et al., 2011). Disability status is often disregarded in the assessment of maltreatment despite it having been found to be a contributing factor for maltreatment (Brandon et al., 2011; Cook & Standen, 2002). Increasingly, financial hardship has been associated with a higher level of family violence and abuse (Murray, 2018; Wynd, 2013). Research has indicated that economic and material deprivation have lifelong negative impacts on the safety and wellbeing of children with intellectual disabilities (Meissen et al., 2016; Wigham & Emerson, 2015). The long-term negative impact on children who have experienced abuse cannot be overstated as research has clearly shown that child maltreatment does not happen in isolation (Naughton et al., 2017; Robinson et al., 2020; Wynd, 2013) but is surrounded by many risk factors. A number of studies have reported that these risk factors are multifaceted and associated with the severity of the child's disability, parental stress, family violence and the interface between social and environmental influences (Naughton et al., 2017; Robinson et al., 2020).

In the past two decades, research has identified several gaps and inconsistencies in how social workers and health practitioners have responded to abuse, neglect, and trauma of children with intellectual disability. Some of these discrepancies have been reported, ranging from disbelief that children with disability are abused (Franklin & Smeaton, 2018; Jones et al., 2017), health practitioners' inability to see past the disability, failure to interpret challenging behaviours as warning signs of abuse and neglect to conduct assessments (Brandon et al., 2011), and unintentionally blurring the boundary between sympathising with parental struggle to deal with complex care and child endangerment and maltreatment (Manders & Stoneman, 2008).These inconsistencies have also been amplified by health practitioners' lack of knowledge about disability (Shannon & Tappan, 2011), inability to manage different communication styles (Algood et al., 2011), and failure to recognise the values and beliefs that can play a part in addressing abuse, neglect, and trauma of children with intellectual disability (Manders & Stoneman, 2008). As children and people with disabilities now have longer life expectancy due to advances in medical treatment and better health and support services, the numbers of children with intellectual disabilities will continue to increase globally, indicating the importance of enhancing knowledge and skills to support their needs. However, data on children with disabilities who experience abuse, neglect, and maltreatment are often complicated and unclear due to the lack of uniform conceptual and operational case definitions that are used across disciplines (Oranga Tamariki, 2020a) and the failure to collect appropriate data on a regular, ongoing basis to address the wider influencing issues of economic and material deprivation (Murray, 2018; Wynd, 2015). Research and the review of literature relating to the prevalence of abuse and neglect of children with disabilities are a growing field, particularly in the United States; yet such information is still scarce in Aotearoa New Zealand (NZ). While the Children's Action Plan and Children's Act 2014 aim to keep children safe and ensure their needs are met, much of the existing research and other grey literature on child welfare and child abuse in NZ continues to focus on children as a homogenous group, with limited reference to children with intellectual disability and their experiences with abuse, neglect, and trauma. Social workers and other health practitioners are urged to draw on their wide-ranging knowledge and skills, including relational practice, socio-ecological frameworks, person-centred approaches, knowledge of human rights and social justice, strength-based perspectives, and advocacy, to develop appropriate assessments and interventions to support children with intellectual disabilities and their wellbeing.

Given that this study was conducted in the Waikato-Tainui region, it was deemed appropriate to use the double vowel to refer to whaanau and Maaori to adhere to their written protocol (Waikato-Tainui, 2018a; Waikato-Tainui, 2018b).

1.2 Research goals and objectives

The overall objective of this research was to explore how social workers and health practitioners have responded to abuse, neglect, and trauma issues with children with intellectual disabilities. The first stage of the study involved the use of a focus group method to gain a wider perspective from social workers and a range of health practitioners' experiences (i.e., a clinical psychologist, social worker, physiotherapist, and occupational therapist) in working with children with intellectual disability who had experienced abuse, neglect, and trauma at both practice and policy levels. Data from the focus groups were used to assist and complement the development of an individual interview template, which was used to interview four qualified social workers to explore challenges, strengths, and opportunities in working and supporting children with intellectual disabilities and their whaanau and families. Thematic analysis was used to generate the key themes (Bryman, 2016), and inductive logic was used to explore the answers gathered from the data collected (O'Leary, 2017).

1.3 Significance of the study

Given the limited NZ-based research on exploring and supporting children with intellectual disabilities in relation to child maltreatment and care and protection issues, this research hopes to shed some light on the challenges faced by social workers and health practitioners working with this cohort of children. In addition, a deeper understanding of the contributing factors that improve assessment, intervention, relationship building, and future support and the role they have in informing best practice in child welfare and care and protection issues. A key issue in effectively addressing maltreatment among children with disabilities is how to identify, assess and develop interventions (Algood et al., 2011; Shannon & Tappan, 2011). It is hoped that results of this study may offer more recommendations on how to influence government policy, learning institutions, community, and statutory agencies to include knowledge and content in disability studies, develop standards on how to address abuse and violence, and strengthen their responsiveness to the needs of children with intellectual disabilities.

1.4 Positioning of the researcher

As a registered social worker for 13 years, my main field of practice has been within the disability sector working with children and adults with intellectual disabilities and their whaanau and families. As such, I consider myself an insider researcher because of my professional roles, understanding and working knowledge. As part of my role, it has not been uncommon for me to be involved with children with intellectual disability who have experienced abuse, neglect, and trauma. Over and over again, I have seen abuse of children with intellectual disability, but it would be too simplistic to place the whole responsibility on the whaanau and family. This scope of responsibility needs to be widened to include the quality of relational practice, service delivery and societal attitudes. It was for these reasons that I felt it was important to capture the experiences of social workers and health practitioners who are involved with children with intellectual disability who have experienced abuse, neglect, and trauma. Having an insider's view can add value to the research process (Dwyer & Buckle, 2009), by not only being equipped with in-depth knowledge and understanding of the disability sector, government agencies and the social and political dynamics fosters, but also to support the positive rapport building with the research participants and enhance the credibility in the research process (Ryan et al., 2007). During the research process, I also learnt to be mindful of and at times suspended my own insider's view to allow myself to navigate the research process without making overarching presumptions or biases, but to focus on the participants' narratives to speak for the research.

1.5 Structure of the thesis

Chapter one

The first chapter is the introduction chapter, outlining the background of the study, research goals and objectives, significance of the study, and structure of the thesis.

Chapter two

This chapter explores the literature and research in relation to social workers and health practitioners' responses to abuse, neglect, and trauma of children with intellectual disability.

It begins with a discussion of the prevalence of abuse, neglect, and trauma identifying what is currently known. This is followed by factors that have informed the understanding of the maltreatment of children with intellectual disability, including professional knowledge and experiences, involvement of whaanau and family, and issues regarding researching violence and maltreatment of children with intellectual disability. The final section presents child welfare perspectives and research in NZ.

Chapter three

This chapter presents the methodology and methods used for the research topic. The chapter begins by discussing the rationale for adopting a qualitative research approach, using focus groups and individual interviews as the data collection methods. It then focuses on describing the criteria and processes for recruiting participants, followed by a discussion of ethical considerations and the processes used in data analysis.

Chapter four

This chapter presents the findings from the focus groups and individual interviews. Theme one explores professional practice, knowledge, and skills, followed by a discussion of systems perspectives in theme two. Theme three explores the context of social work education, professional development, and leadership.

Chapter five

The fifth chapter is the discussion chapter which integrates the results and literature review to enable a discussion about what impacts on social workers and health practitioners' abilities to respond to the abuse, neglect, and trauma of children with intellectual disability. The chapter is organised into three key themes: (1) the intersection between the knowledge of disability and the competence of professionals to identify and assess for signs of abuse, neglect, and trauma; (2) the importance and relevance of relational practice in dealing with abuse, neglect, and trauma; and (3) the challenges in preparing a disability-competent health and social care workforce who can also work at a system level to create change.

Chapter six

The sixth chapter concludes the thesis. It summarises the key findings, reflects on the research processes and discusses the limitations. Then it moves into discussions about the implications for social work practice and identifies several recommendations and ends with a discussion of the impact of the COVID 19 pandemic and the ramifications for ongoing practice with children with disabilities who are at risk of abuse and neglect.

Chapter 2 – Literature review

2.1 Introduction

This chapter explores the literature and research in relation to social workers and health practitioners' responses to abuse, neglect, and trauma of children with intellectual disability. It begins with a discussion of the prevalence of abuse, neglect, and trauma, identifying what is currently known, followed by factors that have informed the understanding of maltreatment of children with intellectual disability, including professional knowledge and experiences, involvement of whaanau and family, and issues regarding researching violence and maltreatment of children with intellectual disability. The final section presents child welfare perspectives in NZ. The chapter concludes with a summary and identifies areas that require addressing in response to gaps identified in the research.

2.2 Prevalence of abuse, neglect, and trauma

Violence and child maltreatment is a serious global social and public health problem (Abbasi et al., 2015; WHO, 2020). The World Health Organisation (WHO) states "that nearly 3 in 4 children aged 2-4 years regularly suffer physical punishment and/or psychological violence at the hands of parents and caregivers, and 1 in 5 women and 1 in 13 men report having been sexually abused as a child" (WHO, 2020). Even though the Conventions on the Rights of the Child (UNCRC) were established in November 1989 (UN, 2021), and 196 countries have ratified and made a commitment to Article 19 to address the abuse and neglect of children, these alarming statistics have continued. According to WHO, child maltreatment is "the abuse and neglect that occurs to children under 18 years of age and includes all types of physical and/or emotional ill-treatment, sexual abuse, neglect, negligence and commercial or other exploitation, which results in actual or potential harm to the child’s health” (WHO, n.d.). In NZ, the definition of child abuse is defined in the Oranga Tamariki Act (1989), Children’s and Young People’s Well-being Act (1989): ‘child abuse means the harming (whether physically, emotionally, or sexually), ill-treatment, abuse, neglect, or deprivation of any child or young person’ (NZ Government, 1989).

Intellectual disability as a term and diagnosis has evolved over the years both internationally and in NZ. Terminologies such as mental retardation (Werner & Abergel, 2018), and handicapped (Keith & Keith, 2013) were commonly used and seen as socially acceptable by society and the medical profession at the time. In more recent times, changes have been made to terminologies to challenge the medical framework of disability. An explicit example of this can be seen in the United States of America where Rosa’s family advocated to change the common place usage of mental retardation to intellectual disability (Rosa’s Law, 2010). Official changes were made in 2010 and intellectual disability is now reflected in federal law books. Intellectual disability as a term has been commonly used in NZ for over 20 years (Higgins, 2014). The following resources provide the diagnoses and definitions which are commonly used in the international context and in NZ:

1. World Health Organisation’s ‘International Statistical Classification of Diseases and related Health Problems (ICD)’ (11th edition) – the diagnostic term used is disorders of intellectual developmental. (World Health Organisation, 2021).
2. The American Psychiatric Association’s Diagnostic and Statistical Manual of Mental Disorders (DSM, 5th edition) – the diagnostic term used is intellectual disability with intellectual developmental disorder in brackets. (APA, 2013)

3. The American Association of Intellectual and Developmental Disabilities, Intellectual Disability: Definition, classification, and systems of support (Higgins, 2014) – the diagnostic term used is intellectual disability (AAIDD, n.d.).

ICD is predominantly used internationally (WHO, n.d.). In NZ, both International Statistical Classification of Diseases and related Health Problems (ICD11) and The American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM5) are used. Not only do these three resources use different diagnostic terms, but at times these descriptors can be used interchangeably in the same piece of research (Connell et al., 2007; Shannon & Tappan, 2011; Sullivan & Knutson, 2000). Although no specific literature has discussed any issues with their interpretations and applications, tension remains as how to ensure consistent conceptual meanings and understandings are used in the assessment and intervention stages to ensure the correct support and interventions are put in place.

Previous international studies have estimated that children and young adolescents with disabilities have a significantly higher risk of being a victim of abuse, neglect, and trauma. Children with severe disabilities have significantly higher incidents of sexual abuse than children with minor disabilities and their ordinary peers (Hershkowitz et al., 2007). Sullivan and Knutson's (2000) epidemiological study identified that children with disabilities are three or four times more likely to be abused and neglected than their ordinary peers. Such results have been reflected in other literature (Jones et al., 2012). Several studies have found that there is clear evidence of an even higher incidence of abuse for children with more complex diagnoses, particularly in the education setting. For example, children with autism are more vulnerable to bullying in schools than their ordinary peers (Blake et al., 2012).Women on the higher end of the autism spectrum were found to be fifty percent more likely to have been abused during their childhood, compared to those at the lower end of the spectrum (Roberts et al., 2015).What this literature has highlighted is that addressing child abuse, neglect, and trauma cannot be seen in isolation. Algood et al. (2011) have argued that it requires a careful examination of the issue from a socio-ecological systems perspective and how people within each environment have a responsibility to address abuse, neglect, and trauma of children with intellectual disability when they identify it.

Research evidence has indicated that children with intellectual disability are more likely to experience multiple incidents of abuse over extended periods of time due to lower socio-economic status and impoverished material circumstances which can impact on the stress levels of parents (Algood et al., 2011; Sullivan & Knutson, 2000). Poverty has been considered as one of the significant stressors for some whaanau and families who are raising children with intellectual disability (Murray, 2019). Research has reported that children with intellectual disability and their whaanau and family are often unable to access the necessities of life such as food, heating, and affordable/accessible housing, alongside money to attend specialist appointments and the ability to easily access financial entitlements (Wynd, 2015).When children with intellectual disabilities are seen by doctors and specialists, it is crucial that they are accurately assessed to address any identified issues and given supports as required (McKenzie & Scott, 2011).Other research indicates that some children with intellectual disabilities have had more re-referrals into child protection services than other groups of children in the system (Connell et al., 2007; Dakil et al., 2011; Perrigo et al., 2018).Perrigo et al. (2018) identified that the reasons for re-referrals can be the additional challenges of parents' lack of knowledge of child development, lower socio-economic contexts and parents with drug and alcohol issues.

Given the inconsistent interpretation of child abuse, neglect, and trauma for the general population, and the additional challenges of collecting appropriate data on disabilities, it is extremely difficult to identify the prevalence, raising concerns that more children with intellectual disabilities have been abused and neglected than what is currently recorded (Jones et al., 2012). Interestingly, Lightfoot et al. (2011) reported significantly higher substantiated abuse cases for children with disabilities than has been identified in other research (Jones et al., 2012; Sullivan & Knutson, 2000). However, when examined closely, data from Lightfoot et al. (2011) combined children with disabilities with those who had used substances and experienced emotional disturbance. Such results could potentially create misunderstandings of the actual prevalence.

Another difficult issue relating to obtaining accurate information about the prevalence of abuse with children with intellectual disabilities is evidenced in research by Child Protection Services (CPS), where data collected is reliant on external factors such as the child meeting the criteria for health and education disability supports and from this is extrapolated how many children with intellectual disabilities are involved with child protection (Oranga Tamariki, 2020a). In addition, concerns were raised when case workers assessed intellectual disability of a child based on their observations rather than a confirmed diagnosis from a qualified professional, which further complicated reporting to provide appropriate interventions and support (Perrigo et al., 2018). Broadhurst et al. (2010) argued that some social workers and health practitioners chose to define child abuse from their own understanding, and this created adverse effects on how responses were made to assessment and service delivery. This was seen by social workers and health practitioners reporting their disbelief that children with intellectual disability can be abused (Robinson, 2015) and the minimisation of abuse due to empathy towards the parents who have a difficult time raising their child (Mallén, 2011). A study by Taylor et al. (2015) reported that the reasons given by children as to why abuse was not disclosed or identified included fear of breaking up their family and not wanting to disclose information due to the perpetrator being in the room. They gave another example where a child with a hearing impairment had to rely on the mother to interpret during an interview with the social worker and later it was identified that the mother was the perpetrator. This situation placed a tremendous amount of stress and trauma on the child. This real-life experience illustrates the missed opportunity for a social worker or health practitioner to assess fully for abuse when they are not equipped with professional knowledge and experience to support children with intellectual disability.

2.3 Factors influencing maltreatment against children with intellectual disability

2.3.1 Professional knowledge and experience

A growing body of literature has investigated the abuse and maltreatment of children with intellectual disability in terms of professional knowledge and the role of social workers (Jones et al., 2017; Prynallt-Jones et al., 2018; Stalker, 2015; Stalker & McArthur, 2012). These studies have reported several common themes that can inhibit or enhance professional judgement, such as developing ongoing professional development (Shannon & Tappan, 2011), improving communication skills and disability knowledge, factoring in lower thresholds for assessing abuse (Brandon et al., 2011; Stalker & McArthur, 2012; Stalker et al., 2015) and the problematic nature of collusion with parents/caregivers (Stalker & McArthur, 2012; Stalker et al., 2015). Stalker et al. (2015) have reported that the inconsistency of identifying and reporting abuse among children with disabilities is largely due to the varied responses of social workers. According to Cook and Standen (2002), when social workers only see the disability as a condition, it can at times create a barrier to identifying potential abuse. Social workers and health practitioners may only connect a behaviour, such as self-soothing by rubbing their genitalia, as part of the condition of the disability instead of looking at underlying reasons for the redness or bruising. In contrast, Ofsted’s (2012) findings showed when abuse was identified, it was because best practice guidelines were followed. While long-term involvement between social workers and health practitioners and whaanau and families can build trusting and collaborative relationships, it can also create a false pretence where the professional is at risk of failing to identify accumulative neglect. Conflict can arise when there is a discrepancy between social work values and personal values. This was evidenced in Manders and Stoneman’s (2008) research where recommendations from risk assessments completed by care and protection social workers was influenced by the empathy they had towards the parents/caregivers. The social worker focused on the intellectual disability as the contributing factor and made recommendations of ‘behaviour management’ instead of considering wider issues where, for example, the parent may have abused or neglected the child.

The difficulty in identifying child abuse and neglect does not just rest with social workers. Research has found that some medical professionals reported having difficulties in identifying child sexual abuse (CSA) unless the child discloses that some form of abuse that has occurred to them. This is because of the similarities between a medical condition and potential CSA indicators within the paediatric setting. Therefore, medical professionals should be trained to be alerted to possible indicators, with the added complexity that some indicators could suggest abuse or an entirely innocent reason (Vrolijk-Bosschaart et al., 2018). Recent research demonstrated that assessments of abuse and neglect among children with intellectual disability can be completed successfully in a child development centre, where results were shown to be five times more reliable than assessments conducted in a community clinic (Schertz et al., 2018). Success in this example was credited to the fact that the assessment was informed by a multi-disciplinary response and that staff received regular training in child maltreatment, assessment, and interventions.

Due to their disability or cognitive capacity to understand inappropriate touching or intimacy, children with intellectual disability can be at risk of abuse and neglect. As such, concerns have been raised that children with intellectual disabilities are less likely to report that they have been abused (Briggs, 2006; Jones et al., 2017; Lightfoot, 2014). According to Franklin et al. (2017), a group of young people reported that they did not disclose to anyone they had been abused because they did not realise it was abuse and, therefore, had no awareness that it was inappropriate. They subsequently only disclosed the abuse when asked the right questions. Even when young people do understand the context of abuse and report them, social workers and health practitioners have been reported to show inconsistent responses and practices to deal with disclosures.

Successful interventions to address child abuse and harm reduction can only be achieved if assessments are conducted properly, systematically, and rigorously (Stalker et al., 2015). It is vital that social workers and other health practitioners integrate knowledge of intellectual disability into their assessments and interventions and contextualise other complexities, such as care needs, additional costs for equipment and resources, grief and loss, anger, and isolation for parents/caregivers as they raise their child with intellectual disability. Good interventions are identified by working in partnership with whaanau and family, which may include addressing the existence of possible abuse and neglect, family violence, gaps in service delivery, therapeutic support, parenting issues, disability education for parents, and behaviour support. For children with intellectual disability, effective interventions create more positive outcomes developmentally, behaviourally, and socially to enhance the child's wellbeing (National Academies of Sciences, Engineering and Medicine, 2016). Similarly, paediatricians have recognised that early interventions with a child with intellectual disability are more likely to have positive outcomes. The child's quality of life is improved if paediatricians are family-focused and work in a multi-disciplinary way across the education, health, and community sectors. In addition, recognising the role of parents in the child's development is paramount and should be supported to enable them to advocate for their child to the best of their ability (The Royal Australasian College of Physicians, 2013).

