School-based abuse prevention for children with communicative and/or cognitive disabilities: Guidelines for program implementation

by

Ellen Amanda Evelina Håkansdotter Nyberg
Student no: 17388602

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SUPERVISOR: Prof. Juan Bornman
CO-SUPERVISOR: Dr. Ulrika Ferm

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The author declares that he/she has observed the ethical standards required in terms of the University of Pretoria's Code of ethics for researchers and the Policy guidelines for responsible research.

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Abstract

Children with communicative and/or cognitive disabilities are at high risk of experiencing abuse, which can have life-long effects on their health and well-being. Primary abuse prevention programs, pitched at school-level with the aim of stopping abuse perpetrated by adults against children before it occurs, have been found to be effective in increasing children's knowledge of abuse and safety skills. This can decrease their risk of being abused significantly. Such programs have, however, been designed for typically developed children, with a paucity of evidence-based guidelines on how teachers, with the support of principals, could adapt these programs to address the needs of children with communicative and/or cognitive disabilities. Therefore, the purpose of this study is to explore the key components, teaching methods and information that should be included in school-based abuse prevention programs and to subsequently develop and evaluate guidelines for teachers, supported by principals, to guide them in adapting school-based abuse prevention programs for 7–12-year-old children with communicative and/or cognitive disabilities. This was achieved through a three-phase exploratory sequential mixed methods research design. Phase 1 (i.e., the development phase) included three different data sources, published as independent studies. The first data source consisted of a scoping review of school-based abuse prevention programs for 7–12-year-old children that included more than one type of abuse (i.e., both physical and sexual abuse) and was taught by teachers in a school setting. The review explored key components, outcome measures and evaluation methods of such programs. The second data source included focus groups with teachers (n = 7) and practitioners (n = 5) as well as semi-structured interviews with parents of children with communicative and/or cognitive disabilities (n = 6). This data source also focused on identifying key components and teaching methods, specifically for children with communicative and/or cognitive disabilities. The third data source entailed a rapid review of the extant literature regarding potential signs of abuse in children with disabilities followed by the social validation of these signs by an international expert panel (n = 39). Despite some differences in the perceived accuracy of the signs, post-traumatic stress disorder (PTSD) was rated as the most accurate. Phase 2 of the study (i.e., the development phase) included the development of guidelines for adaptations of school-based abuse prevention programs for the target population by integrating Phase 1's data using a recursive abstractive thematic analysis approach. The theoretical and conceptual frameworks of the thesis underpinned the guideline development process and highlighted the need for a multi-systemic approach to abuse prevention. The resulting guidelines included recommendations for how teachers, with the support of principals, could conduct adaptations of school-based abuse prevention programs to suit the needs of 7–12-year-old children with communicative and/or cognitive disabilities. Finally, Phase 3 (i.e., the evaluation phase) explored the feasibility and social validity of the guidelines developed in Phase 2 by conducting an online survey and email interviews with three stakeholder groups, namely teachers (n = 6), principals (n = 3) and content experts (n = 10). The results demonstrated that the participants perceived the guidelines as feasible and socially valid and of an overall high quality and importance for children with communicative and/or cognitive disabilities. The overall quality of the guidelines was highly rated by the participants (5.67 out of 7). Some of the participants raised a few concerns regarding the design and structure of the guidelines and also alluded to a lack of resources as well as the need for additional time and funding to implement such a program. All the participants, however, agreed that they would recommend the guidelines for use.

Keywords: Child abuse, communicative disability, cognitive disability, school-based abuse prevention, guidelines, adaptations

CHAPTER 1

PROBLEM STATEMENT AND RATIONALE

1.1. Introduction

Chapter 1 outlines the rationale and the research problem addressed in this thesis. Next, the chapter defines the important terminology and offers a list of abbreviations that were used in the thesis. Subsequently, the seven chapters of this study are outlined. The chapter concludes with a summary.

1.2. Rationale and problem statement

The focus of this thesis is on proposing guidelines for adapting programs delivered by teachers in a school setting to children with communicative and/or cognitive disabilities, with the aim of preventing abuse perpetrated by adults.

Child abuse, comprising of sexual abuse, physical abuse, emotional abuse, neglect, and exploitation is a rampant global public health concern, affecting more than half of the population of children in the world (Hillis et al., 2016). Children with disabilities, particularly those with communicative and/or cognitive disabilities, face an increased risk of becoming victims of abuse - abuse that is characterised as being repetitive (i.e., seldom or never a once-off event), with violence levels that continue to increase and escalate on a prolonged, ongoing basis. All forms of child abuse can have long-term effects on health and well-being, both in childhood as well as into adult life.

Children’s rights to be free of abuse is stated in both the United Nation’s Convention on the Rights of the Child (CRC) (United Nations, 1989) and the Convention on the Rights of Persons with Disabilities (CRPD) (United Nations, 2006). Prevention of child abuse can be divided into three distinct yet interconnected levels, namely primary prevention (i.e., prevention before the abuse occurs), secondary prevention (i.e., prevention when the abuse is currently suspected or occurring), and tertiary prevention (i.e., prevention of further trauma once abuse has occurred). Of these, primary prevention is considered the most effective approach to decrease the incidence of child abuse or avoid it altogether, thereby limiting the need for rehabilitation. However, despite the increased risk of children with disabilities being abused, and the obvious benefits of primary prevention, little research has been conducted on primary abuse prevention programs aimed at children with disability, and even less on the specific sub-group who have the largest risk, namely those with communicative and/or cognitive disabilities.

Schools are considered an optimal venue for disseminating primary abuse prevention programs, as they provide access to most young children (with and without disability) in an easy and cost-effective way. Many examples of effective primary abuse and bullying prevention programs exist (e.g., Learn to be Safe with Emmy and Friends™ (Dale et al., 2016) and the Olweus Bullying Prevention Program (Olweus & Limber, 2010)). Teachers possess skills and knowledge on how to educate children and often have in-depth knowledge of the individual characteristics and needs of the children in their classrooms. Teachers are trusted by parents to educate their children and are often trusted and looked up to by children. Therefore, they are considered the key stakeholders of school-based primary prevention programs with a broad reach. To support and facilitate teachers in implementing prevention programs, principals can also play an important part by ensuring that resources and support are readily available.

However, when looking at the focus of the suggested primary abuse prevention program, research has shown a lacuna in knowledge. Teachers often lack knowledge of abuse against children with communicative and/or cognitive disabilities, as well as how to prevent child abuse (Abrahams et al., 1992; Goldschmidt-Gjerløw, 2019; Kenny, 2004; Márquez-

Flores et al., 2016). This can affect a teachers' ability and comfortability to teach children about abuse prevention in the classroom setting. Similarly, parents of children with communicative and/or cognitive disabilities often lack basic knowledge about abuse and how they can be actively involved in abuse prevention. Furthermore, when children have difficulties with communicating (including both receptive and expressive language), teachers and parents need additional knowledge to be able to interpret and understand potential disclosures of abuse and identify and act on signs of abuse in children.

School-based abuse prevention programs are an effective primary prevention approach to increase children's knowledge regarding their rights, what constitutes abuse and provide them with safety skills such as avoiding and stopping abuse, and who they can tell if they have been a victim of abuse. There are currently several well-researched school-based abuse prevention programs available which have demonstrated positive outcomes (Lam et al., 2018; Walsh et al., 2015; White et al., 2015). However, these prevention programs are not adapted for children with disabilities, let alone children with communicative and/or cognitive disabilities and their specific needs. This presents a challenge for teachers responsible for the education of children with communicative and/or cognitive disabilities, whether in an inclusive or special education setting, as there is little research knowledge on which adaptations are needed to enable the implementation of such a program with this population.

As well-researched school-based abuse prevention programs developed for children without disabilities are readily available, this thesis posits that the most beneficial strategy would be to explore which adaptations are needed to enable children with communicative and/or cognitive disabilities to participate in existing abuse prevention programs and to develop guidelines for teachers which would guide them on how they can adapt such programs for these children. By employing this strategy, the evidence-base for existing abuse prevention programs could also be built upon. Additionally, schools that have existing abuse prevention programs in place could continue using these programs but apply the guidelines to enable the participation of children with communicative and/or cognitive disabilities.

This discussion highlights that even though children with communicative and/or cognitive disabilities are at a high risk of becoming victims of abuse, teachers and parents lack knowledge on child abuse and the prevention thereof. Moreover, little is known in terms of how existing school-based abuse prevention programs could be adapted to suit the unique needs and abilities of these children. Thus, the purpose of this study is to explore the key components, teaching methods and information that should be included in school-based abuse prevention programs and to subsequently develop and evaluate guidelines for teachers. These guidelines must be supported by principals, to guide teachers in adapting school-based abuse prevention programs for 7–12-year-old children with communicative and/or cognitive disabilities.

1.3. Terminology

The following terms are frequently used in this study and therefore defined and explained below. They are presented in an alphabetical order.

1.3.1. Augmentative and alternative communication

Augmentative and alternative communication (AAC) is defined as, “a clinical practice area that addresses the needs of individuals with significant and complex communication disabilities characterized by impairments in speech-language production and/or comprehension, including spoken and written modes of communication” (Beukelman & Light, 2020, p. 21). In this study, the focus is on the use of a variety of aided AAC strategies and systems, namely pictorial support using graphic symbols, including communication boards, communication books, visual schedules, and Talking Mats™, which is a communication framework that uses symbols attached to a mat to discuss and express opinions, used to facilitate both understanding and expressive language of pre-teenage children with communicative and/or cognitive disabilities.

1.3.2. Child abuse

In this study, child abuse is defined as abuse and neglect that affects children under 18 years of age, including physical abuse, emotional abuse, sexual abuse, neglect and exploitation which results in potential or actual damage to the health, survival, development or dignity of the child and which occurs in a relationship based on trust, responsibility or power (World Health Organization, 2020). Below is a working definition that describes the different types of abuse as conceptualised from the authoritative work conducted by the World Health Organization (2006), implemented in the current study:

i) *Physical abuse:* the intentional use of force, such as hitting, kicking, shaking, strangling, or burning, which results in damage or is likely to result in damage to the health, survival, development, or dignity of the child.

ii) *Emotional abuse:* the failure of a parent or primary caregiver to provide a supportive environment adapted to the child’s needs, and includes acts of threatening, blaming, frightening, or belittling the child as well as other forms of rejection or hostile treatment.

iii) *Sexual abuse:* child involvement in a sexual activity that they cannot fully comprehend, provide consent to, is not developmentally ready for, or which violates the laws or social taboos of society.

iv) *Neglect:* the failure of the parent or caregiver to provide for the development and well-being of the child with regards to health, emotional development, education, shelter, and nutrition.

v) *Exploitation:* existing or attempted abuse of a position of vulnerability or trust or differences in power for sexual purposes (World Health Organization, 2017).

1.3.3. Disability

Disability is defined in this study according to the United Nations definition in the CRPD: “Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (United Nations, 2006, p. 4). In the context of this study, disability refers to congenital childhood disability and not disability as a result of abuse. Furthermore, this study focused on children with a specific type of disability, namely communicative disabilities and/or cognitive disabilities, which often co-occur. Children with these types of disabilities are seen as the target population of the guidelines developed in this study. The working definitions are presented below:

i) *Communicative disability:* Difficulties with understanding language (e.g., receptive language skills), producing language (e.g., expressing language skills in either speaking or writing), and processing verbal, nonverbal and graphic symbol systems which can range from mild to profound severity (American Speech-Language-Hearing Association, 1993; MacNeill, 2013).

ii) *Cognitive disability:* Difficulties with memory, learning, attention, decision making, reasoning, and problem solving (MacNeill, 2013) which result from various diagnoses, such as intellectual disability, cerebral palsy, autism spectrum disorder (ASD), and attention-deficit/hyperactivity disorder (ADHD). In this study, cognitive disability is not used synonymously with intellectual disability as cognitive difficulties can exist without a significant impairment in general cognitive functioning consistent with a diagnosis of intellectual disability (IQ <70).

iii) *Intellectual disability*: A significant impairment in general cognitive functioning, social skills and adaptive behaviours (IQ <70) (Patel et al., 2018), including difficulties with verbal comprehension, reasoning, working memory and processing speed (Carulla et al., 2011). In the United Kingdom (UK), the term ‘learning disability’ is used synonymously for intellectual disability.

1.3.4. Ecological models

In this study, ecological models are defined as models which highlight the environmental, social and psychological influences on behaviour, thereby facilitating the consideration of multiple levels of influence leading to the development of comprehensive interventions (Sallis et al., 2015). Due to the intersectionality of abuse against children with disabilities, the proposed solution must address different levels of the problem.

1.3.5. Guidelines

Guidelines are defined as systematically developed presentations of evidence-based recommendations, aimed at guiding stakeholders (teachers and principals in the present study) to make well-informed decisions about the implementation and/or adaptation of a particular intervention, which in the case of this study, is the school-based abuse prevention programs for children with communicative and/or cognitive disabilities (World Health Organization, 2003).

1.3.6. (Primary) prevention

Prevention is the act of stopping or decreasing the occurrence of something, in this case abuse against children with disabilities. Primary prevention is focused on prevention before the act occurs. It can thus be defined as a promotion of health and prevention of illness (in this case abuse) by preventing predictable and interrelated problems (i.e., poverty and lack of social support), maintaining already existing states of health and well-being (i.e., promoting positive relationships), and promoting psychosocial wellness for a specific population (i.e., teaching children safety skills, such as saying no or telling a trusted adult) (Gullotta & Bloom, 2003).

1.3.7. Special schools

In this study, special schools are described and defined in the Swedish context, in which special schools cater for children with intellectual disabilities. Within the special school context, children with severe intellectual disabilities typically attend a specific division which does not focus on school subjects derived and adapted from the regular school context, but instead on everyday activities, communication, aesthetics, and physical coordination. These lessons can take place in a separate school or in a separate classroom as that of a mainstream school.

1.4. Abbreviations

AAC	:	Augmentative and Alternative Communication
ADHD	:	Attention-Deficit/Hyperactivity Disorder
APBT	:	Application of Protective Behaviours Test
ASD	:	Autism Spectrum Disorder
BEM	:	Behavioural Ecological Model
CKAQ	:	The Children’s Knowledge of Abuse Questionnaire
CRC	:	Convention on the Rights of the Child
CRPD	:	Convention on the Rights of Persons with Disabilities
EBP	:	Evidence-Based Practice

IDEA	:	Iterative Decision-making for Evaluation of Adaptation
KTA	:	Knowledge to Action (framework)
MeSH	:	Medical Subject Headings
OPBT	:	The Observed Protective Behaviours Test
PEO	:	Population, Exposure and Outcome
PIO	:	Population, Intervention and Outcome
P-KT	:	Participation-focused Knowledge Translation framework
PRISMA	:	Preferred Reporting Items for Systematic Review and Meta Analyses
ProBeQ	:	Protective Behaviours Questionnaire
PPBC	:	Parent Protective Behaviours Checklist
PTSD	:	Post-Traumatic Stress Disorder
RCMAS	:	Revised Children's Manifest Anxiety Scale
STAI- CH	:	The State-Trait Anxiety Inventory for Children
SPSS	:	Statistical Package for the Social Sciences
UK	:	The United Kingdom
USA	:	The United States of America

1.5. Outline of chapters

This thesis is presented in seven chapters. Chapter 1 includes the rationale and problem statement of the thesis. Next, definitions of the terminology that is frequently used in the thesis is presented, after which a list of abbreviations is provided. Subsequently, an outline of the chapters in the thesis is given before the chapter concludes with a summary.

Chapter 2 includes a review of the relevant literature linked to school-based primary abuse prevention programs for children with communicative and/or cognitive disabilities.

The chapter starts with a discussion on child abuse against children both with and without disabilities, specific risk factors, perpetrators of child abuse, and consequences of child abuse. Subsequently, the public health model and primary prevention is discussed, followed by a review of primary abuse prevention programs for children with disabilities. School-based abuse prevention programs, as well as the role of teachers, principals and parents in such programs are detailed. The study's theoretical framework (a combination of the Behavioural Ecological Model (BEM) and the Knowledge to Action (KTA) framework) are discussed, after which the adaptation of school-based abuse prevention programs is discussed. The chapter concludes with a summary.

Chapter 3 presents the methodology used in the study, namely a three-phase exploratory sequential design. First, the aim of the thesis as well as the sub-aims for the three phases are presented. Next, the research design of the study is presented including a discussion on how triangulation was employed in the study. The research paradigm and the study's conceptual framework are then presented. Subsequently, the ethical considerations as well as the trustworthiness and dependability for the entire study are discussed, before concluding with a summary.

Chapter 4 focusses on Phase 1 of the study, comprising of Phase 1.1, 1.2 and 1.3 which entails exploring key components and methods of school-based abuse prevention programs as well as signs of abuse in children with disabilities. First, the methodology, results and discussion for Phase 1.1 is outlined which includes a scoping review of school-based abuse prevention programs for 7–12-year-old children. Subsequently, the methodology, results and discussion for Phase 1.2 are discussed, during which a qualitative study of components and methods of school-based abuse prevention programs for 7–12-year-old children with communicative and/or cognitive disabilities were explored. Next, the methodology, results, and discussion of Phase 1.3, which includes a rapid review on signs of abuse in children with disabilities followed by social validation using an online survey with an expert panel, was discussed. These three phases were published as separate studies and the pre-print versions of these publications are included in the chapter. The chapter ends with conclusions of Phase 1, practical implications for Phase 2 and a summary of the chapter.

