

**Preventing maltreatment
of adults with intellectual and/or developmental disabilities**

From the assessment of social vulnerability to the development
of a curriculum aiming at preventing abuse and neglect in later life

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Abstract

The overall aim of this doctoral thesis was to deepen and inform the maltreatment prevention possibilities for adults with intellectual and developmental disabilities (IDD) across the lifespan. The first three studies approached maltreatment prevention from the vulnerability assessment perspective, whereas the last study provided a more in-depth focus on prevention at an individual level.

Study I focused on the cross-cultural validation of a self-report measure assessing social vulnerability in adults with ID: the Social Vulnerability Test-22 items (TV-22). Participants were French-speaking adults with ID ($n=29$). Results indicated that the TV-22 is a reliable and valid measure for assessing social vulnerability in adults with IDD.

Study II reported findings related to the implementation of the TV-22. This study used a mixed-method design to assess the implementation outcomes of the TV-22: the acceptability (e.g., the complexity of coding), the appropriateness (e.g., the usefulness of the test), and the assessment fidelity of the TV-22 by special education practitioners ($n=31$) were measured. Results underscored the importance of evaluating implementation outcomes when a new measure is developed to ensure its correct use by stakeholders.

Using the test validated and implemented in the first two studies, Study III aimed to further the understanding of social vulnerability in adults with IDD, more specifically in digital risks. Participants were adults with ID ($n=51$). Participants' answers to the five items of the TV-22 related to digital risks were qualitatively analyzed. Results highlighted the importance of designing, in a comprehensive manner, preventive measures against the victimization of people with ID.

Study IV described the development of a curriculum, in English and in French, to prevent elder abuse in adults with IDD ($n=10$). It deepened the current information on the prevention of abuse of persons with IDD across the lifespan by providing new information on the prevention possibilities of abuse among elder adults, an area of research that was, until present, scarce.

Overall, this doctoral thesis provides theoretical and practical advances in our understanding of maltreatment and its prevention in the IDD population across the lifespan. Findings open research perspectives regarding social vulnerability, its similarities across countries, and its relation to cognitive sub-skills and adaptive behavior; they also propose new avenues for future research on preventing the maltreatment of elders with IDD.

Keywords: intellectual disabilities; maltreatment; social vulnerability; prevention; implementation; cross-cultural

List of studies

The present doctoral thesis is based on the following studies:

- I. Tabin, M., Diacquenod, C., De Palma, N., Gerber, F., Straccia, C., Wilson, C., Kosel, M., & Petitpierre, G. (2021). Cross-cultural preliminary validation of a measure of social vulnerability in people with intellectual disabilities. *Journal of Intellectual & Developmental Disability*, 46(1), 67-79. <https://doi.org/10.3109/13668250.2020.1793450>
- II. Tabin, M., Diacquenod, C., & Petitpierre, G. (2021). Evaluating implementation outcomes of a measure of social vulnerability in adults with intellectual disabilities. *Research in Developmental Disabilities*, 119. <https://doi.org/10.1016/j.ridd.2021.104111>
- III. Tabin, M. (2020). Ressources et vulnérabilités des adultes présentant une déficience intellectuelle face aux risques numériques. [Resources and vulnerabilities to digital risks of adults with intellectual disabilities]. *Revue francophone de la déficience intellectuelle*, 30, 13-24. <https://doi.org/10.7202/1075352ar>
- IV. Tabin, M., Khemka, I., & Hickson, L. (in revision). Preventing elder abuse: Development of a curriculum for elders with intellectual and developmental disabilities. *International Journal of Developmental Disabilities*.

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1 Introduction

“Freedom from exploitation, violence, and abuse” is one of the five priority areas identified by the Council of Europe for its Disability Strategy (2017-2023). Exploitation, violence, and abuse – in other words, maltreatment – of adults with intellectual and developmental disabilities (IDD) across their lifespan is considered as a pervasive human rights violation and a major public health problem. No single work could tackle the multitude of related questions raised by the maltreatment of people with IDD and its prevention. Following the footsteps of a small field of research studies that started thirty years ago, this doctoral thesis aims to deepen, on a theoretical level, and inform, on a practical level, the maltreatment prevention possibilities for adults with IDD across their lifespan.

This doctoral thesis is composed of four studies. After presenting a definition of IDD and maltreatment, this thesis begins with a systematic literature review examining the prevalence of maltreatment of adults with IDD and the risk factors increasing vulnerability to maltreatment. It shows that adults with IDD constitute a heterogeneous group with a wide range of abilities and support needs – and that (inter)personal and environmental risk factors put some adults with IDD at higher risk of maltreatment. Next, approaches to prevent maltreatment of adults with IDD are presented, with a focus on interventions at an individual level. Two primary goals of special education are to evaluate and develop support according to one’s needs. Evaluations and support can take many forms, and various tools exist, like using validated tests for evaluation and specific curricula to support needs and further skills development. Using validated tests – i.e., tests that have valid and reliable psychometric properties – to evaluate those needs is crucial to picture the support needed objectively. The first study of this doctoral thesis thus presents the psychometric evaluation of a test aiming at assessing social vulnerability (i.e., difficulty in perceiving and managing social risks) in adults with intellectual disabilities.

If using valid and reliable tests is essential, ensuring that newly validated tests are used as intended by stakeholders in the field is as critical. Consistently, the second study analyzes implementation outcomes (e.g., assessment fidelity) when special education practitioners use the new social vulnerability test in the field. Using the test developed and implemented in the first two studies, the third study takes a deeper look at digital risks and how they are perceived and managed by adults with intellectual disabilities. Finally, specific curricula can be implemented to better support people with special needs, and some have shown promising results regarding maltreatment prevention. No specific intervention exists for elders with IDD, although they are likely to have specific needs and face various types of maltreatment, like neglect or financial abuse. Therefore, the fourth study describes the development of a curriculum to prevent abuse and neglect in later life for adults with IDD.

Finally, a discussion considers the overall findings and their implications related to the tools developed and implemented to advance and improve maltreatment prevention possibilities for adults with IDD across their lifespan.

1.1 Intellectual and developmental disabilities and maltreatment: definitions

The term *intellectual and developmental disabilities* refers to the combined field of developmental disability and intellectual disability (or intellectual developmental disorder). In this doctoral thesis, we use the term IDD in an inclusive sense to refer to a broad range of people with various conditions, including intellectual disabilities (ID) and developmental disabilities (DD), that result in life-long disabilities (Schalock et al., 2021). Where the research study specifically included or referred to adults with ID, we distinguish by using the term ID rather than IDD. Intellectual disabilities is the most prevalent form of IDD (Brault, 2012). IDD classification includes, for example, autism spectrum disorders and Down syndrome (Masefield et al., 2020). Though the life expectancy of adults with IDD has increased over recent years and now approaches that of their peers without IDD (Hahn et al., 2015; Lin et al., 2016), adults with IDD are likely to present unique aging processes and have complex needs. They are prone to experience premature aging and frailty and face issues beyond those expected with increasing age, like health issues related to various comorbidities or early onset of dementia (McKenzie et al., 2016). It is estimated that adults with IDD constitute approximately 1% of the adult population (Maulik et al., 2011; Rosencrans et al., 2021) – but nuances in definitions and frequent comorbidities (e.g., co-occurrence with mental health issues) make it challenging to identify a precise prevalence of IDD (Hewitt et al., 2013; Rosencrans et al., 2021).

Three diagnostic systems lead the field of IDD in defining and classifying the construct referred to as intellectual disability: the American Association on Intellectual and Developmental Disabilities (AAIDD) (Schalock et al., 2021), the Diagnostic and Manual of Mental Disorders (5th ed.; DSM-5) (American Psychiatric Association, 2013), and the International Statistical Classification of Diseases and Related Health Problem (11th ed.; ICD-11) (World Health Organization, 2019).

While these three diagnostic systems have their own conceptual framework, they are all embedded in a social-ecological model and insist on the multi-dimensionality of human functioning (Institut National de la Santé et de la Recherche Médicale [French National Institute of Health and Medical Research, INSERM], 2016). All three diagnostic systems consider IDD a mismatch between one individual's competencies and the demands of their environment (Hickson, 2021). Adults with IDD constitute a heterogeneous group with a wide range of abilities, limitations, and support needs. The intensity of support needs can be classified into one of those four groups: mild, moderate, severe, and profound (Schalock et al., 2021). Two primary goals of special education are to evaluate the person's needs and develop strength-based support systems according to them. The support systems should be consistent with a social-ecological and social participation approach, i.e., designed comprehensively, encompassing choice and personal autonomy, being person-centered, coordinated, and outcome-oriented (Schalock et al., 2021).

Three criteria are required for a theoretical diagnosis of ID (Schalock et al., 2021):

- (1) the disability originates during the developmental period (i.e., present before age 22),
- (2) the person presents significant cognitive limitations,
- (3) the person presents significant limitations in adaptive behavior. Adaptive behavior is the collection of conceptual skills (e.g., difficulty in choosing a good solution when confronted with a problem; difficulty anticipating the consequences of their behavior), practical skills (e.g., limitations in self-care, domestic skills), and social adaptive skills (e.g., impaired interpersonal skills).

Debate and changes have occurred regarding the definition of ID and those three criteria; the struggle with the definition of intelligence and its assessment has long been – and still is – a debated notion that Greenspan et al. (2015, p.314) put in these terms: “the problem is that, even to this day, intelligence is a poorly defined construct whose meaning is not universally agreed-upon, and there is growing sentiment to the effect that IQ [intellectual quotient] scores are very imperfect measures of ‘intelligence’”. Those imperfect measures led to false negatives and false positives, like an overidentification of low-socioeconomic-status children of ethnic minority groups as having an ID and, as a result, an over-assignment to special education classes – the so-called ‘6 hours children with ID’ (Harris & Greenspan, 2016). Additionally, IQ does not represent reliable categories, especially for IQs below 50, which are difficult to measure, nor does it provide information on the everyday functioning of the person and consequently on the support and accompaniment required, providing little information allowing to identify the person’s needs (INSERM, 2016).

The evaluation of adaptive behaviors in the diagnostic process was thus added, in the 1960s, as a complementary step to the IQ to reduce the risk of false negatives and false positives (Harris & Greenspan, 2016; INSERM, 2016). With calls rising to move from a label-based to a needs-based diagnostic system (Singer, 2020), adaptive behavior – because it provides information on the everyday functioning of the person rather than its academic performance – is anticipated to play a key role in the evolution of the construct of ID (Tassé et al., 2012). In this context, Greenspan et al. (2011) argued that the central question in defining ID should not (anymore) be “what is intelligence?” (as an academic notion) but “what is intelligent behavior?” (in practical everyday life). They underscored the importance of risk awareness in social life and risk consciousness for survival in everyday life, i.e., the importance of (social) adaptive skills (INSERM, 2016). Social adaptive skills are considered the ability to pursue personal goals in social interaction while maintaining positive relationships with others across time and life situations (INSERM, 2016). The acquisition of socially adapted behavior depends on multiple (inter)personal and environmental factors necessary for developing skills underlying social functioning. Significant limitations in social adaptive skills include, for example:

Impaired social/interpersonal skills and learning from experiences (...); increased vulnerability and victimization, especially concerning who can be trusted, whom to follow, and what circumstances are safe; inadequate social responding and social judgment (...); strong desire to please authority figures based on limited understanding of the situation; gullibility, naiveté, and suggestibility in interactions with others (Schalock et al., 2021 p. 30).

Limitations in adaptive behavior, as well as other impairments in intellectual functioning, are likely to increase the vulnerability of people with IDD to maltreatment (Griffin et al., 2019).

Maltreatment is an umbrella term that includes various forms of abuse, neglect, exploitation, and experiences of interpersonal violence and victimization. The terms and definitions used to describe maltreatment and victimization vary and evolve according to the contexts and use. What constitutes maltreatment is the product of social, cultural, and historical contexts: its definition results from current norms that frame what is tolerated or considered an abusive act (Pache, 2020). Currently, broader definitions of maltreatment are preferred to specific and restrictive ones because they allow a better understanding of all its facets (INSERM, 2016). One definition that meets this criterion of comprehensiveness and is adapted in the current western context is the definition proposed by the international working group chaired by Brown and convened by the Council of Europe ([COE] 2003, p.9):

Any act, or failure to act, which results in a significant breach of a vulnerable person's human rights, civil liberties, bodily integrity, dignity or general well-being, whether intended or inadvertent, including sexual relationships or financial transactions to which the person has not or cannot validly consent, or which are deliberately exploitative. Abuse may be perpetrated by any person (including by other people with disabilities) but it is of special concern when it takes place within a relationship of trust characterized by powerful positions based on:

- legal, professional or authority status;
- unequal physical, economic or social power;
- responsibility for the person's day-to-day care;
- and/or inequalities of gender, race, religion or sexual orientation.

It may arise out of individual cruelty, inadequate service provision or society's indifference. It requires a proportional response – one which does not cut across valid choices made by individuals with disabilities but one which does recognize vulnerability and exploitation.

This definition covers various abusive acts perpetrated by different actors (e.g., any person, institution/organization). It underlines that maltreatment can be intentional or unintentional, encompassing multiple types of abuse and neglect. Finally, it recognizes vulnerability and calls for preventive proportional measures that are person-centered and do not hinder choice and personal autonomy, i.e., measures that support self-determination while protecting against victimization risks.

Adults with IDD and those with complex needs, like elder adults with IDD, are at risk of multiple and intersecting types of maltreatment (COE, 2017). The last meta-analysis on adults with ID (Hughes et al., 2012) reported a prevalence of maltreatment of 6.1% (2.5-11.1) in the year before the study. However, they reported substantial heterogeneity in their results, and none of the research studies included in the meta-analysis were conducted in institutional settings. Difficulties in determining the extent of maltreatment are related to several factors, like inconsistencies in definitions of maltreatment,

variations in the categorization of IDD, and the variability of methods used (e.g., interview type, sample groups). As a result, the documented proportion of adults with disabilities who have experienced victimization varies greatly (e.g., 10% to 80% regarding sexual abuse, Collins & Murphy, 2022). When comparing relative risks among people with IDD and the general population, again, the rates vary greatly, but all research studies tend to report (much) higher levels of maltreatment of people with IDD, for example, three times higher at risk of physical assault or twice at higher risk to being financially exploited (Nettelbeck & Wilson, 2002). Despite this difficulty in establishing a clear prevalence, epidemiological studies corroborate the extent of the problem (Collins & Murphy, 2022; INSERM, 2016).

1.2 Victimization and social vulnerability among adults with IDD

Epidemiological studies inform us about the prevalence of maltreatment within certain groups. While trying to capture the problem, the information about its prevalence does not inform us about the risks at an individual level. The concept of (personal) social vulnerability emerged from an effort to identify the factors that make some adults particularly vulnerable to victimization (Nettelbeck & Wilson, 1996). As such, social vulnerability refers to the challenges one may face in identifying and avoiding interpersonal situations that could be harmful (Pinsker et al., 2006). A person is considered socially vulnerable when they are unable to identify and protect themselves against social relationships that may be harmful (Fisher et al., 2018).

Nevertheless, the concept of (personal social) vulnerability has been eyed with suspicion (Clough, 2017). Some argue that this view of vulnerability confines people to an identity of suffering and denies them any initiative; they express concern that the vulnerability discourse leads to paternalistic and protective interventions on those identified as vulnerable (Hollomotz, 2009). At first glance, analyzing social vulnerability seems to fly “in the face of the current paradigm shift” of disability studies (Greenspan et al., 2001, p. 130). It looks like social vulnerability stems from a medical or individual-oriented model of disability based on deficits and labels, where vulnerability is considered part and parcel of impairment (Fineman, 2008). Nevertheless, calls have been rising to reframe (social) vulnerability and its relation to victimization (Fitzsimons, 2017). They emphasize that this vulnerability is best understood from the social-ecological model of disability, highlighting that social vulnerability is not an intrinsic state but stems from interactions between the person and within interpersonal relations, the environment, and the larger social, political, economic, and cultural context (Fitzsimons, 2017). Social vulnerability is, therefore, both personal and situational: it depends on the presence, nature, and danger of social risk in the first place but also on the awareness, ability to react, and alternative responses available to a person or a group (Petitpierre, 2012). Far from an intent to “blame the victim” for being victimized, Nettelbeck & Wilson (2002) emphasized that social vulnerability analysis aims to identify preventable risk factors that may increase an individual’s susceptibility to victimization. Therefore, social vulnerability analysis does not lead to paternalistic interventions that assume vulnerability and a need for protection. In contrast, by identifying preventable risk factors,

analyzing social vulnerability allows for appropriate educational intervention and support to prevent victimization to be designed and empower individuals with ID to manage their social interactions more effectively (Nettelbeck & Wilson, 2002).

One of the first studies analyzing social vulnerability in adults with ID was conducted by Wilson and Brewer in the 1990s, where they highlighted the difficulty in defining the core characteristics that identify a high level of social vulnerability (Wilson & Brewer, 1992). These authors noticed that results on social vulnerability tests seemed likely to indicate which persons are especially at risk of victimization. For example, scores on the Test of Interpersonal Competence and Personal Vulnerability (TICPV), a measure of social vulnerability designed for adults with ID, successfully distinguished victims of maltreatment (physical aggression, sexual aggression, theft, financial exploitation, breaking and entering) from non-victims in a sample of 40 adults with ID (Wilson et al., 1996).

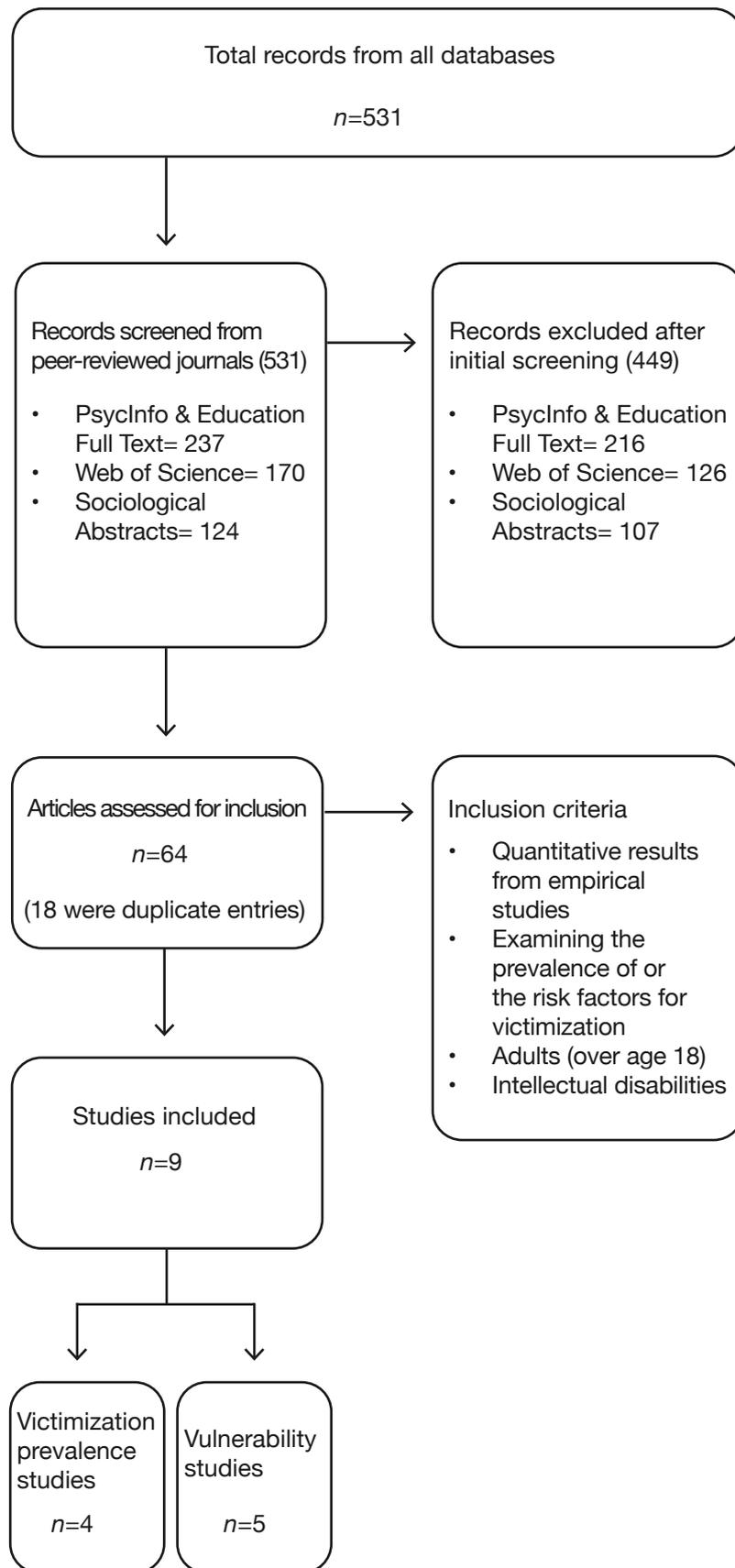
Wilson and Brewer's research paved the way and opened a small sub-field of research studies exploring empirically social vulnerability in adults with ID, which led Fisher et al. (2016) to conduct the first systematic review of research on victimization and social vulnerability.

In the following pages, an actualized review of the research on victimization and social vulnerability is provided, using the same literature search method as Fisher et al. (2016), and a summary of the findings that arose is presented. We first present the findings of Fisher et al. (2016) and then the findings from more recent research studies. More precisely, we introduce and update the answers to the following questions: (1) what types of victimization have been reported? and (2) which risk factors have research studies identified as related to social vulnerability of adults with ID?

Fisher et al. (2016) found 23 articles that were published between 1992-2015 on social vulnerability and victimization in adults with ID. Updating the search to studies conducted between May 2015 (i.e., the date when Fisher and colleagues conducted their review) and August 2022 and using the same search method (i.e., same keys words, same inclusion-exclusion criteria, similar databases), we found nine research studies (see Figure 1). Fisher et al. (2016) structured their findings into two sections, with the first section underpinning results in relation to prevalence studies regarding victimization (i.e., victimization prevalence studies, $n=16$). Next, studies analyzing risk factors of vulnerability to victimization are introduced (i.e., vulnerability studies, $n=7$).

Figure 1

Flow chart for selection of post-2015 articles regarding victimization and vulnerability of adults with ID



Note. We excluded our own publications (n=4) at the beginning of the review process.

Victimization prevalence studies

In their review of victimization prevalence studies, Fisher et al. (2016) identified 16 studies, nine focusing on sexual abuse and seven examining other forms of victimization (e.g., physical abuse, neglect, robbery, verbal abuse).

Updating the review of Fisher et al. (2016), we found four victimization prevalence studies (see Table 1), one regarding sexual abuse and the other three examining various types of victimization (e.g., assault, financial exploitation, and online victimization).

Table 1

Research studies concerning prevalence of victimization of adults with ID

Authors (Year)	Method (Country)	Age (<i>Mean</i> or Range)	Percent of victimization (<i>n</i> victims/total <i>n</i> sample)	Type of victimization	Significant gender differences within ID group
Tomsa et al. (2021)	Meta-analysis (Worldwide)	18-50	32.9% (1130/3434)	Sexual abuse	Males > Females
Fogden et al. (2016)	Case-linkage (Australia)	<i>Mean</i> =35.7 <i>SD</i> =16.57	14.5% (378/2600) 5.1% (133/2600)	Violent victimization Nonviolent victimization	Females > Males –
Nixon et al. (2017)	Case-linkage (Australia)	<i>Mean</i> =28.2 <i>SD</i> =5.5	19.3% (428/2220) 16.9% (376/2200)	Violent victimization Nonviolent victimization	– –
Codina et al. (2020)	Self-report questionnaire (Spain)	<i>Mean</i> =41.6 <i>SD</i> =NA	87.7% (228/260) 59.2% (154/260) 23.5% (61/252)	Common victimization Caregiver victimization Online victimization	– Females > Males Females > Males

Note. Sorted by order of presentation. NA=Not Addressed

Sexual victimization. The nine research studies regarding sexual victimization presented by Fisher et al. (2016) in their review were conducted worldwide, mainly in Europe, Australia, and the USA. Most were conducted in the 1990s ($n=7$), and the most recent was conducted in 2009. In those studies, the prevalence of sexual victimization varied greatly (5-80%), and so did age at experiencing it (17 to over 65), with most victimization occurring when people were in their 20s-30s. Eight of those nine studies reported the prevalence of sexual abuse by gender: a majority of those studies ($n=5$) reported that compared to men with ID, women with ID were more likely to experience sexual abuse – but two reported an even prevalence, and one reported a higher prevalence for men with ID. Regarding the level of ID, no clear trend was identified. Some studies identified no difference ($n=3$), others found a lower prevalence in severe to profound levels ($n=3$), and one had a higher prevalence in severe to profound levels. All studies reported that most of the victimization experiences occurred at multiple occurrences, as opposed to one single episode, with most perpetrators being male (87%-96%) and known to the victim (82-98%). In most studies, the abuse took place at the victim's place of residence.

Updating the review of Fisher et al. (2016), we found one meta-analysis (Tomsa et al., 2021) that analyzed sexual abuse victimization of adults with ID – and included seven of the nine research studies presented by Fisher et al. (2016) in their review. The meta-analysis included 25 research studies that were conducted in twelve countries, mostly in the European region and in the USA. Most of those studies were conducted between 2000-2020 ($n=15$). Tomsa et al. (2021) reported a global prevalence of sexual abuse in adults with ID of 32.9% (95% CI: 22.7-43.0). Tomsa et al. (2021) highlighted that the prevalence of sexual victimization varied greatly (0-71%). Research studies included people with ID between 28 to 50 years old, and age was not a moderator in sexual victimization. Data on sexual abuse in men with ID was scarcer than those on women (16 versus 22 studies) and presented greater variability. Results from the meta-analysis indicate a higher prevalence of sexual abuse in men with ID than women with ID (39.9% versus 31.8%), with men especially more likely to be victimized in institutionalized contexts (27.5% in women with ID; 50.8% in men with ID). Regarding the level of ID, the prevalence of sexual abuse differed significantly among the four subgroups, with the highest prevalence of sexual abuse corresponding to severe levels, followed by moderate, mild, and profound levels. Globally, sexual abuse was more prevalent at “several places” (39.1%, 95% CI: 21.1–57.1), followed by educational or social settings (34.3, 95% CI: 2.3–66.3), institutions (28.1, 95% CI: 12.0–44.1), and at home (13.1%, 95% CI: 10.6–36.9). Most perpetrators were male, more likely a peer, followed by a relative, several abusers, and a professional – but no research study included abuse by a family member, and 62.1% of perpetrators in the meta-analysis consisted of “non-specified” perpetrators.

In sum, results from this meta-analysis report that one in three individuals with ID is a victim of sexual abuse in adulthood (Tomsa et al., 2021). Regarding gender, in contrast to the findings of Fisher et al. (2016), Tomsa et al. (2021) found a higher prevalence for men than women. Tomsa et al. (2021) hypothesized that this difference may stem from gender roles; men with ID tend to experience less

overprotection and greater community participation without supervision, which could put them at a higher risk of victimization. Otherwise, results from the meta-analysis confirm the general trends identified in Fisher et al. (2016) regarding the variability in terms of age at victimization; the fact that perpetrators are mostly known to the victim and males; and the high prevalence rates of abuse occurring at “several places” seem to confirm the pattern of poly-victimization highlighted by Fisher et al. (2016), namely that multiple episodes of victimization seem to be the norm rather than the exception.

Other types of victimization. Seven prevalence studies reviewed by Fisher et al. (2016) assessed types of victimization other than sexual abuse, like physical abuse, financial exploitation, or neglect. Those studies were conducted worldwide, mainly in Europe, Australia, and the USA. They used different methods (case reports from mandatory reporting agencies, interviews, and questionnaires) and different categorizations of types of victimization. All research studies reported high victimization rates of adults with ID – especially regarding physical abuse (assault, physical attack) and financial exploitation (theft, robbery, embezzlement).

Fisher et al. (2016) uncovered no clear gender difference when “all types of victimization” were examined, and no specific information was reported in terms of age. The perpetrator was more likely to be male (52%) and known to the victim. The perpetrators included staff, peers with ID, and family or friends. Finally, adults with ID often experienced multiple occurrences of victimization, as opposed to one episode.

The three research studies published since Fisher et al. (2016) also used different methods (case reports, questionnaires) – and different definitions – to frame the types of victimization. They all included sexual victimization, but those results will not be commented on here, as results from Tomsa et al.’s (2021) meta-analysis are available. Two of the three research studies (Fodgen et al., 2016; Nixon et al., 2017) were conducted by the same research team and used a case-linkage methodology to estimate the risk of crime and victimization in adults with ID in one Australian state. They reported results regarding violent and nonviolent victimization from rates of contact and official records of victimization and criminal charges from different databases (e.g., disability services, public mental health services, and police records). They reported the highest prevalence regarding violent victimization (e.g., assault, aggravated robbery), which was experienced by more than 14% of people with ID in their sample (14.5% in Fodgen et al., 2016, and 19.3% in Nixon et al., 2017). Nixon et al. (2017) reported a 16.9% prevalence of nonviolent victimization (i.e., all forms of victimization that were neither violent nor sexual, e.g., theft) in their sample, while Fodgen et al. (2016) reported a prevalence of 5.1% of nonviolent victimization. Nixon et al. (2017) hypothesized that this difference in prevalence rates stems from the fact that people with ID in Fodgen et al.’s (2016) study had been subject to at least one restrictive intervention, which could then have protected them from nonviolent victimization, either due to a lack of property to be stolen, lack of social context for this type of victimization to occur, or the imposition of a threshold for access to justice. One study (Codina et al., 2020) was conducted

in Spain and analyzed lifetime victimization rates in adults through self-report questionnaires. Regarding the types of abuse, Codina et al. (2020) reported that the most frequent was common victimization (e.g., robbery, assault, experienced by 87.7% of their sample). Online victimization was reported by 23.5% of their sample, mostly in the form of harassment and online grooming.

