School of Population Health

Harmed at Home:
The Maltreatment of People with Intellectual Disability
by a Family Member

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Declaration

To the best of my knowledge and belief this thesis contains no material previously published by any other person except where due acknowledgment has been made.

This thesis contains no material which has been accepted for the award of any other degree or diploma in any university.

Human Ethics The research presented and reported in this thesis was conducted in accordance with the National Health and Medical Research Council National Statement on Ethical Conduct in Human Research (2007) – updated March 2014. The proposed research study received human research ethics approval from the Curtin University Human Research Ethics Committee (EC00262), Approval Number HRE2021-0579.

Signature: J. Keeley

Date: 24/06/2024

Abstract

Maltreatment of people with intellectual disability is a significant community issue. People with intellectual disability are more likely to be maltreated and to experience more complex and severe forms of maltreatment than people without intellectual disability. Neglect is a prevalent form of maltreatment that is especially difficult to recognise. The consequences of maltreatment and neglect can be severe, wide-ranging, and long-lasting. Familial maltreatment can be difficult to identify limiting intervention and prevention opportunities. The aim of the research presented herein was to investigate the maltreatment of people with intellectual disability by family, particularly in relation to surrounding public perceptions. Public perceptions are an important source of information about how social issues are created, endure, and can be changed. This research is enhanced by the involvement of two people with intellectual disability who were consulted as lived experience collaborators throughout the process and contributed to many development and design aspects across the four studies. It was a privilege to work with these individuals and the research is much more relevant to people with intellectual disability because of their time and efforts.

The first study is a scoping review that summarised current literature on the maltreatment of people with intellectual disability by family members. This study aimed to summarise what is known about familial maltreatment experienced by people with intellectual disability. Four databases were searched for key terms in research published between 2006 and 2024. Forty-three studies met the inclusion criteria and were analysed through a process of inductive coding. Findings were presented in the following categories: descriptions of the different types of maltreatment; victim-survivor, perpetrator, and environmental factors that precipitate maltreatment; how responsibility is assigned; how the perpetrators and the community react to maltreatment; and how maltreatment is concealed and disclosed. Systematically compiling and summarising recent and relevant literature

provided a valuable foundation for the subsequent three studies within the PhD research project and makes an important contribution to literature on an under-research topic.

The second study (published in *Disability and Society;* Keeley et al., 2023a) explored how the Australian news media frames the neglect of people with intellectual disability. This study aimed to explore how the Australian news media frames the neglect of people with intellectual disability by family members. Two databases were searched for Australian news articles published between 2016 and 2021 and, after applying the inclusion criteria 27 articles were included in the analysis. Most of the articles addressed a single case of neglect that resulted in the death of a 4-year-old girl with Down syndrome. A Foucauldian discourse analysis was conducted resulting in four discourses: including a Criminal Justice and Law Enforcement discourse (i.e., perpetrator responsibility), a Political discourse (i.e., government responsibility), a Medical discourse (i.e., focused on physical outcomes), and a Graphic discourse (i.e., emphasising gruesome information). Additionally, three subject positions were identified that constructed people with Down syndrome as different to people without, inherently vulnerable to maltreatment, and suffering was barely considered. The neglect of people with intellectual disability is rarely covered in the Australian news media; however, the narratives presented can be harmful and limit opportunities for those so-labelled to participate equally in society.

The third study (published in *Children and Youth Services Review*; Keeley et al., 2023b) compared participant responses to potentially neglectful parenting scenarios involving children with and without intellectual disability. This study investigated the participant factors (i.e., age, gender, parental status, contact with people with intellectual disability) that influence perceptions of neglect of children with and without intellectual disability. Perceptions of severity, perpetrator and victim-survivor responsibility, future mental and physical health outcomes for the victim-survivor, and perpetrator intentionality were also

examined. Further, perceptions of severity of the different subtypes of neglect (i.e., lack of supervision, lack of providing, emotional neglect, educational neglect) were compared. Participants residing in Australia were recruited through Prolific (*N* = 399) and presented with 10 vignettes of potentially neglectful parenting scenarios followed by 6 Likert-scale items, five short answer questions, and demographic questions. Child intellectual disability was not found to impact perceptions of child neglect, but participant gender was influential (i.e., women rated neglect more severely than did men). Lack of supervision was rated the most severe subtype of neglect and lack of providing as the least. The context of neglect was reported as important in the qualitative responses. The public may perceive the neglect of children with and without intellectual disability as equally averse and gender may influence neglect identification in real world settings.

The fourth and final study was based on a community dialogue involving the meaningful dissemination and discussion of the findings from the other studies in the research project with a small group of people with intellectual disability. This study aimed to first present the findings of the research to people with intellectual disability in an accessible way and second to explore how people with intellectual disability understand the familial maltreatment of those so labelled within the context of the PhD research and more broadly. Primarily, this process sought to share and confirm the research conducted within this PhD with people with intellectual disability. Six adults with intellectual disability were involved in the dissemination phase and four in the interview phase. A conventional content analysis was conducted and findings demonstrated an awareness of negative social narratives and ideas about people with intellectual disability, criticism of maltreatment, and an appreciation for family. The perspectives of people with intellectual disability on this research provides additional and essential insights to the PhD findings and the subject more broadly.

Familial maltreatment is a significant social problem in terms of prevalence and the impact it has on the lives of people with intellectual disability, making this topic an important topic of investigation. Understanding public perceptions of the familial maltreatment of people with intellectual disability is significant because they impact identification, intervention, and prevention. Novel findings from this PhD include that people with intellectual disability are often ascribed to be of less value, parental responsibility for maltreatment of people with intellectual disability is diminished, and gender is an influential factor in perceptions of the perpetration of neglect, neglect severity, and maltreatment outcomes. The findings of this research can inform policy and practice that shifts social narratives to change perceptions and improve how people with intellectual disability access their human rights within the context of familial maltreatment.

Acknowledgement of Country

I would like to show my respect and acknowledge the Whadjuk Noongar people who are the traditional custodians of the land on which this research was conducted. I would also like to honour and pay my respects to Elders past and present. I acknowledge the stories, traditions, and living cultures of Aboriginal and Torres Strait Islander peoples across Australia.

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List of Conference Presentations

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Keeley, J., Mancini, V. O., Castell, E., & Breen, L. J. (November, 2021). *Familial neglect of people with intellectual disability: A media analysis*. Presented a poster at the Child Health Research Symposium, Perth, Australia.

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List of Publications

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List of Abbreviations

ABS	Australian Bureau of Statistics
AIHW	Australian Institute of Health and Welfare
CID	Council for Intellectual Disability
FDA	Foucauldian Discourse Analysis
NDIS	National Disability Insurance Scheme
PRISMA-ScR	Preferred Reporting Items for Systematic Reviews and Meta-Analysis Extension for Scoping Reviews
PWDA	People with Disabilities Australia
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities

Chapter 1: Introduction

1.1 Chapter Overview

This chapter introduces the topic of maltreatment of people with intellectual disability by family members and each of the components of the research project. Key terms are explored, and the research is positioned within the context of several models of disability that have presented shifting lenses through which disability is and has been understood and researched. The literature review defines important terms, examines risk and rates, as well as the impacts and outcomes of maltreatment on people with intellectual disability. Additionally, social barriers and family member perpetrators are discussed. The remainder of the chapter includes an overview of the thesis including topic conceptualisation, lived experience collaborators information, the Australian and international context that rationalises the research project, the research aims and objectives, the structure of the thesis, and finally a discussion of ethical considerations.

1.2 Literature Review

Maltreatment of adults and children with intellectual disability is a significant and complex worldwide social and health issue (Dion et al., 2018; Hewitt, 2013; McDonnell et al., 2019). Maltreatment is a broad term encompassing violence, abuse, and neglect experienced by people (in this context) with intellectual disability (Hewitt, 2013; Jones et al., 2012). The content of this literature review includes maltreatment that affects both children and adults. Data is presented thematically and not separated into child and adult literature. There are several reasons for this. First, there is limited literature that specifically addresses the maltreatment of people with intellectual disability by a family member and therefore combining this information was considered necessary to present a cohesive narrative. Second, because much of the literature could not be readily divided into the distinct categories of child or adult because it encompasses the experiences throughout life. For example, there are studies where adults with intellectual disability describe experience of abuse across their lifespan, including during childhood (e.g., Eastgate, 2011; Hewitt, 2013). Thus, to avoid redundancy and provide optimal flow in presenting the background to and rationale for the studies presented in this thesis, literature is synthesised according to topic and not by the categories of child and adult. However, where possible and meaningful, the literature is identified as referring to children or adults with intellectual disability.

1.2.1 Defining and Labelling 'Intellectual Disability'

All people with intellectual disability are unique and have a range of skills and abilities. Intellectual disability impacts an individual's intellectual functioning and behaviour and can result in some challenges (e.g., problem solving and communication difficulties). Like many people without intellectual disability, people with intellectual disability may require support from friends, family, and organisations to assist them in areas such as navigating government systems, managing money, socialising, and in daily tasks including independent living (Inclusion Australia, n.d.). However, people with intellectual disability experience barriers that restrict equal and full social participation (United Nations Convention on the Rights of Persons with Disabilities [UNCRPD], 2006). People with intellectual disability have the right to be treated equally and live life in the way they choose (UNCRPD, 2006). Applying labels such as 'intellectual disability' can be problematic and harmful; despite the potential for harms, this term is considered best practice in Australia (Inclusion Australia, n.d.) and is the term used herein.

1.2.2 Neglect

Neglect is a common and particularly insidious form of maltreatment. In Australia, neglect is the second most common type of child abuse (i.e., 18% of child abuse cases) and often coincides with other forms of maltreatment (37% of child abuse cases; Australian Institute of Health and Welfare [AIHW], 2019a). Children with intellectual disability are additionally significantly more likely to experience neglect compared to those without (Maclean et al., 2017; Paquette et al., 2018).

The definition of neglect includes the deprivation of physical and psychological necessities and rights including food, education, attention, and medical care (Jones et al., 2012; Royal Commission, n.d.). It can involve behaviours that are active and passive and may be intentional or unintentional (Robinson & Chenoweth, 2012). For example, a child who is hungry and malnourished may have been neglected actively and purposefully (e.g., a parent withholds food on purpose) or passively and unintentionally (e.g., a parent either does not have access to food or is not aware of the child's dietary needs).

Additionally, neglect can be divided into subtypes. Barnett et al. (1993 as cited in Goodvin et al., 2007) proposed four subtypes comprising inadequate supervision (e.g., a parent leaves a young child at home for long periods of time), emotional neglect (e.g., a parent does not give their child affection or attention), educational neglect (e.g., a parent does not ensure or encourage their child to attend school), and inability to provide (e.g., a parent being unable to provide adequate clothing for their child). However, some researchers exclude poverty-related or material neglect from their definition of neglect and instead only include behaviours that are purposeful, whether active or passive in nature (Lev-Wiesel & Massrawa, 2020; Turner et al., 2019).

Identifying and intervening in situations of neglect can be particularly challenging as neglect is an ambiguous concept with differing definitions. This lack of classification consistency may contribute to research difficulties that result in the topic being under-researched (Jones et al., 2012; Stoltenborgh et al., 2013). Consequently, there is limited evidence-based information about neglect available to the public. As a result, the public and even victim-survivors themselves have been shown to have difficulty recognising neglectful behaviours and experiences (Lavi & Katz, 2016; Son et al., 2017).

1.2.3 Risks and Rates of Maltreatment

Rates of maltreatment are extremely high for people with intellectual disability. Children with intellectual disability are overrepresented in child protection research and research often finds that intellectual disability is a risk factor for abuse (Águila-Otero et al., 2020; Christofferson, 2022). Systematic reviews of the literature have found that 21% of children with intellectual disability have been maltreated (physical and sexual violence; Jones et al., 2012) and 6.1% of adults have been maltreated within the last year (Hughes et al., 2012). In Australia, it is reported that 14.3% or 1 in 7 adults with intellectual disability have experienced threats or actual violence in the last year (Australian Bureau of Statistics [ABS], 2018).

People with intellectual disability experience maltreatment at higher rates than those without intellectual disability (Hughes et al., 2012; Maclean et al., 2017). A study of maltreatment prevalence in 4988 children in the USA found that compared to the control group (with no reported disability) children with intellectual disability were 2.5 times more likely to have been maltreated and have significantly more allegations and substantiations of maltreatment (McDonnell et al., 2019). Research also demonstrates that children with intellectual disability experience a higher risk of experiencing maltreatment than people with disabilities other than intellectual disability (Brendli et al., 2022; Maclean et al., 2017). Further, a systematic review found that adults with intellectual disability were 1.6 times more likely to experience violence than people without an intellectual disability (Hughes et al., 2012).

There are several factors that can additionally increase maltreatment risk for people with intellectual disability. For example, a large population-based record-linkage study from Western Australia found that children with less severe intellectual disability were significantly more likely to experience maltreatment than children with more severe intellectual disability (Maclean et al., 2017). Maclean et al. (2017) suggested that this may be due to the severity influencing parental expectations of their child's behaviour (e.g., parents may not expect or request that children with severe intellectual disability do household chores and therefore avoid arguments if they are not completed) and the child's capacity to be confrontational (e.g., child with severe intellectual disability may be less likely to argue with parents). However, these rates may also be influenced by communication difficulties that can impact disclosure and are discussed below. Gender is another factor that influences rates of maltreatment for people with intellectual disability, with women being significantly more likely to be affected than men (Hewitt, 2013). The types of maltreatment experienced by children with intellectual disability is also influenced by gender, with girls being more likely to experience verbal abuse than boys and boys being more likely to experience physical abuse than girls (Thomas et al., 2014). Further, people with intellectual disability who identify as LGBTQA+ appear to be more likely to experience abuse and violence than those without. In a study from Australia including people who identified as LGBTQA+ it was found that harassment and abuse was more common for people with intellectual disability (verbal 73.0%, physical 29.0%, sexual 44.5%) compared to those who did not have a disability (verbal 51.3%, physical 12.1%, sexual 23.3%; Hill et al., 2022).

Children with intellectual disability have been shown to experience more complex, severe, and multifaceted maltreatment than children without intellectual disability (McDonnell et al., 2019). Children with intellectual disability tend to have more cases of maltreatment involving multiple forms compared to children without disability (McDonnell et al., 2019). Further, some research suggests that people with intellectual disability can experience more severe forms of maltreatment. For example, compared to children without, children with intellectual disability have been shown to experience more severe emotional neglect (50% compared to 23%; Weiss et al., 2011). Additionally, some forms of maltreatment are related to experiencing other forms. For example, children with intellectual disability who experience physical and emotional abuse are more likely to experience other forms of maltreatment including sexual abuse and witnessing family violence (Catani & Sossalla, 2015). The heightened risk for maltreatment experienced by people with intellectual disability is additionally problematic due to the significant impacts it can have.

1.2.4 Impacts and Outcomes

Experiences of maltreatment can have significant and long-lasting impacts on many aspects of the lives of people with intellectual disability (Hughes et al., 2019; Rowsell et al., 2013). Psychological impacts can include depression, post-traumatic stress disorder (PTSD), and deficits in psychological functioning (e.g., angry outbursts, difficulties remaining focussed; Hughes et al., 2019; Rowsell et al., 2013). Experiences of maltreatment are also associated with physical outcomes such as an increased risk of health conditions including sleep problems, diabetes, and heart disease (Hughes et al., 2019).

Relationships can also be affected by being maltreated. For example, people with intellectual disability who have been sexual abused in childhood are more likely to experience intimate partner violence in adulthood (Catani & Sossalla, 2015). Additionally, experiences of maltreatment are linked to people with intellectual disability (and people without; Bartlett et al., 2017) becoming perpetrators of maltreatment themselves (Weiss et al., 2011; Lindsay et al., 2012).

Maltreatment of people with intellectual disability can also result in death (Manthorpe & Martineau, 2015). Examples of cases in the literature include a father tranquilising and then strangling his young son intellectual disability (Declercq et al., 2017), a mother tranquilising and then smothering her adult son with Down Syndrome (Brown, 2012), and a father poisoning his teenage daughter with intellectual disability (Coorg & Tournay, 2012).

1.2.5 Social Perceptions and Barriers to Disclosure and Support

A fundamental step in addressing maltreatment is disclosure; however, people with intellectual disability experience social barriers that can be obstructive. Disability and non-disability professionals have been shown to have a poor understanding of maltreatment and be unable to provide appropriate support for people with intellectual disability who have experienced maltreatment (Fraser-Barbour, 2018; Fyson & Patterson, 2020). Opportunities for effective support of people with intellectual disability are additionally hindered due to inaccurate and negative social perceptions about people with intellectual disability. For example, in relation to sexual abuse, professionals have been shown to believe that people with intellectual disability are unable to have meaningful romantic relationships, or provide an accurate witness account, as well as being promiscuous and having a heightened sex drive (Fraser-Barbour, 2018; McGilloway et al., 2020; Phasha & Myaka, 2014). These perceptions influence responses to sexual abuse of people with intellectual disability and may lead to cases being minimised and inadequate support being provided (Fraser-Barbour, 2018; Phasha, 2009). When reporting sexual abuse people with intellectual disability have indicated that they were afraid of being blamed, of not believed, of perpetrator repercussions, and the restriction of their freedoms (McGilloway et al., 2020). Further, children with intellectual disability have reported that they could only disclose experiences of abuse to a trusted person (Centre for Evidence and Implementation & Monash University, 2021). It is therefore unsurprising that compared to those without, people with intellectual disability are significantly less likely to report sexual abuse (Soylu et al., 2013).

When maltreatment of people with intellectual disability is disclosed, it may be harder to substantiate than maltreatment of people without intellectual disability. Child protection research found that children with intellectual disability had an increased risk of neglect allegations but not substantiation (De La Sablonnière-Griffin et al., 2021). The authors suggest that communication and social challenges may account for the lack of substantiations that consequently prevent opportunities for intervention (De La Sablonnière-Griffin et al., 2021). People with intellectual disability can experience communication differences but research suggested that these are often not taken into consideration or accounted for during the process of addressing maltreatment (McGilloway et al., 2020). This lack of understanding by those around the victim-survivor with an intellectual disability may result in the continuation of maltreatment and its subsequent harms (Dion et al., 2018).

Effective interventions for the prevention, identification, and early intervention of maltreatment of people with intellectual disability are needed. A scoping review on strategies to prevent violence towards adults with intellectual disability found evidence for the effectiveness of interventions was limited and based on small studies (Araten-Bergman & Bigby, 2023). Further, while people with mild to moderate intellectual disability were shown to develop protective skills, the interventions tended to address the skills and knowledge of adults with intellectual disability and not the social and environmental context of abuse (Araten-Bergman & Bigby, 2023). In research evaluating what is needed for the implementation of a school-based abuse prevention program, Nyberg et al.'s (2021) findings included the need to address poor public knowledge of abuse and teacher reporting confidence. More research is needed to develop interventions and determine their efficacy.

1.2.6 Family Members as Perpetrators

Maltreatment within the family may present a specific risk for people with intellectual disability. Some research suggests that family members maltreat people with intellectual disability more than other perpetrators such as acquaintances or institution staff (Hewitt, 2013; McDonnell et al., 2019; Vadysinghe et al., 2017; Van Horne, 2014). Additionally, research has demonstrated that people with intellectual disability can be maltreated by family members more than people without intellectual disability (Dion et al., 2018; McDonnell et al., 2019). However, these findings are not consistent across the literature. Further, people with intellectual disability who are maltreated at home are additionally more likely to experience maltreatment within institutions (Catani & Sossalla, 2015).

Identification and intervention of familial maltreatment is particularly difficult. Families lack the systematic procedures enforced by formal institutions that are designed to identify and prevent maltreatment such as the requirement of a working with children check (Working with Children Act, 2004)[1]. The literature suggests reasons how and why families may conceal familial maltreatment of people with intellectual disability. For example, family members may have unsupervised access to a person with intellectual disability in the home and they may isolate the victim-survivor or manipulate their existing relationship to maintain secrecy (Meer & Combrinck, 2017). Maltreatment within the family may also be considered a matter to be dealt with within the family to preserve secrecy and in some instances to ensure financial security (e.g., maintain disability pension and perpetrator income; Phasha, 2009).

Additionally, people outside the family have been shown to be reluctant to report suspected maltreatment. Mallén (2011) found that disability support staff were reluctant to report maltreatment of a child with disability when they had good rapport with the family. This suggests that the experience of the perpetrating family members is considered and appreciated above that of the victim-survivor with the intellectual disability. Maltreatment may continue because of these factors that restrict opportunities for intervention.

The impact of the social perceptions discussed above are additionally evident in public and legal responses to the deaths of people with intellectual disability that result from familial maltreatment. Sentencing leniency is demonstrated in a review of six cases where

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[1] Note that requirements such as working with children checks are not foolproof. See https://www.theguardian.com/australia-news/2023/aug/01/calls-for-stronger-childcare-training-after-queensland-man-charged-with-more-than-1600-child-abuse-offences

parents have killed their children with disability in the UK when only one case resulted in jail time (five years, one parent was deceased; Brown, 2012). A mock jury study from the USA found that participants gave a father who killed an infant with intellectual disability significantly shorter sentences than a father who killed an infant without (Bottoms et al., 2011). This suggests that the killing of an infant with intellectual disability was considered a less serious crime, deserving a lesser punishment than the killing of an infant without. A review of sentencing remarks of 10 cases of domestic homicide cases involving victims with disability in Australia found that the deaths were portrayed as an inevitable reaction to the profound burden of caring for people with disability (Sullivan, 2017). The media also contributes to this devaluation when it places focus on the victims rather than the perpetrators when reporting on the deaths of people with disability (Brown, 2012). The responsibility of the perpetrating family members is diminished when people with intellectual disability are framed in this way and reinforces a social narrative that the lives and deaths of people with intellectual disability have little value.

1.2.7 Literature on the Maltreatment of People with Intellectual Disability by Family Members

There is limited research that specifically addresses the maltreatment of people with intellectual disability especially that which occurs in the home (De La Sablonnière-Griffin et al., 2021; Royal 2021; Dion et al., 2018; Paquette et al., 2018). There are several potential explanations for this dearth. First, research may be restricted by difficulties in identifying maltreatment of people with intellectual disability (especially within the family) as discussed above. Second, research may not specifically identify family members as perpetrators (e.g., Simmel & Shpiegel, 2013; Wolf et al., 2018). Third, data may include all people with disability and not specifically people with intellectual disability (e.g., Octoman et al., 2022; Royal Commission, 2020a). The lack of differentiation between people with intellectual disability and people with other disabilities is also demonstrated in policy. For example, Bigby (2020) found that the absence of differentiation in Australia's National Disability Insurance Scheme (NDIS), which provides funding to eligible people with disability so that their participation in society is optimised, was detrimental to adults with intellectual disability (e.g., no specific provision for supported decision making in initial stages of engagement). The need for more research in this area that specifically addressed this area is demonstrated in the literature (discussed above) that describes how people with intellectual disability experience high rates of maltreatment that is often perpetrated by family.

1.2.8 Summary of the Background Literature

In summary, many children and adults with intellectual disability around the world are affected by maltreatment. Neglect is a form of maltreatment that is particularly harmful and invisible. People with intellectual disability are more likely to be maltreated than people without. The impact of maltreatment on people with intellectual disability can be substantial and enduring. Negative social perceptions create barriers that restrict how people with intellectual disability report and access support for maltreatment. People with intellectual disability may be more likely to be maltreated by family members than other perpetrators and people without intellectual disability.

1.3 Thesis Overview

1.3.1 Origin Story

The idea for the topic of this PhD first arose in 2018 while conducting my Bachelor of Psychology (Honours) project on how the Australian news media frames people with intellectual disability in relation to psychotropic medications. I came across a news article describing an elderly couple who had killed themselves after killing their son with physical and intellectual disabilities. The son was framed as imposing burden on his parents, and the parents were portrayed as victims of their son's disability. Near the end of the article, the authors describe the son’s appearance, listing his disabilities and deformities seemingly for the purpose of emphasising that he was ugly and difficult. Within the narrative, the son’s disability appeared to be used to rationalise and even justify his murder. It seemed that the framing of this article demonstrated a lack of value for the lives (and deaths) of people with intellectual disability that on closer inspection was evident throughout society.

I have grown up around people with disability in that I have several cousins with physical and intellectual disability. Additionally, many of my family members have worked in different areas within disability services. Consequently, I have some outsider understanding of the practical and emotional experiences of people with disability and their families. However, before my supervisor (Dr Emily Castell) suggested that I study psychotropic medications and people with intellectual disability for my honours project, I had not critically or academically considered the social factors that can impact the lives of people with disability. I decided I would do so in my PhD and chose to focus on maltreatment of people with intellectual disability that occurs within the family, with specific attention on public perspectives and their influence on outcomes.

I therefore conducted this research from a social constructionist epistemological position. This perspective assumes that what we understand as the ‘truth’ of the world is constructed through ongoing and reinforced social practices that are interpreted through a lens rather than a reflection of reality (Gergen, 1985). From this positioning the notion that disability is tragic is rejected and instead disability is considered a social construction in that it is the result of social and environmental barriers that are hostile to impairment, (Oliver, 1983), and oppressive (Anastasiou & Kauffman, 2011). In this PhD I am interested in social understandings of familial maltreatment of people with intellectual disability and aim to explore, unpack, and challenge these.

1.3.2 Lived Experience Collaborators

From the beginning of this PhD project, it was important to me and my supervisors that the research be conducted *with* and not *on* people with intellectual disability. I do not identify as having a disability and therefore cannot understand this experience nor interpret the research problem through the lens of lived experience. Below, inclusive research and principles are introduced and discussed within the context of this research. Then the processes and outcomes of engaging the lived experience collaborators are explored.

1.3.2.1 Inclusive Research.

Inclusive research is a pursuit involving the collaboration of different perspectives to think and learn together (Nind & Vinha, 2014). ‘Nothing about us, without us’ is a movement that arose from the social model (discussed below) that stipulates the need to include people with disability in research that addresses factors that affect the lives of those so-labelled (Charlton, 2000). Australia’s National Disability Research and Development Agenda (2011) describes the need to improve training for researchers and people with disability to best support the involvement of people with disability in research.

Bigby et al. (2014) categorised the different types of inclusive research with people with intellectual disability into three groups based on an extensive search of the literature and their own experiences. These are:

1. Advisory: People with intellectual disability are consulted on particular matters but do not lead, control, or determine the overall purpose of the research.
2. Leading and controlling: People with intellectual disability are involved throughout the project, have control, and determine the purpose of the research.

3. Collaborative: People with intellectual disability are involved throughout the project but while researchers without disability take lead, control is share by the group.

In a review of recent research that included the involvement of people with disability, Jones et al. (2020) found that most studies employed an advisory approach to inclusive design (compared to Leadership and Control and Collaborative Group) and researchers generally achieved their intended level of inclusion research. However, they also reported that people with severe intellectual disability were rarely consulted, highlighting the absence of this perspective in the literature.

Nind and Vinha (2014) present a model for researchers with and without disability to work together. At the core of the model is support (researchers with disability are the decision makers who are supported by those without disability), negotiation (researchers with and without disability negotiate power), and interdependency (all researchers are treated and valued equally). Adjacent to these core concepts are two opposing yet related ways of working – formalised (planned and structured ways of working) and improvised (responding to situations at the time). Different research teams may emphasise different concepts and ways of working and the focus may change throughout the research process.

While inclusive research is a celebrated way of conducting research and is often required for funding, there are also significant associated challenges. Bigby and Frawley (2010) detailed some of the challenges they experienced conducting inclusive research, such as, difficulties achieving genuine inclusion and managing expectations of the role of the individual with intellectual disability. Achieving genuine inclusion in the research was also noted as difficult because of the necessity to plan and propose research to secure funding. Bigby and Frawley (2010) state that this made it impossible for the co-researcher with intellectual disability to be involved in the conceptualisation and design of the research. Additional challenges included managing the expectations of the co-researcher's role throughout the process and consideration of the notion of ‘experts by experience’. The researchers questioned whether a co-researcher with mild-intellectual disability could represent people with severe intellectual disability better than the researchers without disability (Bigby & Frawley, 2010).

Povee et al. (2014) also critically reflected on the challenges they experienced in conducting inclusive research. They considered issues such as the ongoing challenge of informed consent, the unequal benefits afforded to the researcher (compared to the people with intellectual disability involved), and the stereotypes that shaped interactions (e.g., people with intellectual disability are happy, child-like, and incompetent).

The type of inclusive research conducted in this PhD can best be described as advisory. In advisory research people with intellectual disability are asked to review content, make recommendations, advise on directions for research, and address specific questions around design, recruitment, data collection, and dissemination (Bigby et al., 2014). This type of inclusive research is beneficial to the research and may offer benefits to the individuals with intellectual disability involved (Bigby et al., 2014). For example, the research is improved by becoming more relevant due to the inclusion of the perspective of people with intellectual disability and people with intellectual disability may benefit from gaining skills and receiving reimbursement or being employed (Bigby et al., 2014). However, in advisory research individuals with intellectual disability have no control over the level or uptake of their contribution and involvement can be tokenistic when not properly carried out (Bigby et al., 2014). The success of this research in achieving the intended level of inclusion is reflected on in the Strengths and Limitations section in Chapter 6.

1.3.2.2 Recruitment.

Initial attempts to engage people with intellectual disability were met with many challenges. For example, no applicants applied in two rounds of advertising through a consumer research organisation aligned with the university, a social media campaign, and numerous emails and phone calls to relevant organisations. This was despite extensive research and consultation underpinning the development of the recruitment materials. The expertise of supervisors Dr Emily Castell and Dr Kate Dorozenko (née Povee, supervisor until her parental leave shortly after the approval of my candidacy proposal) were particularly drawn on as they have extensive experience of conducting research with people with intellectual disability. Further, preliminary materials were vetted by a person with intellectual disability and changes were made based on their feedback. See Appendix A for the recruitment advertisement. Eventually a local disability service provider identified several potentially interested individuals, two of whom agreed to be involved in the project.

At the time (to our knowledge) no student in our school (then the School of Psychology) had utilised lived experience collaborators and the university infrastructure available now (e.g., Curtin enAble Institute and its strong emphasis on consumer and community involvement and co-design) was not available for support and direction. As such, the process of developing the role, recruitment, and engagement of lived experience collaborators was a challenge that required extensive consideration and research.

1.3.2.3 Meetings, Contributions, and Benefits.

After consulting with the recruited lived experience collaborators, it was decided that meetings would be arranged over the phone approximately a week before being conducted and would take place face-to-face and one-to-one in each person's home. In preparation for meetings, I would usually send an email containing accessible meeting notes in the form of a Word document and a narrated PowerPoint presentation. An example of one of these documents is available in Appendix B and a list of links to the narrated PowerPoint presentations is available in Appendix C. Providing this information aimed to give members the opportunity to become familiar with the content in ways that were designed to facilitate their engagement in the research; however, individuals were informed that it was not necessary to access this information if they did not wish to. Some meetings were less formal with a narrow scope of discussion and therefore documents and presentations where not deemed necessary. Additional meeting preparation involved consulting Curtin University's 'Site Visit Safety Protocol' and ensuring that I took steps to ensure my own safety while meeting with the lived experience collaborators.