Chapter 5 focusses on Phase 2 of the study, and includes the development of guidelines, aimed at teachers with support from principals, for adaptations of school-based abuse prevention programs for 7–12-year-old children with communicative and/or cognitive disabilities. It begins with the main aim and sub-aims for this phase, after which the guideline development process, including the integration of data from Phase 1.1 to 1.3 using recursive abstractive thematic analysis which is discussed. Subsequently, the results are unpacked, and the guidelines are presented. Finally, a summary of the chapter is given.

Chapter 6 focuses on Phase 3, the final phase of the study, which includes an evaluation of the feasibility and social validity of the guidelines that were developed during Phase 2. The chapter begins with a presentation of the aims and sub-aims of this phase, after which the research design is discussed. The data collection methods, namely an online survey, email interviews and the participant selection process are presented. The process of developing the survey and interview questions is detailed and the data analysis methods are discussed. Next, the quantitative results from the online survey are presented, including descriptive statistics. The results from the e-mail interviews are presented, and a discussion of the results from the chapter is provided. The chapter concludes with a summary.

Chapter 7 presents a summary of the results, after which the clinical implications of the study are discussed. The strengths and limitations of the study are detailed and recommendations for future research are provided. The chapter ends with a summary.

1.6. Summary

This chapter argued why the current study is needed by highlighting the increased risk of being abused faced by children with communicative and/or cognitive disabilities, as well as the lack of school-based abuse prevention programs that have been adapted for this population. Subsequently, the terminology used in the study was presented, and a list of abbreviations was provided. Next, an outline of the chapters of the thesis was given.

The chapter concluded with a summary.

CHAPTER 2
LITERATURE REVIEW

2.1. Introduction

In this chapter the reader is steered through the relevant literature related to school-based abuse prevention for children with communicative and/or cognitive disabilities in order to provide insight and background to the problem statement and rationale for the study. The specific concepts which are discussed in Chapter 2 include child abuse against children both with and without disabilities, risk factors linked to child abuse, frequently described perpetrators and consequences of child abuse, primary prevention and school-based abuse prevention programs including stakeholder's roles in such programs. Following, the proposed theoretical framework (comprising of the BEM and the KTA) is unpacked and the rationale for adapting school-based abuse prevention programs for children with communicative and/or cognitive disabilities is discussed. The chapter concludes with a summary.

2.2. Child abuse

As defined in Chapter 1, child abuse is an umbrella term which includes sexual abuse, physical abuse, emotional abuse, neglect and the exploitation of children (World Health Organization, 2016). It is a prevalent global problem that affects more than one billion children on the planet, half of the children in the world (Hillis et al., 2016). For child sexual abuse specifically, the combined prevalence worldwide has been reported to be 11,8% (Stoltenborgh et al., 2011). Prevalence numbers vary and are typically higher in low- and middle income countries where the majority of the world's children reside, than in higher income countries (Cerna-Turoff et al., 2021; Le et al., 2018). However, the data on violence and abuse against children in low- and middle income countries is limited (Le et al., 2018).

This can in part be due to limited national resources, which can hinder the data collection on the prevalence of child abuse.

2.2.1. Risk factors for child abuse

Young children experience the highest rates of child abuse and are also the most dependent on their parents or caregivers (Zeanah & Humphreys, 2018). Social and economic instability and difficulty, parental mental illness and substance abuse have been found to be strong correlates to child abuse (Doidge et al., 2017). Living in a poor neighbourhood and experiencing individual poverty are also risk factors linked to child abuse (Maguire-Jack & Font, 2017). Further risk factors relating to child abuse include low parental involvement and low child IQ (specifically linked to neglect), difficult temperament in the child (linked to any type of child abuse), and child disability (specifically linked to sexual abuse) (Brown et al., 1998). The risk of child abuse increases exponentially with the number of risk factors experienced by a child (Brown et al., 1998).

Additionally, children can face challenges when trying to disclose abuse. For example in a survey conducted with parents in Australia, a third of the parents said that they would not believe a child who disclosed sexual abuse (Briggs, 2014), further increasing the risk of continuous abuse.

2.2.2. Abuse against children with disabilities

The current thesis specifically focuses on children with disabilities. These children face an increased risk of being abused when compared to their peers without disabilities. In a global review of the existing research, the prevalence of any type of abuse against children with disabilities was 21%, which is estimated to be three to five times higher than the prevalence of abuse for children without disabilities (Jones et al., 2012). Prevalence of physical abuse and emotional abuse was the highest at 27%, whereas the prevalence of sexual abuse (15%) and neglect (8%) was lower (Jones et al., 2012). However, these results reflect both the varying methodologies that were used and the quality of the studies as well as the fact that most of the results came from high-income countries (Jones et al., 2012). Furthermore, children with disabilities have been found to be more likely to experience several types of abuse (e.g., emotional abuse and physical abuse) as well as several episodes of abuse compared to their peers without disabilities (Hershkowitz et al., 2007; Soylu et al., 2013; Sullivan & Knutson, 2000).

One methodology that has often been proposed to capture more accurate abuse prevalence rates is using police records, as abuse is a criminal offence. However, the high prevalence of abuse against children with disabilities is not always reflected in the number of cases regarding abuse which is reported to the police as pertaining to this population. In a recent study by Åker and Johnson (2020), a low frequency of cases involving abuse against persons with disabilities were found in police registers. Contributing factors to the lack of reporting the abuse of children with disabilities to the police include the absence of clear reporting procedures for care workers (Wissink et al., 2018) as well as a lack of knowledge in professionals and communication barriers (Nareadi, 2013). Thus, police registers are not a reasonably credible source in uncovering the real extent of abuse against children with disabilities.

Another methodology that is used to capture abuse prevalence, is self-report of previous or current abuse, by children and adolescents themselves. This strategy has been utilised successfully when examining the prevalence of bullying against children with disabilities enrolled in special education (Rose et al., 2009; Swearer et al., 2012). Self-report through telephone interviews has been used to examine the prevalence of bullying, abuse and sexual abuse in children with disabilities (Turner et al., 2011) and to examine the prevalence of physical, emotional and sexual abuse and neglect experienced by children with disabilities using interviews (Devries et al., 2014). Using self-report as a way to capture prevalence of abuse against children with disabilities could provide an important part of the puzzle to understand abuse against children with disabilities. However, the opportunity for children with communicative and/or cognitive disabilities to participate in such research is limited, as they might not have the ability to independently answer a survey or interview, without the support of a familiar adult – who might possibly be the perpetrator of the abuse.

2.2.2.1. Cognitive disabilities

In a Dutch study, children with mild intellectual disabilities in out-of-home care, such as residential care homes or foster care were found to be at almost three times higher risk of being victims of child sexual abuse than children in out-of-home care without disabilities (Euser et al., 2016). In a Canadian study, examining a sample of children who had been abused, children with intellectual disabilities were over-represented and neglect was the most frequently reported type of abuse in the group (Dion et al., 2018).

Helton et al. (2019) found that more than half of the children in a sample under investigation for child abuse by the Child Protection Services in the United States of America (USA) had a disability. Two groups of children were prevalent in the sample, namely children with intellectual disabilities (many of whom had severe disabilities) and children with emotional or behavioural disabilities (i.e., problems such as anxiety and depression, attention problems, rule breaking, and challenging behaviour) (Helton et al., 2019). In another study from the USA by McDonnell et al. (2019), the odds of established abuse against both children with intellectual disabilities and children with autism spectrum disorder (ASD) has been found to be significantly higher than for children without disabilities. Children with intellectual disability, or a combination of intellectual disability and ASD were two to three times more likely to having experienced abuse compared to children without disabilities (McDonnell et al., 2019). A systematic review on the polyvictimization (multiple forms of victimization in several contexts) among children with ASD or ADHD found that there was a high incidence of abuse and victimization in these populations, but that too little data was available to draw conclusions on polyvictimization (Hellström, 2019). In contrast, a study based on an Australian population sample found that children with ASD did not have an increased risk for reported and substantiated child abuse when compared to their typically developed peers (Maclean et al., 2017).

In a study from the USA, allegations of sexual abuse were found to be twice as likely to involve children with learning disabilities (difficulties with understanding or using spoken or written language) than their typically developed peers (Helton et al., 2018). The girls in the afore-mentioned study who had learning disabilities were more frequently sexually abused and were more likely to have experienced penetrating sexual assaults than girls without learning disabilities (Helton et al., 2018). Additionally, the study also reported that children with learning disabilities were three times more likely to be involved in sexual abuse allegation cases involving online sexual abuse (Helton et al., 2018).

2.2.2.2. Communicative disabilities

An additional barrier to the detection of abuse in children with disabilities, particularly those with severe and complex disabilities, are the potential communication barriers (Barron et al., 2019). Persons with communication disabilities who are victims of abuse are less likely to be able to report crimes and abuse compared to persons who can communicate effectively (Wilczynski et al., 2015). Children with communicative disabilities often have limited verbal skills and might have speech that is difficult to understand. They might also lack the vocabulary that is needed to talk about abuse as well as the language skills to clearly describe the abusive situation (Nareadi, 2013), which is often needed when giving a statement to social services or the police. Additionally, depending on the type of communication disability, they might have difficulties with speech production, such as their speech becoming slurred and therefore unintelligible, or they might lack functional speech. These difficulties can play a significant role in hindering the detection or the reporting of abuse, as the child's disclosure of abuse might not be understood (Barron et al., 2019).

Children with communicative disabilities resulting from intellectual disabilities or ASD also experience difficulties or delays in understanding language (receptive skills) (Kjellmer et al., 2018; Maljaars et al., 2012; Polišenská et al., 2018). These difficulties can impact the child's ability to understand instructions on how and to whom they should disclose the abuse, as well as information relating to abuse prevention such as different types of abuse and safety skills.

Children who have speech and/or language difficulties, intellectual disabilities, cerebral palsy or ASD often have limited literacy skills compared to their typically developed peers (McLeod et al., 2019; Sandberg, 2006; Smith et al., 2009; Van Wingerden et al., 2017; Westerveld et al., 2017). Limited literacy skills may impact the ability to use other methods of communication, such as writing, to disclose and communicate about abuse.

Children with complex communication needs who cannot meet their communication needs through their speech alone, can benefit from AAC to enhance their communicative efficiency and facilitate understanding (Beukelman & Light, 2020). AAC can include both unaided methods of communication (e.g., gestures, manual signs, eye blinking) and aided methods of communication (requires some form of equipment) and range from low technology strategies, such as paper-based communication boards and books, to high technology strategies, such as eye gaze computers (Beukelman & Light, 2020). However, when children use different AAC methods to communicate, that method might only be understood by select people (e.g., manual signs) and might not include the appropriate vocabulary to talk about abuse (Barron et al., 2019; Martinello, 2014). The lack of accessible vocabulary in the AAC system could also lead to these children not using the standard names for body parts (particularly private body parts), which might hinder reporting abuse as well as further investigation by the police, social services or the court system (Nareadi, 2013).

2.2.3. Risk factors for abuse against children with disabilities

Children with disabilities face additional risks of being abused, as discussed above. Risk factors that are prevalent in the general population are also prevalent for children with disabilities. Additional risk factors include dependency on family members and care workers, smaller social networks and social isolation, being socially trained to be compliant and exposure to multiple potential perpetrators (Araten-Bergman et al., 2017). Children with intellectual disabilities are often taught compliance to facilitate both treatment provision (Martinello, 2014) as well as the daily care, which often includes help with intimate tasks. This can put children at a further risk of being abused, as they may not be able to say no or refuse attempts at abuse (Martinello, 2014).

The perpetrators of child abuse are often a trusted person close to the child, most commonly family members (Murphy, 2011). Even when the perpetrator is not a family member, the vast majority of child abuse involving children with disability, is perpetrated by someone who is trusted and known to the child (Wissink et al., 2015). For children with disabilities, this circle of potential perpetrators is often widened due to the fact that these children are typically dependent on support from professional care workers, service taxi drivers, healthcare workers, personal assistants and other professionals in their everyday lives (Sobsey & Doe, 1991; Westcott & Jones, 1999). Additionally, some children with disabilities need assistance with intimate self-care tasks, such as bathing or visiting the toilet, where abuse might occur and where abuse can be easily concealed under the guise of assisting the child (Westcott & Jones, 1999). Furthermore, children who rely on others for help with intimate self-care tasks might have difficulty distinguishing inappropriate from appropriate touching as they are used to having their bodies touched (Murphy, 2011).

2.2.4. Parents as potential perpetrators of child abuse

For parents of children with disabilities, risk factors for parental abuse include mental and emotional stress, particularly in difficult or complicated situations between the parent and the child (Murphy, 2011; Svensson et al., 2013). Further risk factors include parents having to take on increased responsibilities in the coordination of services for their children as well as the absence of open communication between parents and professionals about topics relating to abuse (Svensson et al., 2013). Adding to this, strict parenting styles and parenting stress relating to challenging behaviours in the child might be linked to an increased risk of child abuse (Flynn, 2020). Thus, the quality and the extent of the service that is provided to parents of children with disabilities should be prioritised as part of an abuse prevention intervention (Svensson et al., 2013).

Parents of children with disabilities can have disabilities themselves, which may impact the risk of abuse and neglect. Parents with intellectual disabilities are overrepresented when it comes to their involvement with child protection services (Slayter & Jensen, 2019). Furthermore, parents with intellectual disabilities have been found to be less likely to receive support from child protection services in terms of getting referred to mental healthcare, substance use treatment, and housing services (Slayter & Jensen, 2019).

Families with children with disabilities are more likely to live in social isolation and poverty, which is likely to contribute to the increased risk of children with disabilities being abused (Murphy, 2011) as it is a known risk factor for child abuse (Doidge et al., 2017;

Maguire-Jack & Font, 2017). Parents of children with disabilities face the ongoing and around the clock financial, physical and emotional tasks of taking care of their children, and often receive little support from society (Murphy, 2011). The burden and stress of caring for a child with a disability might lead to burnout and neglect (Algood et al., 2011; Murphy, 2011). Therefore, to reduce the risk of parental abuse of children with disabilities, interventions that are suitable for parents both with and without disabilities aimed at reducing the caregiving burden, the social isolation, and the financial stress that these families face, are crucial.

2.2.5. Other potential perpetrators of child abuse

Teachers and school staff can potentially also be perpetrators of abuse against children with disabilities (Orelove et al., 2000). Working in schools can provide easy access to children and there is a risk of 'professional perpetrators' meaning adults who use their work with children to enable abuse, particularly sexual abuse, seeking out such contexts (Briggs, 2014; Sullivan & Beech, 2002). Verbal and physical abuse perpetrated by teachers is a common occurrence in some parts of the world, such as in several East African countries (Devries et al., 2018; Namy et al., 2017), and children with disabilities are again at an increased risk of becoming victims (Devries et al., 2018).

As children with disabilities can be more dependent on the help and assistance from care workers, they can also face the additional risk of perpetrators in that context. In a study conducted with adults with disabilities, 30% reported one or several types of abuse from their primary personal assistance provider, with verbal abuse being the most common type of abuse (Oktay & Tompkins, 2004). It would be reasonable to believe that children with disabilities experience the same risk of being abused by care workers.

Although the perpetrator of child abuse is typically someone who is known to the child, abuse by strangers, especially sexual abuse, also occurs. In a study from the UK, 6,7%

of children without disabilities had experienced attempted or completed sexual abuse by a stranger, including indecent exposure, touching and attempts at abduction (Gallagher et al., 2008). Additionally, the multiple Internet communication platforms as well as the large number of children, including children with disabilities, who spend time online has provided a new venue for possible abuse without the safeguarding of adults or protective surroundings which allow perpetrators to gain access to children more easily (Kloess et al., 2019). This presents a particular risk for children with intellectual disabilities who might be more easily fooled by online perpetrators who are luring children into sexually abusive situations.

2.2.6. Consequences of child abuse

Being the victim of childhood abuse is a risk factor for long-term problems later in life for children both with and without disabilities. Child sexual abuse has been found to be a significant risk factor for being sexually abused as an adult, a risk which increases with the number of adverse childhood experiences, such as neglect or other kinds of abuse (Ports et al., 2016). In a study by Metzler et al. (2017), it was reported that individuals with four or more adverse childhood experiences such as abuse of various forms, for example neglect, witnessing domestic violence and peer victimization, had a greater risk of not completing high school, leading to unemployment and poverty. Furthermore, childhood abuse has been linked to a lower health-related quality of life in adulthood (Afifi et al., 2007). Individuals who have experienced childhood abuse are also more likely to perpetrate child abuse in adulthood (Milaniak & Widom, 2015).

Adults with intellectual disabilities are more likely to have experienced both child abuse and other traumatic events in their childhood (Catani & Sossalla, 2015). In a study by Catani and Sossalla (2015), 87,5% of the participants (adults with intellectual disabilities) had experienced at least one event of abuse in the family during their childhood, most commonly emotional or physical abuse. Physical and emotional abuse were in turn significantly correlated with every other form of abuse, except neglect (Catani & Sossalla, 2015). Similar to adults without disabilities who were victims of abuse as children, the experience of childhood abuse affected many of these individuals in their adult lives. As many as 25% were diagnosed with post-traumatic stress disorder (PTSD) as adults and 26,8% had above normal scores for depression (Catani & Sossalla, 2015).