Social workers in child protection services have been reported to be ill-equipped to support families and whaanau, and this is not surprising given that they have had minimal exposure to knowledge about intellectual disability while in tertiary education (Jones et al., 2012; Manders & Stoneman, 2009; Mogro-Wilson et al., 2014). Other research focusing on social work education has also reported the lack of opportunities to learn about intellectual disability in the curriculum and if there was an opportunity to learn, it was likely to happen during placement rather than in the classroom (Depoy & Miller, 1996; Laws et al., 2010). There is a growing awareness in the tertiary education sector of the need for disability electives embedded in undergraduate studies to enable practitioners such as social work students to develop their knowledge of intellectual disability through understanding the history of disability and the wide-ranging social issues that affect disabled people, and the role social workers can play in addressing these issues (Meekosha & Dowse, 2007). Research has shown that social work students value the opportunity to learn about disabilities when given the opportunity; thus, there has been calls for it to be a permanent part of the curriculum (Mogro-Wilson et al., 2014).

While the increasing amount of research has pointed to the importance of including intellectual disability as a key field of practice in tertiary study, there are mixed views on this. According to O'Reilly and Dolan (2017), some social work educators reported that specialised training was beyond the scope of what they could offer, and the responsibility should sit with the social workers' employers. However, Kim and Sellmaier (2020) have argued that equity and inclusivity in society must be seen in social work education where social work students of all abilities are able to actively participate in programmes and contribute to the ongoing development of the curriculum and wider structure to reflect the diversity of students. Others have emphasised that when social workers are resourced and have relevant hands-on disability knowledge and experience, they are generally more competent and confident in working with people with disabilities (Haney & Cullen, 2017). Prynallt-Jones et al. (2018) called for attention to the unavailability of disability specific education in the tertiary arena and ongoing professional development once social workers and health practitioners are in practice, further identifying that current practitioners often rely on parents/caregivers for developing their knowledge of intellectual disability. While working and learning about the child with intellectual disabilities from parents/caregivers creates the opportunity to build a trusting relationship, social workers and health practitioners must also be aware that parents/caregivers are often the perpetrators of abuse of this group of children. Therefore, social workers and health practitioners are required to have developed foundational and a competent level of evidence-based knowledge and skills to undertake careful and rigorous assessments and interventions to support the child and their whaanau and family.

2.4 Researching violence and maltreatment among children with intellectual disability

As discussed earlier, children with disabilities are particularly vulnerable to violence although good quality data are still lacking on prevalence, causes and the kinds of prevention of violence against children with disabilities. It is important to acknowledge that research is not only essential to gain a better understanding of health and wellbeing, but the involvement of children with intellectual disability in research as active participants to share their experiences of abuse, neglect, and trauma is also critical to ensure their perspectives are responsibly represented in policy and interventions (Kyegombe et al., 2019). The United Nations Charter for the Rights of the Child states in Article 13 and 19 respectively that ‘the child has the right to freedom of expression’ (OHCHR, n.d.) and ‘there is a responsibility by all adults that they play a role in mitigating any form of abuse and neglect’ (OHCHR, n.d.). Research conducted with children rather than for children can be more empowering and findings can make a significant contribution to policy, therapeutic interventions, and family support (Franklin & Smeaton, 2018; Lansdown & O’Kane, 2014; Radford et al., 2017). When involving children who have experienced abuse and maltreatment in research, additional care and precaution need to be taken. Noble-Carr et al. (2019) have found that in some studies children’s right to contribute was restricted by adults who provided their understanding of children’s experiences of violence instead of supporting the children to do this for themselves where appropriate and possible.

The importance of involving children and hearing their voices has been paramount and is central to assessment and research for abuse and neglect (Allnock & Miller, 2013; Daniel, 2007; Franklin & Smeaton, 2018). Taylor et al. (2015) have argued that efforts to understand, prevent and respond to abuse and violence against children with disabilities rely on having access to good quality data because previous research has indicated the myth of abuse as being non-existent among this group due to disbelief, minimisation, and collusion with parents. Kyegombe et al. (2019) have also concurred that there is still limited evidence regarding which interventions would be effective to prevent violence against children and people with disabilities. Not involving children's experiences of violence in research can perpetuate the existing inequitable responses, and this can have long-term negative impacts on their developmental, psychological, physical, and social wellbeing. More recent research has begun to focus on using big data to gain a better understanding of the prevalence of this issue to inform policy and practice (Jones et al., 2012). Furthermore, others have focused on environmental factors such as rural- and urban-based agencies, the accessibility of resources and knowledge, and the impact that this can have on identification and assessment to improve practice (Lightfoot & LaLiberte, 2006).

Qualitative methods have been preferred, enabling researchers to gather the narratives of children with intellectual disability who have experienced abuse, neglect, and trauma and allowing them the flexibility to share fully their experiences (Kyegombe et al., 2019; O'Leary, 2017). Kyegombe et al. (2019) have stated that many of the hurdles around interviewing children with intellectual disability can be mitigated through adhering to ethical protocols, which should include the wellbeing of the child, having interviewers who are confident and competent in interviewing children with different communication styles, and having a procedure in place to respond to a disclosure of abuse. It has been noted that professionals have been known to prevent children with intellectual disability from participating in research, removing the child's right to make their own informed decision, and resulting in the loss of their valuable contribution to the wider narrative of children with disabilities experiences of abuse, neglect, and trauma (Taylor et al., 2015). From a social work perspective, social workers are required to commit to their code of ethics, and be competent in their practice knowledge (ANZASW, 2013; Bigby et al., 2018; Bishop-Fitzpatrick et al., 2019; DePanfilis, 2014). These foundations should inform social workers of the importance of helping children and young people with disabilities overcome the barriers they face in participating in research to enable transformational change at a practice and policy level.

2.5 Involvement of whaanau and family

Central to providing support for children with intellectual disability is not only about working alongside children, but also providing meaningful support for the wider whaanau and family, including the primary caregiver, who is often the parent or grandparents or other caregivers. It is also important to be aware that children with an intellectual disability can be at a higher risk of being abused by someone they know, often a family member such as parents, siblings, or grandparents, than their ordinary peers (Akbas et al., 2009; Miller & Brown, 2014). Raising children with intellectual disability is often a lifelong journey because of the ever-changing needs across their life span, and this role can be rewarding as well as demanding and stressful. The level of stress and support required can be elevated by several factors within both the family and community systems. Research has suggested that the ability of whaanau and family to function successfully can be improved by additional supports and resources required to support a child with a more complex disability, including dedicated one-to-one support (Dovgan & Muzurek, 2018). Furthermore, there are external factors that can impact on how whaanau and family manage their daily living and wellbeing, such as poverty or financial hardship (Murray, 2019). Recent research has reported that children with disabilities who have experienced poverty or financial hardship are three times more likely to experience negative long-term effects as adults than their ordinary peers (Vera-Toscano & Wilkins, 2020). Lack of suitable, affordable housing that is warm and dry, and long-term security is also an all-too-common experience for ordinary whaanau and families. The additional accumulative stressors experienced by parents raising children with intellectual disability, can lead to increasing the vulnerability of children with intellectual disability to abuse and violence. There can also be an increase in exclusion and being marginalised from accessing the care and needs they require (Statistics NZ, 2020). Whaanau and family with children with intellectual disabilities are often identified as a more vulnerable group in society (Vera-Toscano & Wilkins, 2020; Wynd, 2015) due to the extra needs of the child, which can include homes not being fit for purpose, a lack of respite/support, varying practice between agencies, isolation, accessibility to entitlements, limited natural support from wider whaanau and family and or friends and inadequate transportation (Baumgardner, 2019; Wynd, 2015). When parents were interviewed about using specialist respite for children with complex needs, their access was restricted by availability and frequency, the complexity of the child's behaviour, the skillset of staff and trusting relationships with service co-ordinators or social workers that facilitated parents' access to respite (McConkey et al., 2012).

From a wellbeing perspective, parents can experience a myriad of emotions and feelings as they navigate the different stages of their child's life. Much has been written in the literature about the stress, anger, grief, and loss a parent might experience when having a child with a disability (Brown, 2016; Machalicek et al., 2015; Manders & Stoneman, 2008). Research focusing on siblings' needs and wellbeing has become a focal point in recent years, as siblings are often forgotten by social workers and health practitioners and parents alike because of the more immediate needs of their sibling with intellectual disability (Milevsky, 2015; Shojaee et al., 2020). Siblings are often called on as surrogate carers to attend to the needs of their sibling

(Donnan, 2020; MSD, 2019), whereas a sibling of an ordinary child in comparison is more likely to attend community activities such as sport, have friends over, and have regular one-to-one time with their parents (Adams & Leshone, 2016).The negative impact cannot be overstated and can have a wide-reaching impact on the sibling’s mental, physical, social wellbeing, and academically, into adulthood (Halberg, 2013; Milevsky, 2015).

Grandparents can also play a significant role in the wider whaanau and family when supporting their grandchildren and, in some situations, they may end up raising their grandchildren as the primary caregiver (Dunifon, 2013). Existing literature on grandparents who have grandchildren with intellectual disability has shown similar experiences to their adult children of raising and supporting a child with intellectual disability. This research has reported that grandparents too have experienced grief, loss, and stress; they also struggled with their own limited knowledge of disability and found difficulties in accessing respite and support from the mainstream system (Huang et al., 2020; Miller et al., 2012; Mitchell, 2006; Moffatt et al., 2019). Gordon (2016) researched around 9,500 grandparents raising their grandchildren in NZ and results showed similar experiences to parents raising children, with additional ongoing challenges of managing the long-term effects of substance abuse inherited from their parents in their grandchildren, and at times needing to manage their own health issues. These results are consistent with Kreskas et al. (2014), highlighting the importance of supporting the mental health and wellbeing of the grandparents long term.

Although parents/caregivers may intentionally or unintentionally harm children with intellectual disabilities in their care, research has shown that when they did receive education specifically related to children with intellectual disabilities, for example ‘Stepping Stones and Triple P’ (SSTP), the outcomes were positive and successful for both parent and child (Gray et al., 2017). By affirming the valuable role that parents can play in their child’s life (Machalicek et al., 2015; Mazzucchelli et al., 2019), risk can be reduced, and protective factors increased. Kandel and Merrick (2007) have established that whaanau and family and their children require consistent support throughout their child’s life by putting appropriate interventions in place, not only in their day-to-day lives but also interventions that are responsive to the changing needs and significant events in education, health, and family systems.

2.6 Abuse, neglect, and trauma among children with intellectual disability in NZ

2.6.1 Prevalence and conditions

According to Statistics NZ (2013a), half of children under 15 years will have a learning disability of some kind, in 2018 there were approximately 143,000 children and young people with disabilities, 53,660 were under 9 years of age (Murray, 2019). There has been an increase in children with disabilities born in NZ (Stats NZ, 2013a), and other countries such as Australia (Arabiat et al., 2018) and Korea (Rah et al., 2020). Zablotsky et al. (2019) reported that the numbers of children with developmental disabilities will continue to increase globally, specifically those with attention-deficit hyperactivity disorder (ADHD), autism spectrum disorder (ASD) and intellectual disabilities, signifying the importance of acquiring the necessary knowledge, skills, supports and infrastructure to support this group of cohort’s life-span development and needs. Among children under the age of 15, nine percent of non-Maaori children have a disability compared to 15 percent of Maaori children (Statistics NZ, 2013a). According to the NZ Ministry of Health (2011), a person with intellectual disability will live on average until they are 59 years of age (Statistics, 2014) and it is further forecast that life expectancy will continue to increase (ODI, 2016).

The most significant change for children with intellectual disability was the advocacy of Intellectually Handicapped Children (IHC) in the 1960s for suitable education, followed in the 1980s by the deinstitutionalisation era where children with intellectual disability were integrated into ordinary schools and where residents of institutions – both children and adults – were returned to their community. Similarly, the Individuals with Disabilities Education Act of 1975 in the United States of America came into being (Draper, 2021) and this shift was in part due to people with disabilities advocating for societal barriers to be removed, enabling them to access their communities, schools, have jobs, and valued roles in their community (Bigby & Frawley, 2010). Internationally, NZ has led the development of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (UN, 2008), recognising people with disability were valued members of society (Office for Disability Issues, 2016a). It is important to recognise the emergence of disabled people's advocacy groups, such as People First, (n.d.) and Disabled Persons Assembly NZ (DPA, 2015), who have and continue to advocate for the rights people with disabilities.

2.6.2 Challenges of investigating child abuse of children with disabilities in NZ

NZ has one of the highest rates of child abuse in the developed world according to United Nations Children's Fund (UNICEF, n.d.) and consequently Oranga Tamariki, NZ's child protection agency receives approximately 150,000 reports of concern a year about some form of abuse against a child (UNICEF, n.d.). Research conducted by Rouland and Vaithianatha

(2018) reported that one in four children in NZ before the age of 17 years were likely to have had at least one ‘report of concern’ relating to an alleged form of abuse to Oranga Tamariki, of which ten percent were substantiated. Combining the estimate of one in ten children with intellectual disability who have experienced substantiated abuse, with all substantiated cases between 2015-2019 (Oranga Tamariki, 2019; Oranga Tamariki, 2020a), it would suggest on average there are 1,845 children with intellectual disability who have experienced abuse that come to the attention of child protection services in NZ each year. Given that it has already been noted that children with intellectual disabilities are three to four more times likely to be abused than their ordinary peers, it would not be inconceivable to suggest that the prevalence of abuse is much higher for children with intellectual disability.

The NZ child welfare system has also faced many challenges and reforms in the past five years. Much of the existing research on child welfare and child abuse in NZ has reflected a generic focus on children with social and environmental vulnerabilities such as poverty and substance misuse, but with limited reference to children with intellectual disability and their experiences with abuse, neglect, and trauma. Within the neo-liberal political context, it has been argued that the focus is on ‘troubled families’ in child protection practice, which fails to engage meaningfully and purposefully with whaanau and families who are in challenging and vulnerable situations (Hyslop, 2016a). As such, the child requires fixing to ensure they go onto be a contributing member of society, and secondly the parent is seen as solely responsible for the vulnerability of their child (Featherstone et al., 2014; Wacquant, 2014). Social work scholars have criticised the neo-liberal agenda for forcing social work practice to assume an interventionist approach, focusing on discipline, and punishing the poor, with little thought given to wider influential factors such as poverty (Hyslop, 2009; Keddell, 2017).

Rogowski (2018) points to the negative influence of neoliberalism on social work roles and the boundaries that come with it. These boundaries have perpetuated risk adverse, time-limited, and resource-strapped practice, placing the onus on the parents to address the issues or risk losing their child. Beddoe (2014) presented a wider view where the burden on the individual moves the focus away from the NZ government's responsibility to address underlying influential factors such as poverty and housing. There is little room for social workers to build rapport or relationship with the child and whaanau and family under these conditions. Practice that is time pressed and measured can increase the risk of the loss of core social work skills such as advocacy, justice, strengths-based and social change (Hunt, 2017). Hyslop (2016b) shares similar views by challenging what social workers' professional identity is and the tension that sits between what social work is and what is expected of social workers as they adhere to a restrictive and monitoring role with little room to effect changes in a relational way. A differential in responsiveness to the 'here and now risk' is given weight in Keddell's (2017) research, which showed in part that a child protection social worker's practice is influenced by the critical environment they work in and the ideologies of the government of the day.

Whilst poverty has been identified as an ongoing issue in child welfare and protection in NZ, the Ministry of Social Development (MSD) has claimed that poverty was no excuse for abuse in the White Paper released in 2012 (Bennett, 2012). Longitudinal studies in England have found that poverty can be an influential factor in children experiencing ongoing adverse experiences (ACE) (Lacey et al., 2020), which was similar in NZ where ACE impact on successful outcomes in adulthood (Gibb et al., 2012). However, neither of these studies identified children with intellectual disabilities in their cohort. In NZ, a small number of research studies have started to call for addressing the relationship between child abuse and in some instances disability, when examining the disparities for children living in poverty, and the potential consequences (Murray, 2018; Peters & Besley, 2014; Wynd, 2013). There is also some evidence of preventative sexual violence initiatives in NZ, but these are at a foundational level and require significant expansion and revision to provide education to children and adults with intellectual disability, if they are to be equipped with the knowledge and skills to safeguard themselves against sexual abuse (Moore et al., 2020). Given the limited research in NZ regarding violence against children with intellectual disability and the infamous position of being rated as having one of the highest rates of child abuse in the OECD, it is critical that further research on this subject be conducted to capture the prevalence in NZ and to identify the support and resources that would keep children with intellectual disability safe from harm.

2.7 Summary

In conclusion, this chapter has provided a review of the research and literature completed over 20 years, illustrating growing evidence that children with intellectual disability experience abuse, neglect, and trauma. Children and young people are more likely to be heard and have their needs responded to appropriately in a timely manner if the social workers and health practitioners involved are supported and well-resourced to do this. However, the review has shown major gaps in policy, practice, and research, which signpost key challenges to support the workforce to address violence against this group of children effectively.

Chapter 3 - Methods

3.1 Introduction

This chapter presents the methodology and methods used for exploring the perspectives and experiences of social workers and health practitioners' responses to abuse, neglect, and trauma issues with children with intellectual disabilities. The chapter begins with the rationale for adopting a qualitative research approach, using focus groups and then individual interviews as the data collection methods. It then focuses on describing the criteria for recruiting participants and the processes, followed by ethical considerations, and data analysis.

3.2 Study design

This research was undertaken using a qualitative research approach, which captures the participant's subjective experiences of the phenomena being researched and that develops an understanding of how this informs the work that they do (Ryan et al., 2007). The qualitative data collection methods allowed movement from structured open-ended questions to "unexpected data" (O'Leary, 2017, p. 240) where participants may share information that has not been identified in similar research. This method ensured wide ranging data was captured to meet the purpose of this study, which was to explore social workers and health practitioners' responses to abuse, neglect, and trauma of children with intellectual disability. The interpretive underpinnings of qualitative methodology (Holloway & Galvin, 2016) fit cohesively with the social constructionist paradigm (Burr, 2015; Hunter Revell, 2013), enabling the researcher to interpret and find meaning in the narratives of the participants.

This research used a two-phase approach, with focus groups followed by semi-structured individual interviews, which together made up the data collection processes. The intent of using two types of qualitative data collection was to gain a more in-depth understanding of social workers and health practitioners working with children with intellectual disability and their ability to work with abuse and trauma (Lambert & Loiselle, 2008). The focus group was chosen because it is a facilitated method, drawing on the experiences of participants who have similar professional backgrounds and significant knowledge of the research topic (Yin, 2011). Capturing data from the participants in a group method meant that the data collected are from experts who know their field well, enabling the researcher to collect wide ranging information in a short period of time on a topic that is not widely researched (Patton, 2015).

The expert knowledge gathered in the focus group interviews was then examined in order to inform and validate the development of the semi-structured interview template for in-depth individual interviews. The strength of using the method of semi-structured individual interviews in this research is its ability to capture the participant's thoughts and experiences through a shared conversation between the interviewer and the participant, which is facilitated by the interviewer (Hunter Revell, 2013). Alongside this shared conversation, the interviewer guides the participant through the already identified themes in the interview schedule, which allows flexibility to follow and explore important information and unexpected revelations that the participant may share (Ryan et al., 2007; Yin, 2011).

