Perspective of Persons with Intellectual Disabilities and Their Paid Support Providers Regarding Financial Abuse

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Abstract

The objective of this dissertation was to conduct inclusive qualitative research to add to the literature regarding financial abuse among persons with intellectual disabilities. The project aimed to investigate how individuals with intellectual disabilities and their paid support providers define financial abuse and interpret such situations. We also involved two advisors with intellectual disabilities in different phases of the project. We produced one rapid scoping review which examined the inclusive research literature on involving persons with intellectual and other cognitive disabilities in research and program evaluation teams. The results of the scoping review informed the inclusive strategies that we used during the project. We also conducted two inclusive qualitative studies; one investigated the perspectives of persons with intellectual disabilities regarding financially abusive situations, and another one examined the perspectives of paid support providers regarding financial abuse. We conducted semi-structured interviews using three short vignettes on different forms of financial abuse (i.e., implicit, explicit and no financial abuse) with 12 persons with intellectual disabilities with mild level of support needs and five short vignettes (two implicit, two explicit and one no financial abuse) with 14 paid support providers. For example, explicit financial abuse includes a situation in which someone is forced to pay for another person; and implicit financial abuse comprises a situation in which a support provider or caregiver does not allow an individual to spend their money how they wish to. The support providers included those who directly (i.e., support workers and social workers) or indirectly (i.e., managers and directors) work with persons with intellectual disabilities. Studying financial abuse among persons with intellectual disabilities and their support providers highlights the need for and importance of developing a comprehensive definition of financial abuse to

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help with the identification of abusive situations. This dissertation also adds to the knowledge base regarding some of the factors that impact the interpretations of persons with intellectual disabilities regarding financially abusive situations. Lastly, we discuss our proposed financial abuse prevention strategies, informed by the socio-ecological model, to approach this societal problem in a systematic manner.

Chapter 1: General Introduction

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In 2006, the United Nations Convention on the Rights of Persons with Disabilities stated that individuals with intellectual disabilities should have freedom from cruel treatment or punishment (article 15) and should have the right to be protected from all forms of exploitation, violence, and abuse (article 16) (United Nations, 2006). Furthermore, there have been recent movements to promote social inclusion and safe community living for persons with intellectual disabilities. Despite these recommendations and movements, these individuals remain at a greater risk of experiencing financial abuse, compared to those without a disability (Abbott & Marriott, 2013; Davis, 2018; Fisher et al., 2016). This thesis aims to investigate how individuals with intellectual disabilities and their support providers interpret financially abusive situations, what contextual factors they consider when determining if a situation is abusive, and their emotional and behavioural reactions to such situations.

This dissertation used an inclusive approach, which is defined as research that aims to: 1) contribute to social change by involving individuals with intellectual disabilities, who are often excluded from society, to improve their quality of life; 2) explore problems that are important to persons with intellectual disabilities, and to draw from their experiences to inform research processes; 3) foster collaborations and recognize inputs that persons with intellectual disabilities can make in research; and 4) deliver information that can be used by persons with intellectual disabilities to advocate for change on behalf of others (Walmsley et al., 2018). Inclusion of persons with intellectual disabilities in research teams not only prevents further exclusion of this population (Mertens, 2001) but also has several added values in research, including improving the validity and utility of research (Frankena et al., 2015; Maynard, 2015). Individuals with intellectual disabilities who are involved in research teams have been

Scoping Review of Empirical Knowledge Base: Inclusive Research and Evaluation assigned variable titles and responsibilities (Ghaderi et al., 2023). The findings of a literature review (i.e., Ghaderi et al., 2023) revealed that individuals with intellectual disabilities who were entitled as “advisors”, provided feedback and guidance on the content of research tools, and advised on the development of research processes, recruitment, data collection, data analysis and dissemination of results. Therefore, for this dissertation, we recruited two advisors with intellectual disabilities who were involved in the development of research tools, recruitment, and data analysis. The inclusive approaches and strategies are further discussed in detail in Chapter 4.

Definition of Abuse

The definition of abuse is ‘culturally determined’ (Petitpierre et al., 2013). In other words, what constitutes abuse can differ across time (Tomkiewics, 1992), context (Petitpierre-Jost, 2002), and the advancement of the law (Durning, 2000). According to the Department of Justice of Canada, abuse is defined as a “behaviour that scares, isolates, or controls another person”; and “neglect is the failure to provide care, which can cause serious harm”. There are different forms of abuse including physical (e.g., hitting, pushing, slapping), sexual (e.g., touching in a sexual manner without consent, forceful sexual act), emotional or psychological (e.g., yelling, threatening, humiliating, name-calling), and financial (e.g., taking an individual’s money without their permission, withholding their money to prevent them from, for example, receiving treatment) (Government of Canada, 2019).

Manly (2005) argued that developing a clear research definition of abuse could enhance researchers’ ability to better communicate with different disciplines (e.g., judges, practitioners, and educators). It can also lead to knowledge improvement regarding “the thresholds at which good practice becomes abusive behaviour”

Scoping Review of Empirical Knowledge Base: Inclusive Research and Evaluation (Petitpierre et al., 2013, p. 197). For instance, abuse can be defined differently in a legal context compared to a social context, and the judgment of the law and “common sense” may not overlap. Therefore, the juxtaposition between a legal advisor’s evaluation of a situation and the view of a community regarding the same situation can provide valuable information. In addition to the legal context, an evaluation of a behaviour as abusive may be dependent on the social standards of a society, to which the individual belongs (Christopherson, 1993).

Petitpierre et al. (2013) argued that physical abuse is easier than other forms of abuse to operationally define. Difficulty in properly defining abuse can lead to failure in identifying and reporting it, which in turn will negatively impact the evaluation of prevalence (Petitpierre et al., 2013; Runyan et al., 2005). Runyan et al. (2005) studied the accordance in defining and classifying child maltreatment (also referred to as abuse and neglect) between child protective services in the U.S. and research coding systems. The results revealed differences between child protective services records classification and research coding systems. Nonetheless, the discrepancy in the definition of abuse among different disciplines may have implications in terms of assessment, treatment, policy, and outcomes for populations at risk of abuse victimization including persons with intellectual disabilities.

Financial Abuse

Defining financial abuse is a complex task as it comprises a range of behaviours and practices that are considered exploitative (Brooks et al., 2012). The Government of Canada (2022) defined financial abuse as “taking someone’s money or property without permission; withholding or limiting money to control someone; pressuring someone to sign documents; and forcing someone to sell things or change a will”, as well as theft

and fraud which are considered as crimes. In addition to these definitions, Brooks et al's. (2012) literature review resulted in a few additional definitions including pressuring an individual to withdraw money from the cash machine for them, borrowing money and never paying it back, and taking someone's pension, benefits or inheritance. Several factors and dynamics need to be considered in the assessment of financial abuse, such as 1) the intentions of the (prospective) perpetrator and their relationship with the victim or person at risk of victimization; 2) whether the money is used properly to meet the needs of the individual at risk; and 3) the extent of harm or loss to the individual at risk (Brown, 2003). While some forms of abuse, such as theft or fraud, are easily detected, other forms of financially abusive behaviours are implicit, such as support providers assuming responsibility over an individual's benefits payment or finances and spending such for their gain, and may be easily overlooked (Brooks et al., 2012; Davis, 2018).

In this thesis, the definition of financial abuse is informed by the previous literature (i.e., Brooks et al., 2012) and the definition provided by the Government of Canada (2019) and is defined as theft, fraud, exploitation, and infringing on individuals' rights to their finances. Additionally, financially abusive behaviours include the following acts and practices: taking an individual's money without their permission; pressuring a person to spend their money despite their will; preventing an individual from spending their money how they wish to; stealing an individual's pension or other benefits; forcing or pressuring someone to sign a document against their will; and borrowing money but not giving it back.

Definitions of Intellectual Disabilities

Intellectual disability is a lifelong neurodevelopmental condition characterized by significant deficits in cognitive ability and adaptive functioning (American Psychiatric

Scoping Review of Empirical Knowledge Base: Inclusive Research and Evaluation Association; APA, 2013). Intellectual disability manifests at different ages during the developmental period and may be acquired due to reasons such as genetics (e.g., Down syndrome), acquired brain trauma (during developmental years) that severely impact cognitive skills, meningitis or encephalitis (APA, 2013; McKenzie et al., 2016). Diagnoses such as Down syndrome, Fetal Alcohol Syndrome, Fragile X Syndrome, Autism Spectrum Disorder and Prader-Willi syndrome are often concomitant with a diagnosis of intellectual disabilities (APA, 2013). In the general population, 1 in 100 individuals has a diagnosis of intellectual disabilities; however, the prevalence varies by age (APA, 2013). In 2010, the prevalence of intellectual disabilities among Ontario residents between the ages of 18-64 years was estimated at approximately 0.8% (Lin et al., 2014; Ouellette-Kuntz et al., 2009). In 2019, the global estimate of the prevalence of intellectual disabilities was two percent (Nair et al., 2022), and 85% of these individuals have mild levels of support needs (APA, 2023).

The diagnosis and assessment of intellectual disabilities include a battery of standardized intellectual assessments, clinical evaluation, and an adaptive functioning assessment with multiple informants (e.g., physicians, caregivers, and teachers) (APA, 2013). Based on the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5), the IQ score of individuals with intellectual disabilities is below 70, which is two standard deviations (*SD*= 15) or more below the population mean (*M*= 100). These individuals also show significant impairment in adaptive functioning, which involves conceptual (i.e., memory, language, acquisition of practical knowledge, etc.), social (i.e., interpersonal communication skills, friendship abilities, etc.) and practical domains (i.e., personal care, money management, recreation, etc.) (APA, 2013).

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Intellectual disability is characterized by deficits in different areas of cognitive functioning (APA, 2013). For example, individuals with intellectual disabilities may have limited vocabulary, poor short-term memory, difficulty understanding the abstract association between objects, and a limited level of concrete reasoning (Lifshitz et al., 2011). Deficits in cognitive functioning create different levels of impairments (i.e., mild, moderate, severe and profound) in individuals' different areas of adaptive functioning (i.e., conceptual, social and practical skills; APA, 2013). For instance, persons with intellectual disabilities may experience difficulties with money management, judging novel situations, managing personal care, and regulating their behaviour (American Association on Intellectual and Developmental Disabilities (AAIDD)- 11th Edition, 2010; APA, 2013).

While the DSM-5 uses the term "Intellectual Disabilities", the International Classification of Diseases, 11th Edition (ICD-11) uses the term "Disorders of Intellectual Development (World Health Organization; WHO, 2018); ICD-10 and DSM-IV used the term "Mental Retardation" (APA, 2000; WHO, 1992). However, this term is now considered derogatory as it further perpetuates stigmatization against this population and is socially harmful (Nash et al., 2012). Furthermore, depending on geographic location and research background, other terminologies including "Intellectual and Developmental Disability", "Developmental Disability" and "Learning Disability" are used to label these individuals. For instance, in the United Kingdom, the term "Learning Disability" is used, while this term is used for a different diagnosis in North America. The term "Intellectual Disabilities" will be used in this thesis proposal to refer to persons who experience impairments in their intellectual and adaptive functioning that were present before adulthood.

According to the medical model, disability is a problem rooted in a person's body, which is the cause of any disadvantages that they may experience (Goering, 2015). This model overemphasizes the impairment and explains disability as a technical problem that must be fixed, cured or rehabilitated (Goering, 2015; McKenzie, 2013). However, the social model of disability defines 'disability' as the "disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities" (Oliver, 1996, p. 22). In this thesis, our conceptualization of intellectual disability is coherent with the social model of disability. While we use the term "Intellectual Disabilities" in this thesis project, we recognize its stigmatizing impact on this population and acknowledge that 'disability' is due to restrictions posed by individuals' environments rather than their limitations.

Financial Abuse and Intellectual Disabilities

In the past decade, there has been a significant focus on financial abuse among elderly individuals in the general population (e.g., Bagshaw et al., 2013; Gibson & Greene, 2013; Phelan et al., 2018). Even though individuals with intellectual disabilities are at risk of experiencing all forms of abuse (e.g., Abbott & Marriott, 2013; Fisher et al., 2012), there is a gap in the literature regarding financial abuse among this population. In Canada, persons with intellectual disabilities earn less than average compared to those without a disability, and 49.1% of these individuals living in Ontario receive financial support from the province (Berrigan et al., 2020). Persons with intellectual disabilities often experience financial difficulties due to a lack of employment opportunities (Khayatzadeh-Mahani et al., 2019), limited access to financial resources, and few options in terms of services they can obtain. As a result of such difficulties, they are

pressured to live in environments (e.g., relationships) that further expose them to abuse victimization (Ansello & O'Neill, 2010). However, financial exploitation is detrimental to the autonomy of individuals with intellectual disabilities (Buhagiar & Lane, 2022).

As Northway (2001) discussed, individuals with intellectual disabilities not only earn inadequate income, but they lack control in managing their money, all of which have negative implications for their mental health and social functioning. Similarly, Buhagiar and Lane (2022) found that individuals with intellectual disabilities reported uncertainty regarding how to access their money and financial accounts, due to which they further relied on support providers' assistance. This highlights institutional barriers that this population encounters, which further places them at risk of abuse victimization (Buhagiar & Lane, 2022).

In Canada, individuals with intellectual disabilities have the legal capacity, which is a human right for all individuals, to make decisions about personal matters including finances, property and healthcare (Emerson et al., 2001). Following the deinstitutionalization movement, persons with intellectual disabilities have been provided with more opportunities to be involved in making decisions regarding their financial matters. However, such decision-making opportunities have increased the risk of abuse victimization among this population (Emerson et al., 2001).

Many individuals with intellectual disabilities experience difficulty understanding the notion of money, and those who live independently are often under strict expenditure control (Williams et al., 2007). Researchers investigated the financial decision-making abilities of persons with intellectual disabilities with mild levels of support needs (Suto et al., 2005b). Suto et al. (2005b) found that these individuals have poorer abilities compared to the general population; however, they can make decisions

regarding their finances. Despite such findings, more than 50% of persons with intellectual disabilities do not have control over their money management, and they encounter barriers to accessing and utilizing banking services (Abbott & Marriott, 2013). Additionally, these individuals have reported that someone else decides how they should spend their money (Emerson et al., 2005). Specifically, even though persons with intellectual disabilities, who live in residential homes, have expressed their desire to have more control over their money, they reported that they have limited control over their finances (Buhagiar & Lane, 2022). This highlights the institutional power and systematic barriers restricting individuals' autonomy (Buhagiar & Lane, 2022; Magasi, 2008).

Some individuals with intellectual disabilities may be dependent on others as they require assistance in managing their financial affairs. Nevertheless, being dependent on others to manage their finances can increase the risk of financial exploitation (Abbott & Marriott, 2013). Additionally, Leutar et al. (2014) investigated the experiences and perceptions of individuals with intellectual disabilities (with mild to moderate levels of support needs) regarding abuse. They found that most participants experienced financial abuse perpetrated by people they knew (i.e., volunteer carers, family and friends).

Prevalence of Abuse among Persons with Intellectual Disabilities

According to the results of the 2014 General Social Survey (GSS), women with a cognitive disability (Braddock et al., 2004, p. 49) are at a higher risk of experiencing some type of abuse or violence (i.e., 43%), especially intimate-partner violence by a current or former partner, compared to men with a cognitive disability (i.e., 27%; Cotter, 2014). In this report, cognitive disability was defined as "substantial limitation in one's

capacity to think, including conceptualization, planning, and sequencing thoughts and actions, remembering, interpreting subtle social cues, and understanding numbers and symbols" (Braddock et al., 2004, p. 49) and include intellectual disabilities. Compared to the victims of sexual assault and violent crime who have no disability, the victims with a disability are less likely to report the crime to the police (25% versus 14%). The reason is that they tend to be afraid of retaliation by the offender may feel that the perpetrator would not be condemned or punished (48% versus 28%) and may be apprehensive about dealing with court processes (41% versus 26%; Cotter, 2014).

Fisher et al. (2016) conducted a systematic review of the studies from North America, Europe and Asia regarding victimization and social vulnerability of persons with intellectual disabilities. They found that 5.4% to 80% of individuals with intellectual disabilities experience sexual abuse (more women than men), 42% experience assault, and 41% experience intimidation. Among women with intellectual disabilities, the likelihood of being abused is four times higher than the general population (Martin et al., 2006). Specifically, the prevalence of sexual abuse is approximately between 80% to 90% among these individuals (Matich-Maroney, 2003; Sobsey & Doe, 1991). In addition to sexual abuse, caregivers of individuals with intellectual disabilities have also reported a wide range of abuse (i.e., financial exploitation as well as physical, emotional/psychological abuse) experienced by both adolescents and adults with intellectual disabilities (Fisher et al., 2012).

Abuse Victimization among Persons with Intellectual Disabilities

Despite the global attention on promoting independent living among persons with intellectual disabilities, these individuals are often at a greater risk of exposure to social hazards compared to those without intellectual disabilities (Conder & Mirfin-Veitch,

Scoping Review of Empirical Knowledge Base: Inclusive Research and Evaluation 2020; Emerson & Hatton, 2014). Several individual, environmental and societal factors increase the likelihood of victimization among this population (Hollomotz, 2009). For instance, some of the personal characteristics of individuals with intellectual disabilities may predispose them to being abused. Specifically, individuals' difficulties in taking others' perspectives and recognizing nonverbal and contextual cues have been shown to increase the risk of victimization (Fisher et al., 2012). Furthermore, the results of the systematic review by Fisher et al. (2016) showed that the following characteristics of adults with intellectual disabilities contribute to the risk of experiencing abuse: 1) the presence of intellectual disabilities; 2) individuals with poor interpersonal competence; 3) individuals who use passive or avoidant decision-making strategies; and 4) individuals who have few friends. Eastgate et al. (2011) also identified that limitations in communication skills and others perceiving this population as asexual are some of the risk factors that impede the detection of sexual abuse incidents among this population.

Foster and Sandel (2010) have identified relying on others for their daily living needs as another risk factor contributing to victimization among individuals with intellectual disabilities. Additionally, Hollomotz (2012) conducted semi-structured interviews using 'photo story' vignettes to investigate the knowledge of individuals with intellectual disabilities regarding sexual abuse and violence (i.e., threats, intimidation and physical assault), as well as ways in which they would be involved to safeguard themselves. The findings of the study revealed that most respondents (i.e., 26 of 29) were able to identify danger in the scenarios, were aware of the risk, illustrated self-protective skills when assessing the situation, and showed an ability to plan actions to deal with the situation. The findings showed no significant difference between male and female participants' answers. More importantly, some of the respondents, who had

experienced domestic violence, reported having had difficulties leaving their partners due to “the emotional impact of violence and the power relations within which it occurs” (Hollomotz, 2012, p. 123). Ansello and O’Neill (2010) also indicated that these individuals may remain in an abusive relationship due to financial difficulty or a lack of affordable housing. Therefore, in addition to individuals’ lack of knowledge regarding abuse and violence, situational and emotional factors such as power imbalance and dependence on the perpetrator increase the risk of experiencing abuse among this population.

The results of the study by Fisher et al. (2016) showed that individuals with intellectual disabilities who lacked sexual knowledge believed someone else controlled their sexual experiences, were sexually abused in childhood and lived in group homes or institutions, were more susceptible to experiencing sexual abuse compared to those who did not have such experiences. Also, Northway et al. (2013) conducted individual interviews and focus groups to investigate the views and feelings of persons with intellectual disabilities and abusers regarding abuse and whether they felt one form of abuse was worse than the other. The findings of the study showed that several individuals with intellectual disabilities identified sexual abuse as the worst form of abuse. Others discussed the subjective element of deciding whether a behaviour is abusive and the severity of that abuse. In other words, persons with intellectual disabilities may believe that abuse is part of life, if they lack knowledge regarding their right to be safe. More importantly, not every individual perceives an abusive situation as abuse (Northway et al., 2013). Nonetheless, these findings raise the question as to what factors impact individuals’ subjective interpretations of abusive situations and their judgment in such situations.

Self-protection skills and the ability to decide to keep safe are required in situations that involve abuse. Individuals with intellectual disabilities may exhibit severe limitations in their decision-making skills (Hickson & Khemka, 2013). Decision-making relies on rapid and spontaneous processes based on an individual's personal preferences and impressions. Nevertheless, in situations where consequences are serious, such as abuse, a more cautious and thoughtful process may be required to analyze the consequences and produce a course of action accordingly. Such processes place significant demands on an individual's decision-making ability, which may be challenging for persons with intellectual disabilities (Hickson & Khemka, 2013).

Furthermore, the lack of support provided by healthcare and social systems has been shown to contribute to the increased risk of experiencing abuse among individuals with disabilities (Curry et al., 2001). Hollomotz (2012) also noted that individuals with intellectual disabilities, who experienced abuse, indicated that when they reported the incidents of abuse, others did not always support them, and in fact, they were dismissed as they were believed to be overreacting by others. Nevertheless, Manly (2005) argues that "many of the experiences that could be categorized as maltreatment involve violations of social norms that have no clear standards for appropriate behaviour" (p. 426). In other words, persons with intellectual disabilities, who are the victims of abuse, might be dismissed by support providers due to a lack of clear definition of abuse used among different stakeholders and agencies (e.g., lawyers, social workers, support workers, clinicians).

Many researchers have examined the complex position that individuals with disabilities hold in the context of a patriarchal society (Sobsey, 1994; Hassouneh-Phillips & Curry 2002; Brownridge 2006). Lonsdale (1990) proposed the notion of

rolelessness, which implies women with disabilities not only are stereotyped as passive, dependent and asexual but also, they are stripped of conventional female roles (i.e., mother, wife). In addition, individuals with disabilities continue to be impacted by social stigma, and marginalization, as well as the pervasive effects of negative stereotyping perpetuated by social media portrayal of disability (Curry et al., 2001). Such stereotypic views place individuals with disabilities at a higher risk of abuse. In other words, many forms of abuse including psychological, financial and neglect may not be recognized in this population, which will negatively impact the likelihood of them receiving help and support, and in turn increase the possibility of re-victimization (Curry et al., 2001).

Direct-Support Providers to Persons with Intellectual Disabilities

In 97% to 99% of cases of abuse, the perpetrators are known to individuals with intellectual disabilities, and they include healthcare providers, caregivers, family members, and support providers such as frontline staff (Baladerian, 1991; Stevens, 2012). Even though decision-making is a determinant of human rights, social stigma against persons with cognitive disabilities can result in limitations in individuals' ability to practice their rights (James & Watts, 2014). To enhance the self-determination and dignity of persons with a disability, supported decision-making legislation was proclaimed in Canada to provide them with an opportunity to partake in decisions related to their life circumstances. In other words, in situations in which individuals with a disability may not have the legal or cognitive capacity to make decisions on their own, one or more people (who are fundamental in the decision-making process of these individuals and have formal legal permission) assist or speak on their behalf (James & Watts, 2014).

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Family members and paid caregivers often provide tremendous support to persons with intellectual disabilities in managing their finances (Conder & Mirfin-Veitch, 2020), making choices, expressing their preferences, and exploring options (Carney & Beaupert, 2013; Taylor et al., 2019). In Ontario, persons with intellectual disabilities are provided with self-directed services (i.e., the Passport Program developed by the Ministry of Children, Community and Social Services), which offer them a funding opportunity to hire support staff and purchase services on their own (Developmental Services Ontario; DSO, 2020). Nevertheless, researchers looking at similar programs (e.g., self-directed services in the U.S, individualized funding interventions in Ireland, and a 'personalization' agenda in the UK) have raised concerns regarding the personal safety of persons with intellectual disabilities as they are at a greater risk of experiencing financial exploitation in a less structured support system (Abbott & Marriott, 2013; Bogenchutz et al., 2010; Fleming et al., 2019).

Abbott and Marriott (2013) explored the perceptions of support providers (i.e., service managers, team leaders, support workers, advocates, etc.) regarding the issues of money and finances among persons with intellectual disabilities. The findings revealed that staff reported some individuals with intellectual disabilities, with severe support needs who live in an inpatient facility, do not have control over their money. Second, some staff reported having difficulty assessing what persons with intellectual disabilities know about money, and in some cases, staff assumed that these individuals had a greater understanding and numeracy skills in money management than they possessed. Furthermore, staff reported experiencing difficulty supporting individuals with severe support needs (i.e., those with more complex needs and more severe impairment in cognitive and communication skills) regarding money and finance. Third,

many staff expressed their concerns and confusion regarding the lack of information and direction provided as part of the personalization program. Also, they felt uncomfortable assisting individuals with their financial management, or “having more control over money on a day-to-day basis” (p. 109). Lastly, staff expressed apprehensions about safeguarding persons with intellectual disabilities in relation to money. Their concerns were related to, for example, receiving the wrong change and disclosing their PIN to others. Additionally, they worried about the risk of exploitation and financial abuse perpetrated by others including staff, family and friends. More importantly, many of the direct care staff did not want to be involved in providing money advice due to the risk of being accused of financial abuse. Therefore, these findings illustrate the dilemma that support staff experience when assisting individuals with intellectual disabilities with their money and finances. While they play a significant role in supporting persons with intellectual disabilities, they are concerned about being embroiled in possible situations of financial abuse (Abbott & Marriott, 2013).

When working with individuals with intellectual disabilities, it is crucial to balance protective practices and opportunities for them to become independent (Georges-Janet, 2005; Petitpierre et al., 2013). However, creating such a balance might be complicated, when expectations and guidelines are ambiguous with regard to what constitutes an at-risk situation (e.g., an abusive situation) for persons with intellectual disabilities (Jourdan-Ionescu, 2001). Similarly, Fleming et al. (2019) argued that risk management can be a challenge for support staff. These professionals are required to facilitate positive risk-taking among individuals with intellectual disabilities, and they have to ensure financial abuse (related to funding provided to this population) is prevented. In other words, while support staff attempt to assist individuals with their financial

management, they may limit access to their funding to safeguard them from exploitation (Fleming et al., 2019).