2.3. The public health model of abuse prevention

Although this study is placed within an education context, the public health model of prevention is relevant to the prevention of abuse against children with disabilities. Public health comprises of knowledge from fields such as medicine, psychology, education, epidemiology and sociology and focuses on the health of whole populations, including children with disabilities (Covington, 2013). Adopting a public health approach means understanding that interventions are the most effective when they address issues such as socioeconomics and target comprehensive areas of society, but that these interventions can also be adapted into more specific and focused interventions for higher risk groups (Covington, 2013; Herrenkohl et al., 2015). A public health approach to abuse against children with communicative and/or cognitive disabilities can be said to include at least four broad steps, namely:

i) identifying, defining and monitoring the problem of abuse;

ii) identifying the specific risk factors linked to children with communicative and/or cognitive disabilities as well as potential protective factors;

iii) understanding the effects of abuse; and

iv) developing, implementing and evaluating abuse prevention strategies aimed at children with communicative and/or cognitive disabilities and ensuring the adoption of those abuse prevention strategies (Covington, 2013; Herrenkohl et al., 2015).

Early intervention and prevention in childhood is essential within the public health model to reduce the risk factors and enhance the protective factors before abuse occurs (Covington, 2013; Herrenkohl et al., 2016) as abuse can have long-term negative effects, as discussed previously (Afifi et al., 2007; Catani & Sossalla, 2015; Metzler et al., 2017; Ports et al., 2016).

Prevention within the public health framework includes three stages: primary prevention; secondary prevention; and tertiary prevention. Linked to abuse against children with disabilities, primary prevention entails interventions aimed at preventing abuse from happening in the first place (Bethea, 1999; Covington, 2013). Secondary prevention includes interventions aimed at children who have been abused and aim to stop further abuse from occurring (Covington, 2013; O’Donnell et al., 2008). Tertiary prevention includes interventions aimed at decreasing the effects of abuse such as rehabilitation and medical treatment for children as well as secure placements when it is not safe for the child to stay at home, if that is where the abuse occurred (Covington, 2013; O’Donnell et al., 2008).

Primary prevention is emphasised within the public health model, as the focus is on early and comprehensive intervention (Herrenkohl et al., 2016). A key to successful primary prevention interventions linked to abuse is to provide knowledge, skills and resources to service delivery platforms such as schools to enable the adaptation of services to the needs of specific populations, such as children with communicative and/or cognitive disabilities (Herrenkohl et al., 2016). To situate abuse prevention programs with a public health approach (focused on early intervention) and primary prevention (stopping abuse before it occurs), abuse prevention should be taught to children both before and during the periods of highest risk for abuse (Walsh et al., 2019), which occurs from infancy to adolescence. This implies that the education sector should be involved, as school is one of the environments in which children spend a large amount of time. Therefore, primary abuse prevention focused on primary school aged children (7–12 years of age) are the centre of attention of this study.

2.3.1. Primary abuse prevention programs for children with communicative and/or cognitive disabilities

Mikton et al. (2014) conducted a systematic review on the effectiveness of primary abuse prevention interventions aimed at persons with disabilities. The review identified ten studies of which six included persons with intellectual disabilities and two included persons with developmental disabilities. Four studies focused only on sexual abuse, three studies focused on different types of abuse, one focused only on physical abuse, one focused on child maltreatment and one of the studies did not specify the type of abuse it focused on. None of the interventions were reported to be effective after the risk of bias had been considered. The authors concluded that the review illuminated the major gaps that exist in this field of research (Mikton et al., 2014). Since the review by Mikton et al. (2014), limited progress has been made in terms of addressing these gaps, as is evident from the descriptive overview of the current available research on primary abuse prevention programs for children with communicative and/or cognitive disabilities provided in the following paragraphs.

Kim (2016) evaluated the implementation of a child sexual abuse prevention program with three children with mild to moderate intellectual disabilities. Each child participated in individual training sessions which included teaching them about private body parts, inappropriate and appropriate situations, how to resist attempts at abuse and how to report abuse (Kim, 2016). The generalization of learned concepts was tried through both role-play and staged real life situations (Kim, 2016). All three children learnt sexual abuse prevention skills which were retained for 10 weeks when tested in real-life situations (Kim, 2016).

In another study, 15 girls (aged 10–15 years) with mild intellectual disabilities participated in a sexual abuse prevention program delivered by a trainer in a group setting (Warraitch et al., 2021). The children were taught sexual abuse prevention concepts such as body ownership, private body parts and resisting and disclosing sexual abuse through strategies such as role play and modelling. The program proved effective in improving the children's sexual abuse prevention knowledge and skills, which the authors contribute to the fact that the teaching was conducted in short sessions, each focusing on one subject and taught using colourful materials and strategies such as role play (Warraitch et al., 2021). The program's acceptability and feasibility were evaluated by the participants and found to be satisfactory.

Yu et al. (2017) conducted a study on the knowledge of child sexual abuse and safety skills among 51 children with hearing loss, aged 10–16 years. The results indicated that the children had little knowledge of prevention with regards to child sexual abuse, as well as limited knowledge of safety skills (Yu et al., 2017). The authors concluded that primary prevention programs directed at children who are hard of hearing are urgently needed to develop their knowledge of child sexual abuse prevention and safety skills. Furthermore, the importance of increasing parent's knowledge of child abuse and improving the communication between parents and children on this topic was highlighted (Yu et al., 2017).

Devries et al. (2018) evaluated a school-based intervention with a slightly different focus, which included fostering change in the school setting by implementing activities related to creating a good learning environment, mutual respect, enabling children to participate in decision-making, the use of non-violent discipline, knowledge of the dynamics relating to power and improving teacher's skills in managing the classroom. The intervention was effective in reducing abuse against children with disabilities perpetrated by school staff and peers. Additionally, results showed that when the intervention was not implemented, children with communicative disabilities as well as children in need of support with self-care tasks were at a particularly high risk of being abused in the school setting (Devries et al., 2018).

This brief overview of available abuse prevention programs that have been evaluated for children with communicative and/or cognitive disabilities, shows that the evidence-base as well as the number of interventions developed for this population, are scarce. Adding to this, the programs focused on teaching abuse prevention directly to children all include children with mild or moderate intellectual disabilities. It has been hypothesised that children with severe intellectual disabilities will not be able to benefit from the strategies typically used to teach abuse prevention concepts, even though they are possibly at the highest risk of being abused (Mahoney & Poling, 2011). As abuse prevention programs are generally developed for children without disabilities it means that some of the typical key messages, such as running away and telling, might not be appropriate for children with severe communicative and cognitive disabilities and physical disabilities (Barron et al., 2019). Thus, these children (with severe communicative and cognitive disabilities and physical disabilities) who are in the most dire need of education in terms of private and public parts of the body, the right to say ‘no’ and understand and communicate about personal boundaries, are the least likely to receive such education (Barron et al., 2019).

2.3.2. *School-based abuse prevention for children with communicative and/or cognitive disabilities*

Using schools to disseminate primary abuse prevention programs is an important strategy to enable many children and families to be reached even with limited resources, which is in keeping with the goals of primary prevention within the public health model (Asawa et al., 2008; Herrenkohl et al., 2016). Children who have been victims of child abuse bring emphasis to the importance of school-based abuse prevention programs and increasing children’s knowledge of abuse (Gubbels et al., 2021).

A comprehensive review of- and the rationale for school-based abuse prevention programs for children 7–12 years old, is provided in Chapter 4 of this study. Thus, the reader is encouraged to visit that section for more information on key components and methods of these programs. In this section, a discussion of potential characteristics of school-based abuse prevention programs for children with communicative and/or cognitive disabilities is provided.

As children with disabilities are at a particularly high risk of being abused, schools attended by these children should ensure the provision of school-based abuse prevention programs (Skarbek et al., 2009). Wilczynski et al. (2015) noted that there is a gap in the research in school-based abuse prevention programs for children with disabilities, with specific emphasis placed on teacher training that includes abuse assessments of/for children with disabilities. This might be due to a multitude of reasons such as, the difficulties that can be inherent to teaching children with communicative and cognitive disabilities, outdated myths stating that children with disabilities do not get abused, a lack of training on the topic and a lack of policy regarding the implementation of school-based abuse prevention programs for children with communicative and/or cognitive disabilities.

School-based abuse prevention programs for children with disabilities should include behavioural skills training, which includes self-protection and safety skills (Skarbek et al., 2009). Intervention programs and efforts need to be adapted to various populations and be sensitive to individual differences and needs (Kenny & Wurtele, 2012). School-based abuse prevention programs for children with disabilities should include materials in different formats to allow accessibility (Kenny & Wurtele, 2012), as individuals with intellectual disabilities or severe communication difficulties can experience problems with both understanding that abuse has occurred as well as with communicating about an abusive situation (Wilczynski et al., 2015).

For children with communicative and/or cognitive disabilities, the use of other methods of communication apart from speech only is important to be able to assess potential abuse (Wilczynski et al., 2015). AAC devices must include appropriate and accessible vocabulary for both preventing and reporting abuse (White et al., 2015; Wilczynski et al., 2015). Developing and agreeing on a ‘communication cue’, such as using a specific scream or sound to alert a caregiver, is recommended to enable children with complex communication needs or children with limited vocabulary to still be able to communicate about being abused (Skarbek et al., 2009).

2.3.2.1. Teachers' roles in school-based abuse prevention

The important role that teachers can play in preventing child abuse has been highlighted in several research studies (Finkelhor, 2009; MacIntyre & Carr, 2000; Scholes et al., 2012; Wurtele, 2009). Teachers are pivotal in fostering and maintaining positive classroom dynamics, social interactions and relationships as well as implementing abuse prevention interventions in the classroom (Farmer et al., 2018; Scholes et al., 2012). Thus, teachers should develop their understanding of child abuse as well as their skill in teaching abuse prevention concepts to children as it can benefit the children that they teach immensely (Scholes et al., 2012).

However, many teachers feel ill-equipped or uncomfortable conducting such lessons (Abrahams et al., 1992; Johnson, 1994). This might be due to a lack of training and differing school policies which contribute to confusion regarding routines about reporting abuse

(Abrahams et al., 1992; Kenny, 2004). In 2016, a survey conducted in Sweden showed that information about violence and abuse against children is not included in the coursework required to become a teacher at some universities (Inkinen, 2015). In a study carried out in Spain, 65,3% of the teachers included in the survey had never participated in sexual abuse education training and 90,7% had no knowledge of methods to identify sexual abuse in children (Márquez-Flores et al., 2016). In Norway, 42% of the social science teachers who participated in a study on prevention of sexual abuse against adolescents, stated that they either did not address child sexual abuse in their teachings at all, or only did so to a small degree (Goldschmidt-Gjerløw, 2019). The study conducted in Norway also identified several barriers, such as time restraints, lack of clarity and information in the curriculum as well as lack of knowledge and education (Goldschmidt-Gjerløw, 2019).

Due to the frequency of child abuse, many teachers will meet children who have been or who are currently being abused. As teachers see most of the children in the classroom setting five days a week, they are in a unique position to be able to detect and interpret potential signs of abuse. Furthermore, abuse is often disclosed to teachers and other school staff, making knowledge regarding abuse prevention important (Asawa et al., 2008; Gubbels et al., 2021). However, many teachers are unsure about the reporting procedures that they are supposed to follow when suspecting child abuse (Kenny, 2004; Márquez-Flores et al., 2016). This uncertainty highlights the need for teacher education on the topic, clear procedures and guidelines for reporting abuse, as well as support (Kenny, 2004). Furthermore, many teachers lack knowledge on how to appropriately detect signs of abuse in children (Kenny, 2004). Teachers therefore need the skills to enable them to identify potential signs of abuse (Orelove et al., 2000) and subsequently report child abuse (Mathews, 2011; Orelove et al., 2000).

2.3.2.2. Principals' roles in school-based abuse prevention

Principals can play an important role in ensuring that teachers are supported and that resources are available to implement school-based abuse prevention programs. To combat the risk of neglect or other kinds of abuse against children with disabilities in schools, principals should use their knowledge and training to assess the psychological climate at the school in order to develop strategies to assist teachers in creating a safe and nurturing environment for children (Orelove et al., 2000). Principals have a crucial role in establishing the culture at the school and to drive change, and therefore have an important role in implementing programs relating to public health issues which aim to change the environment in the school, such as abuse prevention programs (Roberts et al., 2016). Support from principals have been reported as the factor most strongly linked to successful implementation of school-based substance abuse programs (Rohrbach et al., 1996) as well as a critical component in the implementation of a school-based suicide prevention program (Stein et al., 2010). Thus, it is likely that principals have a similarly important role in supporting and driving change in terms of school-based abuse prevention programs for children with communicative and/or cognitive disabilities.

2.3.2.3. Parents' roles in school-based abuse prevention

Parents' roles in school-based abuse prevention programs should be expanded and focused on (Wurtele, 2009). Parents can play an important role in supporting their children to talk about abuse prevention concepts, thus facilitating both learning and potential disclosure of abuse. Findings demonstrate that despite parents of typically developed children often having a good understanding of child sexual abuse, they do not necessarily talk to their children about the risks relating to child sexual abuse (Rudolph & Zimmer-Gembeck, 2018). Parents of children with intellectual disabilities have been found to be generally positive to sexuality education for their children and perceive training of safety skills as important for their child, but were also found to underestimate the risk of their child being sexually abused (Stein et al., 2018). Wurtele (2009) suggests that no child abuse prevention program should be implemented with children before first preparing and educating the parents, so that they are comfortable discussing abuse with their children. The involvement of parents should include information about the abuse prevention program, potential signs of abuse, and how to deal with potential disclosures of abuse from their children (Wurtele, 2009). Additionally, parents should be given information on how to talk about sexuality and boundaries with their children and should be encouraged to have these conversations in their home environment (Wurtele, 2009). The generalization of abuse prevention concepts may be facilitated by spreading training out over time as well as using different persons to conduct the training in a variety of settings (Wurtele et al., 1992). This includes involving parents in discussing abuse prevention components in the home environment which might be an important factor to facilitating generalization (Wurtele et al., 1992).

To complicate matters, parents may harbour beliefs that child abuse education, particularly child sexual abuse, might not be effective and risk harming their child (Rudolph & Zimmer-Gembeck, 2018). Therefore, the involvement of parents in school-based abuse prevention programs should include clear information on the potential risk of harm for their children.

2.4. Theoretical framework

For the purpose of this study, the Behavioural Ecological Model (BEM) was used as the underlying theory linked to behaviour change, supplemented by the Knowledge to Action (KTA) framework as the theoretical underpinning of translation of research knowledge to applied practice. Together, these theories form the theoretical framework of the study.

2.4.1. Behaviour change

To successfully prevent abuse against children with communicative and/or cognitive disabilities, behavioural change must occur. Four core principles of ecological models of behavioural change have been proposed by Sallis et al. (2008), namely:

i) There are multiple factors that influence health behaviour on several levels, such as the personal level, relationship level and community level.
ii) Influences on behaviours interact with each other across the levels.
iii) Ecological models should pin-point the most important factors on each level and should be specific to behaviour.
iv) Interactions over several levels are considered to be the most effective approach to changing behaviour.

Ecological models of behaviour change can be used to develop public health interventions (Sallis et al., 2008) when it is believed that focusing only on one level, such as the individual level or the community level, will not produce the desired results. A key characteristic of the ecological models of behaviour change is that they assume that interaction between several levels (e.g., the individual level, the local level, the community level, and the social level) is a requisite for effective health promotion interventions (Sallis et al., 2008). Several different ecological models linked to behaviour change exist such as the ecology of human development model (Bronfenbrenner, 1977), the social-ecological model (used in Phase 1.1. of this study) (Stokols, 1996), and the BEM (Hovell et al., 2009). These models share the focus on the multiple levels of influence on behaviour and the potential of using them as a guide in developing public health interventions focused on achieving change at a population level (Richard et al., 2011). As risk factors for abuse against children with disabilities can occur across different levels (i.e., individual, local, and community) and intersectionality of risk factors can increase the risk of abuse, it can be assumed that a response to abuse against children with disabilities must operate on all levels for the response to be effective.

2.4.1.1. The Behavioural Ecological Model

Hovell et al., (2009) who are regarded as the originators of this model, describe BEM as a work-in-progress health intervention model based on respondent, selectionist and environmental understandings and explanations of behaviours. The main difference between the BEM and other ecological models (such as those mentioned in section 2.4.1.) is the foundation in behaviour analysis, the focus on principles of learning, and the cumulative effect of reinforcements through different levels that effect behaviour change (Richard et al., 2011).

The BEM aligns itself with the logic models of the natural sciences, and is rooted in beliefs that the behaviour of individuals depend on both the past and present environmental context in which they reside (Hovell et al., 2009). The BEM is conceptualised as a hierarchical model that relies on three levels of variation and selection, namely natural selection (the individuals most adapted to the environment in which they exist are the most likely to survive and reproduce), operant selection (behaviour is selected because of its consequences and is shaped by the environment) and cultural selection (behaviour is selected based on variations in cultural practices within both larger and smaller contexts) (Hovell et al., 2009).

The foundation of the BEM is the basic principles of how behaviour is influenced and shaped by the context, such as respondent and operant conditioning, unlearned and learned reinforcers and response classes (Hovell et al., 2009). Respondent conditioning is based on the work of Pavlov, which through his experiments with dogs showed that behaviour could be learnt by conditioning dogs to produce saliva when they heard a signal associated with food (Sallis et al., 2008). A respondent behaviour is an automatic involuntary response, such as emotions, to an antecedent stimuli (Nord & Peter, 1980; Sturmey et al., 2020). Respondent behaviour has an adaptive function as it contributes to keeping the individual safe, which facilitates the survival of the individual (Sturmey et al., 2020). The respondent behaviour can also be elicited by what is perceived as a similar stimulus to the original one, a process known as stimuli generalization (Sturmey et al., 2020). This process occurs in PTSD, when internal or external stimuli similar to a traumatic event, can result in intense psychological and physiological symptoms (Lis et al., 2020).