3.3 Study participants

For this study, a purposive sampling method was chosen. This was deemed appropriate because it aligns itself well with the intentionality of the criteria for participation, for example, there was a requirement that participants – social workers and health practitioners – had professional experience of working with children with disabilities who had experienced abuse, neglect, and trauma that in turn supported the research topic (D’Cruz & Jones, 2004; O’Leary, 2017. Typically, qualitative research is done with a small sample size and the goal is to gain a rich understanding of the research topic as was the situation in this research (O’Leary, 2017). Qualitative research uses open-ended themed questions that allow the participants to share their experiences in their own way instead of the restraints of the quantitative environment where participants are questioned in a controlled and prescribed setting, which can restrict their ability to share wide ranging data (Patton, 2015). When recruiting and interviewing participants, it is also important to ensure that they are informed about the research plan, as well as the intent of the research, including their role as a voluntary participant and what that will look like in the focus group or the one-to-one interviews (Yin, 2011). This approach to research is emphasised by Hunter Revell (2013), who argues that it is essential for qualitative researchers to conduct the study in such a way that the participants can influence the direction of the content dependent on what they share.

3.4 Ethical considerations

Ethical considerations for this research were discussed and overseen by the researcher and her two supervisors. The research was approved by the Massey University Humans Ethics Committee (SOA 19/18 Appendix A). This research aligned with the Massey Code of Ethical Conduct for Research, Teaching and Evaluations Involving Human Participants Revised Code 2017, drawing on the guiding principles of autonomy, benefit, avoidance of harm, justice, and special relationships to inform the researcher’s research framework. Participation in this research was voluntary, and the participants’ identities, privacy and confidentiality were paramount. Their valued input could influence a greater awareness of the subject and potentially strengthen practice and policy (Mack et al., 2005; O'Leary, 2017). Data were stored and secured electronically on the researcher's home personal computer and a hard drive which was only accessible by the researcher using a password. Paper notes were stored securely in a locked cupboard to which the researcher had the only access key.

Before conducting the focus groups or individual interviews, participants were provided with information about the research (Appendices B, C & D), the process and assurance of confidentiality of their data and how this was managed. Participants were reminded that they could decline to answer any questions during the focus group discussion or individual interviews. If anyone had felt uneasy due to the discussions in the interview, they would be encouraged to speak with their own supervisor in supervision. They could also choose to withdraw from the study up until they signed the transcript release authority. All participants in the focus groups signed a Focus Group Participant Consent Form (Appendix E) clearly identifying the individual and collective responsibilities of not only the participants but also of the student researcher. The signing of this document was a commitment to uphold these responsibilities. The ground rules in the Focus Group Schedule (Appendix F) was talked through at the beginning of the discussion and everyone agreed to the ground rules and protocols.

3.5 Focus group - Recruitment

Recruitment commenced for the focus group interviews at the beginning of May 2019. It was essential that participants had relevant qualifications and professional experience to participate in the focus group. The eligibility criteria for the focus group involved qualified social workers who held senior positions in management, social work, policy, or practice leadership and had at least five years relevant experience in working with children with intellectual disabilities, who had also experienced abuse, neglect, and trauma. The initial recruitment emails for focus group participants were sent on the 21 May 2019 to 12 agencies across the Waikato and Hauraki regions. The emails included a letter of introduction (Appendix G) and an information sheet (Appendix B) asking for permission of the CEO/manager to circulate the information sheet to relevant staff. The researcher's own professional network was also used to circulate the information sheet to relevant people and extended networks. The first scheduled focus group was to be held on the 15 June 2019 but unfortunately, one participant was sick, and only one of the other three confirmed participants showed up. The focus group was cancelled with the intent to be rescheduled.

The focus group was re-scheduled for 6 July 2019. This time the same participant who came to the first one arrived; however, the other two did not show up due to sickness and no reason provided. Given the same participant had made the commitment to turn up twice, it was decided that the interview would go ahead to honour the participant's time and professional expertise. This participant was a senior social worker who has had significant practice and disability experience across a variety of sectors. After the interview, this participant offered to assist in recruitment by contacting their networks in Auckland to see if there was a possibility to organise another focus group with relevant professionals. Unfortunately, this did not come to fruition. While the real reasons behind the lack of respondents to participate in the research were unclear, a decision was made after consulting with the supervisors to open the invitation to the study to other health practitioners. These health practitioners must have relevant qualifications and experiences in abuse, neglect, and trauma of children with intellectual disability.

With the modification to the recruitment process, snowball sampling method was also used, where momentum gathers for potential participants as the reach extends outwards from the initial contact (Shaw & Holland, 2014). A revised information sheet (Appendix C) was circulated to the researcher’s other professional networks and previous agencies were contacted via email. Colleagues from other professional backgrounds such as psychology and occupational therapy were also contacted and through different recruitment processes, two focus groups were successfully organised within a short period of time. One focus group was conducted in mid-August 2019, which comprised four participants – three with backgrounds in clinical psychology and one in social work. The other focus group was held in late August 2019 with three participants with backgrounds in clinical psychology, physiotherapy, and occupational therapy. Most of the participants had significant experience in the disability field and drew on knowledge gained from working in a variety of sectors including mental health, education, health, community, and justice. They were all considered to be senior practitioners, and some had their own private practices. None was currently in management or policy roles. All identified themselves as of NZ European descent and two were born outside of NZ.

3.6 Individual interviews - Recruitment

The use of the focus group in phase one provided an overall scope of the issues from experienced social workers and health practitioners who have had management and macro understanding of the abuse, neglect, and trauma in relation to children with intellectual disability issues. In phase two, the intent was to recruit four to five qualified social workers with at least three years practice experience of supporting children with intellectual disabilities. The purpose of these individual interviews was to gain a wider understanding of issues and challenges from front-line social workers who have been supporting this cohort of children and to further investigate what best practices are needed to support and strengthen service provision. Concurrent to the focus group data collection process, the recruitment process commenced for qualified social workers to participate in individual interviews which started on the 30 July 2019. Participants were drawn from the social services community; emails were sent to non-government organisations in the Waikato area (Appendix H) where permission was sought to circulate an advertisement (Appendix I). In addition, permission was sought from Aotearoa New Zealand Association of Social Workers (ANZASW) (Appendix J) to circulate an advertisement (Appendix K) through their website to invite potential applicants across New Zealand to participate in this study.

The researcher's own professional network was also used to circulate the information sheet (Appendix D) to relevant people and extended networks. Interviews were held between September and November 2019. Four qualified social workers who had experience of working with children with intellectual disability, particularly in abuse, neglect, and trauma, were interviewed. The four participants' backgrounds included behaviour management, tertiary education, health, education, mental health, and community. Two of the participants have had lived experience in having a family member with intellectual disability. Three participants identified themselves as having different ethnic backgrounds, and two were born outside of NZ. Given the small cohort of qualified social workers working in this field of practice, only general information about them is provided here to protect their identities. Pseudonyms will be used when reporting the data.

3.7 Data Collection

3.7.1 Focus group

A focus group protocol was developed and revised by the researcher and her two supervisors called a 'Focus Group Schedule' (see Appendix C) to ensure transparency of process and the wellbeing of the participants. The protocol included: a welcome, introduction of the facilitator, consent form, a review of the subject and the valuable role the participants would play in sharing their stories for this study, what the expectations were of the day, housekeeping – toilets, emergency, and refreshments. Before the start of the focus groups, participants signed consent forms and were reminded of their rights and responsibilities in participating in this research. Going through the information sheet and signing the consent forms ensured that confidentiality was assured among the participants and that names of other professionals or the children that they have worked with were not disclosed. Participants were reminded that participation was voluntary, and they could choose to answer or decline to answer any question and there would be no judgement or adverse effects from the group and the facilitators (Office for Victims of Crime, n.d.). The intent of these protocols was to ensure that a safe and respectful environment was created to allow participants to share their own experiences and to clarify and build on other participants' responses to enhance richness to the data collected (Barbour, 2007).

The venues for the two focus groups were neutral spaces in the community. The researcher was the facilitator for the two focus groups. Each focus group lasted for about 60 to 90 minutes. There was a break during the session and morning tea was provided for each group during the break. As noted, the initial focus group only had one participant, so an individual interview style was conducted in the community venue. Both focus groups and the focus group that was run as an individual interview were audio recorded with two voice recorders to ensure that there was a backup recording. This also enabled me to be present in the moment and able to fully focus on the questions and answers (O'Leary, 2017). The individual interview was transcribed verbatim and for the two focus groups, a summary of the key points was completed. The transcript and the summary were emailed back to the participants to check for accuracy and to seek approval for use in the research and to finalise the process via the 'Authority for Release of Transcripts' (Appendix L & M), which was completed by each participant. Both the focus group and individual participants agreed to having their respective summaries and verbatim transcript being used in the thesis.

3.7.2 Individual interviews

Following a preliminary analysis of the focus groups, a series of in-depth interviews with four qualified social workers were conducted (Lambert & Loiselle, 2008). Two participants were interviewed face-to-face using a mutually agreed place, time, and date while two other participants were interviewed via skype in the privacy of their own offices, using the one-to-one interview schedule (Appendix N). Overall, the interviews lasted approximately 90 minutes each. Prior to conducting the interviews, each participant was given the information sheet (Appendix K) and their rights and responsibilities were re-iterated, and their consents were sought (Appendix O). All interviews were audio recorded with two recorders to ensure a backup recording and the interviews were then transcribed verbatim. All transcripts were double checked with the original recording to ensure that data was captured correctly. Transcripts were emailed back to the participants to check for accuracy, and they were asked to give permission via completion of the 'Authority for Release of Transcripts' (Appendix L) for the use of the interview in the thesis. All four participants signed the Release of Transcripts form.

3.8 Data analysis

The focus group data was initially analysed prior to conducting the individual interviews to ensure the semi-structured interview template covered essential aspects to address the research topic. The decision was also made to analyse both the focus group and individual interviews to provide a comparative perspective.

Thematic analysis was used to generate the key themes (Bryman, 2016). Inductive logic was used to ensure impartiality, authenticity and ethical practice was maintained throughout the data analysis process (Elliot & Timulak, 2005; O’Leary, 2017). Initially, I familiarised myself with the data collected through audio transcripts, note-taking and documentation of key points, and visual cues noting preliminary themes (Huberman & Miles, 2002). Using inductive logic allowed the data collected to inform the answers to the research questions rather than beginning with a deductive logic perspective, which focused on looking for evidence to support pre-conceived ideas (O’Leary, 2017). The motivation for this research had come from my experience in the disability sector and the research that has been completed overseas on a similar subject collectively forming the grounds for this research (Jones et al., 2012; Stalker et al., 2010). Once the initial inductive process was completed, those data were analysed from a deductive perspective to see if there was any validation of previous knowledge collected. An in-depth analysis was completed, coding each line, refining, and reducing to specific themes, which were documented accordingly in a structured and organised approach (O’Leary, 2017;

Shaw & Holland., 2014) so that the data analysis could be revisited at any stage in a timely manner (Elliot & Timulak., 2005). The use of triangulation in research, comprised the use of focus groups, followed by analysis, which then led to individual interviews. According to Fielding and Fielding (1986, p. 33), triangulation adds ‘breadth or depth to our analysis’, which aligns with existing literature to enhance what is already known about this subject (Fenech Adami & Kiger, 2005), and which is comprehensive and thorough (Jick,1983).

3.9 Trustworthiness

To ensure rigour throughout the research process, it was imperative for me as a qualified registered social worker with professional experience in working with children with intellectual disabilities who have experienced abuse, neglect, and trauma, to be aware of and maintain my objectivity throughout the research. This was achieved by using a reflective journal to document the research journey. Actively participating in regular supervision with my research supervisors also provided opportunities for me not only to reflect in the written form but also to have ongoing reflexivity within the discussions about initial perceptions and then on the more concrete emerging themes. Undertaking ethical considerations and applying for ethics by drawing on the Massey University Code of Ethical Conduct for Research, Teaching and Evaluations Involving Human Participants Revised Code 2017, alongside consulting with the Aotearoa New Zealand Association of Social Workers Code of Ethics (ANZASW, 2013) was essential in the research process to ensure ethically sound judgements in my research practice.

The validation of credibility was evidenced by the common themes being linked back to the scripts transcribed from the interviews through anonymised participants’ quotes within the body of the thesis (O'Leary, 2017; Patton, 2015). I have ensured that as I journeyed through the analytical process, I was conscious of any preconceived biases and perceptions gained from my professional role working in the disability sector. Dependability and transferability were reflected in the intentionality of the methods to ensure that the authentic findings could be used in other settings (O'Leary, 2017). Triangulation is evidenced drawing data from three different sources, initially from the information contained in the literature review and then from the focus groups and individual interviews (Yin, 2011).

3.10 Summary

A qualitative research approach was used because it provided a framework for capturing the subjective experiences of NZ social workers and other health practitioners involved with children with intellectual disability who had experienced abuse, neglect, and trauma. This chapter provided a discussion of the research methodology and the methods used including ethical considerations, recruitment strategies, data collection and data analysis. The next chapter will discuss the themes derived from the data analysis, what is working well and areas that require addressing from a micro to a macro level.

Chapter 4 – Findings

4.1 Introduction

This research set out to explore social work and health practitioners' perspectives and experiences in responding to abuse, neglect, and trauma experienced by children with intellectual disability. Themes derived from the data analysis and discussed in this chapter reflected the importance of addressing abuse and neglect of children with intellectual disability from a micro to a macro level. The themes also illustrated the lack of understanding of intellectual disability by those who have been involved with the child, for example, parents and social workers, that leads to the need to improve social and community work practice in this often unrecognised and under-researched field.

The thematic discussion in this chapter draws on the data from both the focus groups and individual interviews. Initially, the purpose of the focus group was to capture the subjective experiences from qualified social workers who held senior positions in management, social work, policy, or practice leadership. However, due to recruitment challenges (see Chapter 3 – Methods Chapter), other health practitioners' views were also sought. Individual interviews were then held with qualified social workers who had extensive experience in working in this field of practice. As the data analysis progressed, it became clear the data gathered from both the focus groups and the individual interviews had common and interesting narratives that complemented each other to an extent; hence, it was deemed appropriate to analyse and report them together. Themes presented below showed consistencies among the participants' views on the need to develop a better understanding of intellectual disability, which are conceptualised in three areas: (1) the importance of understanding of what intellectual disability is and its nuances, such as the different diagnoses and needs, and the ability of social workers and health practitioners in reconciling issues related to abuse and maltreatment and those concerning the children's disabilities; (2) the relevance of relational practice and the part it plays in supporting successful outcomes for children with intellectual disabilities and their whaanau and family for better wellbeing; and (3) and the challenges in preparing a disability-competent health and social care force that can effectively respond to abuse, neglect, and trauma from a system perspective.

4.2 Background of the participants

In phase one, two focus groups (four and three participants respectively) were successfully conducted while one participant was interviewed face-to-face due to operational challenges. Seven of the eight participants were female. Two of the participants identified as social workers, four as clinical psychologists, one as a physiotherapist and one as an occupational therapist. They all identified themselves of NZ European descent. Their professional backgrounds stemmed from being senior social workers and health practitioners with extensive practice experiences in disability and other fields of practice, including, mental health, education, child protection, health, community, and justice.

In phase two, four qualified social workers participated in individual interviews. All participants were female, and two of them had lived experience of disability in their whaanau and families. Two participants were of NZ European descent; one participant identified as Maaori and Pasifika, and one as Pasifika. All four participants had more than five years' experience in the disability field, and they drew on their knowledge and experience gained in behaviour management, tertiary education, health, education, mental health, and community in their practice. To maintain the privacy and confidentiality of the participants, pseudonyms have been used and identifying details have been removed. Table 4.1 provides a more detailed description of the participants.

Table 4.1 Background information on study participants

Participants	Gender	Ethnicity	Profession	Practice/Disability experience
Phase One ***Individual Interview***				
Jill	Female	European	Social Worker	35 years practice experience; 10 years disability practice
Focus Group One (FG1)				
Alice	Female	European	Clinical Psychologist	On average 25 years practice experience including 17 years of specific disability experience collectively across different sectors in community and government organisations
Sarah	Female	European	Social Worker	
John	Male	European	Clinical Psychologist	
Jane	Female	European	Clinical Psychologist	
Focus Group Two (FG2)				
Sue	Female	European	Occupational Therapist	On average 10 years practice experience including 5 years of specific disability experience collectively in community and government organisations
Joanne	Female	European	Clinical Psychologist	
Pam	Female	European	Physiotherapist	
Phase Two ***Individual Interview (II)***				
Rachel	Female	European	Social Work/Counsellor	Over 20 years practice experience in community and lived experience of supporting a family member with disabilities
Jackie	Female	Pasifika	Social Worker	Over 5 years practice experience in community and government organisations. Throughout this time has worked with disabilities as part of her wider practice
Colleen	Female	European	Social Work/Teaching	Over 8 years practice experience in community and government organisations, predominantly with disabilities
Rose	Female	Pasifika/Māori	Social Work/Teaching	Over 15 years practice experience in community as a social worker, along with previously working in disability sector and lived experience of supporting a family member with disabilities

4.3 Theme One – Professional practice, knowledge, and skills

Identifying children with intellectual disabilities who have experienced trauma, abuse, and neglect can be a challenging task. It requires social workers and other professionals to respond to abuse appropriately by drawing on their professional practice, underpinned by knowledge, skills and bi-cultural Te Tiriti o Waitangi practice. Complications can occur when the social worker or health practitioner has limited knowledge of disability and this was apparent in the accounts of most of the participants, who reported that at times they relied on the parents or caregivers to interpret what the child was saying. This also meant more time was required to build a relationship with a child with intellectual disability than a neuro-typical child. Many of the participants also indicated that identifying and reporting abuse was not always easy, and it could become very problematic, for example, when the child may not have been aware that they have been abused, making disclosure and support planning challenging. In addition, when the child lacked communication skills or had alternative communication requirements, this also made it difficult to understand and identify potential indicators to assess abuse and its impact on their health and wellbeing.

4.3.1 Knowledge

When participants from both phases were asked to discuss what their understanding of abuse was when working with this group of children and how they have responded, nearly all of them reported that they learnt mostly on the job from working with this group of children to develop their skills, knowledge, and intuitive practice. This practice experience has supported them to navigate not only the nuances of disability whilst critically assessing abuse, but also the inconsistencies in responses to alleged abuse.

There was consensus across all participants on the common definition of abuse, which involved emotional, physical, sexual and neglect. Two participants articulated their perspectives of abuse, indicating their heightened awareness and experiences when it came to assessing children with intellectual disabilities and the importance of knowledge needed to navigate the nuances of disability:

> Different forms of child abuse, physical, emotional, and sexual abuse, from that perspective I do not think I view children with intellectual disability any differently. I do know that children with both intellectual and physical disability are more vulnerable to abuse because they are less likely to have the ability to identify that they have been abused. (Jill, FG 1-1)
>
> This is a high-risk population in terms of their ability to speak out, protect themselves, cognitively be aware that there is abuse, neglect, psychological. Having the skills to manage that, live with that, or to communicate what is happening for them, a vulnerable population in that regard. (Joanne, FG2)

4.3.2 Skills

Participants acknowledged that it was difficult to identify abuse within this cohort of children. Navigating the nuances of disability was at times complex and required social workers and other health practitioners to draw on wide-ranging skills to overcome barriers such as interacting with children who have their own communication style. Jill stated that *we must be willing to engage with people around them who know the child better than we do, and who might be able to provide good information about any changes in the child's behaviour* and Rachel highlighted the importance of *looking through different lenses*. Colleen and Rose identified that communication and child-focused assessment tools were critical for best practice. Rose went onto share that she created a child-focused assessment tool in response to a communication gap in practice and said *that was how I engaged with a child quickly ... Ahurutanga, creating a safe space*. Sarah identified several crucial factors that impeded responsiveness to reports of concern by child protection services. Firstly, she talked about the lack of critical skills among social workers, such as limited knowledge of intellectual disability to enable them to skilfully write good quality reports that reflects this knowledge. Secondly, other issues such as isolation, lack of whaanau and family support, resilience, gaps in service delivery (e.g., respite) and the inability to identify and analyse the care and protection concerns clearly and concisely to engage care and protection services have also impacted on timely service provision.