In addition to such challenges, research also shows that some support providers view individuals with intellectual disabilities as vulnerable and powerless, due to which they believe that these individuals need protection against abuse (Eastgate et al., 2011; Parley, 2011). Nonetheless, viewing persons with intellectual disabilities as vulnerable tends to precipitate support providers exerting power and authority over these individuals (Parley, 2011), and it may negatively impact their sense of autonomy and motivation to gain self-protective skills (Hollomotz, 2012). Therefore, researchers have highlighted the need for appropriate training for professionals on how to best support individuals with intellectual disabilities regarding their financial management (Abbott & Marriott, 2013).

Additionally, Petitpierre et al. (2013) investigated the perspectives of parents of individuals with intellectual disabilities, direct-care professionals and a legal advisor on a video vignette that portrayed problematic care practices. In summary, the vignette was about a situation in which an individual with intellectual disabilities did not abide by the residential program and a direct-care professional utilized forceful behaviour for the individual to perform the task. Also, the vignette consisted of several scenes with variable protective factors (i.e., “absence of problematic behaviour”, residents’ ability to express themselves verbally”, “high level of supervision”, etc.) and risk factors (i.e., “resident’s tendency to remain passive”, “fatigue expressed by the female care worker”, etc.) (p.198). The findings revealed that all the participants disapproved the practices in the vignette however, 21 participants (out of 23), were hesitant to use the word “abuse”. From the legal advisor’s point of view, such practices are difficult to pursue legally as

they are “beyond the scope of justice which concentrates on serious matters” (p. 204). The professionals viewed such practices as alarming as they illustrate negligence in applying ethical and professional rules. Some participants discussed the increased risk in scenes in which the antagonist was, for example, stressed. Therefore, Petitpierre et al. (2013) highlighted the importance of implementing educational programs that increase professionals’ awareness regarding the risk of practicing in an abusive manner. They also emphasized the importance of training professionals to examine their practices regularly to avoid practicing authoritatively. Lastly, they claimed that “the convergence of theoretical, legal, and social points of view provides a sound basis for tackling “borderline” care practices” (p. 205).

Consequences of Abuse on Individuals with Intellectual Disabilities

Studies show that many individuals with intellectual disabilities, who are the victims of abuse, experience mental health problems (Taggart et al., 2010), nightmares and posttraumatic stress disorder (PTSD; Kroese & Thomas, 2006), self-harm, and suicide attempts (Northway et al., 2013). Abuse can be traumatic for individuals with intellectual disabilities, and it can lead to different mental illnesses, as well as physical and social consequences (Brown et al., 2012; Karatzias et al., 2019). Taggart et al. (2007) found that individuals with intellectual disabilities identified suffering from psychological trauma as a result of experiencing physical, emotional and financial abuse (perpetrated by their partners) as one of the risk factors leading to their substance misuse (Taggart et al., 2007).

Abuse may have a ripple effect on individuals with intellectual disabilities. Furthermore, the findings of Northway et al. (2013) revealed that some individuals with intellectual disabilities reported they often develop unhealthy strategies (e.g., committing

an offence, not disclosing the abuse) to cope with their feelings following abuse because they feel unsafe reporting the abuse, or think that others may not believe them. As a result, they often feel helpless, hopeless, embarrassed, powerless and suicidal (Northway et al., 2013).

Interventions Programs Addressing Abuse

There are intervention programs that aim to teach individuals with intellectual disabilities to make effective decisions when dealing with abusive situations (Khemka, 2000; Khemka & Hickson, 2002; Khemka et al., 2005; Hickson et al., 2015). Khemka et al. (2005) implemented An Effective Strategy-Based Curriculum for Abuse Prevention and Empowerment (ESCAPE), which is a curriculum based on cognitive, motivational and emotional aspects of decision-making. The ESCAPE curriculum was demonstrated to be effective in improving knowledge of abuse concepts, as well as empowerment and decision-making among women with intellectual disabilities. Therefore, they concluded that individuals with intellectual disabilities can develop decision-making skills and apply them in abusive situations. Nevertheless, regarding their knowledge of verbal abuse, only 50% of participants in the intervention group provided sufficient definitions of verbal abuse and consent. The authors suggested that these results may be due to individuals' lack of knowledge regarding verbal abuse (Khemka et al., 2005).

Subsequently, Hickson et al. (2015) conducted a randomized controlled trial to evaluate the effectiveness of the ESCAPE-DD curriculum in enhancing the effective decision-making abilities of men and women with intellectual disabilities when presented with vignettes of abuse (sexual, physical and verbal). ESCAPE-DD is a modified version of the ESCAPE curriculum, which is appropriate for both men and women and is based on a theoretical model that "emphasizes the interplay of the cognitive, motivational and

emotional processes involved in decision making" (p. 491). Participants were presented with each vignette before and after the intervention, and they were asked two questions pertaining to their problem awareness and decision-making effectiveness. The results of the study showed the ESCAPE-DD curriculum intervention was concomitant with enhanced decision-making skills in relation to the scenarios on sexual, physical and verbal abuse. Furthermore, participants who participated in this intervention illustrated an increase in their safe-now effective decision-making skills in response to vignettes depicting situations of abuse, compared to the control group. Participants in the intervention group also discussed taking actions to restore immediate safety only 35% of the time, versus 15% of the time for those in the control group. Nonetheless, the results revealed no significant difference in pretest-to-posttest scores in problem awareness between the intervention and control groups. The authors attributed these results to individuals' "incomplete understanding of the potential harm or danger inherent in the abuse situations" (p. 500). Therefore, they highlighted the need for further research to improve problem awareness skills among this population. Additionally, they speculated that such a limited understanding of harm and danger in abuse situations could be a factor contributing to limited effective decision-making among individuals with intellectual disabilities (Hickson et al., 2015).

Additionally, Bruder and Kroese (2005) conducted a review of the literature on preventative interventions for people with intellectual disabilities to protect them against abuse. Similar to the results of Khemka et al's. (2005) study, these authors also found that preventative and protective skills can be learned. However, these authors argue that the knowledge learned during the experiment is not necessarily transformed into protective behaviours applied to real-life situations. This finding raises the question as to

what impedes individuals with intellectual disabilities from applying their knowledge of abuse in a real-life situation.

Rationale

Abuse is four times more prevalent among individuals with intellectual disabilities compared to the general population (Fisher et al., 2016; Martin et al., 2006). Several risk factors (e.g., difficulty understanding the notion of money, impairment in communication skills) play a role in increasing the likelihood of experiencing financial abuse among this population (e.g., Fisher et al., 2016; Foster & Sandel, 2010; Williams et al., 2007). To date, most researchers have investigated sexual abuse among persons with intellectual disabilities (e.g., Byrne, 2018; Hollomotz, 2012); however, research on financial abuse among this population is scarce. Many individuals with intellectual disabilities rely on others to assist them with their financial management, which in turn increases the likelihood of experiencing financial abuse (Abbott & Marriott, 2013). Persons with intellectual disabilities have expressed their aspiration to have more autonomy and control over their finances and their desire to learn how to protect themselves (Buhagiar & Lane, 2022). Nonetheless, as the results of the randomized controlled trial by Hickson et al. (2015) revealed, it is unclear how individuals with intellectual disabilities interpret abusive situations and whether they identify danger in real-life situations. Therefore, these authors emphasized the need for educating individuals with intellectual disabilities regarding abuse, identifying harm and danger in abusive situations and implementing interventions to improve their decision-making skills in such circumstances (Hickson et al., 2015).

Furthermore, many support providers play a significant role in assisting individuals with intellectual disabilities with their financial affairs (Conder & Mirfin-Veitch,

Scoping Review of Empirical Knowledge Base: Inclusive Research and Evaluation 2020; Fleming et al., 2019). These individuals have raised concerns regarding their lack of comfort in assisting persons with intellectual disabilities regarding their financial management, and that they are often worried about being accused of financial abuse (Abbott & Marriott, 2013). Additionally, many support providers experience difficulty identifying implicit cases of abuse perpetrated against individuals with intellectual disabilities (Petitpierre et al., 2013). Despite such findings and the important role support providers play in the lives of persons with intellectual disabilities (i.e., assisting them with their money and finances), there is a gap in the literature regarding what they know about financial abuse as well as their perspectives on this topic.

Finally, abuse has negative implications on the mental health of individuals with intellectual disabilities (e.g., PTSD, self-harm, suicide attempts). Therefore, it is crucial to develop prevention programs and interventions to help persons with intellectual disabilities safeguard themselves against abuse. Prevention and intervention approaches may include implementing educational programs regarding identification of financial abuse, teaching about individuals' rights to their finances, where to refer if they are at risk or have experienced financial exploitation, and what steps to take to prevent victimization (e.g., assertiveness training) (Northway et al., 2013). To provide support, it is imperative to learn how individuals with intellectual disabilities define, process, and interpret financially abusive situations. It is also important to investigate what factors impact their interpretation of an abusive situation, as well as their emotional and behavioural reactions in such situations. This information is crucial because the perspectives of persons with intellectual disabilities impact the likelihood of them reporting abuse, and if they do not report abuse, they will unlikely receive support (Northway et al., 2013).

Also, given support providers play an important role in helping persons with intellectual disabilities regarding their financial matters, it is imperative to investigate how they define and interpret financially abusive circumstances, and what factors impact their interpretations of such situations. Investigating support providers' perspectives about financial abuse among persons with intellectual disabilities will: 1) inform future trainings to increase their knowledge regarding different types of financial abuse, and their skills in identifying red flags associated with this issue; 2) raise awareness regarding their practices to ensure they learn, reflect and prevent practicing in an authoritative manner when providing assistance to individuals with intellectual disabilities with their finances (Petitpierre et al., 2013); 3) raise awareness among policy makers and developmental disability sector to implement guidance and procedures for support providers, who work directly or indirectly with individuals with intellectual disabilities, to address financial abuse (Buhagiar & Lane, 2022; Mitchell & Buchele-Ash, 2000); and 4) more importantly, highlight the importance of the role policy makers and the developmental disability sector play in taking steps to protect individuals with intellectual disabilities from abuse victimisation (Mitchell & Buchele-Ash, 2000).

Overall, there are several gaps in the literature regarding financial abuse. First, there is a paucity of research regarding financial abuse among individuals with intellectual disabilities. Second, there is a lack of research regarding how persons with intellectual disabilities define financial abuse and whether they recognize situations of financial abuse. Third, service providers or support staff often support persons with intellectual disabilities in making financial decisions and encounter dilemmas between their aspirations to promote autonomous decision-making and their duty to protect persons with intellectual disabilities from exploitation. Therefore, we explored (1) how

persons with intellectual disabilities define and interpret financial abuse, and (2) how service providers, who support individuals with intellectual disabilities in making financial decisions, define and interpret financial abuse. To address these objectives, we conducted two studies.

Study 1 addressed the following research questions:

1. How do individuals with intellectual disabilities interpret abusive situations?
2. How would they determine whether a situation is abusive?
3. What factors impact their interpretation of an abusive situation?
4. How would they feel and act in an abusive situation?

Study 2 addressed the following research questions:

1. How do support providers interpret abusive situations?
2. How would they determine if a situation is abusive?
3. What would they believe the victims in an abusive situation should act or do?

Overview of Dissertation

In the following chapter (i.e., Chapter 2), we discuss the rapid scoping review that we conducted to explore how persons with intellectual and cognitive disabilities have been involved in research as active members. We reviewed 32 articles and discussed the inclusion processes that were used by inclusive researchers as well as the experiences of researchers with and without intellectual and other cognitive disabilities. The findings of this scoping review informed the inclusive strategies that we used to meaningfully involve two advisors with intellectual disabilities in this thesis project. We recruited two advisors with intellectual disabilities through Open Collaboration for Cognitive Accessibility social enterprise. We involved the advisors in three phases of research [i.e., validation of research tools, recruitment and data analysis in Study 2 (Chapter 3)], which were critical and practical. The phases of involvement were informed by the evidence in inclusive research. Due to the lack of funding and deadlines posed by the nature of the project (i.e., PhD dissertation), we were not able to involve the advisors in the data collection, which would have required funding, extensive training, scheduling, and transportation accommodations.

Chapter 3 focuses on the inclusive qualitative study that we conducted to explore how individuals with intellectual disabilities define financially abusive situations, as illustrated in three vignettes (i.e., explicit, implicit and no financial abuse). Twelve persons with intellectual disabilities participated in a semi-structured interview. This chapter discussed the findings in relation to how these individuals defined and interpreted the financially abusive situations illustrated in the vignettes, the factors that impacted their interpretations of such circumstances as well as their emotional and behavioural reactions to the scenarios.

In Chapter 4, we discuss the inclusive qualitative study that we conducted to investigate how paid support providers define and perceive financially abusive situations. Fourteen paid support providers who work directly or indirectly with persons with intellectual disabilities participated in a semi-structured interview. These individuals shared their perspectives regarding five vignettes on different forms of financial abuse (i.e., two explicit, two implicit and one no financial abuse). In this chapter, we discuss the findings in relation to the inconsistency in how financially abusive situations are defined among support providers, their perception of the rights and autonomy of persons with intellectual disabilities as well as their lack of training and knowledge regarding resources to consult if they have a question about financial abuse.

Finally, in Chapter 5, we elaborate on the findings of Chapters 3 and 4, draw conclusions regarding the similarities and differences in perceptions of persons with intellectual disabilities and their paid support providers regarding financial abuse, and offer a prevention model informed by the socio-ecological model. In this chapter, we also discuss the overall strengths and limitations of this dissertation. We share our reflections of our inclusive processes, as well as the facilitators and barriers we experienced when involving the advisors in different phases of this PhD thesis project.

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Chapter 2: Including people with intellectual and other cognitive disabilities in research and evaluation teams: A scoping review of the empirical knowledge base

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Abstract

We conducted a rapid scoping review of empirical studies to identify how persons with intellectual and other cognitive disabilities have been engaged as active members of research and evaluation teams. We conducted a literature search using a systematic method that accessed peer-reviewed studies in relevant library databases and all major evaluation journals. The search resulted in 6,624 potential articles, of which 32 met the inclusion criteria for this study. The findings address three categories of interest: 1) methodological underpinnings and practical justifications for using inclusive approaches, 2) different inclusion processes, and 3) reflections by researchers with and without intellectual and other cognitive disabilities. Findings provide conceptual and practical insights for researchers and evaluators when designing inclusive methods involving persons with intellectual and other cognitive disabilities. Gaps in inclusive research and evaluation are discussed and suggestions for future research are proposed.

Keywords: inclusion, research methods, inclusive research, program evaluation, intellectual and other cognitive
disabilities

Introduction

This paper presents and appraises existing empirical evidence on the inclusion of persons with intellectual and other cognitive disabilities in research and evaluation teams. Inclusive approaches are understood to help capture diverse perspectives that persons with intellectual and other cognitive disabilities contribute as active members of research and evaluation teams (Molinari et al., 2011). Their inclusion in such teams serves moral and social purposes, and aims to prevent further marginalization (Mertens, 2001). Moreover, including persons with disabilities can be considered good practice because inclusive approaches reportedly enhance the validity and utility of research and evaluation while limiting potential biases (Chouinard & Cousins, 2009; Frankena et al., 2015; Maynard, 2015; Mertens, 2001). However, persons with intellectual and other cognitive disabilities still tend to experience a lack of power and control over their own lives, and their voices may still be suppressed, such that 'experts' and policy makers make important research, programmatic and life decisions without them (Buchanan, 1996; Maynard, 2015; Molinari et al., 2011).

Walmsley et al. (2018) indicated that the goal of inclusive research is to contribute to "social change and improve quality of life" and it recognizes the contributions that persons with intellectual disabilities can make; it is based on problems that are important to these individuals, which also inform research processes and outcomes; it produces information that can be used by individuals with intellectual disabilities; and it brings individuals with intellectual disabilities together with those who investigate the issues that are important to these individuals (p. 758). Nonetheless, in a review of literature on inclusive evaluation (from 2000-2009) involving persons with various disabilities, Jacobson et al. (2013) found fewer persons with intellectual and

developmental disabilities included in program evaluations compared to those with psychiatric disabilities (13% vs. 47% respectively). They also indicated that while 77% of individuals with disabilities (including persons with intellectual and developmental disabilities) were included in data collection, only 31% contributed to decision-making regarding design or interpretation (Jacobson et al., 2013). There is little available evidence to guide inclusive research and evaluation processes with this population (Yarbrough et al., 2011). We embarked on this review to fill that void and inform good practice.

Different terms are used by researchers and evaluators to describe methodological approaches as they report on collaboration with persons with intellectual and other cognitive disabilities in knowledge building processes (e.g., emancipatory disability research, action research) (Bigby et al., 2014; Frankena et al., 2015). In light of this varying terminology and related conceptualizations, Walmsley and Johnson (2003) argued that ‘inclusive research’ is the most comprehensible to people because it serves as an umbrella term comprising different definitions and approaches, all with the common intent of including populations in research that concerns them. Inclusive research with persons with intellectual and other cognitive disabilities comprises a larger body of literature compared to inclusive evaluation (Maynard, 2015). According to Frey (2018), evaluation uses methodological approaches similar to research while assessing the value, merit and efficacy of programs, policies, products, and processes. Given the similarities between evaluation and research methods, the literature on the latter is applicable to the evaluation field, and vice-versa (Maynard, 2015).

Past literature reviews on inclusive research that involved individuals with intellectual disabilities (Bigby et al., 2014; Di Lorita et al., 2018; Frankena et al., 2015)

revealed discrepancies in the titles and roles that these individuals hold in research. For example, according to Bigby et al. (2014), persons with intellectual disabilities who play a role as “controllers” or “leaders” have more control over research processes compared to those referred to as “advisors”. Frankena et al. (2015) described the role of persons with intellectual disabilities in research as “co-researchers”, “research advisors” and “research partners”. These authors also found that the activities that individuals with intellectual disabilities undertook included making decisions about the topic of research, guiding questions and methods, data collection, applying for ethics approval, literature review, developing accessible materials and analysis of data. On the other hand, Di Lorita et al. (2018) observed that “co-researchers” with intellectual disabilities are often not involved in aspects of research that require higher cognitive processing (i.e., data analysis).

Previous reviews revealed several barriers and practical considerations related to inclusive research. Some of these barriers are assessing the capabilities of persons with intellectual disabilities at the recruitment phase (i.e., whether they have the capacity to understand and examine research topics), the extra time required to plan for the inclusion of persons with intellectual disabilities during the design phase (Frankena et al., 2015), and increased research costs and time that are not always coherent with budget requirements and deadlines imposed by funding agencies (Di Lorita et al., 2018). Despite these challenges, conducting research with persons with intellectual disabilities has several benefits for co-researchers, academic researchers, participants, and the research project (Di Lorita et al., 2018). For example, co-researchers with intellectual disabilities often feel empowered, develop a sense of accomplishment, and increase their social and support system. Academic researchers also benefit from such

a collaboration due to the added value and strengths that co-researchers with intellectual disabilities bring to the projects. Learning about lived experiences of co-researchers can also be instrumental to academic researchers. Participants have also reported feelings of comfort and being understood when interacting with co-researchers who have the same disability as they do. Lastly, the engagement of co-researchers with intellectual disabilities can be invaluable as they contribute their lived experiences to different phases of research (i.e., developing interview guide, designing questionnaires, data analysis and dissemination of findings; Di Lorita et al., 2018).

The involvement of persons with intellectual and other cognitive disabilities has been shown to enhance the validity and relevance of research and evaluation, and it often leads to positive outcomes for all stakeholders. Nonetheless, there are several gaps in the literature with respect to: 1) consistency in defining the roles and titles of evaluators or researchers with intellectual and other cognitive disabilities, 2) consistency in defining how inclusive approaches are enacted by research teams, and 3) clear guidelines in terms of how to work with persons with intellectual and other cognitive disabilities and engage them in research and evaluation, how to approach and accommodate them. With foregoing previous research findings in mind, we embarked on a rapid scoping review that integrates evidence of methodologies used in inclusive research and evaluation frameworks. The initial motivation for this study was our need to conduct an inclusive evaluation study of an early-stage social enterprise focused on improving accessibility for persons with intellectual and other cognitive disabilities. An initial foray into the evaluation literature in search of guidance on good practice to support our work yielded very few empirical studies to provide insights. This prompted

us to conduct a rapid scoping review that also included literature on inclusive research in the social and health sciences.

Method

This rapid scoping review was conducted according to the methodological framework outlined by Arksey and O'Malley (2005). It included five stages: 1) identifying the research objective(s)/question(s); 2) identifying relevant studies; 3) study selection; 4) charting the data; and 5) collating, summarizing, and reporting the results (Arksey & O'Mally, 2005). Our objectives were: i) to uncover international evidence on practical considerations for including persons with intellectual and other cognitive disabilities in research and evaluation processes and teams; and ii) to produce insights that could guide decision-making about inclusive research and evaluation studies and projects.

Articles included in our review met the following criteria: (a) primary focus on adults (above 18 years of age) with intellectual disability, cognitive impairment, or cognitive disability, (b) engagement of adults with intellectual disabilities, cognitive impairment, or cognitive disabilities as participants in some or all aspects of the inquiry, (c) empirically conducted research and evaluations (e.g., individual or multiple case studies, studies examining empirical participatory research, meta-analyses of empirical studies) and conceptual studies that in some fashion drew on empirical findings even if the latter were not the main focus of such studies, (d) peer-reviewed journal articles, books, book chapters, theses and dissertations, and (f) English language papers. We did not limit the search based on year of publication. We conducted the literature search from October 2019 to March 2020.

The search included these databases: APA PsycInfo (Ovid), MEDLINE (Ovid), ERIC (Ovid Platform) and CINAHL (EBSCO). Our interest in identifying practices to

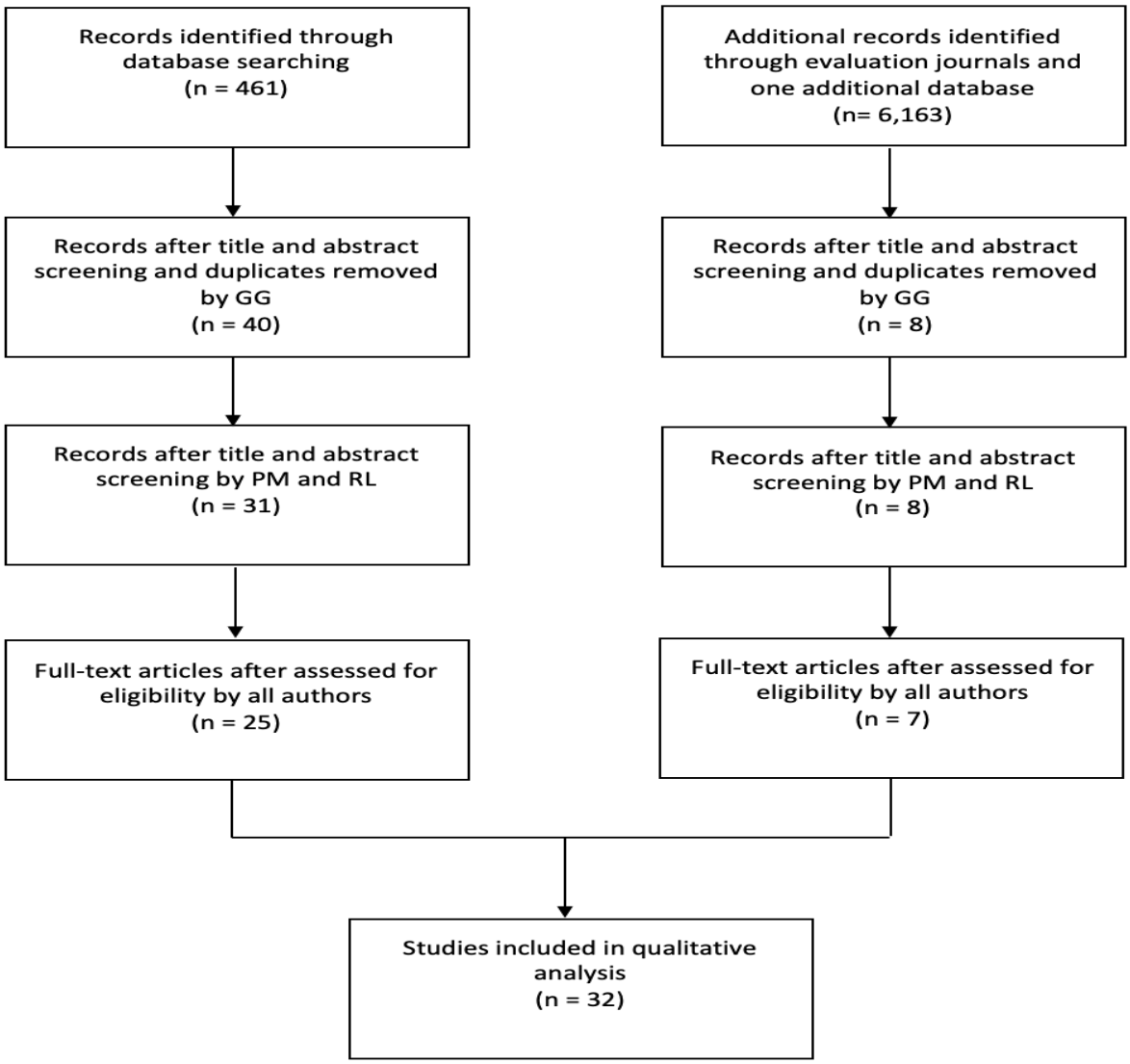
Scoping Review of Empirical Knowledge Base: Inclusive Research and Evaluation guide an inclusive evaluation study led to a complementary, direct search of major evaluation journals: Evaluation, American Journal of Evaluation, Evaluation and Program Planning, Canadian Journal of Program Evaluation, Evaluation Journal of Australasia, and African Evaluation Journal. These searches used combinations of these keywords: “participatory”, “evaluation”, “participatory evaluation”, “inclusive research”, “participatory research”, “emancipatory evaluation”, “empowerment evaluation”, “intellectual dis*”, “learning disability”, “cognitive disability”, “cog* dis*”, “cognitive impair*”, “cognitive impairment*”, “cognitive dis*”, “cognitive disorder*”, “dementia”, “Alzheimer’s”, and “traumatic brain injury”. This search strategy yielded a total of 6,624 articles, which were reviewed (the titles and abstracts) by one of the researchers (GG) according to the established exclusion and inclusion criteria. Following this review and after removing duplicate sources, 48 articles were uploaded to Covidence, an online tool used to screen references. Two other researchers (PM, RL) separately reviewed all the titles and abstracts of the articles in Covidence. This led to 39 articles being included for a full-text review, which was completed by all three researchers. The researchers independently flagged papers that did not meet all inclusion criteria, and then discussed any disagreements that until consensus was reached. This whole process led to 32 articles being included in the sample for this study (see Figure 1).