The first meeting involved developing rapport, ensuring that collaborators understood the research and their role in it, and discussing and obtaining informed consent. Generally, when I met with the lived experience collaborators, we discussed the study previously conducted and how this should influence the next. However, due to the extended recruitment period, a meeting with the lived experience collaborators was not possible before the scoping review was conducted. In meetings I provided a brief and accessible summary of the previous studies (where applicable) and we would discuss how the information could shape the subsequent studies.

Rapport with the lived experience collaborators developed significantly over the years of working together. We met in the lived experience collaborator's residence and would discuss the research in a casual and professional manner. Both collaborators become increasing comfortable to provide their perspective, feedback, and ask questions.

The lived experience collaborators made a significant contribution to the direction of this research. After the first study (Chapter 2), which was a scoping review of maltreatment of people with intellectual disability by family members, I asked the lived experience collaborators if they thought that the topic of the research should continue to be maltreatment as a whole or if the focus should shift to a specific type of maltreatment. The scoping review presented in this thesis is an updated version of the one presented to the lived experience collaborators. Although the updated version includes an additional 15 studies, the themes have remained the same. The individuals concluded that the focus should be more specific and identified several types of maltreatment that most warranted further investigation. Neglect was identified by both members as a primary concern and after further discussion it was decided that subsequent studies should address neglect. Consequently, the research benefited from being more relevant to the community it affects as it reflected the concerns of two people with intellectual disability.

The shift in focus to neglect was significant and somewhat unexpected. I had assumed that the lived experience collaborators would be interested in addressing the more violent and visible forms of maltreatment (e.g., sexual or physical abuse). However, I believe that focussing on neglect meant that the research made a more significant contribution to the literature because it focused on a topic that is particularly difficult to identify, define, and research. As another example, after discussing the findings of the media analysis study (Chapter 3) with the lived experience collaborators, both stated that the focus of the subsequent study should remain on neglect but shift from all people with intellectual disability to children exclusively. Consequently, the vignette study (Chapter 4) focussed on perceptions of the neglect of children with intellectual disability.

Additionally, the lived experience collaborators were consulted on the content and design of dissemination and recruitment materials for the community dialogue study (Chapter 5). Some feedback included that the colours needed to ‘pop’ more and that there was too much text on the poster. They approved a subsequent draft (see Appendix D) for use in this study. Throughout the entirety of the project, the lived experience collaborators were financially compensated for their time and expertise.

1.3.2.4 Challenges.

I experienced some challenges while engaging with the lived experience collaborators beyond those outlined above in relation to recruitment. The primary challenge was ensuring the genuine participation of the lived experience collaborators and managing my position of power in the meetings and across the research. In preparation for the meetings, I consulted the literature and found Bigby and Frawley (2010) and Povee et al. (2014) particularly helpful (described above). For example, Bigby and Frawley (2010) included tips written by a co-researcher with intellectual disability for other co-researchers with intellectual disability that were helpful when developing the role and considering the needs of lived experience collaborators. Further, Povee et al. (2014) illustrated the importance of reflecting on the researcher's role and power. Creating an environment where the meetings were guided but not led by me was an ongoing challenge. It was important that the individuals had their say, would be listened to, and felt heard. In an early meeting one of the lived experience collaborators expressed how they felt that they were ignored and that their role was tokenistic in a previous advisory role. I strived to ensure that this would not be the case for the individual in this role and that their perspective would be honoured. Throughout the research process, I discussed and sought advice from the research supervisors, researchers with expertise in participatory research, and reflected in writing about issues of power and participation (example available in Appendix E).

Communication could also be challenging at times. One of the lived experience collaborators did not have their own email address and relied on support staff to relay the information (e.g., online presentation of research findings) and I emailed prior to meetings which often was not passed on. Additionally, I sometimes found it difficult to understand what the lived experience collaborators were saying or meaning and would have to ask them to repeat information which could be frustrating for us both. It could also be a challenge to find a balance between keeping meetings on topic and providing a space where collaborators felt comfortable to speak openly about a variety of topics. Further, the lived experience collaborators did not communicate with me when they became unavailable for an arranged meeting. This was sometimes due to illness, conflicting appointments, or not feeling like engaging in the topic at the time. I would either return to my home office that was approximately a 50-minute drive away from both residences or wait up to an hour. After this occurred, I began to call to confirm appointments the day before but there were still several occasions where I arrived when the lived experience collaborator was no longer available.

1.3.3 Rationale

1.3.3.1 Theoretical Context.

Models of disability change over time and represent different ways of understanding and researching disability. Disability can be understood through a multitude of lenses that shape and are shaped by social attitudes. Disability is historically and generally described as a medical fault that requires fixing through cure or elimination (e.g., via eugenics; Clifton, 2020). When defined medically, disability is positioned within the individual's body as a defect that requires treatment and/or curing (Ellis & Goggin, 2015; Goodley, 2017). A consequence of this understanding is that people can be defined and identified *as* their disability (Ellis & Goggin, 2015; Goodley, 2017). Further, through this medical lens people with disability can be framed as inherently tragic, impacting disempowering social perceptions (Goodley, 2017). The medical model is widely criticised within the discipline of disability studies because it ignores the environmental and social factors that disable those so labelled (Ellis & Goggin, 2015). Disability activism has sought to de-medicalise disability to shift the perceived problem to one that is a matter of social justice (Oliver, 1996).

The social model of disability emerged in Britain in the 1970s in response to this medical conceptualisation of disability and represents a significant shift in how people with disability are perceived (Ellis & Goggin, 2015; Oliver, 1996). The social model rejects the notion that disability is an individual medical problem and instead states that the problem resides in social equality; that is, society *disables* people (Ellis & Goggin, 2015). For example, the issue is not that a person cannot access a building due to functional limitations that prevent them from navigating stairs, it is that society has not considered it necessary to provide a ramp that ensures equal access. The social model has been highly influential in laying the foundation for important social changes such as those instigated by the UNCRPD (2006). Other significant outcomes that have been attributed to the social model include the creation of disability studies and the advancement of self and community advocacy (Clifton, 2020). However, the social model is criticised for focussing too heavily on the social factors and ignoring the experience of impairment that can be challenging and painful (Clifton, 2020; Shakespeare, 1994). Further, the social model can be understood as rejecting medical treatments and advances that may improve and relieve some of these challenges (Clifton, 2020).

Critical disability theory responds to these criticisms by acknowledging the disabling social construction and the challenges associated with impairment (Procknow et al., 2017). Critical disability studies are seen as reflecting the post-modern, complex context that now exists (Ellis & Goggin, 2015). The concept of Ableism emerged from the critical disability theory and posits that disability is incorrectly constructed in opposition to being without disability, as binary, and abnormal (Procknow et al., 2017). This PhD is conducted with a critical disability study lens.

1.3.3.2 International Context.

As discussed in the literature review (section 1.2), people with intellectual disability face a significant risk of maltreatment (Hughes et al., 2012; Jones et al., 2012). The impacts of maltreatment can be numerous, significant, and lasting (Rowsell et al., 2013). Identifying maltreatment that occurs within the family is particularly problematic. Currently, there is little research that directly addresses maltreatment of people with intellectual disability and the family members who perpetrate it. This research is necessary and significant due to the prevalence, impacts, potential invisibility, and lack of research in the area.

1.3.3.3 Australian Context.

1.3.3.3.1 Royal Commission.

In response to enduring community concern about the treatment of people with disability, the Australian Government established a Royal Commission into the violence, abuse, neglect, and exploitation of people with disability in 2019 (Royal Commission, n.d.). The call and commencement of this Royal Commission demonstrated the importance and relevance of maltreatment of people with disability in Australia. The Royal Commission has made a significant impact and continues to influence changes across many facets of Australian society. These impacts extend to the lives of people with disability, awareness of the violence, abuse, neglect, and exploitation experienced by people with disability, policy and practice, and academic enquiry. Some examples of these impacts include:

- Closure of eight disability service organisations that were identified as not performing in the best interests of people with disability thus setting a higher standard of care and protecting people with disability from adverse outcomes in service provision settings (Royal Commission, 2022).
- McPhillips et al. (2020) posits that the Royal Commission makes a significant contribution to the field of trauma studies and understanding more generally by shifting narratives from those that are traditionally biomedical to a more moral, political, and psychological discourse.
- A review into Western Australian juvenile detention laws, processes, and practices is proposed due to the exposure of information regarding the over-representation of and poor conditions experienced by young people with

cognitive disorders and disabilities in criminal justice settings (Royal Commission, 2022).

Although the scope of Royal Commission included maltreatment within the family, the focus initially centred on maltreatment within formal institutions. For example, the Royal Commission’s Interim Report from 2020 states that “Our early work on homes and living has focused on group homes” (Royal Commission, 2020b, p. 399). In response to this identified gap, the Australian National Research Organisation for Women’s Safety (ANROWS) produced a comprehensive report in 2022 including extensive research addressing family and domestic violence experienced by people with disability (Octoman et al., 2022). This report makes a significant contribution to the literature and brings an important issue into focus. However, although informative regarding all children with disability, there is little data that specifically addresses familial maltreatment experienced by children with intellectual disability (e.g., 22% of children with intellectual disability had an allegation of maltreatment reported in the follow up period of the study; Octoman et al., 2022). Additional resources including the ‘Violence and abuse of people with disability in the home’ issue report have also later addressed this topic (Royal Commission, 2020a). However, again there is limited classification between violence and abuse experienced by people with intellectual disability and those with disabilities other than intellectual.

Families are the largest institution of care (Breen, 2009), with the vast majority (82%) of people with a disability in Australia living at home (ABS, 2014). Although it is often assumed that families should be responsible for and are the ideal carers of people with disability, family care becomes problematic when these expectations cannot be met (Breen, 2009). The research in this PhD is significant because it contributes to research in the field of maltreatment of people with disability and additionally focusses on a triad of under-researched domains including people with intellectual disability, familial maltreatment, and neglect.

1.3.3.3.2 National Disability Insurance Scheme (NDIS).

The continuing implementation of the NDIS in Australia further demonstrates the need and significance of this PhD research project. The National Disability Insurance Agency (NDIA) is an independent statutory agency designed to provide funding and connect people with disability to relevant service providers in their community (https://www.ndis.gov.au/). The increasing number of service providers interacting with people with intellectual disability and their families presents an opportunity to identify and intervene in maltreatment. The NDIS's Code of Conduct states that workers and providers are required to "Take all reasonable steps to prevent and respond to all forms of violence against, and exploitation, neglect and abuse of, people with disability" (NDIS Quality and Safeguards Commission, 2019, p. 5). Any actual or suspected, violence, abuse, neglect, or exploitation should be reported, and providers may be required to investigate these matters further (NDIS Quality and Safeguards Commission, n.d.). However, research demonstrates that the public (including people who work with people with disability) generally have a poor understanding of maltreatment and how to provide support for victim-survivors with intellectual disability (Fraser-Barbour, 2018; Mallén, 2011; McTavish et al., 2017). This suggests that although required to act, NDIS staff may not accurately identify signs of maltreatment of people with intellectual disability. Research can contribute to information needed to educate the public and professionals to optimise maltreatment identification and intervention opportunities in the future.

1.3.4 Ethical Considerations

The research proposal for this thesis was approved by the School of Psychology ethics committee representatives at Milestone 1 (Candidacy). The mixed methods and community dialogue studies required and were granted approval from the Curtin Universities Human Research Ethics Committee. For these studies, informed consent was addressed by providing accessible information about the study that could be kept (i.e., providing downloadable or hard copy of participant information), checking that it is understood (i.e., checking comprehension), and in the case of the community dialogue study reviewing consent throughout (e.g., providing participants with the opportunity to cease participation).

Although the involvement of the lived experience collaborators with intellectual disability, scoping review, and media analysis did not require formal approval, additional ethical considerations were made. For example, one ethical concern was to avoid causing distress and was addressed by designing material to achieve this (e.g., avoiding discussing personal experiences) and providing support information (e.g., websites and contact information with support services). Further details for each of the studies on the specific ethical concerns and the processes taken to mitigate them are presented in the corresponding chapters.

1.3.5 The Studies: Aims, Objectives, Questions, and Methodologies

The overarching aim of this research project was to investigate the maltreatment of people with intellectual disability by family members. This research has a particular focus of exploring perceptions of family maltreatment and specifically neglect. The literature was examined before perspectives were explored from the media, the public, and people with intellectual disability.

The objectives of the research were to:

1. Compile and summarise what was known in the international literature about the maltreatment of people with intellectual disability by family members. This objective was addressed in the scoping review presented in Chapter 2. The limited research available that specifically examined this topic

necessitated a broad focus of enquiry, therefore a scoping review was considered an appropriate approach. This study functions as the foundation in which the other studies are grounded, providing an overview of the literature from which decisions for subsequent studies were made. This study was updated before thesis submission and, although an additional 15 studies were included, the themes remain to the same. The research question for this study was: *What is known about familial maltreatment experienced by people with intellectual disability?*

2. Explore how the Australian news media frames the familial neglect of people with intellectual disability. This is addressed in the media analysis study presented in Chapter 3. A Foucauldian Discourse Analysis was the chosen analysis type for this study because it allows for the exploration of media representations that presents particular narratives that shape how individuals and groups can participate in society (Willig, 2013). Within this PhD, this study serves to provide an understanding of media representation of the maltreatment of people with intellectual disability as these provide insight into public perceptions and commonly accepted 'truths'. The research question for this study was: *How does the Australian news media frame the neglect of people with intellectual disability by family members?*
3. Examine and compare factors that influence public perceptions of the neglect of children with and without intellectual disability. This objective is addressed in the mixed methods study presented in Chapter 4. A mixed methods study was considered appropriate to address this objective because it would allow for a direct and deep exploration of public perspectives and the factors that influence them. The research questions for this study were: *What participant*

factors (age, gender, parental status, contact with people with an intellectual disability) influence perceptions of neglect of children with and without intellectual disability in relation to severity, perpetrator and victim-survivor responsibility, future mental and physical health outcomes for the victim-survivor, and perpetrator intentionality? Further, which subtypes of neglect are perceived as the most severe (lack of supervision, lack of providing, emotional neglect, educational neglect)?

4. Disseminate and discuss the research findings with people with intellectual disability. This objective is addressed in the community dialogue presented in Chapter 5. The purpose of this interview study was to disseminate the findings of the previous research in the PhD meaningfully to people with intellectual disability and explore their perspectives on the research and topic. In this study, the findings of the research and the topic are explored through the lens of the perspectives of people with intellectual disability. This provides additional important and informative insights. The research question for this study was: *How do people with intellectual disability understand the maltreatment of people with intellectual disability by family within the context of the studies previously conducted within the research project and more broadly?*

1.3.6 Thesis Structure

This thesis begins by proving a summary of the current literature, introducing the thesis document and research project (Chapter 1). Chapters 2, 3, 4, and 5 are the individual studies presented in manuscript form and organised into traditional manuscript sections (i.e., introduction, methods, findings/results, and discussion). Two chapters have been published. The study presented in Chapter 3 has been published in *Disability and Society* (Keeley et al., 2023a) and the study presented in Chapter 4 has been published in *Children and Youth Service Review* (Keeley et al., 2023b). The study presented in Chapter 5 has not been submitted for publication because its scope is specific to this PhD. A consequence of structuring the thesis in the way is that some level of duplication is inevitable. For consistency and flow throughout the thesis, the published chapters are presented with modified table numbering and spelling. Additionally, all references and appendices are presented in a master list at the end of the thesis. A sixth and final general discussion chapter will discuss the overarching findings and conclude the thesis.

Chapter 1 opens the thesis by providing a summary of literature addressing the maltreatment of people with intellectual disability by family. The origin of the idea behind the PhD topic are discussed, the process and role of the lived experience collaborators is outlined, and the rationale for the research is presented. Further, the ethical considerations are explored, the aims and objectives of the research are defined, and the structure of the thesis provided.

The first study presented in Chapter 2 is a scoping review of the recent literature on the maltreatment of people with intellectual disability. This study compiles and summarises what is currently known about the topic. A total of 43 studies from 19 countries were included in the analysis. The findings explore the different types of maltreatment (definitions, experiences, and incidence); precipitating factors; and responsibility for, responses to, and concealment and disclosure of familial maltreatment of people with intellectual disability. These findings provided a foundation for the subsequent studies in the PhD by informing their focus (in collaboration with the lived experience collaborators). This study was updated before submission and includes an additional 15 studies; however, the themes presented remain the same.

The second study is a media analysis addressing how the Australian news media frames the familial neglect of people with intellectual disability and can be found in Chapter 3 and has been published in *Disability and Society* (Keeley et al., 2023a). The articles included in the analysis primarily discussed a single case of parental neglect resulting in the death of a 4-year-old girl with Down syndrome. The lack of content addressing the neglect of people with intellectual disability is itself a finding. A Foucauldian discourse analysis was conducted, and discourses and subject positions were developed describing constructions of the topic and their consequences within the narratives. Although the aim was not to focus intentionally on children, all the articles included in the analysis discussed children. Following reflection and discussion, the lived experience collaborators decided that the focus of enquiry for the subsequent study should shift further to specifically address the neglect of children.

Chapter 4 includes a mixed methods vignette study addressing how the Australian public perceive the neglect of children with and without an intellectual disability and has been published in *Children and Youth Services Review* (Keeley et al., 2023b). The study explored perceived severity of neglect subtypes as well as the influence of participant factors (e.g., gender, age) and victim-survivor factors (e.g., described as having an intellectual disability). The qualitative element of the study clarified and elaborated on perspectives on neglectful behaviours and provided participant definitions of neglect.

A community dialogue study is outlined in Chapter 5 where the findings from the studies in Chapters 2, 3, and 4 were disseminated and discussed with a small sample of people with intellectual disability. A poster and presentation summarised the previous findings in an accessible way and were used in the recruitment and delivery of the interviews. Participants were asked about their perspective on the research and the topic more broadly. A conventional content analysis was used to analyse the interviews and findings included reflections on negative social understandings of people with intellectual disability, what maltreatment is, how it is responded to, and the role and importance of family.

The thesis is concluded with the sixth and final general discussion chapter. The chapter begins with the review of the thesis objectives. Then the three major findings from across the research are presented including reduced value of people with intellectual disability, diminished parental responsibility, and the influence of gender. The implications for each of these findings are discussed. Additionally, general strengths and limitations of the research project are presented and recommendations for future research that are categorised into identification, intervention, and prevention. The thesis is concluded with some final closing remarks.

1.4 Conclusion

This chapter introduced the research topic of this thesis on the maltreatment of people with intellectual by family members with a literature review. Additionally, an outline of the research project and thesis were provided. Chapter 2 includes the manuscript for the scoping review that is the first study in the research project.

Chapter 2: Maltreatment of People with Intellectual Disability by Family: A Scoping Review

2.1 Introduction

Maltreatment of people with intellectual disability is a globally significant issue. The UNCRPD (2006) states that people with intellectual disability have the right to be free from exploitation, violence, and abuse (Article 16) and that state parties should prevent neglect by providing families and organisations with necessary supports. Despite this people with intellectual disability are at a significantly greater risk of experiencing maltreatment than people with physical disability and people without disability (Hughes et al., 2012; Jones et al., 2012).

Children with intellectual disability have been shown to be 2.5 times more likely to experience maltreatment than children without disability (McDonnell et al., 2019). Research has found that rates of neglect are higher for children with intellectual disability compared to children with other disabilities and children without disability (Maclean et al., 2017). These risks persist into adulthood. In a meta-analysis, three studies including a total of 772 participants found that adults with intellectual disability were 1.6 times more likely to experience violence than people without intellectual disability in the last year (Hughes et al., 2012). A study from Spain found that verbal aggression (64.5%) was the most common type of victimization experienced by adults with intellectual disability and more often experienced by women (Codina et al., 2022). A recent meta-analysis found that the prevalence of sexual abuse for adults with intellectual disability was 32.9% (Tomsa et al., 2021). In Australia approximately 1 in 7 (14.3%) adults with intellectual disability experienced violence (threats and assault) in the past year (ABS, 2018).

The effects of maltreatment on an individual with an intellectual disability can be profound and lasting (Rowsell et al., 2013). Experiences of maltreatment can have a significant negative impact on the psychological (i.e., depression) and physical (e.g., heart disease) health of people with developmental disability including those with intellectual disability (Hughes et al., 2019). Maltreatment has been found to have long-term impacts on the psychological functioning (e.g., irritability, difficulty concentrating) of victim-survivors with intellectual disability (Rowsell et al., 2013). As a result of maltreatment, children with intellectual disability are more likely to have aggressive behaviours (37.2% vs 10.9%), attachment issues (34.3% vs 49.6%), and a hyperactivity disorders (38.1% vs 7.1%) than those without (Dion et al., 2018). Additionally, high rates of psychiatric disorders resulting from sexual abuse have also been shown in children and adolescents with intellectual disability (74.5%; Soylu et al., 2013). Further, children and adolescents with intellectual disability (10.8%) develop conduct disorder significantly more often than those without (3.9%; Soylu et al., 2013).

People with intellectual disability experience significant social barriers to disclosing maltreatment, one of the first steps to addressing it. In a study from Australia, Fraser-Barbour (2018) found that professionals within disability and non-disability sectors demonstrated an inability to adequately assist people with intellectual disability after sexual abuse. These professionals also demonstrated negative perceptions of people with intellectual disability, such as that they are incapable of being competent witnesses to their own experiences of abuse (Fraser-Barbour, 2018). Additional negative social perceptions have been shown to impact reporting sexual abuse for people with intellectual disability including misconceptions that so labelled individuals are excessively sexual (McGilloway et al., 2020). These influential factors result in people with intellectual disability (25%) being significantly less likely to report experiences of sexual abuse than people without intellectual disability (57.8%; Soylu et al., 2013). Consequently, there is less opportunity for maltreatment of people with intellectual disability to be identified and interceded.

Maltreatment occurring in the family home is particularly concerning as it may be more difficult to detect (Hughes et al., 2012; Jones et al., 2012). The vast majority (82%) of people with intellectual disability in Australia live at home (ABS, 2014). Subsequently, there are nearly 2.65 million informal carers (including family carers) in Australia (ABS, 2018) making their role within disability services vital (Nepal et al., 2011). Although it is often assumed that families are the ideal carers of people with a disability (Breen, 2009), family care becomes problematic when this expectation cannot be met. Maltreatment within the family may be particularly difficult to identify as it may be less likely to be disclosed than when the perpetrator is not a family member and potentially easier to conceal (Lemaigre et al., 2017). Additionally, families who care of people with intellectual disability tend not to have systematic maltreatment identification policies and practices such as those implemented by formal institutions (e.g., working with children checks; Working with Children Act, 2004). As a result, there are fewer opportunities for maltreatment to be identified.

Although research addressing the maltreatment of people with intellectual disability has increased in recent years. further understanding is needed into the specific characteristics of maltreatment of people with intellectual disability that occurs within the family home to ensure that opportunities to identify, prevent, and intervene are maximised. The aim of this research is to examine current literature on the maltreatment of people with intellectual disability by family members, synthesise what is known about the topic, and identify future avenues for research.

2.2 Method

2.2.1 Design

The scoping review framework described by Arksey and O'Malley (2005) and adapted by Levac et al. (2010) guided this study. Arksey and O'Malley (2005) articulate a five-stage process for collecting, analysing, and summarising data. These stages are (1) identifying the research question, (2) identifying relevant studies, (3) study selection, (4) charting the data, and (5) collating, summarising, and reporting the results (Arksey & O'Malley, 2005). Levac et al. (2010) extended on this framework by providing additional practical details on the process of conducting a scoping review. The review is reported according to the Preferred Reporting Items for Systematic reviews and Meta-Analysis extension for Scoping Reviews (PRISMA-ScR; Tricco et al., 2018). The search was conducted in August of 2020 and updated in April of 2024.

2.2.1.1 Identifying the Research Question.

I thoroughly discussed the parameters of this study with my research supervisors to ensure that the scope of the research was informative. The broad nature of the research question reflects the results of initial literature searches, which suggested a lack of data specifically pertaining to the research problem. The research question: *What is known about familial maltreatment experienced by people with intellectual disability?*

2.2.1.2 Identifying Relevant Studies.

The search strategy was informed by reviewing the literature, preliminary searches, and consultation with a university librarian. Different iterations of relevant terms were identified to reflect international definitions (e.g., intellectual disability can be referred to as learning disability in the UK). The final list of search terms can be seen in Table 1. Proquest, Medline, PsycInfo, and CINAHL databases were searched.

The search strategy was originally limited to articles published between 1/1/2006 and 20/8/2020 (when the search was first search was conducted) to capture contemporary research conducted following the UNCRPD (2006). This convention was integral in changing attitudes towards people with a disability by promoting disability rights at an international level (Perlin, 2012). An additional search was conducted using the same terms and strategy on the 9th of April 2024 to identify current literature published after the previous search.

Table 1

Search Strategy Terms

Keyword and Boolean Phrase Search Terms		
Concept 1	**Concept 2**	**Concept 3**
“intellectual* disab*”, “intellectual* impair*”, “developmental* disab*”, “developmental* delay*”, “learning disab*”, autis*, “down* syndrome”, “mental* disab*”, “mental* retard*”, retard*, “mental* handicap*”	maltreat*, violenc*, neglect*, abuse*, murder*, homicide* filicide*, “mercy kill*”, “compassionate homicide*”, “child protect*”, “family violence”, “domestic violence”, “domestic abuse”	famil*, “family member*”, parent*, sibling*, “intimate carer*”, "family carer*"
MeSH Search Terms		
Concept 1	**Concept 2**	**Concept 3**
Intellectual disability	maltreatment	family

Search results were exported to EndNote X9 where duplicates were removed. The full text of two studies could not be accessed due to copyright.

2.2.1.3 Study Selection.

Inclusion and exclusion criteria were developed before commencing the study and adjusted throughout the research process (see Table 2). The titles and abstracts of articles identified through database searches were reviewed against is criteria. Articles that met the inclusion criteria were then reviewed in their entirety. Articles were included if there was any data (even if it was only one statistic or quote) that met the criteria. Relevant grey literature identified in the database searches was not excluded. However, additional grey literature searching was not conducted. An independent researcher applied the inclusion/exclusion criteria to the full text of a randomly selected 10% (n = 23) of studies identified in the original database searches. Minor differences were discussed and reconciled resulting in the clarification and increased specificity of the inclusion/exclusion criteria as well as the complete agreement of study inclusion. Reference list searching was conducted on 5 randomly selected studies identified in the original search but did not generate any additional

Table 2

Inclusion and Exclusion Criteria

Inclusion criteria	Exclusion criteria

• Research published between 1/1/2006 and 9/4/2024
• Published in English.
• Some data referring to people with intellectual disability being maltreated by a family member (i.e., the focus of article does not have to centre around the maltreatment of people with intellectual disability by a family member).
• Victim-survivors are labelled as
  - Having an intellectual disability regardless of diagnosis and/ or
  - Having both intellectual and physical disabilities
  - Having an intellectual disability and any other comorbid condition (e.g., intellectual disability and autism)
• A family member is specifically identified as the perpetrator (i.e., not implied).
• Perpetrator is considered a long-term and close family member by the victim-survivor regardless of whether they are biological related (e.g., a stepfather).
• Perceptions of maltreatment of people with intellectual disability by a family member.
• Relevant peer-review literature.
• Relevant grey literature.
	• No data that specifically referred to people with intellectual disability being maltreated by a family member.
	• Victim-survivor(s) are labelled as having
	  - A disability, but it is not clear if the disability is intellectual.
	  - A developmental delay or learning problems that does not constitutes as a disability or disability status is unclear.
	  - Autism without comorbid intellectual disability
	• Perpetrator is the intimate partner of the victim-survivor.
	• Perpetrator is a short-term or paid carer (e.g., live-in carer).
	• Maltreatment that is confirmed to have caused an intellectual disability (i.e., no pre-existing intellectual disability before maltreatment).
	• Protective factors against maltreatment of people with intellectual disability by a family member (e.g., sexual health education).
	• Efficacy of intervention against the maltreatment of people with intellectual disability by a family member.
	• Long-term effects of maltreatment by a family member on people with intellectual disability.

relevant articles; thus, further reference searching was not conducted. Figure 1 depicts the search strategy.

2.2.1.4 Charting the Data.

I created an excel spreadsheet in consultation with my research supervisors to compile all relevant data from the included studies.

2.2.1.5 Collating, Summarising, and Reporting the Results.

Study characteristics and data specifically relating to familial maltreatment of people with intellectual disability were collated in the previously mentioned excel spreadsheet. After familiarisation with the data was established, categories were developed through a process of inductive coding, reflective discussions with the research supervisors, and grouping related information together.

2.3 Results

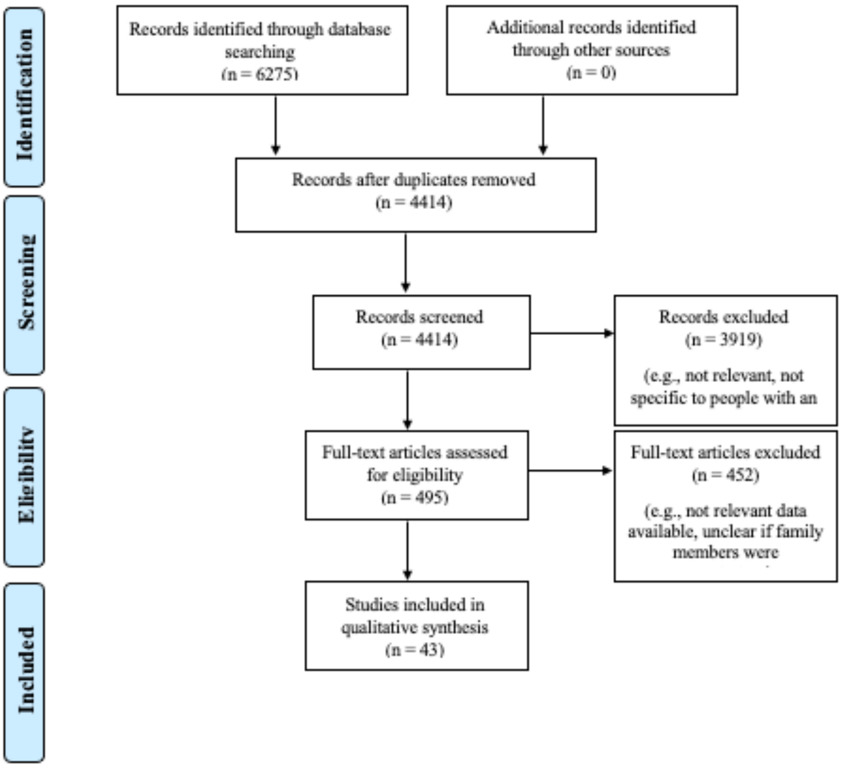
A total of 43 studies were included for analysis in this study. Of these, 19 studies were quantitative, 15 qualitative, 3 mixed methods, 4 case reports, and 2 were review papers. Forty-two were peer-reviewed and one was grey literature. Twenty-six studies focussed on the maltreatment of children and adolescents with intellectual disability, ten on adults, and seven included information about both children and adults or did not clearly specify the age/s at the time of maltreatment. Studies came from 19 different countries including Australia (*n* = 6), UK (*n* = 6), USA (*n* = 5), South Africa (*n* = 4), and Turkey (*n* = 3). Two studies were included from Canada, Israel, Italy, Spain, and Sri Lanka and one study was included from Belgium, China, Croatia, Germany, Ghana, India, Iran, The Netherlands, and South Korea. Two of the studies identified in the second search form part of this thesis and can be found in Chapters 3 and 4 (Keeley et al., 2023a; Keeley et al., 2023b). Further information about each of the included studies can be found in Appendix F. The results are presented in categories that represent both common and unique concepts across the qualitative and quantitative data. For an illustration of how the included studies map onto these categories, please see Table 3.