Two of the participants expressed their concern about emotional abuse, which was less visible and identifiable but just as harmful as other more explicit forms of abuse. John and Sarah said that emotional abuse can have a negative impact on the development and wellbeing of the child with disability, particularly in relation to the ability of the child and parent to bond to form secure attachment. John and Sarah gave the following examples:

> No eye contact, no cuddling, no stimulation …. It was not abuse as they were meeting basic needs, it was a subtle one, there are lots of cases of where people are physically assaulting their kids, but this was more like a delicate one. Child protection and their disability advisor intervened, and placement was found with grandparents. (John, FG1)

> I think the bonding and attachment is a huge one, if the child is not showing the parents the affection the parent can start disassociating from the child. I think the emotional, the psychological and the neglect threshold should have a lower threshold for

> acceptance because of the child’s ability to protect themselves, or vocalise or stand up for themselves. (Sarah, FG2)

When child welfare and safety concerns were identified and reported, there was tension between child protection and community agencies as to whether there was a care and protection issue or a disability issue, such as intellectual disability. Rachel captured this frustration in the following comment:

> I find I have to work really hard to convince them to take on these cases and not to dismiss because they see a bunch of professionals involved so we shouldn’t have care and protection issues shows a lack of understanding and there needs to be an awful lot more education. (Rachel, Individual)

Even when the incident was proven to be a care and protection issue, some of the participants reported that children with intellectual disability were not removed from the home because their care needs were too high and a suitable placement could not be found despite all their siblings being removed, leaving the most vulnerable child behind. These insights highlighted the importance of social workers and health practitioners needing to be competent and cognisant to carry out assessments that are child-centred and holistic, which is critical in enabling them to identify needs and what interventions and safeguards may need to be put in place for these children.

To assist children with intellectual disability who have experienced abuse, neglect, and trauma, it is crucial for social workers and health practitioners to build trusting and respectful relationships with whaanau and families. Relational practice was strongly emphasised among participants as one of the major key practice skills to ensure support and interventions are delivered adequately and sensitively to children with intellectual disabilities and their whaanau and families. Vital to building successful relationships is the notion of being empathetic and non-judgemental and Rose's view reflected this: *having the common respect for the family because what I see happening might be normal for them, works for them versus a judgement.* She went on to share her own personal experience of having a family member with intellectual disability and how important the right relationships with professionals were for her:

> Well the approach in practice is no different, so building that trust I mean more than a phone call, a text, a letter, having been there as a family you know, what I needed to see was a person not just a letter in the post. (Rose, Individual)

Pam and Jill echoed a similar belief in their narratives, both giving examples from their own experiences:

> Respecting and hearing both the families and the child's voice as best you can, and then really hearing what it is they really need from me that is what makes it so successful, and when it is not working ask yourself why is it not working? (Pam, FG2)
>
> Identifying what they need, it may not be in the first instance what I think they need but it is what they need, and then we work around that. (Jill, FG 1-1)

These experiences spoke to the heart of working in the profession, which is to work in a humanistic and client-centred way whilst reflecting on their actions both critically and reflectively. The humanistic way of practicing also allowed professionals not only to capture the explicit but also the implicit or unspoken experiences of the whaanau and families, the first being grief and loss for the ‘normal’ child they thought they were going to have. Grief was identified by Colleen in her interview when she said *I always try to be aware of the grief that the parent might have experienced around having a child getting a diagnosis*. Secondly, parents who have experienced complex trauma in their own lives may also require additional support in order to enhance their ability to parent successfully. Jackie highlighted this in the following comment, recognising the importance of being client-centred to accommodate the different needs:

> You have got these ones who have experienced complex trauma, one that has no trauma and their perspectives on the child and the child’s needs and the support that they are receiving could be completely different, but it is the same needs. (Jackie, Individual)

There was a collective agreement in the first focus group about the value of working with a child and their family from a young age until their teens, giving them an in-depth life-course of knowledge that enabled them to make good decisions. Sarah gave an example of this by saying:

> If a crisis happens you can put it in the context of the family, this is not a crisis for them, this is something they go through weekly, fortnightly, full moon, or be able to say no this is a crisis, we need to step up. (Sarah, FG1)

These findings recognised that children with intellectual disability and their whaanau and families are more likely to be isolated, marginalised, and discriminated against, making them more vulnerable than ordinary whaanau and families. To minimise this vulnerability, focus should be on how to develop a relational, humanistic client-centred way of practicing where professionals build connections based on trust and established relationships to support good quality assessments and interventions.

4.3.3 Bi-cultural practice and Te Tiriti o Waitangi

NZ is a bicultural society, recognising the importance of Maaori as tangata whenua (people of the land), the indigenous culture and the importance of their relationship to the whenua (land) and the understanding of the Te Tiriti o Waitangi. With this acknowledgement comes the expectation that social workers and health practitioners will work culturally competently alongside children with intellectual disability and their whaanau and families. In addition, NZ is also socially and culturally diverse, requiring social workers and health practitioners to be culturally competent when working alongside these families. Participants shared their experiences in working with different cultures who have different cultural and traditional values, meanings, and interpretations of disability.

The challenge of not being able to work competently and sensitively with different cultures was clearly highlighted in Pam's reflection:

> Especially when there is a culture difference, I work with a lot of Somalian, Indian and Muslim families who have a completely different way of viewing the world and when we are coming in there and actually haven't heard it and there is nodding away when actually they are shaking their head inside and they are just telling you what you want to hear you are not being very effective so standing back and asking why is it the way it is? (Pam, FG2)

The results in theme one clearly reflected the importance of competence in disability knowledge, relational practice and being socially and culturally aware to enable children with intellectual disability to live safe and fulfilling lives. Also highlighted were the interface of the different systems that surround the children and the importance they can play to facilitate or inhibit their rights to receive support and be viewed as valuable and trustworthy citizens in society.

4.4 Theme Two – To address child maltreatment requires multi-level responses and interventions

Participants identified strongly that the successful relationships between the different environments such as education, health, and NGOs, which the children with intellectual disabilities and their whaanau and family move within, was critical in ensuring positive outcomes and quality of life.

Jill said in her interview *for me I think it is about society, all of us, schools, kindergartens, parents, the whole family* working together. She then went on to give an example of a successful interface by providing parental education about intellectual disability, *I often have whaanau and family's hui where I explain to mum, grandparents whoever was in the family what intellectual disability is, just get it out there and explain what it is.*

Another successful interface shared by Pam was when a child has been identified at risk, agencies work together to ensure successful outcomes:

> There has been good scaffolding put around the parents when the children are able to stay in that environment that is when I have seen multi agencies working together and not against each other … it is though the minority not the majority. (Pam, FG2)

However, when an ineffective interface in service delivery was identified, it could be detrimental to the wellbeing and safety of the child. Sarah reported a situation when:

> Parents are breaking down; the children are actually getting abused emotionally because of the stress but there is nowhere for the child to go (for respite), what is available has significant waitlists coupled with vulnerable families and no crisis service. (Sarah, FG1)

The participants identified the importance of relationships and communication between the social workers, health practitioners and the whaanau and families. These results were further expanded by other participants, in the subsequent section, who have discussed the impact of education, health and NGOs that could both have a positive or detrimental impact on the child with intellectual disability.

4.4.1 Safeguarding children and young people with intellectual disabilities

Participants raised significant concerns about the vulnerability of children with intellectual disabilities because of the lack of accessible safeguarding resources such as education, which equip children with intellectual disabilities to have healthy interpersonal relationships with those around them. Sarah said the *targeting programmes* (educational) *at the right level* was crucial to ensure that children with intellectual disabilities can have the same healthy and safe relationships as their ordinary peers. Sarah highlighted that as children and young people with intellectual disabilities mature, they can become more aware of the differences between themselves and their ordinary peers, by sharing:

> It is hard when the young person with an intellectual disability starts to realise that they are different from their peers, so they are trying to find someone who accepts them, someone who does not care [that they have a disability], someone who will accept them. (Sarah, FG1)

Sarah provided an example of how the risk of abuse can be safeguarded, where children and young people with intellectual disabilities are able to participate in an appropriate targeted programme, which considers all levels of understanding and abilities. This supports young people to be equipped with knowledge and skills to keep themselves safe and have healthy relationships, *Colours for Sexuality run through Family Planning, which is specifically designed for teenagers with intellectual disability, in line with the school curriculum, in an age appropriate and gentle way ... graduated over several years* (FG1). John agreed it was important to have appropriately targeted programmes to support young people to be equipped with this knowledge, but also highlighted that even with this knowledge, children and young people with intellectual disabilities are still vulnerable:

> If you are a desperately needy teenager and someone starts showing you some interest and smiles at you and you are their friend, all the talk about what you should do when strangers approach you, doesn't apply to your friend does it? (John, FG1)

Several participants expressed concerns about the consequences of not having socially appropriate skills, where children with intellectual disability were unable to differentiate between good touching and bad touching, and why it was inappropriate to expose their private parts in a public place. Alice and Sarah respectively shared examples from their experiences of the consequences when a child or young person with intellectual disability is not equipped with the knowledge and ability to behave in a socially acceptable way, and social workers and health practitioners take a reactive uninform approach. Alice (FG1) said *kids with intellectual disabilities or lower cognitive ability are more likely to be sent to SAFE when they have behaved poorly, not that they have offended they just don't know the boundaries* and Sarah shared a similar situation:

> I had a professional say well should he be going to SAFE, and I said no, no, no, he hasn't offended, he is not at risk of offending, he just doesn't understand and know what's not (appropriate) and it's no good putting him in a group with people that are actually at risk of offending. (Sarah, FG 1)

During the focus group discussions, participants felt that if these children had the appropriate education like their ordinary peers, they would not be labelled as children with sexualised behaviours into the future. Jane went on to share one of her experiences when working in the justice system. She said children and young people with intellectual disabilities were constantly misrepresented and labelled inappropriately:

> It becomes embedded in every report on this child about sexualised behaviour, and I am thinking back it was sexually concerning behaviour with a teenager, the child was implicated and I tracked the back the child's age and the child was (pre-school), and its rather than seeing it as maybe a child with an intellectual disability who doesn't understand and is just developing, it becomes really pathologised and then it becomes part of the personal history of this child and continues on in report after report for the rest of the child's life. (Jane, FG1)

Participants identified the importance of safeguarding children with intellectual disabilities through the appropriate delivery of education, and the part that ill-equipped social workers and health practitioners can play in perpetuating falsehoods about children with intellectual disabilities, through lack of understanding of children with intellectual disabilities, their needs, and behaviours.

4.4.2 Family and whaanau – Education and support

Parents/caregivers and siblings play key roles in supporting children with intellectual disability. For parents/caregivers, raising a disabled child can be rewarding, but can also be complicated when trying to balance organising support workers, managing nurse, doctor, and specialist appointments, and juggling the day-to-day life tasks with little or no support. Moreover, these parents often struggled with grief and loss that was associated with not having a ‘normal’ child, feelings of anger and despair, fear of what the future will bring and who will care for their child once they are gone. It is also not uncommon for siblings to be expected to participate in the care of their disabled sibling. Some may feel isolated from their friends and feel frustrated because they often are unable to have access to their community and social networks on a regular basis because their parents are unable to transport them due to caring for the sibling with an intellectual disability. Siblings may also struggle to understand why their disabled sibling is treated differently to themselves and begrudge the little time they get with their parents. Many of the participants were aware that children with intellectual disability were more likely to be abused by their ordinary peers and those who were meant to love them most. It was, therefore, critical for parents to develop the necessary skills to enhance their parenting and be resourceful to create a safe and nurturing environment for their disabled child/children and their siblings.

With these considerations in mind, participants were asked what protective and risk factors could affect the health and wellbeing of disabled children and their whaanau and families. Participants identified protective factors such as parenting skills and knowledge, education, sibling support, and wider whaanau and family support. Jill shared that parents could unintentionally abuse and neglect their children at some level due to a lack of understanding of their child's disability and how to support them. Protective factors were identified as parents having information about resources and services available to them, working in partnership with service providers, education about their child's disability and if needed, support to manage behaviours. Jackie felt that parents did not need to be experts but *if the parent feels more confident in their parenting or has a greater awareness of their child's needs and understanding of behaviours that are happening, I also see that as a success*. The need for parents to receive education about their child's intellectual disability was often mentioned; most participants verbalised the difference it made in the lives of children with intellectual disability if their parents were proactive and *willing to learn about their children and be realistic* about their child's abilities and needs, as reported by John. Participants in focus group two discussed the importance of the resilience of parents who raised children with an intellectual disability. Pam (FG2) shared that some parents she worked with would soon have the opportunity to voluntarily participate in a research project that would give them psychological skills, such as learning acceptance and managing grief, to assist their lifelong journey of raising a child with a disability. Participants frequently mentioned the grief and loss experienced by the families they worked with when their child was born with a disability. The journey of grief and loss was described as never-ending as it would be triggered by different developmental phases as the child got older. The stigma and isolation attached to this never-ending process could lead to a sense of loss, anger, and depression, as reported by some of the participants.

Jill commented on the importance of focusing on the siblings of disabled children – they too needed support and resources to enable them to navigate their lives with a sibling who has different needs from them. She said *I think we need to work more holistically; we need to acknowledge that Mary is a brother or sister, there are siblings around and to work more with them as well*. Rose identified that whaanau and families were often quality time poor and as a practice response, she created a whole whaanau and families focused programme, which centred on *building quality time with each other. It's one-hour delivery once a week concept which is cheap, easy and requires participation from every family member*, enabling them to strengthen relationships and try to be a whaanau and family in that moment.

There was a strong consensus from all participants that having strong, positive, and supportive natural supports such as grandparents, aunties and uncles was key for whaanau and families raising children with intellectual disabilities. These people provided emotional and physical support through being a sounding board and by providing respite care:

> It takes a village to raise a child so support for the parents, hopefully within all the family so that aunty can just come in and just spend the night with the kids, mum and dad go out for dinner, whatever it is just so they can have a break, because that is more people also to protect the child. (Alice, FG1)

However, this was not always the case for all families. Sarah said that *some whaanau chose to distance themselves from wider family because of the negativity, being treated differently, shame, protective factors, not my fault.* Sarah then went onto say:

> Family around can be a good thing; family around can be a bad thing. This distancing may have been done for good reason, but it also had the potential to raise the risk as this intentional separation would bring its own set of challenges such as how to build a new community around them. (Sarah, FG1)

Rose shared an example of what can happen when whaanau and family misunderstand what intellectual disability is and how it can affect the development of a child with intellectual disability:

> Until they see the stages of development occurring and that person's not moving (progressing developmentally), so they are still into Thomas the Tank at 18yrs and still into Thomas the Tank at 25yrs, then family will go okay why is that? Now we cannot use the judgement of your poor parenting skills anymore, there must be something but in the meantime 18, 20, 25 years has passed by with not engaging with the child, with the family. (Rose, Individual)

Most participants had extensive practice experience with children with intellectual disabilities and reported that it was uncommon with people from different cultures to have their wider whaanau and families to support parents raising children with intellectual disability. Rose shared the following from both her personal and professional experiences:

> So, within Maaori there is this wonderful belief system that the tribe gathers, and you have got this wonderful extended whaanau and families, I can tell you now that is not real. Because it does not matter if you are Maaori or non-Maaori if you have got a child with needs that are bigger than everybody you pretty much flying by yourself. (Rose, Individual)

As demonstrated in this section, if parents are equipped with knowledge of intellectual disability, have adequate natural and paid supports such as grandparents and respite care from non-government service providers, this can go a long way to safeguarding their children with intellectual disability.

4.4.3 Community support

Community can often play a significant role in the lives of children with intellectual disabilities and their whaanau and families. The support from the community includes both government and non-government agencies, for health, mental health, child protection, and income support, counselling, and community programmes. Within this group, disability service providers play a key role in the child's life, responding to the child's and parents' evolving needs across the child's lifespan. This involvement can start in the initial assessment phase and then move into long-term delivery of interventions such as respite, behavioural support, and education about intellectual disability for parents. An example of successful support is when respite care is available regularly and can provide a welcome reprieve for parents/caregivers to look after their own needs and that of the child's siblings. Participants identified several barriers for respite not being accessed, such as living in rural communities, long waitlists, and lack of experienced caregivers. Sarah (FG1) captured the primary reason by saying *society is not setup* *to support these children to be able to stay with these families - that family just need a break; society has not created the break.* Another concerning reason for not accessing respite was identified by Sue:

> Another issue is families think people see what is going on if their child goes into respite, so that is why they don't use it, they might know that they are not parenting or keeping this child clean or fed or something like that …. Someone else might see that so to protect themselves they do not have respite. (Sue, FG2)

Support from within community also includes the availability of counselling to address trauma experienced by children with intellectual disability who have been subjected to abuse. Several participants highlighted the lack of community responsiveness to these children. One of the major reasons was the misconception among some professionals that children with intellectual disability do not have the cognitive ability to experience trauma. Jill stated:

> A child with intellectual disability is entitled to have the same level of support like any other child, however, when you refer kids with intellectual disability to services for counselling regarding trauma abuse and neglect then they tell me no they can't accept this child because the child has an intellectual disability so they assume a child with an intellectual disability cannot be spoken to which is not okay because it is discrimination. (Jill, FG 1-1)

An additional barrier is at times, professionals in schools and service providers were not able to understand that there can be many different reasons why they might see a change in the behaviour of a child. Therefore, these professionals may attempt to address the behaviour that is in-front of them rather than delve deeper to identify if there is an underlying reason, such as abuse, which requires addressing with urgency.

Another concern raised by the participants was the cumulative effects of children with intellectual disabilities living in low-quality housing, which contributed to increased multiple chronic health conditions, more admissions to hospital and less school attendance. Pam felt that preventative measures should include housing: *if we get some of our families into better housing and financially in a better place, and then some of these stresses are taken out*. From Jackie's experience of working with whaanau and families, she identified the following barriers experienced on a regular basis:

> Waitlists (for appointments), getting to their appointments, having reliable transport, letting them know about health shuttles if they do not have transport and making sure the appointments are in a time where they can make it. Do they have to catch a bus, letting them know about disability allowance, these are the barriers to attending these appointments because if they do not go to these appointments then they are going to miss this opportunity. Or they waited on a waiting list for so long, finally after how many months they will get a phone call to say you can bring Johnny in, mum's over it.
>
> I'm a single parent I have got to get to work, I don't have any supports, so of course I am going to leave my 10-year-old and 12-year-old at home but its only for a couple of hours, so you have got that problem but then it becomes a huge risk if the 12-year-old is having to look after a 1-year-old. (Jackie, Individual)

In a similar vein, Jill shared her views on the additional financial pressures that parents experience when trying to meet the needs of their child with intellectual disability:

> If you have a child with a disability you need to have a car where you can put in your child, maybe a wheelchair, you spend more money at home, because you may need an extra person coming, you might not get the funding, you need to go to work so there are all kinds of things happening. (Jill, FG 1-1)
>
> A risk with kids who are severely disabled are more (likely to be) abused than other kids, and I guess there's a risk with kids that if you have a child who is severely disabled then you have other kids in the home, you live in poverty and struggle financially then it may increase the risk for those kids as well. (Jill, FG 1-1)

Participants acknowledged the challenges and issues faced with raising a child with intellectual disability, but when combined with financial hardship, inadequate housing, gaps in service delivery, isolation, stigma, and social exclusion, these became more overwhelming for the whole whaanau and family to manage. These additional pressures can also have a negative impact on the parents' emotional resilience, potentially causing an increase in stress and anxiety and impacting on their ability to meet the needs of their child with intellectual disability.