The results from the three more recent studies reported either no difference between gender (Fogden et al., 2016; Nixon et al., 2017) or a tendency for women with ID to be more likely to be victimized, regarding online victimization (Codina et al., 2020) and violent victimization (Fogden et al., 2016). Codina et al. (2020) also reported a tendency for younger adults to be more likely to be victimized (i.e., aged between 20-40). Fogden et al. (2016) reported that adults with ID and a comorbid mental illness were three times more at risk of violent victimization when compared with the general population. Nixon et al. (2017) reported findings along those lines, with adults with ID having twice the risk of experiencing violent victimization when compared with the general population. Fogden et al. (2016) and Nixon et al. (2017) reported no information regarding the perpetrator. Codina et al. (2020) found that a caregiver was the perpetrator in almost 60% of the victimization experiences reported in their sample but did not report additional information on the caregiver (e.g., gender, paid or informal caregiver, etc.). Finally, Codina et al. (2020) and Nixon et al. (2017) reported, respectively, 38.8% and 25.9% of poly-victims in their sample (i.e., people that experienced multiple occurrences of victimization).

In sum, no clear gender tendency emerges from Fisher et al. (2016) and the most recent research studies on overall victimization prevalence; few studies provide information on age, and its relation to victimization remains unclear. They all frame the types of victimization differently and use diverse methods to assess it, which complicates the comparison of victimization rates across studies. Nevertheless, overall, results from the three most recent studies seem to confirm the general trend identified by Fisher et al. (2016) in their review, namely that adults with ID are likely to experience multiple types of (violent) victimization, many occurrences of victimization, and victimization by various (known) perpetrators.

Vulnerability studies

Vulnerability studies aim to identify risk factors of victimization. In 2016, Fisher and colleagues found seven studies on vulnerability to the victimization of adults with ID. Similar to the research studies on the prevalence of victimization, those seven research studies were conducted mainly in Europe, Australia, and the USA. They assessed vulnerability through different methods: record review ($n=2$); questionnaires completed by third-party (e.g., caregivers) ($n=2$); self-report of adults with ID ($n=1$); and validated assessments developed to measure social vulnerability ($n=2$). Since 2015, five additional vulnerability studies have been published, primarily across Europe, Australia, and the USA (see Table 2). Vulnerability to victimization was assessed through different methods: record review ($n=2$); case-linkage ($n=2$); and validated assessments developed to measure social vulnerability ($n=1$). In those twelve studies, several factors increasing the risk of social vulnerability were identified, some related to (inter)personal factors, others related to the environment (see Figure 2).

Table 2

Research studies examining increased risk of social vulnerability in adults with IDD

Authors (Year)	Method (Country)	Number of adults with ID	Age (Mean or Range)	Disability	Type of victimization	Risks factors
Fisher et al. (2018)	Social Vulnerability Questionnaire (USA)	428	12-53	Williams syndrome Autism spectrum disorders Down syndrome	Victimization	Vulnerable appearance (identifiable physical phenotype) Low social protection Greater community participation (higher social independence) Lower risk awareness Credulity Previous experiences of (emotional) abuse
Koçtürk & Yüksel (2021)	Record review (Turkey)	31	18-43	ID	Sexual abuse	ID Gender (women more often victimized)
Latvala et al. (2021)	Case-linkage (Sweden)	16855	22-33	ID	Sexual abuse Violent victimization	ID Comorbidity with attention deficit hyperactivity disorder Comorbidity with autism spectrum disorders
Thomas et al. (2019)	Case-linkage (Australia)	2200	Mean= 35.71 SD=16.57	ID	Sexual abuse Violent victimization Nonviolent victimization	ID Comorbidity with mental illness
Doherty (2020)	Record review (UK)	27	> 18	ID	Mate crime (exploitation by a friend/familiar person), including sexual abuse, financial exploitation, physical abuse, emotional abuse	Desire for friendship (scare of losing friends; loneliness) Living arrangement (living alone in a deprived urban neighborhood) Significant support for care needs Isolation

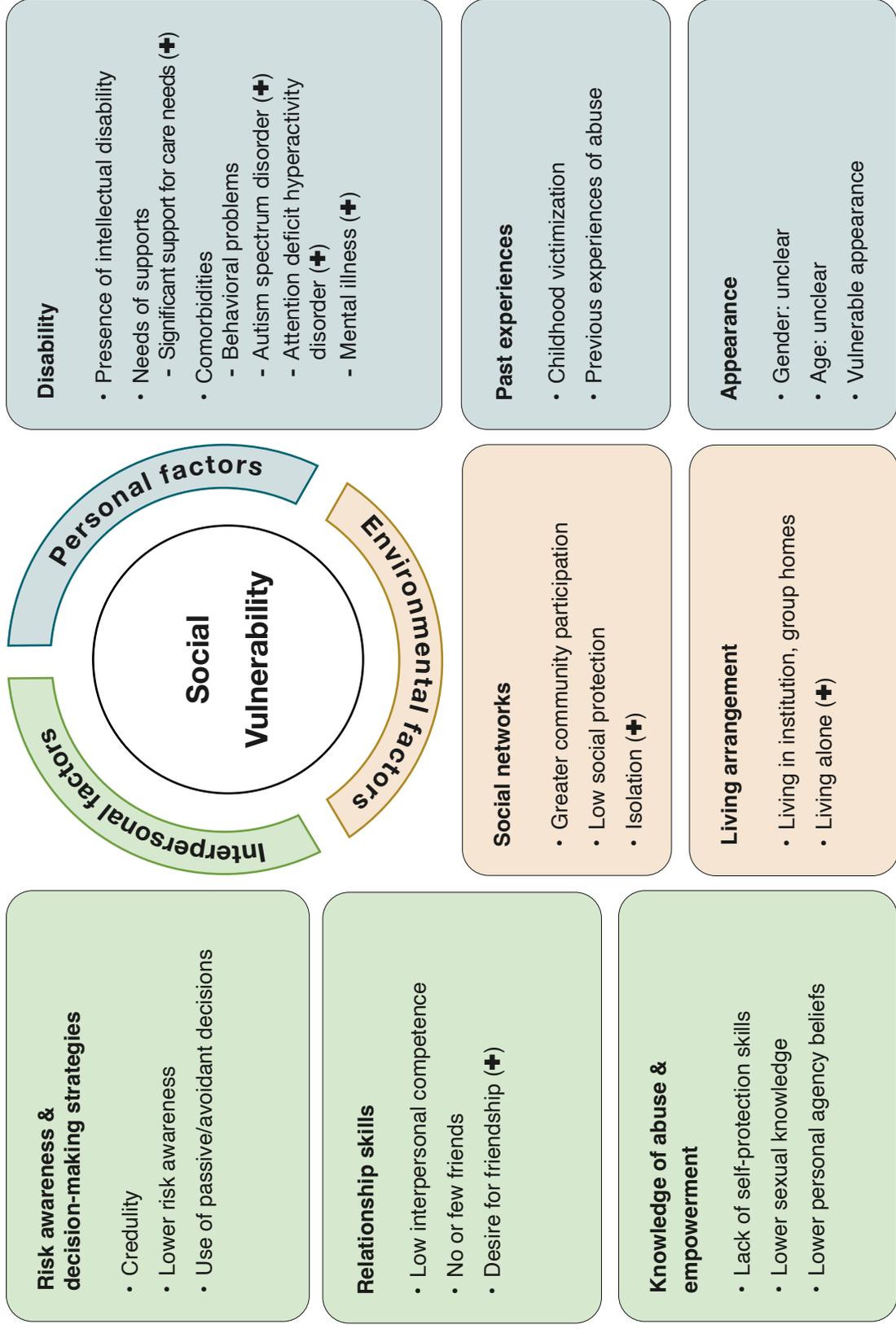
Note. Sorted by order of presentation

(Inter)Personal factors. Overall, studies reviewed by Fisher et al. (2016) acknowledge that the presence of ID increases vulnerability to victimization. In addition to ID, other aspects were identified with heightened social vulnerability in Fisher et al.'s (2016) review: behavioral problems, poor interpersonal competence, using passive or avoidant decision-making strategies, and having no or few friends. Additionally, a higher level of vulnerability was reported in adults with ID with lower sexual knowledge and lower personal agency beliefs regarding their sexual experiences. Adults over 30 years old and those who suffered from victimization in childhood were at increased risk of experiencing sexual abuse, and men with ID were more at risk of experiencing sexual abuse by others with ID. Research studies conducted since 2015 also acknowledge that the presence of ID increases vulnerability to victimization (Fisher et al., 2018 ; Koçtürk & Yüksel, 2021; Latvala et al., 2021; Thomas et al., 2019). They highlight new risk factors: adults with ID and comorbid attention deficit hyperactivity disorder (ADHD), autism spectrum disorders (ASD), or comorbid mental illness are at higher risk of victimization (Latvala et al., 2021; Thomas et al., 2019). Fisher et al.'s (2018) study confirmed the results identified in their previous study (Fisher et al., 2013), already included and reviewed in 2016, and reported that, although social vulnerability is not syndrome-specific, genetic syndromes might pinpoint some specific aspects of heightened vulnerabilities (e.g., related to lower social protection among adults with ASD; related to physical appearance among adults with Williams syndrome and Down syndrome; related to higher past experiences of (emotional) abuse in Down syndrome). Except for Koçtürk and Yüksel (2021), who reported an increased risk of victimization for women with ID, the other studies did not report gender differences. Finally, Latvala et al. (2021) reported a mean age of 20 at first victimization, which is the line of Koçtürk and Yüksel (2021) who reported an increased risk of victimization between 18 to 30 years old. This however contradicted the findings of Fisher et al. (2016), who reported an increased vulnerability in adults aged over 30 years old.

Environmental factors. Some findings from Fisher et al.'s (2016) review are related to aspects of the living environment that increase one's social vulnerability. Though people living in group homes or institutions were more likely to experience victimization, most often from peers with ID, people afforded greater community participation were also found to be socially vulnerable. Their social vulnerability was related to behaviors related to risk unawareness or lack of skills to protect themselves in risky social situations. In abuse cases where the perpetrators were known, Doherty (2020) identified isolation, more specifically, living alone (sometimes with a desire for friendship), and significant support for care needs as factors increasing vulnerability.

Figure 2

Overview of (inter)personal and environmental factors of social vulnerability in adults with IDD identified in the systematic review



Note. (+) = factors identified in the updated review (2015-2022)

Toward a better understanding of social vulnerability. Since Wilson and Brewer (1992), the relevance of understanding social vulnerability to prevent victimization has been increasingly acknowledged. Different risk factors for victimization have been identified, some related to (inter)personal characteristics and others to the environment. The risk factors for social vulnerability identified in this review reflect two lenses, with some characteristics of individuals with IDD that cannot be changed and others that may be modified through intervention (Fisher et al., 2018). The role of gender and age in social vulnerability remain unclear. Most studies focused on (risk factors for) sexual and violent victimization. Few investigated other types of abuse, like online victimization. Only a few research studies – conducted in the USA and Australia – used validated tests specifically developed to assess one’s social vulnerability. Differences in methods and tests used further limit cross-cultural comparison and information on the social vulnerability of adults with IDD. Confirming what Wilson and Brewer (1992) had grasped thirty years ago, recent research studies on social vulnerability underscore the importance of considering several risk factors rather than supposing that the presence of ID will lead to victimization (Fisher et al., 2016).

Overall, despite its importance in indicating which individuals might be at risk of victimization and thus allowing to provide them specific interventions to inform the maltreatment prevention, social vulnerability remains understudied, and tools for assessing social vulnerability are only available in English. More research is needed to understand patterns of social vulnerability, cross-cultural differences and/or similarities, and its development across the lifespan in individuals with IDD.

Looking back at her work in 2016, Wilson (p.74) stated that, moving forward, the goals are clear:

We must identify those at risk through appropriate screening; develop and triage those identified as vulnerable to intervention and appropriate support programs that mitigate this vulnerability, however it might arise; assist the victimized with appropriate utilization of policing and court services; and provide ongoing support post-victimization.

Identifying those at risk through appropriate screening can be performed via validated social vulnerability assessments, while intervention and support programs aiming at mitigating this vulnerability take mainly the forms of risk education curricula (Petitpierre & Tabin, 2021). Those programs are embedded in more global prevention measures to prevent the maltreatment of people with IDD.

1.3 Preventing maltreatment of adults with IDD

Different frameworks exist to consider the prevention of maltreatment in people with IDD. One of those was proposed by Hickson and Khemka (2021). This framework, which reflects a comprehensive approach to effective prevention, is applicable across different life stages and integrates aspects of the individuals and their environments likely to be relevant across cultures. They considered that maltreatment prevention should be acted upon three different levels: (1) the individual level, which should focus on increasing self-protective competencies, (2) the structural level, which should aim to foster protective relationships and networks; and (3) the societal level, which should focus on building protective systems and services (Hickson & Khemka, 2021).

Maltreatment prevention efforts focused on an individual level and including adults with ID have been reviewed in a meta-analysis performed by Park in 2020. A systematic search was conducted on three databases to find reviews published since this meta-analysis (January 2019 to August 2022, as Park (2020) reviewed studies published until 2018) (see Figure 3). The equation used for the search was: (abuse or maltreatment or violence or neglect or victimization) and (disabilit* or “intellectual disabilit*” or “developmental disabilit*” or “intellectual and developmental disabilit*”) and (prevent* or protect* or safe or support or educat* or skill* or training or curricul* or intervention). Since Park’s (2020) meta-analysis, two reviews qualitatively summarized the evidence regarding maltreatment prevention curricula designed for adults with ID (Araten-Bergman & Bigby, 2020; Goh & Andrew, 2021).

The section below presents an overview of the main conclusions that arose from those two different reviews and the meta-analysis (see Table 3; see Petitpierre & Tabin, 2021, for a detailed overview of risk education curricula regarding maltreatment prevention for people with IDD).

Figure 3

Flow chart for selection of post-2018 reviews on maltreatment prevention curricula for adults with IDD

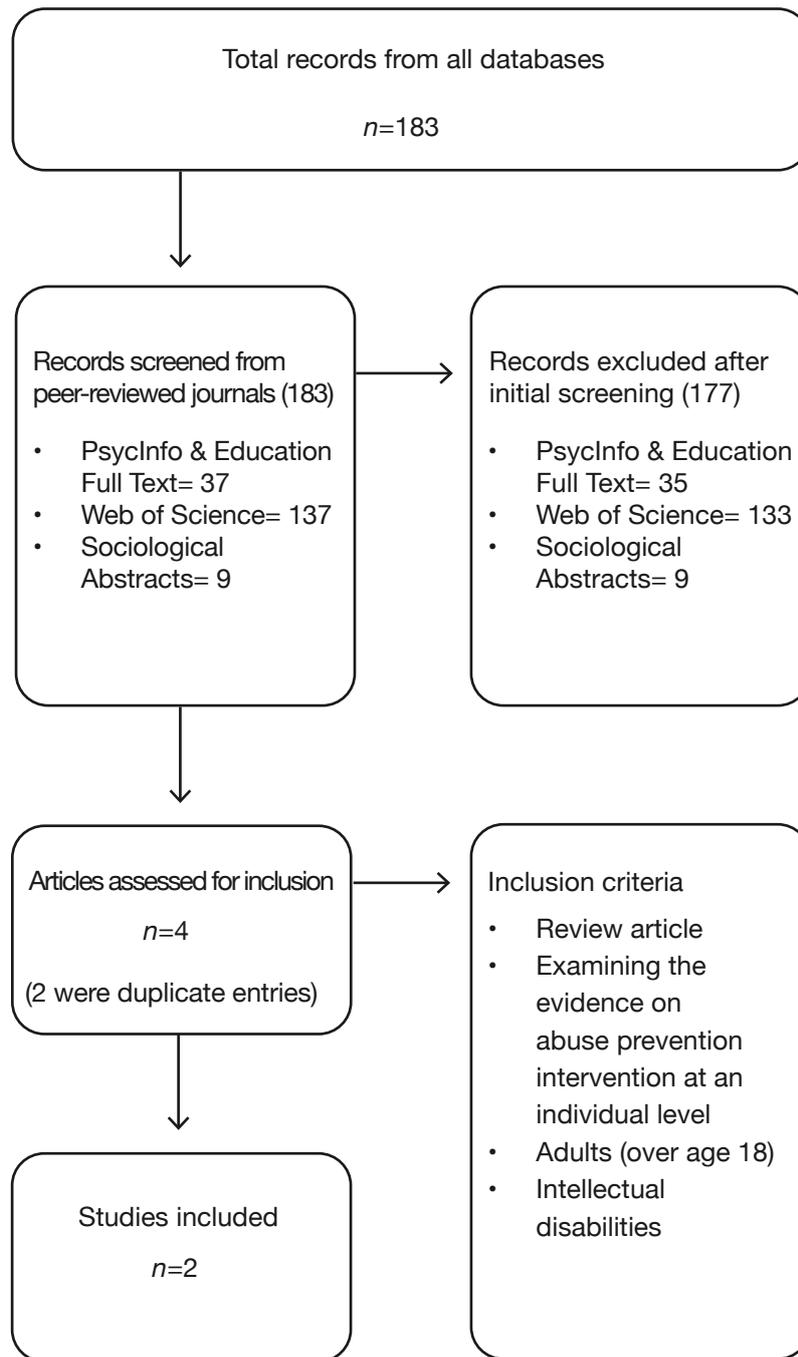


Table 3

Most recent reviews of maltreatment prevention curricula for adults with IDD

Authors (Year)	Type of review (n articles included / n total articles)	Studies included: authors (Year), gender (Mean age or Range), abuse types, country	Main results & conclusions	Research gaps & recommendations
Park (2020)	Meta-analysis (4/6)	(1) Hickson et al. (2015), men and women with mild ID, (Mean=39), verbal, physical, sexual abuse, USA (2) Hughes et al. (2010), women with ID (Mean=50), interpersonal violence, USA (3) Mazzucchelli (2001), men and women with ID (Mean=37), abuse, Australia (4) Ward et al. (2013), men and women with ID (NA), interpersonal violence, USA	Medium effect size indicating overall effectiveness of abuse prevention curricula Significant increase in outcomes assessed in most studies	Promising effects, but few studies Effects of the abuse prevention curriculum depending on age are unknown; individual group studies analyzing a broader range of curricula and (sub-)groups should be accumulated
Araten-Bergman & Bigby (2020)	Scoping review (3/6)	(5) Same as (1) (6) Egemo-Helm (2007), women with mild to moderate ID, (28-46), sexual abuse, USA (7) Bollman et al. (2009), women with mild ID, (49-51), verbal, physical, sexual abuse, USA	Adults with ID can successfully acquire knowledge and skills to recognize and respond effectively to an abusive situation Variety of methods and environments used to assess knowledge and skills	Paucity of evidence-based prevention strategies relevant to people with ID Prevention strategies should be multifaceted (include individuals and their environment)
Goh & Andrew (2021)	Narrative review (5/6)	(8) Same as (1) (9) Hughes et al. (2018), men and women with ID, (NA), interpersonal violence, USA (10) Robinson-Whelen et al. (2014), women with ID (Mean=48), interpersonal violence, USA (11) Robinson-Whelen et al. (2010) women with disabilities (Mean=50), interpersonal violence, USA (12) Fisher et al. (2013), men and women with ID, (20-23), lures from strangers, USA	Adults with ID can benefit from safety training, if curricula are adequately designed to support their learning and participation Community-based participatory research collaboration can inform curricula modification(s) to support people with ID' learning and improve outcomes	Few studies, but improvements regarding their relevance, efficacy, accessibility have been made over the years Futures studies should focus on abuse by known/familiar persons; include a wider range of people with IDD; assess long-terms effects

Note. Sorted by order of presentation; NA=Not Addressed

The development and implementation of effective prevention strategies require an understanding of “what works”. In their meta-analysis, Park (2020) identified four maltreatment prevention training designed for adults with ID specifically and one designed for youths with ID, as well as six other studies focused on safety in general. In their scoping review, Araten-Bergman and Bigby (2020) aimed to review the evidence about the effectiveness of prevention strategies for adults with ID. Three of the six research studies they identified were interventions designed for adults with ID (the other two were designed for practitioners working with adults with ID, and the third was designed for practitioners and women with ID and focused on dealing with trauma post-victimization). Goh and Andrew (2021) proposed a literature review examining recent curricula designed to improve safety awareness and protection skills, including five research studies on adults with ID (six studies in total, one focused on children with ID).

The three reviews (Araten-Bergman & Bigby, 2020; Goh & Andrew, 2021; Park, 2020) identified twelve research studies. Among the twelve research studies, the Effective Strategy-Based Curriculum for Abuse Prevention and Empowerment [ESCAPE] (Hickson et al., 2015) was identified in each review. As such, ten different research studies were reviewed, with each study presenting and evaluating a curriculum to prevent the maltreatment of adults with ID. Those curricula sought to affect individual risk and/or protective factors changes. Overall, results from the reviews reported promising effects of the curricula assessed on the safety skills of adults with ID. Park (2020) reported a medium effect size (0.328, 95% CI [0.237-0.420]) regarding the five abuse prevention training (i.e., including the training on youths with ID), indicating a significant increase in the outcomes assessed in most studies. For example, Hughes et al. (2010) reported a significant increase in self-protection skills (e.g., recognizing abuse, setting limits on how people treat them). Ward et al. (2013) reported a significant increase in the participant’s social network size and a significant decrease in incidents of victimization experienced over time between baseline, post, and follow-up (during the ten weeks preceding measurement). Araten-Bergman and Bigby (2020) also noted that, given supportive delivery methods end environments (e.g., role-play scenario, in-situ training), adults with ID successfully acquire knowledge and skills to recognize and respond effectively to an abusive situation. Goh and Andrew (2020) corroborated those findings and underlined the interest of community-based participatory research collaboration to inform curricula modification to support and enhance people with ID knowledge and skills acquirement.

Besides reviewing evidence on “what works”, those studies also identify knowledge gaps and future research directions to advance evidence-based practices in the field. Except for one research study conducted in Australia (Mazzucchelli, 2001), all curricula were developed and assessed in the United States and English exclusively. While earlier curricula tended to be directed toward women with mild ID (e.g., Egemo-Helm et al., 2007), more recent research studies tend to be more inclusive in terms of gender and geared towards a broader range of levels of ID (e.g., Ward et al., 2013). Adults at different life stages have been included, with most curricula delivered to adults around 35 years old (e.g.,

Hickson & Khemka, 2015). Most curricula are delivered in in-person sessions, with verbal and textual modes of knowledge transmission (e.g., Robinson-Whelen et al., 2014). Except for Hughes et al. (2018), who reported some details on how they developed the curriculum, most do not provide much information on the development process apart from the theoretical model used. The research studies focus on pre-posttests of quantitative assessment, usually including follow-up. While the curricula assessed demonstrate improvement in people's safety knowledge and skills relating to the ability to protect themselves, results from the follow-up evidence remain limited, because most studies included short follow-ups only (1-3 months). Hence, in the medium and long term, skills and knowledge maintenance remain uncertain.

Overall, while results are promising, some areas remain understudied. Other countries besides the USA and English-speaking people are largely absent in the curricula assessed, and some groups, like elder adults, remain overlooked. Future research is needed to evaluate and compare methods for improving self-protective skills across sub-groups, including a wide range of maltreatment types likely to happen in the lives of people with IDD across their lifespan and in languages and countries other than the USA. Although advances have been made, decreasing social vulnerability remains challenging. Except for ESCAPE, which has been translated and successfully used in Europe (e.g., Petitpierre et al., 2016), curricula that aim to prevent maltreatment are a long way from widespread implementation (Wilson, 2016), especially outside the USA.

2 Aims and method

This doctoral thesis aims to deepen, on a theoretical level, and inform, on a practical level, the maltreatment prevention possibilities for adults with IDD across their lifespan. Regarding the theoretical level, this doctoral thesis aims to advance our understanding of social vulnerability in adults with ID – including digital social vulnerability. Regarding the practical level, this doctoral thesis aims to provide concrete tools that stakeholders can use in the field to prevent maltreatment.

2.1 Aims of the doctoral thesis and specific aims of each study

The doctoral thesis consists of four studies with specific aims that contribute to the overall aim of preventing maltreatment of adults with IDD:

- Study I evaluates the psychometric properties of a test aimed at assessing social vulnerability in French-speaking adults with ID
- Study II identifies conditions likely to ensure proper use and implementation of the newly validated social vulnerability test
- Study III analyzes the online social vulnerability of French-speaking adults with ID, more precisely, how they perceive and manage digital risks
- Study IV presents the development and usability evaluation of a curriculum aimed at preventing maltreatment in elders with IDD

2.2 General ethical and methodological considerations

The four studies were conducted between 2018 and 2022. While the Covid-19 pandemic impacted how Study IV was designed in the first place (e.g., exclusively online meetings, no direct contact with participants, etc.), we could conduct all studies as intended. Together, the four studies involved more than a hundred participants (29 adults with ID, 31 practitioners that interviewed 31 adults with ID, 10 elder adults with IDD, 2 trainers, 8 program advisory board members).

The first three studies conducted were approved by the Swiss Ethics Committee on research involving humans (Protocol N°2016-01480); Study IV followed full ethical guidelines at the two participating agencies and institutional review board requirements. Ethical guidelines were followed carefully so that each adult with ID gave informed consent to participate in the research. The first study followed the procedure proposed by Petitpierre et al. (2013), inviting potential participants and their legal representatives to an informational meeting about the study and providing them with an easy-to-read and understand form. Informed consent of the participants and their legal representatives were required to participate in the first study. The other studies involved adults with ID indirectly, as the main participants were practitioners and trainers. Practitioners and trainers provided the adults with

ID with an easy-to-read and understand form (and their legal representatives when needed). Some additional precautions were prepared (but did not need to be used) regarding what to do in case of disclosure of abuse. In Study I, in which the research team conducted the interviews, a support person in the agency was identified for each participant, and they would have followed their agency's procedure in case of disclosure. In the other studies, all practitioners and trainers were aware of the procedure they had to respect in their agencies in case of disclosure of abuse.

All studies conducted in this doctoral thesis were funded: the first three studies were conducted in the context of a project funded by the Swiss National Science Foundation (Petitpierre, 2018, grant N°176196), while the fourth study was funded by a Doc.Mobility Fellowship provided by the University of Fribourg (grant DM-2021-02).

The methods used vary according to the study's aim. The first study used exclusively quantitative methods to assess the psychometric properties of the social vulnerability assessment; the second used a mixed-method design, and the third and fourth used qualitative methods (see Figure 1 for an overview of each study's aims, method, and main results).

Figure 1

Overview of each study's aims, method, and main results

Study I. Cross-cultural preliminary validation of a measure of social vulnerability in people with ID		
Aims	Method	Results
<p>Conduct a preliminary cross-cultural validation of the Test of Social Vulnerability–22 items (TV-22), the French-language, enhanced and accessible version of the Test of Interpersonal Competence and Personal Vulnerability ([TICPV], Wilson et al., 1996)</p>	<p>29 French-speaking adults with ID answered the TV-22, 2 times (2-4 weeks interval; Mean age= 29, 15 women)</p> <p>Other variables assessed:</p> <ul style="list-style-type: none"> • Adaptive behavior (ABAS-3) • Fluid intelligence (Raven) • Level of support (SIS-F) 	<p>Very good internal consistency ($\alpha = .89, \Omega = .93$)</p> <p>Good test-retest reliability ($r_s(29) = .81, p < .01$)</p> <p>Strong inter-rater agreement</p> <p>Correlations:</p> <ul style="list-style-type: none"> ✗ Gender, age, adaptive behavior ✓ Fluid intelligence ($r_s = .47, p < .01$) ✓ Level of support ($r_s = -.52, p < .01$)
Study II. Evaluating implementation outcomes of a measure of social vulnerability in adults with ID		
Aims	Method	Results
<p>Evaluate which characteristics of the assessor influence the quality of the assessment performed with the TV-22, and what adaptations should be made to enhance its implementation. The following implementation outcomes are evaluated:</p> <ol style="list-style-type: none"> 1. Appropriateness 2. Acceptability 3. Assessment fidelity 	<p>31 special education practitioners (8 psychologists, 11 educators, 12 team/center managers) administered the TV-22 during an interview with an adult with ID</p> <p>Qualitative and quantitative analyses were performed</p>	<ol style="list-style-type: none"> 1. Good appropriateness (i.e., TV-22 perceived as relevant) 2. Reasonable acceptability (i.e., TV-22 not too complex to use) 3. Low assessment fidelity: 25% of the practitioners performed the social vulnerability assessment with an extreme lack of adherence to assessment guidelines
Study III. Resources and vulnerabilities to digital risks of adults with ID		
Aims	Method	Results
<p>Assess the resources and vulnerabilities to digital risks of adults with ID. The following questions are addressed:</p> <ol style="list-style-type: none"> 1. To what extent do adults with ID protect themselves against digital risks? 2. What strategies do they use to manage these risks? 	<p>51 adults with ID (27 women) answered the TV-22</p> <p>Qualitative analyses were performed in the 5 items related to digital risks:</p> <ul style="list-style-type: none"> • Sextortion (2 items) • Theft attempt/Scam (2 items) • Phishing (1 item) 	<ol style="list-style-type: none"> 1. Around 13% – even 29% in item N°13 involving scam – don't (know how to) protect themselves against digital risks 2. In the 5 items, most participants used self-determined strategies to handle digital risks
Study IV. Preventing elder abuse: Development of a curriculum for elders with IDD		
Aims	Method	Results
<ol style="list-style-type: none"> 1. Describe the development of a new curriculum targeting elders with IDD, based on earlier versions of ESCAPE (Khemka & Hickson, 2015) 2. Report the results of a usability evaluation conducted using a cross-cultural developmental focus 	<ol style="list-style-type: none"> 1. Development, in collaboration with an international program advisory board, including needs assessment (focus group ($n=6$); survey ($n=86$)) 2. Usability test in the USA and Switzerland: qualitative analysis of the feedback (2 trainers and 10 elders with IDD, age > 50, 3 women) 	<ol style="list-style-type: none"> 1. New curriculum, The Effective Strategy-based Curriculum for Abuse Prevention and Empowerment -for Elders (8 lessons) 2. Modifications were performed to enhance usability; overall positive feedback, suggesting a promising intervention, available in English and French

3 Studies

3.1 Study I. Cross-cultural preliminary validation of a measure of social vulnerability in people with ID¹

Abstract

Introduction. Social vulnerability refers to the ways in which an individual is at risk of being victimised. The Test of Interpersonal Competence and Personal Vulnerability [TICPV] (Wilson et al., 1996) is an Australian assessment tool designed for adults with intellectual disabilities (ID). It aims to evaluate their social vulnerability. This study aims to conduct a preliminary cross-cultural validation of the TV-22, the French-language, enhanced and accessible version of the TICPV.