2.3.1 Types of Maltreatment

Information from across the sample regarding each of the specific types of maltreatment is combined for the purpose of presenting a clear and cohesive narrative. Definitions, experiences, incidence, and perspectives of familial maltreatment of people with

Figure 1

Flow of Studies Through the Review (PRISMA Flow Diagram)



intellectual disability, are presented for each of the different types of maltreatment where it has been available in the data.

2.3.1.1 General or Multiple Types of Maltreatment (n = 19).

Maltreatment is behaviour that is physically, sexually, mentally, and/or financially harmful or neglectful (Hewitt, 2013). In one study, a disability services staff member defined abuse as, “if you take advantage of somebody’s vulnerability then that’s abuse” (Parley, 2010, p. 15). Catani and Sossalla (2015) found that 87.5% of adults with an intellectual disability in their sample had experienced at least one form of maltreatment within the family, while 50% experienced four or more forms. Fifty-eight percent of abuse cases were perpetrated by family members in Hewitt (2013) and 23% in Mansell et al. (2009). Parents perpetrated 92.9% of maltreatment of people with Down syndrome in Van Horne (2014).

2.3.1.2 Sexual Abuse (n = 20).

Sexual abuse was defined in terms of all sexual acts such as touching genitalia, intercourse, and pornography related abuse (Catani & Sossalla, 2015; Loinaz et al., 2019). Several studies presented examples of people with intellectual disability who had experienced familial sexual abuse (Eastgate et al., 2011; Shang et al., 2021; Stoffelen et al., 2013; Strnadová et al. 2022; Taggart et al., 2010; Vadysinghe et al., 2023). For example, a participant in an Australian study shared, "(my grandfather) touched my breasts, he touched my vagina" (Eastgate et al., 2011, p. 228). Mdikana et al. (2018) reported that 42.8% (*n* = 12) of the teachers they interviewed knew of cases where students with intellectual disability had been sexually abused by a family member. For example, "a father raped his own child with intellectual disability (repeatedly)" (Mdikana et al., 2018, p. 511). Catani and Sossalla (2015) found that 12.5% of their sample had been sexually abused by a family member. Several studies reported that family members were the perpetrators of sexual abuse more than any other type of perpetrator including Hewitt (2013; 46%), Vadysinghe et al. (2017; 42%), and Mansell et al. (2009). Vadysinghe et al. (2017) found that 5% of sexual abuse experienced by participants with an intellectual disability was perpetrated by the victim-survivors' father. Three case studies reported instances of sexual abuse that was discovered through medical intervention (Robino et al., 2006; Shang et al., 2021; Vadysinghe et al., 2023).

2.3.1.3 Neglect (n = 12).

Neglect is ignoring, withholding, and/or not adequately providing essential care (Catani & Sossalla, 2015; Meer & Combrinck, 2017). Additionally, the definition of neglect can include essential skills (e.g., toileting) not being taught by families (Hervie, 2023). Intellectual disability was identified as a factor that increased rates of neglect in cognitive caregiving activities (i.e., learning activities such as reading, counting, and drawing; Bizzego et al., 2020). Examples of familial neglect of people with intellectual disability were evident in several studies (Catani & Sossalla, 2015; Parley, 2010; Taggart et al., 2010). In Meer and Combrinck’s (2017) study, familial neglect of people with intellectual disability was described as being extensive and widespread. In Hewitt (2013) 97% of neglect of people with intellectual disability was perpetrated by a family member and 39.3% of the sample in Catani and Sossalla (2015) had been neglected by family. Familial neglect of people with intellectual disability was also shown to result in death (Manthorpe & Martineau, 2015).

2.3.1.4 Physical Abuse (n = 9).

Examples of physical abuse in the studies include victim-survivors being beaten, hit strangled, and shaken (Catani & Sossalla, 2015). Several studies reported that physical maltreatment of people with intellectual disability is frequently perpetrated by a family member (Catani & Sossalla, 2015; Hewitt, 2013; Taggart et al., 2010; Thomas et al., 2014). In Catani and Sossalla’s (2015) sample, 73.2% had experienced physical abuse while Hewitt (2013) found that 55% of physical abuse was perpetrated by a family member. Thomas et al. (2014) found that 46% of mothers interviewed admitted to physically punishing their children with intellectual disability.

2.3.1.5 Emotional and Psychological Abuse (n = 6).

Emotional and psychological abuse is described as the victim-survivor being humiliated and made to feel worthless (Catani & Sossalla, 2015). Catani and Sossalla (2015) found that 76.8% of their sample had experienced emotional abuse by a family member and in Hewitt’s (2013) study 82% of emotional abuse was reported to have been perpetrated by family. Verbal abuse was described as a form of emotional abuse in Thomas et al. (2014) because it has a negative emotional effect on the individual. Thomas et al. (2014) found that 54% of mothers in their sample used verbal punishments.

2.3.1.6 Financial Abuse (n = 1).

Thirty-six percent of financial abuse experienced by the sample in Hewitt (2013) was perpetrated by a family member.

2.3.2 Precipitating Factors of Maltreatment

2.3.2.1 Economic Factors.

Economic factors were discussed as influencing familial neglect in three studies (Brown, 2012; Meer & Combrinck, 2017; Phasha, 2009). Meer and Combrinck (2017) suggested that a lack of resources and time to care for people with intellectual disability is associated with neglect. A social worker in this study from South Africa described a case where a "man in his 80s was too old to care for his sister, herself in her 60s, and could not afford to pay for care, so he locked her in a shed in the backyard, and only visited to feed her" (Meer & Combrinck, 2017, p. 45).

2.3.2.2 Stigma.

Stigma is a fundamental factor in the maltreatment of people with intellectual disability and therefore underpins all related research. The included studies addressed the influence of stigma in varying ways from overtly stating its influence (Phasha & Myaka, 2014) to implying its presence through the need to research the topic (Dion et al., 2018). A non-government service provider in a study from South Africa expressed how women with intellectual disability can be neglected because their families "look down upon (them)" (Meer & Combrinck, 2017, p. 45). In a qualitative study from Ghana, participants reported that fathers sometimes leave mothers when their child is found to have an intellectual disability because it is viewed as a "curse" (Hervie, 2023, p. 5). The mother's social isolation in combination with the challenges of single parenting were reported as sometimes also leading to neglect (Hervie, 2023). Further, Ramasamy et al. (2021) reported cases where adults with intellectual disability were bullied by family members because of they identified as gay.

2.3.2.3 Perpetrator Factors.

Whether the perpetrator was a mother, or father was found to influence maltreatment in David (2021). This study found that compared to children without intellectual disability mothers of children with intellectual disability were 3.87 times more likely to neglect and 2.3 times more likely to abuse their children. Fathers were 4.4 times more likely to neglect and 2.57 times more likely to abuse their children if they had an intellectual compared to those without (David, 2021). Differences between mothers and fathers were also reported in Bizzego et al. (2020) who found that children with intellectual disability were at a greater risk of being neglected by their mothers than children with other disabilities. However, no significant difference was found for fathers (Bizzego et al., 2020).

Drugs and alcohol were discussed as influential factors in two studies (Brown, 2012; Taggart et al., 2010). Mental health was also identified as impacting familial maltreatment of people with intellectual disability (Brown, 2012; David, 2021; Declercq et al., 2017). Mental health issues increased the risk of fathers abusing their children with intellectual disability by 2.3 times (David, 2021). Childhood experiences of abuse were also found to be influential. A study from South Korea found that mothers of children with intellectual disability who were abused in their childhood were significantly more likely to abuse their children than mothers who were not abused (Jahng, 2020). This study also found that parental self-efficacy moderated this relationship, and the authors suggest that high levels of self-efficacy resulted in better coping skills which lead to reduced abuse (Jahng, 2020).

A study from Turkey identified several factors that influenced mothers abuse of their children with Down syndrome (Özçevik Subaşi & Ocakçi, 2021). Factors that increased the risk of mothers abusing their children included having a high school education (vs university education), more than four children, less social support, being unmarried, unemployed, having a lower socioeconomic status, and childhood experiences of abuse (Özçevik Subaşi &

Ocakçi, 2021). Similarly, Bizzego et al. (2020) found that parents with lower education attainment levels had an increased risk of neglecting children with intellectual disability compared to children with other disabilities for cognitive caregiving activities (Bizzego et al., 2020).

2.3.2.4 Victim-survivor Risk Factors.

Intellectual disability was identified as a factor that increased the risk of abuse and neglect (David, 2021; Bizzego et al. 2020). Ramasamy et al. (2021) reported that the risk of abuse to adults with intellectual disability is increased because of the dependency of family members. However, some studies reported that intellectual disability did not influence the risk of maltreatment (Keeley et al., 2023a; Koçtürk & Yüksel, 2023). Keeley et al. (2023a) found that intellectual disability did not impact public perceptions of neglect severity and Koçtürk and Yüksel (2023) reported that intellectual disability did not significantly impact the type of perpetrator (e.g., family member, acquaintance) for sexual abuse. One study identified gender as a risk factor for familial maltreatment experienced by people with intellectual disability (Thomas et al., 2014). Thomas et al. (2014) found that physical punishments were more frequently experienced by boys (33%) than girls (13%) and verbal punishments more frequently experienced by girls (37%) compared to boys (17%). Additionally, familial abuse of adults with intellectual disability was found to be more frequent in those that live at home (70%) rather than in residential care (54%; Codina et al., 2024). This may suggest that living at home is a risk factor for familial abuse for people with intellectual disability. Further, children with intellectual disability were found to have a higher risk of cognitive caregiving neglect than children with other disabilities in countries with both a high and low Human Development Index (Bizzego et al., 2020)

2.3.2.5 Maltreatment as a Risk Factor for Maltreatment.

Some forms of maltreatment were found to be correlated with other forms of maltreatment. Physical and emotional abuse of people with intellectual disability that was perpetrated by family members was found to be significantly related to experiencing sexual abuse but not neglect in one study (Catani & Sossalla, 2015). A significant relationship was also found between people with intellectual disability experiencing violence at home and within institutions (Catani & Sossalla, 2015). Meer and Combrinck (2017) argued that, when women with an intellectual disability are neglected by their families, it provides an opportunity for sexual predators from within and outside of the family to have unrestricted access to abuse them.

2.3.3 Responsibility for Maltreatment

2.3.3.1 The Perpetrator.

Six studies found that maltreatment of people with intellectual disability was most often perpetrated by family members (Cordina et al., 2024; Hewitt, 2013; McDonnell et al., 2019; Ramasamy et al., 2021; Vadysinghe et al., 2017; Van Horne, 2014). Two studies found that people with intellectual disability are more likely to be abused by a family member than people without intellectual disability (Dion et al., 2018; McDonnell et al., 2019). Participants in some qualitative studies also reported that family members were the most common perpetrators of the maltreatment of people with intellectual disability (Strnadová et al. 2022; Taghizadeh et al., 2024).

Six studies did not identify family members as the most common perpetrators of maltreatment of people with intellectual disability (Koçtürk & Yüksel, 2023; Leutar et al., 2014; Loinaz et al., 2019; Mansell et al., 2009; Paquette et al., 2018; Soylu et al., 2013). Mansell et al. (2009) found that people with intellectual disability were similarly likely to experience maltreatment from family members (23%), other service users (27%), and staff

(24%). Leutar et al. (2014) reported that friends were most likely to abuse people with intellectual disability, then parents, acquaintances, with staff in institutions being the least likely abusers. Other studies also found that partners and people from outside of the family were more likely to abuse people with intellectual disability than family members (Koçtürk & Yüksel, 2023; Loinaz et al., 2019; Soylu et al., 2013). Several studies found that people without intellectual disability were more likely to be abused by family members than people with intellectual disability (Loinaz et al., 2019; Paquette et al., 2018; Soylu et al., 2013). Perkins et al. (2011) found that experiences of child maltreatment did not predict that the child would have intellectual disability.

For studies reporting on fatal familial maltreatment of people with intellectual disability, parents were exclusively identified as the perpetrators (Brown, 2012; Coorg & Tournay, 2012; Declercq et al., 2017; Manthorpe & Martineau, 2015). In one study, the father of a 9-year-old boy with physical, intellectual, and language disabilities sedated and then strangled his son (Declercq et al., 2017).

2.3.3.2 Diminished Responsibility.

Two studies addressed the minimisation or displacement of responsibility for maltreatment away from the perpetrating individual(s). Brown (2012) suggested that society should not chastise parents who kill their children with disability (including examples of those with intellectual disability) because the acts are committed not out of malice but because of stress resulting from caring for people with disability. For example, a mother with severe and untreated depression is described as having “snapped” before killing her son with Down syndrome (Brown, 2012, p. 8). Bottoms et al. (2011) found that, while mock jurors assigned equal levels of responsibility to both fathers, they recommended significantly shorter sentences (i.e., less punishment) for a father who killed an infant with intellectual disability in comparison to the father of an infant without intellectual disability. Participants also indicated that it was more likely that the father had a mental illness if he killed his child without intellectual disability than with intellectual disability (Bottoms et al., 2011). Further, a media analysis from Australia found that the responsibility for the death of a girl with Down syndrome was shifted from the parents to the government depending on the types of discourse used (Keeley et al., 2023b).

2.3.3.3 Responsibility of Others.

Non-perpetrators such as family members and day services staff were held responsible for maltreatment in two studies (Manthorpe & Martineau, 2015; Meer & Combrinck, 2017).

2.3.3.4 Maltreatment as a Violation of Responsibility.

The expectations of a family are violated when its members do not adequately care for people with intellectual disability and additionally when they perpetrate maltreatment (Parley, 2010). In Phasha (2009), participants expressed that the family home should be a safe place for individuals with intellectual disability but is instead a significant setting of abuse. In another study, a social worker was quoted as saying "when we expect them to be protected, it is the family members or somebody who knows the family, who is close to the family, they are the perpetrators of violence" (Meer & Combrinck, 2017, p. 45).

2.3.4 Responses to Maltreatment

2.3.4.1 Perpetrator Responses.

Three studies included information regarding the real-life consequences for parental perpetrators of fatal maltreatment. In the eight relevant cases across these studies, all but one involved a perpetrating parent attempting or completing suicide after killing their child with an intellectual disability (Brown, 2012; Coorg & Tournay, 2012; Declercq et al., 2017). Two studies also described the legal outcomes for several cases such as a two-year suspended sentence (Brown, 2012; Declercq et al., 2017). Shang et al. (2021) also reported on legal outcomes in a case study from China, where a father who raped his 14-year-old daughter with intellectual disability received a 5.5-year jail sentence.

2.3.4.2 Community Responses.

The data displayed mixed reactions of the community to cases of maltreatment of people with intellectual by a family member. The range of responses included disgust (Meer & Combrinck, 2017; Taggart et al., 2010) and empathy for the perpetrator (Brown, 2012), greater empathy and relatedness to victims without rather than with intellectual disability (Bottoms et al., 2011), and indifference (i.e., a participant did not consider the organisation of family members to have sex with a person with intellectual disability as constituting abuse; Phasha & Myaka, 2014). One study found that social workers were more likely to want to report the incident to child welfare and the police when parental aggression was more severe and these decisions were not influenced by professional or personal characteristics (Enosh et al., 2008). The legal system is described as responding inconsistently to fatal maltreatment (Brown, 2012). Keeley et al. (2023b) presents media representations of the neglect and death of Willow Dunn a 4-year-old girl with Down syndrome. Responses to Willow Dunn's death include disgust (Medical and Graphic discourses) but also demonstrate a lack of sympathy through her portrayal as different, vulnerable, and due to the limited consideration for her experience of suffering (Keeley et al., 2023b).

2.3.5 Concealing and Disclosing Maltreatment

2.3.5.1 Concealing Maltreatment.

Meer and Combrinck (2017) posited that maltreatment can be concealed over extended periods of time because family members are in the unique position of having unrestricted access to the victim-survivor and can manipulate relationships. The isolation experienced by some people with intellectual disability can mean that abuse is less visible to outsiders and attempts to disclose may not be recognised (Meer & Combrinck, 2017). Family members are also “often the last to be suspected” as potential perpetrators (Meer & Combrinck, 2017, p. 46).

In Phasha’s (2009) study from South Africa, participants described sexual abuse as a family matter. Approaching abuse as a family matter reportedly involves families wanting to maintain secrecy, the utilisation of traditional methods, acting on beliefs about a cure for intellectual disability, abuse being trivialised, and the neglect of people with intellectual disability. Phasha (2009) suggested that families are more likely to cover up sexual abuse if the perpetrator is responsible for the main income of the family. This was also reported in Meer and Combrinck (2017). Additionally, some families are reported as wanting to keep abuse a secret because they relied financially on the victim-survivor’s disability pension and feared that the individual and their pension would be removed if the abuse was revealed (Phasha, 2009).

2.3.5.2 Disclosure of Maltreatment.

Disclosing maltreatment of a person with intellectual disability by a family member was discussed within four studies (Eastgate et al., 2011; Mdikana et al., 2018; Phasha, 2009; Robino et al., 2006). In Eastgate et al. (2011), one participant shared their experience of disclosing abuse: “I said mum I don’t want to go and see grandpa because pop touched me, and then, then my mum talked to my grandma and... my gran said I was a liar” (p. 228). Community members such as teachers and neighbours are described as often being disclosed to and reporting abuse when families will not (Mdikana et al., 2018; Phasha, 2009). In a study from Australia a distressed friend reported to a teacher that another student was being sexually abused by her father (Strnadová et al. 2022).

Three case studies identified that sexual abuse was disclosed through medical evaluation and treatment (Robino et al., 2006; Shang et al., 2021; Vadysinghe et al., 2023). In two of these cases, the perpetrators of familial sexually abuse were identified through DNA

Table 3

Categories and Studies

Study	Types of maltreatment	Precipitating factors of maltreatment	Responsibility for maltreatment	Responses to maltreatment	Concealing and disclosing maltreatment
Bottoms et al., 2011	P*		✓	✓	
Bizzego et al., 2020	N	✓			
Brown, 2012	G, P, N*	✓	✓	✓	
Catani & Sossalla, 2015	G, S, P, EP, N	✓			
Codina et al., 2024	G	✓	✓		
Coorg & Tournay, 2012	G*		✓	✓	
David 2021	G, N		✓		
Declercq et al., 2017	G*	✓	✓	✓	
Dion et al., 2018	G		✓		
Eastgate et al., 2011	S				✓
Enosh et al., 2008	P*			✓	
Hervie 2023	N	✓			
Hewitt, 2013	G, S, P, EP, N, F		✓		
Jahng 2020	P, EP	✓			
Keeley et al., 2023a	N	✓			
Keeley et al., 2023b	N*		✓	✓	
Koçtürk & Yüksel, 2023	S	✓	✓		
Leutar et al., 2014	G		✓		
Loinaz et al., 2019	S		✓		
Mansell et al., 2009	G, S		✓		
Manthorpe & Martineau, 2015	N, EP*		✓		
McDonnell et al., 2019	G		✓		
Mdikana et al., 2018	G, S				✓
Meer & Combrinck, 2017	G, N	✓	✓	✓	✓
Özçevik SubaşI & OcakçI, 2021	G	✓			
Paquette et al., 2018	G		✓		
Parley, 2010	G, N		✓		
Perkins et al., 2011	G		✓		
Phasha, 2009	S	✓	✓		✓
Phasha & Myaka, 2014	S	✓		✓	
Ramasamy et al., 2021	S, EP, P	✓	✓		
Robino et al., 2006	S				✓
Shang et al., 2021	S			✓	✓
Shannon et al., 2023	S	✓			
Soylu et al., 2013	S		✓		
Strnadová et al., 2022	S				✓

Stoffelen et al., 2013	S				
Taggart et al., 2010	G, S, P, N	✓		✓	
Taghizadeh et al., 2024	S		✓		
Thomas et al., 2014	P, EP	✓			
Vadysinghe et al., 2017	S		✓		
Vadysinghe et al., 2023	S				✓
Van Horne, 2014	G		✓		
TOTAL	43	17	25	10	8

Note. G=general maltreatment, S=sexual abuse, P=physical abuse, EP=emotional/psychological abuse, N=neglect, F=financial abuse, *= maltreatment resulted in death, ✓=some data from study relevant to this category.

analysis after the victim-survivors became pregnant (Robino et al., 2006; Shang et al., 2021). In the other case, a brother's sexual abuse of his 15-year-old sister with intellectual disability was identified when doctors found a polythene bag that had been used as a condom while investigating the girl's vaginal discharge (Vadysinghe et al., 2023).

2.3.5.3 Attributions of Credibility and Value.

Maltreatment can remain hidden when the credibility of people with intellectual disability as a witness to their own experience is be bought into question (Eastgate et al., 2011; Meer & Combrinck, 2017; Phasha, 2009). For example, a participant described a parent trying to keep maltreatment hidden saying that "a parent would say—you know how this person is...you cannot take him/her seriously, this person is mentally retarded" (Phasha, 2009, p. 193). This study additionally demonstrated that less value is attributed to people with intellectual disability when a police officer is quoted as saying, "if it happens to a person with intellectual disability it is not reported, but if it happens to a non-disabled person it gets reported immediately, even if the perpetrator is a family member" (Phasha, 2009, p. 195).

2.4 Discussion

To my knowledge, this scoping review is the first of its kind to synthesise available literature on the maltreatment of people with intellectual disability by family members. There were equivocal results regarding people with intellectual disability being at greater risk of maltreatment by a family member than people without intellectual disability. However, the literature generally suggests that people with disability are at greater risk of maltreatment than people without and that people with intellectual disability experience the greatest risk compared to people with other disabilities (Byrne, 2017; Hughes et al., 2012; Jones et al., 2012). Results were also mixed with regards to family members as the most frequent perpetrators of maltreatment of people with intellectual disability compared to other perpetrators.

There may be several reasons for these differences. First, definitions, rates, and methods of reporting maltreatment of people with intellectual disability will vary across different geographical locations, cultural groups, and types of intellectual disability, as well as between researchers. Second, some of the samples in the included studies may not have been representative, resulting in the studies either under or over representing people with intellectual disability. Additionally, the barriers associated with identifying familial maltreatment of people with intellectual disability may make it difficult to research; therefore, it is possible that the literature fails to comprehensively capture experiences and rates.

People with intellectual disability may experience several unique barriers to reporting maltreatment by a family member. The signs and symptoms of psychological trauma, such as that which can result from maltreatment, can present differently in people with intellectual disability compared to those without (McNally et al., 2021). Consequently, identifying and treating trauma experienced by people with intellectual disability may be more challenging to identify and therefore treat. These differences may lead to misunderstandings in professional disability settings (Mallén, 2011). For example, Mallén (2011) found that disability service staff have difficulty identifying sexual abuse experienced by children with intellectual disability because the subsequent behaviours often do not correspond to those that are expected of a victim-survivor. This study also found that disability service staff are reluctant to report suspected family maltreatment of people with a disability when staff have a positive relationship with the family (Mallén, 2011). The current study also demonstrates that some families can be unwilling to report abuse of people with intellectual disability by a family member (Phasha, 2009). This reluctance perhaps demonstrates a tension in public perceptions between the rights of people with disability to be free from violence in accordance with Article 16 of the UNCRPD (2006) and the families right to privacy and freedom from outside interference in accordance with Article 12 of the Universal Declaration of Human rights (United Nations, 1948). However, this unwillingness also suggests that the families are centred and safeguarded in place of the victim-survivor in instances of maltreatment of people with intellectual disability.

Perceptions about the credibility of people with intellectual disability also work as barriers to reporting maltreatment (Phasha, 2009). The credibility of people with intellectual disability after experiences of sexual abuse has also been shown to often be bought into question (McGilloway et al., 2020). Communication differences and perceptions of capacity are described as preventing cases of the sexual abuse of people with intellectual disability from going to court preventing the realisation of justice (McGilloway et al., 2020). The nuances of familial maltreatment of people with intellectual disability may facilitate concealment and underreporting, therefore preventing opportunities for identification, intervention, and prevention.

Two of the included studies presented findings that diminished the responsibility of perpetrators who kill family members with an intellectual disability (Bottoms et al., 2011; Brown, 2012). Sullivan (2017) also found evidence of diminished responsibility in their review of the sentencing remarks of parents who had killed their children with disability in Australia. Sullivan (2017) criticised narratives that portrayed violence as an inevitable consequence of caring for people with disability and thus diminishing parental responsibility.

These harmful constructions have also been shown in news media contexts. In Australian new media reports on murder-suicides including victims with disability, disability was constructed as a legitimate and easily assumed “cause of violence” (Buiten & Cresciani, 2023, p. 68). Responsibility is diminished when murder is justified, and culpability is shifted to the victim. This is especially problematic as such a justification would be unacceptable in domestic violence involving people without disability. Brown (2012) acknowledged similar negative assumptions held by the public and perpetuated by the media that question the validity of the lives of people with intellectual disability resulting in the justification of lenient sentencing for perpetrators.

Besides the studies I conducted (Keeley et al., 2023a; Keeley 2023b), only one of the included studies stated that they included the involvement of people with intellectual disability in their study (Strnadová et al., 2022). ‘Nothing about us, without us’ is a movement that emphasises the need for people with disability to be involved in research that concerns them (Charlton, 2000). Including the genuine participation of people with intellectual disability in research is advantageous to those so labelled who are involved and the research (Bigby & Frawley, 2010).

2.4.1 Strengths

A strength of this study is that it includes research from 19 different countries, providing a global perspective that ensures greater generalisability of the results. However, most studies come from the Global North resulting in these perspectives being overrepresented. This study identifies several gaps in the literature that require further research. For example, financial abuse of people with intellectual disability by family members was only investigated in one study. The lack of research in this area may suggest that financial abuse is particularly difficult to identify and therefore study. The results from this study could be used as a resource for advocates and organisations to highlight issues facing people with intellectual disability and assist in the better identification, intervention, and prevention of the maltreatment of people with intellectual disability by family members.

2.4.2 Limitations

The lack of involvement of people with intellectual disability is a limitation of this study. My ability to make sense of the data is inevitably partial due to my lack of embodied experiences of disability. Further, as a result of imposing strict inclusion/exclusion criteria to exclusively include relevant data, potentially relevant information may have been excluded. For example, several studies examining maltreatment of people with intellectual disability within child protection services implied that family members were perpetrators but did not explicitly state or provide data to suggest this (e.g., Simmel & Shpiegel, 2013). Child protection research has shown that family members are most often the perpetrators of maltreatment within this context, but they are not exclusively responsible (Dion et al., 2018).

Another limitation of this study is that it does not include data on interventions addressing maltreatment of people with intellectual disability. The inclusion of literature pertaining to interventions was considered beyond the scope of this study which sought to describe the familial maltreatment of people with intellectual disability but not how this should be addressed. Quality research exploring effective interventions and preventions strategies for the familial maltreatment of people with intellectual disability are lacking and greatly needed (Araten-Bergman & Bigby, 2023; Dion et al., 2018; McDonnell et al., 2019; Weiss et al., 2011).

2.5 Conclusion

The maltreatment of people with intellectual disability by family members is a significant worldwide issue that may be particularly invisible. This study discussed issues surrounding the different types of maltreatment, precipitating factors, responsibility, responses, and disclosure and concealment. The results indicate that more large-scale quality research is needed to inform effective methods of identification, intervention, and prevention of maltreatment of people with intellectual disability by family members.

Chapter 3: The Neglect of a Child with Intellectual Disability as Reported in Australian News Media: A Foucauldian Discourse Analysis

Author Attribution Statement

This study has been published in *Disability and Society* (Keeley et al., 2023a), an international, peer-reviewed, high-quality journal dedicated to disability research that intersects with human rights, discrimination, policy, and practice. Please see author attributions below.

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<tr><th></th><th>Conception and design</th><th>Acquisition of the Data and Method</th><th>Data Conditioning and Manipulation</th><th>Analysis and Statistical Method</th><th>Interpretation and Discussion</th></tr>
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3.1 Introduction

People with intellectual disability experience a significant risk of being neglected (McDonnell et al., 2019) and much of this neglect is perpetrated by family members (Hewitt, 2013). Neglect is a form of abuse that constitutes a deprivation of essential physical and/or emotional needs such as food, education, attention, and medical care (Jones et al., 2012; Royal Commission, n.d.). It can be active or inactive and purposeful or unintentional (Robinson & Chenoweth, 2012).

People with intellectual disability have been shown to be more at risk of being maltreated than people without intellectual disability (McDonnell et al., 2019). For example, a study of child protective services found that children with intellectual disability (50%) were significantly more likely to have been neglected than children without (33%; Paquette et al., 2018). Additionally, people with intellectual disability can experience neglect at higher rates than people with other types of disability (e.g., physical disability). Maclean et al. (2017) found that children with disabilities other than intellectual and children without disability experienced neglect at a similar rate of around 25% which was significantly lower than rates for children with intellectual disability (33%). Some research also suggests that the severity of neglect may be greater for children with intellectual disability. For instance, children with intellectual disability (50%) were shown to experience significantly higher rates of severe emotional neglect than children without (23%; Weiss et al., 2011). Individuals working in government and nongovernment service provision described the neglect of women with intellectual disability as “pervasive” (Meer & Combrinck, 2017, p. 45). Additionally, it is suggested that the neglect of women with intellectual disability creates opportunities for sexual predators from inside and outside the family to perpetrate sexual abuse (Meer & Combrinck, 2017).

Maltreatment of people with intellectual disability can occur in numerous settings including institutions (Mansell et al., 2009). Some disability support staff have been found to have negative perceptions of people with intellectual disability and have an inadequate understanding of institutional maltreatment (Dorozenko et al., 2015; Fyson & Petterson, 2020). Consequently, this may lead to poor treatment of people with intellectual disability, reduced capacity to detect and prevent maltreatment, and an inability to effectively support victim-survivors. However, research suggests that family members are often the perpetrators of neglect of people with intellectual disability (McDonnell et al., 2019). For example, in a study from the UK of 695 people with intellectual disability accessing psychological services, 12% had experienced neglect in their lifetime, 97% of which was perpetrated by a family member (Hewitt, 2013). Additionally, a study in Germany found that 39.3% of people with intellectual disability attending a specialised welfare centre had been neglected by a family member (Catani & Sossalla, 2015).

Familial neglect may be particularly difficult to identify and therefore intervene in due to the potential for concealment. For instance, families tend not to have formalised intervention and prevention policies such as requiring working with children checks (Working with Children Act, 2004) yet the vast majority (82%) of people with intellectual disability live within the family home (ABS, 2014). Family care of people with intellectual disability is generally considered ideal (Breen, 2009), however, this role cannot always be adequately fulfilled.

The effects of neglect can be significant and long lasting (Power et al., 2020; Raby et al., 2019) and can result in death (Manthorpe & Martineau, 2015). In a large study of maltreatment related deaths in the USA, 14% of children who died because of maltreatment had a disability or chronic illness and neglect was reported as a contributing or causal factor in 65% of those cases (Palusci & Covington, 2014). This suggests that children with disability may face a significant risk of dying as a result of maltreatment.