4.5 Theme Three – Social work education, professional development, and leadership

Participants in the individual interviews were asked about their previous knowledge of intellectual disability before becoming a social worker. Two of the participants reported to have no prior knowledge and the other two had lived experience. They also reported to have different exposure to disability topics from their social work undergraduate degrees. Colleen shared that she had done an internship with children with disabilities and autism spectrum disorder (ASD).

Jackie recalled engaging in a few discussions about disability issues in class and Rachel advocated strongly to have one of her placements within the disability field. Participants felt it was important to be taught about disability and its relevant issues in the social work curriculum. Jackie and Rachel felt strongly that a solid knowledge base in disability should be included and taught in social work undergraduate studies:

> I think it needs to be mandatory in every type of formal education you go to whether it be counselling, or social work absolutely needs to be included, it needs to be part of a standard that must be reached, or you don't get your degree, I believe that strongly. (Rachel, Individual)

Rose acknowledged that it was not possible to cover all fields of practice within the social work curriculum and she understood that there was an onus on the social worker to invest in their own ongoing professional learning within their job. Rachel shared that she was well supported by her employer to attend any professional development she identified as important, but there were limited opportunities to increase her knowledge in the area of intellectual disability due to the lack of educational opportunities such as workshops. Like Rachel, Jackie shared that her agency was incredibly supportive of professional development, but the financial constraints meant they were restricted to low cost or free education or workshops, removing the ability to attend accredited programmes or training that were more work relevant but with higher costs. Despite some restrictions and inadequacies to enrich their ongoing learning in the relevant areas of intellectual disability, the four participants reported utilising the supervision space to engage in critical reflection and discussion on how to improve their practice when supporting children with intellectual disabilities and their whaanau and families. Rachel highlighted this: *I know I don't have to worry about supervision it is an absolute requirement that I have it", "it's not* *even a question, it is so good", "doing the work that I love, getting well looked after"*. Rose stressed how important it was to have supervision when working with children with intellectual disability, making it clear that social workers needed to know what they were doing to *make it safe for the family, for the person, for the individual,* stating *it comes down to good quality supervision, your training, ongoing development, and you as a person are you really invested.*

Social workers often work in stressful environments, carrying large, complex, and critical caseloads. Inadequate support and professional development can affect their ability to provide competent services, which can lead to poor physical and mental health, burnout, or compassion fatigue. Overall, the participants reported that they were well supported by their agencies, through supportive collegial relationships, and supervision, but also recognising the limited professional development opportunities to develop their professional practice on intellectual disability. While the support from their organisation was crucial to ensure compassion and job satisfaction to safeguard staff retention, Colleen felt that social workers themselves also needed to take some responsibility for their own selfcare and ensure that they were proactive in putting strategies in place by working collaboratively with their organisations. She talked about arranging flexible working hours and discussed the provision of mental health days with her organisation:

> At work I feel we are pretty lucky because we have a very flexible employer and I feel very supported by management as well and I feel that selfcare and being able to look after yourself is a priority and I do really feel that my employer is, and I would tell you if it wasn't the case. (Colleen, Individual)

Providing and advocating for appropriate services to support children with intellectual disabilities who experienced abuse, trauma and neglect cannot be done in isolation and without good leadership from other social workers and health practitioners. The participants felt that they needed to be an advocate for the rights of the children they worked with and to educate other social workers and health practitioners who worked directly with these children. However, they also felt they had limited ability to effect consistent social change in government agencies' responsiveness to the vulnerability of children with disabilities and expressed their relentless frustration.

From a social work perspective, Jill said that, to make significant changes in the disability field, they needed to start at the grassroot levels of social work education:

> Social workers need to understand that we do not talk anymore about the medical model we talk about a social model (of disability), we are not talking about the child being a disability, this is a child with a disability so that starts when you study social work, I think there needs to be more awareness amongst social workers about disabilities. (Jill, FG 1-1)

Participants emphasised the importance of all sectors such as health, education, care and protection and justice professionals to acquire and continue to be upskilled in understanding issues relating to disability, not as a medical or health issue but as a socially constructed issue. There were some suggestions that the education sector would in effect become a major change agent in influencing practice delivery by providing education on intellectual disability. Sarah articulated this by saying that an example of successful leadership through education at a national level was highlighted in the child protection sector *where senior advisors were* *employed specifically with a focus on disability support who could sit in on meetings regarding children and young people with disabilities sharing their knowledge and expertise and who have the ability to influence positive outcomes*.(Sarah, FG1).

Some participants shared that they often felt frustrated and powerless as to what to do in response to the inconsistent responses to children with intellectual disabilities when it involved care and protection concerns. One participant went onto say that there were no clear guidelines to initiate a clear response, it would depend on which office and which social worker they were dealing with. Jane shared her frustrations and a sense of powerlessness to effect positive changes for the children and young people with whom she has been involved:

> There have been so many times where I have felt that the child has been let down by care and protection, at what stage do I write a more general letter about this child, what can I do as a professional, to elevate or escalate, I imagine due to under resourcing, but time after time of writing service failure reports. As a professional frustrated about [inconsistent response] what can I do about this? (Jane, FG1)

Despite the ongoing frustrations reported by many participants due to the lack of clear and consistent responses at times to their concerns expressed about abuse, neglect and trauma experienced by children with intellectual disabilities, participants like Jill, Alice, and Joanne expressed a strong sense of duty and responsibility to continue advocating for the rights of these children. Without doing this, they felt that there would be no hope of change at a systemic level locally and/or nationally. Meanwhile, Pam expressed the emotional toll it could take when dealing with abuse:

> I feel like it is one starfish at a time, it feels like that for me, sometimes very disheartening to be honest, it feels sometimes I just feel golly, phew. Had a day like that yesterday, how can there be so much neglect and abuse out there, sometimes your days feel like they are full of it, to make a difference. (Pam, FG2)

When asked how they considered their respective professional bodies may play a role in leading change and advocating for the rights of children with intellectual disabilities, one of the participants, Sue, said *they will advocate and have taken things to Parliament, literally have spoken in the house on behalf of abuse ... the recent submission was focused on vulnerable children in our area ... so it was specifically about children with disabilities* (FG2). Other participants did not seem to be aware of an example of how their professional bodies have implemented strategies to address the rights, care, and protection of children with intellectual disabilities who experienced abuse, neglect, and trauma.

4.6 Summary

This chapter provided discussion of how the lack of knowledge about intellectual disability can impact on assessing abuse, neglect, and trauma of children with intellectual disabilities. Attention was drawn to the importance of making intellectual disability education available or even compulsory for social workers and health practitioners to mitigate the risk of abuse going unrecognised and under addressed. Education about intellectual disability was also highlighted as a need for whaanau and family to strengthen their understanding and support of their child. Participants also discussed the importance of equipping children with intellectual disabilities with skills to safeguard themselves and developing healthy relationships with others to avoid them being at risk of abuse and neglect. The following chapter integrates the discussion of the literature and findings and explores how social workers and practitioners can better respond to the needs of children with intellectual disability and their whaanau and family.

Chapter 5 - Discussion

5.1 Introduction

Following on from the previous chapter, which presented the results of how social workers and other health practitioners responded to abuse, neglect and trauma experienced by children with intellectual disability, this chapter integrates the results and literature review by focusing on three areas of discussion: (1) the intersection between the knowledge of disability and the competence of professionals to identify and assess for signs of abuse, neglect and trauma; (2) the importance and relevance of relational practice in dealing with abuse, neglect and trauma; and (3) the challenges in preparing a disability-competent health and social care workforce who can also work at a system level to create change.

5.2 The intersection of disability knowledge and competence to practice

Participants in this study showed consistent understanding of the definitions of abuse and how to apply these to the experiences of children, including those with disability. Given their diverse experiences, their discussions were quite distinct and illustrated their perceptions of the severe impact of abuse on children with disability, particularly as they are more vulnerable than their ordinary peers. This finding was supported by Jones et al. (2012) who stated that abuse, neglect, and trauma did not exclude children with intellectual disability, but that they were often not rigorously investigated, disclosed, or discussed. Despite increasing focus and prevalence, participants reported that while they were vigilant in screening, assessing, and reporting cases of alleged abuse, they have continually experienced inconsistent responses and actions to their concerns. At times, their concerns were brushed off because of the problematic nature of having a clear and confirmed identification of abuse among this cohort of children. Such concerns corroborate previous work on the lack of action or further investigation due to varying responses to alleged abuse, neglect, and trauma, for children with intellectual disability (Algood et al., 2011; Ofsted, 2012; Shannon & Tappan, 2011; Stalker et al., 2015; Taylor et al., 2015). Differences in dealing with suspected child abuse and neglect may be due to different cohorts (Maclean et al., 2017; Sullivan & Knutson, 2000), identification approaches (Ben-Arieh & Haj-Yahia, 2006) and organisational settings (Louwers et al., 2012). To ensure children with intellectual disability receive reliable assessments, Vrolijk-Bosschaart et al. (2018) have argued that it requires collaborative, exemplary, and evidence-based practice in a multi-disciplinary team using a comprehensive 'medical interview', 'child interview', and 'anogenital and sexually transmitted infection tests' to form a pathway to develop a report about alleged abuse.

In addition to inconsistent responses and lack of resources to aid diagnoses and assessment, the participants also identified a sense of ambivalence among social workers and health practitioners towards the context of abuse among children with intellectual disability. Mallén (2011) argued that the closeness between the disabled children, their parents and social workers may become an obstacle inhibiting the reporting of child abuse and neglect to relevant authorities. Social workers and other health practitioners are often seen as performing a delicate balancing act by juggling the demands of the law, upholding the established social relations within the family and whaanau, the cultural contexts of the family and whaanau and the child, and moral responsibility to their professions. Other research has also explored the barriers to the identification of abuse and neglect among disabled children. These suggested that identification of abuse and neglect rests upon social workers' own values and beliefs, and concerns about the potential outcome for the child if reported (e.g., family breakdown) and the persistent assumptions that children with disability do not get abused (Franklin et al., 2015;

Kelly & Dowling, 2015; Palusci et al., 2015). Teachers and health practitioners have also reported such unreliable responses because of lack of confidence and conflict they felt in reporting abuse because of their loyalty to the families they have worked with, supported, and built trusting relationships with (Schols et al., 2013). These studies highlighted that the process of reporting abuse among children with intellectual disability is not straightforward because some social workers and health practitioners' behaviours and assumptions may hinder reporting and perpetuate the under-reporting of these situations. As more evidence appears in literature to indicate that disabled children are more likely to be at risk for child abuse than neurotypical children (Heinonen & Ellonen, 2013), it is imperative that social workers and health practitioners do not respond to disclosures of abuse, neglect and trauma with disbelief or inaction to ensure children with intellectual disabilities are not left in environments that are harmful (Franklin & Smeaton, 2018; Jones et al., 2016; Robinson, 2015; Robinson & Graham, 2019). Social workers and health practitioners must ensure that they are well-equipped to respond to any abusive behaviours in all the environments children with intellectual disability live within such as home, school and community (Mirfin-Veitch & Conder, 2017; Robinson, 2015). They should also continue to be hypervigilant that harm is still happening and often being inflicted by support staff, whaanau and family, employers, partners, and general members of the community (Roguski, 2013).

Not all disabled children are prone to the same type and extent of child abuse and neglect (Heinonen and Ellonen, 2013). Participants expressed concerns that children with intellectual disability were extremely vulnerable to psychological abuse as at times it was harder to detect its visibility, such as the negative impact on their wellbeing when their equipment or care was removed. Research has highlighted that young people who experienced emotional neglect and abuse are reported to struggle with anxiety, depression, unhealthy relationships with intimate partners and some struggle with addictions as they get older (Naughton et al., 2017). How the relationships were built and fostered between the parents/caregivers and children with intellectual disabilities could influence the development of secure attachment, which can act as a protective factor for abuse and neglect. Prior studies have noted that there was a direct relationship between the complexities of the child's diagnosis, such as communication, engagement, behaviours, and secure attachment (Howe, 2006; John et al., 2012). This was reflected in the participants' narratives that parents who were more open and willing to learn about their child's conditions and have more realistic acceptance and expectations of their abilities demonstrated a more positive secure attachment and relationship. Previous research supports the participants' reflections where the primary caregiver's ability to understand and emotionally accept their child's disability could enable them to intuitively identify their child's needs and to reflect on their role in their child's life (Oppenheim et al., 2012). While it may seem logical to assume professionals have foundational knowledge of attachment and the nuances of disability such as different communication styles, behavioural and adaptive functioning, which are key in supporting children with intellectual disability and their whaanau and family to establish healthy and supportive relationships, research has reported otherwise. According to Alexander et al's (2018) study, only half of the practitioners (from a wide range of backgrounds) in the early intervention setting who worked with children with disability, learnt about attachment before they started working and only 67% believed that this knowledge was 'absolutely essential'. As such, this discrepancy could be a missed opportunity for practitioners to draw on knowledge of attachment theory to support a more holistic and child-centred assessment of a child's wellbeing (Finzi et al., 2001). This could perpetuate the long-term under-reporting of abuse among children with intellectual disability (Riggs, 2010).

The accumulative experience of life events such as family violence and poverty may erode the resilience of a person with intellectual disability more than their ordinary peers, making it more critical for social workers and health practitioners to understand the impact on wellbeing across their lifespan (Wigham & Emerson, 2015). Participants in the current study highlighted that when social workers and health practitioners neglect the wider systemic influences including inaccessibility and poverty (Jones et al., 2017), this can further exacerbate the trauma experience of the child (Thomas-Skaf & Jenny, 2020). Kam (2020) reflecting on the voices of service users with disability has further emphasised that skills such as relational, advocacy, dedication, empowerment, and seeing their role as 'not just a job' (p. 781) are crucial in supporting disabled people.

"Learn on the job" was reported by most of the participants on how they have developed their knowledge and competence in working with children with intellectual disabilities and their whaanau and families rather than through undergraduate study in their discipline. This was consistent with existing literature (Jones et al., 2012; Manders & Stoneman, 2009). The consequences of a lack of disability knowledge can impact on social workers and health practitioners' abilities to provide adequate or even optimal care for this cohort of vulnerable children. Participants shared that some social workers and health practitioners were unable to look past the disability and consider that behavioural changes in a child with intellectual disability could relate to abuse, neglect and/or trauma and was not a consequence of their diagnosis. Most participants indicated the necessity of including disability as one of the main fields of practice in their profession's qualification and training. This was observed in the growing body of literature, which showed positive outcomes for social workers who studied disability in their undergraduate study and so have better knowledge and understanding of intellectual disability (Meekosha & Dowse, 2007; Mogro-Wilson et al., 2014). Although figures are not recorded in New Zealand, the survival rates of children with disabilities to adulthood and older adulthood worldwide are increasing due to advancement of knowledge, medical technology and diagnostic capacity and the rates are likely to continue to rise (Zablotsky et al., 2019). This makes it even more critical that social workers and health practitioners are equipped to assess, report, and provide interventions to address abuse, neglect and trauma of children with intellectual disabilities. Despite the existence of disability and its related issues, John and Schrandt (2019) identified that some social work students struggled to identify the difference between intellectual disability and mental health. It is important that students understand the fundamental difference between intellectual disability, which is permanent and requires some level of consistent support throughout their lifespan, and mental health issues, which require a different kind of support that may only be needed for a limited time. This suggests that although there has been progress in developing and including disability in the teaching curriculum, there is a significant way to go in equipping new graduate social workers to work competently and confidently with children who have an intellectual disability.

What has been identified in the literature and in this research is that social workers and health practitioners could inadvertently or intentionally perpetuate the societal perceptions of what disability means due to the perception generationally entrenched by the medical model of benevolence, treatment, and management (Geoffrey, 2014; Meekosha & Dowe, 2007). The social model of disability provides an opportunity for social workers and health practitioners to not only challenge their own perceptions and prejudices about disability (Flynn, 2020) but to move beyond individual and victim blaming models to develop new and transformative ways of practice as well (Munford & Bennie, 2015). These practices should focus on enabling more time to build relationships, develop purposeful assessment tools and enhance social workers and health practitioners as champions for equity and equality to address deficits and barriers in the social and physical environment and in social policy. Supporting children with intellectual disability to live in a safe and nurturing environment and recognised as valued members of society are all important elements to ensure that their citizenship and rights are respected. In doing so, when a child with intellectual disability requires therapeutic interventions just like their ordinary peers in response to abuse, neglect, and trauma, there should be no societal and structural barrier of prejudice impeding them from accessing a counsellor or psychologist (Adams & Leshone, 2016; Bigby & Frawley, 2010). Building relationships with children with intellectual disabilities is key to safeguarding them from abuse, neglect, and trauma. It was identified by several of the participants that there have been limited therapeutic interventions put in place for children who have experienced trauma due to some misconceptions that children with intellectual disability do not have the cognitive ability to experience trauma and are unable to actively participate in the therapeutic process. Findings in recent research evidence have challenged this notion by showing that indicators of post-traumatic stress disorder (PTSD) were no different in children with intellectual disability and their ordinary peers. Results have shown therapeutic interventions using different methods of engagement such as play therapy can have positive results in supporting children with disabilities, enabling them to strengthen their coping skills and resilience (Meissen et al., 2016; Mora et al., 2018). To work successfully and supportively with children with disability and their whaanau and family, findings of this study have confirmed that it requires social workers and health practitioners to draw on their widely used professional skills and professional principles. These include anti-oppressive and rights-based approaches, adherence to ethical and moral obligations, advocacy and working in partnership to build trustful and respectful relationships as reflected in social work and health practitioners' professional codes of ethics (ANZASW, 2013; Occupational Therapy Board of New Zealand, 2015; Physiotherapy Board of New Zealand, n.d; Psychologists Board, 2012).

5.3 The relevance of relational practice

The importance of developing and sustaining strong relational practice that can support successful outcomes for children with intellectual disability and their whaanau and family was considered paramount to all the participants in this study, and this is consistent with existing literature (Algood & Harris 2013; Munford & Bennie, 2015). Relational practice is a crucial social work response to the complex lives that whaanau and family lead, in part due to the underlying psychological dynamics that can present, such as stress, grief, anger, and trauma. Relational practice provides a secure foundation for whaanau and family who are vulnerable and raw, and for the social worker to stand with them in those moments and to respond to those conversations courageously, with compassion, confident in the knowledge that the relationship built between social worker and the whaanau and family will hold, even when hard things need to be said (Ruch et al., 2018). Issues discussed between the social worker and the whaanau and family could include family dynamics, parents' own childhood experiences (Chamberlain et al., 2019), and how it influences their parenting today (Sudbery, 2002), risk, building resilience and self-determination (Ferguson et. al., 2020). It is worth noting that these critical social work roles, providing emotional, psychological and advocacy support, should not be seen as a substitute for a lack of services and financial supports (Ruch et al., 2018). Whaanau and families also need material supports such as respite, behavioural support, and funding for the additional needs of children with intellectual disabilities. Having easily accessible and available respite, behavioural support, and funding would in part alleviate some of the precursors of stress in these whaanau and families' lives and go some way to reducing the risk of children with intellectual disability being abused. Participants' narratives demonstrated that understanding the significance of the roles they played in the lives of these children and their whaanau and family, and practicing from a participatory, therapeutic, and strengths-based position could contribute to developing and maintaining trusting and meaningful relationships.

Being able to embed person-centred practice into a holistic system can transform practice ecologically (Teater, 2014), firstly for the child with intellectual disability and their whaanau and family to strengthen capacity, self-determination, and resilience. Then secondly, it can affect positive changes within society, schools, health, community, and child protection through advocacy (Kam, 2020), and sharing knowledge about intellectual disability to address child abuse (James et al., 2017). Recent research and literature have further confirmed that working in partnership is the key to successfully supporting children with intellectual disabilities and their whaanau and family to minimise any risky situations (Algood et al., 2013; Cohen & Mosek, 2019). Working in partnership builds on personal attributes of self-awareness, authenticity (Rosenberger, 2014) and being mindful (Naylor et al., 2016), all of which have a natural fit with humanistic attributes of empathy, positive regard, and congruence (Payne, 2005; Washburn & Grossman, 2017). Additionally, results of this study provided evidence that critically reflective practice – reflection on what works and what can be done differently is vital among social workers and health practitioners. This intuitive and intentional practice can enhance social workers and health practitioners’ ability to competently respond to the needs of their clients in real time whilst preserving relationships (Cohen & Mosek, 2019). Effective practice can be seen when social workers and health practitioners draw on their knowledge of intellectual disability to provide help to families who experience grief and loss for a child parents were not expecting, isolation, frustration (Brown, 2016), stress, and discrimination (Gerstein et al., 2009). This practice provides support for addressing the ongoing challenges that can impact on the health and wellbeing of children with intellectual disabilities and their whaanau and families.