Method. Twenty-nine French-speaking adults with ID answered the TV-22. The reliability and validity of this measure were assessed.

Results. Performance on the test was shown to be internally consistent (Cronbach's $\alpha = .89$; McDonald's $\Omega = .93$), stable over time ($r_s(29) = .81, p < .01$) and a valid measure of social vulnerability.

Conclusions. Results provide psychometric support for the use of the TV-22. Further research is needed to confirm these results with a larger sample.

Keywords: intellectual disabilities; social vulnerability; victimisation; cross-cultural validation

¹ This study is a reprint of the article: Tabin, M., Diacquenod, C., De Palma, N., Gerber, F., Straccia, C., Wilson, C., Kosel, M., & Petitpierre, G. (2021). Cross-cultural preliminary validation of a measure of social vulnerability in people with intellectual disabilities. *Journal of Intellectual & Developmental Disability*, 46(1), 67-79. <https://doi.org/10.3109/13668250.2020.1793450>

As this study follows the guidelines provided by the *Journal of Intellectual & Developmental Disability*, British English is used here, whereas in the other parts of this doctoral thesis, American English is used.

Introduction

The ability to protect oneself against victimisation varies from one person or group to another and increases or decreases according to contexts and periods of life. Victimisation is a broad term which includes physical and sexual assault, financial abuse, financial exploitation, neglect, discrimination and psychological abuse, such as bullying and coercion (Fisher et al., 2016). The precautionary principle and the need to think about prevention and protection have led to the designation of certain groups as vulnerable (for example the elderly, people with intellectual disabilities [ID], migrants, children, etc.). The designation of vulnerable groups is based on epidemiological and clinical information (Petitpierre, 2012). The risk faced by these particular groups, given some of their characteristics, is also referred to as “collective vulnerability” (Petitpierre, 2012). Meta-analyses from both Jones and colleagues (2012) and Hughes and colleagues (2012) provided valuable information on prevalence rates of violence on children and adults with ID. Jones et al. (2012) reported a pooled prevalence of physical violence at 27% and 15% for sexual violence on children with ID (combined measure of violence of 21%, 1/5 children with ID). Hughes et al. (2012) estimated the pooled prevalence of any (physical, sexual, or intimate partner) recent violence at 6.1% (2.5-11.1) for adults with ID.

The assessment of collective vulnerability gives only partial indications of the risk faced by a particular individual, however, and few studies have described how individuals’ characteristics can convey individual social vulnerability (Fisher et al., 2012). Social vulnerability refers to the ways in which an individual is at risk of being victimised. Individuals are considered to be socially vulnerable when they fail to avoid negative social relationships (Fisher et al., 2018).

The evaluation of social vulnerability aims to assess (1) the person’s ability to progress in a given environment without taking excessive risks, and (2) his or her ability to defend him- or herself against social risks. Conclusions of the assessment of an individual’s social vulnerability influence the choices and orientations offered (academic or professional perspectives, place of residence, access to leisure, etc.) and therefore play a crucial role in the everyday life of individuals with ID.

Currently, a person’s individual social vulnerability is assessed through clinical evaluation. The caregiver evaluates the person’s vulnerability through his or her observations. Nevertheless, to have a more complete and nuanced picture of the person’s strengths and limitations, it is essential to cross-reference several sources of evaluations and, whenever possible, ask the point of view of the person him- or herself. Proxies’ observations could thus be supplemented by a standardised evaluation procedure. In the last twenty-five years, some promising measures have been developed to assess the social vulnerability of individuals with ID. The Test of Interpersonal Competence and Personal Vulnerability [TICPV] (Wilson et al., 1996), the Social Vulnerability Scale [SVS] (Sofronoff et al., 2011) and the Social Vulnerability Questionnaire [SVQ] (Fisher et al., 2012) are three published instruments that aim to measure social vulnerability.

The SVS and SVQ are both third-party reported measures with items assessing social vulnerability. Proxies have to rate the items on a Likert scale from never to always (example of an SVS item: My child...“is overly trusting of strangers”). Initially aimed at assessing the social vulnerability of people with intellectual and developmental disabilities (Greenspan & Stone, 2002), the SVS has a two-factor structure (gullibility and credulity). It was recently successfully adapted and validated for several other populations. 1) Neuro-typical children (Seward et al., 2018): among a sample of 790 parents of elementary school children (3-12 years) and another sample of 96 parents and teachers, results provided strong reliability and validity evidence ($\alpha = .86$); test-retest reliability ($r(73) = .74$); inter-rater reliability ($r(93) = .29, p = .004$). 2) Children with Asperger syndrome [AS] (Sofronoff et al., 2011): among a sample of 133 parents of children with AS, results provided strong reliability and validity evidence ($\alpha = .94$; test-retest reliability ($r(25) = .85$)). This study also pointed out that among other variables (anxiety, anger, behaviour problems, social skills), social vulnerability was the strongest predictor of bullying. 3) Older adults with and without cognitive impairments (Pinsker et al., 2006): this scale was validated among a sample of 167 undergraduate students who had to complete this informant report by rating a relative or friend aged over 50 years, whether with or without memory problems, stroke, dementia, or other neurological conditions. It had an excellent internal consistency ($\alpha = .88$) and test-retest reliability ($r(14) = .87$).

The SVQ has been validated among a sample of 428 individuals ($M = 21.38$ years; $SD = 8.03$) with intellectual and developmental disabilities (Fisher et al., 2018). The SVQ is characterised by a six-factor structure (vulnerable appearance [$\alpha = .66$], risk awareness [$\alpha = .81$], parental independence [$\alpha = .76$], social protection [$\alpha = .75$], credulity [$\alpha = .82$] and experience of emotional abuse [$\alpha = .91$]). Confirmatory factor analysis on the SVQ delivered good to excellent fit indices (RMSEA = 0.05, TLI = 0.91, CFI = 0.92) and the differential correlation patterns among the six SVQ factors indicated good discriminant validity within the SVQ (Fisher et al., 2018). Lough and Fisher (2016) also compared results at parent report and self-report of 102 adults ($M = 27.83$ years; $SD = 7.96$) with Williams Syndrome [WS] on the SVQ. Compared to self-report, parent’s evaluation reported a significantly higher level of social vulnerability.

The TICPV is an assessment tool designed for adults with ID (Wilson et al., 1996). It aims to evaluate their self-protection abilities in different types of social risks (financial exploitation: 10 items; verbal or physical assault: 2 items; sexual abuse: 5 items; inappropriate request: 3 items). The person is asked to answer 20 questions with a three-option, multiple choice response format. The test was validated among a sample of 40 individuals with ID (Wilson et al., 1996). In the validation study, the test succeeds in convincingly distinguishing between individuals with ID who had suffered from victimisation (assault, sexual assault, robbery, financial exploitation, break-in) and individuals with ID who were not victims. Reliability and validity of the TICPV ($\alpha = .72$) and test-retest reliability ($r(20) = .72, p < .001$) were good. Validation was carried out with a relatively limited number of participants ($n=40$), but the follow-up studies showed good discriminatory validity with larger samples. Indeed, the TICPV has been used in

several research projects with a) 48 adults with chronic schizophrenia (Nettelbeck & Wilson, 1995); b) 53 neurotypical children (Nettelbeck & Wilson, 1995); c) 63 adults with ID (Nettelbeck et al. 2000); d) 60 adults with ID and 60 neurotypical individuals aged more than 16 (Murphy & O'Callaghan, 2004). The TICPV also inspired the development of other tools in English (Lough & Fisher, 2016) and has been used or is advised to be used in clinical practice (British Psychological Society, 2006, 2019).

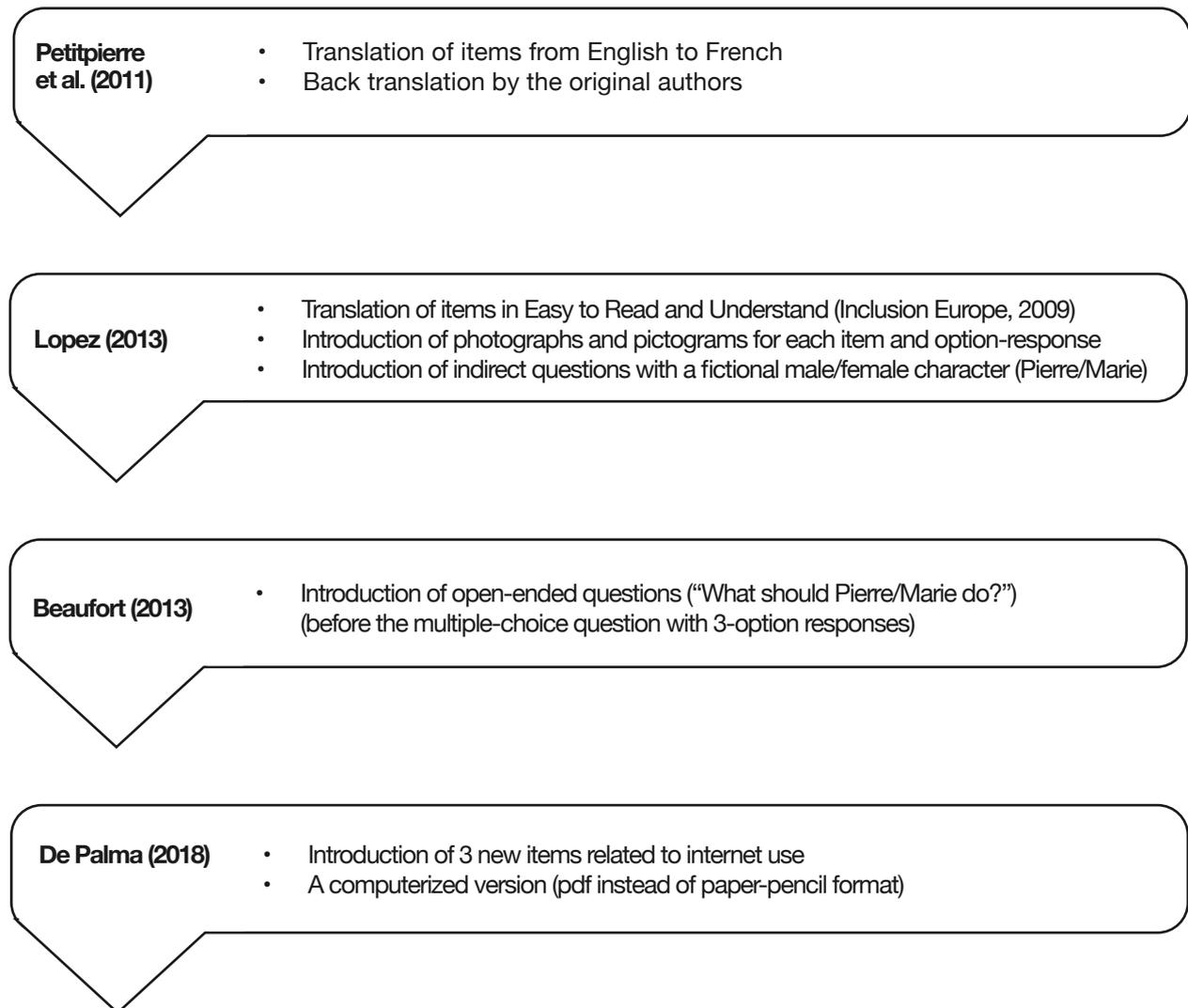
Although these measures are promising and can be part of a clinical assessment battery in order to assess a person's vulnerability to the risk of victimisation, none of them is available in French. There is currently no French-language tool, and no cross-cultural adaptation of a tool built in another language, available in the French-speaking countries.

The TICPV has several strengths: it is a self-reported measure developed specifically for adults with ID, and permits study of the individual's vulnerability to several types of risk (financial exploitation, verbal and physical assault, sexual assault, inappropriate request) and several types of abuser (family, stranger, friend).

A cross-cultural adaptation of the Australian instrument TICPV was conducted for the French part of Switzerland. A cross-cultural adaptation consists of a "process that looks at both language (translation) and cultural adaptation issues in the process of preparing a questionnaire for use in another setting" (Beaton et al., 2000, p.3186). The cross-cultural adaptation aims to best suit the Swiss context (e.g. change from first-person accounts to third-person accounts) and to be more actual (e.g. items involving digital risks were added). It also aims to make the items of the test more accessible according to the principle of universal design applied to assessments (Thompson et al., 2002). An Easy to Read and Understand language (Inclusion Europe, 2009) has been introduced throughout the test (e.g. illustration of the items, use of plain language). The adaptation leads to a French-language, enhanced and accessible version of the TICPV. The cross-cultural adaptation process is summarised in Figure 1.

Figure 1

Cross-cultural adaptation process of the TICPV



After the translation (and back translation by the original authors) of the TICPV into French (Petitpierre et al., 2011), three consecutive studies were conducted in the French-speaking region of Switzerland in order to proceed to the cross-cultural adaptation of the test (Beaufort, 2013; Lopez, 2013; De Palma, 2018). Unlike the original version of the test, which directly appeals to the participant, Lopez (2013) created a female version (with the character of Marie) and a male version (with the character of Pierre). This change from first-person accounts to third-person accounts was made because it was less direct and allowed some distance between the participant and the situation (particularly for the items linked with sexual abuse) and thus allowed the participant to be freer in their answers. Lopez (2013) also adapted the test into Easy to Read and Understand (Inclusion Europe, 2009). Her study, including 27 adults with ID aged 18 to 58 years, and 10 toddlers aged 4 to 8 years, confirmed that the scenario illustrations correspond well to the wording of the initial test, both for the main vignettes and for the response vignettes. When the identification of the illustrated scenario was insufficient (<70% of participants), the material was reworked.

Beaufort (2013) verified the accuracy of the multiple-choice answers. She introduced open-ended questions (i.e., “What should Pierre/Marie do?”) to ensure that the proposed choices were among the solutions spontaneously mentioned by respondents. She was able to confirm this assumption by analysing the responses given by 20 young people with ID, aged 17 to 20 years, and by 20 neurotypical persons matched on chronological age. Beaufort’s analysis of the answers to open-ended questions also underpinned the value of such questions: most of the answers reflected the spontaneous reasoning of the respondents and conveyed very interesting clinical information, for example on the clues used to support the reasoning and/or on the finesse of the reasoning itself.

As Internet access has become more widespread, people with ID may also be exposed to risks related to Internet use (Chadwick et al., 2013). This raises the need for items portraying risk situations related to Internet use. De Palma (2018) generated 3 items (into Easy to Read and Understand [Inclusion Europe, 2009]) on this topic from situations inspired by news stories and scientific literature. These items refer to the risk of being assaulted verbally in an online discussion, of transmitting personal or private data and finally of being sexually solicited on the Internet. Eight academic participants in the field of special education (six Master’s students, one PhD student and one professor at the University of Fribourg) assessed their relevance, their representativeness and the accessibility of the wording for the public with an ID. Four people involved professionally or personally in the field of ID (a person in charge of an institution for adults with a mild to moderate ID; the mother of an adult person with an ID; a specialised educator; a man with an ID) verified that the selected illustrations do not offend sensitivity. Finally, the paper-pencil format of the test was updated through a computerised version (pdf) in order to increase the attractiveness of the test, as well as to be able to disseminate the test at a lower cost afterwards (De Palma, 2018).

In short, direct questions were replaced by indirect questions where the respondent is asked to advise a fictional character. The content of the item was illustrated with photographs (Lopez, 2013). Open-

ended questions have been added to the 3-option responses to multiple choice questions (Beaufort, 2013). Items linked with the use of the Internet were added (De Palma, 2018). These several adaptations have led to a 23-item version submitted to the validation process.

This study aims to conduct a preliminary cross-cultural validation of the French-language, enhanced and accessible version of the TICPV.

Method

Ethical approval for the study was obtained from Swissethics (Swiss Ethics Committee on research involving humans, N°2016-01480).

Sample. Twenty-nine French-speaking adults with ID were interviewed and answered the TICPV French version two times (with two to four weeks in between). Fifty-two percent of the sample was female. The mean age of the participants was 29.07 (SD=13).

Recruitment. The study was conducted in the French-speaking part of Switzerland between March 2016 and September 2018. Potential participants were identified by local leaders of four social institutions for adults with ID. Local leaders were asked to respect the following inclusion criteria: French-speaking adults (i.e. 18 years and older) with mild to moderate ID, able to have a short conversation. According to the procedure proposed by Petitpierre et al. (2013), potential participants and their legal representatives were invited to an informational meeting about the study. Informed consent of both the participants and their legal representatives was required in order to take part in the study.

Measures. Social Vulnerability Measure: Characteristics of the French version of the TICPV. The TICPV French version consists of 23 questions, with an open-ended question followed by a three-option, multiple choice question. There is a male and a female version. In the male version, the participant is asked to counsel Pierre, and in the female version, the participant is asked to counsel Marie. Each of the 23 questions describes an interaction by Pierre/Marie with a stranger (11 items), an acquaintance/friend (10 items) or a family member (2 items). Four risk dimensions are assessed: financial exploitation (9 items), verbal or physical assault (4 items), sexual abuse (6 items), inappropriate request (4 items). In each situation, an inappropriate request or action is made or carried out by the person against Pierre/Marie. After the presentation of the situation, the participant is asked an open-ended question (Que doit faire Pierre? [What should Pierre do?]). Afterwards, the participant is required to choose between three options (a, b, c) (Figure 2). As in the original version, the incorrect responses are either overly helpful or aggressive, while the 'most cautious response' terminates the interaction in a way that minimises harm and hostility. The position (a, b or c) of the 'most cautious response' was randomized amongst the three options for each situation. Only the 'most cautious' responses are considered as 'correct' and scored 1. Incorrect responses are scored 0.

Figure 2

Example of a TICPV French version item (male version, item N°1)



Pierre se promène dans la rue. Une inconnue lui demande de lui donner son argent. Que doit faire Pierre?
[Pierre is walking down the street. A woman he doesn't know comes up and asks him for money. What should Pierre do?]



A) Promettre à l'inconnue qu'il amènera l'argent demain.
[Promise the woman he will give her money tomorrow.]



B) Donner son argent à l'inconnue pour qu'elle s'éloigne au plus vite.
[Give her money so she will go away.]



C) Lui dire «non».
[Say to her « no ».]

Note. The French version asks first for the participant's spontaneous answer, then asks the participant to point the most cautious answer between 3 options.

Convergent and control measures. A convergent measure of vulnerability for victimisation was used. All items from the last Adaptative Behaviour Assessment System [ABAS-3] (Harrison & Oakland, 2015) relating to social vulnerability were collected and translated into French. This third-party report consisted of 14 items rating on a four-point scale of the extent of the social vulnerability of participants (example of item: “distinguishes between truthful and exaggerated claims by friends, advertisers or others”. Rated from “never” [0] to “always” [3]). The highest score possible was 42 points, which would express a low social vulnerability.

The Supports Intensity Scale, French version [SIS-F] (Thompson et al., 2007) was used as a control measure. The SIS-F is a multidimensional scale which aims to assess the pattern and intensity of an individual’s support needs. The scale consists of a main section, followed by two additional sections. The first section is the scale of support needs. It is composed of 6 domains (personal, work-related, social activities, community living, lifelong learning, health and safety). Scores in section 1 are reported in the Supports Needs Index which is divided into 4 levels: Level I (scores 84 or fewer points, mild level of support needed), Level II (scores between 85-99, moderate level of support needed), Level III (scores between 100-115, substantial level of support needed), Level IV (scores higher than 116, pervasive level of support needed). The two additional sections focus respectively on 1) protection and advocacy and 2) exceptional medical and behavioural support needs.

The Raven’s Coloured Progressive Matrices Test ([RCPM], Raven, 2000) was used to characterise the sample. This test measures the individual’s non-verbal, abstract and cognitive functioning. (see Table 1).

Table 1

Convergent and control measure scores (*n*=29)

Measure	Mean (SD)
ABAS-3 short-report (<i>n</i> =26)	31.82 (6.34)
SIS-F Supports Needs Index (<i>n</i> =29)	75.66 (7.513)
RCPM score (<i>n</i> =29)	27.82 (6.37)

Procedure. A research team member with a Master’s degree in special education or psychology interviewed each participant individually, in a room provided by the social institution where the participant was working or living. During the first meeting, Raven’s Coloured Progressive Matrices Test was conducted. After a short break, the TICPV French version was completed. Female participants received the female version and males received the male version. The research team member read for each participant what appeared on the screen of the computer (i.e., the instruction and the items of the TICPV) and wrote down the participant’s answer. The first meeting lasted approximately 1h 30 min. Then a retest on the TICPV French version, with the same assessor, was carried out 2-4 weeks later. This time frame was chosen to reduce the bias of recalling previous answers. Once the TICPV French

version was administered (test and retest), the ABAS-3 short-report and the SIS-F were completed by the caregivers of the participants in accordance with standard procedures (person assessed in daily setting, in real time, by a rater – caregiver – who knows him/her well). Information was sent back to the research team.

All interviews were recorded using a voice recorder and then fully transcribed in order to proceed to the analysis. As our aim was to do a preliminary validation of the psychometric properties of the TICPV French version, the analysis was carried out on the quantitative data resulting from the three-option, multiple choice response format and not on the answers to the open-ended questions which will be presented in another article.

Analysis. SPSS-25 was used to carry out the main data analysis. Given that none of the outcome variables was normally distributed, Spearman's coefficient was used to calculate the correlations (Field, 2014). Two members of the research team reviewed 100% of the participants' answers (to the three-option, multiple choice questions) in order to compute the inter-reliability analysis. Test-retest and inter-rater reliability analysis were conducted using Svensson's rank-based statistical method for disagreement analysis (Svensson, 2001). McDonald's omega and Cronbach's alpha were calculated with R Studio (Dunn et al., 2014 ; Peters, 2014).

Results

All the analyses were calculated on the full sample of 29. Regarding the SIS-F results, the mean score of the Supports Needs Index was 75.66 (SD= 7.513). Most participants had a level of support needs corresponding to Level I (i.e. scores <84). Four participants out of 29 had a level of support needs corresponding to Level II (i.e. scores on SIS-F between 85-99).

One item (N°23 "if someone on the Internet always says mean words to Pierre/Marie, what should Pierre/Marie do?") with no variation in response (i.e., all participants always chose the 'most cautious answer' at the test and the retest) was dropped. This item was one of the three new items added by De Palma (2018). It was the last item of the test and referred to online bullying on the Internet. The removal of this item resulted in a 22-item version "TV-22" on which the subsequent analyses were conducted. Mean score on TV-22 was 17.37 (SD= 4.97) points. Maximum score was 22 points. A quarter of the respondents chose a not cautious answer for items N°12 (financial exploitation by a friend), N°19 (financial exploitation by a friend) and N°4 (sexual abuse by a stranger). Scores on TV-22 were not correlated to participants' gender or age. Neither were they correlated to the scores of the short ABAS-3 report ($\alpha = .99$; $\Omega = .94$). In contrast, scores on TV-22 were correlated to the RCPM's score ($r_s = .47, p < .01$) and to the Supports Needs Index ($r_s = -.52, p < .01$). Among the SIS-F dimensions, two were more specifically correlated with the TV-22 global score: Community Living ($r_s = -.44, p < .05$) and Health and Safety ($r_s = -.40, p < .05$).

As TV-22 is multidimensional, the internal consistency reliability of the global score and the four risk dimensions (financial exploitation, verbal or physical assault, sexual abuse, inappropriate request)

were both evaluated with Cronbach's alpha and McDonald's omega (McDonald, 1981). According to DeVellis' (2017) cut-offs, internal consistency of the global score was very good ($\alpha = .89$, $\Omega = .93$). The Cronbach's alpha and McDonald's omega of the dimension concerning financial exploitation (items N°1-(N°6²)- N°12- N°13- N°14- N°16- N°18- N°19- N°20) were very good ($\alpha = .75$, $\Omega = .86$). The sexual abuse dimension (items N°4- N°7- N°8- N°11- N°17- N°22) showed a "respectable" (i.e. between .70 and .80) to "high" internal consistency ($\alpha = .79$, $\Omega = .89$), while the dimension relating to inappropriate requests (items N°5- N°9- N°10- N°21) reached the "minimally acceptable" score ($\alpha = .64$, $\Omega = .83$). Given the small number of items of the verbal (item N°2) and physical assault dimension (items N°3- N°15), internal consistency of these dimensions was not computed.

Since reliability means a high level of agreement in test-retest and inter-rater assessments, the percentage of agreement (PA) was calculated (Svensson, 2012). Svensson's method was used to calculate the percentage of agreement at T₀ between two inter-raters. Raters agreed in more than 90% of the assessments (PA range = 93% to 100%). Cohen's *k* confirms the strong inter-rater agreement evaluation (Lund Research Ltd, 2018). Cohen's *k* results are shown in Table 2.

² Item 6 was excluded from the internal consistency reliability analysis because of missing data.

Table 2Inter-rater reliability ($n=29$)

Item	Cohen's kappa	
	κ	p
1	.651	< .0005
2	1	< .0005
3	.838	< .0005
4	.930	< .0005
5	.760	< .0005
6	1	< .0005
7	1	< .0005
8	1	< .0005
9	1	< .0005
10	.713	< .0005
11	1	< .0005
12	.859	< .0005
13	.925	< .0005
14	.910	< .0005
15	1	< .0005
16	.901	< .0005
17	.888	< .0005
18	.791	< .0005
19	.858	< .0005
20	.707	< .0005
21	1	< .0005
22	1	< .0005

Test-retest results were stable over time ($r_s(29) = .81, p < .01$). Except for item N°16 (PA = 69%), PA measures for all items range from 72-100%, which means that most participants were stable in their test-retest assessments. Analysis shows a good test-retest reliability for all items except for item N°16 (Marie/Pierre gets home from work and finds someone (s)he doesn't know in her/his house). Nevertheless, the PA of item N°16 is close to the cut-off of satisfactory level (i.e. > 70% according to Kazdin, 1977). See Table 3 for detailed results.