One of the researchers read all the articles several times and charted key characteristics about them into a summary table (see Table 1). All the selected articles were then imported to NVivo 12, a software program for qualitative data analysis, which was used to conduct thematic analysis (Braun & Clarke, 2006). All the articles were reviewed several times and initial coding was performed with respect to i)

Scoping Review of Empirical Knowledge Base: Inclusive Research and Evaluation methodological approaches and rationales that investigators have used to conduct inclusive research or evaluation, ii) inclusive practical considerations, and iii) reported experiences of all research team members (i.e., those with and without cognitive disabilities). The other authors then met and reviewed the codes, discussed any disagreements that arose, and then made changes to the codes and created the themes accordingly. This process took place over several team meetings.

Figure 1.

Search Strategy



Findings

Table 1 presents the main characteristics of the 32 studies in the final sample. Most studies (n=29) involved persons with intellectual and developmental disabilities and three studies involved individuals with other cognitive disabilities (i.e., Robinson et al., 2014; Span et al., 2018; Tanner, 2012).

Table 1.

General Characteristics of the Reviewed Articles

References		Country	Population	Titles	Study Objectives
1	Beighton et al., 2019	UK	Mild to moderate intellectual disabilities	No title	To investigate the perspectives and experiences of adults with intellectual disabilities and their caregivers regarding their public and participant engagement in health research
2	Bigby & Frawley, 2010	Australia	Intellectual disabilities	Co-researcher	To reflect on the support provided to co-researchers with intellectual disabilities in inclusive research
3	Bigby et al., 2014	Australia	Intellectual disabilities	Collaborator	To examine processes involved in inclusive research with self-advocates
4	Bollard et al., 2018	UK	Intellectual disabilities	Collaborator	To explore the experiences of a group of men with intellectual disabilities in terms of health inequalities and their impact on health
5	Chapman, 2014	UK	Intellectual disabilities	Co-researcher	To explore the role of support providers in the self-advocacy groups for persons

					with intellectual disabilities
6	Conder, Milner, & Mirfin-Veitch, 2011	New Zealand	Intellectual disabilities	Co-researcher	To explore issues in relation to effective participation of persons with intellectual disabilities in research
7	Frankena et al., 2016	Netherlands	Intellectual disabilities	N/A	To conduct a Delphi study to gather academics' agreement on different aspects of inclusive health research with persons with intellectual disabilities (i.e., design, methods, important characteristics, and outcomes)
8	Frankena et al., 2019	Netherlands	Mild to moderate intellectual disabilities	Co-researcher	To study long-term collaboration between researchers with and without intellectual disabilities to gain insight to their roles
9	Frankena et al., 2019	Netherlands	Mild to moderate intellectual disabilities	Co-researcher	To develop a consensus statement on how to design and conduct inclusive research, in collaboration with experts with and without intellectual disabilities
10	Garcia-Iriarte et al., 2009	USA	Intellectual disabilities	Co-researcher	To collaborate with self-advocates with intellectual disabilities to develop group capacity for advocacy
11	Hammel et al., 2008	USA	Intellectual and developmental disabilities	No title	To develop a research and policy agenda regarding the evaluation of

					environmental factors impacting the health, function and participation of persons with intellectual and developmental disabilities
12	Hughes et al., 2018	USA	Intellectual disabilities	Advisor	To test the accessibility of interpersonal violence prevention program for persons with intellectual disabilities using a participatory research approach
13	Johnson et., 2014	UK & Ireland	Intellectual disabilities	Advisor	To investigate the contribution of two inclusive research in policy and legislation
14	Kramer et al., 2011	USA	Intellectual disabilities	No title	To discuss the processes used in a participatory action research project to enhance the capacity of self-advocates for advocacy
15	Love & Mock, 2019	USA	Intellectual disabilities	No title	To provide perspective regarding the experiences of students with intellectual disabilities using different communication modalities, as well as the challenges and opportunities they encounter in a rural setting
16	Martin, 2015	UK	Asperger's syndrome	Co-researcher	To investigate the components of emancipatory research in terms of "empowerment, reciprocity, and gain".

17	Morgan et al., 2014	Australia	Intellectual disabilities including Down syndrome	Research partner	To highlight the ethical issues and guidelines in conducting participatory research with persons with intellectual disabilities
18	Morgan et al., 2015	Australia	Intellectual disabilities including Down syndrome	Research partner	To investigate the skills used and developed in a participatory research project with persons with intellectual disabilities
19	Nierse et al., 2011	Netherlands	Mild intellectual disabilities	Research partner	To explore the potential for inclusive research by engaging a small, targeted group of persons with lived experience as a first step towards broad consultation in research agenda setting.
20	Perry & Felce, 2004	UK	Mild intellectual disabilities	No title	To explore the feasibility of training a person with individual disabilities to conduct interviews and to investigate the responsiveness of participants when they are interviewed by an interviewer with intellectual disabilities
21	Puyalto et al., 2016	Spain	Intellectual disabilities	Advisor	To investigate the perspectives of advisors with intellectual disabilities and researchers without disabilities regarding their collaboration on a project
22	Read et al., 2013	UK	Intellectual disabilities	Co-researcher	To investigate the process of developing a

					computerized tool using participatory action research
23	Robinson et al., 2014	Australia	Cognitive disabilities	Co-evaluator	To explore their depth of inclusion (using Weaver and Cousin's model) of persons with cognitive disabilities in an inclusive evaluation
24	Ryan et al., 2015	USA	Intellectual disabilities	Co-researcher	To describe a university course in which student with and without intellectual disabilities collaborated on a participatory action research project
25	Schwartz et al., 2019	USA	Intellectual disabilities	Co-researcher	To gather information from academic researchers and researchers with intellectual disabilities to better understand contributing factors to maintenance of inclusive research collaborations
26	Span et al., 2018	Netherlands	Dementia	No title	To explore the inclusion of persons with dementia in a participatory study on developing an interactive web tool for these individuals
27	St. John et al., 2018	USA	Intellectual disabilities	Co-researcher	To investigate co-researchers' perspectives regarding their involvement in research, and the perspectives of academic researchers on the feasibility of involving coresearchers with

					intellectual disabilities in research
28	Stevenson, 2010	Australia	Down syndrome	Co-researcher	To explore how Emancipatory Disability Research is developed, and how principles are defined to ensure the reliability of disability research design and practice
29	Stevenson, 2014	Australia	Down Syndrome	Co-researcher	To illustrate the skills and perspectives of co-researchers as well as their contribution during data analysis
30	Strnadová et al., 2014	Australia	Mild to moderate intellectual disabilities	Researchers	To discover 1) the support and training that research with intellectual disabilities need to fully participate in research, and 2) the skills needed for academic researchers to successfully collaborate with researchers with intellectual disabilities
31	Tanner, 2012	UK	Dementia	Co-researcher	To discuss the implications of inclusive research for co-researchers with dementia
32	Tavecchio et al., 2019	Netherlands	Mild intellectual disabilities	Participant researcher	To evaluate the impact of an intervention (i.e., participatory peer research) on adults with mild intellectual disabilities who live in a residential care institution

Methodological Approaches and Practical Justifications

Some researchers adopted a specific, existing model or framework to guide the design and implementation of their studies. Most researchers relied on approaches that drew on distinctive methodological frameworks (e.g., participatory action research) to guide study design and execution. A small number instead drew generalized philosophical inspiration from relevant research traditions (e.g., emancipatory research). Eleven of the studies engaged persons with intellectual disabilities in participatory action research (PAR) or action research (AR) for various reasons: 1) to acknowledge the importance of including persons with intellectual disabilities throughout all stages of the research process and give them ownership as representatives of their broader community who will be impacted by research outcomes (Bollard et al., 2018; Conder et al., 2011); 2) to promote social change by collaborating with a marginalized group of people in various stages of research (Garcia-Iriarte et al., 2009); 3) to allow for active engagement of persons with disabilities in the development of research and creating opportunities for the expression of their perspectives (Love & Mock, 2019); 4) to improve practice and products used by these individuals (i.e., storytelling software; Read et al., 2013); and 5) to empower underrepresented communities in solving issues of immediate concern (Ryan et al., 2015; St. John et al., 2018).

Beighton et al. (2019) and Bigby and Frawley (2010) drew on Walmsley and Johnson's (2003) model of inclusive research and Stevenson (2010, 2014) used the Emancipatory Disability Research framework to inform research design and methods. Beighton et al's. (2019) study contributed to patient and public involvement using theWalmsley and Johnson's (2003) model, which has several characteristics, including that the problem should be owned by persons with intellectual disabilities who are

involved and exert control throughout the research process. In contrast, Stevenson (2010, 2014) elaborated the Emancipatory Disability Research paradigm (Barnes, 2001, 2003) into a framework to conduct participatory action research involving individuals with Down syndrome. The Emancipatory Disability Research framework intends to empower individuals with disabilities by fully involving them in all phases of a study based on key principles, which include control, accountability, practical outcomes, the social model of disability, the "problem of objectivity", the choice of methods, and the role of experience. The framework emphasizes transparency in that all components of a study must be explained to 'advisors' with disabilities and the anticipated research outcomes should clearly aim to benefit persons with disabilities (Stevenson, 2010).

Nine studies were guided by a philosophical commitment to the participation of persons with intellectual and other cognitive disabilities, rather than a specific model or methodology. For instance, Robinson et al. (2014) used a participatory approach to support four dimensions of an inclusive program evaluation including "diversity, depth of participation, power relations, and manageability" (p. 495). Hughes et al. (2020) drew on a participatory philosophy to co-create interventions that would have a positive impact on the lives of persons with intellectual disabilities. Morgan et al. (2014) used a participatory approach because it promised to engage persons with intellectual disabilities as 'partners' contributing to various phases of the research and authentically communicating their knowledge and experiences. Tavecchio et al's. (2019) study was guided by a participatory peer research stance that involved persons with intellectual disabilities as participant researchers to give them a significant degree of control and focus their engagement. Other studies reported being guided by a participatory philosophy to design an interactive web tool for individuals with dementia (Span et al.,

Scoping Review of Empirical Knowledge Base: Inclusive Research and Evaluation 2018), and examine the literature related to their research topic and policy implications (Hammel et al., 2008).

Three studies in our sample reported being guided by an emancipatory approach. For example, Martin (2015) conducted a study with service users with Asperger's syndrome to examine key principles of emancipatory research (i.e., empowerment, reciprocity, and gain); while Perry and Felce (2004) reported being guided by an emancipatory philosophy in involving individuals with intellectual disabilities as 'co-researchers' in conducting interviews. Nine studies mentioned being guided by 'inclusive' values or approaches. For example, Chapman (2014) reported using an inclusive approach with the goal of ensuring that all research processes were accessible to persons with intellectual disabilities. Bigby et al. (2014) used 'collaborative group' research to foster inclusion. Puyalto et al. (2016) reported an emphasis on inclusion in investigating the perspectives of self-advocates and advisors with intellectual disabilities regarding their involvement in research processes. Tanner (2012) investigated the process of including individuals with dementia as 'co-researchers' in all stages of research. Additionally, several researchers (i.e., Frankena et al., 2019; Nierse & Abma, 2011; Schwartz et al., 2019) reported conducting 'inclusive' studies in collaboration with persons with intellectual disabilities in which academic researchers did not play a role as 'experts' and where decision-making power was shared among researchers with and without intellectual disabilities.

Inclusion Processes

Sources of Recruitment

In most studies, persons with intellectual and other cognitive disabilities were recruited to participate as 'co-researchers' (or similar roles) through advocacy groups

(e.g., Bigby et al., 2014; Garcia-Iriarte et al., 2009) or existing relationships with the researchers (e.g., Beighton et al., 2019; Robinson et al., 2014). In other studies, they were recruited through the disability rights community (i.e., Hughes et al., 2020), a local authority (i.e., Martin, 2015), a voluntary sector local partner agency (i.e., Tanner, 2012), social and work integration centers for persons with intellectual disabilities (i.e., Puyalto et al., 2016), a residential care institution (i.e., Tavecchio et al., 2019; Span et al., 2018), and non-governmental organizations (Strnadov´a et al., 2014). Some were suggested by colleagues (i.e., Perry & Felce, 2004), and were primary students at a college (i.e., Love & Mock, 2019; Ryan et al., 2015). (See Table 2)

Researchers have discussed some challenges they experienced in recruiting persons with intellectual disabilities to serve as ‘co-researchers’ (or in other related participatory roles). For example, Beighton et al. (2019) recruited individuals with intellectual disabilities who had previous research experience as part of an established team due to barriers put forward by gatekeepers, such as research governance and ethics boards, in terms of ensuring individuals’ capacity to consent to be involved in such research roles. These authors acknowledged two limitations to this approach. First, established groups are often dominated by persons with mild to moderate intellectual disabilities, which means those with severe to profound intellectual disabilities are excluded, thereby introducing potential bias into the knowledge base about inclusive research. Second, the previous relationships researchers have with individuals with intellectual disabilities may cause biases in research processes such as group discussions (Beighton et al., 2019). St. John et al. (2018) noted recruitment challenges when relying on paid workers and/or family members to communicate with potential partners with intellectual disabilities.

Titles and Roles

The findings revealed inconsistencies in the titles authors assigned to persons with intellectual and other cognitive disabilities who played a role in their research teams. In 26 studies, these individuals played roles as “co-researchers” (e.g., Bigby & Frawley, 2010; Frankena et al., 2019; Martin, 2015; Nierse & Abma, 2011; Schwartz et al., 2019; St. John et al., 2018; Tanner, 2012), “collaborators” (Bollard et al., 2018), “advisors” (Hughes et al., 2020; Johnson et al., 2014; Puyalto et al., 2016), “research partners” (Morgan et al., 2014; Morgan et al., 2015) and “participant-researcher” (i.e., Tavecchio et al., 2019). However, six studies did not name the titles assigned to persons with intellectual and other cognitive disabilities (e.g., Beighton et al., 2019; Kramer et al., 2011; Ryan et al., 2015; Span et al., 2018). (See Table 2)

The findings also revealed that ‘co-researchers’ and ‘co-evaluators’ with intellectual and other cognitive disabilities were involved in different phases of evaluation or research including: (A) study design which consisted of making decision regarding the study measures, interview guide, and developing research tools (e.g., Frankena et al., 2016; Read et al., 2013; St. John et al., 2018; Stevenson, 2010); (B) data collection which included conducting interviews and facilitating focus groups, administering questionnaires (e.g., Bigby et al., 2014; Conder et al., 2011; Perry & Felce, 2004; St. John et al., 2018; Stevenson, 2014; Tanner, 2012); (C) data entry (Conder et al., 2011); (D) data analysis and interpretation (e.g., Frankena et al., 2016; Martin, 2015; Stevenson, 2010); and (E) dissemination of the findings which comprised of preparing manuscripts for publication, presenting at national and local conferences, creating an accessible video of findings, presenting at health and social care groups (e.g., Martin, 2015). In Strnadov´a et al’s. (2014) study, persons with intellectual

disabilities were involved in the initial phase of research (i.e., helped with the development of interview tool) and the researcher with mild intellectual disabilities played a role as a mentor to the other three researchers with moderate intellectual disabilities. For instance, she guided the academic researchers when their instructions or explanations were not explicit or accessible enough or provided emotional support to the other researchers with moderate intellectual disabilities.

In a study by Bollard et al. (2018), “collaborators” were involved in the initial phases of the research (i.e., developing and reviewing the consent form and the interview schedule), and validated the findings. In other studies, “collaborators” participated in the process of selecting outcome measures and developing ideas for data analysis, dissemination of findings (i.e., conference presentation) and making recommendations (i.e., Beighton et al., 2019; Robinson et al., 2014; Schwartz et al., 2019). In studies in which persons with intellectual disabilities played a role as “advisors”, they provided input and guidance on the content and format of research and curriculum materials, engaging persons with intellectual disabilities, and advised on many research processes including development of instruments, data analysis and interpretation, and dissemination of results (i.e., developed workshops based on the results of the study, created short films on the narratives of an advisory group, and participated in a discussion panel on a national radio) (Garcia-Iriarte et al., 2009; Hughes et al., 2020; Johnson et al., 2014; Puyalto et al., 2016).

In three studies, “research partners” were involved in data collection (i.e., focus groups and semi structured interviews) and analysis, and some played different roles as a learner, teacher, research director, and they assisted with development of research agenda (Morgan et al., 2014; Morgan et al., 2015; Nierse & Abma, 2011). The “client-

Scoping Review of Empirical Knowledge Base: Inclusive Research and Evaluation researchers" in Tavecchio et al.'s (2019) study were involved in many phases of research including the development of the interview guide, data collection (i.e., questionnaires and semi-structured interviews), data analysis, and dissemination of the results. In other studies, in which persons with intellectual and other cognitive disabilities were not given any titles or specific roles, they provided feedback regarding the design and content of the research tool and were involved in data collection (i.e., focus groups and interviews), analysis and dissemination of results (i.e., created a video of projects) (e.g., Hammel et al., 2008; Kramer et al., 2011; Love & Mock, 2019; Span et al., 2018).

Table 2.

Attributed Titles and Roles to Persons with Intellectual and Other Cognitive Disabilities

Titles of Person with Intellectual and Other Cognitive Disabilities	**Roles Played by Persons with Intellectual and Other Cognitive Disabil**

Co-researcher/Co-evaluator [2, 5, 6, 8, 9, 10, 16, 22, 23, 24, 25, 27, 28, 29, 31, 32]	- Setting research agenda
	- Development of research tools
	- Data collection
	  - Facilitation of interviews and focus groups
	  - Administered questionnaires
	- Data entry
	- Data analysis
	- Dissemination of results
	  - Manuscript preparation

Researcher[30]	- Development of interview tool - Played a role as mentors

Collaborator[3, 4]	- Selecting the process and outcome measures
	- Development and review of consent form and interview schedule to ensure accessibility
	- Developing ideas for:
	  - data analysis
	  - data interpretation
	  - dissemination of findings
	  - making recommendations
	- Verification of the findings

Advisor[12, 13, 21]	- Providing input on the content and format of curriculum materials - Providing guidance regarding: - design of interviews

	- accessing persons with intellectual disabilities - Advised on: - instruments - data analysis - interpretation of data - development of resources emerging from the research
Research Partner[17, 18, 19]	- Playing different roles as a learner, teacher, research director - Assisted with development of the research agenda - Were involved in: - data collection - data analysis
Participant-researcher or client-researcher[32]	- Identifying the research subjects - Were involved in - developing structured questionnaires - data collection - data analysis - dissemination of the results
No title[1, 11,14, 15, 20, 26]	- Providing feedback on the design and content of the research tool - Were involved in: - data collection - data analysis

Practical Considerations Throughout the Inclusion Process

Our analysis revealed several practical considerations and strategies for including persons with intellectual and other cognitive disabilities as 'co-researchers' or similar roles. For example, some researchers have argued that while it is important to focus on 'co-researchers' strengths, knowledge and views, the differences in individuals' needs should not be ignored and the "right" support should be in place throughout the research process (e.g., Bigby & Frawley, 2010). For example, Conder et al. (2011) reported that supporting 'co-researchers' was crucial in enabling their participation. Such support included focusing on the abilities of the 'co-researchers', providing additional time to prepare for administering questionnaires and reflect on issues that arose during focus groups, arranging additional meetings to train 'co-researchers', as well as planning refreshment breaks and fun activities. Similarly, Bigby et al. (2014) acknowledged the importance of recognizing self-advocates' different skills, providing

them with an opportunity to offer their input, having a collegial approach in dispersing power so that they feel comfortable to claim their roles.

Furthermore, some studies used accessible research material (e.g., using larger font size, increasing spacing), plain language (Bigby & Frawley, 2010; Frankena et al., 2019), visual maps to analyze data (Frankena et al., 2019), role-plays (i.e., to teach research skills to 'co-researchers' with intellectual disabilities (Strnadova et al., 2014), several types of prompts (e.g., asking probing questions, using pictorial interview guide and picture cards, PowerPoint presentations), and repetition of information (e.g., Frankena et al., 2019; Hughes et al., 2020; Tanner, 2012). Furthermore, some researchers indicated that being flexible (e.g., Beighton et al., 2019; Bigby et al., 2014; Bollard et al., 2018; Stevenson, 2010), planning for regular meetings (Bigby et al., 2014), regular breaks, fun activities (Conder et al., 2011), and establishing financial payment (Frankena et al., 2016) have enhanced the motivation and involvement of persons with intellectual disabilities in research and evaluation processes. The findings of the review also revealed that in addition to using these different strategies, there are other variables that contributed to enhancing the involvement of these individuals. For instance, researchers emphasized the importance of building a respectful relationship with 'co-researchers' with intellectual disabilities to help build their confidence and trust, and to encourage them to reflect on the research and speak up their opinion (Conder et al., 2011; Frankena et al., 2016).

The Perspectives of Researchers with and without Intellectual and Other Cognitive Disabilities

In numerous studies, researchers with intellectual and other cognitive disabilities reported viewing their participation as authentic, and they felt valued, empowered,

proud, listened to, and were respected without being bullied (e.g., Beighton et al., 2019; Conder et al., 2011; Puyalto et al., 2016; Ryan et al., 2015). They also reported perceiving their participation to have enhanced their confidence (Beighton et al., 2019), knowledge and skills (Nierse & Abma, 2011), advocacy (Bigby et al., 2014), and to have altered their perception regarding other individuals with cognitive disabilities (Robinson et al., 2014). Participation was also reported to have motivated persons with intellectual disabilities to become more active, aware, and responsible for their own situations (Tavecchio et al., 2019).

The findings show that the academic researchers found the involvement of individuals with intellectual disabilities in data analysis and interpretation to be valuable because their personal experiences helped close the gap between research agendas and the actual needs of these individuals and their caregivers (Beighton et al., 2019). Beighton et al. (2019) indicated that individuals with intellectual disabilities provided imperative insights in informing healthcare policy and practice. Similarly, others reported that the involvement of ‘co-researchers’ contributed to different phases of the research, enhanced the depth and quality of the study, and that they learned from each other (e.g., Bigby & Frawley, 2010; Bigby et al., 2014; Chapman, 2014).

Other researchers reported that involving “co-researchers” and “advisors” in research led to change in policy, promoted social change, enhanced the quality of research, and resulted in gradual increase in knowledge regarding the issues that individuals with intellectual disabilities experience (Garcia-Iriarte et al., 2009; Hughes et al., 2020; Johnson et al., 2014; Puyalto et al., 2016). Tavecchio et al. (2019) indicated that working with “client-researchers” expedited the implementation of results. Additionally, some researchers reported that working with persons with intellectual and

other cognitive disabilities provided valuable input on the development of the content and design of research instruments and ensured that the data analysis process was transparent and inclusive (Hammel et al., 2008; Kramer et al., 2011; Span et al., 2018).

In contrast, Bigby and Frawley (2010) discussed several challenges associated with researching with a person with intellectual disabilities. These included a lack of time to put in place appropriate support for the “co-researcher” with intellectual disabilities to participate in initial planning phases of research due to funding deadlines, and difficulty maintaining a mentoring role between the researchers and “co-researcher” during the dissemination phase. These authors also indicated that they may have unintentionally “disempowered” the “co-researcher” by failing to focus on his strengths, knowledge and preferences, and not addressing his difficulties and learning in a “natural context” rather than through formal supports (Bigby & Frawley, 2010).

Discussion

We embarked on this rapid scoping review to identify, analyze, and integrate the existing empirical knowledge base on the inclusion of persons with intellectual and other cognitive disabilities in research and evaluation teams and processes. Our sample was comprised predominantly of articles addressing persons with intellectual disabilities, and it thus appears there is a serious gap in empirical research with respect to the inclusion of persons with other cognitive disabilities. We also yielded very few sources from the evaluation literature, suggesting that evaluation researchers could benefit from conducting studies on this topic and interacting with the more established knowledge base in applied research communities.

Based on its recency, method and search criteria, our study extends the previous reviews on this topic by Bigby et al. (2014), Di Lorito et al. (2018), and Frankena et al.

Scoping Review of Empirical Knowledge Base: Inclusive Research and Evaluation (2015) in several ways. Despite the differences in methodological approaches and practical justifications posed by the studies in our sample, we nonetheless observe that studies on this topic tend to be grounded in the same normative stance: a principled commitment to involving persons with intellectual and other cognitive disabilities as deeply and extensively as possible in research teams and processes. We also observed that studies in our sample do not generally provide sufficient methodological detail to understand what occurs or how inclusion was operationalized.

There was considerable diversity and inconsistency across studies regarding the titles and roles researchers assigned to persons with intellectual and other cognitive disabilities. The inconsistent and somewhat random use of terminology provides little clear guidance to the field in how these roles can be practically actualized. In the three extant reviews, Bigby et al. (2014) described three categories of roles for persons with intellectual disabilities in research teams (i.e., advisor, leader, collaborator), Frankena et al. (2015) defined the roles of such individuals as “co-researchers” and “advisors”, and Di Lorito et al. (2018) identified them as “co-researchers”. Our findings show that persons with intellectual and other cognitive disabilities have carried out various responsibilities under a range of titles. In our sample, ‘researchers’, ‘collaborators’, ‘research partners’, ‘participant researchers’ and ‘client-researcher’ were involved in ways that could be encompassed under Bigby et al’s. (2014) ‘collaborative groups’ approach; while the ‘advisors’ in our sample played similar roles to those suggested by Bigby et al’s. ‘advisory’ approach. But we did not find any evidence in our sample of persons with intellectual and other cognitive disabilities playing roles where they had full control over any aspect of the research process; thus, Bigby et al.’s category of ‘leader’ cannot be applied to sources in our study. Also, looking across our sample, we observe

that persons with intellectual or other cognitive disabilities have been included in different phases of research and evaluation projects, but there is no single study in our sample, where they were involved in all phases. In other words, the extensive participation of persons with intellectual and cognitive disabilities also appears to elude the efforts of those committed to inclusive research and evaluation.