The context of whaanau and family life informs the relational practice of social workers and health practitioners. To build strong relationships with children and their whaanau and family, they must have the ability to understand the additional challenges and difficulties experienced. Recent statistics in NZ have shown that half of the children who live with disability were born with impairment and half of them will have a learning impairment (Statistics NZ, 2013a). Because of the disability, these children and their whaanau and family are more likely to have ongoing relationships with health and social services. Children with disability are more likely to live in crowded housing and twice as likely to live in one parent households (Statistics NZ, 2013b) and one and a half more times likely to live below the poverty line than their ordinary peers (Murray, 2019). Therefore, it was not a surprise that almost all the participants mentioned that many of the whaanau and family with children with intellectual disability experienced some level of hardship. This result is consistent with existing literature, which reported increased fragility in relationships with whaanau and family, grief and loss, and lack of respite, particularly due to financial hardship (Murray, 2018; Sen & Yurtsevery, 2007; Wynd, 2015). While none of the participants reported such direct experiences from the whaanau and families they worked with, research has indicated that economic and material deprivation have lifelong negative impacts on the safety and wellbeing of children with intellectual disabilities (Meissen et al., 2016; Wigham & Emerson, 2015).

The disability and care literature has shown that parenting a disabled child can be time-consuming, stressful, physically challenging, isolating, and expensive (Mark et al., 2017). Parental wellbeing was seen by participants as a key factor in supporting successful outcomes for children with intellectual disabilities. Providing parental support through education about intellectual disability and strategies to support their child can strengthen parental resilience and their ability to bounce back from challenging times (Machalicek et al., 2015). Furthermore, poor socioeconomic conditions and a lack of resources are likely to influence the experiences of parents, whaanau and family and the potential to attain wellbeing. Yoong and Koritsas

(2012) have argued that financial wellbeing and frustration about the health care system have contributed to decreased quality of life among parents with children with intellectual disability. Participants also called for attention to parents who struggle to secure and manage employment and the additional pressure of having to juggle work commitments whilst caring for a child with intellectual disability and managing their own wellbeing. To adequately support parents, flexible employment practices and support systems are required, so that parents can respond to their child's disability related needs and attend ongoing specialist appointments (Brown & Clark, 2017).

Participants identified strategies for addressing the challenges of finding appropriate childcare. One such approach is to develop strong relationships and strengthen the connection with wider whaanau and family members, such as grandparents (Gray et al., 2017; Hibbard & Desch, 2007; Machalicek et al., 2015; Mazzucchelli et al., 2019). Although the role of grandparents is essential in supporting parents in the childcare context, it is not without its challenges. Research with 22 grandparents in Australia reported that grandparents may be unable to or reluctant to help raise their grandchild with intellectual disability due to their age, their retirement plans, and most importantly their need to have education about intellectual disability and support to navigate these factors both emotionally and physically (Miller et al., 2012). Additional research has also indicated that grandparents experience a wide range of feelings such as grief and anger in dealing with disability and they need support and education to enable them to actively participate in the life of their grandchild with disability (Mazzucchelli et al., 2019; Seligman & Darling, 2007). Grandparents are an integral part of the wider whaanau and family and often play a significant role in the lives of grandchildren across their lifespan (Bernhold, 2020). Aside from emotional, physical, and financial support they can provide to whaanau and family, grandparents were reported to utilise their own experiences to take on an advocacy role, where being assertive and resolute was often required to access supports and services for their children and grandchildren (Moffatt et al., 2019). Current trends show that grandparents' life expectancy has increased significantly over the past century (Mitchell, 2006) in which ordinary families are becoming smaller and more likely to have one parent parenting alone (Dunifon, 2013). According to the Ministry of Health in NZ (MOH, 2011), a person with intellectual disability will live on average until they are 59 years of age. This shows that grandparents are more likely to be involved for most of the child's lifespan, making it even more critical that they receive the support and resources from social workers and health practitioners they need to enable them to provide regular support if they wish to (May et al., 2012).

Having a disabled child not only contributes stress for parents but also other members of the whaanau and family and creates differences in family structure, functioning, and the roles of family members. Participants in the current research reported that the needs of siblings were often neglected by not only their parents, but also by social workers and health practitioners. Siblings have an important role in each other's development because they observe and learn from each other things such as life skills and empathy. Research has supported the importance of addressing the needs of siblings, who must be included in the wider assessment process to address potential concerns such as taking on a carer role, isolation from their peer group and community and therapeutic supports (Adams & Leshone, 2016; Donnan, 2020; MSD, 2019; Seligman & Darling, 2007). In NZ, there are approximately 40,000 young carers between the ages of 15 and 24. It is unknown how many carers there are under 15 years of age, but anecdotal evidence suggests that there are children and young people who are caring for their whaanau and family members and that this lack of clarity needs to be addressed (MSD, 2019). Shojaee et al's (2020) research identified that adapting to having a sibling with autism can be fraught emotionally and can result in inadequate quality time with their parents and can require the sibling to take on a carer role. Milevsky (2015) further highlighted the consequences of not addressing the needs of siblings, which can affect them emotionally, socially, and academically and highlights the need for a multi-faceted intervention from educational and therapeutic perspectives. To address the often-neglected needs of the sibling by parents, social workers, and health practitioners, it is important for social workers and health practitioners to build relationships with siblings and include them in the wider assessments and interventions.

Social workers and health practitioners cannot build successful relationships with children with intellectual disabilities if they are unable to communicate with them. Some children with intellectual disability have different communication styles such as verbal, non-verbal, and sign language which can create potential barriers. Previous research and discussions with the current participants have reported that there are various successful ways for social workers and health practitioners to communicate with children with intellectual disability (Tanner et al., 2019). Barriers to achieving successful communication has commonly been attributed to lack of training in intellectual disability, communication skills (Prynallt-Jones et al., 2018; Stalker et al., 2010; Tanner et al., 2019) and persistent stigmatising and discriminative views that children with intellectual disability lack independent thinking and self-awareness (Jones et al., 2017; Tanner et al., 2019). Research has reported that when social workers use non-verbal communication tools such as Makaton or visuals, they are more likely to hear the child's voice and respond appropriately to their needs and concerns (Prynallt-Jones et al., 2018). Social workers and health practitioners already have foundational relational skills, which support person-centred practice in building rapport, working in partnership, and including a human rights focus that adheres to the United Nations Charter for the Rights of the Child (UN, 1989). Therefore, it is even more critical that they include in their practice framework the knowledge and skills, including that of age-appropriate communication, to enable children with intellectual disabilities to share their concerns, and make informed decisions, just like their ordinary peers (Robinson & Graham, 2020).

5.4 Challenges in preparing a disability-competent health and social care workforce

Results of the current study have demonstrated the significant roles whaanau and families, social workers and health practitioners can play in providing a safe environment for children with intellectual disabilities in their developmental journey and to reduce harm and violence exposure. Strong bonds and stable relationships in whaanau and families were reported to be key elements of protective support, while education and training for both whaanau and families, and social workers and health practitioners, was identified as an important mechanism to realise abuse and neglect prevention. These outcomes have been articulated in previous research, which calls for urgent attention to address inconsistencies in awareness, knowledge, and skills, within the context of abuse, neglect, and trauma of children with intellectual disability (Jones et al., 2017; Stalker et al., 2015). Research has revealed the importance of teaching and engaging with children and young people with intellectual disability to promote their personal safety and to increase their agency and capability to deal with adversities in life (Robinson et al., 2017). This involves strengthening social workers and health practitioner's knowledge about how they can best support children and young people to build safe and healthy relationships (Lofgren-Martenson, 2012).

While promoting the individualised focus on the needs of children to achieve quality of life and wellbeing is crucial, the ongoing call for changes at the micro level such as increasing more choice and control by people with disability and their whaanau and families are often influenced by the socio-political context and can be undermined by institutional barriers

(Robinson & Graham, 2019). Services and support to children and young people with intellectual disability are increasingly being impacted by neoliberal agendas of cost-cutting, high turnover of social workers and health practitioners and support workers, individual contracts, and individual responsibility, which has made services and support more precarious (Carey et al., 2018). Participants in the current study acknowledged and recognised that to mitigate risks and abuse among children with intellectual disability and their whaanau and families, social and transformative changes are also required at a macro level. A recent report published by Waikato District Health Board (WDHB, 2019) in NZ '*Disability Responsive Plan'* developed in partnership with people with disabilities highlighted the need to address accessibility barriers such as transportation, diagnostic assessments and interventions occurring in a timely manner and the removal of financial obstacles for those under 15 with disabilities.

As children with intellectual disability move through their lifespan, they are more likely to encounter safety and abuse issues in the wider community and will need to frequently engage with social workers and health practitioners in the wider community, such as direct support staff, police and first responders. It is, therefore, important that social workers and health practitioners can respond appropriately to concerns of abuse, neglect, violence, and trauma among this group. As many children with intellectual disability may receive accommodation support services when they get older, they may also encounter safety and abuse issues in residential settings. Hence, the context of social change is also linked to organisational support. A study by Friedman (2021) suggested that, when service providers implement continual staff development, there can be a significant reduction in cases of abuse and neglect among the people with disability they support. When direct support workers and health practitioners are better educated and resourced, organisations can increase the health and safety outcomes of clients, and staff, which can result in decreased staff turnover and the ability to sustain optimal service provisions.

In the current study, participants supported the notion that knowledge of disability should be a requirement across all non-government and government agencies who interact and engage with this group of children. These findings are consistent with previous research within the police and first responders' field, reflecting that engagement with people with intellectual disability can be negatively impacted by lack of knowledge through, for example, the type of risk assessment (Bailey et al., 2001; Parry 2020; Wolf-Fordham et al., 2014). While risk assessments have become prominent in many areas of social work practice, research has shown that professionals do not always interpret actual information from a factual evidence-based perspective. At times they may respond using their own interpretations of risk based on previous experiences from case-based information or existing work/team culture (Broadhurst et al., 2010) and their own sense of moral duty (Stanford, 2011). Social workers have been criticised for underestimating the prevalence of abuse and neglect among service users across all areas of practice. Taking account of evidence can, therefore, be seen to be a moral response to challenge one's own biases and suppositions. The use of screening and assessment tools can serve the purpose of highlighting the risk of abuse, and inform practice; however, engaging with and listening to those who have been abused and neglected to explore how abuse is experienced should be prioritised (Dixon & Robb, 2016).

When a child with intellectual disability presents with complex behaviours and/or emotional dysregulation, the social worker or health practitioners involved are more likely to default to a medical model perspective where the behaviour needs fixing instead of taking a wider holistic view where the behaviours could be a result of experiencing harm, abuse, and neglect (Franklin et al., 2020). According to the Convention on the Rights of Persons with Disabilities (CRPD) (UN, n.d, pg. 9), "children with disabilities have the right to express their views freely on all matters affecting them … and to be provided with disability and age-appropriate assistance to realise that right". As children with intellectual disability are vulnerable to abuse and neglect, trauma informed care can also inform our understanding of how the current societal structures of ableism and disablism have perpetuated abuse, neglect, and trauma against these children (Kattari et al., 2020; Thomas-Skaf & Jenney, 2020). Findings from this study indicated that participants have witnessed discriminatory and marginalising practice from other social workers and health practitioners who removed the right of the child to access support, such as counselling, due to their prejudices or lack of understanding that abuse, neglect, and violence against children with intellectual disability is not a myth. Participants reported that it required the collective responsibility of not only themselves, but also their agencies and professional bodies to advocate for the rights of children with intellectual disabilities to ensure they received trauma informed care just like their ordinary peers. This collective responsibility was strongly emphasised in recent literature that highlighted the importance of being responsive to the specific needs of these children in order to maintain their dignity (Munford & Bennie., 2015; Thomas-Skaf & Jenny, 2020). This research argued for the integration of trauma informed frameworks into social services in relation to organisations' policies, procedures, and vision statements, and regular trauma training with the intent of providing therapeutic support and minimising re-traumatisation (Fuld, 2018; Harvey, 2012; Munford & Bennie, 2015; Thomas-Skaf & Jenny, 2020). It has also been identified in the New Zealand Disability Strategy 2016-2026 (Office for Disability Issues, 2016b) that one of the eight outcomes is specifically related to health and wellbeing, recognising that there is much work to be done to bridge the gap between policy and practice to address inclusive service delivery and outcomes for people with disabilities. The importance of social workers having the knowledge and understanding of intellectual disability and its related discourses will enable them to practice from a social, relational, rights-based model by developing better socio-political and cultural understandings of childhood disability, mental health, and illness, instead of the historical medical model (Munford & Bennie, 2015). Despite the existing volume of information highlighting the importance of applying a social model to understanding the issues and experiences in the disability field, Muyor-Rodriquez et al. (2019) have argued that many published articles are still rooted in a medical and biological perspective to describe disabled people rather than using a social and holistic perspective. This may also be reflected in the still limited published research on people with disabilities who have experienced abuse and neglect as a child to inform policy and practice (Allnock & Miller, 2013; Flynn, 2020; Franklin & Smeaton, 2017; Jones et al., 2016). This lack of recognition and understanding of children with intellectual disabilities continues to marginalise children with intellectual disabilities. They are more likely to be hidden amongst their neurotypical peers, which creates barriers to effectively addressing their vulnerabilities (Flynn, 2020).

Social change is a fundamental core role of a social worker and is enshrined internationally in the foundations of social work (IFSW, 2014) and nationally with ANZASW Code of Ethics (2013). To be transformative and achieve social change, requires systematic and rigorous approaches to address the inconsistencies in responses to abuse, neglect, and trauma of this group of children. Social workers are urged to manage the complexity and intensity of their roles both at micro and macro levels (Brown, 2020). It is essential that social work, other human service and healthcare disciplines, and disability researchers work collaboratively with people with intellectual disabilities, leaders and the community from a social justice and human rights perspective (Rowe et al., 2016).

5.5 Summary

This chapter highlighted three areas that emerged from the data analysis: the intersection of disability knowledge and competence to practice, the relevance of relational practice, and the challenges in preparing a disability-competent health and social care workforce who are also able to work at a systems level to create change. The findings of this study, combined with current research and relevant literature, have highlighted the urgency of addressing clear gaps in responsiveness to abuse, neglect, and trauma for children with intellectual disability, and their whaanau and family, with a strong focus on an integrated disability practice framework, which encompasses disability education, professional practice, and service delivery. The final chapter will conclude the thesis and present a summary of the findings, implications for policy and practice, a reflection on research processes and recommendations for future research.

Chapter 6 - Conclusion and Recommendations

6.1 Introduction

NZ has one of the highest rates of child abuse in the developed world, and internationally it is well documented that children with intellectual disability are three to four times more likely to be abused than their ordinary peers. This research, supported by the growing body of international evidence, has illustrated that there is an urgent need to develop a better understanding of how to address the abuse, neglect, and trauma of this cohort of children and to provide meaningful support to their whaanau and families. The situation in NZ has been further complicated by the lack of any clear statistics for disabled children who have been abused (Oranga Tamariki, 2020a), and the limited disability training and professional development for social workers to facilitate the interface between abuse and disabilities. This has made it difficult for government, local authorities, and social service sectors to prepare and respond to the needs of disabled children who are being abused, without knowing adequately the degree or type of disability, or the kind of abuse they have suffered (Briggs, 2006). Based on this rationale, this research aimed to add to the body of knowledge by exploring the perspectives of practitioners and their responses to abuse, neglect, and trauma of children with intellectual disability. This chapter will firstly summarise the findings, then describe the limitations of the research, followed by illustrating implications and recommendations for future practice, policy, and research.

6.2 Summary of the findings

Findings from this research clearly identified three key areas that require addressing in order for social workers and health practitioners to respond competently to the abuse, neglect, and trauma of children with intellectual disability. Firstly, results from participants' narratives highlighted issues relating to the intersection of disability knowledge and competence to practice. This has made it difficult to navigate the complexity of intellectual disability and assessing abuse, with the additional difficulties of differentiating between the nuances of disability such as behaviours, communication, and potential signs of abuse. This research has also identified other influential factors, which can perpetuate abuse, neglect, and trauma of children with intellectual disability. These factors revolve around managing the values of social workers and health practitioners, such as being over empathetic to the level of demands of the whaanau and family to instigate a formal reporting, and the frustration of the 'learn on the job' approach, which leads to trying to muddle through their practice.

Secondly, the relevance of relational practice has been identified frequently and strongly throughout this research as a crucial social work response to establishing a supportive foundation between the social worker/health practitioner, the child, their whaanau and family. Even when courageous conversations need to take place between practitioners and whaanau and family regarding the welfare of children with intellectual disabilities, social workers and health practitioners must consider how to facilitate and maintain relationships to help whaanau and family to manage challenging situations (Ruch et al., 2018).

To address and mitigate the risk of abuse, neglect, and trauma of children with intellectual disability, social workers and health practitioners need to understand how the lived experiences of whaanau and families may contribute to child maltreatment. These influential factors range from (but are not limited to) financial deprivation, appropriate housing, limited knowledge about disability, navigating familial and societal discrimination and marginalisation against disability, whilst also negotiating the complex health and social welfare system (Murray, 2018; Wynd, 2015). In addition, raising a disabled child or children, in some cases, may put additional stressors on the already fragile support network, which could cause further emotional distress not only for the whaanau and families, but also for siblings and other wider relationships. While the supportive role of grandparents has been seen as one of the protective factors, results of this study has also called for more education and support for this group, as they can in turn experience stress, burnout, and financial burden when supporting their children to raise their grandchildren with intellectual disability. Some of the participants have raised concerns that social workers and health practitioners could not just focus on working with the whaanau and families of children with intellectual disability without learning how to communicate and build strong and trusting relationships with children with intellectual disabilities. This research has emphasised that social work practice needs to take into consideration ‘child-centred’ rather than just ‘parent-centred’ approaches. Although there are and will be times when social workers and health practitioners need to be creative in practice when it comes to the issue of intellectual disability, it is important to address the lack of practice-oriented spaces in order to generate more conversation, discussion, reflective practice and learning for substantial changes to support disabled children in care and protection.

Finally, there are ongoing challenges in preparing a disability-competent health and social care workforce who can work at both micro and macro levels to create change and develop more effective responses to addressing abuse, neglect, and trauma. There is limited NZ published research on people with intellectual disabilities who have experienced abuse, neglect, and trauma as a child to inform policy and practice. This has added weight to the already recognised gaps in disability research, the provision of education on intellectual disability at tertiary level for social workers, professional practice, and service delivery. These results should not be interpreted as new and surprising but indicate that there is still a long way to go to support and get it right for children with intellectual disability. Social work and social workers must take a stronger stance to advocate for better resources and expertise, and to develop a more rigorous and solid evidence-based and rights-based approach to support children with intellectual disability facing abuse and neglect to influence positive and transformative changes.