Understanding public perceptions of the familial neglect of people with intellectual disability is important because people with intellectual disability face substantial barriers to disclosing and accessing support for maltreatment (Fraser-Barbour, 2018). For instance, a child protection services study found a significant relationship between children with intellectual disability and investigations of neglect but not substantiated neglect (De La Sablonnière-Griffin et al., 2021). De La Sablonnière-Griffin et al. (2021) suggested that neglect of children with intellectual disability may be particularly difficult to substantiate due to social and communication barriers.

These barriers also impact how the public report suspected maltreatment of people with intellectual disability. Mandatory reporters (e.g., teachers, police officers) have been found to be reluctant to report suspected maltreatment of children with disability without obvious physical evidence (e.g., broken bones; McTavish et al., 2017). Additionally, practitioners from various sectors (e.g., disability, education) have also been shown to be reluctant to make referrals where children with a disability were involved, often because of their relationship and empathy for the parents of the child with disability (Mallén, 2011; Stalker et al., 2015). These findings suggest that the experience and value of the suspected perpetrating family members can be regarded above that of the victim-survivor with disability. Other factors including gender have been found to influence perceptions and reporting behaviours of maltreatment of people with intellectual disability. Research suggests that women tend to recognise parental behaviours as more abusive and neglectful than men (Dickerson et al., 2017; Giglio et al., 2011). These influences on reporting behaviours are additionally problematic because children are extremely unlikely to report experiences of abuse and neglect themselves (AIHW, 2019). It is therefore important to understand how the public comprehend and interpret neglect because their reporting behaviours can potentially make a substantial impact on neglect outcomes (Dickerson et al., 2017).

The media both influences and reflects public conceptualisations, opinions, and understandings of people with intellectual disability and maltreatment (Devotta et al., 2013; Gillespie et al., 2014). A media analysis of content relating to people with intellectual disability in Taiwanese newspapers identified that negative representations of people with intellectual disability (77.3%) were significantly more common than positive representations (22.7%; Chen et al., 2012). However, news media representations of people with disability have been shown to change over time. An analysis of Canadian news media found that, between 1998 and 2008, progressive representations (i.e., social determinants of disability) of people with a disability increased significantly (21.4% to 28.9%) but remained less frequent (45.8%) than traditional representations (i.e., existing outside of the norm; Devotta et al., 2013).

Media representations can also impact how people with a disability understand themselves. Representations of people with disability as helpless or ill has been shown to be related to negative self-identity of people with a disability and lead to self-stigma (Zhang & Haller, 2013). Sheehan and Ali (2016) propose a 3-stage process for self-stigma for people with intellectual disability. First, they must be aware of negative stereotypes of people with intellectual disability which may be achieved by accessing media content. Second, the stereotypes are believed by the individual. Third, the person acts on the belief established by the stereotypes. Stigma affects many aspects of the lives of people with intellectual disability including physical and psychological health and wellbeing, safety, education, and employment (Ali et al., 2012; Banks et al., 2017; Shifrer, 2013).

News media plays a significant role in informing the public on the nature and extent of neglect, fostering public support to address the issue, and influencing political agendas

(Lonne & Gillespie, 2014). Research suggests that media coverage of child maltreatment is disproportionate to case numbers in the community with sexual abuse being overrepresented and neglect being underrepresented (Davies et al., 2017; Ho & Chan, 2018). Additionally, abuse perpetrated by strangers and in institutions was presented more often than familial abuse and yet occurs less (Lonne & Gillespie, 2014; Mendes, 2001). These findings indicate that neglect is underrepresented in news media.

Familial neglect of people with intellectual disability is pervasive and invisible (Hewitt, 2013; Maclean et al., 2017). Social barriers influence neglect reporting and disclosure, preventing interventions and allowing it to continue (Dion et al., 2018; Fraser-Barbour, 2018). News media plays a significant role in informing the public on the nature and extent of neglect, fostering public support to address the issue, and influencing political agendas (Lonne & Gillespie, 2014). Investigating these constructions and perceptions provides opportunities to heighten awareness of familial neglect and develop strategies for change (e.g., education tools).

3.1.1 This Study

The study is conducted from a social constructionist epistemological position that proposes that commonly accepted 'truths' are socially constructed and that their validity should be challenged (Gergen, 1985). A critical disability theory perspective informs this study and posits that society constructs an inaccurate, demeaning, and harmful concept of 'disability' (Procknow et al., 2017). The term 'intellectual disability' is used to refer to those so labelled throughout this study. Labels can be problematic for many reasons including that they impose a master status (Dorozenko et al., 2015). However, the term is considered best practice in Australia (People with Disabilities Australia [PWDA], 2019) and can be important for affirming and celebrating diverse identities and experiences.

The aim of this study is to develop an understanding of the narratives that are constructed by and influence public perceptions of people with intellectual disability within the context of familial neglect. These are important to understand because of their ability to impinge on the human rights of people with intellectual disability to participate in society in a manner of their choosing. This study addresses the research question: *How does the Australian news media frame the neglect of people with intellectual disability by family members?*

3.2 Method

Drawing on the principles of community-based participatory research (Asaba & Suarez-Balcazar, 2018), I adopted a participatory methodology to optimise involvement of people with intellectual disability in the project's decision-making processes. A defining feature of participatory methodology is collaboration, which aligns with the 'nothing about us without us' concept central to disability rights (Charlton, 2000). Two people with intellectual disability were involved throughout the PhD research project and were paid for their time and expertise. It is important that people with intellectual disability were involved in the research because neither I nor my research supervisors identify as having a disability. Working alongside people with lived experience sought to ensure that the study was demand driven and served people with intellectual disability.

Before commencing this study, I met with the lived experience collaborators face-to-face to present and discuss the findings of a scoping review conducted as part of the research project. These collaborators were consulted on how the findings from the scoping review should direct a subsequent study and they decided that a media analysis should focus on a specific form of maltreatment and identified that neglect was an issue that warranted further investigation. Lived experience collaborators were debriefed after the study was conducted.

3.2.1 Ethical Considerations

All data included in this study was publicly available and therefore formal ethical approval was not required. However, during the process of designing the PhD research project, the school's ethical committee representatives reviewed and approved this study. The content of the data could potentially cause distress to the lived experience collaborators and researchers. The risk of harm to the lived experience collaborators was mitigated by intermittently reviewing levels of distress and discussing formal and informal avenues of accessing support. Further, regular meetings provided the opportunity to discuss and review reactions and concerns regarding distressing content.

3.2.2 Data Collection

Key terms were searched in Factiva and ProQuest databases and results were restricted to exclusively include news articles from Australia published between 01/01/2016 and 01/01/2021. The literature and initial searchers of the data indicated that it was likely that the number of results would be limited. However, I decided that the 5-year time frame would remain as it facilitated the inclusion of recent data. Public perceptions change over time and the inclusion of news articles prior to this may not reflect current narratives and dilute the accuracy of the findings. Key terms were designed to be broad and inclusive to ensure that all relevant data was captured. For example, some terms that are commonly conflated in Australia with intellectual disability were included (e.g., learning disability). The inclusion criteria were applied to ensure that strictly only relevant data were included in the final analysis. See Table 4 for a complete account of the search terms. The search generated 246 results. After duplicates, including syndicated articles, were removed (n = 144) the inclusion criterion was applied to 102 articles. See Figure 2 for the Inclusion criteria. A final sample of 27 articles were identified for inclusion in the study.

Table 4

Search Strategy

Variable	Search terms
Victim/survivor	"intellectu* disab*" OR "intellectu* impair*" OR "mental* disab*" OR "mental* retard*" OR retard* OR "mental* handicap*" OR "intellectual* handicap*" OR "down* syndrome"
	AND
Perpetrator	famil* OR “family member*” OR “intimate carer*” OR "family carer*" OR parent* OR sibling* OR brother* OR sister* OR mother* OR father* OR mum* OR dad* OR aunt* OR uncle* OR grandparent*
	AND
Maltreatment	neglect* OR negligence

3.2.3 Data Analysis

Data were analysed via a Foucauldian discourse analysis (FDA). This qualitative method posits that discourse is essential in generating the meaning of a phenomenon (Foucault, 1972) which permits and restricts what can be said, done, and felt (Willig, 2013). This study used Willig’s (2016) six stage guidelines for conducting an FDA. The stages are (1) Discourse constructions, (2) Discourses, (3) Action orientation, (4) Positionings, (5) Practice, and (6) Subjectivity. Each article was coded in relation to all 6 stages in consecutive order. I was attentive to and made note of (1) what objects are constructed through the discourse, (2) the kinds of discourses used (e.g., medical, emotional), (3) what was achieved by constructing the object in this way (4) the subject position created through the object’s construction, (5) the actions and (6) emotions available to the object when constructed in this way. Codes and excerpts from the text were then organised with corresponding codes from across the sample within a discourse table (stages 1 to 3) and a separate subject positions table (stages 4 to 6). I discussed these initial discourses and subject positions with my supervision team to enhance rigour. In addition, the quality of the analysis was managed by maintaining an audit trail and practicing reflexivity. Final discourses and subject positions were developed by examining the tables and refining the concepts by exploring the similarities and differences within and between each of the identified codes and their related text excerpts.

Figure 2

Inclusion Criteria

Inclusion Criteria

Publication requirements

- Location: Australian
- Language: English
- Time frame: 01/01/2016 and 01/01/2021

Format requirements

- Articles were included if they were news articles of any length.
- Articles were excluded if they were not considered a news article (e.g., transcripts, crossword, letters to the editor, TV guide).

Content requirements

Articles were included if they

- Directly refer to neglect that was perpetrated by a family member (i.e., not in an institution) experience by someone specifically identified as having an intellectual disability.
- The victim/survivor was identified as having both an intellectual disability and a physical disability.
- The perpetrator had an intellectual disability (as long as the victim/survivor also has an intellectual disability).
- Included some relevant information even if not all of content meets the inclusion criteria. Only relevant information was analysed and included in the study.

3.3 Findings

Of the 27 articles analysed, 25 pertained to one case. This case involved Willow Dunn,[2] a 4-year-old girl with Down syndrome who died on the 23rd of May 2020 (Kohlbacher & Goodenough, 2020, June 3). An ambulance was called approximately two days after Willow Dunn's death and her body showed signs of long-term maltreatment (Kyriacou & Utting, 2020, June 4; Dennien, 2020, May 30). Willow Dunn's father, Mark

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[2] I have chosen to use Willow Dunn's full name in place of her initials to demonstrate her value and to avoid reducing her as an individual or minimising her experience of neglect and death. However, the father and stepmother's initials are used to for identification purposes.

Dunn (MD), and stepmother, Shannon White (SW) were charged with her murder (Siganto, 2020, July 20).

All 27 of the articles were included in the analysis and contribute to the findings. The findings are organised into ‘discourses’ and ‘subject positions’. News media content is influenced by and influences public perceptions and therefore these discourses and subject positions suggest current social understandings of familial neglect of people with intellectual disability that influence individual (i.e., journalist’s) perspectives. The discourses presented reflect the analysis from stages 1, 2, and 3 of the FDA and the subject positions from stage 4, 5, and 6. Additional content specifically relating to stages 5 and 6 is presented in the subject positions conclusion section. See Table 5 for a description of the sample and illustration of how the discourses and subject positions map to each article.

3.3.1 Discourses

The four discourses identified in the analysis are ‘Criminal justice and law enforcement discourse’, Political discourse’, ‘Medical discourse’, and ‘Graphic discourse’.

3.3.1.1 Criminal Justice and Law Enforcement Discourse.

The neglect and death of Willow Dunn was depicted through a criminal justice and law enforcement discourse that communicated ideas around the responsibility and significance of the case. Within this discourse, blame was solely directed at the perpetrators (MD and SW). For example, Siganto (2020, July 20) stated that “Willow's father, Mark James Dunn and her stepmother, Shannon Leigh White, were charged with the child's alleged murder shortly after her death and have been remanded in custody since.” The responsibility of the perpetrators was established through the presentation of their arrests and charges. The assignment of responsibility demonstrated in this discourse contrasts with that of

Table 5

Discourse and Subject Position Sample Representation

Article	**Publisher**	**National or local publication**	**Discourses**				**Subject positions**		
			Criminal justice and law enforcement discourse	Political discourse	Medical discourse	Graphic discourse	Different	Vulnerable	Suffering
Bedo (2020, Jun 3) Toddler’s stepmum charged with murder	news.com.au	National	✓	✓	✓	✓		✓	
Bita (2020, May 31) Our record of neglect marks us as a nation	The Courier Mail	Local	✓	✓	✓	✓	✓	✓	✓
The Courier Mail (2020, June 25) Remembering these faces is the least society should do	The Courier Mail	Local	✓			✓			
The Courier Mail (2020, May 29) Kids can’t be allowed to fall through cracks	The Courier Mail	Local	✓	✓	✓				
Dennien (2020, May 30) Investigation launched into 'horrific' cases of alleged child neglect.	brisbanetimes.com.au	Local		✓				✓	✓
Dillon (2018, November 6) Accused neglect mum is pregnant	The Advertiser	Local	✓		✓				
Dingle (2018, June 22) When carers kill	ABC News	National	✓		✓				
Kohlbacher & Goodenough (2020, June 3) Willow's stepmother charged with murder	AAP General News Wire	National	✓	✓				✓	
Kyriacou & Utting (2020, May 27) Dad ‘left disabled girl to decompose’	The Courier Mail	Local	✓	✓	✓	✓	✓	✓	✓
Kyriacou & Utting (2020, June 4) Stepmum charged over Willow death	The Courier Mail	Local	✓		✓	✓	✓		
Maloney (2020, June 9) Plan to ban unfit workers	The Advocate	Local		✓					✓
Marszalek & Billing (2020, May 30) Shock cases spark child safety probes	The Courier Mail	Local	✓	✓	✓	✓			✓

Molloy (2020, May 31) Cops turn attention to dead 4yo's home life	news.com.au	National	✓	✓	✓	✓		✓	✓
Murray (2020, May 27) Father charged after Willow, 4, lay dead for days	The Australian	National	✓	✓	✓	✓	✓	✓	✓
Murray (2020, May 27) I failed to get help: Willow's dad	The Australian-Online	National	✓	✓	✓	✓	✓		✓
Murray (2020, May 28) Willow's father admits he failed to get her medical help	The Australian	National	✓	✓	✓	✓	✓		
Murray (2020, May 29) Probe ordered into child neglect cases	The Australian-Online	National		✓				✓	
Murray (2020, May 29) The mum Willow lost 'loved us more than anything'	The Australian	National	✓	✓	✓	✓	✓	✓	✓
Murray (2020, May 30) Bridesmaid at centre of Willow probe	The Weekend Australian	National	✓	✓	✓	✓		✓	✓
Murray (2020, June 4) Stepmother charged with murder of Willow	The Australian	National	✓	✓	✓	✓		✓	
News.com.au (2020, May 27) Tragic life of Willow Dunn revealed	news.com.au	National	✓		✓	✓	✓	✓	
Read (2020, May 28) 'Invisible': Advocates call to report child abuse	The Courier Mail-Online	Local		✓	✓	✓			
Roberts (2020, May 27) Online candlelight vigil held in memory of toddler Willow Dunn as father stands charged with murder	ABC News	National	✓	✓	✓		✓	✓	
Roberts & Swanston (2020 , May 29) Death of 4yo Willow Dunn came after 'sustained mistreatment', Brisbane detective alleges	ABC News	National	✓	✓	✓			✓	✓
Siganto (2020, July 20) Father, stepmother accused of murdering toddler Willow Dunn charged with additional child cruelty offences	ABC News	National	✓	✓	✓				✓
Utting & Kyriacou (2020, May 28) Stepmum allegedly says Willow wasn't her responsibility	The Courier Mail-Online	Local	✓	✓	✓	✓			
Wuth (2020, May 29) More charges likely over Qld girl's death	AAP General News Wire	National	✓	✓	✓				✓

the Political discourse (described below) that assigns responsibility away from the perpetrators and focusses it on the government. The case is constructed as important through the inclusion of information about the enlistment of high-grade law enforcement. For example, Kohlbacher and Goodenough (2020, June 3) stated that “South Australia's major crime squad is involved,” suggesting that it is an important case requiring advanced policing. Additionally, the case is portrayed as significant through the police officers’ reactions to the crime scene. For example, “counselling has been offered to the paramedics and police officers who were deeply disturbed by the crime scene” (Wuth, 2020, May 29). The significance of the case is emphasised in the description of the police being disturbed despite often witnessing distressing scenes.

3.3.1.2 Political Discourse.

Within the political discourse the government are constructed as responsible for Willow Dunn’s neglect and death. The child welfare system is ascribed blame when it is described as having “failed these young people” (Dennien, 2020, May 30) when referring to Willow Dunn’s death and the unrelated neglect of two brothers identified as having disability. Further, the government’s responsibility is proposed when it was reported that, “Government agencies need to help parents raise their children properly – but if they can’t, the children must be cared for” (Bita, 2020, May 31). This indicates that the government is ultimately held responsible for the welfare of children. Additionally, government’s responsibility is proposed through the suggestion that it refuses to be held accountable. This is shown when the opposition’s police spokesperson Dan Purdie is quoted as saying “The state Labor government needs to take responsibility” (Murray, 2020, May 30)

3.3.1.3 Medical Discourse.

The medical discourse demonstrates the importance of the physical and visible manifestation of Willow Dunn’s neglect. The physical injuries sustained by Willow Dunn and other victim-survivors with intellectual disability were discussed throughout the analysed articles. Willow Dunn is described as having “had a litany of injuries” (Wuth, 2020, May 29) and being “malnourished” (The Courier Mail, 2020, May 29). The physical consequences of neglect are presented and therefore demonstrated as important, however, there is an absence of consideration for other effects such as the psychological and emotional impacts.

Medical treatment is venerated when the lack of medical intervention is portrayed as fundamental in causing Willow Dunn’s death. For example, “Mr Dunn is alleged to have told police Willow Dunn’s health deteriorated before her death, and he should have sought help” (Murray, 2020, May 28). The sense of tragedy is enhanced by presenting Willow Dunn’s death as preventable. Additionally, a medical understanding of disability is displayed in one article when Willow Dunn is described as someone who “suffered from Down syndrome” (The Courier Mail, 2020, May 29). However, this rhetoric was included in only one article suggesting that this notion exists but is not prevalent.

3.3.1.4 Graphic Discourse.

The neglect and death of Willow Dunn were expressed through a Graphic discourse. Like the Medical discourse (discussed above) this discourse focuses on the physical outcomes of the neglect and additionally presents gruesome details. Willow Dunn is described as having been “found decomposed in her cot with horrific sores on her body” (Read, 2020, May 28) and “left to starve in a filthy bed in a bedroom. Her body had been attacked by vermin” (Molloy, 2020, May 31). The gruesome depiction creates a sense of shock and disgust.

An additional consequence of this discourse is the creation of a sense of repugnance towards the perpetrators. For example,

> *The partner of a man charged with the murder of his 4-year-old daughter allegedly told police as Willow Dunn was not her biological child she refused to care for her,*

> *amid allegations the little girl died in filth, was malnourished, neglected and covered in sores* (Utting & Kyriacou, 2020, May 28).

The discussion of SW's responsibility in proximity to Willow Dunn's death works to create a connection that constructs SW as responsible and deplorable. This can also be seen for MD when it is stated that "Mr Dunn, 43, is now accused of Willow's murder, while police continue to probe how the little girl could die and be left to decay in her bedroom" (Murray 2020, May 29). SW was constructed as an archetypal evil stepmother because she challenges the feminine social norm by not caring for Willow Dunn and her role in Willow Dunn's death is consequently portrayed as intentional. While MD is described as a murderer, he is constructed as more hapless than evil. The Graphic discourse encourages a sense of disgust at Willow Dunn's death and the perpetrators and perpetuates traditional gender roles.

3.3.2 Subject Positions

Although subject positions were noted for several individuals and groups, I present the subject positions identified for Willow Dunn because of her relevance to the research question.

3.3.2.1 Different.

Through the seemingly positive construction of Willow Dunn, negative and othering social attitudes about people with Down syndrome are revealed. Down Syndrome Australia's chief executive Ellen Skladzien is quoted as saying that "children with Down syndrome have skills, talent and dreams like every other child" (Murray, 2020, May 28). The inclusion of these positive qualities suggests that these attributes are not generally assigned to people with Down syndrome and highlights how people with Down syndrome are positioned as outside of the norm through their comparison to other children.

Acceptance of people with Down Syndrome is portrayed as socially progressive in the analysed articles. Willow Dunn's biological mother Naomi who died after childbirth is constructed as a good person when it is presented that “Naomi knew Willow would be born with Down syndrome and she picked her name with husband Mark Dunn” (Murray, 2020, May 29). This acceptance masquerades as positive attitudes towards people with Down syndrome; however, the act of accepting this difference suggests that there is something to excuse. In Australia, the vast majority of pregnancies where the foetus is identified as having Down syndrome are terminated (Maxwell et al., 2015) demonstrating that this acceptance is uncommon and that the general social perception of having a child with Down syndrome is negative. This implies that negative perceptions exist about people with Down syndrome and works to compound an idea that so-labelled individuals are different and not as valuable as people without Down syndrome.

Additionally, the neglect experienced by Willow is portrayed as being worse because of this difference of disability. For example, Roberts and Swanston (2020) presented that, “the death of Willow and the condition of the boys was particular distressing, due to their disability”. This suggests that people with disability are inherently different and subsequently vulnerable.

3.3.2.2 Vulnerable.

Willow Dunn is constructed as a small and powerless victim and is consequently positioned as highly vulnerable to abuse. While her vulnerability is in part due to her young age it is used in the narrative to emphasise the tragicness of the case resulting in a greater sense of pity for Willow Dunn and people with Down syndrome. Willow Dunn’s vulnerability was emphasised by her frequently being described as “little” (News.com.au, 2020, May 27). Willow Dunn’s helplessness was highlighted in the depiction of her death. For example, Willow Dunn was “left to die” (Bedo, 2020, Jun 3). This presents Willow Dunn as passive and highlights her lack of power positioning her as fundamentally vulnerable.

Children with intellectual disability are further positioned as vulnerable when the Child Safety Practice Manual is quoted as saying “Children with disability that affect conduct … may be vulnerable to physical abuse by parents … who may become frustrated by their behaviour” (Bita, 2020, May 31). This excerpt expresses a view that abuse can be reasoned because victim-survivors provoke and consequently make themselves vulnerable to abuse. However, this sentiment was only presented in one article and was not a common idea within the narrative.

3.3.2.3 Suffering.

The consideration for Willow Dunn’s experience of suffering is limited and superficial within the articles. The perpetration of neglect was emphasised over the experience of it. The physical manifestation of Willow Dunn’s neglect is outlined with commentary such as that, “Willow was experiencing serious malnourishment and many other health concerns that indicated sustained mistreatment,” (Murray, 2020, May 30). Here, Willow Dunn’s neglect is acknowledged at surface level and without contemplation for her lived experience of suffering. The lack of consideration for Willow Dunn’s experience of pain suggests that people with Down syndrome (and people with intellectual disability) are considered different (see Different subject position) and are dehumanised as a result. When people with intellectual disability are dehumanised (Dorozenko et al., 2015), considerations for their experiences (e.g., for pain) are prevented.

Few articles discussed Willow Dunn’s neglect with greater consideration for her suffering. For example, Willow Dunn’s experience of pain is expressed in this description of her body “with painful sores so deep the bones on her hips were exposed, police allege” (Kyriacou & Utting, 2020, May 27).

3.3.2.4 Subject Position Conclusion.

These subject positions permit a limited scope for those so labelled to act and emote. Equal social participation is impossible because people with Down syndrome are defined as being outside of the norm and attributed less value than people without Down syndrome. The lack of consideration for Willow Dunn's complexity works to portray her as one dimensional.

3.4 Discussion

This study explored Australian news media representations of a case of familial neglect of an individual with intellectual disability. The included articles primarily centred on a single case where Willow Dunn, a 4-year-old girl with Down syndrome, died as a result of neglect allegedly perpetrated by her father and stepmother. A Foucauldian discourse analysis identified four discourses and three subject positions.

There was a notable lack of media coverage on the neglect of people with intellectual disability by family members, with only 27 articles published in the five-year period. This is further demonstrated by a lack of diversity within these articles with the vast majority pertaining to a single case and none addressing the neglect of adults with intellectual disability. Previous research demonstrates that issues effecting people with intellectual disability are underrepresented in the media (Devotta et al., 2013). Additionally, there is a lack of media content addressing neglect generally (i.e., not specifically people with intellectual disability) in Australia (Lonne & Gillespie, 2014), the UK (Davies et al., 2017), Hong Kong (Ho & Chan, 2018), and the USA (Hove et al., 2013). For example, a study on Australian news media representations of child maltreatment indicated that neglect coverage is underrepresented in relation its prevalence and sexual and physical abuse coverage is overrepresented (Lonne & Gillespie, 2014). Media coverage of both neglect generally and people with intellectual disability is scarce, resulting in the neglect of people with intellectual disability being significantly underrepresented compared to the rate that it occurs in the community (Lonne & Gillespie, 2014).

Media coverage of social issues is important because it informs and mobilises the community. Huck et al. (2009) presents a conceptualisation of mass media agenda setting that posits that the public become aware of issues through the media and that the importance of an issue is dictated by the amount of media coverage it receives. In the current study, it can be suggested that the public may be generally uninformed about the familial neglect of people with intellectual disability and that the media do not consider it an important issue (i.e., newsworthy). Familial neglect of people with intellectual disability is an important community issue as demonstrated by research indicating that it is a common form of maltreatment experienced by those so labelled. However, public awareness and interest is hampered by the lack of news media coverage resulting in limited opportunities to advocate for change.

Davies et al. (2017) suggest that the lack of news media content may reflect a difficulty in identifying and defining neglect. Additionally, Hove et al. (2013) posits that this ambiguity may be the reason journalist avoid reporting these cases unless they are particularly horrific and therefore newsworthy. This may also be the case with regards to the scarcity of research about neglect that has been attributed to its invisibility as well as the diverse use of definitions in the literature (Jones et al., 2012). There is a significant lack of clarity around the definition of neglect that hampers public understanding, news reporting, and academic enquiry.

In addition to news media, social media has also been found to be an effective tool in advocating for social change for people with disability and is used by numerous individuals and organisations for this purpose (Gelfgren et al., 2020). For example, George Julian is a journalist, blogger, and online activist who live tweets inquests into the deaths of people with intellectual disability and autism (see https://www.georgejulian.co.uk/). She aims to increase awareness of the lives and deaths of people with intellectual disability and promoting pro-social perspectives of those so labelled.

This study identifies some harmful stereotypes about people with intellectual disability in the media. For example, Willow Dunn's is constructed as helpless and weak and while her young age certainly contributes to this portrayal, people with intellectual disability are often framed as vulnerable (Renwick, 2016). This construction is problematic because it does not acknowledge that people with intellectual disability are *made* vulnerable through disempowering social practices. Harmful stereotypes were also found in a study of cinematic representations of people with intellectual and developmental disability within the context of occupational participation (Renwick et al., 2014). The study found that cinema perpetuates stereotypes, devalues social participation, and models negative responses to people with intellectual and developmental disability. Renwick et al. (2014) suggests that these representations result in the public unconsciously learning to think about and treat people with intellectual and developmental disability as different, less than, and abnormal. The presentation of harmful stereotypes in cinema and news media works to preserve harmful perceptions of people with intellectual disability as vulnerable.

A criminal justice and law enforcement discourse was used to present Willow Dunn's death as a significant social issue in the current study. Similarly, a media analysis of Australian print media on child maltreatment (i.e., not specifically people with intellectual disability) found that police voices were frequently presented and used to explain the nature of child maltreatment and to position it as a significant social issue (Lonne & Gillespie, 2014). Additionally, Lonne and Gillespie (2014) suggest that 'police' along with the other most frequently presented terms including 'children' and 'sex' are considered newsworthy and therefore used to sell newspapers in a competitive market. In the current study the use of graphic imagery may also indicate an attempt to make content newsworthy for the purpose of selling newspapers.

The politicisation of Willow Dunn's death resulted in the government rather than the perpetrators being held responsible. Negative portrayals of child welfare services were also found in a study of news media in Norway, Denmark, and Germany (Schönfelder & Holmgaard, 2019). As a result of the government being held responsible, the role and responsibility of MD and SW who perpetrated the neglect is reduced. Diminished responsibility for parents who kill their children with intellectual disability was also found in Bottoms et al. (2011). The mock jury study from the USA found that people assigned less severe sentences and mental health problems to a father who killed an infant with intellectual disability compared to an infant without an intellectual disability (Bottoms et al., 2011). This suggests that participants considered the death of the infant with intellectual disability to be a less serious crime (i.e., less punishment given) and require less justification (i.e., lack of mental health problems) than that of the infant without intellectual disability. Bottoms et al. (2011) attributes these responses to the participants having negative attitudes towards people with intellectual disability.

SW's responsibility for Willow Dunn's death is framed as more intentional as reflected in her construction as evil as opposed to MD's positioning as incompetent. This is despite SW not being a biological parent. This finding suggests that gender may play a role in news media representations of perpetrators of neglect. In a study on the role of gender in perceptions of child neglect Dickerson et al. (2017) found that the gender of the perpetrator and victim-survivor were influential factors. The threshold for neglectful parenting was lower for mothers than for fathers. Participants were also more likely to define behaviour as neglectful when the gender of the parent and child were the same (i.e., mothers and girls, fathers and boys) than when they were not (Dickerson et al., 2017). The difference in the construction of SW and MD may reflect public perceptions of gendered parenting expectations and be influenced by SW and Willow Dunn having the same gender. Future research should further investigate how the label of intellectual disability impacts perceptions of parenting in relation to gender.

3.4.1 Strengths and Limitations

This study appears to be the first of its kind to address how the Australian news media frames the familial neglect of people with intellectual disability. This addition to the literature is valuable because research on neglect generally, and specifically within the context of people with intellectual disability, is scarce despite its prevalence in the community. These findings illustrate current public attitudes about the familial neglect of people with intellectual disability in Australia as demonstrated through the media. People with intellectual disability guided this research to ensure that it was respectful and counter to an ableist approach to research. Future research could use this study to demonstrate shifts in media representations of people with intellectual disability, and familial neglect. The findings of this study could be used in education and advocacy tools to demonstrate the negative and unequal representation of issues affecting people with intellectual disability in the media and promote change specifically in relation to media reporting regulations.

These findings have limited transferability because they primarily address a single case. Media representation of family neglect may be distinctive when different circumstances and/or types of intellectual disability are depicted. However, this study provides an in-depth analysis of this case. Additionally, this study only analysed print news media content and did not include other forms of news media such as television news. It is possible that neglect of people with intellectual disability is framed in different ways across news platforms. While print news media readership is declining it is still influential is setting the agenda for television news media and is therefore an important and informative research space (Hove et al., 2013).