Further studies on conditioning has suggested that human physiological responses can differ depending on the environment at hand (Hovell et al., 2002). Seminal work on operant conditioning posits that the environment shapes the individual's behaviour and that reinforcement in the environment directly influences behaviour (Sallis et al., 2008). A conditioned behaviour is thus shaped through the negative (aversive stimuli) or positive (reinforcers) consequences of a particular behaviour (Ginja et al., 2017). This means that if a reward is given for certain behaviour, the chance of that behaviour being repeated increases (Schlüter et al., 2017). Whether or not a behaviour is classified as a respondent or a conditioned response depends on the function of the behaviour (Hovell et al., 2002). In terms of abuse prevention, a spontaneous reaction, such as screaming or pushing someone away when being put in a simulated abuse situation during a role play, would be a respondent behaviour. A conditioned behaviour could be elicited by receiving praise by a teacher for how a role-play situation was handled by saying “No!” forcefully, or leaving the situation, thus being more likely to repeat that behaviour the next time a situation like that occurs. Often, conditioned responses are used when training children to use safety skills in abuse prevention programs.

In addition to respondent and operant conditioning, the BEM is also influenced by several other principles such as generalised response classes (Hovell et al., 2009). Generalised response classes include the explicit reinforcement of some behaviours within a response class which also increases the occurrence of other behaviours in that response class (Poulson et al., 2002). This process has been studied in relation to an infant's imitation of their parents behaviour (Poulson et al., 2002). In abuse prevention programs, the elicitation of a generalised imitation response class is sought by modelling and praising the imitation of strategies or behaviours for the prevention of abuse.

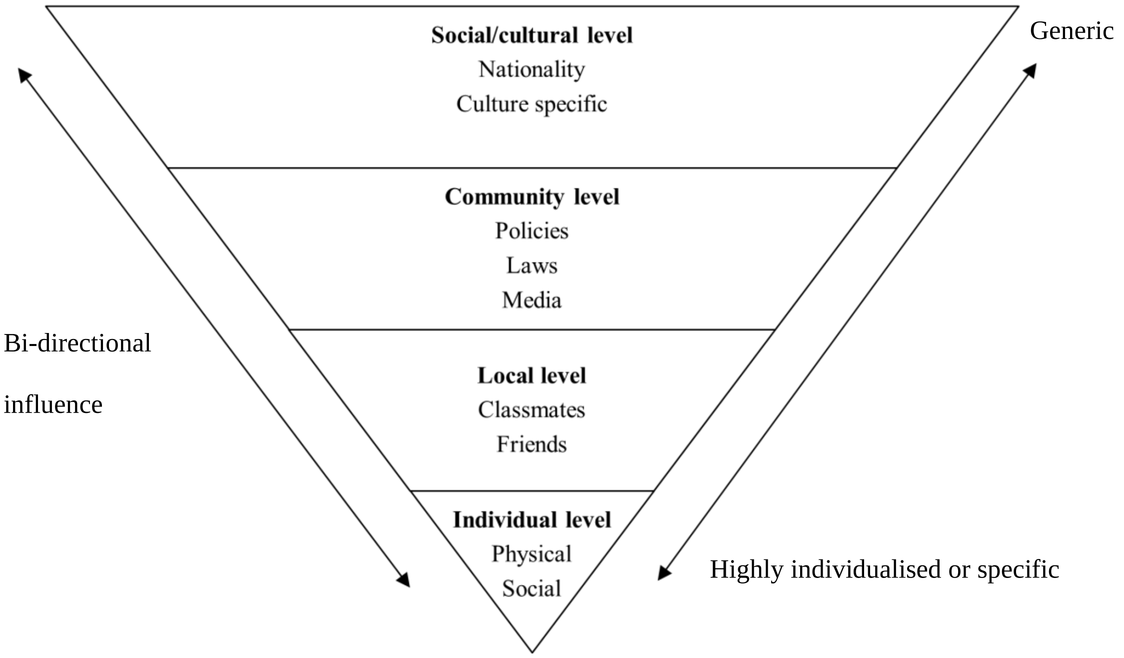
An additional principle of the BEM is that of rule-governed behaviour, which is understood as behaviour that is controlled through verbal communication (Pelaez, 2013). The function of the rule is to influence the behaviour of the listener (or reader) (Pelaez, 2013). This is often a component in health promotion interventions, where patients are expected to follow a set of rules, given either verbally or in writing, to elicit expected and desired health outcomes and are provided with positive reinforcement from a healthcare professional when doing so (Hovell et al., 2002). In the present study, this can be linked to teachers following rules and regulations that relate to the implementation of abuse prevention programs as well as children following the instructions that are taught to them in an abuse prevention program. This can, however, be problematic as reinforcement can be untrue, unrealistic, or not dependable, especially for the individuals themselves (Hovell et al., 2002). In the case of abuse prevention, this could mean that teachers take on the role of positive reinforcement, but as the abuse prevention program ends, or a teacher changes jobs, this reinforcement will cease. Further principles which the BEM stems from are the social learning theory and the social cognitive theory (Bandura & Walters, 1977). These theories emphasise the social environment and personal influences on behaviour (Sallis et al., 2008).

Hovell et al. (2009) acknowledged that the BEM is a working model that requires application in varying research studies and welcome modification of the model. The BEM was originally conceptualised as an upside down triangle, consisting of four contingencies, namely the society contingency, the community contingency, the local contingency and the individual contingency (Hovell et al., 2002). Subsequently, it was developed into a more complex model, replacing contingencies in the upside-down triangle with levels as well as the inclusion of additional figures in a schematic representation relating to the specific genetics and physiology of each individual, including the context and the consequences of behaviour (Hovell et al., 2009). Both iterations of the model have been used in research studies mainly focused on various health promotion interventions, with the original version of the model being more frequently cited than the second iteration of the model.

The aim of this study is not to focus on each individual's characteristics linked to behaviour change, but rather the development of effective guidelines by including all levels that influence behaviour as well as the bi-directional influence of the levels in a broader context and approach, as is a key strength of ecological models (Sallis et al., 2015). The original version of the BEM with the addition of the use of the term 'levels' instead of 'contingencies' were used in this study (Figure 2.1) and subsequently further adapted for school-based abuse prevention (Figure 2.2).

Figure 2.1

The Behavioural Ecological Model



Source: Adapted from Hovell et al. (2002) and Hovell et al. (2009)

2.4.1.2. Applications of the BEM

The BEM has been applied to multiple health promotion interventions aimed at modifying behaviours, but not specifically to abuse and abuse prevention. Most relevant to the purpose of this study are the interventions aimed at abuse prevention targets, specifically towards children and adolescents.

Dresler-Hawke and Whitehead (2009) applied the original version of the BEM to school settings and anti-bullying interventions. These authors defined bullying as the repeated and systematic exposure of a child over time, inflicted by one or more children with the intent to injure or discomfort the target child. Similar to abuse, bullying can manifest in several different ways, such as physical, verbal, or psychological bullying. Dresler-Hawke and

Whitehead (2009) suggested that the attitudes and perceptions of the community at large needs to be addressed and reframed to effectively implement anti-bullying strategies. These authors then describe different types of interventions for the varying levels of the BEM linked to bullying intervention. These include a focus on developing bullying interventions for children at an individual level, adapting the teaching at school to include anti-bullying at the local level, engaging the community in the cause at the community level and identifying and changing social and cultural norms relating to bullying at the social level. It is also stressed that no intervention should rely solely on one level of the BEM, but rather maximise the effect by operating on as many levels as possible to ensure true behaviour change (Dresler-Hawke & Whitehead, 2009).

2.4.1.3. Adapted version of BEM used in the present study

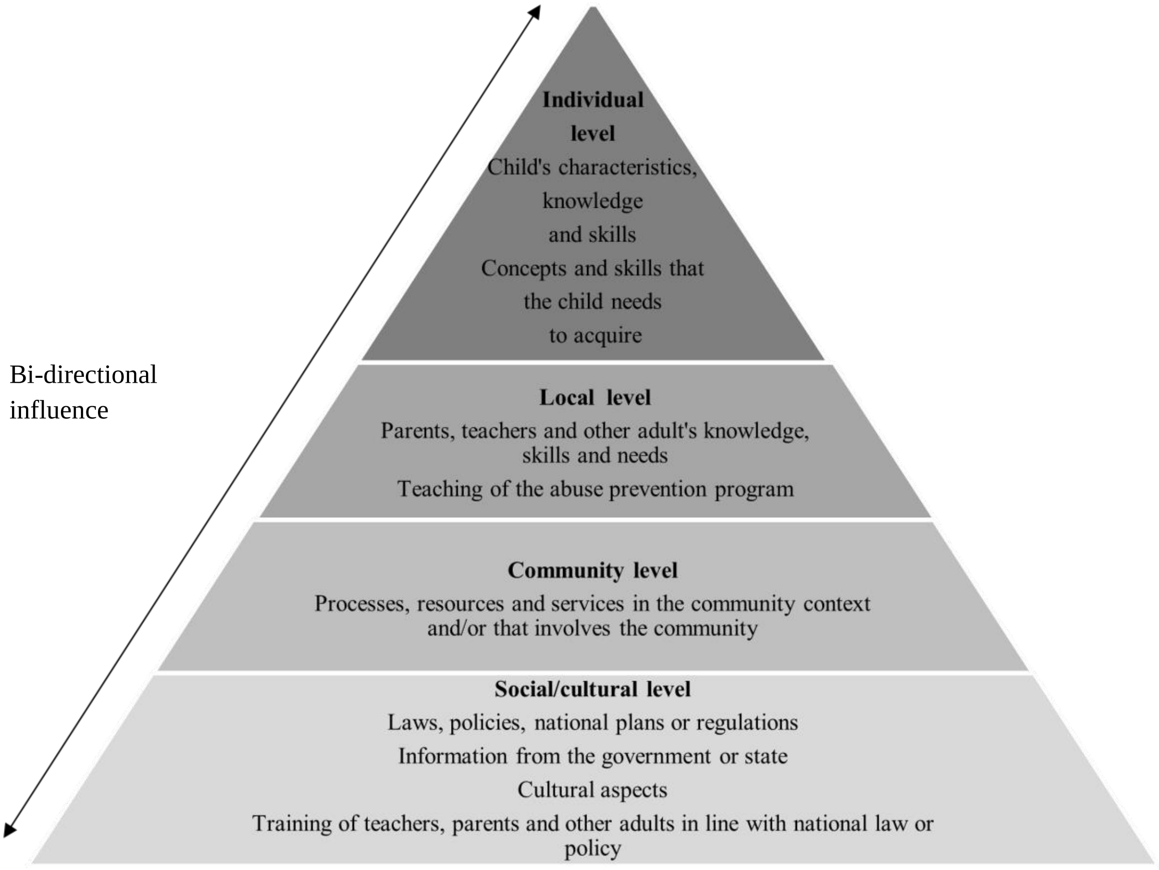
In the current study, the BEM has been adapted and conceptualised as a theoretical model for proposing guidelines for the adaptation of school-based abuse prevention programs for children with communicative and/or cognitive disabilities (Figure 2.2). This adapted version of the BEM contains, as does the original version, four levels which influence behaviour and interact with each other. The social/cultural level in this adapted version of the BEM includes laws, national school policies, curriculums, national plans, and regulations relating to abuse and abuse prevention, as well as the training of teachers and parents regarding abuse prevention in line with national law or policy. The community level includes community resources, collaborations and processes aimed at facilitating implementation of school-based abuse prevention programs. The local level includes teachers' and parents' knowledge and skills relating to the prevention of abuse as well as the teaching of abuse prevention programs to children with communicative and/or cognitive disabilities in a school context. Lastly, the individual level includes the specific needs and characteristics of each child, their skills and knowledge as well as the components relating to abuse that they need to learn and engage with.

The BEM was employed as a theoretical framework in the present study as the focus of the study is on behaviour change linked to school- based abuse prevention for children with communicative and/or cognitive disabilities. At the social/cultural level, behaviour change includes increased knowledge in teachers and parents about abuse and abuse prevention, implementation of the guidelines for adaptations of school-based abuse prevention programs and teacher self-efficacy. At the community level, behaviour change includes increased awareness in the community of the prevalence of abuse and how to prevent abuse as well as the provision of resources and services to aid in the prevention of abuse. At the local level, behaviour change includes increased skills in teachers to teach abuse prevention programs to children with communicative and/or cognitive disabilities, as well as parental empowerment from increased knowledge on how they can support and facilitate their child's participation in school-based abuse prevention programs. At the individual level, behaviour change includes children putting safety skills to use, such as saying no or leaving an unsafe situation, as well as increased knowledge of how to disclose abuse.

As the present study rests on the pillar that the social level is the foundation for all of the other levels in which behaviour change linked to abuse prevention occurs, the upside-down pyramid in the original version has been flipped to reflect this view.

Figure 2.2

The Behavioural Ecological Model for School-based Abuse Prevention



Source: Adapted and conceptualised for school-based abuse prevention from Hovell et al. (2002) and Hovell et al. (2009)

While the BEM provides an in-depth theoretical model linked to behaviour change, interventions linked to behaviour change such as those based on the BEM, have been criticised for lacking evidence which reflects positive results when implemented in the ‘real world’ (Hagger & Weed, 2019). Furthermore, ecological models such as the BEM, are rarely specific in terms of pinpointing the most effective strategies for behaviour change or specifying how the interaction between the levels of the models take place (Sallis et al., 2015). This challenges the stakeholders of public health interventions as they must identify the critical components which make each intervention successful (Sallis et al., 2015). In the context of this study, this means that although the BEM provides ample knowledge on behaviour change linked to multiple level of influence, it provides less theory on how knowledge can be created and translated into practice. Thus, supplementing the BEM with a framework focused on knowledge creation and translation was considered appropriate for this study.

2.4.2. Knowledge to Action framework

The KTA framework is a theory on knowledge translation, which is defined as the synthesis, implementation, and application of knowledge to improve health outcomes through a dynamic and iterative process, such as decreasing the abuse against children with disabilities (Figure 2.3) (Field et al., 2014; Straus et al., 2009). The theory on which the framework rests, developed by Graham et al. (2006), is based on over 30 planned-action theories that can facilitate in translating knowledge to action across all levels of ecological models (Anaby et al., 2021). In a systematic review looking into the use of the KTA framework, it was found that the KTA was integrated into studies of varying topics such as health promotion as well as specific conditions such as a stroke or cerebral palsy (Field et al., 2014). The KTA framework has also been further developed and integrated with other frameworks to form new frameworks, such as the Participation-focused Knowledge Translation framework (Anaby et al., 2021). The focus of this framework is to impact participation of children with disabilities to promote health and well-being. The Participation- focused Knowledge Translation framework is a multi-level collaborative effort that targets the individual level, organizational level and social structure/policy level as different approaches and strategies might be necessary at different levels or contexts to reach the desired outcome (Anaby et al., 2021). This approach is similar to school-based abuse prevention programs that should also operate on several ecological levels, using different strategies to foster change. Graham et al. (2006), divides the knowledge to action process into ‘knowledge creation’ (depicted as a funnel) and ‘action’ (depicted as a cycle).

2.4.2.1. Knowledge creation

Knowledge creation is envisioned as a funnel, in which knowledge is gradually sifted through three different phases to finally consist of only the most important and applicable knowledge (Graham et al., 2006). The knowledge creation process should engage stakeholders throughout the process to ensure that the knowledge and subsequent implementation of the knowledge is relevant and applicable to their needs (Graham & Tetroe, 2010; Straus et al., 2009).

In the knowledge creation funnel, knowledge inquiry is regarded as the first step. This step could be conceptualised as the vast number of primary research studies available on child abuse and child abuse prevention, of varying quality and focus (Graham et al., 2006; Straus et al., 2009). The second step is knowledge synthesis, which consists of the identification, appraisal, and synthesis of studies relevant to the specific research questions, often achieved by conducting a systematic review (Grimshaw et al., 2012; Straus et al., 2013). This step could also include empirical data collection such as social validation studies with stakeholder groups. The knowledge synthesis should not simply consist of one individual study, as this may be insufficient to capture the breadth and depth of the evidence-base related to the specific topic (Grimshaw et al., 2012). In the present study, this step would include the exploration of the topic of school-based abuse prevention for 7–12-year-old children with communicative and/or cognitive disabilities aimed at a specific stakeholder group, namely teachers. The third step in the knowledge creation funnel is to identify and translate key messages and produce knowledge tools, aimed at presenting knowledge in the form of actionable recommendations in an accessible, clear and user-friendly format (Graham et al., 2006; Grimshaw et al., 2012; Straus et al., 2013). The purpose of these knowledge tools is to influence the actions of stakeholders as well as to provide information and knowledge to stakeholders to facilitate the implementation of the knowledge (Straus et al., 2009). In the present study, this step can be conceptualised as the development and external review of guidelines, linked to school-based abuse prevention for children with communicative and/or cognitive disabilities. It should, however, be emphasised that the knowledge creation process is dynamic and that it can be modified throughout by adapting the research questions to address problems identified by stakeholders or adapting the knowledge tools to suit the needs of specific stakeholders (Graham et al., 2006).