Table 3

Test-retest reliability

Items TV-22. Female Version [back translated into English]	Marginal distribution (X(Y))				
	A	B	C	Other	PA (%)
1 Marie se promène dans la rue, une inconnue lui demande de lui donner son argent. [Marie is walking down the street. A woman she doesn't know comes up and asks her for money.]	1 (1)	0 (1)	*28 (27)	0 (0)	93%
2 Un inconnu se met en colère et crie sur Marie. [Someone Marie doesn't know gets angry and yells at her.]	*26 (24)	0 (2)	3 (3)	0 (0)	83%
3 Quelqu'un au travail embête toujours Marie et la frappe [Someone at work always teases and hits Marie.]	*25 (24)	2 (4)	2 (1)	0 (0)	90%
4 Marie est dans les toilettes de son travail, quelqu'un entre et lui dit qu'il aimerait toucher ses parties intimes. [Marie is in the toilet at work. Someone comes in and says he wants to touch her private parts.]	*17 (19)	3 (2)	9 (8)	0 (0)	76%
5 Marie se promène dans la rue, il pleut, une voiture s'arrête et le conducteur lui propose de monter. [Marie is walking down the street and it is raining. A car stops and offers her a lift.]	2 (1)	*23 (23)	4 (5)	0 (0)	83%
6 Un homme sonne à la porte et demande à Marie de signer pour faire partie d'un club de fitness. [Someone comes to Marie's door and asks Marie to sign up to be a member of a gymnasium.]	2 (2)	1 (1)	*25 (26)	1 (0)	79%
7 Une personne que Marie connaît aimerait prendre une photo d'elle sans ses vêtements. [Someone Marie knows says he'd like to take some pictures of her without her clothes on.]	0 (0)	2 (1)	*27 (28)	0 (0)	90%
8 Marie est assise à l'arrêt du bus, un inconnu met son bras autour d'elle. [Marie is at a bus stop. Someone she doesn't know puts his arm around her.]	*22 (23)	0 (0)	7 (6)	0 (0)	90%
9 Marie rencontre d'autres travailleurs, à la cafétéria, qui veulent lui offrir un verre et qu'elle aille avec eux en secret, dans leur maison. [Marie meets some guys at the cafeteria. They want to buy her a drink and want her to come to their home in secret.]	2 (2)	0 (1)	*27 (26)	0 (0)	93%
10 Il est vraiment tard, le soir, Marie attend le bus pour rentrer chez elle, mais le bus n'arrive pas. [It's really late at night. Marie waits for the bus to go home, but the bus doesn't come.]	*26 (24)	0 (2)	3 (3)	0 (0)	86%
11 Un membre de la famille de Marie vient lui rendre visite et veut se coucher avec elle dans son lit. [A member of Marie's family comes to visit and wants to lie down with her in her bedroom.]	3 (2)	*22 (24)	4 (3)	0 (0)	86%

Table 3 Continued

Items TV-22. Female Version [back translated into English]	Marginal distribution (X(Y))				
	A	B	A	Other	A
12 Marie a reçu un téléphone portable pour Noël, une amie lui demande de lui donner. [Marie receives a smartphone for Christmas and a friend asks her to give it to her.]	*16 (18)	0 (1)	12 (10)	1 (0)	83%
13 Quelqu'un sonne à la porte. Marie lui ouvre. La personne dit qu'elle n'a pas d'argent mais qu'elle a besoin d'une nouvelle TV. [Someone comes to Marie's door and says he doesn't have any money but needs a new TV.]	*18 (22)	3 (1)	8 (6)	0 (0)	72%
14 Un homme en uniforme demande à Marie de lui donner de l'argent. [A man in uniform asks Marie to give him money.]	3 (2)	*22 (22)	4 (5)	0 (0)	72%
15 Lorsqu'un membre de la famille de Marie a bu de l'alcool, il la frappe. [A member of Marie's family always punches her when he's had a few drinks.]	0 (0)	3 (4)	*26 (25)	0 (0)	83%
16 Marie rentre du travail et trouve un inconnu chez elle. [Marie gets home from work and finds someone she doesn't know in her house.]	4 (2)	*23 (25)	2 (2)	0 (0)	69%
17 Le petit ami de Marie veut avoir des relations sexuelles avec elle, mais elle ne veut pas. [Marie's boyfriend wants to have sex with her, but she doesn't want to.]	*23 (23)	0 (1)	5 (5)	1 (0)	72%
18 La voisine de Marie lui emprunte son grille-pain et ne lui rend pas. [Marie's neighbor takes her toaster and doesn't give it back to her.]	3 (3)	2 (0)	*24 (25)	0 (1)	76%
19 Marie a mis de l'argent dans sa tirelire. Une amie vole cet argent. [Marie put some money in a piggy bank at home and a friend takes it.]	1 (4)	*17 (13)	11 (12)	0 (0)	83%
20 Une inconnue demande à Marie de lui prêter son vélo. [Someone Marie doesn't know asks if she can borrow her bike.]	3 (2)	*22 (22)	3 (5)	1 (0)	93%
21 Sur Internet, un inconnu demande à Marie de lui donner son numéro de téléphone. [Marie chats with a man on the Internet. This man asks for her phone number.]	*23 (23)	2 (1)	4 (5)	0 (0)	97%
22 Sur Internet, Marie discute avec quelqu'un qui lui demande de se déshabiller. [Marie chats with a man on the Internet. This man asks her to take off her clothes.]	*23 (23)	1 (1)	5 (5)	0 (0)	100%

Note. Descriptive statistics and individual variability between test-retest for the 22 items of the TV-22 ($n=29$). X = marginal distribution at T_0 (test) ; Y = marginal distribution at T_1 (retest) ; PA = percentage of agreement ; * = Correct answer.

Discussion

The TV-22, which was adapted from the Test of Interpersonal Competence and Personal Vulnerability (TICPV), is designed to assess the social vulnerability of adults with ID. The current study examined the psychometric properties of the TV-22. The findings provide preliminary support for the utilisation of the test, as the test demonstrates very good internal consistency and good test-retest and inter-rater reliability. The main findings of this study will be discussed in further details: results suggest that social vulnerability is not linked with gender or age but to level of support needed and to IQ level; they highlight discrepancies between self-report (TV-22) and third-party report of social vulnerability (short ABAS-3); finally, among the 22 items of the test, three were more difficult for the participants, even if the quite high mean global score on the TV-22 suggest a ceiling effect.

Link between social vulnerability and need of support. Results show that scores on TV-22 are negatively correlated to the need of support in daily activities. In other words, it means that the less an individual needs support in the context of community living and for his or her health and safety, the less (s)he is socially vulnerable. These results are similar to those of Lough and Fisher (2016) who explored the social vulnerability of 102 adults with Williams Syndrome, through both self-report and parent-report. Those who reported greater functional independence, as measured with the Activities of Daily Living [ADL] (Seltzer & Li, 1996) also showed less social vulnerability (as measured with the SVQ). More generally, individuals with ID with a higher degree of independence seem to report higher social participation (i.e., interpersonal relations, social inclusion, rights) than their more dependent peers (Simoes et al., 2016; Alonso-Sardón et al., 2019). Social skills of individuals with ID may thus vary not only in relation to the severity and etiology of the ID but also in relation to the opportunities for learning they are offered (Sigafos et al., 2017). Adults with ID may be less independent because they are offered less opportunities for making choices (Simoes et al., 2016). Individuals who need less support may often also be those who attend more diverse and open environments and can benefit from a richer relational environment, offering more opportunities and more examples that inspire learning and the development of a wide range of valuable and diverse solutions. This could explain why the individual's level of independence (and the opportunities of rich self-experiences) probably plays an important role in preventing social vulnerability.

Link between social vulnerability and fluid intelligence. Scores on TV-22 are correlated to the participant's non-verbal, abstract and cognitive functioning (as measured with RPCM). These results are similar to those of the original instrument, where a significant correlation was observed between scores on the TICPV and IQ – as measured with TONI-2 (Brown et al., 1990) (TONI-2, $n=40$, $r_s = .40$, $p < .05$). This outcome suggests a moderate association between ability to protect oneself and fluid intelligence. This relation is theoretically consistent as RPCM score reflects fluid intelligence which is associated with new problem resolution abilities, in particular relational reasoning (i.e., the ability to be creative, identify and consider relationships between multiple mental options) (Crone et al., 2009; Krawczyk, 2012). Intellectual disability is primarily “a disorder of reasoning and judgement” (Greenspan

& Wood, 2014). These specific results can explain the difference with the results of Lough and Fisher (2016) who found no correlation between the SVQ total score (or sub-scores) and IQ measured with the Kaufman Brief Intelligence Test 2nd ed. (KBIT-2, Kaufman & Kaufman, 2004). This difference can be explained by the fact that KBIT-2 is a composite test designed for screening and assessing several cognitive sub-dimensions (receptive vocabulary, verbal reasoning, matrices, including general knowledge) and not intended for the in-depth assessment of fluid intelligence. In view of this statement, further research is needed to explore in a thorough way the role of cognitive sub-skills in risk (un)awareness and social victimisation (Greenspan et al., 2011).

Link between social vulnerability (self-report) and adaptive behaviour (third-party report). The results show no correlation between social vulnerability (self-report with TV-22) and the 14 items from the adaptive behaviour assessment related to social vulnerability (caregiver report with short ABAS-3).

The following explanations can be put forward to account for this outcome:

Since, in the present study, the adaptive behaviour was measured with a non-validated translated version of ABAS-3, we cannot exclude a measurement problem due to the quality of the translation. As the same caregiver responded both to ABAS and SIS-F, we cannot suspect a problem with the informant, but rather with the rigour of the information-gathering tool. The rigour of the measures concerning adaptive behaviour is moreover a prevailing topic (Salekin et al., 2018). It should also be noted that the discrepancy between self-report (TV-22) and caregiver (short version of ABAS-3) on social vulnerability looks very much like the findings of Lough and Fisher (2016). In their study, self-report of adults with Williams Syndrome and parent reports on social vulnerability were significantly different. An explanation for these differences may lie in the type of measurement. Dunning and colleagues (2004) reviewed empirical findings on self-assessment of neurotypical persons and found that the correlation between self-ratings of skill and actual performance in many domains (e.g. health, education, workplace) is moderate to meagre. Informant-report predicts a person's behaviour more accurately than that person's self-prediction (Dunning et al., 2004; Balsis et al., 2014; Galione & Oltmanns, 2013). Overall people seem to commonly overestimate the likelihood that they will engage in desirable behaviours (Dunning et al., 2004). These findings underpin the importance of crossing the sources of evaluations. De los Reyes and colleagues (2019, p.2) argued for the value of a new assessment paradigm termed intersubjectivity which considers that "each method (e.g., subjective, laboratory observation, objective) yields useful information about the experiences and/or contexts in which one observes displays of the phenomenon under study". Rather than embracing the merits of some assessment forms and shunning the use of others, findings from their meta-analysis emphasise the importance of examining sources collectively. Multi-informant and multi-method approaches are critical to understand a phenomenon. Points of convergence and divergence should not be considered as noise that disturbs the understanding but might reflect contextual variations in behaviour and /or in social environment, as they might index meaningful information about the psychological phenomena under investigation (De los Reyes et al., 2019). The fact that the evaluation of the social vulnerability of

the participant by the caregiver does not match the self-report of social vulnerability underlines the need for further theory and research on this intersubjectivity, its meaning and its implication for practice.

Possible ceiling effect. The mean global score (17.37/ 22 points, SD= 4.97) on the TV-22 may suggest a ceiling effect. Such an effect was not observed in the original instrument. For ethical reasons, this study only included participants who had not been abused in the past. If we take this into account, the results are not so far from those of the original study of Wilson et al. (1996), where the average global score on TICPV was 15.00 (SD= 2.23) on 20 points for adults with ID known as not being victims of abuse, but 12.75 (SD= 4.05) on 20 points for people known as having been victimised in the last 10-12 months. The difference can however also be explained in several other ways: the high scores on TV-22 could be related to the changes introduced, e.g., to the fact that the items were presented in the Easy to Read and Understand Format; or to the fact that participants had to counsel Pierre/Marie and not speak for themselves. The change from first-person account to third-person account may have positively affected their answers by introducing a kind of conceptual step back (i.e., the person knows what is the most cautious behaviour for Pierre/Marie, but she/he would not act in this way). Another explanation could refer to a possible rise in social vulnerability scores over generations, resulting in the population's gains across time (i.e., "Flynn Effect" for IQ, Flynn, 1984), as it has been shown for fluid intelligence (Wongupparaj et al., 2015) to which it correlates. Some studies hypothesise that the Flynn Effect is not limited to intelligence tests but may be present across cognitive domains (Trahan et al., 2014).

Heightened social vulnerability. The three most difficult items for all respondents were items N°12 and N°19, which both imply financial exploitation by a friend, and item N°4 (sexual abuse by a stranger). Regarding item N°4 ("Marie/Pierre is in the toilet at work. Someone comes in and says he wants to touch her/his private parts"), while 17 persons answered with the most cautious option (option a, "say that s/he doesn't like people doing that"), nine persons chose to avoid the situation (option c, "don't go to the toilet again") and three persons chose option b ("let them do it because they might get angry"). The fact that one-third of the sample chose not to go to the toilet anymore provides a precious insight into the difficulty of some participants to assess the adequacy – in the long term – of the solution. The response is indeed not a viable option, because no one can do without going to the bathroom for long. Thirteen persons at item N°12 ("Marie/Pierre receives a smartphone for Christmas and a friend asks her/him to give it to her."), did not choose the 'most cautious answer' (option b, "let her listen to music with it but don't give it to her"). Twelve persons chose rather option c, "give her money to buy her own", and one person chose option a ("give it to her because it's good to share"). At item N°19 ("Marie/Pierre put some money in a piggy bank at home and a friend takes it."), rather than choose option b ("tell his/her friend s/he knows she took it), 12 persons preferred option c ("go to the friend's house and take it from her"), while 1 person chose to forget about it (option a). These results may suggest a higher social vulnerability when there is a friendship relation between the victim and the offender, particularly with regard to financial exploitation. These results are similar to results

on the SVQ, where 43 parents (out of 102) of adults with Williams Syndrome, when they were asked to give an example of their child's social victimisation during the last year, provided an example of financial exploitation (e.g. "He has become friends with customers of his store. One of these individuals convinced him to give her money because she was going to lose her house. He used his debit card and gave her \$300.", from Lough & Fisher, 2016). More generally, results on TV-22 tend to confirm the risk of financial exploitation for individuals with ID, a risk which has already been identified as a common form of victimisation for this group (Lough & Fisher, 2016; Fisher et al., 2012; Greenspan et al., 2001; Nettelbeck & Wilson, 2001).

The fact that participants struggled with items involving friendships also corroborates findings of qualitative researches investigating friendships of persons with ID (Bane et al., 2012). In participatory research involving almost one hundred adults with ID, Bane and colleagues found that education on friendships and relationships would help adults with ID to have and keep their social relations. Results on the TV-22 and participants' choice of answer underpins the need for more research on friendships process among individuals with ID, in particular their ability to manage symmetrical relations with peers and self-protection. Such results would allow professionals to better support them in practice, for example through peer mentoring programs aiming at training social skills in more authentic settings (Athamanah et al., 2019).

Limitations, synthesis and implications

Despite a small sample size, results provide psychometric support for the use of TV-22. Nevertheless, a factor analysis of the TV-22 is needed to confirm these results. Future work should consist of a larger random sample in order to confirm these preliminary results.

Other situations of possible victimisation, which would be important to assess nowadays as well (for example, use of social media, sexting, etc.) were not created and the dimensions evaluated were not equal in terms of number of items. Consequently, research could improve this by balancing the explored dimensions (financial exploitation, sexual assault, verbal or physical assault, inappropriate request) and updating them with current social risks.

The cross-cultural adaptation of the TICPV led to several changes in the test, although the French version aimed to stay as close as possible to the original Australian version.

The high scores on the TV-22 and the fact that these were not correlated to the third-party reports underpins that the test is more accurate to highlight learned knowledge or social rules (e.g., "you should not give money to someone you don't know") rather than personal vulnerability in real life. Thus, this also underlines the need to cross-reference the sources and method of measurement. Further research should examine social vulnerability reports through the lens of intersubjectivity in order to inform an understanding of the intersection between vulnerability traits and the social contexts eliciting these traits. As a self-report measure, the TV-22 could be used with the SVQ (Fisher et al., 2018), which

is a third-party report measure. Together, these evaluations would lead to a fuller picture of the person's strengths and limitations in social risky situations.

To summarise, the results highlight the importance of teaching independence in daily activities, but also of providing the necessary social support and education to enable adults with ID to avoid victimisation. Findings of the TV-22 could thus help clinicians to provide better support of adults with ID in their daily life. Clinicians could use the TV-22 to assess the progress of the people with whom they work, either as part of an annual assessment or before/after attending courses on socialisation or abuse prevention. TV-22 could also be used in further research in pre-testing and post-testing to assess the effectiveness of an abuse prevention intervention (e.g., the programme ESCAPE-NOW, Khemka & Hickson, 2015) or a programme aiming at training social skills (e.g., the Friendships and Dating Program, Ward et al., 2013).

Finally, beyond the global score on the test, it seems that the way the person thinks in these situations is a key to assess a person's social vulnerability. We are currently conducting a study which aims to analyse this framework and investigate the answers.

As Atkinson and Ward (2012, p.307) wrote:

we are beginning to understand the severity and intricacies of interpersonal violence for people with ID/DD. A shared awareness of the problem will help to better understand how to best measure the problem and to develop strategies to prevent interpersonal violence in the lives of individuals with ID/DD. There is a paucity of tools to assess these issues.

Further research is needed to address this paucity of tools and to better understand the links between adaptive behaviour, IQ, victimisation and social vulnerability.

3.2 Study II. Evaluating implementation outcomes of a measure of social vulnerability in adults with ID³

Abstract

Introduction. A test identified as valid and accurate in research will not automatically be considered appropriate by those involved in its use, or even be used in the first place. The Social Vulnerability Test-22 items [TV-22] is a measure specially designed for adults with intellectual disabilities (ID). This study aims to evaluate the implementation outcomes of the TV-22; more precisely its acceptability (e.g., complexity), appropriateness (e.g., perceived relevance) and the assessment fidelity (i.e., adherence to assessment guidelines) by special education practitioners.

Method. Thirty-one practitioners (8 psychologists, 11 educators, 12 special education center managers) administered the TV-22 during an interview with an adult with ID. Semi-structured interviews were conducted to collect practitioners' opinions on the acceptability and the appropriateness of the TV-22 for their clinical practice. Quantitative analyses were performed to assess the fidelity of the assessments and the influence of some personal factors.

Results. The results indicate a good appropriateness, a reasonable acceptability – but a low assessment fidelity of the TV-22 by some practitioners. Psychologists stand out for a more rigorous use of the test.

Conclusions. Results highlight the importance of evaluating implementation outcomes when a new measure is developed to ensure its appropriateness and correct use by stakeholders.

Keywords: intellectual disabilities; social vulnerability; implementation outcomes; assessment fidelity; acceptability; appropriateness; user experience

³ This study is a reprint of the article: Tabin, M., Diacquenod, C., & Petitpierre, G. (2021). Evaluating implementation outcomes of a measure of social vulnerability in adults with intellectual disabilities. *Research in Developmental Disabilities*, 119. <https://doi.org/10.1016/j.ridd.2021.104111>

What does this paper add? The assessment of social vulnerability aims to evaluate the ability of a person to detect and handle potentially harmful social situations. The Social Vulnerability Test-22 items (TV-22) is a measure specially designed for adults with ID. Not all social institutions providing services for adults with ID have a psychologist on staff: the assessments are sometimes carried out by educational staff or the team/center manager. In this context therefore, evaluating to what extent the characteristics of the assessor are likely to influence the quality of the assessment is particularly important. In the present research, we aim to evaluate the implementation outcomes (acceptability, appropriateness, assessment fidelity) of the TV-22 by special education practitioners (psychologists, educators, team/center managers). The results indicate a good appropriateness, a reasonable acceptability, but a low assessment fidelity of the TV-22 by some practitioners – which definitely questions the quality of the social vulnerability assessment performed. Despite its important role in interpreting results, assessment fidelity has received little attention to date; more research is needed to explore assessment fidelity and possibilities to enhance it when required.

Introduction

A test considered as valid and accurate in research will not automatically be considered appropriate by those involved in its use, or even be used in the first place. Greenhalgh et al. (2004) discussed the need to move from a “let it happen” mindset to a “help it happen” or even “make it happen” perspective. Evaluating implementation outcomes is one possibility to make this move into the “make it happen” perspective. Implementation outcomes refer to “effects of deliberate and purposive actions to implement new treatments, practices, and services” (Proctor et al., 2011, p. 65). Evaluating implementation outcomes is important: implementation outcomes are not only indicators of the implementation success and processes, they are also essential features of program or innovation evaluations as they affect the outcomes obtained (Durlak & DuPre, 2008).

Acceptability, appropriateness, and fidelity are part of the core set of implementation outcomes (Proctor et al., 2011). Acceptability refers to the satisfaction of implementation stakeholders with various aspects of the innovation (e.g., content, complexity, credibility). Appropriateness is the perceived relevance, suitability, and compatibility of the innovation for a given practice setting. Whereas “appropriateness” and “acceptability” are conceptually similar and sometimes overlapping, it seems accurate to distinguish between them because a given innovation may be perceived as acceptable but not appropriate and vice versa (Proctor et al., 2011). Fidelity consists of the degree to which an intervention was implemented as it was prescribed in the original protocol (Proctor et al., 2011). More precisely, assessment fidelity – also labelled “procedural fidelity assessment” (DiGennaro Reed & Coddling, 2014) – refers to the respect and adherence to assessment procedures or guidelines (Richardson et al., 2016). In clinical practices, assessment fidelity is important to guarantee the quality of the evaluation carried out and the reliability of the outcomes obtained. One construct for which it is important to measure with fidelity is social vulnerability.

Some adults with ID, whether younger or older, men or women, are more socially vulnerable than others (Nettelbeck & Wilson, 2002). Social vulnerability is a dynamic, fluid, and multidimensional construct (Petitpierre & Tabin, 2021). Currently, social vulnerability is defined as the ability to detect or avoid victimization, e.g., physical or sexual assault, financial abuse, or psychological abuse, like bullying or coercion (Fisher et al., 2018). Social vulnerability is not an intrinsic factor of ID. Any individual, including a person with ID, learns to independently navigate potential challenges and thus decrease their social vulnerability through exposure to social situations (Seward et al., 2018). Social vulnerability also depends on the presence or absence of certain risk or protective factors. Studying social vulnerability in adolescents and adults with Williams Syndrome, Down Syndrome, and Autism Spectrum Disorder, Fisher and colleagues (2018) noted the role of friendships in social vulnerability. Indeed, those with lower education and fewer friends also had less awareness of risk, increasing their social vulnerability. Social vulnerability also appears to tap into some skill over and above either IQ, social intelligence or adaptive behavior (Fisher et al., 2018; Sofronoff et al., 2011; Wilson et al., 1996). Social vulnerability does not systematically lead to abuse, but it indicates a likelihood of being abused.

In comparison with other variables such as anxiety, anger, behavior problems and social skills, social vulnerability was found to be the best predictor of bullying victimization for children with Asperger Syndrome (Sofronoff et al., 2011). Likewise, social vulnerability distinguished victims of interpersonal violence (assault, sexual assault, robbery, financial exploitation, break-in) from non-victims in the previous year in a sample of adults with ID (Wilson et al., 1996).

The assessment of social vulnerability aims to evaluate the ability of a person to detect potentially harmful interpersonal situations (Seward et al., 2018). People with disabilities, particularly those with intellectual disabilities, are significantly more at risk of being victims of interpersonal violence than the general population (Dion et al., 2011; Sullivan & Knutson, 2000). Not all social institutions providing services for adults with ID in Switzerland have a psychologist on staff: the assessments are sometimes carried out by educational staff or the team/center manager. In current clinical practices, the social vulnerability assessment of adults with ID is usually conducted by special education practitioners as clinical observations (Petitpierre & Tabin, 2021). This evaluation format, however, leaves a lot of room for the subjectivity of the observers. In this context, standardized tools, like self-reported and/or informant-rated tests, are welcome as they offer more uniform evaluation criteria. Together with clinical observations, they provide a more complete and nuanced picture of a person's strengths and limitations. The Social Vulnerability Test-22 items (TV-22) is currently the only social vulnerability measure validated and specifically designed for adults with ID available in French (Tabin et al., 2021). The test is composed of 22 illustrated vignettes mimicking real-life social situations. In each item (vignette), the person being assessed is asked to advise a third person (Marie or Pierre, according to the gender they identify with) facing a social risk (theft, verbal or physical aggression, sexual abuse, inappropriate requests or attempts at manipulation).

The TV-22 results from the cross-cultural adaptation of the Test of Interpersonal Competence and Personal Vulnerability [TICPV] from Wilson et al. (1996). In the original study, Wilson et al. (1996) analyzed the reliability and the validity of the TICPV in a sample of 40 adults with ID. Internal consistency (Cronbach's $\alpha = .72$) and test-retest reliability ($r(20) = .72, p < .001$) of the TICPV were good; further studies confirmed the good discriminatory validity with larger samples (Murphy & O'Callaghan, 2004; Nettelbeck & Wilson, 1995; Nettelbeck et al., 2000). The TV-22 is the French-language, enhanced (+ 2 items) and accessible version (i.e., following easy-to-read and understand principles, Inclusion Europe, 2009) of the TICPV. The validation was performed on a sample of 29 adults with ID. Internal consistency (Cronbach's $\alpha = .89$; McDonald's $\Omega = .93$) and test-retest reliability ($r_s(29) = .81, p < .01$) of the TV-22 were good. Inter-rater reliability was calculated between two independent coders from the research team with Cohen's κ and ranged from .651 to 1 ($p < .001$) i.e., from substantial to perfect agreement according to Landis and Koch (1977) benchmarks.

In the present research, we aim to evaluate the implementation outcomes (acceptability, appropriateness, assessment fidelity) of the TV-22 as administered by special education practitioners (psychologists, educators, team/center managers). More precisely, we examine the influence of some

personal factors in relation to assessment fidelity and acceptability of the test. We further explore the appropriateness, i.e., the perceived relevance and challenges related to the compatibility of the test, to the participants' practice. These analyses will highlight facilitators and barriers to implementation outcomes, providing information on the modifications required to ensure the adequate use of the TV-22 and its dissemination.

Material and method

This study is the second strand of a mixed methods test validation project. The whole project lasted from February 2018 to August 2020 (Petitpierre, 2018); data for this second strand were collected in Spring 2019. The results of the first strand, focused on the psychometric properties of the test, have been detailed elsewhere (see Tabin et al., 2021). The project was approved by the Swiss Ethics Committee on research involving humans (Protocol N°2016-01480) and funded by the Swiss National Science Foundation (Project N°17196).

Participants. Thirty-one practitioners were identified by the heads of eight social institutions for adults with ID in the French-speaking part of Switzerland. Participants were primarily female, with more than 15 years of experience in the field. They were divided into two groups (see Procedure section for further details). Both groups were invited to a training session on the use of the TV-22. At the end of the training session, each practitioner completed an informed consent document and a short survey. The short survey included questions on demographic information, experience and general attitude towards assessment tools (see Table 1).

Table 1Participant demographics, experience and attitude towards assessment tools ($n=31$)

Characteristic	Group 1 (regular training)		Group 2 (enhanced training)		Total	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Gender						
Male	2	12.5	3	20.0	5	16.0
Female	14	87.5	12	80.0	26	84.0
Age						
20–29	2	12.5	3	20.0	5	16.0
30–39	7	43.7	5	33.3	12	39.0
40–49	2	12.5	4	26.7	6	19.0
50–60	5	31.3	3	20.0	8	26.0
Profession						
Educator	6	37.5	5	33.3	11	35.0
Psychologist	4	25.0	4	26.7	8	26.0
Team/Center Manager	6	37.5	6	40.0	12	39.0
Years of experience in the field of ID						
2–5	3	18.7	5	33.3	8	26.0
6–10	3	18.7	3	20.0	6	19.0
11–15	5	31.3	-	-	5	16.0
> 15	5	31.3	7	46.7	12	39.0
Experience in using assessment tools with people with ID						
Never used	4	25.0	1	6.7	5	16.0
Rarely used	1	6.3	5	33.3	6	19.5
Sometimes used	9	56.3	4	26.7	13	42.0
Often used	1	6.3	5	33.3	6	19.5
Very often used	1	6.3	-	-	1	3.0
Point of view on the usefulness of assessment tools						
Not at all important	-	-	-	-	-	-
Low importance	-	-	-	-	-	-
Neutral	3	18.7	6	40.0	9	29.0
Very important	9	56.3	9	60.0	18	58.0
Extremely important	3	18.7	-	-	3	10.0
No answer	1	6.3	-	-	1	3.0

Material. The participants were provided with the Social Vulnerability Test-22 items [TV-22] and its associated materials.

Administration of the test.

(1) An instructor's manual briefly introduces the concept of social vulnerability, the ethical precautions to follow when using the test and then describes the instructions for administration of the test as well as the procedures for scoring and interpreting the respondent's responses. The main conditions for administration of the test are the following: each person is assessed individually; there is no time limit per item; the length of time to administer the full set of TV-22 vignettes is flexible. It can vary from one respondent to another. The results of the validation procedure indicate an average duration of 70 minutes (min. 43 minutes; max. 132 minutes).

(2) The test is composed of 22 items (88 illustrated vignettes in total). For each vignette introduced, the respondent is first asked to reformulate the situation (What is happening here?). This reformulation requirement aims to check the person's understanding of each vignette. The test, which is administered on a computer (PowerPoint format), consists of two parts following each other. In Part A, the situation (vignette) is presented and the assessor asks for the respondent's spontaneous answer (What do you advise Pierre/Marie to do or say?). In Part B, the vignettes from Part A are followed by three possible answers (a, b, c, also illustrated vignettes). The respondent is then asked to choose the most cautious of the three available answers (see Figure 1). For each answer given, whether spontaneous answer (part A) or the most cautious answer (part B), the respondent has to justify the proposed strategy (Why should Pierre/Marie do that? (A); Why do you think it is the 'most cautious' answer? (B)).

Figure 1

Example of a TV-22 item before the implementation study (female version, item N°17, English translation)



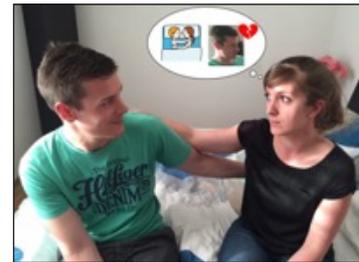
Marie's boyfriend wants to have sex with her, but she doesn't want to.



A) Say she doesn't really feel like it today.



B) Do it, but don't go out with him anymore.



C) Do it, otherwise her boyfriend will love her less.

Note. The assessor asks: what is happening here? What do you advise Marie to do or say? Why? The assessor then shows each of the three following options (A, B, C) and asks: what is the 'most cautious' answer? Why?

(3) One reported answers sheet and two scoring sheets (Sheet A; Sheet B) go along with the test and the instructor's manual. When administering the test, the assessor reports all of the respondent's answers on the "Answer Sheet".