3.5 Conclusion

Some harmful and unhelpful discourses exist about people with intellectual disability in the Australian news media within the context of familial neglect. Further research is needed about the neglect of people with intellectual disability generally and specifically in relation to perpetrators within the family. The media reveals socially dominant discourses which reflect public perceptions. Stigma fuelled attitudes and behaviours towards people with intellectual disability harm those so labelled in numerous and significant ways. Therefore, it is important to understand the nuance of this stigma in different contexts including news media in order to reduce its impact on the lives of people with intellectual disability.

Chapter 4: Factors Influencing Public Perceptions of Child Neglect: A Mixed Methods Study

Author Attribution Statement

This study has been published *Children and Youth Services Review* (Keeley et al., 2023b). This international, peer-reviewed, and multidisciplinary journal focuses on disadvantaged children, their families, and available support systems. Please see author attributions below.

	Conception and design	**Acquisition of the Data and Method**	**Data Conditioning and Manipulation**	**Analysis and Statistical Method**	**Interpretation and Discussion**
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4.1 Introduction

Child neglect is a significant worldwide problem. A meta-analysis of international research on neglect prevalence found that physical neglect was experienced by 16.3% of children and emotional neglect by 18.4% (Stoltenborgh et al., 2013). In Australia, 18% of child abuse cases involve neglect – making it second only to emotional abuse (59%; AIHW, 2019a). Further, neglect co-occurs 37% of the time with other types of abuse (AIHW, 2019a). Some researchers suggest that these reported prevalence rates are underestimated because neglect can be difficult to identify (Stoltenborgh et al., 2013).

The negative effects of child neglect are numerous, substantial, immediate, and enduring. Children who have experienced neglect have been shown to have poorer self-esteem, social problems (e.g., connecting with peers), lower academic achievement, and psychological distress than children who have not been neglected (Lim & Lee, 2017; Raby et al., 2019; Zeng et al., 2020). In adolescents, child neglect has been found to be a predictor of violent behaviour and associated with delayed height growth and puberty (McGuigan et al., 2018; Power et al., 2020). The effects of child neglect can also persist into adulthood. Research suggests that adults who experienced neglect in childhood have a heightened chance of experiencing weight gain, lower academic achievement, depression, a suicide attempt, and poorer outcomes for emotional and cognitive development (Merrick et al., 2017; Power et al., 2020; Raby et al., 2019).

There are many definitions of neglect, and this ambiguity makes identifying, researching, and prosecuting neglect difficult. This research subscribes to the following definition of neglect in line with that presented by AIHW (2019a): child neglect constitutes a carer actively or passively depriving a child of an environment that promotes positive physical and mental development in a way that contravenes cultural norms. Neglect can include the inadequate provision of food, supervision, medical care, education, attention, hygiene, clothing, and housing (Goodvin et al., 2007; Jones et al., 2012; McGuigan et al., 2018). Barnett et al. (1993 as cited in Goodvin et al., 2007) posited a theoretical understanding of neglect based on literature and the expertise of academics and child protection professionals whereby neglect comprises four subtypes: failure to provide (e.g., child has inadequate clothing), lack of supervision (e.g., child is left at home alone), emotional neglect (e.g., child is not given adequate attention and affection), and educational neglect (e.g., child does not attend school). These subtypes were validated by a confirmatory factor analysis in a study of community norms of child neglect (Goodvin et al., 2007). Additionally, neglect can be either intentional or not intentional (Robinson & Chenoweth, 2012). However, some researchers do not include unintentional or poverty-related neglect in their definition of neglect (Lev-Wiesel & Massrawa, 2020; Turner et al., 2019).

Neglect is under-researched despite its prevalence and impact (Stoltenborgh et al., 2013). Some researchers have suggested that the lack of scientific enquiry exploring neglect is the result of its lack of definition clarity (Jones et al., 2012). More research is needed that addresses neglect specifically as the literature suggests that it operates differently to other forms of maltreatment (Turner et al., 2019). Additionally, research on neglect may be hindered by problems identifying and recognising it in the community. For example, Son et al. (2017) found that neglect was the least recognised form of maltreatment compared to psychological and physical abuse among a sample of mothers (*N* = 153) in the USA, South Korea, and Japan. Further, Lavi and Katz (2016) demonstrated that children can find it difficult to identify their own experiences of neglect in a study of child-victim survivors' perceptions of neglect from Israel.

Difficulties identifying neglect are amplified with regards to children with intellectual disability. Children with intellectual disability are more likely to be neglected than children without intellectual disability (Maclean et al., 2017). This heightened risk is also demonstrated in a child protective services study from Canada, whereby Paquette et al. (2018) found that the risk of neglect was significantly higher for children with intellectual disability (50%) compared to those without (23%). Children with intellectual disability also tend to experience more severe forms of maltreatment. For example, Weiss et al. (2011) found that children with intellectual disability were significantly more likely to experience severe emotional neglect compared to children without intellectual disability (50% compared to 23%).

Children with intellectual disability are less likely to report abuse than those without intellectual disability – thus exposing them to increased risk of further neglect and consequences (Soylu et al., 2013). If people with intellectual disability do report maltreatment, they are more likely to be subjected to significant social barriers influenced by stigma (Fraser-Barbour et al., 2018). For example, professionals can misunderstand and misjudge people with intellectual disability and consequently do not provide adequate support (Fraser-Barbour et al., 2018). Barriers such as these can make the neglect of children with intellectual disability particularly difficult to substantiate in child protective services settings (De La Sablonnière-Griffin et al., 2021). Thus, it is likely that much of the neglect experienced by children with intellectual disability is undetected and can therefore continue unimpeded.

Understanding public perceptions is imperative because of their impact on the ways that neglect is identified, reported, and perpetrated. If behaviours are not recognised as neglectful then they are unlikely to be reported, investigated, and substantiated, resulting in the continuation of the neglect (Dickerson et al., 2017). The effect of public perceptions on reporting behaviours is important in the identification of neglect as only 0.2% of children report their own experience of maltreatment and health professions have been shown to have identification difficulties (AIHW, 2019b; Lines et al., 2020). Individual factors, such as gender, influence perceptions of maltreatment and neglect and may subsequently impact reporting behaviours (Bornstein et al., 2007; Bottoms et al., 2011; Dickerson et al., 2017). Compared to men, women tend to view victim-survivors more positively and perpetrator more negatively (Bottoms et al., 2011). The perpetration of neglect may also be influenced by public perceptions as parenting behaviours are shaped by these understandings (Ferguson & Bargh, 2004; Son et al., 2017). Further, the public generally has a poor understanding of child neglect (Son et al., 2017) that in part, may be due to the lack of media coverage. The absence of media content on neglect has been demonstrated in research from around the world (Davies et al., 2017; Ho & Chan, 2018). The media informs the public of social issues, communicates their importance, can influence political agendas, and inspire advocacy (Huck et al., 2009; Lonne & Gillespie, 2014). Public perceptions are highly influential in the identification, intervention, and prevention of neglect and are therefore important to understand.

Many children have been profoundly impacted by neglect worldwide (Lim & Lee, 2017; Stoltenborgh et al., 2013). Neglect can be difficult to identify and define (Lavi & Katz, 2016). Subsequently, neglect research is limited and may underestimate the impact of the issue (Jones et al., 2012; Stoltenborgh et al., 2013). Children with intellectual disability experience additional risks and barriers compared to children without intellectual disability (Maclean et al., 2017; Soylu et al., 2013). Public perceptions are influential in the identification, intervention, and prevention of child neglect. This study aims to explore public perceptions of child neglect and understand the factors that influence them.

4.2 Method

Ethical approval for this study was obtained from Curtin University.

4.2.1 Design

This study is part of a larger PhD research project on the familial maltreatment of people with intellectual disability. This study utilised a randomised between groups design with a mixed methods approach. The aim of this study was to explore the influence of participant variables (age, gender, parental status, contact with people with intellectual disability) on perceptions of neglect of children with and without intellectual disability in relation to severity, perpetrator and victim-survivor responsibility, future mental and physical health outcomes for the victim-survivor, and perpetrator intentionality. Additionally, the research examined public perceptions of the severity of the different types of neglect (lack of supervision, lack of providing, emotional neglect, educational neglect). Two lived experience collaborators with intellectual disability were consulted throughout the PhD research project. The lived experience collaborators identified that this study should focus on neglect as a specific form of maltreatment and children with intellectual disability rather than people of all ages in response to studies previously conducted within the PhD. Lived experience collaborators were also consulted on vignette details such as victim-survivors gender and the outcome of the neglect in the vignettes (i.e., did it result in death or not), for both they did not have a preference. Additionally, the collaborators were asked what they wanted to understand about the public perspectives of the familial neglect of children with intellectual disability. They identified interest in understanding how the public assigned responsibility to both the victim-survivor and perpetrators. The contribution of the lived experience collaborators shaped this study and the PhD research project as a whole.

The research questions for this study are: *What participant factors (age, gender, parental status, contact with people with an intellectual disability) influence perceptions of neglect of children with and without intellectual disability in relation to severity, perpetrator and victim-survivor responsibility, future mental and physical health outcomes for the victim-*

survivor, and perpetrator intentionality? Further, which subtypes of neglect are perceived as the most severe (lack of supervision, lack of providing, emotional neglect, educational neglect)?

4.2.2 Participants

The final sample comprised 399 participants, following the removal of 19 participants due to incomplete surveys (*n* =16) or failing an attention check (*n* = 3). Of the final sample, 195 (48.87%) identified as women, 197 (49.37%) as men, 6 (<1%) as non-binary, and 1 (<1%) as gender-fluid. Participants' ages ranged from 18 to 84. Four participants identified as having an intellectual disability. See Table 6 for additional demographic information.

Participants were recruited via Prolific (www.Prolific.co), an online crowdsourcing platform that provides access to a vetted participant pool and has been identified as a high quality and effective recruitment tool (Palan & Schitter, 2018). The researchers enhanced the representativeness of the sample by recruiting participants according to approximate gender and age ratios in Australia (ABS, 2020). Participation was restricted to adults (18 years and above) who reside in Australia. A sample size of between 360 and 400 was considered ideal as it accounted for the analysis (30 participants per cell x 12 cells [6 dependent variables across 2 groups] = 360) and allowed for attrition.

4.2.3 Materials

4.2.3.1 Perspectives on Child Neglect.

The primary measure used in this study comes from Goodvin et al. (2007) who sought to design a measure to evaluate social norms of child neglect. This measure comprises 19 one-line vignettes followed by a 6-point Likert scale question asking about the seriousness of the potential neglect. The Goodvin et al. (2007) measure was selected because of its

Table 6

Description of the Sample

Variables	**N(%)**
Complete sample	399
Condition groups	
Group 1. Victim-survivor had an intellectual disability	200(50.13)
Group 2. Not provided with any additional information about the victim-survivor (i.e., no intellectual disability)	199(49.87)
Gender	
Men	197(49.37)
Women	195(48.87)
Non-binary	6(1.50)
Gender-fluid	1(0.25)
Age groups	
18 – 29	111(27.82)
30 – 39	108(27.07)
40 – 49	74(18.55)
50 – 59	82(20.55)
60 +	24(6.02)
Parental status	
Parents	183(45.86)
Not parents	216(54.14)
Level of contact with people with intellectual disability	
(Participants could select all that applied)	
Have intellectual disability	4(1.00)
Have no contact	161(40.35)
Have minimal to moderate professional contact	95(23.81)
Have frequent and/or significant professional contact	24(6.02)
Have minimal to moderate personal contact	116(29.07)
Have frequent and/or significant personal contact.	29(7.27)

foundation in the theoretical approach posited by Barnett et al. (1993 as cited in Goodvin et al., 2007), which classified neglect into four subtypes: lack of supervision, failure to provide, emotional neglect, and educational neglect.

The wording of some of the questions were altered slightly to reflect Australian vernacular (e.g., ‘nightstand’ was changed to ‘bedside table’). Other changes include the replacement of ‘their’ for ‘his or her’ to improve readability and one question was removed because it was not considered relevant to an Australian population (i.e., time-restricted access to hot water in the home).

4.2.3.2 Perceptions of Responsibility, Physical, and Mental Health Outcomes of Neglect.

Additional Likert scale questions were added to ask about victim-survivor responsibility, perpetrator responsibility, and potential future mental health problems. These questions came from Giglio et al.’s (2011) study on perceptions of child sexual abuse. The Likert scale for these questions were adjusted from 7-point to 6-point to be consistent with the Goodvin et al. (2007) items. The perpetrator intentionality question was taken from Dickerson et al.’s (2017) study on perceptions of child neglect. The Likert scale for this item was changed from 5-point to 6-point to be consistent with the other items in the questionnaire. I added an additional question about the potential for future physical health problems for the victim-survivor to capture a full sense of the participants’ perceptions of their wellbeing. All the measures included have previously demonstrated good psychometric properties. See Figure 3 for the final vignettes in the current study.

After each vignette, participants were asked to rate the following questions on a 6 point Likert scale: this is not neglect (0) to very serious neglect (5), in this situation, the child should be given all the blame (0) to no blame (5), in this situation, the parent should be given all the blame (0) to no blame (5), as a result of this encounter, in the future, the child will

Figure 3

Child Neglect Vignettes

Emotional neglect

1. A parent shows no interest in their primary school-age child’s achievements.

2. A parent frequently denies their 12-year-old child the opportunity to participate in school activities because it interferes with the parent's plans.
3. A parent consistently rejects their 6-year-old child's attempts to gain attention.
4. A child is doing poorly in school and the parent fails to come to parent teacher conferences.

Lack of supervision

5. An 8-year-old is left at home alone for several hours while the parents are shopping.
6. Household cleaning products are kept in an unlocked cabinet under the kitchen sink in the home of a toddler.
7. A 5-year-old does not ride in a car seat while the parent is driving.
8. Parents allow school-age children to ride in the back of an open ute on the highway.
9. A parent leaves a 3-year-old in a car seat in a locked car while paying for petrol.
10. A parent keeps a loaded gun in their bedside table.

Failure to provide

11. An 8-year-old sleeps on a dirty mattress without sheets.
12. The table for the family meals is too small and a 7-year-old eats his meals on a bed in another room.
13. There are many appliances in the house but most are old and need to be fixed—for example, the refrigerator that does not keep the food very cold.
14. An infant with no medical problems does not gain weight for over 4 months.
15. A child does not have a warm winter coat.

Educational neglect

16. A parent allows their child to miss 25 days of school without explanation.
17. A child has missed 3 consecutive weeks of school not due to illness.
18. A parent excuses their child from school for 25 days in a term.

likely have no mental health problems (0) to many mental health problems (5), as a result of this encounter, in the future, the child will likely have no physical health problems (0) to many physical health problems (5), and the parent is acting intentionally not at all (0) to extremely (5).

4.2.3.3 Short Answer Questions.

The questionnaire included five short-answer questions. These questions asked about impressions of the neglect, victim-survivors, perpetrators, for additional comments, and to define neglect.

4.2.3.4 Demographic Information.

Demographic information was collected including age, gender, parental status, and contact with people with people with intellectual disability.

4.2.4 Procedure

The data were collected between the 11th and the 26th of October 2021. The study was made available to eligible participants through their Prolific account. If participants choose to take part in the study after reading a short description of the study, they were directed to the online survey hosted by Qualtrics™. The survey took approximately 15 minutes to complete, and participants were reimbursed for their time. An information sheet was presented before informed consent was provided. Participants were then randomly assigned into one of two groups: one group was informed that all the victim-survivors in the subsequent vignettes had an intellectual disability. These participants were then presented with the World Health Organisation's definition of intellectual disability and a manipulation check question to ensure that they attended to and understood the information. If participants got this question wrong, they were redirected to the World Health Organisation's definition of intellectual disability and presented with the manipulation check question again. The second group was not provided with any additional information about the victim-survivors with the assumption that they would understand that they did not have intellectual disability.

Pilot testing showed that presenting all 18 vignettes resulted in participant fatigue. Thus, participants were presented with 10 randomly selected vignettes from the pool of 18 items, in a randomised order to control for order effects. Each vignette was followed by six 6-point Likert scale questions (detailed above) presented in a random order. After the vignettes, participants were shown an attention checking question to ensure that they were attending to the task (i.e., "Please do NOT select an answer for this question and move on to the next page"). The short-answer questions were then presented. Participants were encouraged but not forced to respond to each question.

After completing the survey, participants were informed of the specific focus of the study and directed to educational and support resources. Finally, participants were provided with a link that redirected them back to Prolific where their participation was confirmed.

4.2.5 Analysis

Internal consistency (Cronbach's alpha) was calculated using expectation maximisation whereby values that were missing (due to each participant being presented with 10 out of a pool of 18 vignettes) were replaced. A Multiple Factorial Analysis of Variance (MANOVA) was used to determine the interactions between the intellectual disability status of the victim-survivor, participant gender, parental status, and level of contact with people with intellectual disability. A Kendall's Tau-B (nonparametric test) was used to determine whether there was a correlation between participants age and perceptions of neglect severity (the assumption of normality was violated for a Pearson's correlation). A One-way repeated measures ANOVA was used to identify which subtype of neglect (i.e., lack of supervision, lack of providing, emotional neglect, educational neglect) was perceived as being the most severe.

Responses to the short-answer questions were analysed using a conventional content analysis (Hsieh & Shannon, 2005). The data were uploaded to NVivo and each question was analysed separately. After becoming thoroughly familiar with the data by reading and re-reading responses, inductive coding was conducted to identify key concepts throughout the text. Codes were grouped to form meaningful categories based on commonalities within and differences between them. While the analysis was conducted by one researcher, the categories were reviewed, edited, and discussed within the research team to ensure they accurately represented the data and addressed the research question. Finally, categories were summarised with definitions that described the data.

4.3 Results

4.3.1 Internal Consistency

The Cronbach's alpha was excellent for the overall measure ($\alpha = .93$). The internal consistency for each of the measured perceptions was good to excellent: Neglect severity ($\alpha = .87$), victim-survivor responsibility ($\alpha = .85$), perpetrator responsibility, mental health outcomes ($\alpha = .93$), physical health outcomes ($\alpha = .93$), and perpetrator intention ($\alpha = .87$).

4.3.2 Perceptions of Neglect Influences

A Multiple Factorial Analysis of Variance (ANOVA) was used to determine whether perceptions of neglect were influenced by the victim-survivors either having or not having an intellectual disability and the participants' gender, parental status, and contact with people with intellectual disability ($N = 399$). There were no significant effects found between the victim-survivor having an intellectual disability or not and perceptions of neglect severity, F (1, 376) = 2.65, $p = .104$, partial $\eta^2 = .01$ (small effect size). Significant effects were also not shown between perceptions of neglect and the participants' parental status F (1, 376) = .286, $p = .593$, partial $\eta^2 = .00$, or contact with people with intellectual disability F (1, 376) = .286, $p = .593$, partial $\eta^2 = .00$. Due to the lack of differences, no further exploration was deemed necessary for these variables.

A significant association was found between perceptions of neglect severity and the gender of the participant, F (1, 376) = 7.35, $p = .007$, partial $\eta^2 = .02$. To examine the effect of gender on perceptions of neglect more closely, a series of independent sample t-tests were conducted with neglect severity, mental health outcomes, physical health outcomes, and perpetrator intentionality and all were found to be significant with effect sizes ranging from small to medium. Assumptions for the victim-survivor and perpetrator responsibility scales were violated and therefore a Mann-Whitney U (nonparametric) test was conducted and found to be significant for both the victim-survivor and perpetrator with small effect sizes.

See Table 7 for the responses of men and women participants for each of the independent variables.

Table 7

Gender Differences in Perceptions

Independent variables	Women (n= 195)	Men (n = 197)	Effect size		p	Mean difference	Confidence intervals 95%	
	Means (SD)	Means (SD)	*d*	*r*			Lower	Upper
Neglect severity	34.33 (7.61)	32.25 (8.10)	.27		.009	2.08	.52	3.64
Victim-survivor responsibility	46.10 (4.80)	43.46 (6.29)		-0.11	<.001	2.64	1.53	3.75
Perpetrator responsibility	8.19 (5.32)	10.14 (7.28)		-0.24	.033	-1.94	-3.21	-.68
Mental health outcomes	26.94 (8.42)	22.54 (9.27)	.50		<.001	4.40	2.64	6.16
Physical health outcomes	21.32 (9.58)	18.82 (9.22)	.27		.009	2.51	.644	4.38
Perpetrator intentionality	36.63 (7.10)	34.21 (7.40)	.33		.001	2.42	.978	8.86

Note. SD= Standard deviation. Scoring note: Higher scores indicate perceptions of greater severity, intentionality, and that more negative outcomes are likely. With regards to responsibility, lower scores indicate perceptions of greater responsibility.
Data from people that indicated that they were gender binary or gender fluid could not be included because of the small sample sizes.

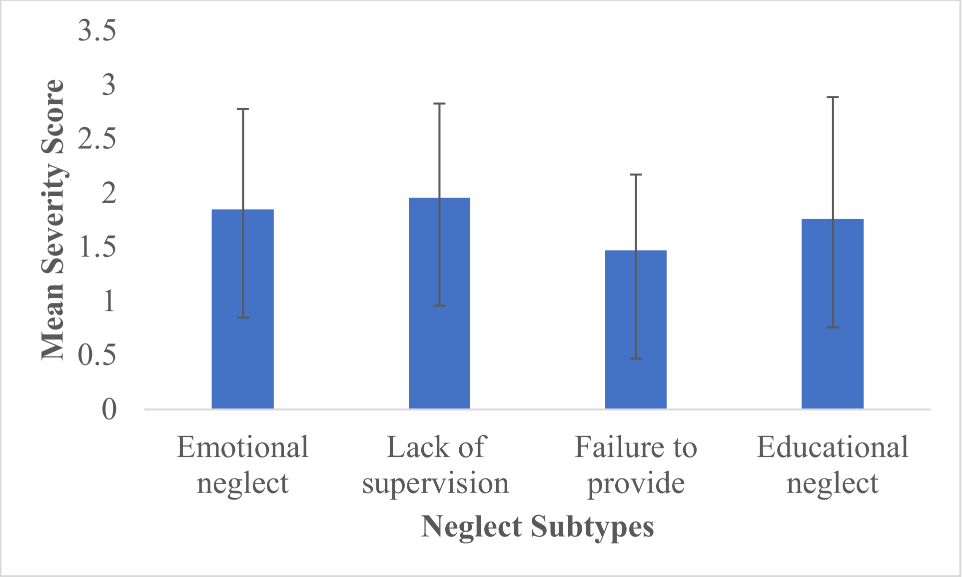
A significant interaction was found between perceptions of neglect severity and participants' gender, parental status, and contact with people with intellectual disability, F (1, 376) = 5.812, p = 0.16. This indicates that the women who are parents and have no contact with people with intellectual disability rated neglect as more severe than men who are not parents and have contact with people with intellectual disability. Participant age was not correlated with perceptions of neglect, with Kendall's Tau-B test indicating no correlation between age and perceptions of neglect severity, τ = - .21, p = .540.

4.3.3 Neglect-type Severity

A one-way repeated measures ANOVA identified that there was a significant difference between perceived severity of the subtypes of neglect F (3, 1173) = 20.10, $p < .001$, partial $\eta^2 = 0.05$. Pairwise comparisons further illustrated these differences. Lack of supervision (M = 1.96, SD = .87) was perceived as being significantly more severe than educational neglect (M = 1.76, SD = 1.13, p = .045) and failure to provide (M = 1.47, SD = .70, p < .001) but not emotional neglect (M = 1.85, SD = .93, p = .691). Emotional neglect was rated as significantly more severe than failure to provide (p < .001) but not educational neglect (p = 1.00). For further illustration of these differences see Table 8.

Table 8

Neglect Subtype Severity Scores



Note. Error bars show standard deviation. Higher scores demonstrate perceptions of higher severity.

4.3.4 Short Responses

Tables 9, 10, 11, 12, and 13 provide a summary of participants' answers for each of the five short-answer questions. The tables provide the question, the number of participants that answered each question, concepts that appeared in the content, the number of participants that referenced each concept, and examples from the data. Concepts that appeared fewer than

10 times in the data were omitted. Minor spelling and grammatical changes were made to the excerpts to improve readability.

A common theme across the short answer questions was that the context of the neglect was important. This consideration was often expressed in relation to the family's financial ability to provide for their children. Another concept that appeared across several short answer questions was that some participants used their own experience as a lens through which to interpret the neglectful scenarios. Experiences were drawn on as a parent and as a victim-survivor of abusive and neglectful parenting. Victim-survivors were discussed as powerless victims who should be adequately cared for. Responses to parents varied with some participants labelling them as bad people and others as having reduced responsibility due to parenting and financial challenges. Across the sample a broad spectrum of definitions of neglect were included with participants considering concepts such the active or intentional nature of the neglect, the child's needs, and the parents' capacity to care.

4.4 Discussion

This mixed methods study explored public perceptions of child neglect. Understanding public perceptions of neglect is important because of their significant influence on the identification, intervention, and prevention of child neglect. The quantitative results revealed that perceptions of child neglect were influenced by participant gender but not victim-survivor intellectual disability nor participants' age, parental status, or contact with people with intellectual disability. Lack of supervision was rated the most severe subtype of child neglect and lack of providing as the least. Qualitative responses from participants emphasised that the context surrounding neglectful behaviours were considered important.

Table 9

What Aspects did you Need to Consider when Answering these Questions? (n = 397)

Concept	*n*	Exemplar responses
Context is important Participant's consideration often extended beyond the scenario to information that was and was not provided the social context. Often more information was desired.	144	"The potential for extended circumstances and the context that I'm not aware of" "Other factors that weren't mentioned and assumptions about the family's background"
Parent factors Different aspects of the parent were considered when answering the questions including the parents overall, their role, point of view, behaviour, ability to provide (e.g., financial restraints, drug and alcohol problems).	113	"Whether the parents were at fault for these problems or if there is an underlying issue that isn't presented (not financially stable)" "What the parents were going through at the time"
Outcomes for the victim-survivor Participant considered the outcomes of neglect for the child.	101	"I thought about if the child will be hurt in any way." "The potential danger of the parents' actions, and the long-term impact on the children."
Parent intentionality Participants considered the parents intentions.	75	"…whether I thought the parent was deliberately or unintentionally negligent" "Whether it was neglect or just unawareness"
Victim-survivor factors Different aspects of the victim-survivor were considered such as age, point of view, power, behaviour, needs, and disability*.	57	"The capacity of the child to influence the situation." "The age and possible mental disability of the children"
Blame Participants considered who was responsible.	39	**"**Who was at fault" "How neglectful or irresponsible certain behaviour was and how to distribute blame and the potential impact on mental and physical health"
Neglect definition Participants considered what constitutes as neglect in terms of severity, duration, repetition, social acceptability, type of neglect (e.g., physical, emotional).	39	"Social rules (in some countries it is considered ok to stay in the back of a pickup)" "Whether the basic physical and emotional needs of the child were being met. The level of risk of adverse outcomes."

Risk to the child Participants considered the risk of potential harm to the child.	31	"What harm might come to the kid if it happened and whether it would be short or long term." "The amount of immediate danger"
Participants' experience Participants considered their own experience and/or world view.	18	"Put me into the situations as the parents and think whether I can accept the behaviours." "Has this event happened to me, and was the outcome bad and affected me negatively"

*Note: One group (*n*= 195) was told that the victim-survivors had an intellectual disability.

Table 10

What was your Opinion of the Children in the Scenarios? (n = 396)

Concept	***n***	**Exemplar responses**
Victims of neglect Participants described the child victim-survivors as neglected, vulnerable, and innocent.	202	"Innocent of any guilt and needing help" "A child should not be blamed by parents' negligence, as children are not supposed to take care of themselves."
Powerless Participants commented on the lack of control, agency, and power that the children had in the scenarios. This was sometimes discussed in terms of a lack of capacity because of their age.	68	"Very young, not at an age where decision making may be optimal" "They aren't developed enough to look after themselves and know what's wrong and right"
More care Participants stated that the child victim-survivors needed more care from their parents.	27	"They were not being nurtured the way they deserve to be." "They weren't being care for properly or appropriately"
Neutral Participants indicated that they had no opinion or neutral feelings towards the children in the scenarios.	25	"Completely neutral" "None in particular"
Context is important Participants indicated that they could not form an opinion without more information.	18	"There was insufficient information to have an opinion of them." "No opinion really as they weren't given much description"

Some victim-survivor responsibility Participants indicated that the child victim-survivors were sometimes somewhat responsible in the scenarios.	13	“In some of the scenarios the children may have had a part to play depending on their age - no age was provided. For instance, a teen may have skipped school, or they may have left their coat at home consciously or not. Apart from this I had no opinion on the children and focused on adult behaviour.” “The children could be blamed for some of the contexts however it can be assumed that the parents need to do a better job”
Disability The victim-survivors disability was mentioned*	10	“I think the children may have been mentally challenged and needs more attention and care.” “The children are faultless. As dependents, they solely rely on parental figures to meet their needs (this applies to children with intellectual disabilities, as well as all other children)”

*Note: One group (*n*= 195) was told that the victim-survivors had an intellectual disability.

Table 11 ***?***

What was your Opinion of the Parents in the Scenarios? (n = 397)

Concept	***n***	**Exemplar responses**
Context is important Context was expressed as important and considered in relation to the scenarios, particularly the parents’ circumstances (e.g., mental health, finances). They also mentioned that the lack of context made it difficult to form an opinion.	123	“They could be victims of unfortunate or unforeseen circumstances; however, I believe that children of such a young age always require a bare minimum of attention and care. that is a parent's responsibility.” “The parents with no other presented stimuli seem to be giving serious neglect to the children and deserved the majority of the blame if there were no underlying issues such as being financially unstable to afford a consistent flow of food”

Neglect Participants' opinion of the parents was discussed in relation to perceived neglect. Neglect was identified at varying levels (i.e., not neglect, some neglect, serious neglect). Sometimes the parents were simply referred to as "neglectful".	107	"Some parents were quite neglectful while others only minorly." "They were neglectful to their children"
Bad parents/people The parents were discussed as being bad parents and people.	102	"Pretty much scum who shouldn't have kids" "They were deliberately doing things that were selfish"
Responsibility Participants' opinions of the parents were influenced by their understanding of the responsibilities of parenthood and in relation to their responsibility for the neglect.	75	"It's the parent's responsibility to take care of their children. If they neglect the child, it's 100% the parents to blame." "My opinion of the parents mainly was that they were to blame for most of the scenarios, although I do understand the pressure of raising special needs children and the need for help with them."
Intentionality Opinions of the parents were influenced by the perceived intentionality of the neglect.	41	"They were all at fault in some way, but I don't believe that all situations were intentionally malicious/neglectful." "Most of them seemed to be intentionally neglecting their kids"
Consideration of the children Participants' opinion of the parents was considered in relation to outcomes of the neglect on the children.	26	"The parents were not too concerned about the child's safety and wellbeing; they were more concerned about themselves" "They should put their kids first"
Sympathy for the parent Consideration for the parents in the situation.	21	"Most parents are doing the best they can, given their circumstances, especially financially" "They were in a difficult position. Society may deem their decisions unfair, but I believe they had their valid reasons."
Need for additional support Participants discussed how the parents in the scenarios needed help to raise their children as well as for themselves.	12	"Some completely negligent. Some possibly suffering mental health issues themselves, or in need of some assistance." "They need better assistance and education"

Don't know better Participants discussed the parents neglect in relation to their lack of knowledge and education.	11	"They are people who don't know how to parent, perhaps brought up in similar circumstances themselves." "Sometimes neglectful, but often it will be lack of knowledge or there could be circumstances which make them blameless (e.g., socio-economic reasons for not having a winter coat)"

*Note: One group (*n*= 195) was told that the victim-survivors had an intellectual disability.