2.4.2.2. Action cycle

Graham et al. (2006) envisions the ‘action’ part of the KTA as a cycle, which leads to the implementation of knowledge tools, such as guidelines as shown in Figure 2.3. The different stages in the action cycle are dynamic and changeable, and the process can be iterative (Field et al., 2014; Graham et al., 2006; Straus et al., 2009). The action cycle begins with the identification of a problem and the identification and review of a solution to the problem (e.g., guidelines to support abuse prevention) by a group, such as teachers, or organizations, such as schools (Graham et al., 2006; Straus et al., 2013). In the present study, such a problem could be linked to a lack of knowledge of abuse and abuse prevention in teachers who work with children with communicative and/or cognitive disabilities or a lack of knowledge of abuse and safety skills in children with communicative and/or cognitive disabilities. This step might also work the other way around, with schools and teachers becoming aware of the availability of practice guidelines related to a certain topic, thereafter, determining whether there is a knowledge gap in that particular setting that the guidelines can fill (Graham et al., 2006).

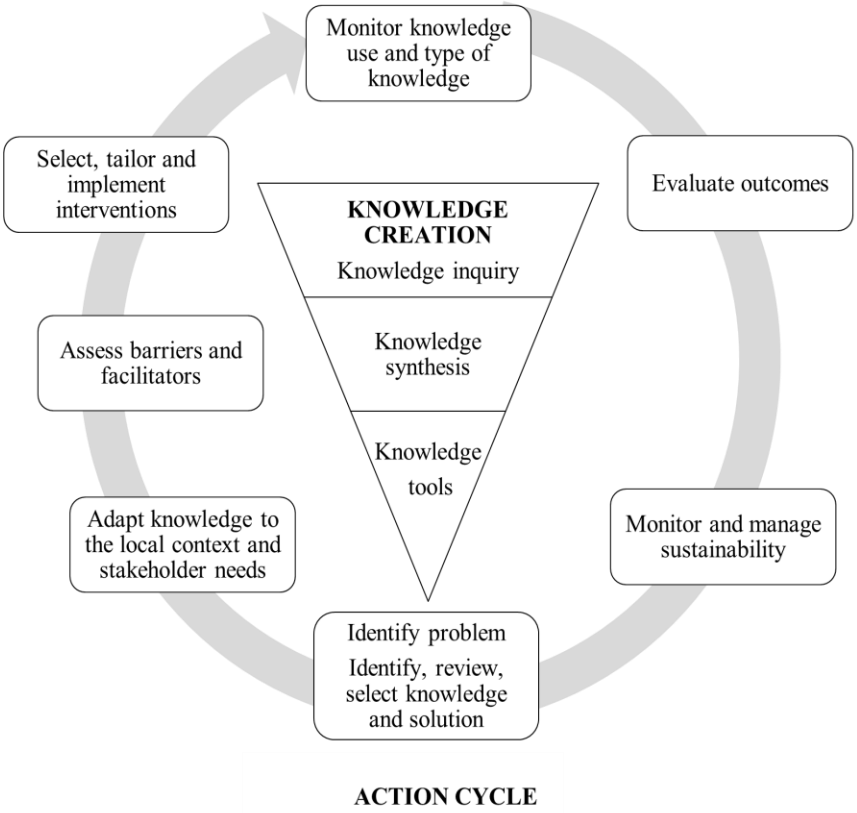
Next, the action cycle suggests an adaptation of the knowledge to the local context by, in this case, schools (Vogel et al., 2016). This could include making decisions based on the value, importance, and appropriateness of particular recommendations in the knowledge tool relating to the specific context, and tailoring the content to suit the needs of the stakeholders (Graham et al., 2006).

Next, an assessment of potential barriers and facilitators to implementation is done, with the aim to identify such barriers so that they can be dealt with expediently before the implementation commences (Graham et al., 2006; Vogel et al., 2016). Likewise, facilitators can be used to build on existing strengths such as involving stakeholders as they have direct knowledge of the challenges and opportunities linked to implementation (Vogel et al., 2016). After this assessment, interventions to address the perceived barriers of implementation are selected and implemented. In the context of this study, this could include addressing an identified barrier, such as time constraints, to the implementation of a knowledge tool linked to the prevention of abuse against children with communicative and/or cognitive disabilities. Furthermore, this step also includes the implementation of the knowledge tool which has been identified (Graham et al., 2006).

The next step includes monitoring the use or uptake of the knowledge, and also determining which type of knowledge is being used (Straus et al., 2010). For example, conceptual knowledge includes changes in understanding, knowledge and/or attitudes which can inform practice (Straus et al., 2010), while instrumental knowledge includes practical applications of knowledge, resulting in changes in practice and behaviours. Furthermore, persuasive or strategic knowledge includes manipulation of knowledge to reach specific outcomes of power or profit (Graham et al., 2006; Straus et al., 2010). By evaluating the knowledge use, and the type of knowledge use, information regarding the level of implementation can be obtained (Graham et al., 2006; Straus et al., 2010). The subsequent steps of the action cycle entails evaluating the outcome of the knowledge implementation, and whether the knowledge had the intended impact. The final step in the action cycle includes monitoring and managing the sustainability of the knowledge.

Figure 2.3

Knowledge to Action Framework



Source: Adapted from Graham et al. (2006)

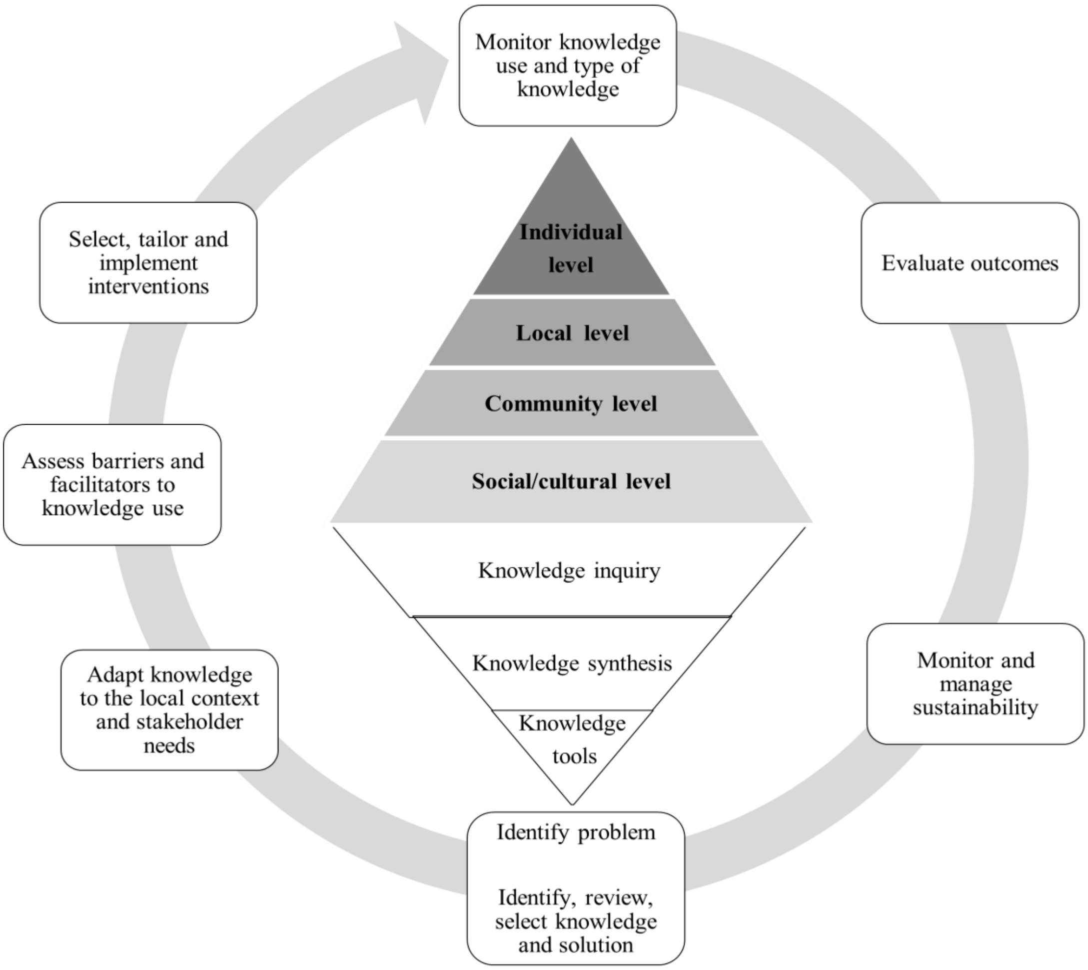
2.4.3. Integrated theoretical framework of the study

While the KTA framework presents a comprehensive view of how research knowledge can be translated into practice, there are potential barriers to knowledge translation. The access to knowledge in the form of research evidence or knowledge tools can be limited for stakeholders, as well as the time to read and appraise sources of knowledge (Grimshaw et al., 2012). This points to the need for knowledge tools that are specifically written for stakeholders that can describe key messages in a suitable way. Additionally, there may be barriers or facilitators within the organization, such as in the school context, that impact on the implementation of the knowledge tool. These barriers can consist of structural barriers, organizational barriers, and professional barriers (Grimshaw et al., 2012). The action cycle presupposes the availability of resources to identify problems and review knowledge, to adapt the knowledge, assess the barriers, select/tailor interventions, monitor knowledge use, evaluate outcomes, and sustain knowledge use. This is a considerable task for any organization, and might explain why although the KTA framework is heavily cited in research literature, few studies have incorporated the full framework, including both the knowledge creation funnel and the action cycle (Field et al., 2014). Instead, the framework seems to be used often as is proposed for the present study, to inform or supplement other underlying theories or frameworks. This shows that the KTA framework is flexible and can be adapted to the context and needs of a particular research study (Field et al., 2014).

Therefore, an adapted version of the BEM supplemented with the KTA was used as the theoretical framework for the study. Thus, the BEM is viewed as the overarching theory, through which the knowledge inquiry, selection, and knowledge creation is filtered, and which guides the development of knowledge tools. The BEM also guides the action cycle, through the implementation of interventions aimed at behaviour change, thus focussing on all levels of the BEM, as illustrated in Figure 2.4.

Figure 2.4

Theoretical Framework of the Study



2.5. Adapting abuse prevention programs

In the review of abuse prevention programs for persons with disabilities by Mikton et al. (2014) it is suggested to consider the applicability of existing well-researched abuse prevention strategies to suit the needs of persons with disabilities. This can be a strategy used to expand an intervention to focus on other populations (such as children with disabilities) as well as to limit the amount of resources needed to develop and implement an intervention

(McKleroy et al., 2006). Cultural adaptation of abuse prevention programs using a structured framework has shown to be successful, in which the adaptations included targeting areas such as language, extended family, relationship development, preferred learning styles and racism and discrimination (Beasley et al., 2014). It could be argued that adapting a school-based abuse prevention program for children with communicative and/or cognitive disabilities is a form of cultural adaptation where similar adaptations in terms of the language, preferred learning styles, relationships with family, and professional care workers as well as discrimination and rights, need to be considered.

There are several benefits of adapting school-based abuse prevention programs that have already been established and reviewed for use in schools. Firstly, if a school-based abuse prevention program is already being utilised at a particular school, there is no need for teachers and principals to search for and implement a new program. By adapting the program to suit the needs of children with communicative and/or cognitive disabilities, the same program can be used by adding relevant materials and methods of teaching. This can alleviate the burnout and stress which many special education teachers face due to the challenges of teaching children with a variety of needs in a demanding work environment (Emery & Vandenberg, 2010). Teachers working in inclusive settings are also prone to burnout and stress, often linked to time constraints (Skaalvik & Skaalvik, 2018), which could be alleviated by not having to implement an entirely new program, but rather building on programs and strategies that they are familiar with.

Secondly, by adapting an already existing school-based abuse prevention program, particularly one that has been well-researched, a certain level of confidence in the program's ability to achieve the desired goals and outcomes for the children who are participating can be assumed. Implementing adapted versions of evidence-based programs that have had successful outcomes in other contexts can also save both financial and staff resources as well as build the evidence-base for the intervention in question (Movsisyan et al., 2019).

Adapting an existing school-based abuse prevention program requires time as well as knowledge about which adaptations are needed to make the program suitable for children with communicative and/or cognitive disabilities. Pre-service teachers believe that adaptations for children with intellectual disabilities in inclusive settings are important to facilitate learning (Cameron, 2017). The ability of teachers to adapt their instructions by using different teaching methods and strategies for different children in their classrooms can be seen as key for inclusive education (Majoko, 2019). However, student teachers have low confidence in their own ability to make these adaptations (Cameron, 2017). In addition, adapting interventions are time consuming and may fall beyond the scope of the teachers' and principals' roles and job descriptions. To facilitate adaptations of school-based abuse prevention programs, guidelines of school-based abuse prevention programs aimed at 7–12-year-old children with communicative and/or cognitive disabilities have been explored, developed, and evaluated in the present study.

2.6. Summary

Chapter 2 focused on relevant literature relating to school-based abuse prevention for children with communicative and/or cognitive disabilities.

First, the prevalence of and risk factors linked to the abuse of both children with- and without disabilities was discussed, demonstrating the increased risk of being abused, which children with disabilities face. A discussion on the potential perpetrators of child abuse followed, in which the situation of families with children with disabilities was specifically focused on.

Next, the public health prevention model was introduced, and the merits of primary, secondary, and tertiary abuse prevention was presented. This was followed by a review of primary abuse prevention programs aimed at children with communicative and/or cognitive disabilities, which highlighted the dearth of research on this topic. Subsequently, the potential benefits of using schools as a venue for implementing primary abuse prevention programs for children with communicative and/or cognitive disabilities was discussed. This was followed by a discussion of teachers', principals', and parents' potential roles in school-based abuse prevention.

Subsequently, the theoretical framework of the study was discussed in detail and its potential application to school-based abuse prevention programs for children with communicative and/or cognitive disabilities was presented. The chapter concluded with discussing the rationale for adapting existing school-based abuse prevention programs for children with communicative and/or cognitive disabilities. The findings from Chapter 2 will be used to inform the methodology used in the study.

CHAPTER 3
METHODOLOGY

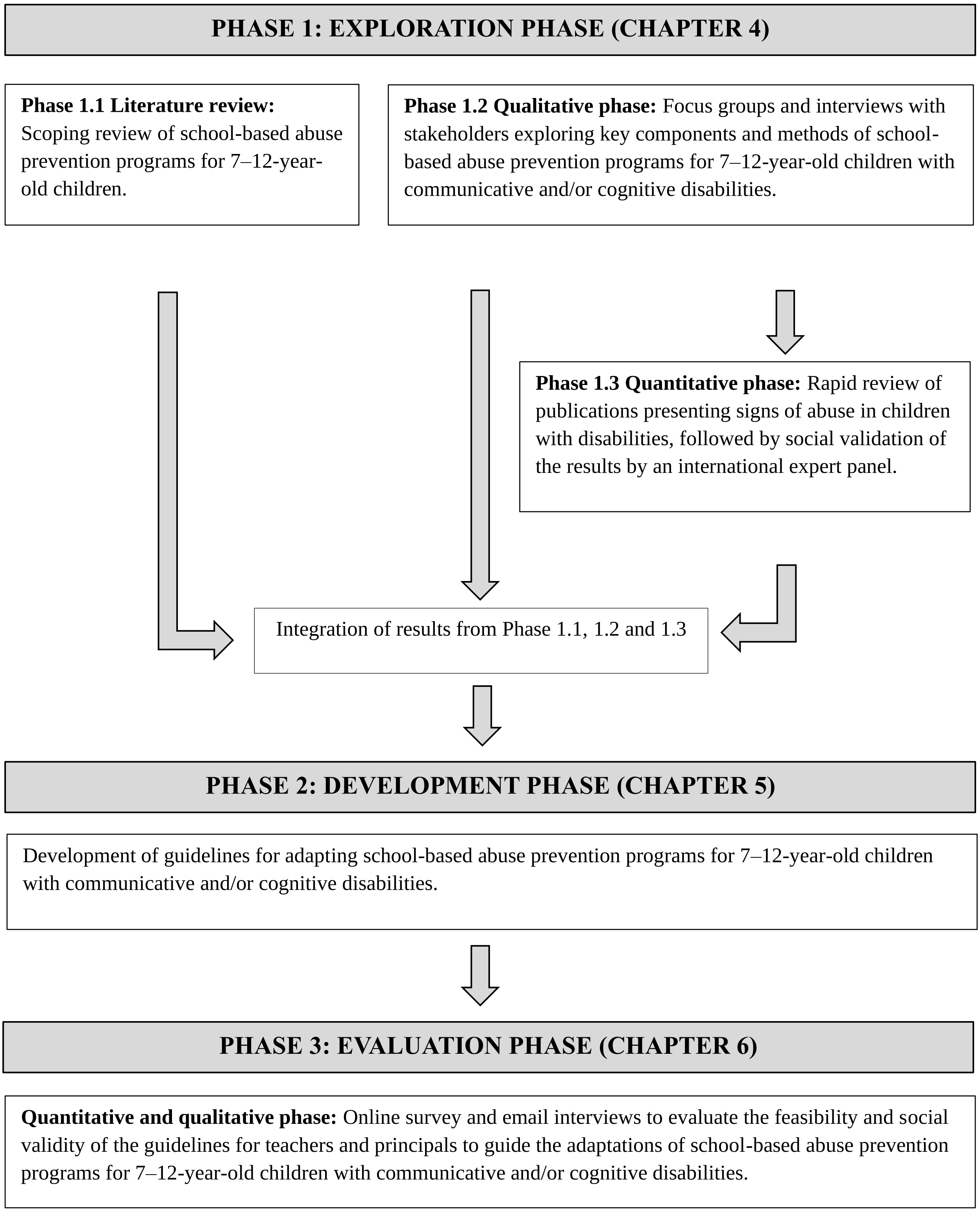
3.1. Introduction

This chapter provides an overview of the research methodology used in this study, namely a three-phase exploratory sequential design (Creswell & Creswell, 2018). The design and outline of the different phases is presented in Figure 3.1. The chapter starts with the main aim of the thesis, followed by the sub-aims of the three different phases. Thereafter the research design and the conceptual framework of the study are discussed. The ethical considerations for the overall study are then discussed before the chapter concludes with a brief summary.