6.3 Limitations of the research

This study is unique and relevant because it examined social workers and health practitioners' responses to support disabled children, their whaanau and families when it comes to abuse, trauma, and neglect, contributing to an under-developed area in NZ's care and protection of children. However, there are some limitations to this study. Firstly, the initial intent to recruit social workers in senior management positions, with experience in supporting disabled children who had experienced maltreatment, to participate in a focus group to draw upon their management, policy and practice leadership was unsuccessful after several attempts. This difficulty could be due to the already stretched human services field in the region where the recruitment took place and the lack of social workers in senior management roles. Secondly, with a small sample size, caution must be applied as these findings may not be transferable to all other social workers and health practitioners. Thirdly, the generalisability of these results is subject to certain limitations where the experiences of supporting children with intellectual disability from Maaori, Pasifika, and other ethnic groups were not explicitly captured. Despite the limitations, this study adds to our understanding of NZ social workers and other health practitioners’ response to abuse, neglect, and trauma to children with intellectual disability from a NZ context.

6.4 Implications and recommendations for future practice, policy, and research

6.4.1 Practice

Given the lack of knowledge, competence, and confidence among social workers in the area of disability, best practice responses of assessment and interventions should be a priority if the practitioner involved is to be equipped with some of these essential elements, such as having a clear understanding of intellectual disability (Dovgan & Mazurek, 2018; Lightfoot et al., 2011; Lightfoot & La Liberte, 2006; Shannon & Agorastou, 2006), and receiving ongoing professional development and supervision (Manders & Stoneman, 2008; Shannon & Tappan, 2011; Stalker et al., 2015). Recommendations suggest that social workers and health practitioners will be able to practice confidently and competently when there is an integration of intellectual disability knowledge into tertiary education, alongside placement opportunities for social workers and other health practitioners within the disability sector. To maintain this competency, it would also be necessary for these social workers and health practitioners to continue to participate in education and professional development about intellectual disability on an ongoing basis. As such, this may mean that social work education focuses on learning the importance of applying a social model of disability across the life span to reduce the discrepancy of seeing disability as separated from human development and to promote inclusivity and relational practice. In this study, participants strongly emphasised the lack of consistency in recognising, assessing, and responding to the initial allegation of abuse of children with intellectual disability within the community and within the child protection triaging system. Therefore, a possible solution could be the introduction of multi-disciplinary approaches with comprehensive and wide-ranging professional knowledge of children with intellectual disability and their experiences of abuse, neglect, and trauma (Vrolijk-Bosschaart et al., 2018). Even when allegations were substantiated, results from the study indicated that it was often difficult to access appropriate services for children with intellectual disability and their whaanau and family, where many services were not fit for purpose and often of limited availability. Therefore, from a best practice perspective, recommendations would focus on including trauma informed therapeutic care to support children and young people with intellectual disability to address the effects of abuse and trauma. In addition, there is an urgent need to address the unacceptable amount of time children with indicators of a learning disability and their whaanau and family have to wait for a confirmed diagnosis. This delay in confirmed diagnosis potentially impedes the child and their whaanau and family's ability to access services and supports quickly, resulting in unnecessary distress.

6.4.2 Policy

Despite the heightened risk of child maltreatment, the abuse of disabled children often goes undetected, under-reported, and under-studied (Oranga Tamariki, 2019). A critical area in need of addressing with urgency is the collection of statistics on children in NZ, which should be expanded to identify children with intellectual disability. If the current inconsistent safeguarding responses are to be addressed, it will firstly be important to collect accurate statistics on children with intellectual disability and their record of child maltreatment in NZ (Oranga Tamariki, 2020a), followed by identifying areas of support such as disability specific support, housing, financial and transportation needs (Murray, 2018; Wynd, 2015). Once a clear understanding of the statistics is available, then it will be possible to work towards addressing the identified gaps. This could be achieved by including a space in the intake assessment form to record types of disability and communication style and support needs required by the child in order to provide a more comprehensive view of the needs of the disabled child and whaanau and families and to inform a national co-ordinated response. If unaddressed needs are identified, the data collected then can also be analysed and the findings can be used to inform the relevant government departments future planning and policy development (Penner & Dodge, 2019).

The insights from the participants support the exploration of developing specialised areas/scopes of practice in disability for social work and health practitioners, where social workers and health practitioners have attained competence to work with children with intellectual disabilities. Examples of this already exist in Australia for social workers as a scope of practice (AOSW, n.d. & AASW, 2016) and in nursing in NZ where disability is recognised as a specialised area of practice on practicing certificates, which indicates having attained a certain level of competence in working with people who have an intellectual disability (NZ Nursing Council, n.d.). Wider policy and legislative development should take into consideration the voices of disabled children themselves, their whaanau and families (Prynallt-Jones et al., 2018), along with organisations such as People First, Ngā Tāngata Tuatahi (People First, n.d.), Disabled Persons Assembly NZ (DPA, n.d.), Child Poverty Action Group (Wynd, 2019), CCS (Murray, 2019). Guidance can be drawn from existing safeguarding policies and procedures internationally (DCSF, 2009) for children with disabilities, which sit within a wider legislative framework. These safeguarding policies should explicitly identify children with disabilities throughout and the responsibility of all in the community to address the welfare of children with disabilities to enable them to live their lives to the fullest, and free from abuse (HM Government, 2018; Wayland & Hindmarsh, 2017).

6.4.3 Research

More research is recommended to address the lack of data and statistical evidence of disabled children who have experienced abuse, neglect, and trauma in NZ. To do so, children with intellectual disability and their whaanau and family should be supported to actively participate in the research so that they can give their views about the issues and decisions affecting them (Jones et al., 2016; Kyegombe et al., 2019). It would also be beneficial to explore the relationships between poverty and abuse experienced by children with intellectual disability from a socio-ecological framework, as the literature suggests there is a contextualised relationship between these two factors (Meissen et al., 2016; Wigham & Emerson, 2015). A significant piece of recent NZ research has shed some important spotlights on examining the wellbeing and care of siblings who are in carer roles of their brother or sister with intellectual disabilities (Donnan, 2020), which is consistent with the issue raised in the current research. This has further added more justification to the need to capture the accurate numbers of those in this caring role and then using data from recent research to address their needs. Finally, research should also be used as a conduit to engage social workers and health practitioners, not only as participants, but also as researchers, drawing on their experiences in effecting change at a wider systemic level within the disability field. Their knowledge and skills can provide valuable recommendations and strategies on possible pathways to increase their efficacy and ownership in making changes to support successful outcomes for children and young people with intellectual disabilities.

6.5 The impact of COVID-19 on disability and abuse

This study has provided further evidence for a continuing concern for children with intellectual disability who have experienced abuse, neglect, and trauma. It is also widely known that emergencies and natural disasters increase the risk of child abuse because they tend to weaken care and protection services and disrupt preventative measures (Goldfield et al., 2020; Seddighi et al., 2021). NZ like the rest of the world has been exposed to COVID 19. The government imposed a nationwide lockdown (level 4) from March 25 to April 28, 2020: "at 11:59pm, New Zealand moves to Alert Level 4, and the entire nation goes into self-isolation. A State of National Emergency is declared at 12:21pm" (para 3) with the Prime Minister Jacinda Ardern directing NZ to work as a team by isolating themselves at home in their bubbles and to adhere to strict social distancing and hygiene practices (NZ Government, 2020). Therefore, schools and childcare centres were closed (NZ Government, 2020), and out-of-school activities were no longer available, requiring children to spend more time at home. The lack of social care and monitoring during a lockdown means that child abuse and family violence may be undetected and unreported (MSD, 2020; Oranga Tamariki, 2020a). Although disasters and pandemics are different, they can affect people's emotional responses in similar ways. Research carried out on the effect of disasters on families and children evidences not only an increase in violence, but it continues during the rebuild and recovery (Molyneaux et al., 2020). When family members spend more time in close contact with each other, there is additional stress and burden on already fragile whaanau and families to try and cope with existing and new challenges (Caron et al., 2020). Research has shown that existing disparities may be further exacerbated by COVID 19 (Munford, 2021), bringing the additional challenges of increases in job loss (Lawson et al., 2020) and isolation to already more vulnerable members of the community and children (Ramaswamy & Seshadri, 2020). Furthermore, child protection statistics in NZ

(Oranga Tamariki, 2020b) showed a significant drop in reports of concern (abuse) during the Alert Level 4 lockdown period. With limited face-to-face encounters, interactions and monitoring by practitioners such as social workers and teachers for incidents of abuse and family violence, potential abuse and risky situations were not easily identified and reported, highlighting concerns about undetected abuse (Caron et al., 2020). Moreover, children with intellectual disability faced additional challenges of changes in routine, including social distancing (Asbury et al., 2020; Patel, 2020), inaccessible education, reduced health support, and increased parental stress (MSD, 2020; Stakeholder Group of Persons with Disabilities for Sustainable Development, 2020). From a social work perspective, visiting children to address abuse concerns may require wearing PPE, which can add additional challenges in communicating with the child, particularly to those with hearing impairments and intellectual disability (Banks et al., 2020). Hampton et al. (2020) identified the need for medical professionals to speak louder to counteract the barrier of a PPE mask to address the potential risk it made to patient safety.

Whilst not a contributory factor to this research as data collection occurred before the pandemic, it is important to comment on COVID 19 as this is an emerging factor in care and protection social work and social work with disabled children and their whaanau and families. The impact of COVID 19 has further urged social and health practitioners to continue maintaining continuity and hypervigilance in practice during times of disaster and uncertainties. The aftermath effects of COVID 19 will linger for a longer period as the economic stress of the pandemic will continue disrupting families and their financial capacity (MSD, 2020) and this could further endanger the safety of already vulnerable children with intellectual disabilities. Social workers and health practitioners may need to alter some of their methods of contacting, interacting, and engaging with their clients but they need to equip themselves with knowledge and skills to detect and recognise risk for family violence and other violence against children and disabled children. Many whaanau, families and caregivers of disabled children were affected significantly mentally, physically, and psychosocially from lockdown and other restrictions during COVID 19 (Chen et al., 2020; Mbazzi et al., 2021). We can take lessons from the learning during this time, such as promoting a more collective level of support for whaanau and families caring for children with intellectual disability, just like neighbours were encouraged to support older people during the pandemic.

6.6 Conclusion

This research has provided an opportunity to gain a better understanding of social workers and health practitioners' experiences in supporting children with intellectual disability and their whaanau and families. Their dedication and desire to make a difference in practice is admirable and provides important insights into moving forward to address abuse, neglect, and trauma of children with intellectual disability. The disability field is a unique field of practice that requires social workers and health practitioners to be equipped with disability knowledge, competent practice skills and the ability to build respectful and sustainable relationships with children with intellectual disability and their whaanau and families. Frontline social workers can play an important role in drawing attention to important social issues as both researchers and research participants. To achieve this, social workers and health practitioners need to engage in critically reflective practice that enables them to establish trusting relationships and provide meaningful support to children and their whaanau and families. This relational practice will be supported by an inclusive community, which values the experiences and contribution of children with intellectual disability and their whaanau and families. Success will be evidenced when this group of children’s wellbeing is treated with the same respect and dignity as their ordinary peers, enabling them to live in safe and nurturing environments where they are free from abuse, neglect, and trauma.

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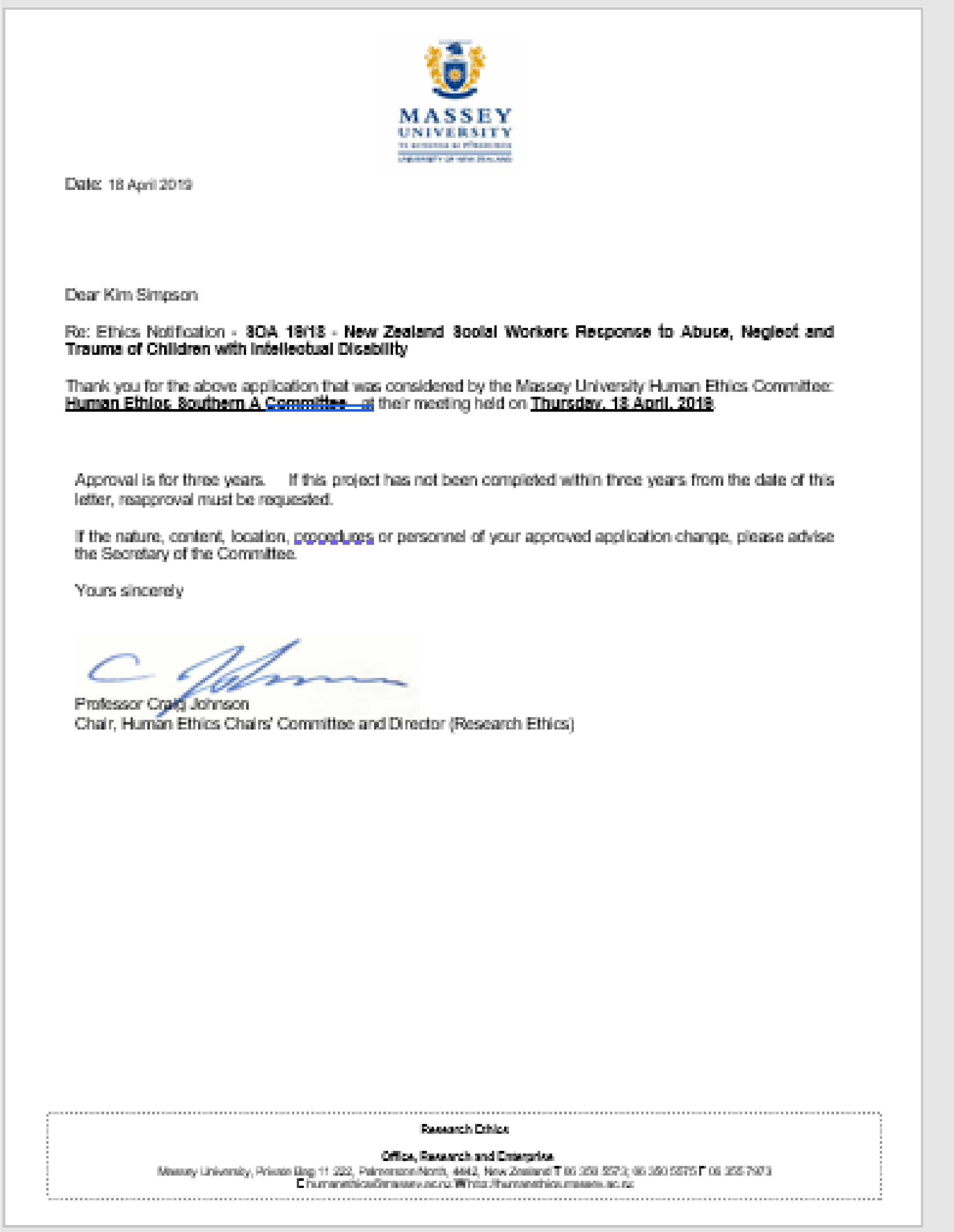
Appendix A: Massey University Human Ethics Committee SOA number 19/18



MASSEY UNIVERSITY

Date: 18 April 2019

Dear Kim Simpson

Re: Ethics Notification - **SOA 19/18 - New Zealand Social Workers Response to Abuse, Neglect and Trauma of Children with Intellectual Disability**

Thank you for the above application that was considered by the Massey University Human Ethics Committee: **Human Ethics Southern A Committee** at their meeting held on **Thursday, 18 April, 2019**.

Approval is for three years. If this project has not been completed within three years from the date of this letter, reapproval must be requested.

If the nature, content, location, procedures or personnel of your approved application change, please advise the Secretary of the Committee.

Yours sincerely

Professor Craig Johnson
Chair, Human Ethics Chairs' Committee and Director (Research Ethics)

Research Ethics

Office, Research and Enterprise
Massey University, Private Bag 11 222, Palmerston North, 4442, New Zealand T 06 350 5573; 06 350 5575 F 06 355 7973
E humanethics@massey.ac.nz W http://humanethics.massey.ac.nz

Appendix B: New Zealand Social Workers Responses to Abuse, Neglect and Trauma of Children with Intellectual Disability – Information Sheet – Focus Group

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA

New Zealand Social Workers Responses to Abuse, Neglect and Trauma of Children with Intellectual Disability

INFORMATION SHEET – FOCUS GROUP

Kia ora/Greetings

My name is Kim Simpson and I am currently studying the Master of Social work through the School of Social Work, Massey University, Palmerston North. As part of my study, I am undertaking a research thesis about New Zealand social workers' responses to abuse, neglect and trauma of children with intellectual disability.

Purpose of the study

The purpose of this research is to explore New Zealand social worker's perspectives and experiences in responding to abuse, neglect and trauma experienced by children with intellectual disability. It is clearly evidenced that children with disabilities are three to four times more likely to be abused and neglected than their ordinary peers. Social workers in government and non-government agencies are often involved in the lives of these children in variety roles, community, statutory, health and education. Social workers must ensure that all children they work with are heard and are free from abuse and neglect. The intent of this research is to use a qualitative approach to capture social workers perspectives and experiences on dealing with issues of abuse and neglect of children with intellectual disability.

Research procedures

I would like to invite four to five qualified social workers in the Waikato region who have current roles of management, social work and policy and practice leadership with at least five years or more of relevant experiences in working with children with intellectual disability who have experienced abuse, neglect and trauma to participate in a focus group. The intent of the focus group is to gain participants' perspectives and experiences from working with this group of children at both practice and policy level. Information gathered will form the construction of parts of the semi-structured interviews which is phase two of this research. The focus group will be held at 35 Von Tempsky St, Hamilton East, Hamilton for up to two hours, including time for refreshment and a short break. After the focus group, a summary of the key points will be emailed for you to check for accuracy and approval to be used for the research.

All written and recorded data along with consent forms and hard-drives will be kept in a locked cupboard at my home and only accessible by me. The digital data stored on hard-drives will also be password protected on Dropbox in the cloud and only accessible by me and my research supervisors.

Confidentiality is assured and your name will be omitted from the thesis or other academic reporting. On completion of the research, I will email or post you a summary of the findings.

Participant's Rights

You are under no obligation to accept this invitation. If you choose to participate in this study, you will have the right to:

- Decline to answer any particular question;
- Withdraw from the study (up until the approval of the summary of the focus group);
- Ask any questions relating to this study at any time prior and during participation;
- Provide information in the understanding that your name will not be used for research purposes
- Be given access to a summary of the project findings once the project is finalised
- Ask for the recorder to be turned off at any stage in the interview

Project Contacts

If you have further questions or feel that this research topic has caused you any discomfort, you can contact me or my research supervisors.

Student Researcher	Research Supervisor	Research Supervisor
Kim Simpson Mob: [redacted] Email: [redacted]	Dr. Polly Yeung School of Social Work Massey University Palmerston North 06 356 9099 xtn 83514 p.yeung@massey.ac.nz	Professor Robyn Munford Practice Research and Professional Development Hub Massey University Palmerston North 06 356 9099 xtn 83513 r.munford@massey.ac.nz

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application 19/18. If you have any concerns about the conduct of this research, please contact Dr Negar Partow, Chair, Massey University Human Ethics Committee: Southern A, telephone 04 801 5799 x 63363, email humanethicsoutha@massey.ac.nz.

Appendix C: Professional Responses to Abuse, Neglect and Trauma of Children with Intellectual Disability – Information Sheet – Focus Group

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA

Professional Responses to Abuse, Neglect and Trauma of Children with Intellectual Disability

INFORMATION SHEET – FOCUS GROUP

Kia ora/Greetings

My name is Kim Simpson and I am currently studying the Master of Social work through the School of Social Work, Massey University, Palmerston North. As part of my study, I am undertaking a research thesis about New Zealand social workers' responses to abuse, neglect and trauma of children with intellectual disability.

Purpose of the study

The purpose of this research is to explore New Zealand qualified professionals perspectives and experiences in responding to abuse, neglect and trauma experienced by children with intellectual disability. It is clearly evidenced that children with disabilities are three to four times more likely to be abused and neglected than their ordinary peers. Professionals in government and non-government agencies are often involved in the lives of these children in variety roles, community, statutory, health and education. Professionals must ensure that all children they work with are heard and are free from abuse and neglect. The intent of this research is to use a qualitative approach to capture professional perspectives and experiences on dealing with issues of abuse and neglect of children with intellectual disability.