Table 12

Do you Have Anything Else to Add? (n = 339)

Concept	*n*	Exemplar responses
Context is important Participants commented on the context of the neglect and indicated that it was important by commenting that they would like more information to accurately answer the questions.	57	"Consider adding further detail to the scenarios. Judgement on the severity of the neglect may change depending on any extenuating circumstances" "Some of those situations would depend on the capabilities of the children."
Participant experience Participants related the scenarios to their own lived experience either as someone who works in a related field, a parent, or as a victim-survivor.	25	"A couple of the scenarios did give me pause to reflect on my own behaviours (especially in relation to children's attention-seeking behaviours)." "As someone who came from a broken family it pains me to see how much suffering these children have to go on a daily basis without even realising that they aren't being properly cared for."
Parenting role The role of parents was mentioned in relations to responsibility, pressure, difficulties, need for support, importance, and impact (on the children).	21	"If we bring the child to this world, we are responsible to do whatever is required" "I know it's not always so straight forward, and I feel sad to know that I would readily judge a struggling parent so harshly, however it is always a parent's responsibility to

		provide the utmost care to their defenseless, developing child. I wish every child in the world was warm, comfortable, loved, supported. Life should not be without challenges, but your parents should always be a source of safety.”

Table 13

How do you Define Neglect? (n = 398)

Concept	*n*	Exemplar responses
Types of neglect/outcomes Participants referenced or provided examples of different types of neglect and/or the different ways that neglect can have an impact.		
Physical	109	“Deliberately through action or inaction having a negative impact on the physical or mental health of a person” “Not providing for a child or other vulnerable person the necessities of survival, including emotional, physical (such as food, shelter, clean living conditions etc.)”
Mental (including emotional, mental, and psychological)	102	“An act where the parent fails to care for the child in an appropriate way whether that is emotionally or physically.” “Anything that puts a child at risk be it physical or mental. Children need all our attention and care at all times.”
Intellectual/educational	10	“Absence of care and protection for physical, emotional, medical, educational etc. needs” “Not meeting fundamental needs (comfort, nutrition, education, safety) of someone, usually intentionally.”

Care Participants defined neglect as a lack of caring (emotionally) and a need to care (practically) for the child.	128	“An act where the parent fails to care for the child in an appropriate way whether that is emotionally or physically.” “Not caring or providing appropriate support for someone in need”
Needs Participants discussed neglect in terms of the needs of the victim-survivor not being met, or not being met to a satisfactory level.	98	“Basic needs aren't being met my someone whose role it is to meet them” “No providing with basic needs”
Intentionality Participants discussed neglect in terms of whether or not they perceived it as intentional.	95	“Intentional causing physical, mental or spiritual harm to another living being” “Parent who is unable or unwilling to provide care”
Outcome Participants defined neglect in terms of the outcomes for victim-survivors, including the negative impacts and the prevention of positive outcomes	92	“Intentional or unintentional actions (or lack thereof) that have the potential to cause physical, mental or emotional harm” “Acting or failing to act in a manner that causes harm to a child”
Responsibility Participants referenced the responsibilities of the parent and how their neglect constitutes a violation of these responsibilities.	49	“Failure to perform basic duties that form the task of raising a child, from fulfilling basic needs like food and shelter to emotional needs, whether done consciously or not doesn't matter” “The action of ignoring and avoiding the responsibilities and wellbeing of your child”
Attention Participants discussed how children need attention and that a lack of attention constitutes neglect.	47	“When you are not paying attention ignoring the things” “Basic needs not been met, love and affection not shown and given, time not spent”
Active/passive Participants referred to neglect as active and/or passive.	42	“Actions or lack of actions that harm a child or increase the risk of harm of any kind” “Doing things or not doing things in the best interest of the child.”
Ignore	30	“Ignoring (either purposefully or not) important aspects that help children grow up to be safe, happy and healthy.”

Participants discussed neglect in terms parents ignoring the children and their responsibilities.		"Intentionally ignoring the needs and wants of a child"
Risk Participants defined neglect in terms of the risk it posed to the child victim/survivors.	24	"Knowingly exposing the child to any form of risk or doing /not doing something that could cause psychological and or physical issues for the child" "Acting purposefully without considering risks associated"
Capacity Participants defined neglect in terms of the parents' capacity to care for their children (e.g., financially, mental health problems)	16	"If it is not within a parent's means to provide, then it cannot be neglect e.g., if the child has no winter coat because the parent is unable to provide it, that's not neglect; that's just sad and pitiful and such parents ought to be encouraged to seek State help. In all likelihood, such parents may be having some mental issues themselves" "Inability to care for someone else"
Dependent Participants referred the child victim-survivors as being dependent and relying on their parents.	12	"Fail to look after a dependent's wellbeing" "Repeated intentional refusal to act in the best interests of a dependent with full comprehension of the consequences"
Frequency/longevity Participants discussed how the definition of neglect was influenced by the frequency and/or time span of the behaviour.	12	"Where a child's needs both physical and emotional are not being met on a consistent basis." "Ongoing lack of providing reasonable care and support of a child and their developmental needs"

*Note: One group (*n* = 195) was told that the victim-survivors had an intellectual disability.

No differences were found in perceptions of child victim-survivors with and without intellectual disability. This finding does not align with some current literature that suggested that public perceptions of people with intellectual disability are commonly negative (Renwick et al., 2014; Werner, 2015). There are several potential reasons for this lack of difference in perceptions. First, the findings may suggest that portrayals and perceptions of people with intellectual disability are changing as has been shown in some research (Devotta et al., 2013) and that the public perceive and value people with and without intellectual disability similarly. Second, the absence of difference may indicate a ceiling effect whereby all child neglect is considered equally abhorrent regardless of disability. This could suggest a social understanding and appreciation for the vulnerabilities, rights, and value of all children. Further, the results may suggest that the questionnaire was not sensitive enough to capture the nuances of perceptual differences as has been shown in some research (Bottoms et al., 2011; Werner, 2015). For example, Bottoms et al. (2011) found that participants assigned similar verdicts, perpetrator responsibility, and infant worth in a mock jury study comparing perceptions of a case where a father killed an infant with and without intellectual disability. However, more subtle, and sensitive measures within the study did demonstrate a difference in perceived worth of the murdered infant (i.e., lower sentences and less mental illness attributed to the father who killed the infant with intellectual disability). This suggests an implicit bias that was not captured through explicit questioning that may also be the case in this study. Future research should seek to further explore the nuances and impacts of public perceptions of neglect of children with intellectual disability.

Gender influenced perceptions of neglect, with women in the study perceiving neglect as more severe than men. Gender differences in perceptions of maltreatment are well documented in the literature (Bornstein et al., 2007; Bottoms et al., 2011; Dickerson et al., 2017). For example, Bornstein et al. (2007) found that women rated child abuse as more severe than men in a study of perceptions of child physical and sexual abuse from the USA. Additionally, women were more likely to believe the victim-survivors and that the abuse would reoccur (Bornstein et al., 2007). The findings of this study suggest that men may be less likely than women to recognise neglect in real world settings. Future research should investigate how these gender differences in perceptions of child neglect impact identification and intervention in education, health care, legal, and child protection settings. This information could inform effective education and training for professionals (e.g., teachers, doctors) and the community (e.g., media campaign on recognising the signs of neglect).

Lack of supervision was considered the most severe type of neglect. Lack of supervision has been shown to be the most common type of maltreatment and can have detrimental and long-lasting effects (Notrica et al., 2020; Snyder & Merritt, 2016; Sokol et al., 2021). Lack of supervision can result in children experiencing a multitude of serious injuries (Notrica et al., 2020). Contextual factors for supervisory neglect include inattentive, distracted, and incompetent caregiving, parental mental health and substance abuse issues, the parent having inadequate problem-solving skills, lack of home adaptation and safety compliance, poor access to childcare, child’s exposure to domestic and inter-personal violence, child’s access and/or use of substances, and the child being permitted to partake in risky behaviour (Notrica et al., 2020; Sokol et al., 2021). As a result of its prevalence and impact, future research should seek to investigate supervision neglect as a unique form of neglect to further understand how it could best be identified and addressed. Research could inform effective strategies to identify families at risk of supervision neglect and develop tools that educate and empower parents to make changes to improve their children’s safety. The ParentsCAN program is an example of how evidence-based parent training programs can effectively increase awareness and understanding of child abuse and neglect (Sahillioglu & Akma, 2021).

In the qualitative responses, participants often conveyed that the context of neglect was important, with some participants stating that they could not provide accurate responses without additional information. This desire for background information suggests that participants are reluctant to make assertions about parenting behaviours without full understanding of the situation. This unwillingness to judge may be due to participant empathy regarding the challenges associated with parenting as expressed by some participants in this study and in other maltreatment research (e.g., study on parents who killed their children with disabilities; Brown, 2012). Further, some of the scenarios may be considered less neglectful because they are regarded as poverty related, as expressed by some participants who stated that a potential lack of financial resources may justify the parents' behaviour. Additionally, participants rated lack of providing as the least severe form of neglect, again indicating that participants may not consider a person's financial inability to provide for their child/ren as a form of neglect or perhaps a minor form. The relationship between neglect and poverty is a contentious issue in some child maltreatment research with some arguing that the link is intrinsic and others that behaviours resulting from poverty are not intentional and therefore should not be considered neglectful (Golden et al., 2003; Lavi & Katz, 2016). This finding suggests that the public identify poverty as an important issue in relation to child neglect. This social concern should inform government and organisation resource allocation to support those experiencing poverty (e.g., school meal programs), and working towards reducing it (e.g., increasing wage and working opportunities).

In this study, some participants expressed that they examined the vignettes through the lens of their personal history (e.g., abuse or neglect, experience as a parent). The impact of past experiences on perceptions has previously been demonstrated in the literature. For example, in a study of community reporting behaviours of child maltreatment in the USA, Wolf et al. (2018) found that participants with more adverse childhood experiences were more likely to intervene in and report maltreatment. This was despite evaluating the scenarios in a similar way to those without adverse childhood experiences (i.e., not more severe). Wolf et al. (2018) suggests that people who have experienced abusive parenting may have greater empathy for the victim-survivor and therefore feel compelled to intervene. Further, parental and professional experiences have been shown to impact how professionals within health, child protection services, education, and the police understand and react to child neglect and maltreatment (Grégoire-Labrecque et al., 2020; Lines et al., 2020). More research is needed to understand how parenting and adverse childhood experiences impact reporting behaviours of child neglect to enhance the efficacy of community education and child protective services.

4.4.1 Strengths

This study contributes to child neglect literature, which is an under-researched form of maltreatment, especially regarding children with intellectual disability (Jones et al., 2012; Stoltenborgh et al., 2013). As previously discussed, understanding public perceptions is imperative because they inform how people understand and behave in relation to child neglect which influences detection and perpetration (Dickerson et al., 2017; Ferguson & Bargh, 2004; Son et al., 2017). Though our findings do not support previous literature describing differences in perceptions of people with and without an intellectual disability, this may reflect broader beliefs that all children are vulnerable (compared to adults) or may reflect some methodological limitations in the current study (e.g., measure sensitivity). Importantly, this study was guided by two people with intellectual disability. Involving people with intellectual disability is important because people with intellectual disability should have input into research about them (Bigby et al., 2014).

4.4.2 Limitations

The vignettes used in this study purposefully present low levels of neglect to identify the threshold of when behaviours are defined as neglectful. More severe neglect scenarios may have elicited responses that demonstrated differences between perceptions of children with and without intellectual disability. However, very few validated neglect perceptions scales were available when this study was conducted, and the scale used was considered the best fit for the research question. Additionally, while extensive discussions were had regarding coding within the research team, the rigor of this study would have been enhanced if a second researcher had reviewed the coding. Future research should seek to develop and validate a scale that can examine perceptions of extreme neglect to understand whether these create differences in perception of children with and without an intellectual disability.

4.5 Conclusion

Child neglect is an important and often overlooked social issue that impacts many children around the world in profound and lasting ways. This study contributes to the understanding of perceptions of child neglect by adding to literature regarding gender differences and providing information on the perceptions of severity for the different sub-types of neglect. Further, it provides a platform for further investigation into the nuances of perceptions of the neglect of children with intellectual disability. These findings are enhanced by the qualitative data that further illustrates and provides depth to the nuances of child neglect perceptions. Understanding how the public define and consider child neglect is imperative to improving how it is identified, intervened in, and ultimately prevented.

Chapter 5: Familial Maltreatment of People with Intellectual Disability: A Community Dialogue Study

5.1 Introduction

Maltreatment of people with intellectual disability is a significant social issue (Dion et al., 2018; McDonnell et al., 2019). People with intellectual disability are more likely to be maltreated than those without (Maclean et al., 2017) and the physical and psychological effects of these experiences can be severe and long-lasting (Rowsell et al., 2013). Neglect is one form of maltreatment that is particularly pervasive (Stoltenborgh et al., 2013). Compared to other forms of maltreatment (i.e., physical and psychological abuse), neglect is the most challenging to detect (Son et al., 2017) and can also be difficult for victim-survivors themselves to recognise (Lavi & Katz, 2016).

There are several barriers associated with identifying and intervening in maltreatment for people with intellectual disability. As previously mentioned, the public may find it challenging to identify the neglect of people with intellectual disability (Son et al., 2017). This difficulty in detection extends to professionals working with people with disability (Mallén, 2011) who can additionally hold negative perceptions of those so labelled in maltreatment settings (e.g., unable to provide an accurate account of abuse, Fraser-Barbour, 2018). Further, people with intellectual disability are less likely to report their experiences of maltreatment than those without (Soylu et al., 2013). Communication barriers may also influence the challenges associated with substantiating claims of neglect of children with intellectual disability within child protective service settings (De La Sablonnière-Griffin et al., 2021). Thus, opportunities to intervene in maltreatment of people with intellectual disability are greatly diminished.

For people with intellectual disability, the family home presents additional risks factors for maltreatment. Some research suggests people with intellectual disability are more likely to be maltreated by a family member compared to any other type of perpetrator (Hewitt, 2013; McDonnell et al., 2019; Vadysinghe et al., 2017) and at greater frequency compared to people without intellectual disability (Dion et al., 2018; McDonnell et al., 2019). This is problematic given the many barriers to identification of familial maltreatment of people with intellectual disability. For example, families tend not to have maltreatment policies and practices such as those enforced in organisational settings (e.g., working with children checks; Working with Children Act, 2004), families are often not suspected as perpetrators of maltreatment (Meer & Combrinck, 2017), and maltreatment perpetrated by a family member is less likely to be disclosed than maltreatment perpetrated by persons outside the family (Lemaigre et al., 2017). As a result, opportunities to identify and intervene in familial maltreatment of people with intellectual disability are limited, despite it being the most frequent form of maltreatment.

5.1.1 The Present Study

The purpose of this study was to meaningfully disseminate and confirm the findings of the PhD research with people with intellectual disability. This purpose is achieved by addressing three primary aims. First, to disseminate the findings from previous studies within the research project (Chapters 2, 3, and 4) in a meaningful and accessible way to people with intellectual disability and the wider community. Dissemination has an important role in enhancing public knowledge and practice when conducted in a meaningful and accessible manner (Brownson et al., 2018). To achieve meaningful dissemination, we created materials that were shared with relevant people and organisations and by discussing the topic in an accessible way with people with intellectual disability. People with intellectual disability should have access to research about them, including research on important social issues such as familial maltreatment (Chinn & Homeyard, 2016).

Second, to explore how people with intellectual disability perceive the findings and the topic more broadly. It is important to explore the perspectives of those with lived experience because it provides a depth of understanding only possible from this first-hand perspective. Consequently, the participants provide an informative and important lens through which the research and topic can be interpreted. Although participants were not required to have experienced familial maltreatment to take part, they all had the experience of having an intellectual disability and were therefore considered experts by experience. Involving people with intellectual disability in the research is intended to be beneficial and ethical, for the people with intellectual disability who participate and for the broader field of research (Bigby & Frawley, 2010). The setting provides an opportunity for people with intellectual disability to share their ideas with researchers and peers.

Third, to disseminate these perceptions in academic, professional, and community settings. It is important that the research is examined and informed by people with intellectual disability because none of the researchers have a disability and therefore lack the ability to interpret the findings through this lens (Rios et al., 2016). Further, the voice of people with intellectual disability contributes a valuable perspective to academic enquiry. It is hoped that this will be achieved through the publication of this thesis, discussions with peers, potential future publications reflecting on the process of working with people with intellectual disability in this research (not specifically regarding the findings presented in this Chapter), and conference presentations.

This community dialogue study involves the dissemination and exploration of previous research conducted on the maltreatment of people with intellectual disability by family. The valuable perspective of people with intellectual disability on the important social issue of familial maltreatment is explored through discussion of the findings of previous studies within the research project.

5.2 Methods

This community dialogue study is conducted from a social constructionist position that posits that commonly accepted ‘truths’ are socially constructed and should be contested (Gergen, 1985). Further, a critical disability theory perspective informs this research which proposes that the social construction of disability is inaccurate and harmful (Procknow et al., 2017). The research project is guided by two people with intellectual disability to ensure that it is serves the interests of those so labelled.

5.2.1 Research Question

The research question for this study is: *How do people with intellectual disability understand the maltreatment of people with intellectual disability by family within the context of the studies previously conducted within the research project and more broadly?*

5.2.2 Participants

Six people with intellectual disability participated in this study. Of these, 4 were men and 2 were women ($M_{\text{age}} = 41.67$ years). Although all participants took part in the dissemination phase of the study, the two women chose not to contribute to the interview component. Two participants were interviewed together and two were interviewed individually, as per their preference. Recruitment involved the distribution of dissemination materials (described below), discussions with the lived experience collaborators, the engagement of a disability service organisation reference group, and through word of mouth.

This sample size was smaller than originally anticipated. Similar to the experiences of recruiting the lived experience collaborators, it was difficult to recruit people with intellectual disability to participate in this study. McCarron et al. (2022) identified several barriers to recruiting older adults with intellectual disability, some of which likely apply and contributed to the recruitment problems experienced in this study. Three of the barriers most likely to impact recruitment in this study include (1) Difficulties accessing this population (i.e., challenging for the researchers to find people with intellectual disability who were also willing to participate), (2) Communication difficulties (i.e., some people with intellectual disability experience communication differences), and (3) Dependence on gatekeepers such as family and staff (McCarron, et al., 2022).

5.2.3 Materials

5.2.3.1 Dissemination Material.

Dissemination materials including an accessible poster and a presentation were created to share the findings of previous research and recruit participants. One poster provided a summary of the results of the research project, recruitment information, a QR code linking to the presentation, and ethics information (see Appendix D). The second included definitions of the key terms used in the research as was used in the interviews (see Appendix G). The presentation was a recorded PowerPoint slideshow with video narration that summarised the findings from the previous studies and was 7.52 minutes in duration (https://www.youtube.com/watch?v=ehuBU67Afiw). The presentation could be accessed by the link or via the QR code on the summary poster. The research lived experience collaborators and another person with intellectual disability provided feedback on the dissemination materials and changes were made accordingly. The final dissemination materials were emailed to contacts of the supervision team who were invited to share the information with potentially interested parties and were posted on my social media pages and the Curtin University Psychology Facebook page.

5.2.3.2 Interview Guide.

I created the interview guide with the supervision team and the lived experience collaborators (Figure 4). The aim of the guide was to explore the perspectives of people with intellectual disability on the maltreatment of people with intellectual disability by family members. The guide included broad questions with potential prompts that avoided the inclusion of specific personal information. Questions focussed on how participants understood maltreatment and neglect, what research findings they deemed most important, and explored examples of neglect. The guide was designed for a one-hour interview.

Figure 4

Interview Guide

Interview guide

Introduction

- Welcome and thank participants
- Go through consent form
- Read through poster

Interview

- What does maltreatment mean to you?
- What does neglect mean to you?
- What information on the poster or presentation did you think was most important?
  - How did this information make you feel?
- How would you help someone who you knew was being neglected by a family member?
  - What would you tell them to do?
- How do you think things could change so that people with intellectual disability are not maltreated by family members anymore?
- Who do you think should be told this information? Brainstorm on the board
- How do you think we should we tell them? Brainstorm on the board (Letters, press release, art, presentation)
- Is there anything else you would like to say?
- Additional probes
  - Could you explain more what you mean by that?
  - Could you give me an example?

Cards

- Which of these cards would you like to talk about?
  - What is happening on this card?
  - Why do you think it is important?

Conclusion

- Thank participants and conclude interview

5.2.3.3 Getting Help Card.

This card contained information for different ways (i.e., phone, text, online chat, and website information) an individual could access help from relevant organisations for any potential distress caused by the interview and/or maltreatment (see Appendix H).

5.2.3.4 Stop Card.

Participants were provided with a red card reading ‘stop’ that could be used to indicate that the individual would like to pause or discontinue participation (see Appendix I). Northway et al. (2013) included this practice in their study on perceptions held by people with intellectual disability on abuse and perpetrators of abuse in the UK. The card allows participants to indicate a desire to stop without needing to interrupt proceedings, which may be uncomfortable in the interview environment.

5.2.3.5 Picture Cards.

Eight cards depicting potentially neglectful scenarios with a brief description were used in the interviews to facilitate conversation (see Appendix J).

5.2.4 Ethical Considerations

Ethics approval was ascertained from Curtin University before commencing the study (including the sharing of dissemination materials). This study conforms to the National Statement on Ethical Conduct in Human Research (NSECHR; 2007) by ensuring that merit and integrity, justice, beneficence, and respect are upheld throughout the research process. Chapter 4.5 of the NSECHR (2007) outlines that additional considerations are necessary when conducting research with people with intellectual disability. To ensure that the study was conducted and communicated in an accessible way, I discussed and reviewed procedures and content with the lived experience collaborators and research supervisors. For example, changes were made to the first draft of the dissemination poster after the lived experience collaborators recommended a decrease in the quantity of content and an increase in the colour contrast. Research was also conducted in line with best practice literature for conducting research with people with intellectual disability (e.g., Bigby & Frawley, 2010; Gate & Waight, 2007; Northway et al., 2013). For example, consent was an ongoing consideration throughout the interview through discussion and the use of the stop cards (Gate & Waight, 2007).

The topic and content of the research has the potential to cause distress. Considerations were made to minimise the chance of causing distress (e.g., excluding questions that address personal experience from the interview guide) and providing support if distress did occur (e.g., Getting Help Card). Additionally, recruitment information highlighted that experience of maltreatment was not necessary. This allowed people with intellectual disability to take part for altruistic reasons and avoids unnecessarily burdening those with a history of maltreatment. Further, participants were provided with opportunities to take breaks or cease their participation (e.g., stop card).

5.2.5 Procedure

The group interview was conducted during the disability organisations monthly reference group meeting, the two lived experience collaborators associated with this research were interviewed in their homes, and one interview was conducted in a café. Each participant was provided with a pack that included a copy of the research summary poster, a getting help card, a stop card, a demographic information form (which was completed and returned), and two participant information sheets (one to for the participant to keep and one to sign and return). Each component of the pack was explained before the interview began. Informed consent was obtained by thoroughly discussing the participant information sheet to ensure that the information was understood. The participant information sheet was then signed, the audio-recording equipment turned on, and the interview commenced. The duration of the interviews ranged from 31 to 54 minutes ($M = 43$ minutes). All participants were given a $30 gift voucher to compensate them for their time. Picture cards were used in all of the interviews and the ‘stop’ card was not used in any. I called each participant approximately a week after their interview to discuss whether the interview had caused distress and if they had additional information to provide. All participants indicated that the interview had been a largely positive experience, and none provided additional information.

5.2.6 Analysis

Recordings of the interview were transcribed using the transcription function available in the online version of Word via Outlook. I checked the transcripts and made necessary changes to ensure that they were accurate. Transcripts were then uploaded to NVivo where a conventional content analysis was performed. This form of analysis was chosen to describe the perspectives of people with intellectual disability on the findings and the topic without imposing predetermined concepts from existing theories (Hsieh & Shannon, 2005). While reading through each transcript I identified concepts that described important ideas within the data that were then developed into codes. The definitions and labels for these codes were created and refined throughout the analysis process. Similarities and differences within and between and categories were considered in this process of refinement (Hsieh & Shannon, 2005). These codes were organised into overarching groups within a table that included finalised definitions and illustrative excerpts from the data.

5.3 Findings

The findings from the conventional content analysis are presented in Table 14. The categories are organised into the three overarching research foci disability, maltreatment, and family to enhance the readability. Categories are presented with definitions, sample representation information, and examples from the data.

Negative public attitudes towards people with intellectual disability were identified and often discussed through the lens of personal experience. Some participants challenged these perspectives by pointing out that they were incorrect at the time of the event or upon reflection in the interview. Maltreatment was defined in general (e.g., lack of food and shelter) and in disability specific terms (e.g., differential treatment due to disability).

Maltreatment of people with intellectual disability was described as terrible and participants expressed sympathy for victim-survivors. Participants identified that maltreatment should be addressed at a broader community level through research and by government organisations. One participant discussed the role that people with intellectual disability can play in improving public perceptions of those so labelled. Psychological and emotional outcomes were identified as consequences of neglect for people with intellectual disability. The role of family in the lives of people with intellectual disability was discussed. Participants identified that families should support, accept, and build capacity for independence in people with intellectual disability. Some expressed gratitude for the care and support of their families.

5.4 Discussion

This study explores the perceptions of people with intellectual disability on the familial maltreatment of those so labelled. Examining the findings through the lens of people with intellectual disability is an important addition to the research project. A conventional content analysis identified negative social attitudes towards people with intellectual disability, responses to maltreatment, and the important role of family.

Participants observed negative perceptions of people with intellectual disability in the community such as that they were generally considered outside of the social norm. The literature also finds negative perceptions of people with intellectual disability. Some examples include research where participants assigned significantly shorter sentences for a father who killed an infant with intellectual disability compared to a father of an infant without (Bottoms et al., 2011), child protection service professionals who were shown to be reluctant to report abuse due to empathy for their families (Stalker et al., 2015), and documented cinematic representations which discourage social participation and interactions with people with intellectual disability (Renwick et al., 2014). However, some research suggested that perceptions of people with intellectual disability are improving as demonstrated by an increase in prosocial media content (Devotta et al., 2013) and positive perceptions expressed by university students (Phillips et al., 2019). Participants in this study also expressed hope for constructive change, as one participant articulated, “watch this space” (P3).

Participants identified several approaches to respond to the maltreatment of people with intellectual disability by family members. This study addressed one of the strategies; that is, to review and research the topic. The literature also calls for further research into the maltreatment of people with intellectual disability as it is an under researched topic (Dion et al., 2018). Participants additionally stated that people with intellectual disability and their families require support around maltreatment. This support could take the form of education and training for people who interact personally or professionally with people with intellectual disability, including family (Robinson & Chenworth, 2012). However, training and education could also be directed at people with intellectual disability themselves. Providing people with intellectual disability with tools has the potential to not only be empowering but additional presents an opportunity to prevent maltreatment rather than respond to it (Buhagiar & Azzopardi Lane, 2022).

Participants expressed that families play a significant role in the lives of people with intellectual disability, including in the development of life skills. Families can be an important part of supporting self-determination for people with intellectual disability, part of which involves developing life skills to live outside of the family home (Taylor et al., 2019). This was demonstrated in a study of self-determination promotion of people with intellectual disability within two Canadian families (Taylor et al., 2019). In this study life skills were developed through formal training programs as well as the family modelling behaviours such as cooking, cleaning, shopping, social and problem-solving skills with the mutual goal of

Table 14

Categories with Sample Representation and Data Examples

Category	**Description**	**Total**	**P1**	**P2**	**P3**	**P4**	**Excerpt**
Disability							
Negative perceptions of people with intellectual disability	Negative public and perpetrator perceptions of people with intellectual disability. Discussion was both general (e.g., describing people with intellectual disability as existing outside of the norm) and in relation to maltreatment (e.g., contributing to maltreatment).	37	4	2	17	14	“They didn't rate people with disabilities, and they didn't want her involved with people with disabilities.” P1 “I guess I got treated differently because they're not smart enough to to think for themselves. So, when everybody when they keep asking for help then their members are like like try and do it yourself. And if you're not smart after to do it they they they tend to like trying to, I guess mentally bash up for it because they think that you can do it, but use your brains not working the way they want you to work it” P2 “I think I think a lot of this abuse come comes from oh, uh, I think a lot of this abuse comes from non-acceptance.” P3 “And she said, but but you're not normal and I said yeah, yes we are. We we might look a bit different, but the experience is just the same.” P3 “I think eh if they put themselves in the mindset of someone with a disability or they had it written down then they’ll get the gist of what it's like to be with a disability or actually have the training or put themselves in that position of some of the disability then they’ll actually say ah right now I know what it feels like and

							I'll actually change the way thinking about how I've discriminate against someone with a disability and be able to help and support them." P4
Maltreatment							
Understanding maltreatment and neglect	Descriptions of behaviours that constitute maltreatment and neglect.	10	1	2	0	7	"Treating them differently to their brothers and the sisters." P1 "Ahh not feeding them, not showering them. Not what do you call it, got giving them a roof over their heads, not giving the proper bed to sleep on um." P2 "I think being pushed around, not treated right so like being locked away, just not being fed. Just being treated like a little kid rather than being treated like an adult just getting along with other people being included into social stuff rather than being excluded." P3
Aversion to maltreatment	Disapproval and disgust in responses to examples and information about maltreatment and neglect.	15	12	0	1	2	"Yeah, and it's very sad. Yeah, no, that's not good." P1 "Well, I would hope I would hope in this day and age they wouldn't be, but you can't, you can't totally rule it out 'cause in this day in this day and age it's it still happens on on on on it still happens on a occasions all we gotta do is keep it try keep it front, front, front and center." P3 "I think, yeah, like house arrest like they're being restricted, they're being treated like a little kid rather than being able to express how they feel so." P4
Responding to maltreatment	What should be done to address maltreatment of	19	2	1	7	9	"Well, I just think it should be looked at so people can be helped more." P1

	people with intellectual disability by family. This includes research, government action, changing perspectives (through discussion and action of people with and without intellectual disability), and supporting families and victim-survivors.						"I think what is it Child Protective Services probably get involved as well." P2 "Yeah, I don't mean I don't mean uh, other being specific sectors are mean in general if we're if we want to be perceived as so called normal normal participants in the community, then it's our civil then it's our civil duty to put ourselves in in such in such positions, such as." P3 "It comes down to research, but if people don't research what it's like be with a disability or in the mindset of someone with a disability then if they have then they will know OK, this is the research we've done if they haven't, yeh, just again it's just going to get worse, and it's just going to upset other people so." P4
Neglect outcomes	The outcomes of neglect on people with intellectual disability such as the negative impacts on self-esteem, school participation, and the individual's emotional state.	3	1	1	0	1	"That's no good, yeah, and that that builds this low self-esteem you feel down on yourself." P1 "Yeah, I just got the state or just refuse to participate in the PE and whatnot 'cause I wasn't really being encouraged to do so." P2 "But if I don't do anything about it, it's just going to keep eating away at the person to the point that one they're going to feel depressed, two they're gonna end up and it's sad, like depression and suicide, as well as other things." P4

Sympathy for the victim-survivors	Sympathy for the victim-survivors with intellectual disability who have been of maltreated by family.	3	2	0	0	1	“I just think it's sad that people don't have that same sort of treatment and it's just I just don't think that's really good.” P1 “I just think it's not fair on the person with the disability or even without, yeah, yeah meant yeah, it's just hard to get your head around sometimes so.” P4
Family							
The role of parents and family	What parents and families do and what they *should* do.	15	11	2	2	0	“I don't think it should should happen and think I think you know people and families should be encouraged to help their their family member who has an intellectual disability to to be happier and and everything like that.” P1 “But some people have them regardless.” Referring to children P2 “Although mine was much much less than what we are talking about here there's still that stigma attached and some parents some parents can't accept that and say I might have a I might have a relative that suffers from disability but I I treat them like a normal person.” P3
Family value	Loving and caring families are strongly valued and discussed in contrast to the experience of those who have been maltreated.	9	7	0	0	2	“It makes me think in in my life that that I'm happy that I have have a family” P1 “One of my (sport) mates, he still lives with his parents, he goes well and everything. His parents or his mum wants him to move out, but his is dad wants him to be at the house he doesn't think he's ready. Wants him to go out drinking and everything, but I'll go round to my

							(sport) mates place and I see like his dad sitting on the couch just drinking the whole time thinking what's sort of role model is he getting from his other parent or his dad. But when a (sport) mate sees my parents like active during the gardening they think, OK, that's a good role model, and that's what my mate has actually said that he relies on my not relies, but looks up to my parents as doing the right thing and my mates actually said that dad that he actually looks at him like a good role model yeh." P4
Capacity building	Part of caring and supporting people with intellectual disability involves building their capacity for independent living.	9	4	0	0	5	"Mum always says like when we tell you to put your socks up and help you like that it's good that we do that, 'cause if we weren't good, good, like good parents or good, we wouldn't help you like that." P1 "I'm thinking if other people saw the way I interacts I live I actually cook clean wash, take care myself, then they'll get another understand of oh OK so if he can do it then. OK, I'll try that so but if I don't do anything and if I just leave it to someone else then for me I'll let myself down, I would let my family, and I would actually let my health down" P4

Note. P1, P2, P3, P4 represent each of the four participants who contributed data to this study. The number of times each category was expressed by each participant and all participants combined is included. An excerpt is provided for each participant who articulated each category.

facilitating the opportunity to live independently. In this study the findings may suggest that neglect can also constitute the lack of skill provision for people with intellectual disability by families because it restricts opportunities to exercise autonomy and live outside of the family home.