The next three chapters (Chapter 4–6) each address a specific phase of the study, and hence they should be read in conjunction with each other. Chapter 4 focuses on Phase 1, namely the exploration of key components of school-based abuse prevention programs for children with communicative and/or cognitive disabilities and the specific teaching methods employed in these programs as well as signs of abuse in children with disabilities. Next, Chapter 5 focuses on Phase 2 and outlines the development of guidelines of school-based abuse prevention programs for children with communicative and/or cognitive disabilities. This is followed by Chapter 6 that details the last phase of the study, Phase 3, which consists of an evaluation of the feasibility and social validity of the proposed guidelines of school-based abuse prevention programs for children with communicative and/or cognitive disabilities. Figure 3.1 shows the complete three-phase exploratory sequential mixed methods design captured in the thesis.

Figure 3.1

Three-phase Exploratory Sequential Mixed Methods Design



PHASE 1: EXPLORATION PHASE (CHAPTER 4)

Phase 1.1 Literature review: Scoping review of school-based abuse prevention programs for 7–12-year-old children.

Phase 1.2 Qualitative phase: Focus groups and interviews with stakeholders exploring key components and methods of school-based abuse prevention programs for 7–12-year-old children with communicative and/or cognitive disabilities.

Phase 1.3 Quantitative phase: Rapid review of publications presenting signs of abuse in children with disabilities, followed by social validation of the results by an international expert panel.

Integration of results from Phase 1.1, 1.2 and 1.3

PHASE 2: DEVELOPMENT PHASE (CHAPTER 5)

Development of guidelines for adapting school-based abuse prevention programs for 7–12-year-old children with communicative and/or cognitive disabilities.

PHASE 3: EVALUATION PHASE (CHAPTER 6)

Quantitative and qualitative phase: Online survey and email interviews to evaluate the feasibility and social validity of the guidelines for teachers and principals to guide the adaptations of school-based abuse prevention programs for 7–12-year-old children with communicative and/or cognitive disabilities.

3.2. Research aims

The main aim and sub-aims of the overall study are presented below.

3.2.1. Main aim

The main aim of this study is to explore the key components, teaching methods and information that should be included in school-based abuse prevention programs and to subsequently develop and evaluate guidelines for teachers, supported by principals, to guide them in adapting school-based abuse prevention programs for 7–12-year-old children with communicative and/or cognitive disabilities.

3.2.2. Sub-aims

In order to realise the main aim of the study, specific sub-aims were set for each of the three phases as follows:

i) To explore key components included in school-based abuse prevention programs and the teaching methods used to deliver these programs as well as to explore signs of abuse in children with disabilities in order to inform the identification of potential victims from this population.

ii) To integrate data from Phase 1 using a recursive abstractive thematic analysis approach to allow for the development of guidelines that could be used by teachers with the support of principals to adapt existing school-based abuse prevention programs for 7–12-year-old children with communicative and/or cognitive disabilities.

iii) To explore the feasibility and social validity of the proposed guidelines of school-based abuse prevention programs for 7–12-year-old children with communicative and/or cognitive disabilities using qualitative and quantitative indicators.

3.3. Research design

The study uses an exploratory sequential mixed method design with three distinct phases (Creswell & Plano Clark, 2017). Rigorously collected qualitative and quantitative data were used to respond to research sub-aims, after which the different data sources and their results were combined to address the overarching aim of the study. This was done in the context of a specific conceptual framework, namely the customised framework for adaptations developed in this study (Table 3.2).

Mixed methods designs incorporate both qualitative and quantitative methods in the same study to obtain multiple forms of data (Creswell, 2014; Johnson et al., 2007; Leech & Onwuegbuzie, 2009; Schoonenboom & Johnson, 2017). One advantage of mixed method designs is that the gathering of both quantitative and qualitative data forms a deeper and more nuanced understanding of the research problem (Creswell, 2015), which is especially pertinent with regards to complex populations, such as children with communicative and/or cognitive disabilities, and when investigating sensitive topics, such as child abuse. Another strength in mixed methods research is that the combination of qualitative and quantitative data enhances not only the strengths of each method but also the results and conclusions arrived at (Creswell & Creswell, 2018; Johnson et al., 2007; Schoonenboom & Johnson, 2017). Additionally, some research questions may be most fully answered using mixed methods designs, as is the case in the current study. Furthermore, mixed methods designs can offer the opportunity to include diverse views on topics, such as the use of participants who represent different stakeholder groups from different backgrounds in the focus groups and semi-structured interviews in the context of this study (Schoonenboom & Johnson, 2017). All mixed methods designs include a point of integration, meaning a point where the qualitative and quantitative data are integrated (Schoonenboom & Johnson, 2017). In the present study, that integration occurs at the end of Phase 1 (Figure 3.1).

However, a mixed method design also presents some challenges. One such challenge is that the researcher needs to be skilled in both qualitative and quantitative methods of data collection (Johnson et al., 2007). Constraints in resources and time can also be challenging, as a mixed methods study typically involves more data collection and analysis, hence spanning over a longer time period, as opposed to either a quantitative study or a qualitative study (Creswell & Plano Clark, 2017; Johnson et al., 2007). Considering the different types of methods on their own, qualitative data has been critiqued as potentially biased because of the personal interpretations done by the researcher (Creswell & Plano Clark, 2017) and the limited generalisability of the findings to other settings (Johnson et al., 2007). Whereas, quantitative data has been said to not take the environment or context of the participants into consideration as well as not giving a voice to participants directly (Creswell & Plano Clark, 2017). Combining these two types of methodology in mixed methods research addresses these specific challenges.

After careful consideration of both the advantages and disadvantages of a mixed-methods design, this design was selected for the current study as the process of developing guidelines for adapting existing programs should be informed by different data sources to develop a thorough understanding of the needs of the target population (i.e., children with communicative and/or cognitive disabilities), which is complex and diverse. Furthermore, Creswell and Plano Clark (2017) explain that the exploratory sequential design is appropriate when a researcher needs to develop a solution to a real-world problem (i.e., an intervention) where no solution exists, taking relevance and cultural sensitivity into consideration (Creswell & Creswell, 2018), which aligns with the overall aim for the present study.

Typically, a three-phase exploratory sequential design starts with the collection of qualitative data to explore a topic. This data is subsequently used to construct new interventions which are tried during the third and final phase using quantitative methods

(Creswell & Creswell, 2018). In the present study, the first phase included both qualitative (Phase 1.2) and quantitative (Phase 1.3) methods. The purpose of the first qualitative phase is to root the intervention (in this case the guidelines) in the setting (in this case schools), context and culture of the participants (in this case Sweden) (Creswell & Plano Clark, 2017). This data was integrated into the development of the guidelines in the second phase, which are subsequently explored in terms of feasibility, using both quantitative and qualitative data collection methods in the third and last phase of the design.

Both Phase 1 and Phase 3 of the study included participants: the participants included in Phase 1 are described in Chapter 4 and the participants included in Phase 3 are described in Chapter 6. Creswell and Creswell (2018) state that a good procedure in exploratory sequential mixed methods design is to draw samples for both the first and last phase of the study from the same population group thereby using a nested sample approach (Onwuegbuzie & Leech, 2007), without including the exact same individuals. In the present study, two participants were included in both Phase 1.3 and Phase 3. All other participants only participated in one phase of the study.

3.4. Triangulation

Triangulation is an important tool to ensure validity and reliability of the findings that were obtained from the study (Fusch et al., 2018). By combining several data sources and methods, the hypothesis was that the quality of the research was improved compared to only using either qualitative or quantitative data collection methods (Creswell & Creswell, 2018; Patton, 1999). Denzin (2017) suggests that multiple methods of collecting data must be used, as no one method used on its own is ever sufficient to fully capture a phenomenon or test the development of a theory.

Triangulation can be achieved either by combining multiple qualitative methods which use multiple samples and perspectives or by combining qualitative and quantitative methods (Patton, 1999). However, the purpose of triangulation is not necessarily to show that the different methodologies, samples, and perspectives result in the same findings but rather to test for consistency and in doing so, form a better understanding of the inconsistencies that may be present (Patton, 1999). Triangulation can lead to divergent and contradictory results, which in turn, can (if handled correctly) result in richer data (Fusch et al., 2018).

Different types of triangulation have been described in the literature. Denzin (2017), who is considered the seminal author on the topic of triangulation, has suggested four different types of triangulations, namely data source triangulation, investigator triangulation, theoretical triangulation, and methodological triangulation. In the present study, methodological as well as data source triangulation were used in Phase 1 and 3 by combining both qualitative and quantitative methods as well as different participant groups (Table 3.1) (Carter et al., 2014; Patton, 1999). In doing so, a complimentary view of the topic was expected and strived for (Patton, 1999).

Data source triangulation can include three points of data, namely time, people, and space (Denzin, 2017). These points of data are linked to each other and represent different data sets of the same construct (Fusch et al., 2018). The purpose of data source triangulation can be to identify patterns and similarities (data convergence) in the data sets as well as differences (divergence) (Thurmond, 2001). In the present study, the data source triangulation includes the collection of data from different stakeholder groups; namely teachers in special schools, parents of children with communicative and/or cognitive disabilities and professionals working with children with disabilities who have been abused. Further stakeholder groups are; professionals and researchers working with children with disabilities, child abuse or both principals with experience of working with children with communicative and/or cognitive disabilities, and content experts of varying professions (i.e., psychologists, researchers, senior clinicians) with experience working with children with disabilities, abuse and/or AAC (Table 3.1) (Carter et al., 2014).

Methodological triangulation is the collection of data on the same topic using multiple methods of data collection (Carter et al., 2014). Methodological triangulation can be used to offset each method's flaws against each other to strengthen the overall validity of the results obtained (Denzin, 2017). Methodological triangulation can occur either within methods or between methods. An example of within-method triangulation is collecting qualitative data using multiple data collection methods, as in Phase 1.2 of the present study (Table 3.1) (Fusch et al., 2018). Between-method triangulation involves using data collected with both quantitative and qualitative data collection methods, such as during Phase 3 in the present study (Table 3.1) (Denzin, 2017; Fusch et al., 2018).

Table 3.1

Employment of Triangulation

Type of triangulation	Data source/ Methodology	Use of strategy in the current study	Phase
Data source triangulation	Stakeholders	• Teachers working in special schools • Parents of children with communicative and/or cognitive disabilities • Professionals working with children with disabilities who have been abused	1.2
Data source triangulation	Stakeholders	• Professionals and researchers working with child abuse • Professionals and researchers working with children with disabilities • Professionals and researchers working with both child abuse and children with disabilities	1.3
Data source triangulation	Stakeholders	• Teachers with experience working with children with communicative and/or cognitive disabilities • Principals with experience working with children with communicative and/or cognitive disabilities • Content experts with experience working with children with disabilities, child abuse and/or AAC.	3
Methodological triangulation	Within-methodology (qualitative)	Conducting focus groups and interviews with stakeholders to explore key components and methods of school-based abuse	1.2

Type of triangulation	Data source/ Methodology	Use of strategy in the current study	Phase
		prevention programs for 7–12-year-old children with communicative and/or cognitive disabilities.	
Methodological triangulation	Between-methodology (qualitative and quantitative)	Conducting an online survey and email interviews to explore the feasibility and social validity of guidelines of school-based abuse prevention programs for 7–12-year-old children with communicative and/or cognitive disabilities.	3

3.5. Research paradigm

A research paradigm can be characterised as an analytic lens from which to understand a phenomenon. A research paradigm includes epistemology, ontology, methodology and axiology (Lincoln & Guba, 1985). Epistemology describes the nature of knowledge and how it can be acquired and shared with others (Kivunja & Kuyini, 2017). This study is grounded in the research paradigm of pragmatism, which has been described as a view that is concerned with applications and solutions, which focuses on the research problem and beliefs that are connected to actions, and employs the available and needed methods to solve that problem (Creswell, 2014; Morgan, 2014). Pragmatism is often linked to mixed methods research, as it is not committed to one view of reality, but view truth as what works at a given time, and is focused on what to research and how to research it (Creswell, 2014).

Ontology includes the study of existence and reality and the underlying beliefs and assumptions that are made about whether something is real and makes sense (Kivunja & Kuyini, 2017). Ontology has historically been an issue which has not been considered much in pragmatism, as it has mostly been viewed as an epistemological and methodological stance and pragmatism has been criticised for this lack of clarity on its ontological position (Maarouf, 2019). Maarouf (2019) has attempted to conceptualise the ontology of pragmatism as ‘the reality cycle’ The reality cycle states that reality is context-dependant and that there are multiple realities, just as there are multiple contexts. This process is described as a cycle, in which reality is perceived in various ways by humans, and this perception of reality influences their behaviours, which interact and lead to the construction of a new context (over time), which subsequently generates a new reality (Maarouf, 2019).

Methodology includes the research design, participants, data collection methods, and analysis described further on in this chapter as well as in Chapters 4, 5, and 6 (Kivunja & Kuyini, 2017). The axiology involves the ethical issues and understanding and defining right and wrong behaviour linked to the research that is being conducted (Kivunja & Kuyini, 2017). This includes reflecting on views of the human value of the participants in the research project (Kivunja & Kuyini, 2017). The ethical considerations of this study are described in Section 3.7.

3.5.1.1. Student positionality statement

Positionality refers to the worldview, political and social context of the student and is based on ontological and epistemological assumptions as well as views on how individuals interact with their environment and how they relate to it (Holmes, 2020). A critical reflection on the power and positionality of the student in relation to the stakeholders and communities which are involved in the research study is therefore important (Fenge et al., 2019). By reflecting on the research and the research process, important insights can be gained into the effect the researcher has on the participants and research process as well as how the research process and participants affect the researcher (Fenge et al., 2019; Holmes, 2020). This reflection is especially important when conducting research on sensitive and challenging topics, such as child abuse (Fenge et al., 2019). Below is the student’s positionality statement.

> *In critically reflecting on my positionality in conducting this study, it is acknowledged that I am a white, middle-class verbal Swedish woman. I have worked as a speech-language therapist for 10 years, of which five years have been spent working with*

children with severe communicative and/or cognitive disabilities, mostly linked to AAC and communication support. I have also been the manager of a Swedish project on using pictorial support for adults with communication disabilities to enable them to speak about violence and abuse. However, I do not have a communicative or cognitive disability, nor do I have a child that does and therefore I cannot claim that I have an insider perspective. In addition, I have no personal experience of child abuse. I do, however, consider myself as a disability ally and I frequently advocate for the use of AAC and the disability community. My aim during the entire research process is to be an ally to children with communicative and/or cognitive disabilities by working towards minimising the risk of abuse and facilitating the detection of abuse. I acknowledge the potential effect of me being viewed by participants as an expert and thereby affecting their answer but have continuously strived to minimise that risk by developing a relaxed and informal atmosphere during all meetings with participants.

3.6. Conceptual framework

The theoretical framework described in Chapter 2 represents the underlying theoretical structure of this study and forms the foundation of the analysis of interpretation of the results of the study (Kivunja, 2018), whereas the conceptual framework situates the study by defining the main concepts and guides the research conducted in the study (Rocco & Plakhotnik, 2009).

Several different models and frameworks for adaptations of evidence-based programs have been proposed, with a large body of research emerging in recent years. Escoffery et al. (2019) conducted a scoping review of existing frameworks for adaptations of public health evidence-based interventions. They identified 13 frameworks all of which outlined different steps of the adaptation process. From these frameworks, 11 common key adaptation steps were identified and described in the review. Almost in tandem, Movsisyan et al. (2019) conducted a systematic review of adaptations of complex health interventions and also reported on 11 steps to adapting an intervention, which are similar, but not identical to the steps suggested by Escoffery et al. (2019).

Miller et al. (2020) present another perspective to adaptation and conclude that the models containing different steps for adaptation can be limited, as the models say little about the interactions between the different stages. In order to identify this limitation, these authors suggest that depending on the circumstances in the adaptation process, certain steps might need to be expanded on and will be more important than others. Consequently, Miller et al. (2020) constructed a framework for making decisions throughout the adaptation process, called the Iterative Decision-making for Evaluation of Adaptation (IDEA). This framework assumes that a program built on evidence-based practice (EBP) principles has already been selected and that the next step is exploring whether and how the program could be adapted (Miller et al., 2020). The IDEA framework consists of four distinct decision points in which the researchers or stakeholders are expected to take a stand on questions, leading them to the next step.

To ensure a comprehensive view on the adaptations conducted in the present study, these three frameworks and outlines for adaptations of EBP programs were combined and adapted to provide a framework for the guidelines developed in the present study (Table 3.2).