This tension we detect between aspirations and empirical experience resonates with findings from the three other extant reviews on this topic, which identified some barriers and challenges in deeply and extensively involving persons with intellectual disabilities in research teams and processes. Foremost among these were resource constraints related to the amount of time and funding required to conduct inclusive research projects that substantially involve persons with intellectual disabilities as team members throughout the process (Bigby et al., 2014, Frankena et al., 2015), along with unrealistic deadlines imposed by funders (Di Lorita et al., 2018). Our observation that there appear to be limitations on the degree of control that persons with intellectual disabilities are afforded or able to exercise in research and evaluation processes was also signaled in two of the previous reviews. Di Lorita et al. (2018) reported that persons with intellectual disabilities working as “co-researchers” were frequently not involved in aspects of the research process deemed to be too cognitively demanding (i.e., data analysis); while Bigby et al. (2014) discussed the potential impact of “intellectual deficit” on conducting research as an issue in terms of quality and rigor. In our sample, we note that Frankena et al. (2019) included persons with moderate intellectual disabilities in the data analysis phase in a project by using visual maps to support the process. This suggests there are innovative techniques that exist and can be developed to overcome at least some of the reported barriers and challenges in previous reviews. The

accommodation strategies highlighted in these studies are an important contribution to the field; however, the knowledge base could benefit from additional reporting on such innovative strategies and techniques.

These latter issues also link to inclusive researchers' aspirations to enhance the representativeness and diversity of persons with intellectual disabilities and other cognitive disabilities being involved as team members. In their previous review, Bigby et al. (2014) reported that most of the individuals with intellectual disabilities participating in research teams in their sample of studies had mild disabilities. In our review, most authors did not specify the degree of severity support needs of intellectual or other cognitive disabilities among 'co-researchers' in their research or evaluation projects. This is a potential problem with respect to operationalizing the principled stance of inclusive research and evaluation in that it appears the benefits of inclusion tend not to be extended to persons with more severe level of support needs. Frankena et al. (2015) concluded from their review that conducting assessments of level of support needs at the recruitment phase in inclusive research projects seemed to pose challenges for researchers. Resolving assessment issues in recruitment, and developing, testing and reporting on innovative techniques for involving a wider range of persons with intellectual and other cognitive disabilities, become important pieces in solving the puzzle of more representative inclusion. Findings from our review revealed how some researchers pursuing inclusive goals have used multiple recruitment strategies and sources. However, little information was provided about the strengths and limitations of such strategies and sources, and there is a lack of transparency regarding inclusive research processes, which again highlights this as an area for further research.

Based on our sample, it was not possible to derive guidelines for good (or best) practices in inclusive research and evaluation to help resolve some of these thorny issues leading to a gap between aspirations and reported experiences. This is because authors tended to report on how persons with intellectual and other cognitive disabilities were included in specific aspects of research and evaluation projects but did not tend to discuss why such individuals were not included in other aspects. Nonetheless, as a complement to the findings of Di Lorito et al. (2018) and Frankena et al. (2015), our sample provides insights on a variety of approaches (i.e., general statements about methods used) and strategies (i.e., statements about specific methods) to promote the meaningful inclusion of persons with intellectual and other cognitive disabilities in research and evaluation. These insights are summarized in Table 3.

Table 3.

Practical Guidelines

Phases of Research and Evaluation	**Inclusive Approaches**	**Inclusive Strategies**
Developmental and planning phase	- Acknowledging individuals' different skills - Focusing on strengths, abilities, knowledge and views of persons with cognitive disabilities - Providing everyone with an opportunity to offer their input - Dispersing power collegially - Developing a strong and respectful relationship	- Providing extra time - Providing training - Using accessible language - Using visual illustrations - Using larger font size, increasing spacing - Using plain language - Training about rights and responsibilities
Recruitment	- Recruiting persons with cognitive disabilities with diverse support needs - Learning how to build relationships	- Using various recruitment strategies through advocacy groups, organizations, snowball sampling - Using accessible flyers and advertisements - Accessible recruitment and consent forms

Data collection	- Accommodating differences in abilities and needs	- Providing extra time to:
		  - administer the questionnaires
		  - reflect and debrief regarding issues arose during interviews and focus groups
		  - for travel
		- Planning and providing transportation
		- Planning refreshment breaks and fun activities
		- Providing training on research skills
		- Planning accessible meetings (time, duration, location)
		- Engaging in role plays about research skills
		- Using pictorial interview guide, picture cards, asking probing questions
		- Repeating information

Data analysis		- Using visual maps to analyze data - Engaging in role plays

In line with the findings of reviews by Di Lorito et al. (2018) and Frankena et al. (2015), our study revealed that persons with intellectual and other cognitive disabilities reportedly felt valued, empowered, and listened to because of their active involvement in research and evaluation processes and teams. Their inclusion also reportedly enhanced their knowledge, skills, confidence, and motivation due to participating in research on topics that impact their lives. Consistent with the findings of Di Lorito et al's. (2018) review, researchers without disabilities in our sample also reported benefits from the involvement of persons with intellectual and other cognitive disabilities in research and evaluation teams. Specifically, researchers and evaluators reportedly observed improvements in the accessibility and quality of research design and tools; they also gained perspective regarding the personal experiences of individuals with intellectual and cognitive disabilities, which in turn helped with informing policy and practice.

Limitations

Given this literature search was conducted between 2019 and early 2020, several recent studies and reviews on inclusive research (e.g., Jones et al., 2020) have not been included. However, there is an urgent need to build evidence in a coherent and consistent manner to inform inclusive research methods, especially due to a rapidly growing interest and capacity in such methods. Therefore, even though this scoping review does not include some of the more recent studies on inclusive research, it has significant implications in the field as it provides evidence to inform inclusive research practices and research priorities.

Furthermore, the studies included in this scoping review focused on empirically conducted research and evaluations, and therefore other types of studies that may have included inclusive strategies may have been missed. Given a few evaluation studies were identified, subtle differences in approach between theoretical research and evaluation studies could not be identified. Lastly, the experiences, needs, and supports for community-engaged research with people with cognitive disabilities may greatly differ from a group to another. For example, individuals with intellectual and developmental disabilities have a life-long experience of disability that may impact their engagement in research in a different way than for people with traumatic brain injury or dementia, which are later-onset acquired cognitive disabilities. Therefore, inclusive approaches and strategies discussed by researchers who involved persons with cognitive disabilities may need to be tailored to the specific group they wish to involve.

Conclusion

Inclusive approaches to research and evaluation have gained significant attention over the past four decades, and they are philosophically aligned with the

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contemporary focus on equity, diversity and inclusion in academic research and evaluation. Researchers and evaluators in our study demonstrated principled commitment, regardless of the methodological approaches they used in their research. Despite a record of innovation with respect to strategies, techniques and interventions, challenges and barriers still exist to the deep and extensive inclusion of persons with intellectual and other cognitive disabilities in research and evaluation teams and processes. A coherent set of practical, evidence-based guidelines for conducting inclusive research and evaluation is not available in the empirical literature. Thus, deriving guidelines from the current knowledge base would prove difficult because studies tend not to report on why persons with intellectual and cognitive disabilities are not included in certain tasks in research and evaluation teams. Nonetheless, the existing knowledge base offers important insights with respect to the roles that persons with such disabilities can play in research teams, and strategies and techniques that can be used to advance their inclusion in various phases of research and evaluation processes.

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Chapter 3: Exploring the complex cognitive, affective and behavioural processes of individuals with intellectual disabilities in financially abusive situations

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Abstract

Background: Understanding the cognitive processes of individuals with intellectual disabilities in financially abusive situations is critical to develop effective prevention strategies.

Aims: This study investigated how persons with intellectual disabilities define and analyze financially abusive situations, and how they would feel and act in situations that they consider abusive.

Materials and Methods: Twelve participants with intellectual disabilities participated in a semi-structured interview where they were asked to reflect on three vignettes illustrating financial abuse. We analysed the interviews using thematic analysis.

Findings: The findings revealed that individuals with intellectual disabilities considered the type of relationship between the victims and the perpetrators, the behavioural patterns of the perpetrators, and their own experiences when interpreting the situation. Furthermore, they discussed their emotional and behavioural reactions to the vignettes.

Conclusion: This study has important implications in supporting the autonomy and decision-making rights of persons with intellectual disabilities regarding their finances and developing effective preventions against financial abuse among this population.

Keywords: decision-making processes, financial abuse, financial exploitation, intellectual disabilities, social justice, support workers

Introduction

Persons with intellectual disabilities are four times more likely to experience various forms of abuse, including financial abuse, compared to those without a disability (Cotter, 2014; Fisher et al., 2016). Many individuals with intellectual disabilities rely on others to support them with their financial affairs, which increases the risk of financial exploitation (Abbott & Marriott, 2013). Financial abuse against individuals with intellectual disabilities tends to be chronic and more severe compared to the general population (Davis, 2018; Powers et al., 2009). To prevent such abusive situations, persons with intellectual disabilities need to recognize a situation as being harmful and coercive (Hickson et al., 2015; Leutar et al., 2014). It is therefore critical to analyze how persons with intellectual disabilities interpret situations that may be financially abusive to better tailor interventions. This study aims to investigate how persons with intellectual disabilities define financial abuse, what factors they consider in their analysis of situations that may constitute financial abuse, what their thought processes are when analyzing such situations, and how they would feel and act in situations that they consider abusive.

Definitions of financial abuse include actions like stealing, asking for money for a social visit, borrowing money and never paying it back, fraud, and coercion in terms of wills (Brooks et al., 2012). Some forms of financial abuse are unequivocal and reprimanded by law (i.e., theft and fraud); others are subtle and require an interpretation of the situation (i.e., coercing someone to spend their money, caregivers infringing on individuals' right to spend their money how they choose to, or withholding their money; Brooks et al., 2012; Davis, 2018). In a study by Brooks et al. (2012), only 26 out of 53

individuals with intellectual disabilities defined financial abuse, and the examples were related to theft, abuse of trust, and lack of justice in relation to property or money being taken away unfairly from someone. The authors did not discuss if implicit situations of financial abuse or infringement in decision-making rights were listed by participants.

Factors that increase the risk of financial abuse victimization among persons with intellectual disabilities include, but not limited to: (1) difficulty understanding the notion of money (Williams et al., 2007), (2) increased difficulty making financial decision compared to the general population, (3) often relying on others to assist them with their financial management (Abbott & Marriott, 2013); (4) perpetrators threatening to withdraw their support if persons with intellectual disabilities report the abuse (Ansello & O'Neill, 2010); (5) caregivers' controlling behaviours (Ansello & O'Neill, 2010); (6) learned compliance due to social isolation and their desire to feel accepted by their peers and to please others (Ansello & O'Neill, 2010); and (7) low self-esteem, poor assertiveness and personal safety skills (Ansello & O'Neill, 2010). Cognitive processes involved in financial decision-making are complex and may be challenging for persons with intellectual disabilities (Suto et al., 2005a). Furthermore, social and emotional factors and past experiences in relation to decision making have shown to be correlated with individuals' decision-making abilities (Suto et al., 2005b).

Financial exploitation is often underreported and difficult to detect among individuals with intellectual disabilities due to several reasons: (1) there is a lack of consistency in the definition of financial abuse which creates obstacles to reporting; (2) many individuals with intellectual disabilities may have difficulty recognizing subtle cases of financial abuse in order to report or prevent them (Davis, 2018); and (3) many

individuals with intellectual disabilities are afraid of reporting the perpetrators of financial abuse, who are often known to them (e.g., caregivers and friends), due to the fear of losing their relationship or support (Brooks et al., 2012; Davis, 2018). There are several concerns associated with financial abuse victimization among individuals with intellectual disabilities including infringement on their autonomy and it can be detrimental to their wellbeing (Buhagiar & Lane, 2022; Taggart et al., 2007). Strategies that have been placed to protect individuals with intellectual disabilities from financial exploitation have shown to infringe on their autonomy to make decisions regarding their finances and to learn to protect themselves (Callus et al., 2019; Jokinen et al., 2013). Interventions aiming to develop protective skills have demonstrated positive outcomes among persons with intellectual disabilities. However, they do not necessarily transfer and apply their knowledge into protective behaviours in real-life situations (Bruder & Kroese, 2005). The extent of the current knowledge leads to raise the question as to what risk factors impede persons with intellectual disabilities from applying their knowledge of abuse in real life situations. Therefore, to develop effective prevention strategies and improve the financial decision-making abilities of persons with intellectual disabilities, it is critical to understand the cognitive processes at play and the risk factors that impact such abilities (Suto et al., 2005b).

This study will address the following research questions:

1. How do individuals with intellectual disabilities interpret abusive situations?
2. How would they determine whether a situation is abusive?
3. What factors impact their interpretation of an abusive situation?
4. How would they feel and act in an abusive situation?

Method

We used a qualitative inclusive approach to investigate the perspectives of persons with intellectual disabilities regarding financial abuse. Inclusive research enables individuals with intellectual disabilities to take an active role on a research team in order to share their perspectives regarding a topic relevant to their lives (Molinari et al., 2011). Including persons with intellectual disabilities in research has shown to enhance the validity of research, limit potential biases (Chouinard & Cousins, 2009; Frankena et al., 2015), and they can make invaluable contributions regarding their lived experiences to various stages of research processes (Di Lorito et al., 2018). Nonetheless, the results of a scoping review revealed that there is no study where individuals with intellectual disabilities were involved in all phases of research (Ghaderi et al., 2023). Furthermore, there is a notable inconsistency in the titles and roles assigned to persons with intellectual disabilities (Ghaderi et al., 2023). For instance, in studies in which persons with intellectual disabilities played a role as an ‘advisor’, they provided feedback and guidance on the content of research tools and materials or advised on different research processes including recruitment and data analysis (Hughes et al., 2020; Johnson et al., 2014; Puyalto et al., 2016). In this study, we involved individuals with intellectual disabilities as advisors to seek their input regarding our research tools, data analysis, and to involve them in recruitment.

Advisory committee

Two persons with intellectual disabilities with mild levels of support needs (one male, aged 32 years and one female, aged 39 years) served as advisors throughout different phases of this research project. We recruited the advisors through a social

enterprise providing services to support inclusive research with persons with cognitive disabilities. An employee of this social enterprise emailed four members of their team of advisors self-identified as having intellectual disabilities who were able to understand and communicate in English. These four individuals received information about the study and their role, in easy read language. Two advisors agreed to have their contact information shared with the first author. The first author then reviewed with the advisors information pertaining to the study and consent forms, all of which were written in easy read. Additionally, the first author answered their questions prior to obtaining consent. Both advisors had research experience through previous contributions to research projects. The advisory committee provided feedback regarding the design and content of the vignettes, interview questions, their accessibility and relevance, as well as data analysis and interpretations of the findings. The first author met with the advisors five times over the two years of research period, at critical decision-points.

We obtained ethics approval from the University of Ottawa's Health Sciences and Science Research Ethics Board (H-05-21-6429).

Recruitment Procedure

We used convenience sampling (Lavrakas, 2008) through advocacy groups and not-for-profit organizations providing supports (e.g., residential, employment and recreational) to persons with intellectual disabilities in Ontario, Canada. Ontario is the most populated province in Canada with more than 15 million inhabitants. These organizations distributed the recruitment materials to persons with intellectual disabilities, who were invited to contact the academic researchers if they were interested in participating in this study or consented to have their support providers

share their contact information with the researchers. We also asked the organizations to distribute the recruitment letter and consent form, which were written in accessible language, with persons with intellectual disabilities. We also used chain sampling, in which participants were invited to forward information about the study to other individuals with intellectual disabilities. We recruited individuals: (1) with intellectual disabilities with mild level of 'severity of disorders' (Tassé et al., 2019, p.17). The level of support needs was determined using the behavioural indicators developed and validated by a panel of international experts (Tassé et al., 2019). Specifically, Tassé et al. (2019) collaborated with an interdisciplinary expert team to develop behavioural indicators that are comprised of both intellectual functioning and adaptive behaviour across the lifespan. The behavioural indicators assist clinicians to determine the presence of intellectual disability and degree of impairment in intellectual and adaptive behaviour functioning (Tassé et al., 2019); (2) who have sufficient comprehension and communication skills (with or without support, with or without alternative communication methods or devices) to answer questions and participate in the semi-structured interview; and (3) who live in Ontario.

Participants

Eleven individuals with intellectual disabilities (*n*= 11) who expressed willingness to participate in the study, participated in a screening call, via telephone or Zoom video call platform, with the first author to determine if they met the inclusion criteria. The researcher also arranged an in-person meeting to accommodate the participation of one individual (*n*= 1). The meeting took place in an office space at the organization building which provides services to this individual. The interviews were scheduled at a time and

a platform convenient to the participants. The first author reviewed the description of the study and consent forms during the initial call and answered any questions that they had regarding the study. Research shows that recruitment letters and consent forms can be difficult for individuals with intellectual disabilities to understand due to their complex language (Scott et al., 2006). Therefore, such recruitment documents (i.e., recruitment letter and consent forms) were written in accessible language [i.e., 'using simple words, short sentences, and simple fonts and layouts' (Cobigo et al., 2019, p. 186)].

Data collection and interview procedure

Twelve adult participants (i.e., 18 years and older) participated in a semi structured interview, which took place via Zoom (*n*= 8), Google Meets (*n*= 1), telephone (*n*= 2) and in-person (*n*= 1), and no one was screened out. Prior to each interview, the first author explained the study in detail and asked them comprehension questions (e.g., 'Do you have to answer every question that I ask you?', or 'what will I ask you about?') to ensure they provided informed consent to partake in the study (Cobigo et al., 2019, p. 190). After, the participants were asked questions pertaining to their demographic information (See Table 1) as well as different aspects of their money management (See Table 2). Then, the first author, who conducted the interviews, presented the participants with the vignettes (in virtual interviews), one by one on the screen (using the 'share screen'). In both virtual and phone interviews, she read the vignettes a second time if the participants asked her to do so or showed hesitance in responding to the questions. After each vignette presentation, the researcher asked open-ended questions regarding their knowledge and perspectives about the content of the vignettes

and provided enough time for responding. In terms of the participant who participated in an in-person interview, the researcher provided her with a copy of the vignettes and read each vignette out loud. All the interviews were digitally recorded.

Table 1.

Participants' Demographics

Demographic Characteristics	**Number of Participants**
Number of participants (n)	12
Average age (M)	45 years
Age range (min-max)	32-64
Gender (n, %)	
Male	6 (50%)
Female	6 (50%)
Place of Residence (n, %)	
Eastern Ontario	8 (66%)
Central Ontario	2 (16%)
Western Ontario	2 (16%)
Living arrangement (n, %)	
Lives alone	8 (66%)
Lives with parents	3 (25%)
Lives in group home	1 (8%)
Highest level of education (n, %)	
High school	11 (92%)
College degree	1 (8%)
University degree	0
Employment (n, %)	
Retired	2 (16%)
Employed	6 (50%)
Unemployed	4 (33%)

Table 2.

Participants' Money Management Strategies

Participants	Financial Management	Banking Methods	Independent shopping (yes/no)	Payment Methods (grocery, restaurant, etc.)
P1	Parent helps with finances: • Monitors bank account • Transfers money between accounts • Notifies when there are insufficient funds in the account	• Bank account • Debit card	yes	Cash (counting change is sometimes challenging)
P2	A family member is a trustee: • Pays the bills • E-transfers money if needed	• Bank account • Debit card • Used to have a credit card	yes	Sometimes cash, but always checks the change with a cashier to ensure it is correct
P3	A community agency helps with finances (following experience of financial abuse incident): • All the bills go to the agency • Case manager helps with money management	• Used to go to bank tellers rather than using ATM machines (doesn't know how they operate) • No longer due to experiencing financial abuse	yes	Cash
P4	Does not receive any support	• Bank account • Debit card • Credit card	yes	Does not use cash
P5	Receives minimal support from his mother Pays the bills and manages his money independently	• Bank account • Debit card • Credit Card	yes	Uses cash for coffee but credit card for larger transactions
P6	Support worker helps with monthly budgeting	• Bank account • Debit card	no	Uses cash with the worker's assistance
P7	A family member helps with: • Depositing money for grocery and spending, on a weekly basis • Ensuring all the bills are paid	• Bank account • Debit card	yes	Uses cash for coffee and debit card for all other purchases

P8	Used to a have a trustee in the past Receives support from a community agency which: • Keeps the money in an account • Pays the rent (using his money) • Provides monthly allowance (money is given to him through his support worker)	• Bank account is managed by the community agency • Debit card	yes	Uses cash
P9	Receives assistance from a parent with the power of attorney who: • Makes sure all the bills are paid • Ensures she has spending money, weekly	• Bank account • Debit card	yes	Only uses debit card; not comfortable using cash
P10	Receives assistance from parents who help paying for rent Receives support from a financial team who aids with setting "things" up	• Used to own a bank account but no longer owns one • Not allowed to have any cards, but used to have several credit cards in the past • Not allowed to have cash due to experiencing financial abuse	no	Does not shop independently due to experiencing financial abuse
P11	Does not receive any support	• Bank account • Debit card • Credit card	yes	Uses cash and credit card
P12	Receives assistance from parents with: • Online banking • Paying for credit card • Writing expenses • Handling Ontario Disability Support Program (i.e., provincial financial and employment assistance given to individuals with disabilities) and Passport funding (i.e., funding provided to individuals with developmental disabilities by the Ministry of Children, Community and Social Services to assist with community participation services and supports)	• Bank account • Debit card • Credit card	yes	Uses cash at restaurants

Measures and Materials

We conducted semi-structured interviews, which incorporated three written vignettes consisting of stories about financial transactions, two illustrating a situation of abuse (i.e., explicit, implicit), and one illustrating a situation where no financial abuse occurred. Two of the vignettes (i.e., explicit and no financial abuse) were informed by the Ann Craft Trust training material on ACTing against abuse (Brooks et al., 2012). Another vignette on implicit financial abuse was informed by a real-life situation of financial abuse against some individuals with intellectual disabilities as observed by one of the authors (See Table 3). After presenting each vignette, we asked participants open-ended questions. Each question was created to capture participants' knowledge (i.e., whether they could identify abuse) and their perspectives regarding financial abuse (i.e., how they would describe what was happening in the scenario, how they interpreted the behaviours of the perpetrators in the vignette, and how they thought the victim should act in the situation). Please see Table 4 for a list of questions asked after the first vignette. We asked similar questions following each vignette. Eleven semi-structured interviews took place using a videoconference system or via telephone, and one interview was conducted in person.

To ensure the internal validity of the vignettes (Leung, 2015; Østby & Bjørkly, 2011), we pilot tested them with our advisors. Specifically, we presented and read the vignettes to the advisor and asked questions to ensure the vignettes were clear, authentic, understandable, meaningful, and relevant to individuals' experiences of financial abuse (Hellzen et al., 2018; Hughes & Huby, 2004). After, we modified the

vignettes, and then presented them to another advisor and repeated the same procedure.

Table 3.

Vignettes

Vignette #1 (Explicit financial abuse)	One day, Monica went to the Tim Hortons (coffee shop) with her friend, Sharon. Sharon ordered a large coffee and a chicken salad sandwich for herself. When the cashier asked how she would like to pay, Sharon turned to Monica and told her to pay for her. Monica did not order anything for herself, but she paid for Sharon's coffee and a sandwich.
Vignette # 2 (Implicit financial abuse)	Sarah lives in a group home. Her worker, Rick, helps her manage her money. One day, Sarah asked Rick to give her money to buy cigarettes, but Rick told Sarah that she had smoked a lot lately. Sarah said she really wanted cigarettes, but Rick told her that she could buy some cigarettes in two days.
Vignette # 3 (No financial abuse)	Anna has recently moved into her boyfriend's house. They decided to split the bills. They decided that Anna would pay for the gas bill and her boyfriend would pay for the electricity bill. One day, her boyfriend paid for the electricity bill and told Anna.

Table 4.

Interview Questions

Interview Questions
1) What do you think about this story? What do you think happened to Monica? 2) How do you think Monica feels? 3) What do you think about what Sharon did? 4) What do you think Monica should do? Why? 5) How would you feel if you were in this situation? 6) How would you handle the situation? 7) How would you feel if Monica had to pay for Sharon's meal at a restaurant instead of Tim Hortons? 8) How would you feel if only Monica had an intellectual disability? 9) How about if both Monica and Sharon had an intellectual disability? Why?

Data Analysis

We analyzed the interviews using thematic analysis (Braun & Clarke, 2022) to capture a better understanding of participants' knowledge and perspectives of financial abuse. First, the first author (GG) digitally recorded and transcribed the interviews verbatim. The transcripts were then imported into NVivo 12, which is the latest version of the qualitative data analysis computer software. Second, GG read the transcripts (on the screen) several times to familiarize herself with their content, to gather initial ideas, and to systematically organize data into relevant codes (i.e., highlighting important sections and ascribing codes to them). Third, she reviewed the codes several times to collate them to create themes (i.e., words, phrases, and sentences), which were further reviewed and refined in collaboration with the second author (VC). Then, after several meetings to review the themes, a descriptive label was given to each theme. Additionally, prior to finalizing the themes, we asked our advisors to review the summary of data (i.e., quotes from the participants), and reflect on what stood out to them, surprised them, and if they related to any information shared by the participants. Then, the advisors met individually with the first author through Zoom and shared their interpretations of the findings. Finally, we all agreed on the themes and subthemes in relation to the factors impacting individuals' interpretations of the abusive situations.

Findings

The findings of this study revealed three primary themes which represent individuals' complex processes when faced with a dilemma or an abusive situation (i.e., the vignettes). The themes are: (1) Interpretation of the situations, which focuses on how the participants defined the situations illustrated in the vignettes, and their initial

thoughts regarding what happened in the stories; (2) emotional reactions, which captured a range of emotions that the characters and participants would feel if they were in such situations; and (3) behavioural responses, which focused on what the participants would do if they were in an abusive situation. The first two themes represent several sub-themes which are the factors impacting each of these complex processes.