Scoring and interpretation of the test results. Once the test is performed, the assessor qualitatively analyzes the respondent's spontaneous answers given (Part A) on "Sheet A". The scoring of spontaneous answers from part A provides a first – qualitative – picture of the person's abilities and/or limitations in recognizing the risk present in the situation and their ability to propose strategies to mitigate the risk (for more details about Part A, see Tabin, 2020). The answers given can be categorized in two major categories: either the respondent identifies and handles the risk (1) or s/he does not (2). When the respondent answers that there is a problem in the situation presented (risk awareness), and mentions one or more protection strategies, their answer is coded according to five sub-categories ((1)A self-protection; (1)B indirect protection; (2)C no strategy; (2)D emotional strategy; (2)E avoidance strategy). Cohen's κ was run to determine agreement between two independent coders from the research team on the categorization of spontaneous responses collected in Part A in 20% of the data ($n=6$). Cohen's κ ranged from .700 to 1, i.e., from substantial to perfect agreement according to Landis and Koch (1977) benchmarks.

The results from Part B provide a score of social vulnerability and are reported on 'Sheet B'. The 'most cautious' answer is scored 1, whereas the other options are scored 0. The higher the score (22 points maximum), the more capable the person is of choosing strategies that tend to protect Pierre/Marie. Inter-rater agreement between the two independent coders from the research team on the categorization of multiple-choice responses collected in Part B (on 20% of the data) was similar to Part A and ranged from $\kappa = .667$ to 1.

Procedure. All participants were invited to a training session of approximately 90 minutes on the use of the TV-22. They were divided into two groups according to a stratified random distribution principle by function. The purpose of dividing the participants into two groups was to assess which kind of training was most suitable for an optimal appropriation of the principles of administration of the TV-22.

The first group ("regular training", $n=16$) received a general introduction on the origin and goals of the test. Practitioners were given the instructor's manual and test materials (a USB flash drive with the test, reported answers sheet, scoring Sheet A, scoring Sheet B).

The second group ("enhanced training", $n=15$) followed the same procedure, with the difference that they received a tutorial in addition to the instructor's manual. This tutorial describes the administration of the test in video format: it consists of a PowerPoint file with recorded comments (21 minutes) describing the instructions for administration of the test, and the procedures for scoring and

interpreting the respondent's responses. It also includes a short video (4 minutes) of an administration example with an assessor and a respondent using the TV-22.

At the end of the training session, each practitioner was required to administer the TV-22 with an adult with a mild to moderate ID with whom they were working, to record the interview on audio tape, score the responses of the person they had assessed, and then send the recording of the test and the scoring results to the research team within one month. Two out of 31 practitioners (one from each group) encountered technical difficulties and were unable to record their interview. Twenty-nine interviews were fully transcribed by the research team.

Semi-structured interviews were conducted with practitioners to elucidate their experience using the TV-22, with a focus on identifying barriers and facilitators to implementation. Interview duration was approximately 40 minutes. One member of the research team conducted the interview, whereas the other reported what the participant said. The interviews were also recorded, to be able to go back to the exact words used if needed. The interview was divided into three parts:

- The first part addressed the assessment fidelity of the TV-22 and, more precisely, correct administration and use of the materials provided: 12 questions were dichotomous (yes/no type) (e.g., assessor and respondent were sitting next to each other; they were alone in a room; the reported answers sheet was used during the administration).
- The second part addressed the acceptability of the TV-22: five open-ended questions were asked (e.g., What did you find easy or, conversely, difficult during the administration of the TV-22? What do you think about the 22 vignettes of the test?) and three 5-point Likert-type scale questions ranging from very easy (1) to very difficult (5) about the complexity of administering the TV-22, the complexity of the scoring, and the complexity of the interpretation of the social vulnerability scores.
- Finally, five open-ended questions were about the appropriateness of the TV-22 (e.g., Why do you think that the TV-22 will (not) be useful for your clinical practice?).

Analysis. In order to evaluate the assessment fidelity of the TV-22, quantitative analyses (using SPSS, version 26) were conducted. The evaluation of the fidelity was based on (1) analysis of the interview transcripts between the practitioner and the adult with ID, the scoring Sheet A and the scoring Sheet B completed by the practitioner; and (2) the answers given by the practitioner to the first 12 questions of the semi-structured interview. Three dimensions of the assessment fidelity were analyzed: compliance with the administration conditions (12 criteria), conformity to the assessment procedure (4 criteria*22 items), and scoring of the items (2 criteria*22 items), comprising a total of 144 structural-procedural critical components (see Table 2 for details). These components were coded independently by two members of the research team for each fully completed test administration ($n=29$). Inter-rater agreement, calculated on 20% of the data ($n=6$) for the 144 components, ranged from $\kappa = .667$. to 1, i.e. from substantial to perfect agreement according to Landis and Koch (1977) benchmarks.

Table 2

Structural-procedural critical components evaluated for assessment fidelity

Dimension		Criteria	Rating
Compliance with the administration conditions	12 criteria	5 criteria: Compliance with the general administration conditions (e.g., assessor and respondent were alone in a room); 7 criteria: The use of prescribed material (e.g., the reported answers sheet was used during the administration);	Dichotomous (yes, criteria respected =1/no=0)
Conformity to the administration procedure	4 criteria * 22 items	1*22: Reformulation asked (What is happening here?) 1*22: Part A question asked (What do you advise Pierre/Marie to do or say?) 1*22: Justification asked (Why should Pierre/Marie do that?) 1*22: Part B question asked (What is the 'most cautious' answer (A, B or C)?)	Trichotomous (yes=2/partially=1/no=0) ^a Dichotomous Dichotomous Dichotomous
Scoring the items	2 criteria * 22 items	1*22: Open-ended questions (Part A) 1*22: Multiple-choice questions (Part B)	Agreement between the scoring given by the practitioners and the member of the research team

^aNote. The reformulation was sometimes skipped by the practitioners when the respondents spontaneously reacted (e.g., laughed, said "oh my god"). Because it reflects to some extent an understanding – which is the aim of the reformulation requirement –, if the practitioner did not explicitly ask for the reformulation, those reactions were coded as 'partially' fulfilled (1 point).

In order to assess the factors influencing the assessment fidelity and the acceptability of the test (e.g., gender, age, profession), quantitative analyses (using SPSS, version 26) were performed. Qualitative analyses (using NVivo, version 12) were conducted to assess the appropriateness of the test. We conducted a thematic analysis (Paillé & Mucchielli, 2012). This analysis requires that segments of text ranging from a phrase to several paragraphs were assigned codes based on a priori (i.e., from the semi-structured interview guide) themes. Afterwards, these themes were further analyzed to check whether they repeat from one segment to another and how they intersect, join, contradict or complement each other (Paillé & Mucchielli, 2012). This analysis constructs a panorama which identifies the major trends of the phenomenon, here the facilitators and barriers to implementation outcomes.

Results

Among special education practitioners, psychologists emerged as using the test more rigorously. Assessment fidelity was related to years of experience in special education, current profession and experience with assessment tools; but not to gender, age or type of training. Acceptability of the measure was not influenced by any of the practitioners' characteristics. The results of the qualitative analyses of the appropriateness revealed the relevance and usefulness of the test as well as the most common challenges faced by the practitioners when using the TV-22: fatigue linked to the respondent being required to reformulate; reporting the respondent's responses during administration of the test; analysis of open-ended questions. Each outcome provides valuable information on the modifications needed to ensure the adequate use of the TV-22 and promote its dissemination.

Assessment fidelity. Assessment fidelity has been analyzed separately for: (1) compliance with the administration conditions (12 criteria= 12 points), (2) conformity to the administration procedure (4 criteria*22 items, coded either in a dichotomous or trichotomous way= 110 points) and (3) scoring of the items (2 criteria*22 items= 44 points).

(1) Administration conditions. The results show that the conditions for administration were followed by most participants. The 12 criteria assessed (e.g., quiet room; Sheet B was used as described in the user's manual) were respected to a great extent ($M=96.5\%$, with a range between 87.1% to 100%).

(2) Conformity to the administration procedure. Regarding the administration of the items (i.e., asking the questions to assess the respondent's social vulnerability), practitioners obtained, on average, a score of 69 ($SD=26.09$) – a score which displays a relatively low adherence to the administration guidelines. A maximum score of 110 per administration can be obtained; the higher the score, the better the administration, as it reflects that the practitioner asked each of the questions required to be asked in order to assess the respondent's social vulnerability, on each of the 22 items of the test. The maximum total fidelity score achieved is 109. Seven practitioners obtained fewer than 50 points; 5 (17% of the sample) obtained 44 points or less, which means that they asked fewer than 50% of the questions required to perform the assessment.

(3) Scoring of the items. The inter-rater reliability (i.e., the rating given by the research team member versus the rating given by the practitioner) was calculated separately for open-ended questions (Part A) and multiple-choice questions (Part B).

For open-ended questions the inter-rater reliability, calculated with Cohen's κ , is fair for 7 out of 22 items ($\kappa < .400$); moderate for 13 items; and substantial for 2 items ($\kappa > .610$) (Landis & Koch, 1977; see Table 3 for detailed Cohen's κ results). Cohen's κ is globally unsatisfactory for the open-ended questions, as it ranges below what could be expected at an individual level and is also way below the agreement found between two independent coders from the research team, which ranged between .700 and 1 (see section Scoring and interpretation of the test results).

We can also note that with regard to compliance with the guidelines underlying Part A of the test (open-ended questions), the number of participants varies and never reaches 29 (i.e., the total number of participants expected for these analyses): some open-ended questions were systematically and fully skipped by some practitioners and were thus coded as 'missing data' and excluded from reliability analysis on the scoring fidelity.

As regards the multiple-choice questions, except for item 3 ($\kappa = .540$; $p < .001$), the inter-rater reliability ranged between .638 and 1, i.e., substantial to excellent agreement (Landis & Koch, 1977; see Table 4 for detailed Cohen's κ results). This result is also similar to the agreement found between two independent coders from the research team, which ranged between .667 and 1 (see Scoring and interpretation of the test results section)

Table 3

Inter-rater reliability scores of open-ended questions

Items	Group 1 (regular training)			Group 2 (enhanced training)			Total		
	<i>n</i>	<i>κ</i>	<i>p</i>	<i>n</i>	<i>κ</i>	<i>p</i>	<i>n</i>	<i>κ</i>	<i>p</i>
1	12	.652	< .001	13	-.054	.657	25	.442	< .001
2	10	.714	< .001	13	.490	< .001	23	.568	< .001
3	11	.421	.002	13	.725	< .001	24	.596	< .001
4	12	.526	.002	13	.755	< .001	25	.660	< .001
5	12	.339	.005	13	.253	.060	25	.316	.001
6	10	.375	.062	12	.167	.157	22	.361	.003
7	12	.442	.029	11	-.065	.621	23	.228	.039
8	12	.435	.002	12	.721	< .001	24	.544	< .001
9	11	.457	.014	12	.200	.190	23	.417	< .001
10	11	.353	.018	13	.278	.038	24	.314	.002
11	10	.778	.003	13	.217	.222	23	.448	.003
12	12	.314	< .001	13	1	< .001	25	.497	< .001
13	11	.233	< .001	13	.711	< .001	24	.458	< .001
14	12	.377	.015	13	.325	.029	25	.353	.001
15	12	.400	.000	12	.700	< .001	24	.557	< .001
16	10	.022	.747	13	.443	.001	23	.240	.001
17	12	.642	.001	13	.536	.001	25	.593	< .001
18	11	.667	.001	12	.294	.020	23	.576	< .001
19	10	.600	< .001	13	.669	< .001	23	.641	< .001
20	10	.302	.074	13	.639	.001	23	.449	< .001
21	11	.522	.017	13	.494	.001	24	.506	< .001
22	11	1	.001	13	.297	.015	24	.217	.071

Table 4

Inter-rater reliability scores of multiple-choice questions

Items	Group 1 (regular training)			Group 2 (enhanced training)			Total		
	<i>n</i>	<i>κ</i>	<i>p</i>	<i>n</i>	<i>κ</i>	<i>p</i>	<i>n</i>	<i>κ</i>	<i>p</i>
1	14	.827	< .001	14	1	< .001	28	.874	< .001
2	13	.639	.001	14	.641	.001	27	.638	.003
3	15	.464	.002	14	.641	.001	29	.540	< .001
4	14	.877	< .001	14	.481	< .001	28	.816	< .001
5	15	.694	< .001	14	1	< .001	29	.843	< .001
6	15	.697	< .001	14	1	< .001	29	.773	< .001
7	14	1	< .001	14	.825	< .001	28	.894	< .001
8	14	1	< .001	14	.641	< .001	28	.844	< .001
9	14	1	< .001	14	1	< .001	28	1	< .001
10	14	.720	< .001	14	1	< .001	28	.851	< .001
11	15	.571	.003	13	.863	< .001	28	.723	< .001
12	15	.868	< .001	14	1	< .001	29	.920	< .001
13	15	1	< .001	14	1	< .001	29	1.00	< .001
14	15	.727	.002	14	.641	.003	29	.765	< .001
15	15	.737	< .001	13	.527	.020	28	.668	< .001
16	14	.580	< .001	14	1	< .001	28	.704	< .001
17	14	1	< .001	14	1	< .001	28	1	< .001
18	14	1	< .001	14	.770	< .001	28	.873	< .001
19	14	.592	.007	14	.867	< .001	28	.736	< .001
20	15	1	< .001	14	1	< .001	29	1	< .001
21	15	1	< .001	14	1	< .001	29	1	< .001
22	15	1	< .001	14	1	< .001	29	1	< .001

Factors influencing implementation outcomes. The assessment fidelity, more specifically the administration of the items (i.e., asking all the questions required to be asked in each item in order to assess the respondent's social vulnerability – What is happening here? What should Pierre/Marie do? Why? Which is the most cautious answer?) was influenced by the profession, the years of experience in the field of intellectual disabilities and the experience with assessment tools with people with ID.

Psychologists administered the test more rigorously than educators, who, in turn, complied more closely with the criteria than team or center managers ($n=29$, $H(2) = 9.324$, $p = .009$, $\eta^2 = 0.282$, $d_{\text{cohen}}=1.252$). Participants who reported using – or having used – tools to conduct assessments with people with ID are more rigorous in their administration ($n=29$, $H(4) = 9.917$, $p = .042$, $\eta^2 = 0.247$, $d_{\text{cohen}}=1.144$). On the other hand, years of experience with ID are negatively correlated with assessment fidelity ($n=29$, $r_s = -.481$, $p < .01$). This means that the more experience participants have with people with ID, the less formal they were and the less they complied with the recommended guidelines.

With respect to the acceptability of the materials, with an overall average of 11.12 out of 15 ($SD=2.09$), participants found the TV-22 user-friendly and easy to administer, score and interpret. The overall perception of the acceptability of the test was not influenced by the personal characteristics of the participants (age, gender, profession, years of experience in the field of ID), nor by their experience with assessment tools. The instruction conditions (group 1 – regular training – versus group 2 – enhanced training), influence the perceived appropriateness level: participants who benefited from the tutorial and the manual tend to find the tool more user-friendly than those who benefited only from the manual ($U = 81$, $z = -1.585$, $p = .065$ (one-tailed), $r = -.28$, $\eta^2 = 0.077$, $d_{\text{cohen}} = 0.576$).

Appropriateness

Relevance and compatibility of the test to the practice. Twenty-six participants highlighted the relevance of the content of the TV-22 items, like this practitioner who reported that “the test refers to many situations that have been talked about or experienced within the institution, so they are truly vignettes that correspond to reality, to observations”. All participants acknowledged the compatibility of the test for their practice, albeit for different reasons: (1) as an assessment tool to improve support of adults with ID (17 occurrences); (2) as a support to stimulate discussions on certain themes/risks (10 occurrences); as a tool for assessing progress (test-retest) (5 occurrences); and finally, (3) as a “mediator” between teams and/or with legal representatives when there are different opinions on a person's ability to manage socially risky situations (5 occurrences), like this practitioner who said: “it's an interesting tool for exchanges between teams: sometimes there are disagreements [around the question of risks versus self-determination], a tool like this makes things clearer and more objective”.

Challenges faced when using the test. During the administration of the test, participants reported having faced difficulties relating to assessor neutrality, like this participant who reported “it's hard not to comment when the respondent chooses a non-cautious answer”. Participants have also reported some difficulty in abiding by the test administration instructions. More specifically, some faced the

dilemma of choosing a literal – but potentially robotic or unnatural – way of administering the test and a more spontaneous – but unstandardized – one. A majority of participants found the test (too) long to administer or reported that the respondent seemed to be annoyed by the fact that s/he had to reformulate what was going on at each new vignette (i.e., the “what is happening here” question). Nineteen participants also stated that they struggled with reporting the respondent’s answer, mostly either because there was not enough space on the reported answers sheet or because it interrupted the thread of the interview, reducing the opportunity to deepen the discussion with the respondent.

The most common challenge faced by participants when using the TV-22 was the analysis of answers to open-ended questions (Part A) – which confirms the results from the reliability analysis described above. Some participants also faced difficulties in interpreting the respondents’ scores. Table 5 summarizes the challenges reported by participants when using the TV-22.

Table 5Challenges reported by practitioners when using the TV-22 ($n=31$)

Test phase	Challenge reported	Frequency, n (%)		
		Group 1 (regular training)	Group 2 (enhanced training)	Total
Administration	Assessor Neutrality	2	5	7 (23)
	Robotic versus unstandardized administration dilemma	2	2	4 (13)
	Fatigue with requirement to reformulate to check if the person has understood the situation	7	7	14 (45)
	Length of the test administration	6	5	11 (35)
	Report of Responses	9	10	19 (63)
Scoring	Analysis of Part A responses	11	10	21 (68)
Interpretation	Interpretation of Part B scores	8	5	13 (42)

Discussion

Challenges for implementation: modifications to the materials and instructions. The qualitative and quantitative results highlight several potential challenges for implementation of the TV-22. With an intentional focus on retaining the core content of the test, a series of modifications and improvements were made to the TV-22 materials and instructions to address these challenges and reduce barriers to dissemination (see Table 6).

Table 6

Summary of key modifications to the TV-22

Implementation outcome	Challenge identified	Type of modification
Fidelity	<ul style="list-style-type: none">• Assessment fidelity not always guaranteed;• Respect of Part A core component (open-ended questions; coding of responses) not guaranteed	<ul style="list-style-type: none">• Training recommended for non-psychologists;• Questions written directly on the test itself;
Acceptability	<ul style="list-style-type: none">• Tutorial could enhance acceptability	<ul style="list-style-type: none">• Demonstration videos made available online
Appropriateness	<ul style="list-style-type: none">• Assessor Neutrality; Robotic versus unstandardized administration dilemma;• Report of Responses; analysis of Part A responses; interpretation of Part B scores;• Fatigue with requirement to reformulate to check if the person has understood the situation;• Length of the administration	<ul style="list-style-type: none">• Additional information added in the instructor's manual (administration, scoring, results interpretation);• Record audio of test administration to check response reporting and scoring;• Reformulation required for each new item (i.e., 22 times) – and not each new vignette (i.e., 88 times);• Part A and Part B performed at different times

First of all, it appears to be necessary to offer half-day training sessions in TV-22 administration for practitioners who are not psychologists. This adjustment aims to improve fidelity. Furthermore, to ensure assessment fidelity, every question that the assessor has to ask is now written directly on the test so that it can simply be read.

In order to enhance acceptability, two short demonstration videos (Part A and Part B) have been made available online (see Figure 2).

The poor inter-rater reliability result for the coding of part A (open-ended question) and the qualitative results from the appropriateness analysis have led us to refine considerably the scoring instructions for open-ended questions in the instructor's manual. It is also now recommended to record the audio of the test administration to be able to check response reporting and scoring afterwards.

The results of the appropriateness analyses also highlighted the need to add important details in the manual. Two changes were also made in the instructions to counter the challenges linked to the reformulation and the length of the administration (see Table 6 for details).

Figure 2

Example of a TV-22 item after the implementation study (female version, item N°17, English translation)

Situation n°17Part A



What is happening here?

What do you advise Marie to do or say?

Why do you advise her to do or say that?

Marie's boyfriend wants to have sex with her, but she doesn't want to.

Situation n°17Part B



(A) Say she doesn't really feel like it today

(B) Do it, but don't go out with him anymore

(C) Do it, otherwise her boyfriend will love her less

Marie's boyfriend wants to have sex with her, but she doesn't want to.
Which is the most cautious answer? Why?

Note. The assessor or the respondent successively reads the scenario, the question and the optional answers. Then the respondent answers the questions and justifies their answer. Approximately one week later, both meet again to take part B of the test.

Assessment fidelity: differences between practices and assumption of an error-free use. Reliable assessments are important to guarantee quality of care. Yet, although reliable assessments are developed and validated through research processes, some gaps between research and practice remain. Newly developed assessments may sometimes get lost in the so-called “leaky” research pipeline (De Geest et al., 2020). By evaluating implementation outcomes related to the use of the TV-22, a newly validated test, we aimed to identify the potential challenges related to its use, and thus overcome translation barriers between research and practice. The results of this study indicate a good appropriateness and a reasonable acceptability – but nevertheless a low assessment fidelity of the TV-22 by some practitioners.

The picture that emerges from the fidelity analysis is one of different assessment practices depending on one’s profession. We have noticed a difference between current profession and adherence to assessment guidelines. On the one hand, it is not surprising that psychologists, who are trained and used to performing assessments with standardized procedures, are more rigorous in their administration of the test than educators and team/center managers. On the other hand, it is striking that 25% ($n=7$) of the practitioners complied with less than one half of the assessment guidelines – which definitely questions the quality of the social vulnerability assessment performed. Similarly, in a study examining administration and interpretation of reading tests, Reed and Sturges (2012) reported 8% of extreme lack of fidelity in test administration and 91% of accurate test administration – but still with correctable errors. Nevertheless, research on assessment fidelity remains scarce (Reed et al., 2014; Richardson et al., 2016). In a literature review on assessment fidelity in special education, more precisely in reading interventions among children, Reed et al. (2014, p. 310) noted that “there appears to be an assumption that the measures are always used in an error-free fashion” (p. 310). This assumption leads to low reports of assessment fidelity in implementation researches, despite its important role for interpretation of the results.

Implementation of an innovation and the need to make adaptations: tensions and perspectives.

The results relating to the assessment fidelity, appropriateness and acceptability of the TV-22 by practitioners have led to several modifications of its associated materials. While the preliminary validation study of the test reported good psychometrics properties (Tabin et al., 2021), one may wonder if the modifications carried out had an impact on its reliability. This tension between the implementation of an innovation and the need to make (local) adaptations is not new (DeGue et al., 2020; Elliott & Mihalic, 2004). It is part of a debate between a balance-adaptation mindset and those who consider that any bargaining away of fidelity will negatively impact the effectiveness of the program or the innovation (Elliott & Mihalic, 2004). In this study, the modifications were not made to the content of the test itself but to its associated materials; they aimed to improve clarity of the guidelines and overcome assessment fidelity issues observed. These modifications should thus increase assessment fidelity, supporting its reliability rather than being a threat to it. Likewise, the modifications made should enhance appropriateness and acceptability of the test, supporting its

dissemination. Nevertheless, additional studies are required to assess the impact of these modifications and explore whether aspects of training and administration can be manipulated to improve implementation outcomes, and more specifically assessment fidelity – an area of research that has, at present, received little attention (Richardson et al., 2016).

Limitations

The present research has several limitations worth noting. The small size and heterogeneity of the sample (psychologists, educators, and team/center managers) may have hindered finding group differences. A study with a larger sample size would have been necessary to explore this type of effect. Furthermore, we did not collect data on the characteristics of the person being evaluated (e.g., severity of ID, age, comorbidity). We cannot rule out that these characteristics have had an impact on the measured outcomes, thus raising the question of the generalization of the results. Future work should look to further explore the relationships between the characteristics of the person being evaluated and the TV-22 implementation outcomes in a larger sample of practitioners. Additionally, results focusing on acceptability and appropriateness come from semi-structured interviews that we conducted with the practitioners. As the same research team validated the test and performed the acceptability and appropriateness evaluations, social desirability and politeness bias may have prevented practitioners from raising criticism of the test. To prevent this bias, future research should use validated measures to assess implementation outcomes – nevertheless, despite recent improvements (Mettert et al., 2020), implementation outcomes instrumentation is underdeveloped (Lewis et al., 2015), the first steps should consist of developing and validating psychometrically sound implementation outcome instruments in French.

Conclusion

Potential adopters should have the opportunity to try out the innovation, while having sufficient autonomy to “work around” and refine the innovation to improve its compatibility with the intended purpose (Greenhalgh et al., 2004). Thanks to the collaboration of practitioners, modifications were made to the newly developed test, in order to increase its adequacy to the practice’s needs. This study delivers insight into the implementation processes of a new measure in the special education field. The results highlight the importance of evaluating implementation outcomes when a new measure is developed to ensure its appropriateness and correct use by stakeholders – and prevent it from getting lost in the “leaky” research pipeline.

3.3 Study III. Resources and vulnerabilities to digital risks of adults with ID⁴

Abstract

Introduction. Information and communication technologies (ICT) offer many opportunities for social participation. However, ICT exposes people who use them to risks such as cyberbullying or financial abuse. Adults with intellectual disabilities (ID) experience high rates of victimization, both online and offline. This study aims to assess the resources and vulnerabilities to digital risks of adults with ID.

Method. Structured interviews with 51 adults with ID were conducted using a social vulnerability assessment measure, the TV-22.

Results. Results of the thematic content analysis show that most of the participants know self-determinate strategies to handle digital risks.

Conclusions. These results underpin the value of a positive risk-taking approach to improve on and offline social participation of adults with ID.

Keywords: intellectual disabilities; digital risks; social vulnerability; information and communications technology; Internet

⁴ This study is a translated version of an article originally published in French: Tabin, M. (2020). Ressources et vulnérabilités des adultes présentant une déficience intellectuelle face aux risques numériques. [Resources and vulnerabilities to digital risks of adults with intellectual disabilities]. *Revue francophone de la déficience intellectuelle*, 30, 13-24. <https://doi.org/10.7202/1075352ar>

Introduction

Present in almost all areas of life, information and communications technologies (ICT) lie at the heart of digital processes. ICT devices like smartphones, computers, and televisions provide many opportunities for social participation, be it relational, cultural, or professional. ICT can thus be used to prevent the exclusion of certain groups such as people with intellectual disabilities (ID) (Lussier-Desrochers et al., 2017; Salmerón et al., 2019). The importance of ICT for the social participation of people with ID has already been reported in a variety of domains: information and education (e.g., learning new skills, looking for a job), social identities (e.g., showing family members how Facebook works), new forms of entertainment (e.g., films, online gaming), and social interactions (e.g., new friendships) (Chadwick & Fullwood, 2018; Chadwick et al., 2018).

People with ID nevertheless face a range of barriers that limit their use of ICT, especially social networks (Borgström et al., 2019; Caton & Chapman, 2016). On the one hand, they are rarely consulted during the technological development process (Chadwick et al., 2013). The little interest accorded to their user experience means that they often face difficulties due to the skills required (i.e., literacy, memory, or fine motor skills; Wong et al., 2009) or, more generally, a lack of proper equipment (Chadwick et al., 2013). On the other hand, several research studies emphasize that the use of the Internet by people with ID is heavily influenced by the educational approach of their support network (i.e., practitioners, teachers, parents) (Chadwick et al., 2013; Löfgren-Mårtenson, 2004; Molin et al., 2017). Indeed, if the support network of people with ID considers them to be vulnerable to online abuse, they may limit their access to and use of ICT (Seale, 2014; Seale & Chadwick, 2017).

The most recent bi-annual report on the safety of information in Switzerland and abroad (Centrale d'enregistrement et d'analyse pour la sûreté de l'information MELANI, 2020) mentioned the three most prevalent digital risks in 2019: 1) phishing, which is a "fraudulent online technique designed to acquire confidential information to steal the identity of the victim" (Le Robert, n.d.); 2) sextortion, which is "the extortion of money or sexual favors from a person contacted via the Internet or text messaging under the threat of disseminating sexually explicit images" (Office québécois de la langue française, 2018); and 3) theft attempt or scam. The report states that no information is available on the profile of cybercrime victims.

Adults with ID experience a high rate of victimization both offline (Hughes et al., 2012) and online (Buijs et al., 2017; Jenaro et al., 2018; Normand et al., 2017). Even if their support network seems aware of the benefits of ICT (Ågren et al., 2020), some ambivalence still exists between the potential benefits and risks of ICT use by people with ID (Chadwick, 2019). The potential advantages of ICT are sometimes tempered by the fears of family members with regard to online risks (Salmerón et al., 2019). This leads to tensions between the protection of people with ID against digital risks on the one hand and their self-determination on the other.

In this context, research on the risks and benefits of ICT use among youths and adults with ID unanimously recognizes the importance of a positive risk-taking approach (Chiner et al., 2017; Löfgren-Mårtenson, 2004; Molin et al., 2017; Ramsten et al., 2019; Salmerón et al., 2019; Seale, 2014; Seale & Chadwick, 2017) and the potential danger of risk-averse approaches based on the denial or avoidance of risks, which tend to reduce the inclusion of people with ID and hamper the development of their digital skills (Chadwick, 2019). A positive risk-taking approach does not imply denying the existence of risks, but rather learning to manage them. This approach is characterized by the shared decision-making of people with ID and their support network regarding risk management. It favors the elaboration of strategies so that the risks associated with an activity are weighed against its benefits.

Hickson and Khemka (2013, p. 6) assumed that “at the start of the decision-making process, identifying and defining the problem (and hence recognizing that a decision has to be made) are essential components that must occur before solution strategies can be engaged.” Identifying the problem or risk is thus a key ability required in the early stages of the decision-making process, which then allows the implementation of solutions. While positive risk-taking based on shared decision-making can be an emancipatory process and a vector of self-determination, it requires that people with ID identify – or learn to identify – the risks associated with ICT and then use strategies to manage them.