Research procedures

I would like to invite four to five qualified professionals such as social work/psychologist/occupational therapist/teacher who have current roles of management, policy and practice leadership e,g, senior social worker, practice leader, team leader, agency manager, chief executive, area manager, deputy principal/principal. With at least five years or more of experiencing as part of this role relevant experiences in working with children with intellectual disability e.g. FASD and ASD with intellectual disability, Global Developmental Delay, Downs Syndrome, Fragile X Syndrome (FXS), Prader-Willi Syndrome who have experienced abuse, neglect and trauma to participate in a focus group.

The intent of the focus group is to gain participants' perspectives and experiences from working with this group of children at both practice and policy level. This broader knowledge gathered will form the construction of parts phase two of this research. The focus group will be held - at a venue and date to be advised - for up to two hours, including time for refreshment and a short break. After the focus group, a summary of the key points will be emailed for you to check for accuracy and approval to be used for the research.

All written and recorded data along with consent forms and hard-drives will be kept in a locked cupboard at my home and only accessible by me. The digital data stored on hard-drives will also be password protected on Dropbox in the cloud and only accessible by me and my research supervisors.

Confidentiality is assured and your name will be omitted from the thesis or other academic reporting. On completion of the research, I will email or post you a summary of the findings.

Participant's Rights

You are under no obligation to accept this invitation. If you choose to participate in this study, you will have the right to:

- Decline to answer any particular question;
- Withdraw from the study (up until the approval of the summary of the focus group);
- Ask any questions relating to this study at any time prior and during participation;
- Provide information in the understanding that your name will not be used for research purposes
- Be given access to a summary of the project findings once the project is finalised
- Ask for the recorder to be turned off at any stage in the interview

Project Contacts

If you have further questions or feel that this research topic has caused you any discomfort, you can contact me or my research supervisors.

Student Researcher	Research Supervisor	Research Supervisor
Kim Simpson Mob: [redacted] Email: [redacted]	Dr. Polly Yeung School of Social Work Massey University Palmerston North 06 356 9099 xtn 83514 p.yeung@massey.ac.nz	Professor Robyn Munford Practice Research and Professional Development Hub Massey University Palmerston North 06 356 9099 xtn 83513 r.munford@massey.ac.nz

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application 19/18. If you have any concerns about the conduct of this research, please contact Dr Negar Partow, Chair, Massey University Human Ethics Committee: Southern A, telephone 04 801 5799 x 63363, email humanethicsoutha@massey.ac.nz.

Appendix D: Information sheet – Individual Participant

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA

New Zealand Social Workers Responses to Abuse, Neglect and Trauma of Children with Intellectual Disability

INFORMATION SHEET – INDIVIDUAL PARTICIPANT

Kia ora/Greetings

My name is Kim Simpson and I am currently studying the Master of Social work through the School of Social Work, Massey University, Palmerston North. As part of my study, I am undertaking a research thesis about New Zealand social workers' responses to abuse, neglect and trauma of children with intellectual disability.

Purpose of the study

The purpose of this research is to explore New Zealand social worker's perspectives and experiences in responding to abuse, neglect and trauma experienced by children with intellectual disability. It is clearly evidenced that children with disabilities are three to four times more likely to be abused and neglected than their ordinary peers. Social workers in government and non-government agencies are often involved in the lives of these children in variety roles, community, statutory, health and education. Social workers must ensure that all children they work with are heard and are free from abuse and neglect. The intent of this research is to use a qualitative approach to capture social workers' perspectives and experiences on dealing with issues of abuse and neglect of children with intellectual disability.

Research procedures

Recently I conducted a focus group with some senior practitioners, policy advisors and management staff with extensive experiences in dealing with children with intellectual disabilities in regard to abuse, neglect and trauma. Their information has helped contributing to parts of the interview schedule that will be used in this part of the research. In order to further enrich the topic concerned, I would like to invite four to five qualified social workers in the Waikato region who are currently in frontline roles and have at least three years practice experience of supporting children with intellectual disabilities to deal with abuse, neglect and trauma to participate in one to one semi-structured interviews (60-90 minutes) to explore opportunities and challenges working in this area and the kind of support that are needed to enhance social work practice to support disabled children at risk of violence and harm The interviews will be conducted at a mutually agreed space, date and time, factoring in your other commitments. After the interviews are complete, the recorded data will be transcribed and forwarded to you to seek your approval before including the information in my report.

All written and recorded data along with consent forms and hard-drives will be kept in a locked cupboard at my home and only accessible by me. The digital data stored on hard-drives will also be password protected on Dropbox in the cloud and only accessible by me and my research supervisors.

Confidentiality is assured and your name will be omitted from the thesis or other academic reporting. On completion of the research, I will email or post you a summary of the findings.

Participant's Rights

You are under no obligation to accept this invitation. If you choose to participate in this study, you will have the right to:

- Decline to answer any particular question;
- Withdraw from the study (up until the approval of the individual interview transcript);
- Ask any questions relating to this study at any time prior and during participation;
- Provide information in the understanding that your name will not be used for research purposes
- Be given access to a summary of the project findings once the project is finalised
- Ask for the recorder to be turned off at any stage in the interview

Project Contacts

If you have further questions regarding this research, you can contact me or my research supervisors.

Student Researcher	Research Supervisor	Research Supervisor
Kim Simpson Mob: [redacted] Email: [redacted]	Dr. Polly Yeung School of Social Work Massey University Palmerston North 06 356 9099 xtn 83514 p.yeung@massey.ac.nz	Professor Robyn Munford Practice Research and Professional Development Hub Massey University Palmerston North 06 356 9099 xtn 83513 r.munford@massey.ac.nz

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application 19/18. If you have any concerns about the conduct of this research, please contact Dr Negar Partow, Chair, Massey University Human Ethics Committee: Southern A, telephone 04 801 5799 x 63363, email humanethicsoutha@massey.ac.nz.

Appendix E: New Zealand Social Workers Responses to Abuse, Neglect and Trauma of Children with Intellectual Disability – Focus Group Participant Consent Form

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA

New Zealand Social Workers Responses to Abuse, Neglect and Trauma of Children with Intellectual Disability

FOCUS GROUP PARTICIPANT CONSENT FORM

I have read, or have had read to me in my first language, and I understand the Information Sheet provided. I have had the details of the study explained to me, my questions have been answered to my satisfaction, and I understand that I may ask further questions at any time. I have been given sufficient time to consider whether to participate in this study and I understand participation is voluntary and that I may withdraw from the study at any time.

1. I understand that I have an obligation to respect the privacy of the other members of the group by not disclosing any personal information that they share during our discussion.
2. I understand that all the information I provide will be kept confidential to the extent permitted by law, and the names of all people in the study will be kept confidential by the researcher.

Note: *There are limits on confidentiality as there are no formal sanctions on other group participants from disclosing your involvement, identity or what you say to others in the focus group. There are risks in taking part in focus group research and taking part assumes that you are willing to assume those risks.*

3. I agree to participate in the focus group under the conditions set out in the Information Sheet which I have read.

Declaration by Participant:

I ___________ [print full name]__________ hereby consent to take part in this study.

Signature: _______________________ **Date:** ________________

Appendix F: New Zealand Social Workers Response to Abuse, Neglect and Trauma of Children with Intellectual Disability – Focus Group Schedule

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA

New Zealand Social Workers Response to Abuse, Neglect and Trauma of Children with Intellectual Disability

FOCUS GROUP SCHEDULE

Researcher's welcome and introduction of self and of note taker along with instructions for the participants

Thank you for participating in this focus group and would like to acknowledge the time you have put aside for this, it is much appreciated

Researcher and note taker's names and background

Setup of a group contract with ground rules and protocol

- One person speaking at a time.
- Every answer is important, so please respect different points of view.
- Collectively ensure that each group member is heard.
- If someone wishes for time out, please say so and feel free to leave for a few minutes.
- Confidentiality, what is shared in the room stays in the room and not to be shared with others.
- Does anyone have any questions?

Warm up

- First, I'd like everyone to introduce themselves, if you could share a little about your professional background, how long you have been practicing as a social worker, what fields you have worked in and your current role?
- All of these questions are written with the intent to draw on your experience and perspectives not only as a social worker but in the senior roles you currently hold in your organisations.

Themes for focus group discussion:

- How do you view the definition of child abuse and its connection with children with intellectual disability? Is it viewed differently from their ordinary peers?

- Research would suggest that abuse of children with intellectual disability is not all equal. What is your understanding of the differential and what have been your experiences in these circumstances? And has this influenced how social workers have responded to abuse, neglect and trauma of children with intellectual disability within your organisation?

- What is your understanding of the level of abuse, neglect and trauma experience by New Zealand children with intellectual disability? What are some of your experiences?

- What are the protective factors that can mitigate or eliminate risk factors that decrease the health and wellbeing of disabled children and their whanau/families? What are some examples?

- When reflecting on successful outcomes for a child with intellectual disability what has been identified as key factors to enable this to happen? E.g. relationships/whanaungatanga with whanau and professionals, collaborative responses, professional development, knowledge, tools, resources?

- As social workers in leadership roles how are you able to influence positive change at a systemic level nationally to eliminate abuse, neglect and trauma of children with intellectual disabilities? Can you give examples?

After sharing your experiences today has there been anything that you think has been missed? If after leaving you would regret not sharing?

Conclusion

- Thank you for participating, I really appreciate the time you have taken today to share your valuable knowledge and experience.
- Just a reminder that the identity of the other participants and what they have disclosed is confidential.
- A summary of the transcribed notes will be provided to you for your feedback

Appendix G: Letter requesting permission Non-Government Organisations – Focus Group

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA

Letter requesting permission Non-Government Organisations

Focus Group

Kia ora/Greetings

My name is Kim Simpson and I am currently studying towards the Master of Social Work through the School of Social Work, Massey University, Palmerston North.

As part of my study, I am undertaking a research thesis about New Zealand social workers' responses to abuse, neglect and trauma of children with intellectual disability in the Hamilton region.

The intent is to recruit four to five qualified social workers to participate in a focus group who currently hold senior positions in management, social work, policy or practice leadership who have at least five years or more relevant experience in working with children with intellectual disability who have experienced abuse, neglect and trauma. Using the focus group, I would like to gain in-depth understanding from their perspectives and experiences working in leadership roles in the Waikato area supporting this group of children.

I would appreciate it if you would pass on this letter and the enclosed information sheet to potential participants.

Nga mihi

Kim Simpson

Project Contacts

If you have further questions regarding this research, you can contact me or my research supervisors.

Student Researcher	Research Supervisor	Research Supervisor
Kim Simpson Mob: [redacted] Email: [redacted]	Dr. Polly Yeung School of Social Work Massey University Palmerston North 06 356 9099 xtn 83514 p.yeung@massey.ac.nz	Professor Robyn Munford Practice Research and Professional Development Hub Massey University Palmerston North 06 356 9099 xtn 83513 r.munford@massey.ac.nz

Appendix H: Letter requesting permission Non-Government Organisations - One to One Interviews

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA

Letter requesting permission Non-Government Organisations

One to One Interviews

Kia ora/Greetings

My name is Kim Simpson and I am currently studying towards the Master of Social Work through the School of Social Work, Massey University, Palmerston North.

As part of my study, I am undertaking a research thesis about New Zealand social workers' responses to abuse, neglect and trauma of children with intellectual disability in the Hamilton region.

The intent is to recruit four to five qualified social workers with at least three years practice experience of supporting children with intellectual disabilities to deal with abuse, neglect and trauma to participate in individual interviews. The purpose of these individual interviews is to gain a wider understanding of issues and challenges from these front-line social workers who are supporting this cohort of children and to investigate what best practices are to support better service provision.

I would appreciate it if you would place the enclosed advertisement in areas accessible to social workers in your organisation.

Nga mihi

Kim Simpson

Project Contacts
If you have further questions regarding this research, you can contact me or my research supervisors.

Student Researcher	Research Supervisor	Research Supervisor
Kim Simpson Mob: Email:	Dr. Polly Yeung School of Social Work Massey University Palmerston North 06 356 9099 xtn 83514 p.yeung@massey.ac.nz	Professor Robyn Munford Practice Research and Professional Development Hub Massey University Palmerston North 06 356 9099 xtn 83513 r.munford@massey.ac.nz

Appendix I: Advertisement Non-Government Organisations

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA

Advertisement Non-Government Organisations

My name is Kim Simpson and I am a Master of Social Work student at Massey University, Palmerston North.

As part of my study, I am undertaking a research thesis about New Zealand social workers' responses to abuse, neglect and trauma of children with intellectual disability.

Participation will involve one interview of approximately an hour at a mutually agreed time and place. Participation is voluntary and all of your identifiable details will be kept confidential.

If you are a qualified social worker in the Waikato area with at least three years practice experience of supporting children with intellectual disabilities to deal with abuse, neglect and trauma and would like to share your perspectives and experiences in this area, I would like to invite you to participate in this research.

If you are interested in participating or want to find out more information, please contact:

Kim Simpson

[redacted]

Appendix J: Letter requesting permission ANZASW – One to One Interviews

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA

Letter requesting permission ANZASW

One to One Interviews

Kia ora/Greetings

My name is Kim Simpson and I am currently studying towards the Master of Social Work through the School of Social Work, Massey University, Palmerston North.

As part of my study, I am undertaking a research thesis about New Zealand social workers' responses to abuse, neglect and trauma of children with intellectual disability in the Hamilton region.

The intent is to recruit four to five qualified social workers in the Waikato area with at least three years practice experience of supporting children with intellectual disabilities to deal with abuse, neglect and trauma to understand their perspectives and experiences working as a front-line social worker.

I would appreciate it if you would place the enclosed advertisement on your website and/or your newsletter and other communication media for social workers to access.

Nga mihi

Kim Simpson

Project Contacts
If you have further questions regarding this research, you can contact me or my research supervisors.

Student Researcher	Research Supervisor	Research Supervisor
Kim Simpson Mob: Email:	Dr. Polly Yeung School of Social Work Massey University Palmerston North 06 356 9099 xtn 83514 p.yeung@massey.ac.nz	Professor Robyn Munford Practice Research and Professional Development Hub Massey University Palmerston North 06 356 9099 xtn 83513 r.munford@massey.ac.nz

Appendix K: Advertisement Aotearoa New Zealand Association of Social Workers

Advertisement Aotearoa New Zealand Association of Social Workers

My name is Kim Simpson and I am a Master of Social Work student at Massey University, Palmerston North.

As part of my study, I am undertaking a research thesis about New Zealand social workers' responses to abuse, neglect and trauma of children with intellectual disability.

Participation will involve one interview of approximately one to one and half hours at a time and place convenient to you. Participation is voluntary and all of your identifiable details will be kept confidential.

If you are a qualified social worker in the Waikato area with at least three years practice experience of supporting children with intellectual disabilities to deal with abuse, neglect and trauma and would like to share your perspectives and experiences supporting this group of children, I would like to invite you to participate in this research.

If you are interested in participating or want to find out more information, please contact:

Kim Simpson

[redacted]

Appendix L: New Zealand Social Workers Response to Abuse, Neglect and Trauma and Children with Intellectual Disability - Authority for the Release of Transcripts

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

COLLEGE OF HEALTH
TE KURA HAUORA TANGATA

New Zealand Social Workers Response to Abuse, Neglect and Trauma and Children with Intellectual Disability

AUTHORITY FOR THE RELEASE OF TRANSCRIPTS

I confirm that I have had the opportunity to read and amend the transcript of the interview(s) conducted with me.

I agree that the edited transcript and extracts from this may be used in reports and publications arising from the research.

Signature: .... **Date:** ....

Full Name - printed ....

Appendix M: New Zealand Professionals Response to Abuse, Neglect and Trauma and Children with Intellectual Disability – Authority for the Release of Transcripts

New Zealand Professionals Response to Abuse, Neglect and Trauma and Children with Intellectual Disability

AUTHORITY FOR THE RELEASE OF TRANSCRIPTS

I confirm that I have had the opportunity to read and amend the transcript of the interview(s) conducted with me.

I agree that the edited transcript and extracts from this may be used in reports and publications arising from the research.

Signature: .... **Date:** ....

Full Name - printed ....

Appendix N: New Zealand Social Workers Response to Abuse, Neglect and Trauma of Children with Intellectual Disability - One to one Interview – Schedule

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA

New Zealand Social Workers Response to Abuse, Neglect and Trauma of Children with Intellectual Disability

One to one Interview

Researcher's welcome and introduction of self, along with instructions for the participant

Thank you for participating in this interview today and I would like to acknowledge the time you have put aside for this, it is much appreciated

Researcher background shared

Setup of ground rules and protocol

- Every answer is important, there is no right or wrong way to answer
- If you wish to take a break, please say so and feel free to leave for a few minutes.
- Do you have any questions?
- I would appreciate it if you could share a little about your professional background, how long you have been practicing as a social worker, what fields you have worked in and your current role?

Guiding Aims and Checklist

Explore how professionals identify disabled children who are at risk of abuse, neglect and trauma

- As a frontline social worker, how do you identify if an ordinary child is at risk of abuse, neglect and trauma?
- As a frontline social worker, how do you identify if a child with an intellectual disability is at risk of abuse, neglect and trauma?
- Reflecting on these answers what is the difference, if any? In how you identify this.
- How confident do you feel in building a relationship with a child with an intellectual disability? How are you are supported to do this/training etc.
- If a child you are working with is non-verbal, has complex needs and or behavioural, how would you go about assessing this child, how do you ensure their voice is heard?
- What is your understanding of family dynamics when working with a family who has a child with intellectual disability?

Identify interventions and strategies used by professionals and their services to support children with intellectual disability who are at risk of abuse, neglect and trauma

- What interventions and strategies have you found have been effective in supporting this group of children? How successful have they been?
- What barriers have you encountered that impede the effectiveness of these interventions and solution used? Can you give me an example?

Examine strengths and challenges in service provision in supporting disabled children at risk of abuse, neglect and trauma

- What examples of strengths and challenges in service provision that you are aware of or have direct experience of that you can share?
- What gaps are there in services for children with intellectual disability who have experienced abuse, neglect and trauma?
- What do you think is best practice to enhance service provision when working with this group of children?

Explore what professional development enables social workers to be equipped and well supported when working with children with intellectual disability who have experienced abuse, neglect and trauma.

- What knowledge did you have about intellectual disability when you started working with this group of children?
- What ongoing professional development do you think is needed?
- What recommendations would you make to the education, service and government sectors to ensure that social workers receive the knowledge and support they need to respond to this group of children.

Identify what professional support social workers receive to maintain their well-being in the workplace while working with this group of children, with the intent to minimise compassion fatigue and vicarious trauma.

- What professional support do you receive in the workplace while working with this group of children? Tell me your experiences.

After sharing your experiences today has there been anything that you think has been missed? If after leaving you would regret not sharing? Or would like to share separately?

Conclusion

- Thank you for participating, I really appreciate the time you have taken today to share your valuable knowledge and experience.
    - A transcript of the notes will be provided to you for your feedback.

Appendix O: New Zealand Social Workers Responses to Abuse, Neglect and Trauma of Children with Intellectual Disability – Participant Consent Form

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA

New Zealand Social Workers Responses to Abuse, Neglect and Trauma of Children with Intellectual Disability

PARTICIPANT CONSENT FORM

I have read, or have had read to me in my first language, and I understand the Information Sheet provided. I have had the details of the study explained to me, any questions I had have been answered to my satisfaction, and I understand that I may ask further questions at any time. I have been given sufficient time to consider whether to participate in this study and I understand participation is voluntary and that I may withdraw from the study at any time.

1. I agree/do not agree to the interview being sound recorded.
2. I wish/do not wish to have my recordings returned to me.
3. I agree to participate in this study under the conditions set out in the Information Sheet.

Declaration by Participant:

I ___________ [print full name]__________ hereby consent to take part in this study.

Signature: _______________________ Date: ________________