5.4.1 Strengths and Limitations

A strength of this study is that people with intellectual disability were involved throughout, contributing to the design, recruitment materials, and providing their perspective. Involving people with intellectual disability has been found to be both beneficial for the research and individuals themselves (Bigby & Frawley, 2010; Stack & MacDonald, 2014). Engaging with participants in this manner helped to ensure that the current research was *with* people with intellectual disability, rather than *on* them. Further, the perspective of people with intellectual disability validates and expands on the findings of the research project. However, the small sample size ($N = 4$) of this study limits the transferability of these findings. Despite generating interest through dissemination of the research project very few people sought to participate in the study. This may be the due to the nature of the subject matter which is potentially distressing and may deter involvement (Edwards et al., 2009).

5.5 Conclusion

People with intellectual disability have a unique and valuable lens through which research on important social issues can be understood. This study explores the perspectives of four people with intellectual disability on the findings of the research project and the topic more broadly. Participants discussed familial maltreatment of people with intellectual disability by considering negative social attitudes of people with intellectual disability, definitions and responses to maltreatment, and the valued role of family. Ultimately, people with intellectual disability should have a say in research that is about them.

Chapter 6: General Discussion

6.1 Chapter Overview

This final chapter reviews the thesis objectives and discusses how they were addressed throughout this thesis. The three major findings of the research are explored, and their implications discussed. The overall strengths and limitations of the research are presented in addition to directions for future research. This chapter concludes with some final remarks.

6.2 Review of Thesis Objectives

People with intellectual disability experience a high risk of maltreatment and the family home presents unique factors that make identification and prevention additionally challenging (Maclean et al., 2017; McDonnell et al., 2019; Meer & Combrinck, 2017). Public perceptions of familial maltreatment of people with intellectual disability influence identification and perpetration behaviours that can restrict intervention and prevention opportunities (Dickerson et al., 2017; Ferguson & Bargh, 2004; Mallén, 2011; Son et al., 2017). The overarching objective of this thesis was to develop understanding of the maltreatment of people with intellectual disability by family members, with particular focus on public perceptions. Contributing to this knowledge was particularly important as there is limited research that specifically focuses on maltreatment of people with intellectual disability by family members. This central objective was addressed in four studies, each with contributory aims. These were:

1. To compile and summarise what was known about the maltreatment of people with intellectual disability by family members (Chapter 2).
2. To understand how the Australian news media frames the neglect of people with intellectual disability by family members (Chapter 3).

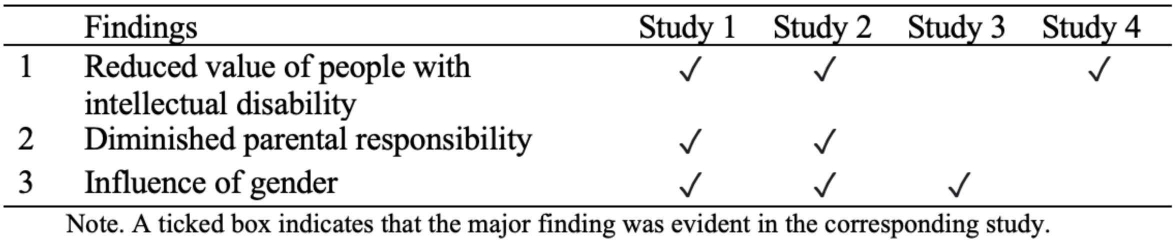
3. To explore differences in public perceptions of the neglect of children with and without intellectual disability and the factors that influence these (Chapter 4).
4. Meaningfully disseminate and discuss the findings of the previous studies within the research project with people with intellectual disability (Chapter 5).

6.3 Summary of Major Findings and Implications

The findings from each of the four studies are presented in their discrete chapters; however, this chapter presents three major findings identified across the research. These underpinning findings address the research objectives in different ways. Table 15 depicts the representation of these findings within each the four studies.

Table 15

Major Findings Study Representation



	Findings	Study 1	Study 2	Study 3	Study 4
1	Reduced value of people with intellectual disability	✓	✓		✓
2	Diminished parental responsibility	✓	✓		
3	Influence of gender	✓	✓	✓	

Note. A ticked box indicates that the major finding was evident in the corresponding study.

6.3.1 Reduced Value of People with Intellectual Disability

A lack of value ascribed to people with intellectual disability was a common finding in the research. The media analysis and community dialogue study found that people with intellectual disability are constructed as different, outside of the norm and therefore devalued. In the media analysis, news narratives presented positive traits of people with Down syndrome (e.g., skills, dreams) in comparison to children without Down syndrome seemingly because these abilities and similarities are not generally anticipated by the public. Similar sentiments were discussed in the community dialogue study when participants indicated experiencing negative social attitudes toward people with intellectual disability. For example, one participant in the community dialogue study recounted a conversation where they were described as “not normal”. Representations of people with intellectual disability as passive and vulnerable were also demonstrated in the media analysis and work to degrade those so labelled. People with intellectual disability were attributed limited value in the media analysis study when the suffering of Willow Dunn was not considered. The absence of recognition for this suffering is dehumanising and may suggest that the public feel less like to people with intellectual disability and consequently experience less empathy.

Further, people with intellectual disability were devalued due to the lack of news content found in the media analysis. Even against the backdrop of the Royal Commission this topic was still not widely discussed in the media demonstrating that the neglect of people with intellectual disability is not prioritised in the media or a prominent social concern. However, Winterbotham et al. (2023) found 29 news stories about the mistreatment of people with intellectual disability within institutions and by families in Australia between 2013 and 2018 (NDIS role out period). The manuscript does not specify the type of mistreatment discussed nor how many new stories addressed the familial abuse, but the findings suggests that a broader range of maltreatment of people with intellectual disability content exists. Neglect can be difficult to identify and is generally underrepresented in the media (Davies et al., 2017; Son et al., 2017), however, research demonstrates that many people with intellectual disability experience neglect making it an important social issue (Paquette et al., 2018). Media coverage on this topic should better represent the issue especially because of its important role in creating community concern and action around social issues (Huck et al., 2009).

The scoping review study included a mock jury study by Bottoms et al. (2011) that demonstrated the limited value attributed to people with intellectual disability in criminal justice settings. Despite participants indicating equal responsibility, fathers who killed their infant with intellectual disability were given significantly shorter sentences or less punishment than fathers who killed infant without intellectual disability. The lesser punishment suggests that a perception that the lives of people with intellectual disability are less valuable than those of people without.

It is important to note that the results from the mixed methods study did not indicate a difference in value of people with and without intellectual disability. Perceptions of severity were not significantly different for victim-survivors of children with and without intellectual disability suggesting the victim-survivors were not valued differently on the basis of disability status. However, some research suggests that explicit questioning of perceptions of people with intellectual disability can fail to identify differences, but sensitive measurement can find disparities (Bottoms et al., 2012; Werner, 2015). The measure in the mixed methods study may not have been sensitive enough to identify whether differences exist.

6.3.1.1 Implications.

There are several significant implications of the lack of value ascribed to people with intellectual disability. Limited punishments for family member perpetrators and victim blaming may validate and perpetuate ideas that people with intellectual disability are burdensome and that their lives are without value (Brown, 2012; Sullivan, 2017). This may set a dangerous precedent that maltreating people with intellectual disability is socially acceptable thus allowing the problem to persist.

When people with intellectual disability are constructed as different it reinforces the harmful misperception that disability is binary and undesirable (Procknow et al., 2017). Further, describing people with intellectual disability as vulnerable reinforces a tragic stereotype and holds those so labelled to a different standard as it supposes inaccurately that people without intellectual disability are not vulnerable. Public perceptions such as these negatively impact of how people with intellectual disability can participate in society (Haller, 2010). Negative public perceptions limit opportunities for people with intellectual disability in many different facets of life including education, occupational participation, and in relationships (Procknow et al., 2017)

6.3.2 Diminished Parental Responsibility and Implications

The diminishment of parental responsibility for maltreatment of people with intellectual disability was found to manifest in the research in several ways. Responsibility for maltreatment of people with intellectual disability is reduced when it is shifted away from the family member perpetrators. Responsibility can be assigned to organisations, governments, and even the victim-survivor with intellectual disability. In the scoping review, research demonstrated that organisations can be held responsible for failing to identify and prevent familial maltreatment of people with intellectual disability (Manthorpe & Martineau, 2015; Meer & Combrinck, 2017). Similarly, the media analysis found that the Australian government was constructed as responsible for Willow Dunn's death within the Political discourse when policies and practices are described as deficient. Winterbotham et al. (2023) also found that the Australian news media positioned the government as responsible for the mistreatment of people with intellectual disability. Further, in the community dialogue study a participant highlighted the role of child protection services in maltreatment and neglect of people with intellectual disability indicating their significant role in the issue.

Shifting responsibility away from perpetrators is most problematic when responsibility is directed at victim-survivors with intellectual disability. The scoping review includes Brown's (2012) study that presents three examples of parents killing their adult children with intellectual disability in a criminal justice setting. In one case, a coroner emphasised the burden of the son with intellectual disability and stated that it was a "tragic loss of a devoted mother" (Brown, 2012, p. 9) who completed suicide after concealing the death of her son whose body was found emaciated in a suitcase after suspected neglect. Here, the perpetrators experience is centred, and the burden of the son's disability is implied as contributing to his death. In another example, a mother was described as having "snapped" when she tranquilised and smothered her 36-year-old son with Down syndrome (Brown, 2012, p. 8). This killing is framed as being a consequence of the son's behaviour rather than the full responsibility of the perpetrating parent. Brown et al. (2012) additionally shifts responsibility away from parents by arguing that society should not harshly judge parents who kill their children with disability as it is the result of stress and not malice. Consequently, people with intellectual disability are framed as partly responsible for their death instead of holding the perpetrators solely responsible.

6.3.2.1 Implications.

There are several implications for the limited responsibility assigned to parents who maltreat and/or kill family members with intellectual disability. While governments and organisations play an important role in the identification, intervention, and prevention of familial maltreatment of people with intellectual disability; it is problematic to dilute perpetrator accountability by assigning blame to outside entities. Further, reducing the responsibility of perpetrating parents may contribute to lenient sentencing of carers who kill family members with intellectual disability and demonstrates and disseminates social messaging that degrades people with intellectual disability. As discussed above, negative social narratives and perceptions can have substantial impacts on how people with intellectual disability can participate in society (Haller, 2010).

6.3.3 Influence of Gender

Gender was found to be an influential factor across three of the four studies in this research project. Perpetrator gender was found to influence perceptions of neglect in the media analysis study. Differences in the attribution of responsibility were observed and described in the Graphic discourse where the stepmother's behaviour was framed as evil and intentional because she defied traditional gender norms by not caring for Willow Dunn.

Contrastingly, the father is constructed as hapless and less intentional. The consequence of these representations is that the stepmother is positioned as more responsible for Willow Dunn's neglect and death than the father. Additionally, observer gender was found to influence perceptions of neglect severity in the mixed methods study. The results found that women completing the study tended to rate the scenarios as more severe than the men. Finally, the scoping review included a study that found that victim-survivor gender influenced outcomes of maltreatment. Mothers of children with intellectual disability administered more verbal punishment to girls compared to boys and more physical punishments to boys compared to girls (Thomas et al., 2016). These findings suggest that gender is a highly impactful factor in the maltreatment of people with intellectual disability by family members as the gender of the victim-survivor, perpetrator, and observer have all been shown to influence perceptions and outcomes.

6.3.3.1 Implications.

Gender appears to impact the maltreatment of people with intellectual disability by family members in a multitude of ways. There are several real-world implications for these findings. Firstly, neglect perpetrated by men may be less recognisable to outsiders than neglect perpetrated by women. Dickerson et al. (2017) also found that gender was an influential factor in a study on perceptions of neglect experienced by children without disability. The behaviour of fathers was considered less neglectful than mothers and neglect was more likely to be recognised when the perpetrator and victim-survivor were described as having the same gender (i.e., mothers and daughters, fathers and sons). Second, men might be less likely to recognise cases of neglect than women. Public perceptions of neglect are important because people with intellectual disability are less likely to report their own experiences of maltreatment than people without (Soylu et al., 2013) and therefore identification rests heavily on others identifying and reporting maltreatment. These results suggest some cases of neglect may not be recognised by men and may indicate the need for education and training that specifically addresses these differences. Third, children might be more likely to experience certain types of maltreatment according to their gender. This information could identify the increased risk faced by particular children with intellectual disability.

6.4 Strengths and Limitations

The specific strengths and limitations for each of the four studies are outlined in their corresponding chapters. Here, the overall research strengths and limitations of the project are outlined. This research makes a significant contribution to an under researched body of literature. Despite its prevalence, there remains limited research that addresses the maltreatment of people with intellectual disability, and even less that specifically addressed familial maltreatment and neglect, or the public perceptions of these. Additionally, this research highlights the importance of the issue, and aims to generate interest, dialogue, and encourage future research in the area.

The primary strength of this research is that people with intellectual disability were involved. Throughout the research, two people with intellectual disability were consulted on various aspects of the studies providing an invaluable contribution. The lived experience collaborators influenced different aspects of the research from the focus of the research becoming more specific (from maltreatment to neglect) to the quantity of text on dissemination materials. Conducting research with people with intellectual disability supports disability rights that posit ‘nothing about us without us’ (Charlton, 2000). Including the perspective of people with intellectual disability has been shown to be advantageous for the individual and the research (Bigby & Frawley, 2010; Stack & MacDonald, 2014). However, this research would have been improved if people with intellectual disability could have been involved from the point of conceptualisation to ensure that the overall focus of the work was demand driven. Similar to the barriers experienced by Bigby and Frawley (2010), it was also impossible for this PhD to be completely inclusive due to research funding structures. It would be unethical to engage the lived experience collaborators without being able to compensate them for their time. However, candidates do not have access to their budget until successful completion of Milestone 1 which requires the presentation of a thorough plan of the intended research. This process does not allow for people with disability to initiate the overarching focus of the research.

A limitation of this research is that it did not explore perspective of people who hold professional roles in the lives of people with disability. Originally, the plan for my PhD included a study exploring the perspectives of people who work in the disability sector on their role in the identification, intervention, and prevention of maltreatment of people with intellectual disability by family. This perspective would have provided insight into practices and processes but ultimately it was not possible to conduct due to PhD time and resource restraints and feedback at the mid-candidacy presentation that the scope of the PhD was bigger than required. However, some of these perspectives are presented indirectly via the scoping review.

6.5 Future research

Recommendations for future research relating to each of the four studies are also presented in their specific chapters. Additional or extended recommendations are presented here to address underlying foci of the thesis—the identification, intervention, and prevention of maltreatment and neglect of people with intellectual disability by family members.

6.5.1 Identification

Maltreatment – and particularly neglect – of people with intellectual disability is difficult to identify especially when it occurs within the family. Future research should seek to develop screening tools to identify families at risk that can be used by disability service providers. Large high quality quantitative research should be conducted that specifically addresses familial maltreatment of people with intellectual disability to identify risk factors. Subsequent qualitative enquiry should explore effective strategies that support families at risk of maltreating people with intellectual disability through interviews and focus groups. This information could further inform organisations such as Carers WA that support families and carers of people with disability in a multitude of ways including counselling, respite, peer support programs, and support to navigate services (CarersWA, 2022).

Additionally, future research should seek to further understand how the public defines neglect to improve understanding and identification. The mixed methods study in this research provides a foundation for how neglect is defined in Australia, but additional qualitative enquiry should further explore the nuances of these perceptions. Quantitative investigation could complement these findings by identifying general deficits in knowledge and inform public and professional education (e.g., for nurses, disability workers) materials that encourage accurate identification of maltreatment of people with intellectual disability by family. Further, research that compares contemporary Australian media representations of maltreatment and/or neglect of people with and without intellectual disability would provide important insights into the social perspectives of this issue.

6.5.2 Intervention

Future research should explore the perspectives of people with intellectual disability who have experienced maltreatment by family. This information could be used to inform effective methods of supporting people with intellectual disability experiencing familial maltreatment such as those outlined by PWDA (2022). Additionally, the perspectives of people who work with people with intellectual disability should be examined regarding their role in the identification, intervention, and prevention of maltreatment of people with intellectual disability by family. Both these suggested studies could use qualitative data collection methods including interviews and/or focus groups. Understanding the processes, practices, and problems around maltreatment of people with intellectual disability could result in the development of recommendations that could be presented to government and non-government disability service organisations with the aim of improving policy and practices.

6.5.3 Prevention

Perceptions have a significant impact on public behaviours and influence the identification, intervention, and prevention of maltreatment of people with intellectual disability by family. Future research should build on this research and investigate additional factors that influence public perceptions. Research should explore the effective means by which perceptions can be modified or changed to improve outcomes and ultimately prevent familial maltreatment of people with intellectual disability. Smythe's et al. (2020) systematic review on stigma reduction for children with disability and their families could be used as a guide for future avenues of enquiry. For example, Smythe et al. (2020) identifies some approaches that were shown to increase knowledge about disability and decrease negative attitudes within organisations. Additionally, Smythe et al. (2020) highlights the need for quality research in this area. The outcomes from the subsequent research could inform a media campaign to educate the public on maltreatment of people with intellectual disability generally and within the family. This campaign could be shared across different media platforms (e.g., television, news, and social media) and address definitions, signs of maltreatment, and practical advice on how to report and provide support for victim-survivors with intellectual disability. 'Our Health Counts – End Deadly Disability Discrimination' is a campaign in Australia that aims to educate the public on the high levels of preventable deaths of people with intellectual disability, and improve health care for people with intellectual disability (Council for Intellectual Disability [CID], n.d.). Additionally, future research should investigate and develop maltreatment interventions programs such as the research conducted by Nyberg et al. (2021) that investigates what is needed for successful implementation of school-based prevention programs for children with disability.

6.6 Concluding Remarks

People with intellectual disability have a significant risk of experiencing maltreatment and familial maltreatment represents additional challenges. Neglect is a type of maltreatment that is particularly common and difficult to identify. Public perceptions have a significant impact on responses and outcomes of social issues including the maltreatment of people with intellectual disability by family. The media simultaneously influences and is influenced by public perceptions and can provide an indication of current perspectives on social issues. The involvement and perspectives of people with intellectual disability are valuable.

This thesis provided an important contribution to the literature on the familial maltreatment of people with intellectual disability. Summarising the literature provided a foundation for this and other research to build on and revealed inconsistencies regarding the frequency of familial maltreatment experienced by people with intellectual disability. The media analysis demonstrated that there is a lack of news coverage on the neglect of people with intellectual disability by family and identified that damaging narratives are present that devalue people with intellectual disability. Public perceptions were not found to be influenced by intellectual disability; however, gender was suggesting that men may be less likely to recognise neglect in real world settings. Finally, in review of the research project, people with intellectual disability identified negative attitudes towards people with intellectual disability, described and denounced maltreatment, and explored the role of family.

The maltreatment of people with intellectual disability by family is a significant issue that affects many children and adults worldwide. It is a particularly relevant topic in Australia at this time under the backdrop of the Royal Commission into the violence, abuse, neglect, and exploitation of people with disability and the ongoing role out of the NDIS. This important issue deserves further academic enquiry that includes the input of people with intellectual disability to ensure that responses are appropriate, and demand driven.

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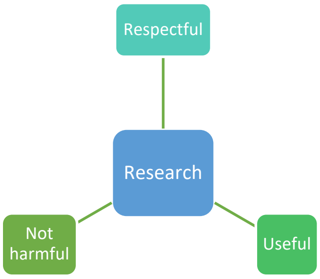
Appendix A: Lived Experience Collaborator Recruitment Advertisement

New Vacancy/Involvement opportunity

Vacancy Title: Violence, abuse, and neglect of people with intellectual disability

Excerpt/intro

- Researchers from Curtin University are looking for people with intellectual disability to help with a research project.
- We would like to talk to people with intellectual disability about how we can do our research in a way that is **respectful, useful, and not harmful**
- The research is about people with intellectual disability who experience violence, abuse, and neglect.
- We hope this research will give some ideas about how to support people with intellectual disability who experience violence, abuse, or neglect.



About the project/vacancy (Plain Language Summary)

- My name is Jess Keeley, I am a researcher doing my PhD at Curtin University.
- My three supervisors and I make up the research team.
- We want our research to uphold the principles of the United Nations Convention on the Rights of Persons with Disability which promotes equality for people with disabilities.
- We hope this research will give some ideas about how to support people with intellectual disability who experience violence, abuse, or neglect.

- This study could help other researchers to learn and do respectful research alongside people with intellectual disability on topics that are important to people with intellectual disability.

About the position

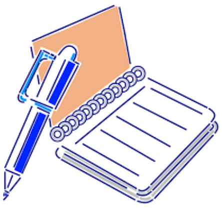
- We are looking for two (2) people with intellectual disability to be expert consultants on how we do the research.
- You will be paid for your time and expertise.

What skills or experience do I need?

- We invite you to apply if you are 18 years of age or older, live in Perth, and are interested in giving your advice on this research.

What am I expected to do?

- We would like to ask for your ideas about how we can do our research in a way that is **respectful, useful, and not harmful**
- For example, we will ask you to give us advice on how we can design the research, who we should be talking to in the research, and how we can tell people about the research when we are done.
- We will meet with you in person to talk about the research. You can bring someone with you if you like.
- You will be invited to participate in a group chat with other people with intellectual disability about the research results. You do not have to participate if you do not want to.



- We will provide you with regular updates on the research by email or phone.
- We can meet in Perth City, or at Curtin University Bentley Campus. You will be paid for attending these meetings.

- You do not need to bring anything with you to these meetings.

How long am I expected to be involved?

- We would have about six (6) meetings and one (1) group chat over three (3) years (from 2019-2021).

- It would be good if you could be involved for at least one (1) year.

- You do not have to be involved for the whole time and can stop when you like.

What support is offered?

- If you take part, you will be paid $30 an hour.

- Jess and her supervisors will be available to help and support you.

- The people from the Consumer and Community Health Research Network will be able to help and support you.

Contact:

- Please contact me (Jess) if you want to know more about the position or the research.
    - My name: Jess Keeley
    - My phone number: 0468 792 565
    - My email address: jessica.keeley@postgrad.curtin.edu.au

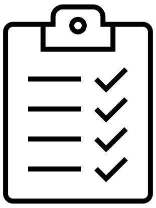
Please share this information with anyone you feel may be interested in applying for the role.

Appendix B: Lived Experience Collaborator Meeting Document Example

Meeting 2

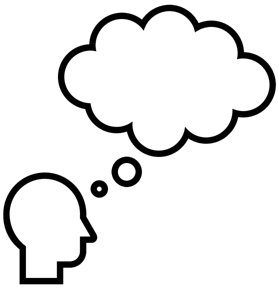
What we will talk about

1. The last meeting
2. Your thoughts
3. The last study
4. The next study
5. Next meeting



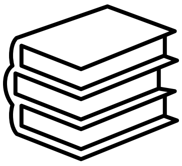
1. The last meeting
    - Got to know each other
    - Working together
    - What we will do in the reference group
    - Organised some things
    - Maltreatment
    - Alan’s tips
    - Next meeting

2. Your thoughts
    - Ideas
    - Thoughts
    - Comments
    - Questions



3. The last study

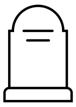
- Why did we do the research?
    - More people with intellectual disability are maltreated
    - Harder to see
    - Need more research
    - We want to know more to make it easier to see and stop



- How did we do this research?
    - Searched for all the studies about people with intellectual disability that have been maltreated by a family member
    - Found 38 studies
    - All the important information in a table
    - Looked for things that were similar and different
- Study results
    - About the studies

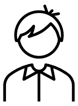
Maltreatment

Different types of maltreatment	18
Sexual abuse	10
Killing	4
Physical abuse	3
Physical abuse, emotional and psychological abuse	2
Emotional abuse	1



People with intellectual disability

Children	27
Adults	7
Both	4

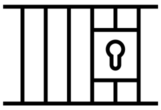


- Different depending on if they were a girl or a boy.
    - Girls verbally abused more than physically abused
    - Boys physically abused more verbally abused
- Maltreatment was also different for children of different ages.

-Older children more likely maltreated

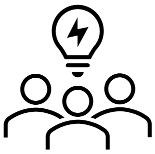
- Some types of maltreatment are related to other types. For example,
  -Physical abuse and emotional abuse = more chance of neglect.

- Family members
  -Problems with drugs and alcohol
  -Mental health problems or stressed
  -Jail



- Maltreatment can be kept a secret so it can keeps happening

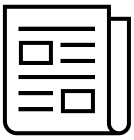
- Some examples of what people thought
  - Maltreatment of people with intellectual disability is bad
  - Feel sorry for the family member who maltreated the person with an intellectual disability.
  - People WITH intellectual disability = LESS sorry compared to
  - People WITHOUT an intellectual disability = MORE sorry



- Seeing and telling people about maltreatment can be hard. For example,
  - Do not understand the way the person is acting.
  - Do not think that family members would maltreat people with intellectual disability.
  - Do not understand or believe people with intellectual disability when they say they have been maltreated.

- What do the results mean?
  - Maltreatment happens in different amounts in different countries.
  - People understand maltreatment differently in different countries.
  - Maltreatment is harder to talk about in some countries than others.
  - Sometimes people care more about family members than people with intellectual disability that have been maltreated.
  - Sometimes people with intellectual disability are cared about less than people without a disability who are maltreated because some people think that having a disability is bad and not ‘normal’.

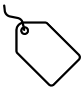
4. The next study
    - How does the media talk about the maltreatment of people with intellectual disability by a family member?
    - Australian news articles
    - What sort of ways do they talk about it?
    - Why do they talk about it in that way?



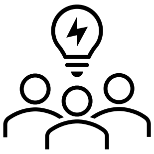
    - Your ideas
        - Type of maltreatment
            - All types
            - Violence
            - Sexual abuse
            - Physical abuse
            - Psychological abuse
            - Emotional abuse
            - Financial abuse
            - Death
            - Neglect

        - People with intellectual disability
            - Children
            - Adults
            - Children and adults
            - Autism
        - Family members
            - All
            - Specific types
            - People with intellectual disability

        - Words used in the media to describe people with intellectual disability
            - Intellectual disability
            - Intellectual impaired
            - Mentally disabled
            - Mentally handicapped
            - Mentally retarded
            - Developmental disability
            - Developmental delay
            - Down Syndrome
            - Other specific types



        - Age of the news articles
            - 5 years
5. Next meeting
    - In November
    - How the public think about maltreatment of people with intellectual disability vs people WITHOUT an intellectual disability



Appendix C: Lived Experience Collaborator Meeting Presentations

Date	Title	Link
14/08/2020	Meeting 1	https://www.youtube.com/watch?v=DjpM7EoUh5k
14/08/2020	Important words	https://www.youtube.com/watch?v=BWIE55t47fs
30/9/2020	Research summary: Scoping review	https://www.youtube.com/watch?v=1sXcbi2AVuE
30/9/2020	Meeting 2	https://www.youtube.com/watch?v=fA7KAAvUL_8
5/5/2021	Meeting before study 3	https://www.youtube.com/watch?v=MNcs-j241YM
5/4/2022	Maltreatment of people with an intellectual disability by family	https://www.youtube.com/watch?v=ehuBU67Afiw

Appendix D: Research Summary and Dissemination Poster

Curtin University

Maltreatment of people with an intellectual disability by family

We want to share some research that we did and hear what you think. Our research looked at maltreatment of people with an intellectual disability by family.

What is maltreatment?

- When someone is not treated well and their body or mind is hurt.
- There are different types. Physical abuse, sexual abuse, mental abuse, and neglect.
- People with an intellectual disability are maltreated more than people without an intellectual disability.

Who is responsible?

- Some studies say that family members maltreat people with an intellectual disability more than others and more often than people without an intellectual disability
- Not all the studies say this

What do people think?

- Research says that some people feel sorry for people with an intellectual disability who are maltreated by their family.
- Research says that some people feel sorry for the families who maltreat people with an intellectual disability.
- Research says that some people think it is not as bad to mistreat someone who has an intellectual disability.

Hiding maltreatment

Research says that families can hide maltreatment so it can last a long time.

Telling people

Research says that sometimes when people with an intellectual disability tell someone about being maltreated by family they are not listened to or believed.

What is neglect?

- When someone is not helped in the way they should be helped.
- This might be on purpose or not on purpose.

Thinking about child neglect

- In our study people thought about the neglect of children with and without an intellectual disability in the same way.
- Our research showed that women think neglect is worse than men.

What is the news?

- Neglect of people with an intellectual disability is not talked about much in the news.
- The news talked about a girl with Down syndrome who died from being neglected by her parents.
- Some bad ideas about people with an intellectual disability were shown. For example, that they are not accepted by everyone.