Although several studies have examined the experiences of victimization among youths and adults with ID with regard to ICT use (Begara Iglesias et al., 2019; Buijs et al., 2017; Jenaro et al., 2018; Normand et al., 2017), research on the identification of digital risks and the strategies used by this population is rare (Molin et al., 2017; Lough & Fisher, 2016). Understanding how adults with ID experience and manage digital risks could help guide shared decision-making processes and thus support the opportunities for social participation offered by ICT.

This study aims to evaluate the resources and vulnerabilities of adults with ID when faced with the three most prevalent digital risks reported in 2019: sextortion, phishing, and theft attempt/scam. More specifically, the aim is to answer the following two questions: 1) to what extent do adults with ID protect themselves against the risks associated with ICT? and 2) what strategies do they use to manage these risks?

Method

This study is part of a broader research project (Validation of the Test of Interpersonal Competence and Personal Vulnerability, French version, Petitpierre, 2018), financed by the Swiss National Science Foundation [FNS, project N°176196]. It received the approval of the ethics committee of the Vaud canton [protocol 2016-01480].

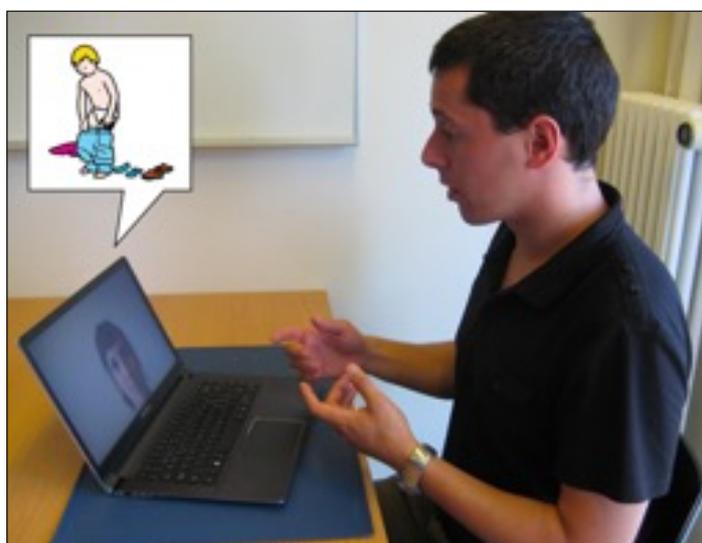
Instrument: TV-22, part A. Fifty-one structured interviews were conducted using the 22-item Test of Social Vulnerability (TV-22, Tabin et al., 2021). The TV-22 is a social vulnerability assessment test with good psychometric properties (internal coherence $\alpha = 0.89$, $\Omega = 0.93$; test-retest, $r_s[29] = 0.81$, $p < 0.01$).

Specifically designed for adults with ID, it aims to observe their abilities and/or limitations in recognizing and proposing protective strategies in different types of social risks: verbal, physical or sexual abuse, and financial exploitation. The TV-22 is composed of 22 illustrated vignettes depicting a social risk. For each item (vignette), interviewees are asked to advise another person – of the gender they identify with (Pierre or Marie) – faced with a risky situation. The risk may involve known (friends, family members, partner) and unknown individuals.

The test, which is taken on a computer, has two parts. In part A, the situation (vignette) is presented, and the interviewee has to spontaneously say what they would advise Pierre or Marie to do (see Figure 1). In part B, the interviewee is presented with the same vignettes but with three possible responses (a, b, or c). They are asked to choose the most cautious option (see Tabin et al. (2021) for further details on part B). Of the 22 vignettes in the TV-22, five items assess the relative risks associated with the use of ICT. One item refers to phishing: Marie (or Pierre) chats with someone on the Internet who asks for her phone number. Two items relate to sextortion: first, Marie meets someone on the Internet who asks her to undress in front of the screen; and second, someone Marie knows says he'd like to take pictures of her without her clothes on. Finally, two items refer to a theft attempt/scam: first, Marie's friend wants her to give him her smartphone; and second, a stranger asks Marie for her television.

Figure 1

Example of a vignette from the TV-22 (masculine version, item N°22, part A)



Pierre chats with a woman on the Internet.
This woman asks him to take off his clothes.

Note. The assessor asks: what is happening here? What do you advise Pierre to do or say? Why?

Participant recruitment. The project, conducted in the French-speaking part of Switzerland, was implemented in two phases. The first phase from March 2016 to September 2018 aimed to validate the psychometric properties of the TV-22. A total of 29 adults with ID participated in this first phase. Potential participants were identified by the managers of four social institutions for adults with ID. The local managers were asked to respect the following inclusion criteria: French-speaking adults aged 18 years and older with mild to moderate ID and able to have a short conversation. Following the procedure proposed by Petitpierre et al. (2013), potential participants and their legal representatives were invited to an information meeting about the study. All the documents respected easy-to-read guidelines (Inclusion Europe, 2009). Each participant and at least one of their legal representatives provided informed consent to participate in the study.

The second phase took place between October 2018 and May 2020 with the aim of assessing the implementation outcomes of the TV-22, more specifically its assessment fidelity (i.e., adherence to assessment guidelines), acceptability (e.g., complexity) and appropriateness (e.g., perceived relevance) by special education practitioners. Overall, 31 practitioners (psychologists, educators, and social institution managers) participated in the second phase. They were identified by the managers of eight social institutions for adults with ID and invited to a training session on the use of the TV-22. They were then asked to administer the TV-22 to an adult with mild to moderate ID with whom they worked and to make an audio recording of the assessment. Of the 31 practitioners participating in this second phase, two were unable to record the assessment due to technical difficulties. Quantitative analyses (using SPSS, version 25) were performed to assess the fidelity of the assessments. Over 150 criteria were evaluated: for example, the assessor administered the test question; the assessor asked the question for item 1; or the participant was assessed individually in a quiet room. Overall, 22 interviews were conducted with a satisfactory fidelity (i.e., they obtained an accuracy score above 50/166).

The current study involves 51 participants with ID (24 men and 27 women) based on 29 assessments from the first phase and 22 valid assessments from the second phase. Although measures such as age, fluid intelligence, or levels of support were assessed in the first phase of the study for the validation of the psychometric properties, the characteristics of participants, with the exception of gender, were unknown to researchers in the second phase. Two reasons explain this situation. First, as the second research phase focused on the use of the TV-22 by practitioners with the aim to observe the manner in which the test was used, the characteristics of participants were deemed irrelevant. Second, only the gender of participants was reported in the second phase of the study, because it was used as a criteria for assessment fidelity (i.e., verifying whether each participant received the masculine or feminine version of the TV-22 according to the gender they identify with).

Procedure. A total of 51 structured interviews were conducted. All interviews took place in a quiet room that was made available by the social institution where the person with ID worked or lived.

Members of the research team with a Master's degree in special needs education or psychology carried out the 29 interviews in the first phase of the study. The remaining 22 interviews were conducted by practitioners working with the adults with ID (i.e., psychologists, educators, and social institution managers). The TV-22 was individually administered to each participant. The assessor (i.e., research team member or practitioner) read out the instructions and copied the participant's answers. The interviews lasted between 30 and 90 minutes. All interviews were recorded using a voice recorder and then fully transcribed by the research team for analysis.

Coding and analysis. Qualitative analysis was performed on the answers to the open-ended questions (part A) of the TV-22: "What do you advise Pierre/Marie to do or say?" The transcriptions of the 51 interviews were analyzed with the N-Vivo software (version 12) using thematic content analysis (Paillé & Mucchielli, 2012). The first 29 interviews (i.e., from the first phase of the research project) were coded, leading to the development of a thematic analysis grid following the sequential thematic approach of Paillé and Mucchielli (2012).

Two members of the research team then separately coded the remaining 22 interviews (i.e., from the second phase of the research project). Cohen's kappa (κ) was calculated to determine the agreement between the two coders for slightly more than 20% of these interviews ($n=6$). Inter-coder agreement ranged from .700 to 1, indicating satisfactory to perfect agreement (Landis & Koch, 1977). In-depth analysis of the coded responses improved the grid and resolved any differences in coding. The final analysis grid (Table 1, "proposed strategies") was then applied to the entire corpus of data by a member of the research team. Finally, continuous thematic analysis (Paillé & Mucchielli, 2012) was performed: participants' justifications to explain their use of particular strategies were listed and then classified thematically using a progressive methodology (Table 1, "justifications").

Table 1

Final coding grid used to classify the responses of the TV-22

Proposed strategies		Definition
Mitigation = Responses that reduce or eliminate the risk	Indirect protection	The interviewee advises the person to ask others for help (e.g., a trusted person, police, doctor).
	Self-protection	The interviewee advises the person to calmly refuse, say “no”, protect him/herself by taking cover, ignore the other person, not respond, close the door, etc.
Acceleration = Responses that do not reduce or eliminate the risk	No response	The interviewee does not give any advice, saying “I don’t know” or not responding.
	Submission	The interviewee advises the person to say “yes,” do what is asked, give money, etc.
	Emotional	The interviewee advises the person to: <ul style="list-style-type: none"> - respond <u>aggressively</u> (i.e., with physical or verbal aggression), respond with a threat, etc. - be excessively <u>empathetic</u> (e.g., suggesting that they watch TV together, giving money to the friend to buy the same phone) - ask <u>naively</u> “why?” (e.g., “Why do you want a nude picture of me?”)
Justifications		Definition
Risk		The interviewee mentions a risk to justify the strategy (e.g., risk of disseminating the photo/video/phone number, risk of harassment, risk of theft)
Relation		The interviewee justifies the strategy by the fact that the person in the vignette is a friend, stranger, etc.
Property		The interviewee explains the strategy by justifying that “It’s private,” “It’s intimate,” “It belongs to him/her,” etc.
Learned rule		The person refers to social norms such as “That’s not done,” “You don’t do that,” “He/she is not allowed,” “It’s not normal,” etc.

Results

The results for the two research questions are presented below. First, we report the proportion of adults with ID who protect themselves against the risks associated with the use of ICT. We then detail the strategies and justifications used to manage these risks.

Self-protection against digital risks. In four out of the five items relating to ICT, more than 84% of participants protected themselves against the associated risks using one or more strategies to mitigate their risk exposure. For each item, two to six adults gave contradictory answers: in other words, they proposed strategies that both reduced and increased risk exposure (mitigation and acceleration). Item 13 in which a stranger asks Marie/Pierre for a new television was the most challenging vignette for participants. Twelve participants failed to use a strategy to protect themselves against this risk, while three others gave contradictory responses. Table 2 provides an overview of the proportions of adults with ID who protected themselves against the various digital risks described in the vignettes of the TV-22.

Table 2

Proportion of responses highlighting the resources and vulnerabilities of participants in the five vignettes (feminine version) of the TV-22

Risk	Item	Proposed strategy					
		Mitigation response		Contradictory response		Acceleration response	
		<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Sextortion	N°7 Someone Marie knows says he'd like to take some pictures of her without her clothes on. (<i>n</i> =49)	42	85.71	6	12.25	1	2.04
	N°22 Marie chats with a man on the Internet. This man asks her to take off her clothes (<i>n</i> =51)	44	86.28	5	9.80	2	3.92
Theft attempt/ Scam	N°12 Marie receives a smartphone for Christmas and a friend asks her to give it to her (<i>n</i> =51)	46	90.20	2	3.92	3	5.88
	N°13 Someone comes to Marie's door and says he doesn't have any money but needs a new TV (<i>n</i> =51)	36	70.59	3	5.88	12	23.53
Phishing	N°21 Marie chats with a man on the Internet. This man asks for her phone number (<i>n</i> =50)	42	84	6	12	2	4

Types of strategies and justifications used to manage digital risks. All the strategies mentioned by participants (several possible responses per item) are presented below for the three categories of ICT-related risks based on the TV-22: sextortion, theft attempt/scam, and phishing.

Sextortion. Item N°7 “Someone Marie knows says he’d like to take some pictures of her without her clothes on.”

Almost all the interviewees ($n=48/49$) use a self-protection strategy: they spontaneously advise Marie (or Pierre) to refuse to take the photo. Among the 48 people who spontaneously refuse the photo, the majority ($n=42$) provided justifications. For example, one woman explained: “Tell him no, because you don’t know if he’s going to put the photo on the Internet. If there’s a naked picture of you on Facebook or other social networks, then your boss might fire you and you’ll have other problems. Or the person taking the photo might have problems.”

Like 14 other participants, she justified her refusal by the possible dissemination of the photo. One participant mentioned the risk of sexual assault: “She shouldn’t show her body to him, she shouldn’t do it. You don’t know if he’s going to touch her. Maybe she doesn’t like him.” Another justification relates to intimacy ($n=14$), as one participant explained: “It’s none of his business. I would be embarrassed if someone asked me to do that.” Other reasons include “It’s not right” ($n=9$) or “He’s not allowed” ($n=2$). Finally, two participants recommend refusing to take the photo because the person is an acquaintance and not a girlfriend or boyfriend.

One of the interviewees nevertheless considered complying with the request. Six people gave contradictory answers, that is, they proposed both mitigation (self-protection and/or indirect protection) and acceleration strategies. One male participant initially suggested: “He should say yes, but only do it in private,” because it is more discreet to “do it in private than in a room” with other people. However, he later said: “Say no, because it’s a bit embarrassing.” Among the other contradictory reactions, three answers are categorized as “emotional,” as the interviewees wanted to “ask why she wants to take a naked picture and what’s the point” ($n=2$) or to first “get to know each other better” ($n=1$). Another participant initially did not know what to do (coded as “no response”), but after being asked again by the assessor, she said that she would say no. Finally, one participant said that Marie “should not undress,” but then changed her mind when the assessor confirmed that Marie knows the person: “She should do it, and that’s it!”

Item N°22 “Marie chats with a man on the Internet. This man asks her to take off her clothes.”

Almost all the interviewees ($n=49/51$) proposed a mitigation strategy. One participant suggested seeking help from another person, while another spontaneously proposed two options (self-protection and indirect protection). Among the 49 people who refused to take off their clothes, the majority ($n=39$) justified their refusal, as explained by the following interviewee: “If you don’t know the person, you

should say no. Because he can take photo and put it all over the Internet, but it's private. If you don't want to do it and the person insists, you should talk to your parents."

This participant thus provided several reasons for her refusal and employed different strategies (saying no, talking to trusted people). Other participants stressed that the person is a stranger ($n=8$) or referred to the dissemination of the image on the Internet ($n=13$), as explained by one woman: "You don't know if he's going to put it on Facebook or social networks." Another reason ($n=13$) relates to the intimacy of the request: "Say no, it's private, it's intimate" or "It's not right" ($n=11$). Two people justified their refusal by the fact that they are "not allowed" to take off their clothes.

In response to item N°22, two of the 51 participants nevertheless agreed to undress. One of them imposed a condition: "[Pierre] should say yes. But only if she is the only one looking." Five participants gave contradictory answers. One initially did not know what to do, but after being asked again by the assessor, he said that he would say no. Four people first suggested asking why (i.e., "He should say: why should I take off my clothes?") but then said "no."

Theft attempt/ Scam. Item N°12 "Marie receives a smartphone for Christmas and a friend asks her to give it to her."

Almost all the interviewees ($n=48/51$) proposed a mitigation strategy. One person mentioned two strategies (self-protection and indirect protection). Among the 48 people who refused to give away the smartphone, the majority ($n=40$) explained their refusal ($n=44$ justifications). Several participants specifically mentioned that the phone was a Christmas present ($n=15$): "Say no because it's the phone he got for Christmas. It's not right to give it away." Others stress that the phone was Pierre's ($n=15$): "Me, I'd say no. Because it's his phone"; or if Pierre gives it away, "then he won't have a phone" ($n=2$). Among the other reasons cited for refusing to give away the smartphone, five participants referred to the private information on the phone: "After, he could go through the numbers and look at the private numbers." Four people explained that it is necessary to have a phone: "What's more, it's important to have a phone to make an urgent call." Two people spoke of the cost of phones: "Well, it's a gift, but it's expensive, so she shouldn't give it away." Finally, one person refused "because after she might call someone else and then ask for things and annoy the person on the phone, and the person wouldn't like it."

Three of the 51 interviewees did not propose a strategy to mitigate their exposure to this risk. Two agreed to give away the phone without further explanation: "She should give it to him." The third suggested going "to the shops to buy one" for her friend, believing this to be the most appropriate solution because they know each other. Two participants provided contradictory responses. One first suggested giving away the phone, while the other said "Ask him why he wants the phone, it's my present?" Both subsequently changed their mind and decided not to give it away.

Item N°13 “Someone comes to Marie’s door and says he doesn’t have any money but needs a new TV.”

Over three-quarters of the interviewees ($n=39/51$) proposed a self-protection strategy, with 28 providing a justification to explain their refusal. Twelve participants mentioned that it was Pierre’s money, with one saying: “Because that’s it, it’s his money, so he can do what he wants with it.” Another simply said that “Pierre’s not a bank.” Five participants stated that the television belongs to Pierre (or Marie), with one saying, “He’s not a shop.” Another said: “It’s his TV, so he shouldn’t give it away.” Others emphasized the fact that the person is a stranger ($n=4$): “She shouldn’t do it. She doesn’t know the person.” In general, the participants said that it was not “normal” and that Marie “shouldn’t”: “She shouldn’t give her money or TV to this man” ($n=6$). Or even that it is not Pierre’s problem: “Because, there you go, he doesn’t want to give her his TV or his money, because it’s, you know, it’s not right. And then, well ... if she doesn’t have any money, well, that’s her problem.”

Overall, 12 of the 51 participants agreed to the stranger’s request, while three people gave contradictory responses, that is, they proposed both mitigation (self-protection and/or indirect protection) and acceleration strategies. Among the strategies proposed by these 15 participants, one person did not know how to respond, while another suggested that Pierre “takes the TV and puts it on the doorstep.” Thirteen participants provided empathetic responses such as inviting the stranger to watch TV with him/her ($n=3$), or asking questions (What is his/her name? Why is he/she knocking on the door? Why does he/she want money?) ($n=3$). Several participants provided justifications: “It looks like she needs to talk to somebody” ($n=1$); “Give him money so he can buy the same one” ($n=7$); “If he doesn’t have any money, he can’t buy a TV” ($n=6$); or “Because that way, he’ll leave her alone” ($n=2$).

Phishing. Item N°21 “Marie chats with a man on the Internet. This man asks for her phone number.”

Almost all the interviewees ($n=48/50$) proposed a strategy that was categorized as self-protection ($n=46$) – and some also indicated an indirect protection ($n=2$), as explained by the following participant: “She could say, ‘Listen, I don’t know you, I don’t give my number to strangers...’ Because she doesn’t know the man. Because sometimes you don’t know who you’re going to meet on the Internet... If he has her number, well, this stranger, he could bother her with messages and calls, so it’s better not to do that.”

Other participants gave similar reasons for their refusal ($n=40$ participants with 48 justifications). The majority refused because an unknown person made the request ($n=22$) or because they may harass the person or share the phone number ($n=18$). Eight participants simply said, “It’s not right” or “You shouldn’t give” your number on the Internet.

Two of the 50 interviewees did not propose a strategy to mitigate their exposure to this risk, while six provided contradictory answers. Among the strategies proposed by these eight participants, two said, “I don’t know,” and then affirmed “He shouldn’t share it.” A third participant explained that she should

say no and then “Tell him to go to jail, because that hurts.” Two other people suggested asking the stranger why they want the number, with one of them then refusing to give it. One participant even recommended turning off the computer and not going on the Internet again. Finally, three participants agreed to give their number to the stranger, although two subsequently changed their minds and refused, saying, “He shouldn’t give it” or “Because he doesn’t know her, it’s not right to share it.”

Discussion

By asking people with ID for their reactions to specific vignettes, this study provides a first overview of their resources and vulnerabilities when faced with digital risks. The results not only show the extent to which adults with ID protect themselves against these risks and employ a range of strategies, but they also draw attention to the difficulties faced by this population in terms of ICT risks. These findings provide important indications for the development of online safety interventions.

First, the results demonstrate that in the five vignettes from the TV-22, most participants used self-determined strategies to protect themselves against digital risks. These results are similar to those reported by Molin et al. (2017). The results of their study, based on interviews with 27 young people with ID, highlight that these youths are aware of the risks and benefits associated with the Internet and social networks, as reported by Mia, aged 17:

I am very, very careful on the Internet, because you never know if you will get into trouble... I would rather not meet people on the Internet because I’m afraid something bad will happen, e.g., me being abused by someone (Molin et al., 2017, p. 651).

Second, a non-negligible proportion of participants (around 13%, except for item N°13 with 29%) did not employ strategies to decrease their risk exposure or used ambivalent strategies. Unaware of the potential risks associated with ICT, these individuals may be vulnerable to victimization (Greenspan et al., 2011). This proportion of 13% is supported by the study of Begara Iglesias et al. (2019) on cyberbullying among adolescents with ID. In their study on 181 adolescents (45 with ID, 31 with Asperger’s syndrome, and 105 ordinary teenagers), 13.3% of youths with ID (vs 2.85% of ordinary teenagers) responded affirmatively to the item: “Without my consent, someone has taken photos or made video recordings of me with sexual content and has disseminated them via mobile phone or the Internet.” Likewise, Jenaro et al.’s (2018) findings on a sample of 269 adults with ID reported that 15% of their participants were victims of cyberbullying.

Third, nearly 30% of participants had difficulty in determining protection strategies to deal with item N°13: “Someone comes to Marie’s door and says he doesn’t have any money but needs a new TV.” One hypothesis to explain this vulnerability could be related to the type of risk presented in this vignette. Unlike the other items, Marie or Pierre is not asked to undress or give away their phone (or any personal information). The vignette in item N°13 may be considered to deal with a more social context. This is supported by the findings of Lough and Fisher (2016) on 28 adults with Williams syndrome. After analyzing the responses to online safety vignettes, the authors reported that the

majority proposed risk-minimizing strategies, although the participants were more likely to suggest strategies that amplified the risks in social vignettes (e.g., sending photos of oneself to a stranger online) compared to “non-social” situations (e.g., sharing bank account details). Another hypothesis may explain the disparity between item N°13 and the other vignettes. Although most participants seemed to understand the risks associated with ICT and used self-determined strategies to protect themselves, they may simply have been reiterating the safety measures taught to them, as suggested by the high number of justifications based on the learned rules “You shouldn’t do it” or “It’s not right.” Indeed, the least successful item involved a vignette for which participants were not “prepared” in advance, as the television vignette was somewhat implausible. Based on her interviews with 10 young people with ID, Löfgren-Mårtenson (2008) demonstrated that they understand and use strategies to manage the risks associated with Internet use. Nevertheless, the author hypothesized that they may simply repeat the safety advice they have been taught and, depending on the context, they may not follow them.

Our study highlights the importance of developing holistic preventive measures to counter the victimization of people with ID. The findings, especially the difficulties encountered with item N°13, seem to confirm Finkelhor’s (2014) assertion that these problems are not specific to ICT but rather apply more broadly to social interactions. In other words, the factors contributing to the social vulnerability of people with ID in the real world tend to act as risk factors in the online world (Lough & Fisher, 2016). Instead of avoiding digital risks or developing specific programs for their prevention, it would therefore be more pertinent to include this type of prevention in programs for prosocial and emotional skills or conflict and anger management (Sallafranque-St-Louis, 2015; Wells & Mitchell, 2014).

Our results confirm the importance of a positive risk-taking approach (Seale, 2014). Understanding how adults with ID perceive and negotiate risks constitutes a preliminary stage, allowing us to reflect on and organize support measures for the better social participation of this population – both off- and online. Despite being a vector of risk, ICT provide opportunities for social participation that are potentially emancipating for people with ID (Löfgren-Mårtenson, 2008; Molin et al., 2017; Sorbring et al., 2017).

Conclusion

This study has several limitations. First, although the TV-22 allows us to assess the theoretical knowledge of participants, it is uncertain whether their real-life reactions would reflect this knowledge. Second, the study did not report the participants’ use of ICT in their everyday lives (e.g., frequency and use of their phone, computer, Internet, or social media). Third, we did not investigate whether the participants had already experienced the situations presented in the TV-22 or whether the vignettes were completely fictive. Fourth, the strategies described by participants may have been motivated by their desire to please the assessor: as the interviews were audio-recorded and not filmed, it was not

possible to analyze the potential influence of the assessor's non-verbal reactions to the strategies proposed by participants, especially in the case of contradictory responses. Fifth, beyond the inclusion criteria (aged 18 years and older and presenting ID), the profiles of participants (e.g., age, need for assistance, place of residence), except for gender, were not known to the research team, which limits the analysis and development of hypotheses. Finally, the sequential thematic analysis, though giving an efficient and uniform analysis of the corpus, may have contributed to the loss of potentially important details (Paillé & Mucchielli, 2012).

Despite these limitations, this study offers insights into how adults with ID perceive and negotiate digital risks. In addition to providing new knowledge on the resources and social vulnerabilities of adults with ID, it has the advantage of directly analyzing their own words instead those of their support network. In the five vignettes examined here, most participants seemed to understand the risks of ICT and used self-determined strategies to protect themselves. However, some may simply reiterate the safety rules taught to them with limited integration. This is suggested by the high number of justifications with the learned rule "You shouldn't do it" or "It's not right". In addition, a minority of participants (around 13% except for item N°13 with 29%) did not employ risk-minimizing or otherwise used ambivalent strategies, which could put them at greater risk of victimization.

This study is an initial exploratory evaluation of the resources and vulnerabilities of adults with ID when faced with ICT risks. Further research is needed to better understand the interactions between online and offline vulnerability as well as the risks and opportunities afforded by ICT. Analyzing the responses to the non-digital vignettes of the TV-22 would highlight if this population presents similar levels of resources and vulnerabilities in the other vignettes or if these results are specific to digital risks. The behavioral validity of the TV-22 should be further explored: research could examine the real online behavior of people with ID and compare it with the responses provided in the TV-22. Future research could also investigate the situations of risk and/or victimization experienced by this population and explore the real-life strategies they implemented.

Given the high rates of offline and online victimization among adults with ID, it is essential to promote the development, implementation, and evaluation of prevention programs to improve their social skills as well as their risk identification and decision-making abilities. Despite the development of some promising programs in North America (Khemka & Hickson, 2015; Ward et al., 2013), their effectiveness is yet to be confirmed (INSERM, 2016; Mikton et al., 2014). At present, such programs are uncommon in French-speaking countries (Petitpierre & Tabin, 2021).

3.4 Study IV. Preventing elder abuse: development of a curriculum for elders with IDD⁵

Abstract

Introduction. Despite the high risk of abuse faced by elders with intellectual and/or developmental disabilities [IDD], targeted abuse prevention training is fairly limited for them. This article describes the development and usability evaluation of a curriculum designed specifically to address the needs of (English-speaking and French-speaking) elders with IDD.

Method. Based on earlier versions of ESCAPE (Khemka & Hickson, 2015), the Effective Strategy-based Curriculum for Abuse Prevention and Empowerment – for Elders [ESCAPE-E] was developed in close collaboration with an international program advisory board [PAB]. The development of ESCAPE-E included a needs assessment (online survey ($n=86$)) and a usability assessment, with a field test in two countries involving two trainers and ten elders with IDD.

Results. Results from the needs assessment and inputs from the PAB yielded critical information that helped shape the curriculum's development. Feedback from the trainers and elders with IDD validated the usefulness of the information covered in the lessons and revealed suggestions for enhancing the usability of the curriculum.

Discussion. ESCAPE-E appears to be a promising intervention, available in English and French, for building the knowledge and skills needed by elder populations with IDD to protect themselves from abuse and maltreatment.

Keywords: abuse; intellectual disabilities; elders; elder abuse; intervention; maltreatment; prevention

⁵ This study is a reprint of the first version of the following article: Tabin M., Khemka, I., & Hickson, L. (in revision). Preventing elder abuse: Development of a curriculum for elders with intellectual and developmental disabilities. *International Journal of Developmental Disabilities*.

Introduction

Elder abuse is considered a pervasive human rights violation and a major global public health problem.

Elder abuse is defined as:

a single or repeated act or lack of appropriate action, occurring within any relationship where there is an expectation of trust which causes harm or distress to an older person. It can occur in both community and institutional settings and can take many forms including physical, psychological, financial/ material, sexual abuse and neglect (World Health Organization [WHO], 2022, p.1).

In a global meta-analysis on the prevalence of elder abuse, Yon et al. (2017) found that elder abuse affected around 16% of adults aged 60 and older who were living in a community setting the year before the study. In the literature involving elders with intellectual and developmental disabilities (IDD), the term maltreatment is widely used to refer to intentional acts, such as physical, sexual, and verbal/psychological abuse, or failure to act, such as neglect and exploitation that result in harm for an elder.

Abuse of elders, with and without IDD, appears to be particularly prevalent regarding financial exploitation (especially for those with IDD, Burnett et al., 2020), neglect (especially in institutionalized settings, Yon et al. 2018) and psychological abuse (Krüger et al., 2020; Yon et al., 2018).