Theme 1: Interpretation of the situations

Participants' interpretations of the first and second vignettes varied greatly. Regarding the first vignette, one participant described the situation as ‘money abuse’ (Participant 7), three participants reported that Sharon ‘took advantage’ of Monica (Participants 4, 5, and 9), and one participant described the situation as a ‘rip off’ (Participant 8). Participant 7 also described Sharon's behaviour as ‘Greedy and selfish’. Nonetheless, other participants did not describe the situation as abusive. For instance, Participant 11 indicated that ‘maybe the person [Sharon] in the story wasn't exactly organized as they should have […] or maybe one of the friends is trying to help out a friend who is maybe on like low income’. Participant 3 also interpreted the situation as though Sharon does not have enough money to pay for her meal. Participant 10 described Monica's behaviour as an ‘act of kindness, saying thank you for being with me’, and Participant 6 indicated ‘it's only a coffee, it's not a big deal’.

When we asked the participants regarding their initial impressions of the second vignette, seven of them reported that Rick did the ‘right thing’ by protecting Sarah from future health and financial problems, and that he is abiding by his obligations. For instance, Participant 10 stated that Rick should tell Sarah ‘Hey, look at your budget, this

has to stop now before it's too late… cause your life will be shortened'. On the other hand, Participant 4 described Rick's behaviour as 'controlling', and two other participants alluded to Sarah's right to spend her money (Participants 2 and 5). For example, Participant 5 indicated that,

> It's not really up to the worker to tell her when to buy cigarettes unless she has no more money left for cigarette […] Rick is working against Sarah by telling her not to buy cigarettes when he hasn't looked at her finances.

Regarding the third vignette, 10 participants interpreted the story as 'good' in that they did not identify any abuse or problems with what Anna's boyfriend did. For instance, Participant 10 described Anna's boyfriend's behaviour as 'open and honest' and participant 11 indicated 'I applaud her boyfriend for telling her that he paid for, for the electricity bill'. Participant 2 also described what Anna's boyfriend did as 'sharing responsibility'. However, Participants 1 and 12 disagreed with what Anna's boyfriend did because he just 'went ahead' and paid for the bill.

Sub-theme 1: Type of relationship

The findings revealed that the types of relationship between the characters in the vignettes seemed to have impacted participants' perspectives regarding the situations. In other words, most participants (n = 10) justified or argued against Sharon's or Rick's behaviours because Sharon is Monica's friend, or Rick is in a place of authority. For instance, Participant 4 indicated that if she was in the same situation as Monica, she would 'feel obligated to; she asked me, she is my friend, I don't want to be without, um, but secretly I would have gone home and went, oh crap, now, what am I going to do with my budget'. In relation to the second vignette, Participant 6, for example, stated 'If

my worker would tell me I smoke a lot, I'd say okay no problem I'll try to cut down'. Similarly, Participants 11 indicated 'Well, if the worker knows what's best for her situation, then obviously no is no'.

Sub-theme 2: Behavioural pattern

The synthesis of the interviews revealed that the behavioural pattern of a person or a perpetrator in a situation impacted participants' interpretations of the first vignette. Specifically, half of the participants asked about Sharon's behavioural pattern when they attempted to interpret the situation. For instance, one of the participants mentioned 'it all depends on the situation […] like, if it's a thing, because sometimes people do that, and they'll do a one time thing and then they'll pay them' (Participant 2). Similarly, Participant 11 indicated 'if she is okay to pay for a friend, that is ok, but if this becomes a regular thing, and her friend never pays her back down the road, that might get to be a problem someday'.

Sub-theme 3: Personal judgements and experiences

Participants' personal judgement and experiences were shown to be another factor impacting their interpretations of the vignettes. For instance, Participant 10 did not raise concern regarding the first vignette as she reportedly has been in similar situations, in which she and her friend took turns in paying for each other's meals. However, some other participants (i.e., Participants 5 and 7) raised concerns regarding Sharon's behaviour because they have been in Monica's shoes in the past. For example, Participant 5 stated that 'Well, Monica probably made the same mistake that I did and say I'll pay for your and then Sharon never spoke to her again, took advantage of her'. Regarding the second vignette, Participant 6 justified Rick's behaviour,

indicating that ‘if I go grocery shopping, I want to buy apple cider, and [support providers name] says that is too expensive, you can't afford that, I say okay, let's go buy something else then’. On the other hand, Participant 6 had difficulty providing his perspective regarding the third vignette because he does not have a girlfriend and therefore has never been in such a situation.

Participants' personal judgement regarding cigarettes and group homes also seemed to have impacted their responses in relation to the second vignette. For instance, some participants justified Rick's behaviours because ‘smoking’ is harmful for health (i.e., Participants 9, 10 and 12). Another participant expressed his feeling against smoking when discussing his interpretation of the situation. Specifically, he reported ‘I hate people smoking […] I don't mind if their choice is they want to smoke, […] I wouldn't give money for cigarettes’ (Participant 2). Furthermore, some participants (i.e., Participants 2, 3 and 4) their negative judgements regarding group homes when discussing their interpretation of the situation. For instance, Participant 2 stated, ‘She's [Sarah] in a group home and I hate group homes […] I know that they're cruel, some staff punish you […] they say, I have your money, I can decide what you get with your money’.

Theme 2: Emotional reactions

We asked participants to share their perspectives regarding the characters' emotions in the stories. Participants reported a range of emotions regarding the first vignette. For instance, Participant 1 indicated that she thinks Monica felt ‘slightly’ offended because she did not order anything for herself but had to pay for Sharon's meal. Two participants reported that Monica feels ‘confused’ because she does not

know how to handle the situation or 'stand up for herself' (i.e., Participants 5 and 7), while three other participants indicated that Monica feels 'mad', 'upset', 'taken advantage of' and 'angry' (Participants 4, 9 and 12). Also, Participant 2 indicated that Monica 'could have been sad, awkward and not knowing, because she is in a predicament in front of all these, and there could have been people too, right there'. Participant 4 also reported that 'it is so hard to stick up for yourself on financial stuff. I can see myself in this little story'. However, Participants 3 and 11 stated that Monica feels 'right', 'happy' and 'choosing her heart' because she helped Sharon. Participants 6 and 8 also indicated that Monica feels 'bad' for Sharon because she does not have money to pay for her meal.

We also asked participants how they would feel if they were in the same situations. For instance, Participant 4 indicated that despite her financial constraint, she would feel 'obligated' to pay for her friend to ensure her friend can eat, however she would feel 'hurt and taken advantage of'. Two participants stated that they would feel 'confused' because they would not know how to handle the situation (Participants 5 and 7). Additionally, Participant 8 described his feelings as 'upset, anxious and depressed', explaining that he has been in such a situation many times in the past. Similarly, Participant 9 reported that she would feel 'very mad', and that she used to be pressured to purchase 'stuff' for her boyfriend. On the other hand, Participant 11 stated she would feel 'bad', 'sad', 'worried' and 'concerned' for her friend, if she did not know how to manage her finances.

With regard to the second vignette, eight participants reported that Sarah feels 'mad', 'frustrated', 'sad', 'disappointed', 'angry', 'upset', 'horrible' and 'terrible'. For

instance, Participant 11 indicated, 'I'm sure Sarah must be feeling very frustrated and quite a bit upset because maybe she's had a long week'; Participant 6 stated Sarah 'probably got mad; it's my money, and Rick is trying to help her'; and Participant 1 reported 'I don't think she's feeling very happy. I would feel robbed of the fact that, […] if he is helping me manage my money, why isn't he giving me my money'. Furthermore, Participant 2 indicated 'if I was in that situation, I would be freaking', and Participant 4 reported that she would feel 'out of control. I don't have any control on my life; […] I would feel disempowered, I would feel unmotivated, I feel bad about myself, I am worth it, you know, nobody cares'.

Regarding the third vignette, 11 participants indicated that Anna feels 'happy', 'good', 'relieved', and 'involved' for various reasons. The majority of them discussed a sense of equality, fairness and trust between Anna and her boyfriend, and some indicated that Anna feels relieved because the bill is paid. However, one participant reported that Anna feels taken advantage of because it is not fair that her boyfriend paid the bill without consulting with her (Participant 1).

Sub-theme 1: Disability

We asked the participants how they would feel about the scenarios if the characters had intellectual disabilities. With regard to the first vignette, Participants 1, 2, 4, 5 and 6 reported that Sharon is 'taking advantage' of Monica. Another participant indicated that she would feel 'sad' for Monica (i.e., Participants 3). When we asked how they would feel if both (Monica and Sharon) had intellectual disabilities, four participants commented on the variability in symptom severity and level of support individuals with intellectual disabilities may need. For instance, Participant 11 stated 'I think I would feel

again a little worried, and a bit concerned because it can be hard for people with intellectual disabilities to manage their money […] especially depending on the severity or the degree of the disability'. Participant 7 also reported that many people with intellectual disabilities are 'vulnerable' and 'don't understand money'. Nonetheless, this participant reported that if both Monica and Sharon had intellectual disabilities, he 'would feel upset but just because you have a disability doesn't mean you can get away with things'.

In response to the same question following the second vignette, only Participants 1 and 4 discussed feeling 'mad' or 'angry' with Rick. For instance, Participant 1 stated 'if Rick knew she [Sarah] had an intellectual disability, then if I was in Sarah's position, I'd be really mad'. She further explained that if Monica has intellectual disabilities, she may not understand why Rick, who helps her manage her finances, is not giving her money. Participant 4 also indicated 'I would feel more angry at Rick'. Furthermore, Participant 5 discussed his answer from two perspectives: 'If she [Sarah] is high functioning, I would feel sad for her because, like, high functioning means that, she can manage her finances on her own, but then Rick is there for minimal support. […] If she was low functioning, then I wouldn't feel bad for her because she needs the help, and that she needs to listen to her worker'. Participant 7 also stated that he would feel 'perfectly fine', adding that 'that's why she has a worker in the first place is because she probably has a disability and needs guidance to progress better'. Nevertheless, three participants did not provide a response due to their lack of knowledge about intellectual disabilities or difficulty to put themselves in Sarah's shoes.

Theme 3: Behavioural reactions

We also asked the participants regarding their perspectives about what Monica, Sarah or Anna should do in the scenarios, and how they would handle the situation. Participant 11 stated that Monica should tell Sharon 'I am happy to pay for you once in a while, not all the time. I have my limits and my boundaries'. Additionally, Participant 6 discussed setting expectations to prevent the situation happening again in the future and Participant 10 discussed taking turns in paying for the meal so 'it's more equal'. Participant 7 discussed reaching of to the authority such as police or a support worker to receive help. Other participants indicated that Monica could pay for Sharon's meal in order to help her out, but she should ask her to pay back (Participants 3, 8, 9, 10). However, Participant 12 stated that Monica will pay for Sharon's meal to make her feel better. Furthermore, most of the participants indicated that they would handle the situation similar to what they think Monica should do in this situation.

In terms of the second vignette, some participants reported that Sarah should listen to Rick (Participants 1, 6 and 7); to be 'understanding for what staff in this group home do' (Participant 11); and, to ask him to assess why he is not giving her money because if Sarah is 'running low on cash', then Rick's behaviour is 'understandable' (Participant 5). On the other hand, Participant 2 indicated that Sarah should:

> Speak to either the supervisor […] I'd say, look, if you're not going to fight, fire him. I'll go to the, umm, I'll call up the [lawyers], […] but if she didn't have advice for or if she didn't know about [lawyers] or whatever, then I think then you would have to either call the police if she has—but, the police might not do anything because they'll say, you have to deal with it, because it's not really considered an

> emergency, based on cops probably. So, I don't know, being in a group home is a very hard subject […]. (Participant 2).

Similarly, Participant 9 stated that Sarah should tell 'the manager that Rick is not giving her money when it's her money'. Participant 4 also indicated that Sarah should:

> Tell somebody, other worker, um, tell another person that lives there; they can come up with a plan to go outside and see what their options are. Um, yeah, group homes are hard. Go for a walk, go to a neighbour, talk to a… it's so hard, what do you do? Is she allowed to go outside? (Participant 4).

In addition, Participant 10 indicated that Sarah should speak with Rick to explain what is 'bothering her and that's why she takes it out on smoking'.

In terms of how participants would handle the situation if they were in Sarah's predicament, three participants provided assertive behavioural responses to the situation juxtaposed with a sense of helplessness. For instance, Participant 1 stated 'I might be rebellious a little bit in terms of, you know, you need to give me my money […] I should be able to spend it the way I want to spend it'. Participant 2 also discussed,

> I might have been shy and thing, but at some point, […] I probably would say ok or for thing, but at some point, I would say I had enough of this […] I would actually speak up and if the supervisor doesn't do anything, I go to a higher supervisor.

Furthermore, Participant 4 discussed feeling helpless because she would not know where to go to receive support without getting into trouble by the staff. She also reported:

> I know in my situation with personal support workers, everybody has the close net family, like within the organisation, […]. So, you complain to one person, that person complains to the other person in management, they're both friends, and then the staff hears about it, and then they come in and go, 'Why did you say that?' (Participant 4).

With regard to the third vignette, one participant reported that Anna does not need to do anything (Participant 2) while others indicated that she should also pay her bill (Participants 3, 4, 8, 9, 10, and 11), and thank her boyfriend (Participants 4, 5, and 9). Participant 10 also stated that if she was in this situation, 'we would be open, honest and willing to accept our responsibility and willing to work together'. Nonetheless, Participant 7 stated he would ask his support worker or uncle to help with paying the bills.

Discussion

The findings of this study provide further evidence regarding the interactions between individuals' cognitive, emotional, and behavioural processes when they are faced with financially abusive situations. Findings revealed that individuals with intellectual disabilities do not always identify an abusive situation as abusive. This is consistent with findings from Brooks et al. (2012) who discussed the difficulties that individuals with intellectual disabilities may experience in identifying subtle cases of financial abuse.

Findings also show that individuals with intellectual disabilities use different terms to describe financial abuse (i.e., 'money abuse', 'taking advantage of', 'rip off'). Words that individuals with intellectual disabilities use to name and define a financially abusive

situation will impact the likelihood of receiving appropriate support and prosecution of alleged perpetrators (Davis, 2018). While ‘financial abuse’ is considered a crime in Canada (Government of Canada, 2022), being ‘taking advantage of’ or ‘ripped off’ are considered incidents. Therefore, if individuals with intellectual disabilities report an abusive situation using the terms ‘financial abuse’, they perhaps will be taken more seriously by authorities, which in turn will provide them with an opportunity to receive appropriate support, compared to using other terms.

This study shed light on decision-making processes of individuals with intellectual disabilities when they are faced with abusive situations. Indeed, financial decision-making abilities imply complex cognitive processes, as well as social and emotional factors (Suto et al., 2005b). For instance, the type of relationship between the person with intellectual disabilities and the perpetrator seem to impact their interpretation of the situation or subsequent behaviours. Given longstanding experiences of social isolation among persons with intellectual disabilities, they tend to engage in behaviours to feel accepted by others (i.e., people pleasing) (Ansello & O'Neill, 2010). Therefore, even when they are faced with an explicit case of financial abuse, their perception of the situation may be distorted due to their desire to maintain their friendships. Another explanation may be that individuals with intellectual disabilities may not perceive perpetrators' behaviour as abusive if they have a close relationship with them (Gibson & Qualls, 2012). Additionally, the findings of this study add to the existing knowledge base regarding the inclination of individuals with intellectual disabilities to comply to others, especially when they rely on them to receive support with their financial matters (Abbott & Marriott, 2013; Ansello & O'Neill, 2010). Worsening matters for persons with

intellectual disabilities is when they are faced with subtle cases of financial abuse, in which the perpetrator assists them with their financial management and is in a position of authority. In such situations, their learned compliance may influence their interpretation, and as a result, they may not identify the red flags associated with financial abuse (Ansello & O'Neill, 2010).

The behavioural pattern of the perpetrator is another factor influencing the judgement of individuals with intellectual disabilities and their assessment of the situation. In other words, they seemed to perceive a situation as financially abusive when the perpetrator's behaviours are repeated over time. To our knowledge, operational definitions of patterns of behaviours that constitute financial abuse among individuals with intellectual disabilities are inexistant. As reported in the literature on financial abuse among elderly population (Santos et al., 2019), this gap in knowledge adds to the complexity of preventing victimization and re-victimization among persons with intellectual disabilities. Excusing a perpetrator's abusive behaviour even on a single occasion can lead to revictimization among this population.

Similar to the findings of Suto et al. (2005a), our findings illustrate how previous experiences of persons with intellectual disabilities impact their interpretation of a situation. In other words, participants who had similar experiences as the vignettes were better able to identify abuse in the stories, compared to those who did not have such experiences. Therefore, findings highlight the impact of individuals' past experiences on their decision making and suggest that opportunities to make effective decisions regarding finances will help them develop and apply protective behaviours (Suto et al., 2005b).

Furthermore, our study suggests that when individuals interpret a situation as abusive, they believe that the victims should assert themselves, report to authorities or tell someone they know. Individuals with intellectual disabilities can acquire protective skills but they may not transfer their knowledge into protective behaviours in abusive situations (Bruder & Kroese, 2005). In other words, awareness of appropriate courses of action in an abusive situation may not result in these actions being implemented (Brooks et al., 2012; Davis, 2018). Our findings illustrate how feeling helpless or powerless in an abusive situation leads to inaction. Depending on the status of the perpetrator (e.g., support worker, friends), individuals' inclination to engage in protective behaviours may vary. They are likely to set boundaries with their friend but may hesitate to report a worker due to fear of losing support, feeling helpless and not being heard by authorities.

Limitations

Some limitations of the study are noteworthy to help understand the transferability of the findings. First, given the inclusion criteria and recruiting only persons with mild levels of support needs, the findings of this study may not be transferrable to individuals with moderate, severe, and profound levels of support needs. Second, we only used three vignettes to illustrate cases of implicit, explicit and no financial abuse; however, financial abuse consists of many different forms of exploitative behaviours directed toward victims. Therefore, factors that impacted the participants' interpretations, emotional and behavioural reactions to the vignettes may differ if they are presented with other forms of financial abuse. Third, participants' analyses of the vignettes may have been impacted by the fact the protagonists in all the

vignettes were female (i.e., gender bias effect). That is, women are often perceived as victims and vulnerable, versus men as abusers (Reynolds et al., 2020). Lastly, several factors such as ethnicity and sexuality were not explored as part of participants' demographic information. We recommend that future research should use an intersectionality approach and consider the impact of such factors on the complex processes of individuals with intellectual disabilities when they encounter financially abusive situations.

Conclusion and Implications

Persons with intellectual disabilities often rely on others to assist them with money management, which increases the risk of exploitation (Conder & Mirfin-Veitch, 2020). Therefore, acknowledging the importance of choice, autonomy, and decision-making rights of persons with intellectual disabilities is an important step toward implementing effective prevention approaches (Robinson & Chenoweth, 2011). It is also crucial to support persons with intellectual disabilities in acquiring knowledge about different forms of financial abuse, and developing protective behaviours (Buhagiar & Lane, 2022). Interventions would be more effective when considering different types of relationship between victims and perpetrators, behavioural patterns of the perpetrators, people's past experiences, as well as the cognitive, psychological, and emotional factors that impact individuals' interpretations of financially abusive situations. Laing (2017) also recommended holistic and person-centered interventions that are in line with the needs and experiences of victims of abuse who have intellectual disabilities.

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Chapter 4: "It's not about control, It's about education": Support providers' perspectives regarding financial abuse among persons with intellectual disabilities

Ghaderi, G., & Cobigo, V. (In review). "It's not about control, It's about education": Support providers' perspectives regarding financial abuse among persons with intellectual disabilities. *Disability and Society*.

Abstract

Research shows that support providers have reported experiencing difficulties assisting individuals with intellectual disabilities managing their finances. While they tend to safeguard persons with intellectual disabilities from financial abuse, they may infringe on their autonomous decision-making and limit access to their funding. Therefore, this study investigated whether support providers are able to recognize incidents of financial abuse, how they define financial abuse, and what their perspectives are regarding this issue. Fourteen support providers participated in a semi-structured interview where they were asked to reflect on five vignettes illustrating different forms of financial abuse. The interviews were analyzed using thematic analysis. The findings revealed even though many of the participants were able to identify the red flags associated with abuse in the vignettes, most of them did not define the scenarios as “financial abuse”. Furthermore, participants discussed their perspectives regarding the decision-making rights and autonomy of persons with intellectual disabilities when they discussed their interpretations of the vignettes. Also, the support providers reported that they did not receive proper trainings on financial abuse and that there is a lack of clarity regarding who to refer to ask questions about this matter. This study has implications in raising awareness among policy makers and organizations to implement clear guidelines and programs to teach support providers regarding different forms of financial abuse and guide them how to assist individuals with intellectual disabilities with their finances without infringing on their decision-making rights.

Keywords: financial abuse, support providers, intellectual disabilities, policy makers, social justice

Introduction

Direct support providers tend to report a lack of knowledge and skills in providing support to persons with intellectual disabilities regarding their financial management (Abbott and Marriott 2013; Fleming et al. 2019). This lack of knowledge leads to situations where they may infringe on individuals' autonomous decision-making and limit access to their funding; thus, perpetrating explicit or implicit financial abuse themselves (Fleming et al. 2019). Therefore, it is crucial to examine the knowledge and perspectives of support providers regarding financial abuse to implement targeted trainings that improve their skills and competence in assessing and identifying red flags of abuse. Such trainings should encourage support providers to reflect on their own biases (e.g., perceiving persons with disabilities as vulnerable; Buhagiar and Lane 2022) and practices when assisting persons with intellectual disabilities with their finances. Finally, understanding situations where persons with intellectual disabilities experience financial abuse will inform policy development, prevention, and intervention programs to protect individuals with intellectual disabilities from financial abuse (Mitchell and Buchele-Ash 2000).

According to the United States Department of Justice (2023), financial abuse is defined as "the illegal, unauthorized, or fraudulent use, or deprivation of use, of the property of a vulnerable adult with the intention of benefiting someone other than the vulnerable adult". Similarly, the Government of Canada (2022) defines financial abuse as taking an individual's "money or property to control or exploit them", and it can include the following behaviours: "taking someone's money or property without permission; withholding or limiting money to control someone; pressuring someone to

sign documents; and forcing someone to sell things or change a will" (Government of Canada 2022). While some of these behaviours are reprimanded by law (i.e., theft), subtle forms of financial abuse (e.g., withholding someone's money) require interpretation of the context (Brooks et al. 2012). Furthermore, the findings of the literature review on definitions of financial abuse among the elderly population (i.e., Carr 2022) showed that there is no single definition for financial abuse across Canada. In other words, every province and territory has developed their own definitions, legislations, and reporting requirements in response to financial abuse (Carr 2022). In the absence of an operational definition of financial abuse, "the thresholds at which good practice becomes abusive behaviour" may become blurry (Petitpierre et al. 2013, p. 197). Therefore, support providers may have difficulty understanding and identifying financial abuse among persons with intellectual disabilities.

Even though many individuals with intellectual disabilities experience financial abuse, it is difficult to establish a precise prevalence among this population. Financial abuse is often undetected and underreported due to several reasons (Murphy and Clare 2021). First, given there is no single definition and a reporting procedure for financially abusive situations, the threshold at which behaviours become abusive tends to be blurry (Petitpierre et al. 2013). Second, support providers, who are often direct (i.e., frontline staff) or indirect paid support providers (i.e., supervisors and directors; Crocker 2015), family members or volunteers, may have difficulties assessing financially abusive situations, especially among individuals with disabilities (Fleming et al. 2019; Mitchell 1997). Third, support providers' lack of knowledge regarding what constitutes abuse and when intervention is necessary may lead to difficulty in detecting or reporting

financially abusive situations (Aylett 2016). Fourth, financial abuse tends to occur in domestic circumstances as persons with intellectual disabilities often rely on support providers to receive help with their finances (e.g., bill payment, monitoring expenses) and therefore, abuse may remain hidden (Murphy and Clare 2021). Lastly, many individuals with intellectual disabilities are hesitant to report their experiences of abuse perpetrated by people known to them due to the fear of losing their support or friendship (Ansello and O'Neill 2010). Furthermore, the results of a systematic literature review revealed that shortcomings in management (i.e., lack of staff training, poor relationship between management and frontline staff, lack of support to frontline staff), poor implementation of adult protection policies and complex processes and procedures for reporting abuse, are risk factors within an organization that exacerbate the issue of abuse against persons with intellectual disabilities (Collins and Murphy 2022). Collins and Murphy (2022) also argued that a lack of clear guidance among paid support providers may lead to variable thresholds for reporting abuse.

Support providers often help persons with intellectual disabilities in different areas of their daily lives (i.e., personal support needs, finances, etc.) (Government of Ontario 2023; Wille et al. 2022). They are also expected to be competent in assessing the needs of individuals they support, advocating for them, helping them make decisions, linking them to services, and providing them with individualized support (Crocker 2015). Individuals with intellectual disabilities have also identified receiving appropriate assistance (e.g., budgeting advice) with their finances as instrumental in independent living and meeting their goals (Conder and Mirfin-Veitch 2019). They also value autonomous decision-making (Bigby et al. 2017; Conder and Mirfin-Veitch 2019).

Even though individuals with intellectual disabilities may need assistance with managing their finances, their rights to spend their money how they wish to should be respected (Hart et al. 2007). However, support providers may hold biases towards individuals with intellectual disabilities and view them as powerless and vulnerable to abuse. As a result of such biases, they tend to perceive their role as being responsible for protecting these individuals (Eastgate et al. 2012; Parley 2011). Such a stereotypical image of persons with intellectual disabilities negatively impacts their autonomy and readiness to acquire self-protection skills (Hollomotz 2013). Also, perceiving this population as vulnerable leads to controlling behaviours and overprotection among support providers, which further exacerbates the risk of abuse (Buhagiar and Lane 2022).

Petitpierre et al. (2013) investigated the perspectives of different support providers including direct-care providers regarding a video vignette portraying problematic care practices. Specifically, the vignette illustrated a situation in which a female carer forced a person with intellectual disabilities to perform a task, in a residential setting. The findings revealed that all the direct-care providers condemned the practices in the vignette, but most of them were hesitant to define the situation as abusive, and instead, they identified the antagonist's behaviours to be disrespectful. Therefore, these authors recommended that support providers need to examine their attitudes and practices regularly to be able to identify early signs of risk factors (e.g., stress, increased workload) precipitating abusive behaviours to prevent "borderline" cases of abuse (i.e., cases that have emerging characteristics of abuse but are not covered by existing laws).