To have your say contact Jess:
jessica.keeley@postgrad.curtin.edu.au, 0468 792 565
Jessica Keeley is a PhD student at Curtin University.
This poster shows the findings of her PhD studies.

Scan the QR code to watch a presentation with more information

Curtin University Human Research Ethics Committee (HREC) has approved this study (HREC number 2021/0579). Should you wish to discuss the study with someone not directly involved, in particular, any matters concerning the conduct of the study or your rights as a participant, or you wish to make a confidential complaint, you may contact the Ethics Officer on (08) 9266 9223 or the Manager, Research Integrity on (08) 9266 7093 or email hrec@curtin.edu.au.

Appendix E: Reflection Example Excerpt

22/9/2020

Yesterday I had my first meeting with a lived experience collaborator. I was apprehensive before the meeting for serval reasons; I knew from our phone conversations that communication could be an issue—new people, situation, and environment for both of us—and I wanted to make a good impression. As soon as we started talking, I felt at ease. IL is passionate about being involved and has lots of experience and opinions as a disability advocate. He has worked on serval committees in disability service settings including as an advocate for his house. One of the staff members said that IL called him at 6.30am last week because they had agency staff in, and it wasn't working well. IL spoke of being apprehensive about being involved in this research because he thought it might be a clinical and dehumanising experience. I tried to convey how I thought our meetings could go (casual chats) and that I also wanted to assure him of my intentions to create the opposite of a clinical or dehumanising experience. This made me glad that I was wearing jeans and I made a mental not to keep things casual (yet professional) in the future and to try not to be too much of a "lab coat" researcher. He added that in his experience people listen to what he has to say and then he gets "fobbed off". I tried to get across that his ideas and opinions would be valued and integrated into the research and that I wanted to work *with* him as much as possible. He later stressed that his main hope is that I take on board what he has to say.

Appendix F: Description of the Scoping Review Studies

Author(s)	Year	Country	Methodology	Study population	Relevant findings
Bizzego Lim, Schiavon, Setoh, Gabrieli, Dimitriou, & Esposito	2020	Italy	Quantitative	29, 525 children 2 to 5 years. Data from the UNICEF's 2005 – 2007 Indicator Cluster Survey	• Developmental status (typically developing, intellectual disability and other disabilities was significantly related to being neglected by all caregivers (mothers and fathers) in cognitive ($\chi^2(2, N = 29{,}525) = 18.26, p < 0.001$, Cramer's $V = 0.025$), socioemotional ($\chi^2(2, N = 29{,}525) = 13.68$, $p = 0.001$, Cramer's $V = 0.022$) and total caregiving activities ($\chi^2(2, N = 29{,}525) = 17.19, p < 0.001$, Cramer's $V = 0.024$). • Children with intellectual disability were more likely to be neglected by their mothers than children with other disabilities ($OR_{ID/OD} = 1.11$). No significant relationship was found for fathers. • Uneducated parents were found to have an increased risk of neglecting children with intellectual disability compared to children with other disabilities for cognitive caregiving activities (χ $(1, N = 2992) = 6.56, p = 0.010$, Cramer's $V = 0.047$, $OR_{ID/OD} = 1.24$). • Children with intellectual disability were found to have a higher risk of cognitive caregiving neglect than children with other disabilities in countries with both a high ($\chi^2(2, N = 11, 476) = 15.47, p < 0.001$,

					Cramer’s $V = 0.037$) and low ($\chi^2(2, N = 18,049) = 13.31$, $p = 0.001$, Cramer’s $V = 0.027$) Human Development Index.
Bottoms, Kalder, Stevenson, Oudekerk, Wiley, & Perona	2011	USA	Quantitative, mock jury study	177 undergraduate psychology students.	• Disability status did not influence whether jurors convicted the father F(1, 173) = 1.22, ns. • The father who killed the infant with a disability was given shorter sentences (M = 13.42 years, SD = 11.22) compared to the infant without a disability (M=18.69 years, SD=17.30), F(1, 124)=4.09, p<.05. • Disability status did not influence ideas around the father’s intent to kill and responsibility (Fs ≤ 3.06, ns) nor sympathy, empathy, and similarity to the father (Fs ≤ .73, ns). • Jurors had more empathy for the infant without a disability (M = 3.16, SD = 1.50) compared to the infant with a disability (M = 2.45, SD = 1.24), F(1, 170) = 11.62, p < .01. • Jurors felt greater similarity to the infant without disability (M = 2.80, SD = 1.37) than with disability (M = 2.23, SD = 1.35), F(1, 170) = 7.51, p < .01. • Jurors were equally sympathetic towards the infants with and without disability F(1, 169) = 0.35, ns. • Father who killed the infant without disability was more likely to be perceived

					to need hospitalisation for a mental illness (M = 2.60, SD = 1.09) than the father of the infant with disability (M = 2.22, SD = 1.06) F(1, 172) = 5.78, p < .05. • Disability did not affect beliefs about the father or the infants worth. Fs ≤ 1.89, ns.
Brown	2012	UK	Qualitative, media analysis study	Six legal cases (1999-2009) where people with a disability were killed by a family member.	• Three of the 6 cases were relevant to the current study. • Society strongly chastises parents who kill their children with intellectual disability. However, murders were not motivated by malice but the result of mental illness and distress. • Inconsistent responses by the legal system. • Case 1: Male with Downs syndrome (36 years). Mother sedated and suffocated him before attempting suicide. 2-year suspended sentence. Mother had depression and had previously unsuccessfully sought government assistance. • Case 2: Male with Chromosome ring 22 (22 years). Emaciated body found in suitcase. Death concealed. Mother completed suicide. Family did not have a social worker. Mother was reportedly depressed, a heavy drinker, smoked cannabis, in a relationship that was ending, and in debt. Coroner described death as the “tragic loss of a devoted mother”. • Case 3: Female with an intellectual disability (18 years). Two daughters (1

					with an intellectual disability) and mother in a car when mother set it on fire. Mother also had intellectual disability and reportedly could not cope with being harassed by local youths. Media blamed youths and called their harassment a hate crime.
Catani & Sossalla	2015	Germany	Quantitative, cross-sectional study. Data collected via structured interview.	56 people with a medical diagnosis of intellectual disability.	• Participants' childhood experiences of maltreatment by a family member - One or more types of abuse: 49 (87.5%) - Four or more different types: 28 (50%) - Emotional abuse 76.8% - Physical abuse: 73.2% - Neglect: 39.3% - Sexual violence: 12.5% • Familial physical and emotional abuse were significantly correlated with all other types of abuse except neglect. • Experiences of institutional violence were significantly associated with familial abuse.
Codina, Díaz-Faes, & Pereda	2024	Spain	Quantitative	260 adults with intellectual disability (59.2% male).	• Family members (63.4%) were found to be the most common perpetrators for adults living at home (70%) and in residential care (54%).
Coorg & Tournay	2012	USA	Quantitative, media analysis study.	21 articles describing 22 children killed by filicide-suicide published between 1982 and 2010 in the USA.	• Four of the 21 cases were included in the current study. • Victim-survivors - Intellectual disability x 2 - Intellectual disability and autism x1 - Angelman syndrome x1

					• Cause of death - Poisoning (intravenous lines, carbon monoxide, generator) x 3 - Medication overdoes x1
David	2021	Israel	Quantitative, cross-sectional study	522 parents adjudicated for child maltreatment in Israeli courts.	• Neglect of children with intellectual disability was 3.87 more likely for mothers and 4.4 times more likely for fathers. • Abuse of children with intellectual disability was 2.3 more likely for mothers and 2.57 times more likely for fathers. • Fathers with mental health issues were 2.3 time more likely to abuse their children with intellectual disability.
Declercq, Meganack, & Audenaert	2017	Belgium	Case study.	A father who killed his son with physical, intellectual, and language disabilities.	• Father sedated and then strangled son (9 years) with physical, intellectual, and language disabilities • Attempted suicide • In jail • Father's reported reasons include spousal revenge and altruism
Dion, Pacquette, Temblay, Collin-Vezina, & Chabot	2018	Canada	Quantitative, cross-sectional study.	5,797 cases of substantiated child maltreatment (0 to14 years old), 656 of which had an intellectual disability	• Primary caregivers were the perpetrator of abuse - In 86.8% of all cases, - 89.5% of cases of children with intellectual disability, and - 86.6% of cases of children without an intellectual disability.
Eastgate, Van Driel, Lennox, & Scheermeyer,	2011	Australia	Qualitative, interview study	Nine women with an intellectual disability.	• Examples of familial sexual abuse - "[my grandfather] touched my breasts, he touched my vagina..." (interview 5)

					- “my brother... I was 12... he put his finger, his pizzle, he was on me he put it in me” (interview 6). • Example of disclosing abuse - “I said mum I don’t want to go and see grandpa because pop touched me, and then, then my mum talked to my grandma and... my gran said I was a liar” (interview 5).
Enosh, Duvdevany, & Arzi,	2008	Israel	Quantitative, vignette study.	59 social workers employed at welfare services.	• The professional (academic and work experience) and personal (thoughts about child abuse and people with intellectual disability and socially desirable responses) characteristics of workers did not significantly influence their preferred mode of intervention. • The social worker was more likely to intervene when the parent’s reaction was severe but not to partially remove the child from the home. • Authoritative intervention (reporting to child welfare, police) was most strongly related to parental violence • Parental violence had less of an impact on supportive or therapeutic interventions such as parental counselling, paraprofessional family assistance, and after-care.
Hervie	2023	Ghana	Qualitative, descriptive study	17 participants including 8 parents/guardians of children with intellectual disability and 9 teachers	• Participants reported that some parents neglect their children due to the stigma associated with intellectual disability. Intellectual disability viewed as a curse.

				of children with intellectual disability.	• Fathers leave the family because of stigma. Consequently, mothers can then neglect their children because of the additional challenges. • One example where a child with intellectual disability was left by both parents. • One example of neglect was described where an 11-year-old had not been toilet trained and continued to defecate on themselves. • One example where a father did not see the value in spending money on a child who he felt would not survive or take care of him later in life.
Hewitt	2013	UK	Quantitative, retrospective survey study.	695 people with intellectual disability who accessed a psychologist at a psychological service facility specifically for people with intellectual disability between 2009 and 2011.	• Perpetrator is a - Family member: 160 (58%) - Staff member: 35 (13%) - Acquaintance: 29 (11%) - Service users: 15 (5%) - Partner: 14 (5%) - Stranger: 12 (4 %). • Abuse by family members - Emotional: 82% - Sexual 46% - Physical 55% - Financial 36% - Neglect 97%
Jahng	2020	South Korea	Quantitative.	134 mothers of children aged 2 to 8 years with intellectual and	• Mothers experiences of childhood emotional abuse ($B = 1.89$, $t(126) = 6.40$, $p = .000$, 95 % CI[1.3072, 2.4774]) and physical abuse ($B = 2.23$, $t(126) = 5.00$, $p =$

				developmental disabilities.	.000, 95 % CI[1.3490, 3.1191]) were associated with abusing their own children. • Self-efficacy was a moderating factor between emotional abuse in childhood and abusive parenting (B = -.06, t(126) = -2.33, p = .022, 95 % CI[-.1142, -.0092]) and between physical abuse in childhood and abusive parenting (B = -.07, t(126) = -2.64, p = .009, 95 % CI[-.1283, -.0184]). • Emotional abuse in childhood (F(7, 126) = 8.33, p < .001, R2 = .32) and physical abuse childhood (F(7, 126) = 7.40, p < .001, R2 = .29) models were significant. • The impact of self-efficacy on childhood emotional and physical abuse and abusive parenting was strongest when self-efficacy was at its highest (-1 SD from the mean).
Keeley, Mancini, Castell, Breen	2023a	Australia	Mixed methods, randomised between groups design	399 participants	• No significant difference was found between perceptions of neglect severity for children with and without intellectual disability.
Keeley, Mancini, Castell, Breen	2023b	Australia	Qualitative, media analysis	27 Australian news articles (2016 -2021)	• Criminal justice and law enforcement discourse: Neglect and resulting death was significant and parents were responsible. • Political discourse: Government responsible for the neglect and death. • Medical discourse: Physical outcomes (absence of consideration for emotional consequences) and medical intervention are important.

					• Graphic: Shock and disgust for neglect and death. • Willow Dunn (victim) constructed as different to others and inherently vulnerable because she had Down syndrome. • A lack of consideration given to Willow Dunn's experience of suffering.
Koçtürk & Yüksel	2023	Turkey	Quantitative	124 adults and children with intellectual disability and 54 children without intellectual disability	• Perpetrator of sexual abuse; partner n = 32 (26.4%), unknown n = 25 (20.7%), familiar person n = 18 (14.9%), friend n = 17 (14%), relative n = 13 (10.7%), Imam marriage wife (religious marriage) n = 6 (5%), schoolteacher n = 6 (5%), biological/stepfather n = 3 (2.5%), Sibling n = 1 (0.8%). • There was no difference between child and adult victims-survivors for whether the perpetrator was an acquaintance (83.5% vs. 75.9%; χ2 (sd = 1, n = 120) = .861, p > .05), fellow (28.6% vs. 20.7%; χ2 (sd = 1, n = 120) = .699, p > .05) or a family member/relative (19.8% vs. 17.2%; χ2 (sd = 1, n = 120) = .091, p > .05). • There was no difference between children with and without intellectual disability for whether the perpetrator was an acquaintance (83.5% vs. 70.4%; χ2 (sd = 1, n = 145) = 3.484, p > .05), or a family member/relative (19.8% vs. 9.3%; χ2 (sd = 1, n = 145) = 2.881, p > .05).

Leutar, Vitlov, & Leuta,	2014	Croatia	Qualitative, interview study.	10 people with a diagnosis of a mild or moderate intellectual disability.	Most frequent perpetrators were friends, acquaintances, and volunteer carers.
Loinaz, Bigas, & and Ma de Sousa	2019	Spain	Quantitative, retrospective case review study.	221 forensic cases of children (3-18 years) who experienced abuse between 2013 and 2016.	• 30 cases involved people with intellectual disability. • Perpetrators from outside the family were more prevalent in the intellectual disability group (p = .017; OR = 3.053). • People with intellectual disability - 7 (7.1%) had been abused by someone within the family - 27 (19.9%) had been abused by someone from outside the family • People without an intellectual disability - 34 (35.8%) had been abused by someone within the family. - 40 (36%) had been abused by someone from outside the family
Mansell, Beadle-Brown, Cambridge, Milne, & Whelton	2009	UK	Quantitative, cross-sectional study.	6148 adults with protection recorded referrals.	• People with intellectual disability represented 32% of the sample. • People with intellectual disability were equally likely to have referrals relating to abuse perpetrated by service users (27%), day staff (24%), as family members (23%).
Manthorpe & Martineau	2015	UK	Qualitative, documentary analysis study.	21 cases reviewed.	• One case was relevant to the current study. • Male (20 or older) with severe intellectual disability died from fitting related to other health conditions and neglect. • Staff found to have not adequately responded to signs of manipulation and

					intimidation by the family for fear that the victim would be removed from day services. • In the months before the death there were several concerns documented regarding deprivation and neglect.
McDonnell, Boan, Bradley, Seay, Charles, & Carpenter	2019	USA	Quantitative, population-based record linkage study.	4988 children. 1280 people with intellectual disability, 291 with an intellectual disability and autism, 316 people with autism, and 3101 controls.	• People with intellectual disability had more reported cases of abuse by a family member compared to people without a disability (control group; mean difference = 0.72, p = .000) • People with intellectual disability had more substantiated cases of abuse by a family member than people without an intellectual disability (mean difference = 0.87, p = .000)
Mdikana, Phasha, & Ntshangase	2018	South Africa	Qualitative, thematic analysis study.	28 teachers from a school specialling in disability education.	• 12 (42.8%) participants reported knowing students with an intellectual disability who had been sexually abused by a family members and close relatives. • Examples from the text - “A father raped his own child with intellectual disability [repeatedly]” Nozibele (40 years, female). - “We had one incident where it was reported that a boy raped his younger brother” Karabo (38 years, female). - “Forced her son to sleep with her” Willem (57 years, male). - “... rape cases have been reported to us” (Luthando, 40 years, male).

					- "…. [the] rape, that gets reported here was a case of incest..." (Pieter, 55 years, male).
Meer & Combrinck	2017	South Africa	Qualitative, interview study.	58 staff members from non-government disability service providers.	• Neglect was described as "pervasive" and sometime related to "socio-economic hardship". • Families can be involved in violence towards women with an intellectual disability either by being the perpetrator or ignoring the violence. • Examples provided where families would "would look down upon", ignore or treat female family members with an intellectual disability "like [...] she doesn't exist". • Neglect associated with a lack of financial resources. Some families don't have the time or money to care for family members with an intellectual disability. • A participant provided an example where a man in his eighties had a sister with an intellectual disability who he kept locked in a shed because her could not afford care for her. • Participants expressed that neglect and isolation can create situations where family, friends and neighbours have unrestricted access to sexually and physically abuse people with intellectual disability. The neglect and isolation can also impede on the detection and disclosure of abuse.

					• “When we expect them to be protected, it is the family members or somebody who knows the family, who is close to the family, they are the perpetrators of violence”. • Participants reported that abuse within the family can occur for years without detection because the perpetrator can manipulate the trust of the person with an intellectual disability to conceal the abuse. • Family members are rarely suspected of being the perpetrator.
Özçevik Subaşi & Ocakç	2021	Turkey	Quantitative, cross-sectional study.	158 mothers of children with Down syndrome.	• Parent education level had a significant impact on abuse levels with higher education attainment resulted in less abuse. Middle school or lower $M = 59.58$, high school $M = 58.14$, University $M = 50.19$. $KW = 24.479$, $p < 0.05$. • Number of children in the family had a significant impact on abuse levels with more children resulting in increased abuse levels. 1 $M = 55.05$, 2 $M = 55.56$, 3 $M = 58.30$, 4+ $M = 62.00$. $KW = 14.905$, $p < 0.05$. • Family type had a significant impact on abuse levels with nuclear families having lower cases of abuse. Nuclear family $M = 55.42$, Extended family $M = 61.22$, fragmented families $M = 62.00$. $KW = 21.452$, $p < 0.05$. • Marital status had a significant impact on abuse levels with married families

					experiencing lower levels of abuse. Married *M* = 56.54, Single *M* = 62.37. MWU = 361.000, $p < 0.05$. • Perceived socio-economic level had a significant impact on abuse levels with low levels indicating higher abuse levels. Low *M* = 61.59, Mid 56.73, High *M* =43.00. KW 23.038, $p < 0.05$. • Abuse in childhood had a significant impact on abuse levels with abuse levels being higher for parents who had experienced abuse in childhood. Yes *M* = 62.74, No *M* = 54.42. t = 7.17, $p < 0.05$.
Paquette, Bouchard, Dion, Tremblay, Tourigny, Tougas, & Hélie	2018	Canada	Quantitative, cross-sectional study.	1012 children (6-17 years) with substantiated reports of maltreatment to child protective services with (n=62) and without an intellectual disability (n=950).	• The alleged perpetrator of maltreatment is a caregiver - People with intellectual disability: 79.7% - People without an intellectual disability: 75.8%
Parley	2010	UK	Qualitative, interview study.	20 care staff across the government and independent care sector.	• Bullying: “They are bullied into doing things that makes life a bit easier for the staff or for the carers or the parent.” • Neglect: “I would probably agree that that would come under the bracket of abuse of some sort if the person has been neglected by their parents or even by their support staff not doing their job in some sort of way.”
Perkins, Smith-Darden, & Graham-Bermann	2011	USA	Mixed methods study	115 incarcerated male adolescents between (13-20 years).	• The relationship between cognitive delay and child maltreatment was not significant.

Phasha	2009	South Africa	Qualitative, grounded theory method study.	20 participants, including 4 people from police services, 2 school nurses, 4 care givers, and 10 educators from schools specialising in educating people with intellectual disability.	• The family home should be a safe place but is instead a setting for sexual abuse. • Sexual abuse of people with intellectual disability is rarely reported by families regardless of the perpetrator's relationship to the victim-survivor. Instead abuse is most often reported by a neighbour or teacher. • Sexual abuse of people with intellectual disability is described as a ''family affair'' for several reasons: - To conceal abuse - Neglect - Wanting to address the issue using traditional methods - Cultural beliefs about curing intellectual disability - Minimalisation of the abuse. • Sexual abuse within the family is often concealed, especially when the perpetrator is the main source of income for the family. Also, when the family depend in the victim-survivor's disability grant for fear that the person and the money will be removed. • Families threaten those who attempt to help the victim-survivor. • Examples from the text - "They keep it a secret and they could not care less whether it affects the person or not."

					- "If it happens to a person with intellectual disability it is not reported, but if it happens to a non-disabled person it gets reported immediately, even if the perpetrator is a family member." • Families can abuse people with intellectual disability because they know that schools and agencies cannot intervene without the family's permission and people with intellectual disability cannot report abuse on their own.
Phasha & Myaka	2014	South Africa	Qualitative, interview study.	17 participants, including 8 life orientation teachers, 2 school nurses, a clinical psychologist, 2 social workers, 2 parents, a traditional healer, and a spiritual diviner.	• Families allow relatives to sexually abuse people with intellectual disability as an act of pity because they believe that people with intellectual disability are overly sexual and unable to maintain a romantic relationship. • One teacher called it very common practice and did not consider this arrangement sexual abuse.
Ramasamy, Rilotta, & Alexander	2021	Australia	Systematic review of qualitative studies.	15 studies, 3 relevant to this study (1 of the relevant studies is already included in this study's sample as so these findings are not reported here (Stoffelen et al., 2013).	• People with intellectual disability are taken advantage of because of their dependency on family and staff members. • Verbal abuse and bullying often came from family members. • See Stoffelen et al. (2013).
Robino, Barilaro, Gino, Chiarle, Palestro, & Torre	2006	Italy	Medical case report.	21-year-old woman described as having severe physical and intellectual disabilities.	• DNA material from a women's miscarriage after an unknown pregnancy was tested to reveal the paternity.

					• Probability of brother's paternity was found to be 499.99999% • The conception was deemed sexual abuse because of the women was not considered able to provide consent due to the severity of her intellectual disability.
Shang, Katz, Tian	2021	China	Case study.	14-year-old girl with intellectual disability	• 14-year-old daughter with intellectual disability was raped by father and became pregnant (later aborted) • Reported to the police by cousin. • Initially reported that the uncle had raped her, but DNA tests showed it was the father. • Father was arrested and sentenced to 5.5 years in jail. • Laws in China are changing to consider the best interests of the child. • Girl was removed from her family and put into an aged care facility. She was not deemed capable of being involved in these arrangements.
Shannon, Wilson, & Blythe	2023	Australia	Scoping review	18 studies included in the study, 2 of which are relevant to this study. Both are already included in this study's sample and so the results are not presented here (McDonnell et al., 2019; Van Horne, 2014).	See McDonnell et al. (2019) and Van Horne (2014).
Soylu, Alpaslan, Ayaz, Esenyel, & Oruc	2013	Turkey	Quantitative, cross-	256 children (6-16 years) who accessed one of	• Perpetrator is a close family member

			sectional study.	three child mental health units after being sexually abused. 102 had an intellectual disability and 154 did not.	- People with intellectual disability: 8 (7.8%) - People without an intellectual disability: 26 (16.9%) • Perpetrator is a member of the extended family - People with intellectual disability: 7 (6.9%) - People without an intellectual disability: 9 (5.8%) • Perpetrator is an acquaintance - People with intellectual disability: 50 (49%) - People without an intellectual disability: 87 (56.5%) • Perpetrator is a stranger - People with intellectual disability: 33 (32.4%) - People without an intellectual disability: 32 (20.8) • Perpetrator is unknown - People with intellectual disability: 3 (2.9%) - People without an intellectual disability: 0 (0%)
Strnadová, Loblinzk, & Danker	2022	Australia	Qualitative, interview and focus group study.	10 high school teachers who work with students with intellectual disability	• Six teachers reported experiences with students who had been sexually abused. • The perpetrator often reported as a relative. • “One was with a dad, so the student was sort of in a relationship with the dad, and I had to—we had to do a child wellbeing referral, and go to FACS [Family and

					Community Services] and have that investigation underway, so not only did I have to support her but I had to support her friends who had disclosed to me as well. And we'd spoken about, you know, what they can do to support their friend. And then also, I think because the girl didn't understand why we were making such a big deal of it. Didn't understand that there was that abuse of power and that that shouldn't be happening to her" (p. 8).
Stoffelen, Kok, Hospers, & Curfs,	2013	The Netherlands	Qualitative, interview study.	21 people with a mild intellectual disability.	• 10 male participants reported experiences of sexual abuse, predominantly when they were children. • 4 of these had been abused at home by a father or stepfather. Others had been abused while participating in leisure activities or in institutional settings. • "Yes, in bed, I had to touch my penis . . . I also had to masturbate. My father was interested in that. Well, not very nice actually." (Male, 53 years).
Taggart, McMillan, & Lawson	2010	UK	Qualitative, focus group study.	32 participants including, 15 (nurses specialise in intellectual disability), 10 social workers, 2 psychiatrists (specialise in intellectual disability), 2 senior managers (from an intellectual disability	• Participants knew of cases where people with intellectual disability - Had grown up in dysfunctional family settings. - Experienced emotional, verbal, sexual, and physical abuse within the family. • Excessive alcohol use was perceived to be associated with familial abuse.

				setting), and 1 residential worker.	
Taghizadeh, Farahani, Shiadeh, & Qaderi	2024	Iran	Qualitative, interview study.	21 participants including 8 mothers, 6 caregivers, 7 specialist caregivers who work with women with intellectual disability.	• Sexual abuse was a common concern. • Family members often identified as perpetrators. • “Unfortunately, some of them are sexually abused by their relatives” (p. 6).
Thomas, Kumar, & Deb	2014	India	Mixed methods study.	60 mothers whose children 10-23 years with an intellectual disability attend a school specialising in education people with a disability.	• Mothers’ perceptions about the likely setting that their children with intellectual disability would be abused - At home: 53% (31) - Lonely places: 40% (25) - Public and strange places: 7% (4) • Mothers’ perceptions about the likely perpetrators of abuse - Family member or someone known: 86% (52) - Stranger: 14% (8) • Mothers who punished their children with intellectual disability - Punished:100% - Physically punished: 46% (28) - Male children: 33% (20) - Female children: 13% (8) - Verbally punished: 54% (32) - Male children: 37% (22) - Female children: 17% (10) • Examples from the text - “It’s not fair to beat the girls”. - “Beating boys for wrongdoing is not a crime, it is a necessity”.

Vadysinghe, Dassanayaka, Sivasubramanium, Senasinghe, Samaranayake, & Wickramasinghe	2017	Sri Lanka	Quantitative, cross-sectional, study	82 people (11-20 years) with mild or moderate intellectual/ developmental disability.	• Perpetrators of abuse - Relatives: 42.1% - Family acquaintances: 38.2% - Neighbours: 7.9% - Boyfriends: 6.6% - Fathers of the victim-survivors: 5.3% - Stranger: 7.9%
Vadysinghe, Ekanayake, & Kulathunga	2023	Sri Lanka	Case study	Two cases included. One relevant to this study including a 15-year-old girl with intellectual disability.	• Went to hospital after 3 to 4 months of vaginal discharge. • Removed a polythene bag that was causing discharge. • Revealed that the older brother had raped the girl on several occasions and had used the bag in place of a condom.
Van Horne	2014	USA	Quantitative, population-based study. Thesis.	2,977,758 children, 95% of all children born in Texas between 2002 and 2011. 3743 had Down syndrome, 98 of which had reported maltreatment.	• Children with Down syndrome - Parents were the perpetrators of abuse in 92.9% (91) cases, RR= 1.04 95% CI [.99, 1.10]. - Relatives were the perpetrators of abuse in 1% (1), RR= 1.10 95% CI [.01, .68]. - Less likely to be abused by a non-parental relative compared to children without a disability, RR = .10, 95% CI [.01, .68].

Appendix G: Important Words Poster

Curtin University

Important words and what they mean

Maltreatment: Violence, abuse, neglect.

Violence: If someone is hurting you physically*.

Abuse: If someone is treating badly*. There are different types of abuse.

Physical abuse: If someone is hurting you physically.

Sexual abuse: If someone makes you do sexual things that you do not want to do.

Mental abuse: If someone makes you feel sad and not good about yourself.

Financial abuse: If someone uses your money in a way that they should not.

Neglect: If someone is not helping you the way they are supposed to help you*.

Family member: Someone who you are closely related to. They may or may not live in the family home.

These words and their meanings are based on the ones made by the Royal Commission into violence, abuse, neglect, and exploitation of people with disability. The words with the * next to them are the same as those made by the Royal Commission.

Appendix H: Getting Help Card

Getting help card

If you are in danger always call 000

Talk to someone

Lifeline

Lifeline for people who are feeling sad. You can call, chat online, or text at any time of the day or night.

- Call: 13 11 14
- Chat: https://www.lifeline.org.au/crisis-chat/
- Text: 0477 13 11 14
- Website: https://www.lifeline.org.au/

1800Respect

1800Respect help people who have had violence or sexual abuse done to them. You can call or chat online at any time of the day or night.

- Call: 1800 737 732
- Chat: https://chat.1800respect.org.au/#/welcome

Get help

Crisis Care

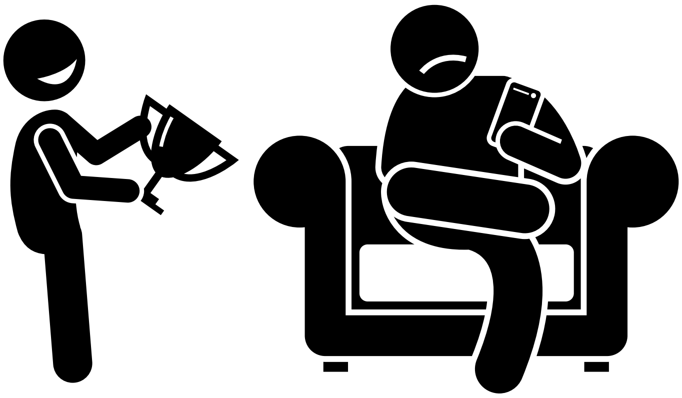
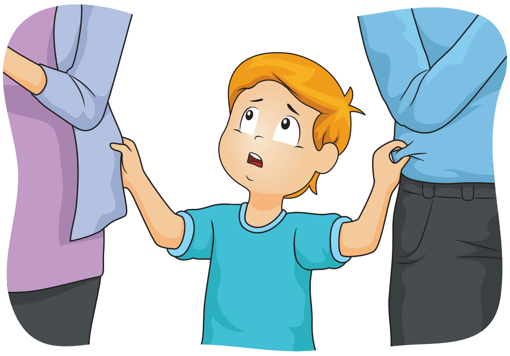
Crisis Care help people who have a violent home life, people who do not have a home, and people who are worried about a child. You can call any time of the day or night.

Call: 1800 199 008

Appendix I: Stop Card

stop

Appendix J: Picture Cards

 The person’s parents are not happy when they win an award.	 The person is hungry all the time.
 The person’s parents do not pay attention to them.	 The person’s fridge does not work.

The family do not take the person to the doctor when they are sick.

The person is not allowed to see friends.

The person's parents do not make them go to school.

The person never has clean clothes.