The term IDD has been used in an inclusive sense to refer to a broad range of individuals who encompass a variety of conditions, including intellectual disabilities [ID] with significant deficits in intellectual skills and adaptive behavior functioning and/or developmental disabilities [DD] resulting in life-long disabilities from severe mental/or physical impairments (see Schalock & Luckasson, 2021). People with disabilities, particularly those with ID, are significantly more at risk of being maltreated than the general population (Wilson, 2016). The last meta-analysis on this topic found that 6.1% of adults with ID were affected by maltreatment in the year before the study (Hughes et al., 2012). Elder adults with IDD make up the largest proportion of the adult population living in institutions in the European region (WHO, 2018), with many relocating to group homes or institutions when their family members are no longer able to provide care or supervision (Bowers et al., 2014). Although the uniqueness of the aging process in people with IDD has been frequently acknowledged (McKenzie et al., 2016), the impact of age on the maltreatment of people with IDD remains poorly understood (Stalker & McArthur, 2012). People with IDD are likely to experience premature aging and to face additional struggles beyond those expected with increasing age (e.g., health issues related to lifelong conditions that deteriorate; issues related to various comorbidities; early diagnosis of dementia) (McKenzie et al. 2016). Dynamics of power and control are known to intersect with ageism and ableism, making abuse of elders with disabilities more prone to happen. Abuse of elders with and without IDD is suspected to be severely underreported due to factors like dependency on the abuser or social isolation (Lachs & Berman, 2011). The presence of internalized ageism – the extent to which people think about themselves negatively because of their age – may contribute to the underreporting of elder abuse

(Shepherd & Brochu, 2021); and the presence of (intellectual) disabilities increases the likelihood that the elder adult may not be able to recognize acts of abuse, and/or will not disclose the abusive acts (Frazão et al., 2015; Kamavarapu et al., 2017).

Prevention of elder abuse. The understanding of elder abuse and its prevention in aging individuals with IDD is still limited. Currently, there is no intervention that successfully addresses issues of abuse specific to elder populations with IDD (Beaulieu, 2022; Hickson & Khemka, 2021). According to Hickson and Khemka (2021), a comprehensive approach to effective prevention of maltreatment of elders with IDD should be acted upon on several levels: individual (increasing self-protective competencies), structural (fostering protective relationships and networks), and societal (building protective systems and services). Prevention at the individual level for adults with IDD takes mainly the form of curricula that aim to enable people to understand abuse and teach them how to handle abuse (Mikton et al., 2014; Park, 2020). While several promising curricula exist for adults with IDD, none have been specifically developed and evaluated for elders with IDD. Designed for adults with IDD, the effectiveness of the Effective Strategy-Based Curriculum for Abuse Prevention and Empowerment [ESCAPE] (Khemka et al., 2002) (and its later version ESCAPE-DD, Khemka & Hickson 2008) has been supported. After having participated in the decision-making strategy-based intervention, adults with IDD provided more prevention focused decisions in response to scenarios (presented as hypothetical vignettes) involving verbal, physical, and sexual abuse in comparison to their peers in a control group (ESCAPE: Khemka et al., 2005 and ESCAPE-DD: Hickson et al., 2015). ESCAPE-DD (and its updated version, ESCAPE-NOW), comprised of 12 structured, small-group instructional lessons, addresses both noncognitive (e.g., motivational and emotional) and cognitive factors underlying effective decision-making in interpersonal situations of abuse. Although continuing to provide for a robust and comprehensive approach to abuse prevention for adults with IDD, the curriculum does not address issues relevant to elders with IDD.

With age comes increased knowledge and experience across many life domains, which are likely to influence the decision-making process adopted by elders with IDD. Studies on decision making in elders suggest changes in the ways the decision-making process is performed over the lifespan as a person ages (Bruine de Bruin et al., 2020; Del Missier et al., 2020, Spreng et al., 2021) – changes that are also likely to occur in elders with IDD (Suto et al., 2005). While the overall framework of ESCAPE is likely to address many of the needs of elders with IDD, the content of earlier versions of the curriculum may provide insufficient attention to issues that are more specific to abuse of the elder population (types of abuse; internalized ageism). In addition, adaptations in the format and delivery of the curriculum (e.g., length and number of lessons, activities) may be needed to adjust to aging influences relating to stamina, attention, memory.

Developing a curriculum for elders with IDD. An adaptation of ESCAPE to meet the needs of elders with IDD could thus constitute the first intervention specifically designed to prevent elder abuse of adults with IDD. Involving key stakeholders in the development process and offering them the

opportunity to suggest adaptations is a crucial aspect of implementing new interventions (Greenhalgh et al., 2004). Furthermore, testing the usability – the extent to which a new training intervention can be used easily and effectively to achieve its objectives – is particularly important as it can reveal critical issues and characteristics likely to be predictive of its adoption (Lyon et al., 2021). The purpose of this article is (1) to describe the development of a new version of ESCAPE, the Effective Strategy-Based Curriculum for Abuse Prevention and Empowerment for Elders [ESCAPE-E], targeting elders with IDD, and (2) to report the results of a usability evaluation conducted using a cross-cultural developmental focus.

Cross-cultural curriculum development method

ESCAPE and its later versions are widely used, not only in the United States but also in Europe. For example, ESCAPE-DD has been successfully translated and implemented in the French-speaking part of Switzerland (Noir & Petitpierre, 2012; Petitpierre et al., 2016). Adopting a cross-cultural development approach (simultaneously in the United States and in the French-speaking part of Switzerland) generates important insights and broadens perspectives; it also ensures that the new intervention is appropriate across all participating cultures and contexts (Vivat et al., 2013).

The development of ESCAPE-E was informed, on the one hand, by the approach proposed by Schneiderhan et al. (2019) on curriculum development, and the other, by Hockley et al.'s (2019) framework for cross-cultural development and implementation of interventions. Accordingly, the development of ESCAPE-E included the following phases: (1) performing a needs assessment, (2) determining content and design, (3) implementing and evaluating the usability of the curriculum. Further, all aspects of development (e.g., recruitment, informed consent by participants, protocols for participating in training), including validation of curriculum content and scripts for training, followed full ethical guidelines at the two participating agencies and Institutional Review Board (IRB) requirements at the first two authors' primary institutions.

Procedure

Phase 1. Performing a Needs Assessment

Focus Groups

First, two focus groups with current trainers ($n=6$, from two different agencies) in Switzerland, who were familiar with the French translation of ESCAPE-DD, were conducted to collect trainer suggestions on which components would be necessary to consider when adapting ESCAPE to meet the needs of elders with IDD in Switzerland. The two focus groups were conducted online (i.e., one meeting per agency) and followed the same structured interview guide. The key recommendations that emerged from these meetings were taken into consideration during the initial design of the new curriculum. They included the need to adapt the content to integrate the concept of neglect that is highly prevalent in the lives of elders with IDD; adjust the mode of delivery (i.e., constitute smaller groups, e.g., 3-5 people); use accessible language (i.e., follow the easy-to-read and understand format, Inclusion Europe, 2009).

Online Survey

Additionally, we cast a wide net of practitioners and researchers working in the field of IDD and/or elder abuse in the United States and Switzerland ($n=86$, recruited via e-mails or posts on relevant websites) to complete an online needs assessment survey (English and French version) during winter 2021-2022 (see Table 1). The survey aimed to gather views on the maltreatment of elders with IDD and its prevention. The global results are presented in more detail elsewhere (Khemka et al., in preparation). Responses to two open-ended survey questions were of particular interest to this study and are presented here:

(1) One question probed respondents to list considerations that they deemed important for designing a maltreatment prevention curriculum for elder adults with IDD. Twenty-four recommendations made focused on an individual level (e.g., addressing scenarios more likely to occur with elders, including financial exploitation, not providing appropriate medical care, not providing social interaction while giving care; increasing self-awareness within relationships with family, friends, partners; understanding different levels of abuse primarily financial exploitation and being able to be more financially aware and knowing the levels of neglect from family, friends, and staff). These recommendations aligned closely to the recommendations that arose from the two focus groups and therefore provided a strong basis to be taken into account for the curriculum development's next steps (content, design).

(2) Additionally, one question asked respondents to describe one (or more) situation(s) where they have witnessed (or became aware of) maltreatment of elder adults with IDD. Forty-five respondents provided one or more examples of maltreatment situations (64 examples in total). Except for sexual abuse, where no example was given in French, situations of elder abuse described in French (Switzerland context) were largely similar to situations described in English (US context); with more situations

recalled for types of maltreatment common to elders such as financial exploitation and neglect (social exclusion; medical care). A few examples of situations described by survey respondents included: ‘Person’s niece moved into the individual’s apartment, took control of SSI and other financial benefits, and limited person’s access to money and acceptable living standard’; ‘Witnessed aide push elder adult aggressively back in their wheelchair when attempting to stand up’; ‘Aide wouldn’t drive them unless she performed oral sex’.

Table 1

Online survey: demographic information on survey respondents

	English-Speaking Respondents		French-Speaking Respondents		Total	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Gender						
Male	6	12	10	27.8	16	18.6
Female	44	88	26	72.2	70	81.4
Country						
US	29	33.7	–	–	29	33.7
Switzerland	–	–	25	29.1	25	29.1
Other	2	2.3	3	3.5	5	5.8
Missing	25	29.1	2	2.3	27	31.4
Professional Group						
Social (e.g., social worker, teacher)	25	50	28	77.8	53	61.6
Health (e.g., psychologist, doctor)	11	22	5	13.9	16	18.6
Other (e.g., researcher, government employee)	12	24	3	8.3	15	17.4
Missing	2	4	–	–	2	2.4
Experience with elders with IDD						
Little experience (0-3 y.)	6	12	9	25	15	17.4
Some experience (4-9 y.)	9	18	9	25	18	20.9
More than 10 years	20	40	7	19.4	27	31.4
Missing	15	30	11	30.6	26	30.2
Familiar with ESCAPE						
Yes	9	18	6	16.7	15	17.4
No	41	82	30	83.3	71	82.6
Considerations for designing a maltreatment prevention curriculum for elder adults with IDD						
Individual level (increasing competencies)	15	33.3	9	20	24	53.3
Structural level (relationships, networks)	13	28.9	5	11.1	18	40
Societal level (systems, services)	1	2.2	2	4.4	3	6.7
Situations of elder abuse witnessed/ aware of						
Psychological Abuse/verbal abuse	5	7.8	9	14.1	14	21.9
Physical Abuse	5	7.8	4	6.3	9	14.1
Sexual Abuse	2	3.1	–	–	2	3.1
Financial Exploitation	11	17.2	2	3.1	13	20.3
Neglect: social exclusion	9	14.1	6	9.4	15	23.4
Medical Care Neglect	4	6.2	7	10.9	11	17.2
Total	36	56.2	28	43.8	64	100

Phase 2. Determining Content and Design

Cross-cultural perspective and supports

The content and design were determined in collaboration with an international Program Advisory Board (PAB), composed of eight members. Four members came from the French-speaking part of Switzerland (self-advocate, social educator, psychiatrist, researcher); three members came from the United States (psychologist, directors of agencies serving adults with IDD); and one member was from Sweden (researcher). Members were intentionally recruited to serve as advisors to the development of ESCAPE-E given their extensive clinical experience with adults and/or elders with IDD and having prior knowledge (or understanding) of ESCAPE. Nine one-hour online meetings were held with the PAB (five in French, four in English). During the meetings with the PAB, we requested feedback regarding the curriculum's content (objectives, topics) and design (accessibility, delivery). During the seven-month iterative development process, the PAB provided input that helped ensure that the curriculum met the needs of elders with IDD, and refinement to the curriculum content was made on an ongoing basis to reflect their inputs.

To ensure full participation by the self-advocate on the PAB, one member of the research team met them online a few days before each PAB meeting to review materials together and clarify any questions. The process of developing curriculum and meeting materials in two languages was well planned, with English serving as the source language and translations done in French. Although most of the translation corresponded with the original text words, there were a few instances when the word form had to be changed while keeping the original meaning. For this, the translation and the choice of words was informed by the previous work conducted to create a French version of ESCAPE (Petitpierre et al., 2016) and feedback of the French-speaking PAB members.

Vignette development

A key instructional feature of ESCAPE is the use of illustrated vignettes designed to depict in training real-life scenarios involving a protagonist and a perpetrator(s). The vignettes for ESCAPE-E were selected from three main sources: (1) the 64 example situations from the needs assessment survey, (2) the existing 42 vignettes from ESCAPE-NOW, and (3) a literature review on elder abuse incidents (see Figure 1). The literature review was performed on Web of Science. The equation used for the search was: ("elder abuse" or "elder maltreatment") and (vignette* or scenario*). The search found 49 references; among them, 16 references were screened for further exclusion/inclusion, and one reference was found in the references list in one article. Seventeen articles were included to generate new vignettes. As one article often held more than one vignette, the literature review generated a total of 55 potentially new vignettes. Drawing from all the above sources, the research team created an initial set of 49 vignettes (eight vignettes for each abuse or maltreatment type), following a list of pre-defined rules (e.g., maximum of four sentences; present tense; every character introduced has a name). To categorize the different forms, maltreatment was labelled to include financial exploitation, social exclusion, and neglect. These forms of maltreatment are known to commonly occur with elders

with IDD and were also identified on the online survey. More severe acts such as physical, sexual and verbal abuse were grouped as abuse.

Three PAB members then rated the 49 vignettes for their level of importance (very important: definitely include in the curriculum; important: maybe include in the curriculum; not important: do not include in the curriculum). Fourteen vignettes were excluded because one or more members rated them as 'not important', whereas 22 vignettes were kept, as they were unanimously rated as very important/important. Six additional vignettes were selected from those rated as very important or important to balance for type of situation. In total, 28 vignettes were finalized for ESCAPE-E, with a minimum of four vignettes per abuse/maltreatment type with a balance for gender, settings (e.g., home, workplace, community), and interpersonal situations (e.g., caregiver, family, friends) depicted. Each vignette comprised a short description of an interpersonal decision-making situation featuring a protagonist as the decision maker in a case of abuse (verbal, physical, sexual) or maltreatment (financial exploitation, social exclusion, neglect). Additionally, six vignettes depicting non-abusive (positive) interpersonal situations were adapted from existing non-abusive vignettes in ESCAPE-NOW to bring them closer to the focus of the curriculum on elders. All vignettes were newly illustrated with black and white graphic images (see Figure 2).

Figure 1

Vignette creation flow chart

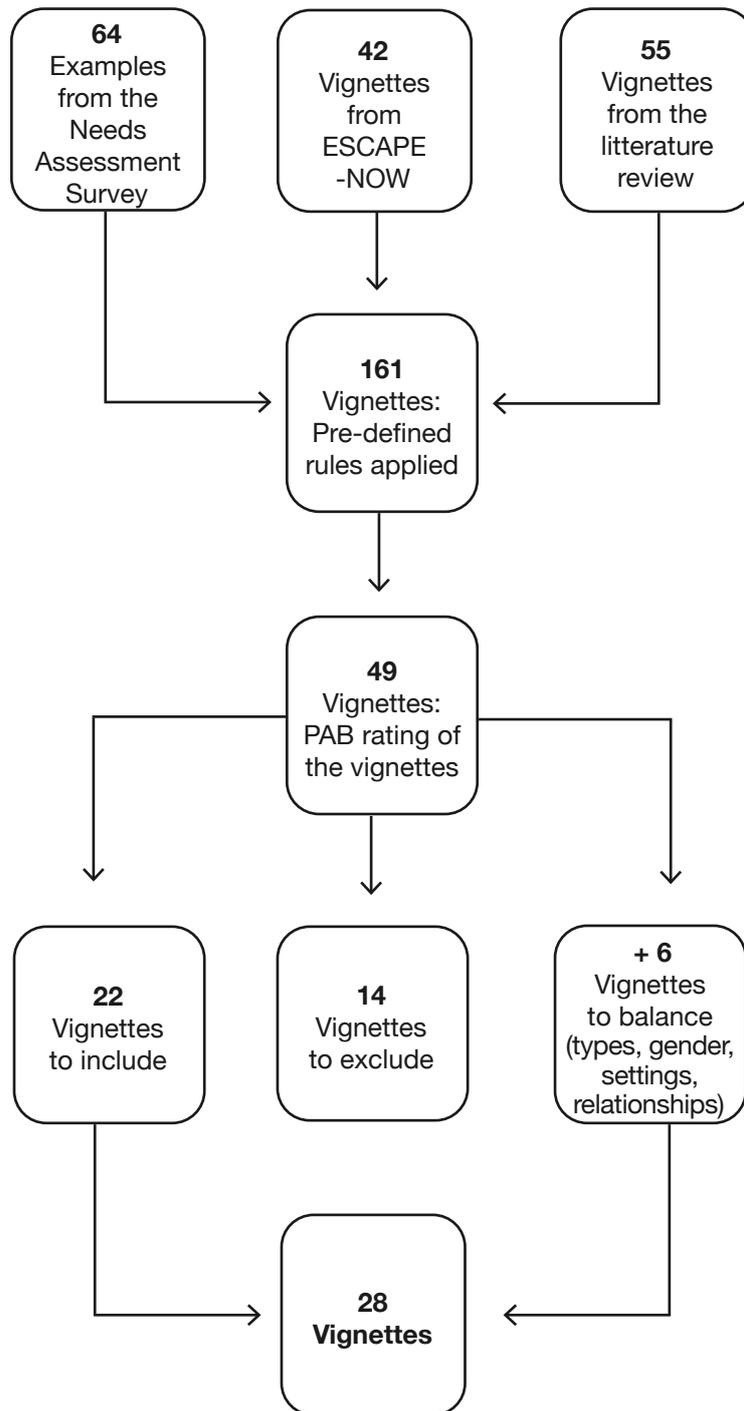


Figure 2

Example of a vignette (financial exploitation) from ESCAPE-E



Patricia asked her nephew Carlos to move into her house as she cannot stay by herself and does not want to go to a nursing home.

Shortly after Carlos moves in, Carlos begins to take money from Patricia's account for his own use.

One day, Carlos tells Patricia:

'If you don't let me use the money in your bank account, I will move out.'

Instructional Content and Design

The curriculum structure was grounded in a decision-making framework already used in other ESCAPE and adjusted to reflect recent theoretical advances in the understanding of interpersonal social decision making in individuals with IDD (see Khemka & Hickson, 2021, for a detailed explanation of pathways of decision processing). The content was also informed by and built upon the results of the online survey, literature review, and PAB discussions. Additionally, the content was carefully chosen to provide an increased understanding and awareness of the dynamics (and power imbalances) between caregivers and elders with IDD that can lead to abuse and maltreatment (e.g., caregiver work overload, financial strain, victim-perpetrator relationship, Ernst, 2019; Pillemer et al., 2016). The vignettes canvassed varying interdependence of family/caregiver roles and functions and emotional complexity commonly seen in elder relationships. This way, participants can recognize feelings associated with healthy and abusive supported relationships (emotional component) and learn how to address abuse/maltreatment using a four-step decision-making strategy within a supported relationship (cognition component). For example, a broad range of supported relationships are covered in the vignette (e.g., driving to doctor appointments, arranging meals, providing personal care, assisting with money management, assisting with medications). Finally, because it is essential to believe in one's ability to change a problem situation to take action on a decision (motivation component), all lessons are framed in an empowering way, aiming to counter possible internalized ageism and to enhance personal agency beliefs.

The curriculum design and activities were chosen to maximize accessibility to a wide range of intellectual and adaptive functioning. It follows a user-oriented design similar to that described by Vereenoghe and Westermann (2019), for example, by using easy-to-read language, large font size, images to illustrate concepts, and a clear structure, with the same design for each topic. The review activities in the curriculum are based on sorting tasks specific to revising the content of each lesson. By allowing for repetition and checks for understanding/recall, these activities are likely to be appropriate to address the learning needs of a broad range of elders with IDD, including those with dementia (Regier et al., 2017).

Proposed curriculum outline

The initial proposed ESCAPE-E comprised six lessons that aimed to last 45 minutes (pro lesson) and to be delivered in small groups (three to five elders with IDD per trainer). In each lesson, the trainer used a script, based on an explicit instructional model (approximately 15 pages per lesson), and several activity sheets (either printed or displayed via a PowerPoint); the participants received individual binders with one to five activity sheets to complete per lesson, by including stickers for response choices.

The first two lessons trained participants to recognize verbal, physical, and sexual abuse and other forms of maltreatment commonly experienced by elders with IDD such as financial exploitation, social exclusion, and neglect in interpersonal situations. The next two lessons focused on identifying

emotions related to positive and negative relationships and applying emotional coping strategies in case of distress. The last two lessons trained participants to follow a four-step decision-making strategy to make self-protective decisions (i.e., with the key goals to be safe now and stay safe later) in interpersonal situations guided by four key questions: (1) Is there a problem in the situation? (2) What are the possible choices? (3) Would the choice meet the two safety goals (safe now, safe later)? (4) Decide how to act upon the selected choice: What can (protagonist's name) do to stop the problem right away and what can (protagonist's name) do to make sure that the problem does not happen again? (See 3 for an example of a Decision-Making Chart [DM Chart]). The decision-making strategy instruction allowed the participants to learn and practice, through role play, skills that might help them to prevent abuse and maltreatment from happening (linked to the goal of being safe now) right away and/or reporting to others (linked to the goal of being safe later) for support and prevention.

Figure 3

Example of a DM Chart used in ESCAPE-E

<p>Step 1: Problem? Is there a problem in this situation?</p>	<p>What type of relationship is this and how does Mike feel?</p> <p>relationship sticker <input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>feeling sticker <input type="checkbox"/> No <input type="checkbox"/> No</p>	<p>Is the situation causing distress?</p> <p><input type="checkbox"/> Yes <input type="checkbox"/> No</p>	<p>Is there a problem?</p> <p><input checked="" type="checkbox"/> Yes <input type="checkbox"/> No</p>
<p>Step 2: Choices? What are the possible choices?</p>	<p>Choice sticker →</p>	<p>Choice sticker →</p>	<p>Choice sticker →</p>
<p>Step 3: Consequences? Would the choice meet the two safety goals?</p>	<p>Choice sticker →</p> <p>Safe now <input type="checkbox"/> Safe later <input type="checkbox"/></p> <p>Yes, choice meets both goals <input type="checkbox"/> No, think of another choice <input type="checkbox"/></p>	<p>Choice sticker →</p> <p>Safe now <input type="checkbox"/> Safe later <input type="checkbox"/></p> <p>Yes, choice meets both goals <input type="checkbox"/> No, think of another choice <input type="checkbox"/></p>	<p>Choice sticker →</p> <p>Safe now <input type="checkbox"/> Safe later <input type="checkbox"/></p> <p>Yes, choice meets both goals <input type="checkbox"/> No, think of another choice <input type="checkbox"/></p>
<p>Step 4: Decision Decide how to act upon the selected choice.</p>	<p>What can Mike do to stop the problem right away? _____</p> <p>What can Mike do to make sure that the problem does not happen again? _____</p>	<p>What can Mike do to stop the problem right away? _____</p> <p>What can Mike do to make sure that the problem does not happen again? _____</p>	<p>What can Mike do to stop the problem right away? _____</p> <p>What can Mike do to make sure that the problem does not happen again? _____</p>

Phase 3. Implementing and evaluating the usability of ESCAPE-E

We partnered with two agencies that provide services to adults with IDD to conduct a usability test of ESCAPE-E. Both agencies were represented on the PAB. One of the agency directors located in New York City selected one staff member (psychologist) to implement ESCAPE-E for the field test. The social educator from the Swiss agency, after having received approval from the director, agreed to implement the French version of ESCAPE-E. The two designated ESCAPE-E trainers each recruited five participants, within their agencies, meeting the following criteria: 50 years or over in age and able to participate in a small conversation. They gave and/or read with the prospective participants a short one-page consent form, written in an easy-to-read and understand format, with the intervention described. They were asked if they wanted to participate. Ten participants (i.e., five at each agency) gave their informed consent and agreed to participate.

Trainers' Formation

One member of the research team met with each trainer, online, three times for approximately one hour. At each meeting, procedures and materials for two lessons (aims, script, activities, stickers) were reviewed. The trainer had opportunities to discuss the information and ask questions.

Implementation

Implementation took place during Spring 2022 at the two agency sites, one in New York City and one in the French-speaking part of Switzerland. Of the ten individuals who consented to participate across both sites, nine attended the six lessons of ESCAPE-E (six men, among them four French-speaking, and three women, among them one French-speaking). One participant attended the first lesson and afterwards decided not to attend anymore.

Participants met with the trainer in a quiet room at their day program site for the six intervention sessions. Intervention sessions were scheduled on a weekly or bi-weekly basis whenever possible. If a participant was absent for one session, they were given an individual make-up session before their next training session.

Trainers' feedback

After each lesson, trainers completed an online feedback form. The form comprised four sections: (1) general information (e.g., date, numbers of participants, duration of the lesson); (2) implementation checklist (seven items to rate on a five-point scale from never to always, e.g., 'I read the exact wording of the script to the participants'; 'I reinforced correct responses'); (3) lesson rating (five items to rate on a five-point scale from strongly disagree to strongly agree; e.g., 'the trainer instructions were clear and easy to implement', 'this lesson is useful and effective for elders with IDD'), (4) lesson feedback (three open-ended questions; e.g., 'what did you find particularly helpful/relevant in this lesson?'). Trainers took, on average, eleven minutes to complete the form.

Participants' feedback

The trainer administered a brief feedback form comprising four questions at the end of the six lessons to record each participant's impressions on the usability and usefulness of the curriculum in their lives. The first and last question used a Likert scale – Yes, I don't know, No – indicated by three face images. The questions were the following: (1) Has this training been helpful? If yes, what parts of the training were helpful? (2) What are some important things you need to think about when you have to make a decision? (3) Do you have suggestions for how to improve this training? (4) Would you recommend this training to someone else?

Results

Trainers' feedback

Globally, the curriculum was implemented as intended, with an average mean of implementation fidelity ranging from 3.7 to 5. The least well-adhered to fidelity criterion in each lesson for both trainers was 'I read the exact wording of the script to the participants'. The trainers reported that repeating short phrases and doing frequent informal probes to check for participants' understanding by paraphrasing was helpful, suggesting that some flexibility from reading the script verbatim might be necessary to individualize the pace and keep participants engaged in a lesson. The trainers' instructions were mostly rated as clear and easy to implement, and the trainers perceived the level of instruction for elders with IDD as appropriate (see Table 2). Lesson 4, centered on empowerment and coping, was perceived as least relevant and efficient for the French-speaking group. The feedback from the two trainers on the open-ended questions was very similar. For example, both trainers considered the vignette images as helpful and reported that participants enjoyed the illustrations and the activities – especially using stickers to complete their sheets. Each lesson lasted about fifteen minutes more than the 45 minutes initially planned, and not all tasks could be completed within the allotted time, necessitating another look for how the content could be distributed across the lessons.

Table 2Lesson rating (*n*=2)

Lesson Trainer	1		2		3		4		5		6	
	ENT	FRT										
The instructions for the trainer are clear and easy to implement.	4	5	4	5	4	4	4	2	4	4	4	3
The overall level of instruction is appropriate for elders with IDD.	3	4	4	4	4	4	3	2	3	4	3	4
The activities are appropriate for elders with IDD.	3	4	4	4	3	4	3	2	3	2	3	4
The vignette images are helpful for understanding the situations.	3	5	3	5	4	4	4	5	4	4	4	5
This lesson is useful and effective for elders with IDD.	3	5	3	5	4	4	4	4	4	5	3	4

Note. Rating: 1= strongly disagree, 2= disagree, 3= neutral, 4= agree, 5= strongly agree. ENT = English speaking trainer, FRT= French speaking trainer

Participants' feedback

To the question (1) 'has this training been helpful?' all participants replied yes; three drew attention to the vignettes when they were asked 'what parts of the training were helpful?' ('story'; 'picture'; 'pictures'), three other participants found it helpful to 'know how to say stop' or protect themselves; one participant referred to the stickers, and two participants did not fill in this part of the question/did not know. Regarding the second question ('What are some important things you need to think about when you have to make a decision?'), four participants replied, '(stay) safe now, safe later'. The other four participants' responses were more related to asking for help when needed, talking to someone, and thinking about possible choices. One participant did not fill in this question. (3) Regarding the suggestions for improving the training, most (7) replied that they liked it how it was. One participant wrote 'need more people', which prompted another participant to write 'will my people'. (4) Except for one participant who did not know, all indicated that they would recommend this training to someone else.

Adaptations performed to enhance the usability

We used the results of the usability assessment to perform minor and substantial adaptations to enhance the usability of ESCAPE-E: the curriculum was structured differently to spread out the content more evenly across lessons (i.e., the curriculum was divided into eight lessons instead of six lessons with a final Wrap Up session; the review activities were shortened); the instructor's manual was enhanced to improve clarity about how trainers can adapt the curriculum with different groups based on time and participants needs (e.g., additional information on accommodation were provided, with recommendation like, the lesson should not last more than one hour with a break – ideally 30-45 minutes sessions; group of three to five participants, depending on the group, a co-trainer can be helpful to support participants); and the content of Lesson 4 in French was reviewed to better convey the notions of empowerment and coping (i.e., after discussion with the French-speaking members of the PAB, the activities on empowerment and coping were revised around the topic of “what helps me” and the script was reviewed to be easier to understand). Table 3 provides an overview of ESCAPE-E, revised.