Table 3.2

Key Adaptation Steps and Descriptions

Escofferey et al. (2019)	Movsisyan et al. (2019)	Miller et al. (2020)	Customised framework (combined and adapted)
Assess community (Step 1)	***Initial assessment (Step 1)***		***Assess the current situation***
• Identify behavioural determinants and risk behaviours of the new target population • Assess organizational capacity to implement the program	• Identify the need for a new intervention for the target population • Conduct a multilevel needs assessment of system, process, organization, provider, and characteristics of the target population • Identify relevant contextual factors and community best practices	• Does stakeholder input, evaluation, published data or needs assessment data suggest that an adaptation is needed?	• Identify the needs, risk behaviours and situations of target population (Chapter 2, Phase 1.2 and 1.3) • Identify the capacity in organizations and community surrounding the target population (Phase 1.2) • Conduct a needs assessment with stakeholders (Phase 1.2) • Identify published literature on the topic as well as adjacent topics (Chapter 2, Phase 1.1)
Understand the intervention (Step 2)	***Explore intervention (Step 3)***		***Review and explore interventions***
• Identify and review relevant EBP programs and their program materials • Understand the theory behind the programs and their core elements	• Obtain the original intervention materials • Identify the intervention's core components and best-practice characteristics • Examine the theory base behind the intervention • Determine the interventions adaptability to the new target population and setting	• Are core elements or core functions of the intervention known?	• Review literature of relevant programs (Phase 1.1) • Identify theory base of programs (Phase 1.1) • Identify core elements of programs (Phase 1.1)
Select intervention (Step 3)	***Select intervention (Step 2)***		***Select intervention/interventions***
• Select the program that best matches the new population and context	• Identify and review evidence-based interventions that address the public health problem of interest, risk behaviours, and environmental factors		• Identify common characteristics, themes, and methods of selected programs (Phase 1.1) • Determine the relevance of characteristics, themes, and methods to the target population (Phase 1.2) • Determine goals and outcomes of selected programs (Phase 1.1)

Escofferey et al. (2019)	Movsisyan et al. (2019)	Miller et al. (2020)	Customised framework (combined and adapted)
	• Determine whether the intervention goals, outcomes and content are relevant to the target population • Judge the fit of the intervention to the problem, organization, and target population • Select the best matching intervention		• Determine the relevance of goals and outcomes of selected programs to target population (Phase 1.2)
	Identify potential mismatches (Step 4)		***Identify barriers***
	• Identify and categorise potential mismatches (e.g., among intervention goals or characteristics of the target population), implementation barriers, barriers to participation • Assess fidelity/adaptation concerns for the particular implementation site	• Can barrier/concern be addressed while preserving core intervention element?	• Identify barriers and concerns in the original programs related to target population and implementation (Phase 2)
Consult with experts (Step 4)			***Consult with stakeholders and experts***
• Consult content experts, including original program developers and incorporate advice into program			• Consult with experts and stakeholders on specific components related to the target population that should be included in the program (Phase 1.2, 1.3 and Phase 3) • Include stakeholder advice in guidelines (Phase 2)
Consult with stakeholders (Step 5)	***Establish networks, capacity, and infrastructure (Step 6)***		***Engage with stakeholders and community in terms of implementation***
• Seek input from advisory boards and community planning groups where program implementation will take place • Identify stakeholders who can champion program adoption in new setting and ensure program fidelity	• Assess organizational capacity and stakeholder input and secure stakeholder's involvement • Consult with the relevant stakeholders and the community to develop an implementation plan • Identify and recruit implementers		• Consult with stakeholders regarding program implementation (Phase 1.2) • Provide recommendations for potential stakeholders in the community using guidelines (Phase 2) • Explore capacity of organizations (special schools) to implement the program (Phase 1.2 and Phase 3)

Escofferey et al. (2019)	Movsisyan et al. (2019)	Miller et al. (2020)	Customised framework (combined and adapted)
	• Use community resources and build capacity to increase accessibility and sustainability • Balance community needs and scientific integrity by an iterative process among all stakeholders		
	Develop intervention model (Step 5) • Define the extent of adaptation needed • Develop an overall logic model, timeline, and implementation plan for adapting and implementing the intervention • Consider how components can accommodate population characteristics, delivery systems, and community contexts • Draft a user-friendly manual (i.e., ‘package’) of the intervention		***Develop intervention model*** • Define the level of adaptation that is needed (Phase 1.2 and 1.3) • Produce guidelines for implementation (Phase 2)
Decide what needs adaptation (Step 6) • Decide whether to adapt EBP and identify what needs to be adapted • Test selected EBP program with target population and stakeholders to generate adaptations • Determine how risk and protective factors differ for original and new target population/setting • Retain fidelity to core elements • Reduce mismatches between the program and the new context systematically			***Implement first stage of adaptation process*** • Obtain stakeholder’s input as to what components of the programs need to be adapted (Phase 1.2) • Identify needs for adaptations in the program while retaining the core elements/functions (Phase 2) • Identify differences regarding risks and protective factors between the original and new target population (Phase 1.2, Phase 2)

Escofferey et al. (2019)	**Movsisyan et al. (2019)**	**Miller et al. (2020)**	**Customised framework (combined and adapted)**
Adapt the original program (Step 7)	***Undertaking modifications (Step 7)***		***Implement second stage of adaptation process***
• Develop adaptation plan • Adapt the original program content through collaborative efforts • Make continuous cultural adaptations throughout the pilot testing • Avoid modifying core components responsible for change	• Develop an adaptation plan • Consider adaptations that may be necessary for the new target population, while ensuring that core elements remain intact • Consider possible local adaptations to improve cultural/context fit • Develop a 'mock-up' version of the adapted material (if applicable) • Consider intervention training • Adapt the relevant intervention components through collaborative efforts		• Develop an adaptation plan (Phase 2) • Maintain core elements/key components responsible for change (Phase 2) • Construct adaptations to suit the target population (Phase 2) • Consider relevant cultural and local adaptations (Phase 2) • Construct guidelines for the adaptions (Phase 2)
Train staff (Step 8)			***Training stakeholders***
• Select and train staff to ensure quality implementation			• Draft guidelines for stakeholder training (Phase 2)
Test the adapted materials (Step 9)	***(Pilot) testing (Step 8)***		***Conduct feasibility study***
• Pre-test adapted materials with stakeholder groups • Conduct readability tests • Pilot test the adapted EBP program in the new target population • Modify EBP program further if necessary	• Pilot test the adapted intervention components and procedures with representatives from the target group, get feedback and revise as necessary • Monitor the fidelity of the intervention delivery	• Does the timeframe of the proposed rollout of the EBP program allow for a pilot study that includes the proposed adaptations?	• Explore the feasibility of the guidelines and adaptations with stakeholder groups (Phase 3) • Revise guidelines and adaptations (beyond the scope of this PhD-study)
Implement (Step 10)	***Revise and implement intervention (Step 9)***		***Explore feasibility of implementation of guidelines***
• Develop implementation plan based on results generated in previous steps • Identify implementers, behaviours, and outcomes	• Refine adaptations based on results generated in previous steps • Synthesise stakeholder feedback and finalise the implementation plan		• Suggest recommendations (in the guidelines) for implementation of adaptations (Phase 2) • Evaluate feasibility of guidelines for implementation of adaptations (Phase 3)

Escofferey et al. (2019)	Movsisyan et al. (2019)	Miller et al. (2020)	Customised framework (combined and adapted)
• Develop scope, sequence, and instructions • Execute the adapted program based on EBP principles	• Implement the adapted intervention • Establish ongoing support, feedback, and refinement		
Evaluate (Step 11)	***Evaluation (Step 10)***		***Explore feasibility of evaluation methods***
• Document the adaptation process and evaluate the process and outcomes • Plan data collection, analysis and reporting and write evaluation questions • Employ empowerment evaluation approach framework to improve program implementation	• Decide how to evaluate and develop an evaluation plan that reflects the core mechanisms of change within the original program theory, as well as adaptations made • Implement outcome evaluation • Provide routine, ongoing supervision • Assess acceptance of- and engagement in the intervention • Revise the intervention by adopting effective or dropping ineffective adaptations	• To what extent is the adapted EBP program successful? Is ‘voltage drop’ (i.e., failure of the program to achieve the expected outcomes based on previous research) acceptable to stakeholders?	• Suggest methods for evaluation (in the guidelines) of the adapted program (Phase 2) • Evaluate the feasibility of the suggested methods for evaluation (Phase 3)
	Maintenance and evolution (Step 11)		***Maintain and revise***
	• Establish a wide-scale dissemination of the adapted intervention, if the intervention is successful and is embraced by the community • Develop training systems to widen the dissemination • Implement an ongoing re-assessment		(Beyond the scope of this PhD-study)

Source: Conceptualised from Escoffery et al. (2019), Movsisyan et al. (2019) and Miller et al. (2020), and integrated into the conceptual framework for adaptation used in the present study

Note: Chapter 2: Literature review, Phase 1.1: Scoping review (Chapter 4), Phase 1.2: Focus groups and interviews (Chapter 4), Phase 1.3: Rapid review with social validation (Chapter 4), Phase 2: Program development (Chapter 5), Phase 3: Feasibility study (Chapter 6)

From Table 3.2, it becomes clear that the adaptation of interventions and EBP programs is a comprehensive task that ought to include several steps which should be clearly documented. Adaptations should not be carried out without the involvement of stakeholders and adaptations should be thoroughly tried and evaluated. The customised framework for adaptations developed in the present study incorporates the suggested steps for adaptation from three different studies (Escoffery et al., 2019; Miller et al., 2020; Movsisyan et al., 2019) to ensure that the adaptations are comprehensive and satisfactory.

3.7. Ethical considerations

This study received ethics approval from the Ethical Review Board of the University of Gothenburg (Appendix A1) and the Research Committee of the Faculty of Humanities, University of Pretoria (Appendix A2). Phase 1 and Phase 3 of the study included research participants. For both these phases, the World Medical Health Associations Declaration of Helsinki was considered in order to ensure the participant's safety and other ethical principles were adhered to. Most of the participants included in the present study participated in their professional capacity (e.g., teachers, clinicians, and researchers). However, parents of children with communicative and/or cognitive disabilities were also included in semi-structured interviews. Parents of at-risk populations (as was the case in the current study) can be considered a vulnerable group. Moreover, the topic of the discussions was also a sensitive one, namely the prevention of abuse against children with communicative and/or cognitive disabilities. Additionally, adhering to ethical principles can be particularly important when conducting qualitative research, as the research methods are more in-depth in nature (Arifin, 2018). To further protect this group, it was decided not to conduct a focus group with the parents participating in Phase 1.2 but rather conduct individual interviews. This decision was reached as the topic was of a sensitive nature which could potentially be challenging for the parents to talk about in a group setting. This also meant that data confidentiality could be increased, as the parents only met with the student and not with any other participants or research assistants.

Data collection for Phase 1 was concluded before the global Covid-19 pandemic. The data collection in Phase 3 was carried out during the pandemic which meant that using face-to-face methods was not possible. Thus, the data collection methods had to be adapted into online methods, namely an online survey and email interviews. For the participants, this meant that the data confidentiality was increased as they did not meet the other participants in the study.

Furthermore, a number of specific ethical principles were considered in the study which are each described in more detail.

3.7.1. The principle of informed consent

The ability to provide informed consent includes being able to make decisions and comprehend what one is consenting to (Biros, 2018). Researchers must consider the vulnerability of a specific population and how that vulnerability may influence the participant’s risk of harm during the research process.

All the participants in the present study were considered capable of making their own decision as to whether or not they wished to participate in the research study (Biros, 2018). Participants were first contacted by means of email, in which they were informed about the exact nature of the research without any deception and explained what would be expected of them as well as that no compensation would be included. The student’s contact details were also provided should any unforeseen questions arise (Ketefian, 2015). If the prospective participants were interested in the study, they were provided with comprehensive information regarding the study, either through e-mail or were directed to a website (Appendix B1–B5).

The information outlined the background, aim and method of the study, what was expected of each participant, risk of harm, confidentiality and anonymity, data storage practices, and contact details to get in touch with the student and the main supervisor (Kadam, 2017; Ketefian, 2015). The participants were informed about the sensitive nature of the topic and their right to withdraw from the study at any time without the risk of negative consequences. Participants were provided with an opportunity to read the letter of informed consent which outlined the ethical principles guiding the study at their own time and pace (Arifin, 2018). The consent letters were written using easy language and formatted for increased readability and understanding (Kadam, 2017; Ketefian, 2015). The participants were encouraged to voice questions or concerns after reading the letter and could contact the student by means of email or phone for this purpose. The participant consent letter also contained a ‘reply slip’ which participants could complete electronically (in Phase 1.3 and 3) (Appendix B4 and B5) or in person (in Phase 1.2) (Appendix B1, B2 and B3) after reading the letter of informed consent.

3.7.2. The principle of voluntary participation

The participants were not offered any incentives to participate in the study and were not in any way coerced to do so. All the participants agreed to participate after consideration of the full study details that they were provided with in the email containing the informed consent letter (Kadam, 2017; Ketefian, 2015) and were given sufficient time to do so (Arifin, 2018). The participants were informed that their participation in the study was entirely voluntary and that they could withdraw from the study at any time without any negative consequences (Arifin, 2018; Ketefian, 2015). The participants travelled to the agreed venue for the focus groups and interviews independently. The data collection for Phase 3 was done using online methods to ensure the participant’s safety during the Covid-19 pandemic.

3.7.3. The principles of deception and clinical use

Due to the sensitive nature of the topic at hand, extra care was taken to inform the participants of the nature of the study and in which way the research was intended to be used. The participants were not mislead or deceive in any way and were provided written information about the study prior to the commencement thereof (Ketefian, 2015). The data collection methods used were pilot-tested by a PhD-student peer group as well as by the study supervisors to ensure accuracy and relevance (Anney, 2014). The data obtained was not fabricated or falsified in any way during the process, and the student's positionality, which could impact on the interpretation of qualitative data, was reflected on as stated in section 3.5.1.1. To ensure the accuracy of the data in Phase 1.2 which consisted of audio recordings, verbatim transcription was carried out of the recordings of focus groups and interviews and the participants were given the opportunity to read the transcribed materials (Carlson, 2010; Noble & Smith, 2015). The results from the three data sources in Phase 1 were published as separate studies and thus underwent a scrutinous peer-review process. Furthermore, all three phases were conceptualised, executed, discussed, and analysed using the supervisors of this study as a sounding board.

3.7.4. The principle of confidentiality

The principle of confidentiality in research includes not sharing information provided by a participant with others and reporting information or results in a way that makes it impossible to identify a participant (Wiles et al., 2008). In the present study, the identity of the participants were protected by not revealing any personal details in the analysis and reporting of the results of the study (Arifin, 2018; Kaiser, 2009). This was achieved by means of de-identified data that used participant codes, which used an alpha-numeric code during the transcription and analysis process to protect the participants' identities. Records of their real identity were only available to the student (Arifin, 2018). Transcriptions and handling of the raw data was done in a secluded room, using headphones when conducting transcriptions (Arifin, 2018). All data was stored on a password protected computer.

Confidentiality was also influenced by the specific way in which data was collected. As is the nature of focus groups, only external confidentiality can be promised to the participants (Tolich, 2009). As the participants in the different focus groups in Phase 1.2 met in person, they gained information about their fellow participants. However, the participants were urged to respect the identity of their fellow participants and not disclose their identities, or the matters discussed during the focus group to persons outside of the group. Due to the high level of trust that was established in the groups, the student is confident that this transpired. Partly due to the potential lack of internal confidentiality in focus groups (Tolich, 2009), individual interviews instead of focus groups were conducted with the parents of children with disabilities. In Phase 1.3 and Phase 3, the participants could not access each other’s answers and were not aware of the identities of the other participants as online data collection methods were used.

3.8. Trustworthiness and dependability

The rigor of a study in terms of the confidence in the methods and data analysis that is used in the study to produce findings is often referred to as trustworthiness in qualitative research and validity in quantitative research (Connelly, 2016). The stability of the research data across populations, contexts, and time is referred to as dependability in qualitative research and is similar to reliability in quantitative research (Connelly, 2016).

In addition, several other criteria for trustworthiness and dependability exist. In qualitative research, the criteria credibility, transferability, confirmability, and authenticity are considered in trustworthiness (Guba & Lincoln, 1994). Credibility is the confidence and dependence on rigorous methods as well as the quality of the methods and analysis and is similar to internal validity in quantitative research (Anney, 2014; Connelly, 2016; Patton, 1999). Transferability is the concept of how well the findings are applicable to other settings, which is similar to external validity in quantitative studies (Connelly, 2016; Hadi & Closs, 2016). Confirmability, similar to objectivity in quantitative research, is the degree to which the results of a study can be repeated and are consistent (Ali & Yusof, 2011; Connelly, 2016). Authenticity is the degree in which a researcher includes and portrays different participants lives and realities in a complete and fair manner (Connelly, 2016).

In mixed-methods research, a combination of the criteria for trustworthiness, validity, dependability, and reliability can be applied to the different phases of the study. The strategies used to enhance the trustworthiness and dependability in the current study are presented in Table 3.3.