Support providers' values, experiences, perceptions of individuals' decision-making abilities, and risks linked to the decision that is being made may lead support providers to coerce individuals with intellectual disabilities to make decisions against their will or preference (Browning et al. 2021). For instance, Browning et al. (2021) found that support providers used different strategies including verbal praise, negotiation, offering rewards, and withholding information, to persuade and impact individuals' preferences and decisions. Support providers have also reported that they often encounter dilemmas between their aspirations to promote autonomous decision-making among persons with intellectual disabilities and their responsibility to safeguard them from exploitation (Fleming et al. 2019). Nonetheless, knowledge remains scarce on how to best support individuals with intellectual disabilities with their finances without infringing on their rights. Also, there is a gap in the knowledge base regarding what support providers know about financial abuse among persons with intellectual disabilities, and their perspectives regarding different types of financial abuse (i.e., implicit, and explicit cases of abuse).

Therefore, this study aimed to investigate how support providers understand financial abuse, as well as factors that influence their interpretations of abusive situations. With the foregoing goal in mind, this study addressed the following research questions:

4. How do support providers interpret financially abusive situations?
5. How would they determine if a situation is abusive?
6. What do they believe the victims in an abusive situation should do?

Method

This study is part of a larger project that utilized a qualitative inclusive approach to inform strategies to prevent financial abuse among persons with intellectual disabilities. Inclusive research contributes to social change and empowerment of persons with intellectual disabilities by involving them on a research team to share their perspectives regarding issues that are important to them (Walmsley et al. 2018). Inclusive research is an approach that facilitates the implementation of equity, diversity, and inclusion models in academic research (Ghaderi et al. 2023). Including persons with intellectual disabilities in research processes has been shown to improve the validity of research outcomes, limit researchers' biases (Chouinard and Cousins 2009; Frankena et al. 2015), and their input regarding their lived experiences can be invaluable in various stages of research processes (Di Lorita et al. 2018). In this study, two persons with intellectual disabilities (one male, aged 32 years and one female aged 39 years) were involved on the research team as advisors. The female advisor had been an advisor in another research project coauthored by the second author, but the male advisor had only been involved in research as a participant. The advisors contributed to different phases of this research project, including validating the vignettes. Detailed information regarding the advisors and the inclusive approaches will be published in another paper. We obtained ethics approval from the University of Ottawa's Health Sciences and Science Research Ethics Board (H-05-21-6429).

Recruitment procedure

We used convenience sampling (Lavrakas 2008) through community agencies that provide support and services to individuals with intellectual disabilities, in Ontario,

Canada. We emailed the recruitment materials to these organizations and agencies which distributed them to their paid support providers who work directly or indirectly with individuals with intellectual disabilities. We also used chain sampling, by which paid support providers shared recruitment materials with other paid support providers or other targeted agencies whom they knew.

Participants

Paid support providers who expressed willingness to participate in the study, were invited to contact the authors (via telephone or email) to ask any questions that they may have had and schedule a meeting for an interview. The interviews were scheduled based on the time and platform convenient to the participants. Finally, 14 paid support providers (i.e., directors, managers, social workers, and frontline support workers) participated in a semi-structured interview (See Table 1). The first author conducted virtual interviews (via Zoom platform) with 12 participants (*n*= 12), one in-person interview at the office building of the organization where the participant was employed (*n*= 1), and one phone interview (*n*= 1). In qualitative research, samples as small as five have sometimes been sufficient to reach saturation (Dworkin 2012). In this study, we recruited as many participants until we reached saturation in data, which is defined as "when gathering fresh data no longer sparks new theoretical insights, nor reveals new properties of your core theoretical categories" (Charmaz 2006, 113).

Participants were asked several demographic questions such as age, sex, years of employment in the field (see Table 1), as well as questions such as their extent of involvement in assisting individuals with intellectual disabilities with their finances, and previous training on financial abuse (see Table 2).

Table 1.

Participants' Demographics

Demographic Characteristics	**Number of Participants (*n*=14)**
Average age (M, SD)	45.5 (9.5)
Age range (min-max)	32-61
Sex (n, %)	
Male	3 (21%)
Female	11 (79%)
Geographic Area of employment (n, %)	
Central Ontario	4 (29%)
Eastern Ontario	10 (71%)
Highest Level of education (n, %)	
High school diploma	2 (14%)
College	5 (36%)
Undergraduate degree	3 (21%)
Graduate degree	4 (29%)
Years of employment in the field* (min-max)	5 – 41
Works with individuals with intellectual disabilities (n, %)	
Directly	10 (71%)
Indirectly	4 (29%)

**Note*: M and SD are not available for 'years of employment in the field' as participants reported range.

Table 2.

Participants' Scope of Work and Training on Financial Abuse

Participants	Type Of Employment (Works directly or indirectly with persons with intellectual disabilities) *	Scope of Assistance with Financial Management	Previous Training on Financial Abuse	Knowledge of Resources to Consult Regarding Financial Abuse
P1	Leadership role (indirectly)	- Ensures continuous oversight of individuals' money - Oversees staff keeping accurate records of individuals' finances - Provides financial records to trusted family members	- Not specific to financial abuse	- No specific resources - Usually tries to sort through with the Ontario Disability Support Program and banking system
P2	Support provider (directly)	- Assists with budgeting and navigating support services regarding issue with their trustee or public guardian - Completes paperwork in relation to provincial financial assistance	- Not specific to financial abuse	- To call ReportON
P3	Leadership role (indirectly)	- Provides guidance to staff who directly work with individuals with intellectual disabilities	- No training	- No specific resources

P4	Leadership role (indirectly)	- In the past, he helped with:
		  - creating a budget
		  - managing money, paying rent, buying groceries, and bringing them to the bank
			- Attended annual mandatory training on abuse prevention including financial abuse	- No specific resources
				- There is little discussion on financial abuse.

P5	Support provider (directly)	- Is involved in financial planning during the intake process	- General abuse prevention training offered by the organization	- Disability law firm
P6	Support provider (directly)	- Completes some individuals' bank and reconciliation statements on a monthly-basis - Supports some individuals with purchases, reviewing their bank statements, etc.	- Has had a training on financial abuse	- Speak with the manager

P7	Support provider (directly)	- Has full access to a client's account - Helps the client to write cheques, pay his rent, does reconciliations, and balances a check book	- No direct training on financial abuse - Some discussions regarding abuse in general and financial procedures	- No specific resources - Speak with the manager
P8	Support provider (directly)	- Assist individuals with their finances, budgeting and banking - Involved in monthly reconciliations of their accounts	- Yes. Attended training offered by the organization regarding financial abuse and human rights	- Call the police - Go to the management
P9	Support provider (directly)	- Does not assist with financial management	- No training	- Go to a legal clinic
P10	Leadership role (indirectly)	- In the past, as a direct support worker, she used to assist with budgeting	- No training	- Call the police, elder care unit - Refer individuals to lawyers to - Called the investigations unit with the Public Guardian and Trustee - Connect individuals to Salvation Army
P11	Support provider (directly)	- helps those who have an account within the agency to withdraw money to pay for their groceries	- No training	- No specific resources - "All we have is the community policing and community house"
P12	Support provider (directly)	- Supervises staff who assist individuals with intellectual disabilities with their finances	- No training	- ReportON
P13	Support provider (directly)	- Assists with monthly budgeting - Applies for financial support, if needed	- No specific training on financial abuse	- No specific resources
P14	Support provider (directly)	- Assists individuals with their banking, and grocery shopping	- Yes; receives training every two years	- No specific resources

Note: *Leadership role consists of positions including executive, supervisory, or program coordinator roles. Support provider role consists of positions including social worker, intake worker, case or program manager or support worker roles.

Measures and Data Collection

The first author conducted semi-structured interviews which incorporated five written vignettes consisting of stories regarding financial transactions, four of which depicted situations of explicit and implicit financial abuse, and one illustrated a situation where no financial abuse occurred. Three of the vignettes were informed by Ann Craft Trust training material on ACTing against abuse (Brooks et al. 2012). Another one (i.e., implicit financial abuse) was informed by a real-life situation of financial abuse against some individuals with intellectual disabilities as observed by one of the authors (See Table 3). Following the introduction of each vignette, the first author posed open-ended inquiries to the participants. These questions were developed to delve into the participants' understanding of abuse, and their viewpoints on financial abuse. Specifically, we sought to understand how they would characterize the events unfolding in the scenario, how they perceived the actions of the perpetrators in the vignette and their thoughts on how the victims should respond in financially abusive situations. The interviews took place via telephone, Zoom, and in person with the first author, and they lasted between 20 to 45 minutes.

We pilot-tested three of the vignettes (i.e., Vignettes 1, 4, and 5) with the advisors to ensure their internal validity (Leung 2015; Østby and Bjørkly 2011), clarity, authenticity, understandability, meaningfulness, and relevance to individuals' experiences of financial abuse (Hellzen et al. 2018; Hughes and Huby 2004). After presenting and reading each vignette to one advisor, we modified them and then presented them to another advisor and repeated the same procedure.

Table 3.

Vignettes

Vignette #1 (Explicit financial abuse)	One day, Monica went to the Tim Hortons (a coffee shop) with her friend, Sharon. Sharon ordered a large coffee and a chicken salad sandwich for herself. When the cashier asked how she would like to pay, Sharon turned to Monica and told her to pay for her. Monica did not order anything for herself, but she paid for Sharon's coffee and a sandwich.
Vignette #2 (Explicit financial abuse)	One day, Veronica told her support provider, John, about an incident, in which she bought an item from a grocery store, but the cashier gave her the wrong change. The next day, John went to visit Veronica to convince her to sign a Power of Attorney to manage her finances. When Veronica refused to do such, John told her that she is unable to manage her money and that she has to sign the document.
Vignette #3 (Implicit financial abuse)	Enya has a support provider, Julia, who helps managing her money and spends most of the day with Enya at her apartment. Enya does not have a television in her apartment; therefore, Julia decided to buy a small television for Enya using Enya's money without letting her know.
Vignette #4 (Implicit financial abuse)	Sarah lives in a group home. Her worker, Rick, helps her manage her money. One day, Sarah asked Rick to give her money to buy cigarettes, but Rick told Sarah that she had smoked a lot lately. Sarah said she really wanted cigarettes, but Rick told her that she could buy some cigarettes in two days.
Vignette #5 (No financial abuse)	Anna has recently moved into her boyfriend's house. They decided to split the bills. They decided that Anna would pay for the gas bill and her boyfriend would pay for the electricity bill. One day, her boyfriend paid for the electricity bill and told Anna.

Data Analysis

We conducted thematic analysis (Braun and Clarke 2022) to analyze and capture participants' knowledge and perspectives on financial abuse to help answer our research questions. First, the primary author (GG) digitally recorded and transcribed the interviews word-for-word and imported them into NVivo 12, the most recent edition of qualitative data analysis software. Both researchers then read the transcripts on-screen multiple times to become familiar with their content, write notes, and generate initial

insights. Second, GG systematically categorized the data into relevant descriptive and interpretive codes, which were reviewed with the second author (VC) and Any disagreements that arose were discussed in a meeting until a consensus was reached. Then, the codes were collated and segments of data that were relevant to the codes were compiled. Third, GG consolidated the codes into overarching themes, encompassing words, phrases, and sentences, which were reviewed by VC. This process was collaborative, involving discussions regarding the themes, their similarities and differences, collapsing those that were similar, creating subthemes, as well as refinements of themes. Fourth, GG and VC reviewed the themes in relation to the entire dataset, to ensure they were meaningful and relevant to the research questions. Finally, the researchers defined the themes and sub-themes and assigned them descriptive names.

Findings

The findings of this study revealed two primary themes which provide a comprehensive representation of participants' complex processes when faced with different forms of abusive situations (i.e., implicit and explicit financial abuse) as well as their overall experience regarding this issue. The themes are: 1) interpretation of the stories, which focuses on how participants interpreted the scenarios and described the perpetrators' behaviours illustrated in the vignettes; and 2) perceptions regarding behavioural reactions, which encompasses participants' perspectives regarding what the agonists in the vignette should do as a result of abuse, as well as how they would react if they were the support provider or a friend of the agonists in the vignettes. Every theme represents several sub-themes which further shed light on the participants'

complex cognitive processes when interpreting situations that could be considered as financial abuse and making decisions regarding possible actions.

1. Interpretations of the Stories

1.1 Abuse Identification and Perspectives Regarding Perpetrators' Behaviours

Participants were asked to discuss their initial impressions of the vignettes and their perspectives regarding the perpetrators' behaviours. When presented with the first vignette (i.e., explicit financial abuse), most of the participants (*n*= 8) reported that Sharon "took advantage" of Monica, some of whom described Sharon's behaviour as "disrespectful and potentially exploitative" (Participant 1); "incredibly insulting and, you know, certainly, taking advantage of an individual's desire for friendship" (Participant 3), "demanding" (Participant 7), "aggressive" (Participant 13) and "rude" (Participant 14). Similarly, Participant 2 reported that on one hand, Sharon's behaviour may be "manipulative" or "demanding", but on the other hand, "it could be survival […] it could be a situation where Sharon's living on her own, […] money's tight and, she doesn't have, like, cash to pay for a coffee or sandwich at Tim Hortons". Even though Participant 11 did not define the situation as financially abusive, she described Sharon's behaviour as "abusive". Only Participant 4 defined the situation as "financial abuse". Also, Participant 9 indicated "I'm not sure about their friendship or the relationship, but I know that there is some sort of power differential where Monica is the one paying, and Sharon expects Monica to pay". Nonetheless, Participants 5, 6, 10, and 12 were unable to provide their interpretations of the story. These participants indicated that they require more information regarding whether Monica feels pressure to pay, whose turn it is to

pay, or the type of friendship between Monica and Sharon. Participant 10 indicated “I am not concerned about Sharon's behaviour, unless I knew what the background was”.

In terms of the second vignette (i.e., explicit financial abuse), only Participant 4 defined the situation as “financial abuse” and described John’s behaviour as “hugely financially abusive, and it's just to me completely negligent on John's behalf and reckless”. Three participants also interpreted the situation as a “violation” and “infringement” of Veronica’s rights (i.e., Participants 1, 2, 5), and Participant 2 described John’s behaviour as “controlling, abusive and coercive”, and Participant 5 indicated,

> I think, using the word abuse, it like, it carries a lot of weight. Just, you know, words mean different things to different people. But if I'm thinking about it, that is abusive behaviour, because he is telling her that she has to sign it and, like, yeah, that's, that's abusive.

Furthermore, Participant 1 indicated “as opposed to trying to assist her [Veronica] in this matter, he's just taking all her rights and freedoms away of her decision-making”. Five participants (i.e., Participants 3, 7, 11, 12, 14) described the situation as an “overreaction” to a common mistake. These participants described John’s behaviour as “controlling”, “impulsive”, “uneducated”, “a little over the top”, and “inappropriate” because Veronica made a mistake that is very common among most people. Four participants (i.e., Participants 6, 8, 9, 10, 13) did not define or label the situation; however, Participant 8 reported “Nobody can force anybody to sign any document that they don't want to”; Participant 10 indicated “Deplorable and like, that would be absolutely grounds for dismissal and reporting to police”; and Participant 9 indicated,

> John doesn't understand what supported decision-making is. John doesn't understand that it's not necessary to enter into a power of attorney simply because someone got the wrong change. I get the wrong change all the time, you know, um, and so yeah so that's, John needs education.

When reacting to the third vignette (i.e., implicit financial abuse), most of the participants (*n*= 13) identified the problem in the scenario (i.e., Julia should not have spent Enya's money without her permission). Nonetheless, there was a notable variability in participants' definition of the situation. Specifically, four participants defined the situation as "financial abuse" or "abuse of trust and theft" (i.e., Participants 3, 4, 9), and "violation of rights" (Participant 2); and they described Julia's behaviour as "abusive", and "arrogant, misinformed, uneducated, harmful". Furthermore, five participants described the situation as "wrong" (i.e., Participants 1, 5, 6, 7, 11), and some of whom specifically described Julia's behaviour as "inappropriate" (Participants 1, 5) and "micromanaging" (Participant 11). Participant 10 also indicated that Julia is "taking advantage of" Enya, and she explained, "I don't think this is crossing the line... I think this is an education moment. If that continued, then I could see that as becoming a, you know, a flag for abuse" (Participant 10). On the other hand, Participant 12 reported "Julia manages Enya's money. So, there could be an implied consent that Julia can buy a small TV for Enya".

Participants' interpretations of the fourth vignette (i.e., implicit financial abuse) varied considerably. Most of the participants (*n*= 11) identified the red flag in the story and discussed Sarah's decision-making rights. For instance, Participant 11 indicated "that's really bad. Rick has no right telling Sarah how to spend her money. If Sarah

wants to smoke, she should be able to smoke". Participants 12 and 13 also described Rick's behaviour as "illegal" and "disrespectful", as he did not accept Sarah's "choices". Furthermore, three other participants described Rick's behaviour as "inappropriate" and "controlling" (Participants 2, 3, 14). However, except for Participant 4, who defined the situation as "financial abuse", the other participants did not define or label the situation as abusive, and they were conflicted about how to describe Rick's behaviour. For instance, Participant 5 stated,

> I would say that he's like coming from a good place, but maybe is just misguided. Like, he's, I think he's trying to be caring about her health […] But it's still inappropriate, the way he's implementing his way; […] it's still not right, but I think he's coming from a good place at least.

Similarly, Participant 7 indicated,

> But with my background, that could be a whole slew of other things going on. I mean if Sarah doesn't have a lot of money and Rick being the support provider, they could be on a budget plan; right, that she might have agreed to this budget plan and she's kind of veering off and Rick's trying to just guide her back to that plan that she agreed to or what, you know. […] We've had many people in this situation, and it's, it's a tough one. It's a really tough one. Same thing with buying alcohol and stuff like that, it's a tough one.

Some other participants indicated that Rick's behaviour is "not supportive", "wrong" and "abrupt" as he did not explain to Sarah why she cannot have her money (Participants 10, 6) and that he treated her like a child (Participant 11). Furthermore, three participants were ambivalent regarding the scenario as they found the situation "tricky".

Specifically, Participants 6 and 10 indicated that Sarah may not have enough money and Participant 5 stated,

> He's not telling her "No, period" about buying smokes, but he's like trying to negotiate to maybe help her not smoke too much, which is coming from a good place but at the same time, yeah, so it's tricky, I would say, but still not right because it's not his money to spend, it's hers.

In terms of the last vignette (no abuse), none of the participants raised concerns regarding the situation, and they described it as “good” or “fine”. They also described Anna’s boyfriend’s behaviour as “responsible”, “nice”, “reasonable” (e.g., Participants 2, 3, 4).

***1.1.1 Perpetrators’ Behavioural Pattern*.** The findings revealed that some participants considered the behavioural patterns of the perpetrators when discussing their perspectives. For instance, regarding the first vignette, Participant 7 indicated,

> I mean, they’re friends, […] it's very normal to go to Tim Hortons with a friend and you kind of take turns, […] we need to know has this happened before, is it a regular thing? you know, and that's, we have to look for patterns in this situation.

Participant 8 also reported that “it could be financial abuse, if it happens regularly. Not just maybe a once in a blue moon thing”.

1.2 Perspectives and Biases Regarding Disability

We asked participants regarding their perspectives of the vignettes, if some of the characters (i.e., Monica, Sharon, Veronica, Enya, Sarah, Anna) had intellectual disabilities and whether such information would influence their answers. All the participants (*n*= 14) indicated that their interpretations of the second (i.e., explicit

financial abuse), third (i.e., implicit financial abuse) and last vignettes (i.e., no abuse) would not change. For instance, Participant 12 indicated “So, whether it's mental health, intellectual disability or nothing at all, people have the right to make their own decisions, manage their money, even if we don't agree with it”. Nonetheless, in terms of the first vignette (explicit financial abuse), most participants (*n*= 9) reported that they would perceive the situation as more “abusive” if Monica had intellectual disabilities, but not Sharon. However, if both Monica and Sharon had intellectual disabilities, these participants reported that they would perceive the situation as less abusive because Sharon is “trying to survive”, and the “power dynamic” would be different (e.g., Participants 2, 9).

In terms of the fourth vignette (i.e., implicit financial abuse), most of the participants (*n*= 13) indicated that their perceptions of the vignette would not change if Sarah had intellectual disabilities. For instance, Participant 10 explained, “Nobody should be controlling what somebody does with their money, if they have the money to spend”. However, Participant 5 indicated,

> If she [Sarah] were, let's say in a mental health boarding home, like, no intellectual disability, I would probably be more likely to say, tell Rick to get lost, you don't need him to manage your money […] But, having an intellectual disability, like, I guess I acknowledge that the support could be very helpful to her […] So, it's more difficult to find like that balance of the appropriate level of support without not infringing on her rights.”

Furthermore, some participants reported that individuals with intellectual disabilities are “vulnerable” (Participants 7, 10), due to which they are “overprotected” (Participant 12)

and are “easily taken advantage of” (Participant 7). Participant 2 also indicated that “vulnerability” is a risk factor precipitating persons with intellectual disabilities to feel pressured to maintain their friendships with money.

1.3 Perspectives Regarding Decision-Making Rights, Choice and Autonomy

Most participants (*n*= 11), regardless of whether they work directly or indirectly with persons with intellectual disabilities, discussed their perspectives on the decision-making rights of this population. For example, Participant 9 reported that in situations similar to the third vignette, “regardless of that person's cognitive ability, they should have been consulted, you know, on the most basic level”. Furthermore, in response to the fourth vignette, several participants indicated that it is Sarah’s right to use her money to purchase cigarettes (e.g., Participants 1, 13). Furthermore, Participant 1 indicated “I mean, you provide with education, you provide with options and choices, but in the end, people have to make their own choices and they then have to live with the consequences of those choices”. Participant 3 also discussed the evolution in the developmental disability sector, and he explained,

> Over the years, many individuals who have been in the field have taken up paternalistic approach with people, which is not okay, and it may have been historically, but obviously the sector has moved on and it's, again, it's how do you educate? How do you support? How do you help the person understand the limitations and the restrictions that come with limited financial resources?

2. Behavioural Reactions

2.1 What Victims Should Do in Financially Abusive Situations

We asked participants about their opinions regarding what the victims in the vignettes should do. With regard to the first vignette, 11 participants proposed different approaches such as: Monica should "stand up" for herself and not pay for Sharon's meal; Monica should either say "no" and be "assertive" in the moment, or have a conversation with Sharon afterward to ask her to pay her back; or, Monica should speak with someone trusted (i.e., family member or friend) or call the police. Three participants (*n*= 3) also considered Monica's need for friendship when they discussed how they believed Monica should react in the situation. For instance, Participant 13 indicated,

> You know, this might potentially be one of Monica's only friends and feels like she needs to do that because she wants to maintain that relationship. Um, but I think, my advice for Monica would be to try to work through not having to pay for her friend. (Participant 13)

In terms of the second vignette, all the participants indicated that Veronica should speak with a trusted family member or friend, another support provider, John's manager, or a lawyer. Furthermore, Participant 2 stated,

> She [Veronica] should talk to someone about the situation and hopefully they can educate her about her rights […], you can't assume someone's capacity like that without having a basis and, you know, some kind of assessment or document to just jump to the conclusion someone can't manage their money from like one small incident, you know, not how it works.

Similarly, Participant 9 indicated that Veronica should “talk to a lawyer; learn about her legal rights”. Participant 4 also shared her previous observation of individuals with intellectual disabilities who have been in similar situations. Specifically, he reported,

> In my experience, it's really difficult for people with intellectual disability to do that [speak to a supervisor]; a) they need to understand the process and, there's that power differential where, you know, they're relying on somebody, and then at the same time, you know, they have to call them out on something and sometimes they're fearful that they’re going to lose their supports. (Participant 4)

Participants also discussed their perspectives regarding what Enya should do in the third vignette. Participants suggested various approaches that Enya should take to tackle the situation, and they include: Enya should “stand up” for herself and talk to Julia not to take her money without her permission (Participants 2, 3, 5, 6, 7, 8, 10), “and if she's reluctant to do that, then I'd be saying, encouraging her to call the police” (participant 3); tell Julia to return the television (participants 1, 11); “clarify what managing her money means” (Participant 12); speak to a trusted person or report Julia to her agency, her supervisor, or another support worker (Participants 4, 5, 9, 13); or, find a more “trustworthy person to manage” or help her manage her money (Participant 14). Similar to this vignette, all the participants (*n*= 14) reported that Sarah (in Vignette 4) should talk to Rick and tell him how she is feeling, or talk to a family member, a trusted person or report Rick to a supervisor because she should be able to access her money. Additionally, Participant 4 indicated that Sarah might “fear of consequences, backlash, but she needs to report it to a supervisor […] even if there’s a confidential line to do this”. Participant 12 also suggested that “if there was a place that she knew about

that she could ask about her rights, that would be the place to go", but this participant did not discuss specifically who to refer to seek information.

2.2 What Support Providers Would Do in Financially Abusive Situations

Five participants discussed what they would do as a support provider in situations similar to the ones illustrated in the vignettes. For instance, Participant 3 indicated "We have to train the support provider to say it's not about control, it's about education". He also provided an example regarding how they handle financially abusive situations within his organization, adding,

> If it was one of our employees that we suspected had taken money, that would be our first, first thing would be to suspend the person, second call would be to the police department to say "we need you to investigate this; we believe there's been theft of this person's money". Other times, if there's a dynamic with family, we would assist the individual to contact, um, we've often had them contact [the name of a community organization providing education and legal service referrals].

Participant 1 suggested that as support providers, it is important to implement a system to help persons with intellectual disabilities manage their finances and provide them with "education, options and choices" to make their own choices. Similarly, Participant 10 reported that in the group homes affiliated with their agency, they are respectful of individuals' autonomy in managing their money, while asking them how they would like the staff to support them.

Participant 6 highlighted the importance of including individuals with intellectual disabilities in decisions regarding their money and day-to-day banking. Furthermore,

this participant indicated “I've never made a purchase of anything without them being with me. I don't care how big or small; it’s their money, not my money”. Additionally, in relation to the second vignette, Participant 9 reported that regardless of individuals’ cognitive ability, they should be consulted, and that the provider should ask “Do you want a TV? […] here’s how much money you have in your bank account […] Do you want to spend a lot or a little on the TV”. Participant 13 also discussed how typical the fourth scenario is in group homes, based on her extensive experience as a direct support provider in the field. Specifically, she indicated,

> There are things that are typical; like, support providers taking advantage of people and making those decisions for people depending on their level of intellectual disability and management. And obviously I think they should always be consulted in everything they purchase, and smoking is so common in group care where people, you know, try to control those things, or alcohol use and whatnot.