Table 3

Overview of ESCAPE-E

Lesson	Objectives	Materials and key activities
1	<ol style="list-style-type: none"> 1. Define verbal, physical, and sexual abuse 2. Discriminate between different types of abuse 	<ul style="list-style-type: none"> • 12 vignettes (verbal, physical, sexual abuse) • Stickers (types of abuse) • Activity Sheets (group and individual activities) • Interactive board game (sorting cards for types of abuse)
2	<ol style="list-style-type: none"> 1. Define financial exploitation, social exclusion, and neglect 2. Discriminate between different types of maltreatment 	<ul style="list-style-type: none"> • 12 vignettes (financial exploitation, social exclusion, neglect) • Stickers (types of maltreatment) • Activity Sheets (group and individual activities) • Interactive board game (sorting cards for types of maltreatment)
3	<ol style="list-style-type: none"> 1. Define positive and negative relationships 2. Identify feelings associated with positive and negative relationships 3. Distinguish between positive and negative relationships 	<ul style="list-style-type: none"> • 12 vignettes (positive and negative relationships) • Stickers (positive, negative relationships) • Activity Sheets (group and individual activities) • Interactive board game (sorting cards for types of relationships)
4	<ol style="list-style-type: none"> 1. Identify perceptions of self-empowerment 2. Recognize distress 	<ul style="list-style-type: none"> • Two vignettes (positive and negative) • Activity Sheets (group and individual activities)
5	<ol style="list-style-type: none"> 1. Handle distress 2. Distinguish between helpful and not helpful ways of thinking and coping with distress 	<ul style="list-style-type: none"> • Five vignettes (positive and negative) • Activity Sheets (group and individual activities) • Interactive board game (sorting cards for helpful/not helpful ways of thinking and coping)
6	<ol style="list-style-type: none"> 1. Identify personal safety goals 2. View a 4-step strategy for making decisions 	<ul style="list-style-type: none"> • Two vignettes • DM Charts (trainers and participants) • Stickers (decision choices) • Decision role play chart
7	<ol style="list-style-type: none"> 1. Review safety goals and DM chart 2. Apply a 4-step strategy for making decisions 	<ul style="list-style-type: none"> • Two vignettes • DM Charts (trainers and participants) • Stickers (decision choices) • Decision role play chart
8	<ol style="list-style-type: none"> 1. Practice applying a 4-step strategy for making decisions with group feedback 2. Independently practice a 4-step strategy for making decisions 	<ul style="list-style-type: none"> • Two vignettes • DM Charts (trainers and participants) • Stickers (decision choices) • Decision role play chart
Wrap Up	<ol style="list-style-type: none"> 1. Create a Decision-Making cue card and a personal identification card to identify individual support network 	<ul style="list-style-type: none"> • DM Cue Card • Personal Identification Card

Discussion

The purpose of this article was to describe the development and report the results of a usability evaluation, of both the English and the French versions, of a newly developed curriculum for the prevention of abuse in elders with IDD – ESCAPE-E. While the content of the curriculum was grounded in research on decision-making and past intervention efforts (see Khemka & Hickson, 2021), its development was guided by the results of a needs assessment and feedback of an international program advisory board. Cross-cultural development and usability assessment ensured that the curriculum's content and design were appropriate in the American and Swiss contexts. The usability assessment highlighted common and specific challenges in each field test – challenges that we addressed through minor and substantial adaptations to ESCAPE-E. The main difference between the curriculum's English and French versions lies in the lesson centered around empowerment and coping – two words that do not have an exact equivalent in French (Knafo et al., 2014; Lipietz, 2018). The usability assessment highlighted a translation problem around those concepts, which led to adaptation in the content and activities to convey their meaning better and reduce the complexity induced by a too close translation of the English version.

Results highlight that the intervention is promising. Overall, the content of the curriculum is perceived as appropriate; for all lessons, trainers rated the lesson as effective for elders with IDD. Participants' responses on the feedback questionnaire demonstrated learning acquisition, with their overall rating of the intervention being positive. Participants' feedback on how the curriculum could be improved was similar to the feedback received by Hughes et al. (2018), who developed The Safety Class, an abuse prevention program for adults with disabilities. Some participants that participated in The Safety Class responded: 'More people. Not enough people. I know it would take time, but more people need it' (Hughes et al., 2018, p.11). Similarly, participants' suggestions to share and make the ESCAPE-E intervention accessible to more people highlight their interest in abuse prevention training. The ESCAPE-E curriculum addresses a critical gap in service provisions, as no curriculum focusing on the training needs of elders with IDD regarding abuse and neglect was available.

Overall, participants' and trainers' feedback confirm the interest in developing accessible prevention training to reduce the risks of victimization for people with IDD across the lifespan. People who receive such training might be more likely to recognize and disclose abusive acts (Hughes et al., 2018), and the targeted focus on enhancing personal agency beliefs and tackling ageist perceptions in the curriculum might be helpful in preventing elder abuse (Chang, 2021). Nevertheless, those possible outcomes have to be studied, and further research is required to assess ESCAPE-E's efficacy in preventing elder abuse in adults with IDD.

Despite broadening perspectives in the abuse prevention field, ESCAPE-E remains a prevention program focused on an individual level. Although adopting a comprehensive approach is necessary to address elder abuse, interventions and solutions on structural and societal levels are equally essential.

At present, no effective solutions have been found, and the field of elder abuse appears to be at the same stage where child maltreatment and intimate partner violence research were two decades ago (Teresi et al., 2016). The lack of effective solutions has been identified by the WHO (2022) as one of the five priorities for the United Nations Decade of Healthy Ageing (2021-2030) in its report on tackling abuse of elder people. Increasing solutions available and developing effective interventions at all levels are needed to end elder abuse of people – with and without IDD.

Conclusion

Research on elder abuse and its prevention for aging individuals with IDD is scarce (Beaulieu et al., 2022). This pilot study documented the development and usability evaluation of ESCAPE-E in English and French. As a promising curriculum that aims to build knowledge and decision-making skills of elders with IDD to resist abuse and maltreatment in support of a higher quality of life, ESCAPE-E hopefully opens new avenues for future research on the prevention of elder abuse in people with IDD.

4 Discussion

Despite the high rates of maltreatment faced by adults with IDD across their lifespan, tools for preventing victimization at an individual level for this population are scarce – if not non-existent in French-speaking countries. Using a mixed-method design involving 70 people with IDD and 33 practitioners in special education, this doctoral thesis aimed to enhance our understanding and advance the prevention possibilities regarding the maltreatment of people with IDD across the lifespan.

From a theoretical perspective, this doctoral thesis contributes to a better understanding of the vulnerability to the victimization of adults with IDD. From a practical perspective, this doctoral thesis provides two new tools that practitioners can use with French-speaking adults with IDD, one test evaluating social vulnerability and one curriculum aiming at preventing abuse and neglect in later life. Those two perspectives will be discussed in more detail in the following section, focusing first on the theoretical information provided by our studies regarding preventing the maltreatment of adults with IDD across the lifespan. Next, the aspects related to implementing new tools and interventions will be discussed from a practical perspective. Moving ahead, the limitations, implications for research and practice, and perspectives will be addressed.

4.1 What does this thesis add?

To investigate social vulnerability in French-speaking adults with ID, we first validated the French adaptation of the Test of Interpersonal Competence and Personal Vulnerability (Wilson et al., 1996), the TV-22. While a factor analysis involving a more significant sample remains necessary to confirm the good psychometrics properties from preliminary findings, results suggest that the TV-22 is a reliable and valid measure for assessing social vulnerability in French-speaking adults with ID.

The main difference between the French and English original versions of the test was that open-ended questions were added (i.e., after displaying a vignette, instead of showing the three possible response options directly, first asking ‘What should Pierre/Marie do?’). This addition to the test provided key information as it informed how the person thinks spontaneously when facing an interpersonal problem rather than directly providing direction (in the form of option responses). Results from the implementation study further informed us – to guarantee optimal implementation and assessment fidelity – of the relevance of performing the assessment within two sessions (one with the test with the open-ended questions and the second with the multiple-choice options). There is a fair amount of inter and intra-individual variability between effective open-ended and correct multiple-choice responses in the social vulnerability assessment. This variability may be linked to the different abilities involved in the decision-making processes in the two types of questions. In open-ended questions, the decision-making process is likely to rely on an intuitive search for recollection of past decisions (Kahneman, 2011); by contrast, in multiple-choice questions, asking the person to think about the possible

consequences of the three answers presented as a, b, or c involves hypothetical thinking, which simultaneously engages demands on cognitive, motivational, and emotional processes (Hickson & Khemka, 2013). In the section that follows, the main findings that arose from both types of questions are discussed. Discussing the main findings that arise in both types of questions (i.e., results from Study I and Study III) provides nuanced data that pinpoint specific elements that were particularly challenging for adults with ID in our studies.

Overall, results from our studies are in line with previous studies that underlined that social vulnerability has many layers and takes its roots in both (inter)personal and environmental factors (see Figure 1). Our results regarding digital risks corroborate findings from previous research studies highlighting that factors contributing to the social vulnerability of individuals with ID in the real world act as risk factors in the online world (Finkelhor, 2014; Lough & Fisher, 2016). They provide further support stressing that cognitive difficulties and limitations in (social) adaptive skills are likely to contribute to – but are not the same thing as – socially vulnerable behaviors. Far from an intent to confer the person into a victim identity, the assessment of social vulnerability, by identifying modifiable personal characteristics that can enhance susceptibility to victimization, opens promising and important avenues regarding interventions to prevent maltreatment and support to empower persons with ID to manage their social interactions more effectively (Nettelbeck & Wilson, 2002).

(Inter)Personal factors increasing social vulnerability

The results of the social vulnerability assessment were not correlated to gender. This is consistent with past research on adults with IDD and older adults with neurological conditions indicating that being socially vulnerable is not related to gender (Fisher et al., 2018; Sofronoff et al., 2011; Wilson et al., 1996). Correlational analyses indicated that social vulnerability is not associated with age. These results corroborate earlier findings on older adults with neurological conditions (Pinsker, 2011) and adults with IDD (Fisher et al., 2018). Overall, findings from social vulnerability research seem to indicate that as they age, social vulnerability decreases in neurotypical children, but for some adults – with and without IDD – social vulnerability remains high (Fisher et al., 2018; Teunisse et al., 2020; Wilson et al., 1996). Pinsker et al. (2006) found that elder adults with neurological conditions have a general decline in cognitive functioning, but this decline does not necessarily lead to an increase in social vulnerability. This is also consistent with broader research studies on decision making in risky social situations, which report that although some changes happen in the way the decision-making process is performed, the decision-making effectiveness remains stable through age-related improvements in other skills (Bruine de Bruin et al., 2020; Spreng et al., 2021). Therefore, cognitive tests designed to assess cognitive functioning cannot determine social vulnerability in (elder) adults with or without IDD (Pinsker, 2011).

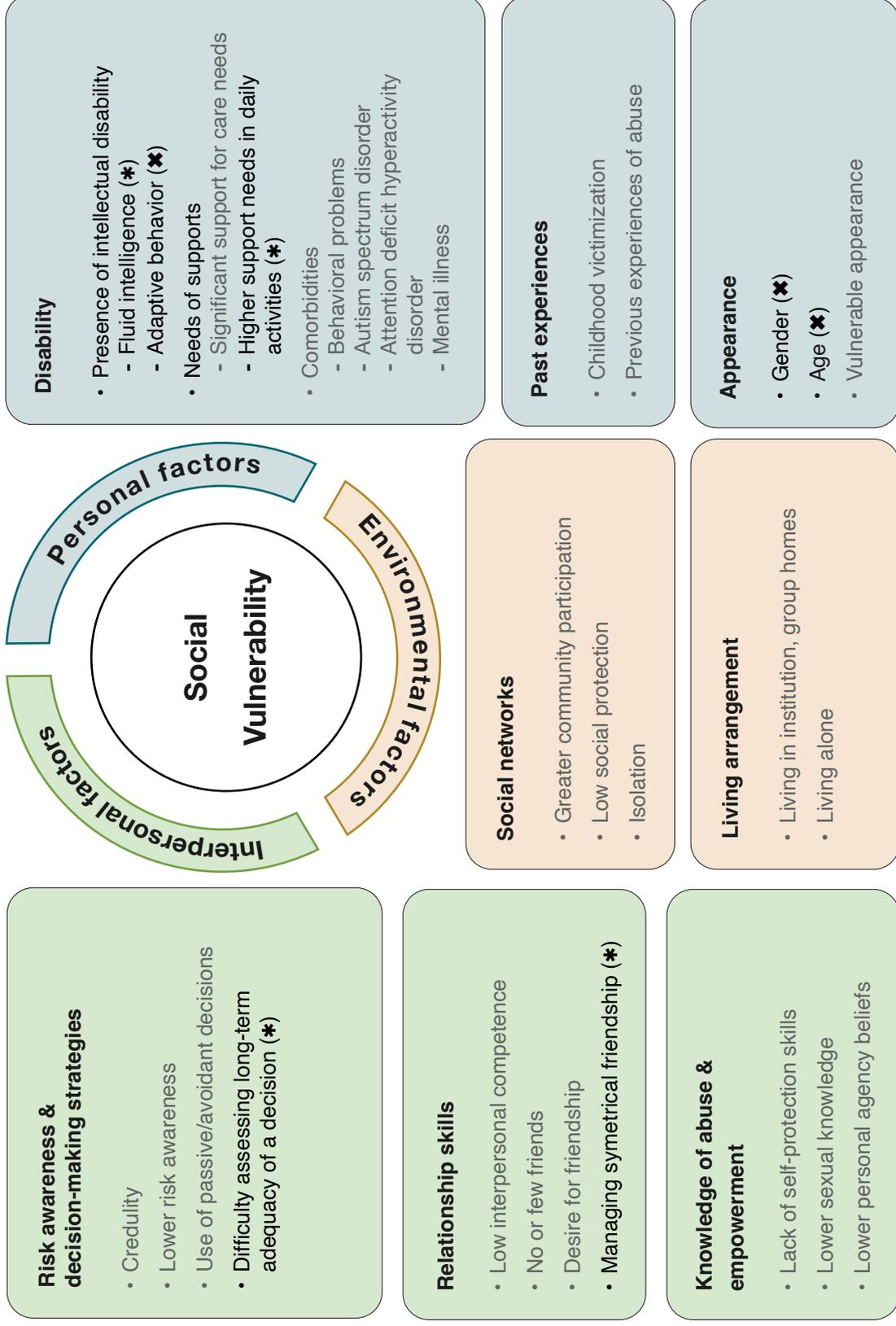
We found a moderate association between the ability to protect oneself and fluid intelligence. These results are theoretically consistent as fluid intelligence comprises problem-solving abilities and

relational reasoning (e.g., understanding the relations among people) (Krawczyk, 2012). More specifically, the ability to take others' perspectives and detect socially untrustworthy cues might be more relevant to understanding social vulnerability (Teunisse et al., 2020). A way to explore this relationship would be to analyze the relationship between social vulnerability and the theory of mind – the ability to understand people's beliefs depending on their perspectives (Harari & Weinstock, 2021). However, the only research studies (Pinsker & McFarland, 2010; Seward, 2018), to our knowledge, that explored social vulnerability and its relation to the theory of mind yielded unclear results about the relationship between the two constructs. Seward (2018) hypothesized that more advanced aspects of the theory of mind might be involved in one's social vulnerability, like the strategic theory of mind (i.e., the ability to understand people's beliefs depending on their perspectives and to use this knowledge to predict people's behavior (Sher et al., 2014) or interpretive theory of mind (i.e., the ability to understand that people interpret ambiguous information differently, Carpendale & Chandler, 1996). Additionally, recent research on neurotypical children found that interpretive theory of mind plays a unique role in developing social understanding (Harari & Weinstock, 2021) – which could then decrease social vulnerability.

One unanticipated finding was that social vulnerability assessment did not correlate with the assessment of (social) adaptive behavior. This result surprised us because it is theoretically inconsistent. While one cannot exclude measurement issues related to the adaptive behavior assessment (e.g., translation, items chosen), this result highlights discrepancies between self-report and third-party reports. These discrepancies could be related to the fact that people have a tendency to overestimate the likelihood that they will engage in desirable behaviors (Dunning et al., 2004). It also accords with our subsequent observations underpinning the high number of justifications mobilizing a “learned rule” (e.g., “it's not right”). Those observations tend to indicate that adults with ID might reiterate rules with limited integration. In other words, the TV-22 measures a theoretical knowledge – but there can be some mismatch between the theoretical knowledge and the actual behavior. Foremost, these findings underpin the importance of crossing the sources of the social vulnerability evaluation, like using the TV-22 in combination with direct observations or validated social vulnerability questionnaires completed by proxies.

Figure 1

Updated overview of (inter)personal and environmental factors of social vulnerability in adults with IDD



Note. (*) = factors identified in our studies (✖) = factors assessed but not significantly related to social vulnerability in our studies

Interactions between (inter)personal and environmental factors increasing social vulnerability

Our findings highlight that participants displayed a heightened social vulnerability when they had to make a decision where one is safe not only now but also later. Adults with ID seem likely to display a higher social vulnerability if they have to assess the adequacy – in the long term – of a choice. The fact that some participants chose passive/avoidant options is consistent with previous studies on social decision-making in adults with ID. For example, Hickson et al. (2008) observed decision-making styles in vignettes involving abuse in women with ID with and without a history of abuse. They reported that women with a history of abuse were more prone to use passive/avoidant responses and/or unregulated emotional coping strategies, like crying or smashing something. Despite displaying an awareness of the risk, those responses are likely to be the least effective in dealing with the situation and preventing the continuation of abuse.

Regarding risk awareness, our results demonstrate that most adults with ID seem to display an awareness of digital risks – although, in some items, a certain percentage (13-29%, depending on the item) do not seem to perceive the risk present in the vignette. These results reflect those of Fisher et al. (2013), who found that the social vulnerability of individuals with autism spectrum disorder and Down syndrome was related to lessened abilities to detect risk in some social situations and that those individuals were then less likely to report it spontaneously if something questionable happened (e.g., tell an authority figure about bullying). Interestingly, our findings underscore the fact that most adults with ID use self-determined protection to manage digital risks, like turning off the computer if someone bothers them. While those results highlight important self-determined behaviors, what shows up in the shadows is that most also do not spontaneously share their issue with someone. This is consistent with studies that examine self-referral rates of abuse and underlines that people with ID are under-reporting (Health & Social Care Information Centre [HSCIC], 2014; Mansell et al., 2009; Willott et al., 2020). For example, the HSCIC (2014) found that self-report rates of abuse of vulnerable adults were as low as 2% in their referrals.

Difficulties found in reporting abuse underscore the importance of providing a communication framework that allows people to express their views. As Cameron and Matthews (2017) highlighted, “people [with ID] cannot be expected to disclose the big issues of their lives, if they have not been encouraged to reflect and share the small ones” (p.58). Above and beyond that, their words underline the importance of not only focusing on upskilling individuals but adopting a broader approach that encompasses their living environment.

In our studies, we did not ask or observe the relation between the living environment (e.g., group home, institution) and the social vulnerability assessment. However, our results show that higher needs for support in daily activities are correlated to higher social vulnerability. These findings further support the hypothesis that higher degrees of independence contribute to higher exposure to social situations, offering opportunities for learning and experiences navigating them, hence decreasing social vulnerability (Seward, 2018). Additionally, our results highlight that one source of social vulnerability could be related to difficulty managing symmetrical friendships. This relationship between friendships and social vulnerability is consistent with Fisher et al.'s (2013) findings reporting that having one friend (or more) reduces social vulnerability.

Although our first three studies were not focused on elders with IDD and underscore the fact that social vulnerability seems not to be associated with aging, they still report some interesting findings that can be linked with existing studies on elder abuse. For example, premature aging and frailty – phenomena well documented in elders with IDD – are likely to reduce one's level of independence and increase one's support needs. Needing more support is known to be related to not reporting elder abuse: similar to the report of adults with IDD, elder abuse is known to be underreported, and it is estimated that “for every case of elder abuse that comes to the attention of a responsible entity, another 23 cases never come to light” (National Center on Elder Abuse, 2013, p.8). Elders with and without IDD might experience several reasons for not reporting victimization, like not being educated about their rights, fear of not being believed, uncertainty about whether their experience constitutes abuse, or lack of a person of trust (Buhagiar & Lane, 2022; Willott et al., 2020). Additionally, results underpin a tendency for passive/avoidant solutions that are hypothesized to stem from low personal agency beliefs (e.g., “I can do nothing”) (Hickson et al., 2008). As people age, internalized ageist perceptions (i.e., thinking about oneself negatively because of one's age) might arise, further deepening the low personal agency beliefs. While it is hypothesized that people that receive abuse prevention training might be more likely to recognize and disclose abusive acts (Hughes et al., 2018), more research on ESCAPE-E is needed to assess its efficacy. Likewise, the focus through the curriculum on enhancing personal agency beliefs and tackling ageist perceptions might help prevent elder abuse (Chang, 2021), but it remains to be assessed. Equally, while some abuse prevention interventions have shown positive effects on environmental factors of social vulnerability, like an increased social network (e.g., Ward et al., 2013), those effects remain to be examined in ESCAPE-E. Consistent with the findings from the first studies showing that social vulnerability takes its roots in various ways, the curriculum developed in the last study sought to address a variety of interpersonal factors identified in social vulnerability, e.g., related to risk awareness and decision-making strategies, relationship skills, knowledge of abuse and empowerment.

Analyzing the interaction between personal, interpersonal, and environmental factors increasing vulnerability leads to interventions that aim to support self-determined abilities in a thicker and more meaningful sense (Clough, 2017). While the studies from this doctoral thesis focused on the individual

level of prevention specifically, we acknowledge that the prevention of maltreatment should be acted upon different levels. Beyond the individual level, for example, Wiesel et al. (2021) called for more risk-enabling spaces for encounters. They defined these spaces as spaces “where safety and risk are balanced one against the other: where a sense of familiarity or knowability, is balanced by unknowns and surprise; (...)where co-production brings both the safety and risks of control and responsibility” (p.42). Such spaces are embedded in a broader approach that sees risk-taking possibility as part of the quality of life and human rights (Araten-Bergman & Bigby, 2020). The possibility of investing in those risk-enabling spaces would not only allow experiential practices, contributing to a positive appreciation of the risk of unexpectedly meeting with a stranger, an acquaintance, or a friend (Wiesel et al., 2021), but also possibly decrease one’s social vulnerability through this social exposure and opportunities to bond with others and develop friendships.

4.2 From research to practice: implementing new tests and interventions

“The implementation gap”, “the valley of death”, “the leaky research pipeline”, “the research waste”: those of some of the many terms used to illustrate the slow translation or the lack of translation of scientific findings into practice (De Geest et al., 2020). It is estimated that, on average, 17 years happen between the development of innovation in research and its application in practice (Balas & Boren, 2000; Morris et al., 2011). Though implementation science research took its roots first in the medical field in the early 1970s, its applicability to (special) education soon arose, with calls emerging at the end of the 1990s for special education research that is trustworthy, accessible, and usable (Odom et al., 2020). Recognizing the failure of the “single-day workshop” approach to bridge the research-to-practice gap (see Fixsen, 2015), Odom et al. (2020) highlighted the need for strategies to implement effective research-based practices in special education. Following the “make it happen” perspective (Greenhalgh et al., 2004), the research design used in some of our studies reflects an implementation lens and uses concrete strategies to prevent a research-to-practice gap.

Acknowledging the lack of effective interventions to prevent abuse in elders with IDD, one of our studies focused on the development and usability evaluation of a new intervention to reduce social vulnerability in elders with IDD. A traditional view on intervention development may have pleaded in favor of a more linear design (e.g., intervention development, efficacy study, and then implementation study), but this perspective has been recognized to contribute to the abovementioned 17 years’ research-to-practice gap (Balas & Boren, 2000). As such, the research design we used was consistent with Boyd et al.’s (2022) call for a shift to implementation research in parallel to intervention research – i.e., develop intervention and use implementation research methods to support the systematic adoption, use, and sustainment of research-based practice in the real world (Boyd et al., 2022).

Regarding assessment fidelity, the findings highlight that – despite an assumption of an error-free use – there are differences between practitioners in special education practices when they use a (new) test to assess one person’s social vulnerability. The fact that 25% of the practitioners used the test with an extreme lack of adherence to the guidelines had several implications: on the one hand, it led us to clarify what type of formation to recommend for people interested in using the new test. On the other hand, we performed some adaptations in order to improve fidelity (e.g., writing all the questions that have to be asked directly in the test itself and not in the user’s manual; enhancing the user’s manual about how to proceed, and what types of accommodation practitioners can make). Results from the usability intervention assessment also led to adaptations (e.g., structuring the curriculum differently to spread out the content more evenly across lessons). The need to make adaptations is a well-debated topic within implementation science research (De Gue et al., 2020). Historically, implementation science viewed interventions as static protocols – but it is now acknowledged that “there is no implementation without adaptation” (Lyon & Bruns, 2018, p.1) and that adaptations are likely to substantially increase the usability of the intervention tested (Lyon & Bruns, 2019).

The research designs used are well-aligned with the growing research practice of co-creation in implementation research, which implies involving key stakeholders to create and sustain research-based innovation in practice (Metz et al., 2019). Co-creation and implication of key stakeholders in research are also characteristics consistent with the current trends of research practice in special education, often summarized under the slogan “Nothing about us without us” (Stack & McDonald, 2014). Consistent with other studies on maltreatment in people with IDD (Hughes et al., 2018; Lund et al., 2022), the curriculum was created in collaboration with an international program advisory board composed of various stakeholders, including one self-advocate who self-identified as an elder with ID. Nevertheless, time constraints and a lack of resources hindered a truly participative approach, and the design used, while implying a variety of stakeholders, could have been more inclusive and participative – which leads us to general limitations, implications, and perspectives that the findings from this doctoral thesis open.

4.3 Moving ahead: limitations, implications and perspectives

In the 1990s, Wilson and Brewer's landmark study highlighted the difficulty in defining the core characteristics of social vulnerability in adults with ID, paving the way for a new sub-field of research studies. Thirty years later, if the relevance of understanding social vulnerability to prevent victimization has been increasingly acknowledged, many unanswered questions about social vulnerability in adults with IDD remain.

Overall, results from our studies have contributed to corroborating and refining (inter)personal and environmental risk factors identified in previous research studies. Nevertheless, these results must be considered within the general limitations of our studies. Among them, studies were conducted with small sample sizes, exclusively with adults with ID able to participate in a small conversation. Additionally, we only assessed open-ended question results concerning digital items and not on the whole items set. Notwithstanding its limitations, results from this doctoral thesis support the relevance of the TV-22 as a social vulnerability assessment test and raise intriguing questions regarding the role of cognitive sub-skills and adaptive behavior in risk (un)awareness and social victimization, like the advanced theory of mind or friendships processes.

Beyond the test developed, the (inter)personal and environmental risk factors identified generate implications for practice by providing information on the support needs that can promote a satisfactory quality of life for the person. They underpin the importance of supporting friendships development and developing risk-enabling spaces that allow for social exposure and social learning. Furthermore, our results seem to support the assumption that social vulnerability is not culturally dependent – at least within a western context. As our results are the first to report findings related to French-speaking adults with ID, further research investigating cross-cultural differences in the social vulnerability of adults with ID will need to be undertaken. It is also important to note that our results are part of a research stream that has been conducted only within a western context, mostly from the USA and Australia (Arnett, 2008). Future studies on social vulnerability, including broader and more diverse samples, are needed. By underlying possible cross-cultural differences and similarities, such research could significantly improve our understanding of the (inter)personal and environmental factors contributing to victimization and provide valuable information about the core characteristics of social vulnerability in adults with IDD. This information might constitute a pivotal step in identifying and addressing specific risk factors of victimization for adults with IDD (Fisher et al., 2016). Notwithstanding its acknowledged importance, decreasing social vulnerability remains challenging (Wilson, 2016). Looking back at more than two decades of research studies on victimization and social vulnerability, Fisher et al. (2016, p.124) pointed out, despite progress, the paucity of research conducted to design effective abuse prevention curricula, and concluded:

Perhaps this dearth of interventions has occurred because we really do not know where to begin. When so many risk factors are identified, it becomes difficult to pinpoint which one is the most important to address.

This difficulty is likely one reason why research on abuse prevention in elders with (and without) IDD is underdeveloped. While our results regarding the development and usability evaluation of an abuse prevention intervention for elders with IDD are promising, they foremost call for more research. Our study is the first to report the development of an abuse prevention intervention cross-culturally, developed conjointly for American and Swiss contexts; it is also the first to focus on elder adults with IDD specifically. Its efficacy and possible cross-cultural differences remain to be assessed.

Finally, we concur with Hughes et al. (2018, p. 13), who stated:

Arming with education is necessary but not sufficient. Society needs to challenge the injustice of abuse (Northway, 2017; White et al., 2003) by addressing societal beliefs, environments, and cultures that promote victimization of people with intellectual disability.

Despite promising advances in the maltreatment prevention of adults with IDD, there is still abundant room for further progress. Rigorous evidence-based research is arising about the types of positive organizational culture and practices (e.g., consistency of practice, service quality) associated with good quality of life outcomes and contributing to preventing maltreatment of people with IDD (Araten-Bergman & Bigby, 2021), holding promise for the future. Lastly, because what constitutes maltreatment is constantly reshaped according to specific social contexts and results from current norms that frame what is tolerated or considered an abusive act (Pache, 2020, 2021), the current definition of maltreatment is called to evolve, and with it, the prevention practices will need to be reshaped.

5 Conclusion

Following in the footsteps of a small field of research studies that started thirty years ago, the four studies composing this doctoral thesis contribute to a better understanding of the vulnerability to maltreatment of adults with IDD. They provide concrete tools, one test (for evaluation), and one curriculum (for support) that practitioners can use to prevent maltreatment in adults with IDD. Findings from this doctoral thesis open research perspectives regarding social vulnerability, its similarities across countries, and its relation to cognitive sub-skills and adaptive behavior; they also propose new avenues for future research on preventing the maltreatment of elders with IDD.

Much progress has been made in the past thirty years – but more is needed to ensure the rights and dignity of people with IDD across their lifespan. “Freedom from exploitation, violence, and abuse” will likely remain a priority area of the Council of Europe for its Disability Strategy after 2023.

6 References

Introduction

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