Discussion

The findings of this study add to the knowledge base regarding the issue of financial abuse among persons with intellectual disabilities from the perspectives of support providers. Most of the support providers, even those who were in leadership roles, refrained from defining the vignettes as financial abuse. This is consistent with the evidence on support providers’ hesitation in defining problematic care practices as abusive, even though they criticized the perpetrators’ wrongful behaviours (Petitpierre et al. 2013). Nonetheless, support providers’ apprehension in defining a financially abusive situation as abusive has implications for persons with intellectual disabilities. If support

providers do not label financially abusive situations as abuse, they will be less likely to provide appropriate support to victims with intellectual disabilities (Davis 2018). Additionally, depending on how an abusive situation is described (i.e., “taking advantage of” versus “financial abuse”), perpetrators may not be prosecuted, and victims will likely not be taken seriously by authorities (Davis 2018; Fleming et al. 2019).

Support providers are expected to be competent in assessing the needs of individuals with intellectual disabilities and helping them make decisions regarding different areas of their lives, including their finances (Bigby et al. 2019; Crocker 2015; Wille et al. 2022). The findings of this study revealed that even though most of the support providers assist persons with intellectual disabilities with their finances in different capacities, they did not receive proper training and education regarding financial abuse. Lack of awareness and education among direct and indirect support providers regarding practices that constitute financial abuse may precipitate and perpetuate abuse among persons with intellectual disabilities (Aylett 2016). In other words, if support providers are unaware of practices that constitute abuse, they may be at a higher risk of engaging in exploitative behaviours with persons with intellectual disabilities (Fyson and Patterson 2018). Furthermore, many support providers in this study were unsure of resources with which they could consult if they had a question regarding financial abuse. Nonetheless, lack of guidance and support among support providers are risk factors that may lead to abusive practices (intentional or unintentional) against persons with intellectual disabilities (Collins and Murphy 2021).

Parely (2011) found that most of the support staff in her study viewed persons with intellectual disabilities as vulnerable, due to which they felt that they had the

authority to take protective measures to keep them safe. Perception of vulnerability is often coupled with inability to make decisions and therefore, it portrays individuals with intellectual disabilities as persons with a lack of agency and autonomy (Butler 2016). Nonetheless, the findings of this study revealed that only a few support providers perceive persons with intellectual disabilities as vulnerable and requiring protection. In fact, the support providers discussed the importance of respecting the autonomy and decision-making rights of persons with intellectual disabilities, which they believed to be as equal as to those without a disability. In addition, most support providers perceived the perpetrators' behaviours in the vignettes as problematic, regardless of whether the victims had intellectual disabilities or not.

The findings of this study also revealed that there is a lack of clarity among support providers regarding what victims of financial abuse must do after they experience abuse. Support providers provided variable responses regarding the behavioural reactions of the victims in the vignettes, ranging from setting boundaries, reporting to a trusted family member, or reporting to the police, another support provider or a manager. Furthermore, as discussed by support providers, there seems to be a lack of organizational guidelines for reporting financial abuse among persons with intellectual disabilities and appropriately addressing this issue. These findings are in line with the elderly abuse literature in that there is variability in legislation and reporting requirements in response to financial exploitation (Carr 2022). Currently, there are no clear guidelines in Canada dictating how financial abuse, especially implicit cases, is assessed and addressed by law and whether perpetrators are prosecuted. As Fyson

and Patterson (2018) stated, support providers have difficulties with applying their conceptualization of abuse in practice.

Limitations

This study has several limitations that are important to help understand the transferability of the findings. First, even though a relatively large sample of support providers was recruited for this study, their perspectives may not be transferable to all support providers who work in different regions of Ontario, other provinces in Canada or internationally. Second, we only used five vignettes to exemplify cases of implicit, explicit and no financial abuse; however, there are many more forms of financial abuse. As a result, participants' interpretations and behavioural reactions to the vignettes may differ if they are presented with other types of financial abuse. Lastly, participants' interpretations of the vignettes may have been influenced given the protagonists in all the vignettes were female (i.e., gender bias effect). In other words, women are often perceived as victims and vulnerable, versus men as perpetrators (Reynold et al. 2020).

Conclusion and Implications

Support providers have raised concerns regarding their lack of knowledge and competence in assisting individuals with intellectual disabilities with their financial management (Abbott and Marriott 2013; Fleming et al. 2019). For individuals with intellectual disabilities to receive help and feel supported, there must be a consensus and a clear understanding of what financial abuse entails and how it is defined by support providers. To address the variability in defining financially abusive situations, future research may investigate the views of legal advisors and policymakers regarding all forms of financial abuse. Individuals with intellectual disabilities continue to be

discriminated against and are subjected to biases and negative experiences stemming from ableism (Ontario Human Rights Commission 2016). Despite support providers' intentions to support and protect individuals with intellectual disabilities from harm, the outcomes of their safeguarding and paternalistic behaviours may result in exploitive practices and infringe on individuals' autonomy and decision-making rights (Browning et al. 2021; Fleming et al. 2019). Additionally, research shows that when individuals with intellectual disabilities report incidents of abuse, they are not taken seriously by the healthcare and social systems (Hollomotz 2013). Therefore, intersectoral initiatives are required to develop guidelines and programs to educate support providers regarding financial abuse. Specifically, training should include information about how to recognize financial abuse and act when in a financially abusive situation, individuals' human rights to autonomy regarding their finances regardless of their disabilities, and how to prevent financial abuse. Furthermore, it is crucial to educate all support providers (both individuals who work directly or indirectly with persons with intellectual disabilities): 1) regarding the decision-making rights of individuals with intellectual disabilities, regardless of the severity of their support needs; 2) to avoid practicing in an authoritative or an abusive manner; and 3) how to best support individuals with intellectual disabilities with their finances without infringing on their rights and autonomy.

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Chapter 5: General Discussion

Overview of Dissertation

This dissertation aimed to investigate what individuals with intellectual disabilities and their paid support providers know about financial abuse, and how they define and recognize financially abusive situations. Even though many individuals with intellectual disabilities experience financial abuse, to our knowledge, it is the least studied type of abuse among this population. Research shows that not only is abuse victimization prevalent among persons with intellectual disabilities (Fisher et al., 2016; Pestka & Wendt, 2014) but it is often committed by people known to these individuals (Baladerian, 1991; Stevens, 2012). The risk of financial abuse victimization is high among persons with intellectual disabilities due to factors such as relying on others to support them with their finances (Abbott & Marriott, 2013; Buhagiar & Azzopardi, 2022), difficulty understanding the concept of money (William et al., 2007) and fear of losing support if they report the abuse (Ansello & O'Neill, 2010). Furthermore, while persons with intellectual disabilities can learn how to make decisions in an abusive situation, they do not always apply their knowledge in real-life situations (Hickson et al., 2015). Therefore, this raises questions as to what individuals' understanding of financial abuse is and what impedes their ability to apply their decision-making skills and protective behaviours in an abusive situation (Bruder & Kroese, 2005; Hickson et al., 2015; Khemka et al., 2005).

In addition to persons with intellectual disabilities, paid support providers have expressed several concerns with regard to supporting persons with intellectual disabilities with their money management. Specifically, they have raised concerns regarding the complexity of safeguarding individuals with intellectual disabilities against

financial abuse without infringing on their rights to make decisions regarding their finances (Fleming et al., 2019). Additionally, many support workers lack knowledge about what abuse encompasses, as well as when and how to intervene if they detect financial abuse (Aylett, 2016). More importantly, due to the inconsistency in how financial abuse is defined, paid support providers may encounter difficulties recognizing implicit and chronic types of financial abuse among persons with intellectual disabilities (Petitpierre et al., 2013). Therefore, we utilized a qualitative inclusive approach to gain a better understanding of whether individuals with intellectual disabilities and their paid support providers were able to recognize financial abuse in scenarios and their perspectives regarding such situations. This information is crucial to raise awareness among several stakeholders including healthcare professionals, lawyers, policymakers, lawmakers, legislators, law enforcement, and family members, to address this debilitating issue.

The general discussion is divided into five parts. First, a brief overview of each manuscript and its findings is provided. Second, this general discussion intends to review the primary findings of the three studies in this dissertation. Third, the socio-ecological model of prevention is discussed. Fourth, the implications of this dissertation with regard to informing financial abuse prevention, and research are discussed. Finally, the strengths and limitations of this dissertation as well as future research directions are discussed. A discussion of our inclusive approach and its impact on our research processes is provided.

Summary of Findings

Manuscript 1 (i.e., Chapter 2). We conducted a rapid scoping review of the literature to investigate how persons with intellectual disabilities have been involved in research

teams and to inform the inclusive methodology for this dissertation (Ghaderi et al., 2023). Thirty-two articles were included in the data analysis. This study had several important findings: 1) studies included in this scoping review did not provide detailed information regarding their methodological approaches and how they operationalized inclusion; 2) there was a notable inconsistency in the titles and roles assigned to persons with intellectual disabilities, in that these individuals performed various responsibilities under different titles; and 3) researchers reported several barriers in conducting inclusive research, including lack of time and funding, and impracticable deadlines imposed by funders (Ghaderi et al., 2023).

Manuscript 2 (i.e., Chapter 3). We conducted a qualitative inclusive study which investigated how individuals with intellectual disabilities interpreted financially abusive situations presented in three vignettes (implicit, explicit and no financial abuse) (Ghaderi & Cobigo, 2024). The findings of the scoping review by Ghaderi et al. (2023) informed the inclusive strategies (i.e., accessible language, training, using visuals, etc.) that we used to involve the advisory committee in this dissertation. The findings of this study revealed that: 1) there was variability in how persons with intellectual disabilities defined financially abusive situations; 2) several factors including the type of relationship between the victim and perpetrator as well as the perpetrators' behavioural pattern seem to have impacted participants' interpretations of the vignettes; 3) participants' past

experiences and personal judgments in relation to the scenarios either mitigated or intensified their judgement of the perpetrators' behaviours; and 4) there is a link between individuals' interpretations of the vignettes and their emotional and behavioural reactions to such situations. In other words, those who interpreted the stories as 'financial abuse' were inclined to suggest an assertive behavioural approach to deal with the situations compared to those who did not identify abuse.

Study 3 (i.e., Chapter 4). We conducted a qualitative inclusive study exploring the perspectives of paid support providers regarding financial abuse among persons with intellectual disabilities. The findings from this study showed that most support providers did not define the financially abusive situations in the vignettes as abusive, despite identifying the red flags in the stories and criticizing the perpetrators' behaviours. Furthermore, there is a lack of education and training regarding financial abuse available to direct and indirect paid support providers, despite their role in supporting individuals with intellectual disabilities with their finances. More importantly, many support providers were unsure where they could obtain information regarding financial abuse. Also, there is a lack of reporting guidelines within the organizations, in which support providers are employed, which leads to difficulties and confusion in terms of prevention and intervention of financial abuse among persons with intellectual disabilities. In this study, most participants also shared their perspectives concerning the decision-making rights of persons with intellectual disabilities and the negative implications of perceiving this population as vulnerable.

Overall, the results of Manuscripts 2 and 3 provided important information on the perspectives of individuals with intellectual disabilities and their paid support providers

regarding financial abuse, factors that impacted their interpretations of abusive situations as well as their emotional and behavioural reactions to such circumstances. Additionally, these findings play a significant role in informing financial abuse prevention and intervention as they provide evidence regarding how individuals with intellectual disabilities and their paid support providers perceive and define financially abusive situations. Implementing an effective financial abuse prevention model is particularly crucial among persons with intellectual disabilities because: 1) in Canada, many individuals with intellectual disabilities live in poverty, and half of Ontarians with intellectual disabilities receive disability financial support (Berrigan et al., 2020); 2) not only do these individuals earn an inadequate income, but they often lack control in managing their money (Northway, 2001); 3) discrimination against disabilities and societal attitudes negatively impact the likelihood of seeking help and support among victims of abuse who have intellectual disabilities, which in turn increases the possibility of re-victimization (Curry et al., 2001; Fraser-Barbour, 2018); 4) lack of support provided by the social and justice systems (Beadle-Brown et al., 2010; Curry et al., 2001; Didi et al., 2016; Hutchison & Stenfert Kroese, 2015), socioeconomic disadvantages, as well as inadequate housing and support place these individuals at a greater risk of experiencing financial abuse (Burge, 2009); and 5) as a result of victimization, these individuals often experience homelessness, incarceration (Levine et al., 2018), trauma (Kroese & Thomas, 2006), substance abuse (Taggart et al., 2007), and involvement with the law and child welfare systems (Levine et al., 2018).

Therefore, in the following section, we discuss: 1) the literature on the socio-ecological model of abuse prevention; 2) the implications of this dissertation in informing

and developing effective abuse prevention among persons with intellectual disabilities and research; 3) the strengths and limitations of this dissertation; and 4) the conclusion and suggestions for future research in this field.

Abuse Prevention Model: Socio-Ecological Framework

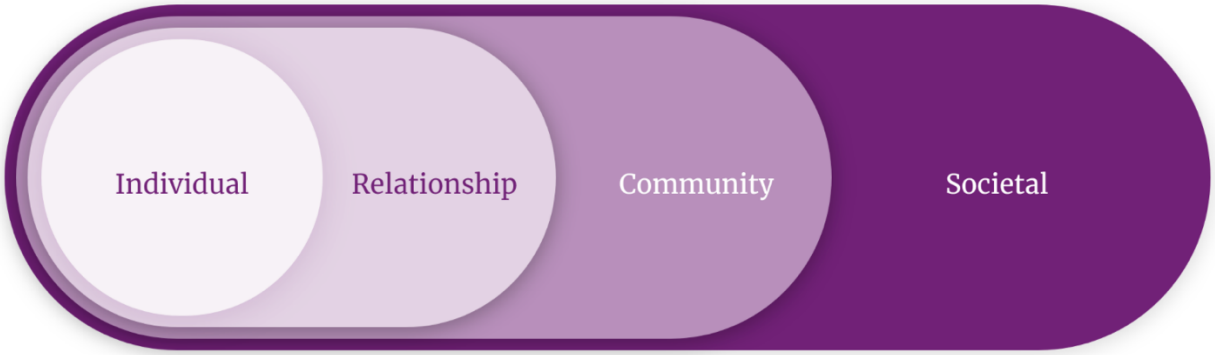
Prevention is conceptualized as a set of strategies to prevent or delay the onset of a problem from occurring and mitigate its impact while improving policies at institutional, community and government levels (Romano & Hage, 2000). Prevention science intends to promote knowledge, attitudes and behaviours to enhance individuals' overall well-being (Romano & Hage, 2000), decrease psychological distress, and decrease the cost of mental health care (American Psychological Association, 2014; Nation et al., 2003; Tolan & Dodge, 2005; World Health Organization, 2008). According to the American Psychological Association (APA, 2014), "successful preventive interventions are typically theory-driven, culturally relevant, developmentally appropriate, and delivered across multiple contexts" (p. 285). Prevention is an important area of research, practice, and training in the field of psychology (APA, 2014).

The Centers for Disease Control and Prevention (CDC, 2022) utilizes the social-ecological model to capture the causes and consequences of victimization as well as prevention strategies to address abuse and violence among at-risk communities. The social-ecological model represents the complex interrelated relationship between individuals and their social and physical environment as well as cultural contexts (Araten-Bergman & Bigby, 2023; Fisher et al., 2016; World Health Organization, 2004). The CDC (2022) proposes that to achieve sustainable prevention efforts and significant impact at the population level, it is imperative to address multiple levels of the model

simultaneously (i.e., individual, relationship, community, and societal; CDC, 2022). This model is useful in identifying intervention and prevention strategies that can be used at every level (WHO, 2004).

Figure 1.

Social-Ecological Model (Centers for Disease Control and Prevention, 2022)



In this model, the individual level captures: 1) personal history; 2) biological factors that impact individuals' behaviours and risk of victimization; 3) individuals' characteristics, and presence of any developmental or physical disabilities or psychological disorders; and 4) history of abuse victimization, all of which may impact the risk of victimization (CDC, 2022; WHO, 2004). Prevention strategies that are used at this level are aimed to educate those who are at risk of victimization (e.g., skills training and healthy relationship skills program) and help them develop skills and protective behaviours to prevent abuse.

The relationship level focuses on family, friends, and romantic partner associations which may affect individuals' risk of victimization. At this level, prevention approaches may focus on family- or organization-focused prevention programs,

promoting awareness regarding abuse, and improving problem-solving skills (CDC, 2022).

The community level refers to contexts such as schools, residential settings, neighbourhoods and workplaces where social relationships are formed. Risk factors associated with such contexts may be interpersonal conflicts among group members, substance use, poverty, level of unemployment (WHO, 2004), or support providers' protective behaviours. Prevention approaches that target community factors focus on enhancing the physical and social environments (e.g., workplace, group homes) and address the conditions under which abuse occurs (CDC, 2022).

Lastly, factors at the societal level that either exacerbate or impede abuse victimization, including: 1) health, social, economic, and educational policies that promote inequality among different groups such as minority communities; and 2) social and cultural norms that, for instance, promote ableism or supports violence and abuse as a conventional strategy to resolve conflicts (CDC, 2022; WHO, 2004). Prevention strategies that appropriately target societal factors should focus on promoting societal norms that protect individuals against abuse, and endorse efforts that improve social and financial security, employment opportunities as well as policies that influence determinants of physical and psychological health (CDC, 2022).

Implications

Financial Abuse Prevention Among Individuals with Intellectual Disabilities

The literature on the risk of victimization that contributes to the high prevalence of financial abuse, in conjunction with the findings of this dissertation provides evidence on different levels of factors that increase the risk of victimization among persons with

intellectual disabilities. As previously discussed, some of the risk factors are individuals' lack of awareness regarding financial abuse, desire for friendship, relying on others to receive support with financial management, and support providers' lack of knowledge and competence (Abbott & Marriott, 2013; Ansello & O'Neill, 2010; Fisher et al., 2016; Gilmour & Cuskelly, 2014). Such risk factors highlight the importance of developing intervention and prevention programs that address all levels of risks contributing to victimization among persons with intellectual disabilities (Araten-Bergman & Bigby, 2023; Fisher et a., 2016).

The United Nations Convention on the Rights of Persons with Disabilities (2007) urges "States Parties [to] take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects" (Article 16). Nonetheless, the prevention and intervention programs thus far have targeted abuse among persons with intellectual disabilities at an individual level and none has proven to be effective in preventing abuse and violence among this population (Araten-Bergman & Bigby, 2023).

The social-ecological model provides a guide to develop and implement comprehensive intervention and prevention strategies to protect individuals with intellectual disabilities from financial abuse. According to WHO (2004), a sustainable multi-sectoral response is crucial to effectively prevent interpersonal violence, including abuse. Below, we propose a prevention approach based on the socio-ecological model. In this model, we recommend prevention and intervention strategies that are informed by the findings of this dissertation and the literature on financial abuse among the

elderly population and individuals with disabilities, including those with intellectual disabilities. Furthermore, we discuss prevention strategies that are specific to each level of the model and target the factors that contribute to abuse victimization among this population.

Implications at the Individual Level: Interventions and Research

The findings of this dissertation have implications for research and practice at the individual level. Specifically, several individuals with intellectual disabilities who participated in this project shared their personal experiences regarding financial abuse. They indicated that due to their credit card debt, their credit and banking cards (i.e., debit card) were removed by their support providers or credit card companies. As a result, they have to rely on their support providers to provide them with weekly or monthly allowance or they are closely controlled by them in terms of their money management. This again highlights the importance of teaching these individuals about credit card debt and scams, and how to develop a priority list in terms of how to spend their money so that they do not need to be overly reliant on their support providers.

Financial abuse prevention at the individual level of the socio-ecological model would focus on enhancing the knowledge and perspectives of persons with intellectual disabilities regarding this issue. Individuals with intellectual disabilities often experience difficulty understanding the notion of money (Williams et al., 2007) and may have poorer financial decision-making abilities compared to those with a disability (Ansello & O'Neill, 2010). Therefore, it is crucial to implement financial literacy educational programs and training for these individuals to teach them how to manage their money (i.e., how to pay bills, budget, keep track of payments, banking, etc.), how to use assistive technology for

their financial management (Wehmeyer et al., 2011), and who to refer to seek assistance with their day-to-day banking and financial management (e.g., to speak to a banking advisor, a trusted family member or a support provider).

Skill-building and self-advocacy groups have also been shown to increase individuals' self-confidence and empower them to learn how to protect themselves against abuse (Jenkins & Davies, 2011). Furthermore, ARC England conducted an efficacious project in collaboration with the Financial Services Authority, which aimed to help persons with intellectual disabilities understand the notion of money and money management. As part of this project, they developed a helpful toolkit that was comprised of information and exercises regarding topics such as, "understanding how much things cost", "raising awareness of money issues", "learning about essential and non-essential spending", and "budgeting" (ARC England, 2011).

Many individuals with intellectual disabilities rely on their support providers to assist them with their financial management (Murphy & Clare, 2021), and therefore, they have learned to comply with them (Ansello & O'Neill, 2010). Nonetheless, according to the Joint Position Statement by the American Association on Intellectual and Developmental Disabilities (AAIDD) and The Arc (2016), persons with intellectual disabilities must be recognized as competent similar to their peers without a disability. Also, they must receive education, support and life experiences to promote their decision-making abilities from an early age. Furthermore, even though some individuals with intellectual disabilities may have communication difficulties, they must not be perceived as incompetent in making decisions (AAIDD, 2016). Therefore, it is imperative to teach persons with intellectual disabilities regarding their rights to their

finances (Ticoll, 1994) and that they should be able to spend their money however they wish to (Buhagiar & Lane, 2022), even if they receive support from family members, support workers, or friends with their financial management. Educational materials or training should include accessible information regarding relevant legislation and the decision-making rights of adults. Such information should be available to all individuals with intellectual disabilities in different formats (e.g., brochures, videos) via different platforms such as organizations' websites.

In the past, several intervention programs aimed to enhance the decision-making skills of persons with intellectual disabilities when dealing with abusive situations. However, they proved to lack efficacy because even though these individuals can learn protective skills, they do not necessarily apply their knowledge and skills to protective behaviours in real-life circumstances (Bruder & Kroese, 2005; Hickson et al., 2015; Khemka's et al., 2005). Furthermore, persons with intellectual disabilities tend to have difficulty identifying financially abusive situations when there is a power imbalance or a friendship between a perpetrator and a victim (Ghaderi & Cobigo, 2024). Individuals' judgments and personal experiences tend to impact their perception of an abusive situation, in that they may not perceive a situation as abusive if they believe a support provider has authority over the victim (Ghaderi & Cobigo, 2024). Therefore, it is crucial to provide these individuals with assertiveness training and self-protective skills to empower them against financial abuse. To develop effective educational training, it is crucial to: 1) involve individuals with intellectual disabilities during program development and implementation (Ghaderi et al., 2023); 2) include case examples of financially abusive situations perpetrated by friends, family members, support providers and

strangers to provide them with opportunities to reflect on different forms of financial abuse; 3) teach them assertiveness skills (i.e., how and when to say 'no') in an accessible language including several opportunities to role-play different skills; and 4) include concrete information in plain language regarding who to go to report the perpetrators and to seek safety and support. Educational programs may also be implemented as a series of workshops and webinars in different contexts such as schools, workplaces, residential settings, and group homes. Future research should also investigate the efficacy of such programs and materials in enhancing the knowledge of persons with intellectual disabilities regarding their rights to their finances and how to manage their finances.

Implications at the Relationship Level: intervention and Research

To develop an effective prevention strategy at the relationship level, several important factors must be considered. First, many support providers play a tremendous role in supporting individuals with intellectual disabilities with their financial management (Abbott & Marriott, 2013). However, while they attempt to safeguard individuals with intellectual disabilities from financial abuse, they may in turn engage in abusive behaviours (Fleming et al., 2019). Furthermore, perceiving individuals with intellectual disabilities as 'vulnerable' has shown to contribute to engaging in restrictive and abusive behaviours toward this population (AAIDD, 2016; Buhagiar & Lane, 2022; Parely, 2011). Therefore, it is crucial to provide paid and unpaid caregivers (i.e., family members, friends, support workers, etc.) with information regarding financial abuse and how to detect red flags associated with financial abuse, such as when an individual runs out of money sooner than usual, or when they express signs of distress in relation to their

finances. Training should incorporate many examples of different forms of financial abuse. Support providers would also benefit from training on the rights of individuals with intellectual disabilities to their finances even if they have a legal guardian or Attorney, as well as guidance on how to best support these individuals to make decisions without infringing on their rights or engaging in abusive behaviours (AAIDD, 2016). Furthermore, the efficacy of such training and workshops (in increasing the knowledge of support providers regarding financial abuse) should also be investigated through research and outcome evaluations.

According to the Ontario Human Rights Commission (2021), “In general, a person is deemed to have capacity if they are able to understand the information that is relevant to making a decision and able to appreciate the reasonably foreseeable consequences of a decision or lack of decision”. More importantly, the law states that “environments should be designed inclusively to facilitate participation in decision-making, wherever possible” (Ontario Human Rights Commission, 2021). For instance, individuals with intellectual disabilities should be provided with accessible information and resources (i.e., self-help and trained staff) to help them make decisions, and they should be informed about outcomes that may result from their decisions (Ontario Human Rights Commission, 2021). If an individual with intellectual disabilities chooses to spend their money on cigarettes or alcohol, their support provider may provide them with education and inform them about the consequences of their behaviour (e.g., they would not have enough money to pay for groceries or rent); however, the individual should not be controlled or coerced to spend their money how they wish to. Also, individuals with intellectual disabilities who have difficulty managing their finances

discussed the importance of being involved in their financial management (Bihagiar & Lane, 2022).

Implications at the Community Level: Organizational Guidelines and Policy

Many support providers in this project reported that they were unsure of resources to gain information regarding financial abuse or who to go to report cases of abuse. Also, research shows that support providers often have difficulties evaluating financially abusive situations, especially among individuals with disabilities (Fleming et al., 2019; Mitchell, 1997). In the absence of appropriate information and guidelines concerning financial abuse, support providers are at a high risk of perpetrating financial abuse or not detecting red flags associated with abuse. Furthermore, in the absence of guidelines at an organizational level, responses to financial abuse will depend on support providers' knowledge, attitude and skills in managing abusive situations among service users (i.e., persons with intellectual disabilities; Ticoll, 1994). Despite the recommendations put forward by some researchers in the past two decades (e.g., Ticoll, 1994), there seems to be a lack of evidence that improvements were made at the community level. This has become evident given the concerns raised by the support providers in this project regarding the lack of organizational policies and procedures to guide them on how to prevent financial abuse or intervene when they detect abuse.

Therefore, prevention should address the environments of service agencies by way of implementing clear guidelines and protocols for support providers to guide them to prevent financial abuse or intervene once they detect an abusive situation. Specifically, organizational policies and guidelines should clearly define all forms of financial abuse and abusive behaviours (Ticoll, 1994), and include detailed information

regarding: 1) the rights of individuals with intellectual disabilities to their finances, 2) how to detect and assess financially abusive situations among persons with intellectual disabilities, 3) how to help individuals with intellectual disabilities manage their finances without infringing on their rights or perpetrating financial abuse, and 4) who to refer to if they detect an abusive situation and how to provide support to the victims of financial abuse. Furthermore, as part of systematic changes and prevention, it is crucial to provide individuals with intellectual disabilities with employment opportunities and higher income support, so they are not impoverished or have to rely on others (i.e., paid or unpaid caregivers) for financial support (Ticoll, 1994).

Financial abuse prevention should also target the implicit stigma and ableist culture that continue to exist in organizations providing support to persons with intellectual disabilities (Magasi, 2008). Even though residential settings, such as group homes and assisted living residences, are meant to support individuals with intellectual disabilities, institutional power can impede the rights and autonomy of this population (Buhagiar & Lane, 2022; Magasi, 2008).

Implications at the Society Level: Legislation and Advocacy

Abuse victimization among persons with intellectual disabilities is an important societal problem and a policy issue (Fisher et al., 2016). Elder financial abuse research shows that currently, in Canada, there is no consistent federal or provincial law mandating reporting of financially abusive cases, except for older adults who live in residential care settings or when there is an ongoing criminal investigation (Carr, 2023). Furthermore, as Carr (2023) argues, the Criminal code does not include many forms of financial abuse, and therefore they are not considered prosecutable offences.

In 2017, the Australian government developed the National Disability Insurance Scheme (NDIS), which led to reforms in policy, procedures, and service standards to support the human rights of persons with disabilities and to prevent abuse victimization among this population (Araten-Bergman & Bigby, 2023). The NDIS provides a framework for disability services which outlines expectations for abuse prevention, monitors and manages the quality of services and dictates reporting guidelines for incidences of violence and abuse (Araten-Bergman & Bigby, 2023; Department of Social Services, 2017). Nonetheless, such a framework is nonexistent in Canada. The Government of Canada has instead taken initiatives to create and share knowledge regarding, for example, facts about financial abuse among the elderly population and how these individuals can protect themselves against victimization (Government of Canada, 2017). In the absence of nationally consistent policy and legislation regarding systematic approaches to prevent abuse among persons with intellectual disabilities, this population will continue to remain at a high risk of victimization in Canada.

Financial abuse prevention at the societal level in Canada must be addressed by the federal and provincial/municipal governments. The federal government plays a crucial role in funding initiatives and implementation of programs that target abuse prevention. For example, the government of Canada has provided funding to prevent intimate partner and gender-based violence across different provinces (Public Health Agency of Canada, 2022). Furthermore, elder abuse research has shown that public awareness and education campaigns are recommended as they lead to increased awareness regarding financial abuse (Fealy et al., 2012; Lowndes et al., 2009). Currently, in Canada, there are campaigns such as the Public Safety National

Awareness Campaign which received funding in 2009. The objectives of this campaign are to: 1) increase knowledge about technology-facilitated violence and abuse, 2) mitigate social stigma against reporting abuse, 3) help parents, children and teachers to identify child sexual exploitation; and 4) increase knowledge regarding how to report and disclose abuse. The campaign website also provides information and resources to the public regarding child sexual exploitation (Government of Canada, 2021). Similar to the activities of this campaign, there is a significant need for a national awareness campaign on financial abuse among persons with intellectual disabilities. Such a campaign would play an important role in raising awareness regarding financial abuse among many stakeholders who are involved, directly or indirectly, in the financial management of persons with intellectual disabilities. Additionally, the campaign would facilitate access to resources on financial abuse prevention and intervention, which would otherwise be more challenging to accomplish.

In Canada, similar to Australia, there is a significant need for provincial policymakers and legislators to develop policy as well as specific and clear organizational guidelines to address the issue of financial abuse among service agencies providing support to persons with intellectual disabilities. Such policies and guidelines must: 1) clearly state the laws regarding the decision-making rights of persons with intellectual disabilities; 2) comprehensively define financial abuse and provide examples of different types of financially abusive situations and behaviours; 3) state the consequences of engaging in an abusive behaviour; 4) inform support providers regarding their role and responsibilities when assisting individuals with intellectual disabilities with their financial management; 5) how and who to report

incidents of financial abuse; and 6) to mandate all the organizations providing services to people with intellectual disabilities to implement comprehensive training for their staff to teach them about financial abuse and how to support people with intellectual disabilities with their finances without infringing on their rights. Furthermore, the federal, provincial and municipal governments in Canada oversee law enforcement (i.e., police, court and corrections), and therefore, they play a significant role in developing a comprehensive and consistent definition of financial abuse which would capture all forms of financial abuse. Following a clear and encompassing definition of financial abuse will enable law enforcement to prosecute perpetrators and protect the victims with intellectual disabilities.

Furthermore, there is a need for policymakers to pass legislation to urge banking institutions to create a more cognitively accessible environment and banking services for individuals with intellectual disabilities. Persons with intellectual disabilities must be viewed as capable of managing their money, with support if needed. To educate the public, raise awareness among legislators and policymakers and promote change in people's negatively held beliefs toward this population, it is critical to collaborate with advocacy groups (WHO, 2004). Advocacy groups tend to consist of individuals with intellectual disabilities as well as activists whose primary goal is to facilitate change and can contribute to rapid and enduring achievements in bringing political will and commitment to prevention (WHO, 2004).

Prevention of financial abuse at the societal level should also focus on several factors precipitating and perpetuating victimization among persons with intellectual disabilities. First, people with intellectual disabilities are often subjected to erroneous

attitudes held by the public which are driven by beliefs and stigma (Dell'Armo & Tassé, 2021; Seo & Chen, 2009). Specifically, people with intellectual disabilities are often viewed as incapable of learning or mastering new skills (Dell'Armo & Tassé, 2021). Stigma and discrimination against this population increase the risk of victimization because such views influence perpetrators to take advantage of people with intellectual disabilities, and support providers infringe on these individuals' rights and decision-making regarding their finances.

Strengths and Limitations

This thesis has several strengths. First, utilizing an inclusive methodology was a significant strength of this dissertation. In the past two decades, persons with intellectual disabilities have made notable contributions to research relevant to their lived experiences (Zaagsma et al., 2022). Through their involvement in research, persons with intellectual disabilities have reported learning new skills and gaining a boost in their self-esteem (Frankena et al., 2015; Stack & MacDonald, 2018). Furthermore, involving individuals with lived experience in research teams has also shown to improve the validity and relevance of research (Nind, 2014; Puyalto et al., 2016) and limit academic researchers' biases (Frankena et al., 2015).

Therefore, we involved two advisors with intellectual disabilities to learn from their lived experiences. Specifically, we involved the advisors in three phases of research: 1) designing and validating the research tools (i.e., vignettes on different types of financial abuse); 2) recruitment; and 3) data analysis. The advisors' contribution during the first phase of this study was invaluable as their comments and feedback helped improve the vignettes significantly, in terms of content, relevance, accessibility

and validity. Specifically, both advisors provided thorough feedback regarding the accessibility and clarity of the vignettes and questions. They also commented on the format, design and content of the slides. Furthermore, the advisors had the opportunity to reflect on the research tools to ensure the content of the vignettes was of interest to persons with intellectual disabilities and relevant to their lives, which is an important step toward social change (Bigby & Frawley, 2010). While the advisors attempted to recruit individuals with intellectual disabilities or paid support providers, their efforts were unsuccessful. This outcome may have been impacted by the pandemic in that reaching out to people via telephone or email may have limited the advisors' ability to reach out to a broader population and impacted the response rate. During the data analysis phase, we experienced barriers due to the lack of guidelines on how to appropriately train advisors regarding data analysis, difficulty providing an accessible definition of 'data analysis', as well as lack of time and funding. Di Lorita et al. (2018) identified data analysis as cognitively demanding for persons with intellectual disabilities. Nonetheless, we believe that with proper training to orient individuals with intellectual disabilities to the processes and using accessible strategies, they will be able to contribute to this stage of research. Additionally, some researchers conducted data analysis (in-person) with persons with intellectual disabilities, using notes and papers to post quotes which were then clustered into themes on the wall (Carnemolla et al., 2022). Parallel to these aspirations, we acknowledge that the lack of practical and evidence-based guidelines on how to conduct inclusive research is a significant challenge in inclusive research (Ghaderi et al., 2023).

Using vignettes is another strength of this thesis project as it was a useful tool in capturing the participants' awareness of different types of financial abuse as well as their perspectives regarding this sensitive topic (Barter & Renold, 2000). Furthermore, we recruited a relatively large sample of participants with intellectual disabilities and paid support providers, due to which we were able to capture a large range of perspectives regarding financial abuse.

Several limitations are noteworthy to acknowledge. First, in this dissertation project, we did not collect information regarding participants' cultural backgrounds. However, elder abuse research shows that individuals' cultural backgrounds impact their interpretations of financially abusive situations (Amani et al., 2021; Lee et al., 2011). In other words, financial abuse is defined and conceptualized differently across different cultures which shape people's beliefs, expectations and values (Amani et al., 2021). Second, this dissertation only captured the perspectives of persons with intellectual disabilities and their paid support providers. Nonetheless, the perspectives of other stakeholders such as lawyers, law enforcement, financial institutions, and policymakers, who play a role in abuse prevention and intervention, as well as family members and friends of people with intellectual disabilities, some of whom provide support to these individuals with their financial management, are also warranted. Lastly, participants' responses to the vignettes may have been influenced by their awareness of the study topic. In other words, participants were informed that the study was about financial abuse, and their awareness of the topic may have influenced their interpretations of the vignettes. Therefore, the findings of Studies 3 and 4, in terms of

participants' perspectives regarding the vignettes, may not be generalized to real-life situations.

General Conclusion

This dissertation adds to the knowledge base regarding the perspectives of persons with intellectual disabilities and their paid support providers about financial abuse. Financial abuse is a significant societal and interpersonal problem among people with intellectual disabilities, which requires further attention in research and practice. Specifically, existing definitions of financial abuse are not inclusive of all forms of financial abuse. In the absence of a clear and comprehensive definition of financial abuse, the threshold at which behaviours become abusive tends to be blurry (Petitpierre et al. 2013). While financial abuse is a common form of abuse experienced by persons with intellectual disabilities, there is a paucity of research regarding this matter and a lack of attention given by the Canadian government to this societal issue. This is evident by the lack of education and information available to support providers to inform them regarding financial abuse or how to assist people with intellectual disabilities manage their money without infringing on their rights. Also, currently, there are no federal or provincial legislation that enforces the prosecution of perpetrators of implicit cases of financial abuse, perhaps due to the lack of breadth and depth of existing definitions.

Future research should: 1) investigate the prevalence of financial abuse among persons with intellectual disabilities; 2) examine how financial abuse is defined across different sectors and fields (i.e., the developmental disability sector, law enforcement, banking industries, etc.); 3) capture existing complaint systems in place for persons with intellectual disabilities to report abuse; 4) examine the experiences of support providers,

including family members and friends, who assist this population with their financial management; and 5) monitor interventions to ensure desired outcomes in relation to financial abuse prevention are attain. Dissemination of knowledge gained through research will be imperative in informing policy, practice and preventative programs and initiatives. Further research in this area will raise awareness among different stakeholders and will urge policymakers and legislators to pass laws to prevent financial abuse among people with intellectual disabilities.

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Appendix A- Proof of Ethics Approval

Université d'Ottawa
Bureau d'éthique et d'intégrité de la recherche

University of Ottawa
Office of Research Ethics and Integrity

CERTIFICAT D'APPROBATION ÉTHIQUE | CERTIFICATE OF ETHICS APPROVAL

Numéro du dossier / Ethics File Number	H-05-21-6429
Titre du projet / Project Title	Perspectives of Individuals with Intellectual Disability and Support Providers Regarding Financial Abuse
Type de projet / Project Type	Thèse de doctorat / Doctoral thesis
Statut du projet / Project Status	Approuvé / Approved
Date d'approbation (jj/mm/aaaa) / Approval Date (dd/mm/yyyy)	20/07/2021
Date d'expiration (jj/mm/aaaa) / Expiry Date (dd/mm/yyyy)	19/07/2022

Équipe de recherche / Research Team

Chercheur / Researcher	Affiliation	Role
Golnaz GHADERI	École de psychologie / School of Psychology	Chercheur Principal / Principal Investigator
Virginie COBIGO	École de psychologie / School of Psychology	Superviseur / Supervisor

Conditions spéciales ou commentaires / Special conditions or comments

Please note that Study 3 (workshop) is not included in the approval at this time given that the REB cannot approve a research activity that is not yet defined and/or planned out. A Request for Modification or new submission will need to be submitted at a later date when more details and information become available. (Please consult with Kim Thompson as to how the PI should proceed for Study 3).

Appendix B- Inclusion Criteria Based on the Behavioural Indicators

Behavioural Indicators	Inclusion Criteria	Screening Questions or Observation
Most can communicate fluently	The person can communicate using sentences, with or without support or assistive device	I will observe and listen to the individuals' communication style and whether they can use sentences to communicate
Many can tell or identify their birth date	The person can tell or identify his/her birthday	**Question**: Can you tell me what your date of birth is? (included as part of the demographic questions)
Most can communicate about past, present and future events	The person can tell stories that are in the past or talk about the future	This information will be observed through their answers to the demographic questions
Most can attend to and follow up to three-step instructions	The person can follow 3-step instructions	This will be observed in my virtual or telephone interaction with individuals
Most can identify different denominations of money (e.g., coins) and count money more or less accurately	The person can identify different types of coins (e.g., 25 cents, 1 dollar), or cash, and may be able to count money	This will be observed through their answer to the demographic question " Do you use cash to pay for your grocery, restaurant, coffee…?
Most can orient self in the community and learn to travel to new places using different modes of transportation with instruction/training	The person can use public transportation to travel to places, even to new places when provided with instructions	**Question**: How would you travel to a bank or ATM if you need money? Do you use public transportation?
Most can communicate their decisions about their future goals, health care and relationships	The person may be able to speak about their goals in the future, health care support that they may receive and their relationship with other people	This information will be observed during the interview. For example, they may talk about their desired support for managing their finances when I asked if they receive help regarding such.
Most can match skills needed for employment that they desire	The person demonstrates skills that match the employment that he/she desires	This will be partly observed through their answer to the demographic questions " Do you have a job? If yes, where do you work? What do you do? If no, did you have a job in the past? Where? What did you do?"

Most have difficulty in handling complex situations such as managing bank accounts and long-term money management	The person may have difficulties with managing their finances	**Question**: are there things you find difficult to do on your own when managing your money or paying for something?
Most can read and write up to approximately a level expected for someone who has attended 7 to 8 years of schooling (i.e., start of middle school) and read simple material for information and entertainment.	The person is able to read and write simple information (at an elementary level)	This information will be partly observed through the demographic question " Did you go to high school? If yes, do you remember the name of the school? Did you finish high school?"

APPENDIX C: TELEPHONE SCRIPT – Individuals with Intellectual Disabilities

The information in this guide is organized as follows:

I. Incoming telephone calls about the study
II. Possible questions and answers about the study
III. Verbal consent for participating in the semi-structured interview
IV. Demographic questionnaire
V. Booking the interview

I. Incoming telephone calls about the study

If someone calls, ascertain the following:

1. **Do they have questions about the study?** If YES, go to **Section II (below)**. After answering all their questions, ask them if they are interested in participating. If they say YES, go to **Section III (below)**.
2. **Are they interested in participating?** If YES, go to **Section III (below)**.

II. Possible questions and answers about the study

Do I have to take part in this study?
No, you do not have to take part in this study. Nothing will change if you do not take part. We will not tell anyone if you do or do not take part.
I don't understand the study; can you explain it to me? Why are you conducting this study?
We want to understand what you know about financial abuse and if you can identify financial abuse in a situation that you may face. We also want to know what you think about situations, in which a person's rights are violated or when they are financially abused.
What is expected from me?
If you want to participate in our study, you will be asked to attend one interview session, lasting approximately 30 minutes to 1 hour. The session will be held either on the telephone or through a video call such as zoom, google meets, or any platform that is convenient for you. The interview will be held at a time convenient for you. I will show you several stories about different people who are in situations in which they may be taken advantage of financially. After you read each story, I will ask you several questions because I want to know what you think about these situations. The interview will be audio recorded.

III. Verbal consent for participating in the semi-structured interview

Would you like to meet with me to participate in this study? We will read different short stories and talk about what you think about them. Your participation in this study is very important for us, because it will help us to better understand what you know about

financial abuse in order to develop trainings to teach you as well as other individuals with intellectual disabilities about how to protect yourselves against being taken advantage of. YES or NO. If NO, thank them for their time and end call. If YES, then proceed to demographic questionnaire section.

IV. Demographic questionnaire

Is this a good time to ask you a few questions to learn about you to prepare the interview and describe you better when I tell people about what we learned in this study? If no, then ask to schedule a time to ask these questions.

1. How old are you?
2. What town or city do you live in?
3. Do you live alone or with other people? if yes, who is NAME?
4. Did you go to high school? If yes, do you remember the name of the school? Did you finish high school?
5. Do you have a job? If yes, where do you work? What do you do? If no, did you have a job in the past? Where? What did you do?
6. Who helps you manage your money? How does he/she help you manage your money?
7. Do you have a bank account? Do you have a debit or credit card? Do you use cash to pay for your grocery, restaurant, coffee…?
8. Can you shop on your own? Are you able to take the bus or subway to go shopping or to the bank?
9. What else do you do during the day?
10. Did you ever hear a physician or a psychologist say that you have an intellectual disability?
11. Are there any other words that a physician or a health professional might have used to describe the challenges or difficulties that you have?

Booking the interview

If YES, proceed to booking an appointment with them.

If participating via telephone: **can I have a phone number where I can reach you or leave you a message? As a reminder, I will also call you the day before the interview.** I can also remind you of the meeting by sending you an email. **Would you like me to send you an email? Can I have your email address, please?**
When do you prefer to meet (evening, at noon…)? Or, **if you prefer to call me, you can reach me at [phone number].**

Or, if they are participating virtually: **is there a type of video call (e.g., Zoom, google meets, Skype) that you have used before or comfortable using?**

If you need to cancel or if you will be late, call me at [phone number]. Leave a message if I don't answer. Don't forget to leave your name and say that the message is for me, Golnaz. You can also email me at --- if you need to cancel or if you will be late.

If they say YES to a reminder phone call, include their telephone number and/or email address on page 3 in the verbal consent box. This document will be detached and stored on a password protected computer in a locked research team office of Prof. Cobigo.

Thank you very much for answering my questions today. I will see you/ talk to you on [date, time, and (interview platform: virtual or telephone)].
End call.

Verbal consent for participating in the interview □YES →*Complete following items* □NO
Name of participant: _____
Participant's pseudonym: _____
Participant's telephone number: _____
Preferred time to be reached: _____
Participant's email address: _____
Name of person recording verbal consent: _____
Date: _____

Appendix D- Demographic Questionnaire: Support Providers

I would like to begin by asking a few questions about you:

1. How old are you?
2. What is your level of education?
3. What is your current employment?
4. Do you work with individuals with intellectual disabilities?
5. How long have you been employed in the field of intellectual disabilities?
6. Can you please describe to me your interaction or work with individuals with intellectual disabilities?
7. Do you help individuals with intellectual disabilities with their money management? If yes, to what extent? Can you give me an example?
8. Have you ever received or attended training on financial abuse or how to support persons with ID managing their money? If yes, tell me about the training you received.
9. Are you aware of resources you could consult regarding financial abuse? If yes, please provide examples.

Appendix E- Vignettes Used in Data Collection with Persons with Intellectual Disabilities

Thank you for participating in this interview. I will read to you three different case scenarios about a person and her interactions with different individuals. After, I will ask you several questions about the scenarios you just read or heard about. Do you have any questions before we start?

Vignette # 1: Explicit or severe financial abuse

One day, Monica went to the Tim Hortons with her friend, Sharon. Sharon ordered a large coffee and a chicken salad sandwich for herself. When the cashier asked how she would like to pay, Sharon turned to Monica and told her to pay for her. Monica did not order anything for herself, but she paid for Sharon's coffee and a sandwich.

Questions:

- What do you think about this story? What do you think happened to Monica?
- How do you think Monica feels?
- What do you think about what Sharon did?
- What do you think Monica should do? Why?
- How would you feel if you were in this situation?
- How would you handle the situation?
- How would you feel if Monica had to pay for Sharon's meal at a restaurant instead of Tim Hortons?
- How would you feel if Monica had an intellectual disability? Why?
- How about if both had an intellectual disability? Why?

Vignette # 2: Implicit or borderline financial abuse

Sarah lives in a group home. Her worker, Rick, helps her manage her money. One day, Sarah asked Rick to give her money to buy cigarettes, but Rick told Sarah that she had smoked a lot lately. Sarah said she really wanted cigarettes, but Rick told her that she could buy some cigarettes in two days.

Questions:

- What do you think about this story? What do you think happened to Sarah?
- How do you think Sarah feels?
- What do you think about what Rick did?
- What do you think Sarah will do? Why?
- How would you feel if you were in this situation?
- How would you handle this situation? Why?
- How would you feel if Sarah had an intellectual disability? Why?

Vignette # 3: No abuse case scenario

Anna has recently moved into her boyfriend's house. They decided to split the bills. They decided that Anna would pay for the gas bill and her boyfriend would pay for the electricity bill. One day, her boyfriend paid for the electricity bill and told Anna.

Questions:

- What do you think about this situation? What do you think happened to Anna?
- How do you think Anna feels?
- What do you think about what Anna's boyfriend did?
- What do you think Anna will do? Why?
- How would you feel if you were in this situation?

- How would you handle this situation? Why?
- How would you feel if Anna had an intellectual disability? Why?
- How about if both had an intellectual disability? Why?

General questions at the end of the interview:

- Is there anything else you would like to tell me about how persons with Intellectual disabilities manage their money?

Appendix F- Vignettes Used in Data Collection with Support Providers

Thank you for participating in this interview. I will read (or show if virtual interview) to you 5 different case scenarios about a person and her interactions with different individuals. After, I will ask you several questions about the scenarios you just read or heard about. Do you have any questions before we start?

Vignette # 1: Explicit or severe financial abuse

One day, Monica went to a Tim Hortons with her friend, Sharon. Sharon ordered a large coffee and a chicken salad sandwich for herself. When the cashier asked how she would like to pay, Sharon turned to Monica and told her to pay for her. Monica did not order anything for herself, but she paid for Sharon's coffee and a sandwich.

Questions:

- What are your first impressions of this vignette?
- How would you describe Sharon's behaviour?
- How do you think Monica feels in this situation?
- What do you think Monica should do? Why?
- What is your perspective regarding a situation in which Monica has to pay for Sharon's meal at a restaurant instead of Tim Hortons?
- What would you think about this situation if Monica had an intellectual disability? How about if both had an intellectual disability? Why?

Vignette # 2: Explicit or severe financial abuse

One day, Veronica told her support provider, John, about an incident, in which she bought an item from a grocery store, but the cashier gave her the wrong change. The next day, John went to visit Veronica to convince her to sign a Power of Attorney to

manage her finances. When Veronica refused to do such, John told her that she is unable to manage her money and that she has to sign the document.

Questions:

- What are your first impressions of this vignette?
- How would you describe John's behaviour?
- How do you think Veronica feels in this situation?
- What do you think Veronica should do? Why?
- What would you think about this situation if Veronica had an intellectual disability? Why?

Vignette # 3: Implicit financial abuse

Enya has a support provider, Julia, who helps managing her money and spends most of the day with Enya at her apartment. Enya does not have a television in her apartment; therefore, Julia decided to buy a small television for Enya using Enya's money without letting her know.

Questions:

- What are your first impressions of this vignette?
- How would you describe Julia's behaviour?
- How do you think Enya feels in this situation?
- What do you think Enya should do? Why?
- How would you think about this situation if Enya had an intellectual disability? Why?

Vignette # 4: Implicit financial abuse

Sarah lives in a group home. Her support provider, Rick, helps her manage her money. One day, Sarah asked Rick to give her money to buy a pack of cigarettes, but he told her that she had smoked a lot lately, and when Sarah insisted, he told her that she could buy a pack in two days.

Questions:

- What are your first impressions of this vignette?
- How would you describe Rick's behaviour?
- How do you think Sarah feels in this situation?
- What do you think Sarah should do? Why?
- How would you think about this situation if Sarah had an intellectual disability? Why?

Vignette # 5: No abuse case scenario

Anna has recently moved into her boyfriend's house. They decided to split the bills. They decided that Anna would pay for the gas bill and her boyfriend would pay for the electricity bill. One day, her boyfriend paid for the electricity bill and told Anna.

Questions:

- What are your first impressions of this vignette?
- How would you describe the boyfriend's behaviour?
- How do you think Anna feels in this situation?
- What do you think Anna should do? Why?
- How would you think about this situation if Anna had an intellectual disability? How about if both had an intellectual disability? Why?

General questions at the end of the interview:

- Is there anything else you would like to tell me about how persons with Intellectual disabilities manage their money?