Table 3.3

Criteria and Strategies for Trustworthiness

Criteria	Strategy	Phase	Use of strategy in the current study
Dependability/Reliability Transferability/External validity	Minimising retrieval bias	Phase 1.1 Phase 1.3	For the literature searches, keywords, synonyms and Medical Subject Headings (MESH)-terms were used and several electronic databases were searched (Aromataris & Riitano, 2014). A number of exploratory searches and pilot searches were conducted using an iterative process to determine the relevance of the search terms (Aromataris & Riitano, 2014; Kable et al., 2012). The search terms and data bases that were considered for use were discussed and pilot tested with a research librarian (Aromataris & Riitano, 2014). An intentionally broad search strategy was used to include all potentially relevant publications, as the purpose was to identify the important characteristics linked to the topics as well as identify knowledge gaps in the research field (Munn et al., 2018). Searches were conducted in English, Swedish, Danish, and Norwegian and articles from 1989 to present date were included.
Dependability	Peer examination	Phases 1 to 3	The results from all phases were consistently discussed in a peer-group of fellow doctoral students (Anney, 2014) every six weeks during a weeklong online discussion forum and during in-person discussions on campus. The peer group consisted of fellow PhD-students with varying backgrounds, including speech-language therapists, educational psychologists, and occupational therapists. Additionally, the results from Phase 1.1 to 1.3 have been published in accredited peer-reviewed journals, a process which is conducted to ensure that only high-quality dependable research is published (Lipworth et al., 2011).
Dependability/Reliability Credibility/Internal validity Authenticity	Recording and transcription	Phase 1.2	The focus groups and the interviews were audio recorded and transcribed verbatim to ensure the accuracy of the statements (Jayasekara, 2012; Noble & Smith, 2015). Transcriptions were checked for accuracy by the co-supervisor. Participants were offered the opportunity to check the transcriptions of the interview or focus group that they participated in as part of a member-checking procedure (Birt et al., 2016).
Dependability/Reliability Confirmability/Objectivity	Logging, note-taking, and peer-debriefing	Phase 1.2 Phase 3	Notes and logbooks were kept throughout the focus groups and interviews as well as during the analysis process (Renz et al., 2018). The findings were discussed with the study's supervisors as well as a peer-group of PhD-students (Connelly, 2016; Lincoln & Guba, 1986) on multiple occasions.

Criteria	Strategy	Phase	Use of strategy in the current study
Transferability	Thick description	Phase 1.2 Phase 3	A detailed description of different aspects regarding the research, such as the biographical information of the participants and the setting, was provided to enable evaluation of the applicability of the results to other contexts and participant groups (Amankwaa, 2016).
Transferability/External validity	Including a diverse population	Phase 1. 2 Phase 1.3 Phase 3	Focus groups, interviews, online surveys, and email interview participants came from several different geographical areas, different contexts (e.g., special schools, social service centres, homes) and included both males and females. Inclusion criteria was used to ensure the desired background and knowledge of the participants (Patino & Ferreira, 2018). Furthermore, the participants' biographical details were included in the study and in the publications emanating from the study.
Transferability/External validity Credibility/Internal validity	Focus group and interview script	Phase 1.2 Phase 3	The same focus group script was used for the focus groups and interviews in Phase 1.2 to enable data source triangulation (Denzin, 2017). The interviews included added questions pertaining to the specific role as a parent. In Phase 3, all email interviews used the same interview questions across participant groups, again to enable data source triangulation (Denzin, 2017). Using a focus group script or interview questions is essential to ensure replicability (Jayasekara, 2012).
Transferability/External validity Confirmability/Objectivity	Methodological description	Phase 1 to 3	The participants, context, data collection methods and analysis, and adaptation process was explained fully to facilitate the readers determination if the results would be applicable to their setting and to enable replication of the findings (Connelly, 2016; Lincoln & Guba, 1986). Search strategies used for the scoping review and rapid review were also clearly explained (Kable et al., 2012).
Confirmability/Objectivity	Audit trail	Phase 1 to 3	The research steps taken were clearly and precisely explained, from the start to the end of the research study to create an audit trail (Amankwaa, 2016). The data collection methods and analysis process were recorded and set out fully in the publications and in the thesis (Carcary, 2020).
Credibility/Internal validity	Member-checking	Phase 1.2 Phase 3	A summary of the focus group discussion was presented at the end of each focus group during Phase 1.2 to enable participants to correct any misinterpretations or to clarify statements (Birt et al., 2016). Furthermore, all participants were given the opportunity to read the transcripts of the focus group or interview which they participated in (Birt et al., 2016). Adding to this, participants were invited to read the synthesised results from the study before publication (Birt et al., 2016; Lincoln & Guba, 1986; Noble & Smith, 2015; Shenton, 2004). In Phase 3, participants were asked to expand on or clarify their written statements when needed as a form of member checking.

Criteria	**Strategy**	**Phase**	**Use of strategy in the current study**
Credibility/Internal validity	Exploration of previous research	Phase 1.1 Phase 1.3	Previous studies on school-based abuse prevention programs for children and signs of abuse in children with disabilities were thoroughly explored and reported on (Shenton, 2004) to ensure representativeness and thus truth value of the results in relation to the topic at hand (Noble & Smith, 2015).
Credibility/ Internal validity	Using well-established research methods	Phases 1 to 3	Different data collection methods were included, namely a scoping review, a rapid review, focus groups (both face-to-face and online), in-depth interviews and surveys. These methods have all been used in similar research projects (e.g., program and guideline development, abuse prevention) and are considered well-established qualitative methods (Shenton, 2004).
Credibility/Internal validity	Peer-review of the research	Phases 1 to 3	The three publications stemming from Phase 1 have been subjected to the peer-review process of accredited journals and have been found suitable for publication (Lipworth et al., 2011; Shenton, 2004). The research produced in Phase 1 has been presented at conferences and the opportunity for fellow researchers at that venue to provide feedback has been encouraged (Noble & Smith, 2015; Shenton, 2004).
Credibility/Internal validity	Researcher background and qualification	Phases 1 to 3	The student is a trained speech-language therapist with over 10 years of working experience. She has several years of experience working with the population considered for this study (children with communicative and/or cognitive disabilities) and their social network (Shenton, 2004).
Credibility/Internal validity Confirmability/Objectivity	Data source triangulation	Phase 1.2 Phase 3	Using several different participant groups when exploring the same topic is a strategy to increase the credibility and confirmability of the results (Amankwaa, 2016; Denzin, 2017).
Credibility/Internal validity Confirmability/Objectivity	Methodology triangulation	Phase 1.2 Phase 3	Different data collection methods were used to explore the consistency in the findings (Amankwaa, 2016). Within-method triangulation was used in Phase 1.2, where interviews and focus groups were used to explore the same topic (Denzin, 2017). Between-method triangulation was used in Phase 3, where an online survey (quantitative) and email interviews (qualitative) were used to explore the same topic (Denzin, 2017).

By employing these strategies to improve the trustworthiness and dependability of the research study, the overall quality and correctness of the data obtained was improved. All aspects described above were considered throughout the study but were more and less important in certain phases of the study, which is reflected in the ‘Phase’ column of Table 3.2.

3.9. Summary

This chapter commenced by explaining the main aim of the research, namely to explore key components, teaching methods and information included in school-based abuse prevention programs and to subsequently develop and evaluate guidelines for teachers with support from principals, to guide the adaptations of school-based abuse prevention programs for 7–12-year-old children with communicative and/or cognitive disabilities. Next, the three-phase mixed method exploratory-sequential research design was described, highlighting the distinct data sources included in Phase 1, before critically reflecting on the strengths and limitations of this type of research design. Subsequently, the research paradigm and researcher positionality were presented. This chapter then carefully detailed the customised framework for adapting evidence-based programs which were constructed, based on earlier work (Escoffery et al., 2018; Miller et al., 2020; Movsisyan et al., 2019). Next the specific ethical issues that were considered in the study to protect the participants were described, as the study deals with vulnerable participants and a sensitive topic.

Finally, trustworthiness and dependability criteria for the full study was presented, providing information about each criterion and strategy considered and their practical application in the study.

CHAPTER 4

PHASE 1: EXPLORATION PHASE

Research methodology, results, and discussion

4.1. Introduction

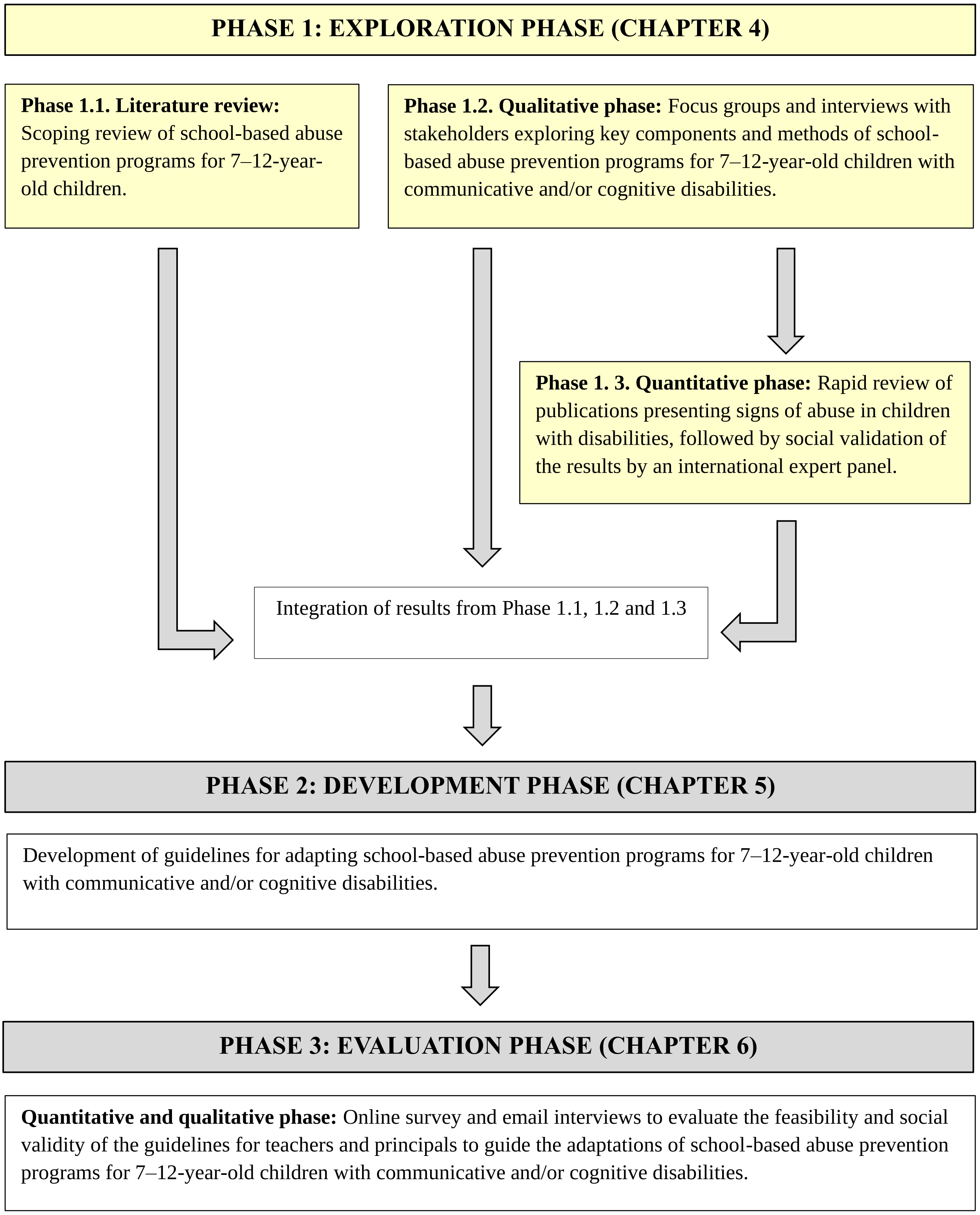
This chapter is the first of three chapters explaining the research methodology, results, and a discussion of each of the three phases of this research study. Chapter 4 focuses on Phase 1, the exploration phase, which included three sub-phases, each representing a distinct data source. Phase 1.1 consisted of a scoping review of published research literature on school-based abuse prevention programs for 7–12-year-old children. Phase 1.2 consisted of focus groups and in-depth interviews with Swedish teachers, parents, and practitioners to explore key components and teaching methods of school-based abuse prevention programs for 7–12-year-old children with communicative and/or cognitive disabilities. In Phase 1. 3, a rapid review of published literature on signs of abuse in children with disabilities was conducted. The results from the rapid review were socially validated using an international expert panel, thereby contributing to a novel methodological approach.

Chapter 5 will focus on Phase 2, in which guidelines of school-based abuse prevention programs for 7–12-year-old children with communicative and/or cognitive disabilities were constructed. These guidelines are based on the integration of results from the different data sources employed in Phase 1 using the conceptual framework as the basis.

Chapter 6 will focus on Phase 3, which includes exploring the feasibility of the guidelines of school-based abuse prevention programs for 7–12-year-old children with communicative and/or cognitive disabilities, using an online survey and email interviews with three different participant groups. These three chapters should thus be read in conjunction as per the outline shown in Figure 4.1.

Figure 4.1

Three-phase Exploratory Sequential Mixed Methods Design with Current Phase Highlighted



PHASE 1: EXPLORATION PHASE (CHAPTER 4)

Phase 1.1. Literature review: Scoping review of school-based abuse prevention programs for 7–12-year-old children.

Phase 1.2. Qualitative phase: Focus groups and interviews with stakeholders exploring key components and methods of school-based abuse prevention programs for 7–12-year-old children with communicative and/or cognitive disabilities.

Phase 1. 3. Quantitative phase: Rapid review of publications presenting signs of abuse in children with disabilities, followed by social validation of the results by an international expert panel.

Integration of results from Phase 1.1, 1.2 and 1.3

PHASE 2: DEVELOPMENT PHASE (CHAPTER 5)

Development of guidelines for adapting school-based abuse prevention programs for 7–12-year-old children with communicative and/or cognitive disabilities.

PHASE 3: EVALUATION PHASE (CHAPTER 6)

Quantitative and qualitative phase: Online survey and email interviews to evaluate the feasibility and social validity of the guidelines for teachers and principals to guide the adaptations of school-based abuse prevention programs for 7–12-year-old children with communicative and/or cognitive disabilities.

This chapter starts with reiterating the main aim of the research study before focusing on the specific aims of Phase 1. Thereafter, each of Phase 1's three sub-phases are described in detail, namely the scoping review, focus groups and interviews and finally the rapid review with social validation. These three sub-phases were all published as separate studies. This chapter concludes with a summary of the main discussion points of this phase.

4.2. Aims and sub-aims

The main aim for the overall study as well as the main aim and sub-aims for Phase 1 are presented below.

4.2.1. Main aim: Overall study

The main aim of this study is to explore the key components, teaching methods and information that should be included in school-based abuse prevention programs and to subsequently develop and evaluate guidelines for teachers, supported by principals, to guide them in adapting school-based abuse prevention programs for 7–12-year-old children with communicative and/or cognitive disabilities.

4.2.2. Main aim: Phase 1

The overarching purpose of Phase 1 was to explore key components included in school-based abuse prevention programs and the teaching methods used to deliver these programs, as well as to explore signs of abuse in children with disabilities in order to inform the identification of potential victims from this population. Five specific sub-aims were set for this phase of the study.

4.2.3. Sub-aims for Phase 1

i) To identify key components, outcome measures and evaluation methods of school-based abuse prevention programs for 7–12-year-old children by investigating the extant literature on the topic.

ii) To identify key components, teaching methods and adaptations that should be included in a school-based abuse prevention program for 7–12-year-old children, specifically for those with communicative and/or cognitive disabilities by exploring the perceptions of key stakeholders.

iii) To identify the perceived challenges to implementation of a school-based abuse prevention program for 7–12-year-old children with communicative and/or cognitive disabilities as perceived by stakeholders.

iv) To identify the pertinent role of parents of 7–12-year-old children with communicative and/or cognitive disabilities in an abuse prevention program for their children, delivered in the school context.

v) To identify and describe potential signs of abuse in children with disabilities by reviewing the published body of literature on the topic, in order to inform the identification of potential victims of child abuse.

4.3. Phase 1.1: Scoping review of school-based abuse prevention programs for children

In order to address the first sub-aim of this phase, a scoping review was conducted to identify and review published literature on the topic, identify the theory base, core elements, common characteristics, themes, methods, goals, and outcomes of the selected programs in accordance with the conceptual framework of the thesis (Table 3.2).

Several of the following paragraphs were adapted from an excerpt of the pre-print version of "*School-based Abuse Prevention Programs for Children: A Scoping Review*" by Nyberg et al. (2021a) which was published in the International Journal of Disability, Development and Education.

4.3.1. Introduction

Child abuse can have serious long-term physical, psychological, behavioural, societal and economic consequences (Bulik et al., 2001). Primary abuse prevention has been proposed as an important strategy to decrease child abuse (World Health Organization, 2016). These prevention programs are required to address multiple types of abuse and be informed by evidence (Mikton et al., 2016). Furthermore, the United Nations stresses the importance of ensuring that all information provided to children is appropriate, accurate and in an accessible format. Such information must strengthen and empower their competence related to life skills as well as their rights; it must address specific potential risks, and increase their self-protection (e.g., by developing positive relationships with peers and combating bullying) (United Nations, 2011). As they are typically regarded as places of close and continuous contact between children during a life stage when they are vulnerable to abuse, schools are considered to be an optimal place for delivering abuse prevention programs (Johnson, 1994). Teachers play an important role in school-based abuse prevention by providing trusted relationships with the children, making them trusted adults, while also positioning them to implement programs and model non-violent conflict resolutions in their classrooms (Abrahams et al., 1992).

In a Cochrane Library review on school-based programs for preventing child sexual abuse in children aged 5–12 years and adolescents aged 13–18 years (Walsh et al., 2015), it was reported that the included programs were effective in increasing prevention skills and knowledge of concepts of sexual abuse. These programs focused on teaching concepts such as different kinds of touches, safety rules, different types of secrets, who to tell (reporting) and private parts of the body. There was no evidence of any potential harm from participating in any of the programs (Walsh et al., 2015). Brassard and Fiorvanti (2015) found that abuse prevention programs that included active participation, didactic instruction, and group discussions, and that used a variety of methods (e.g., roleplaying, videos, instruction) as well as covered a range of concepts and safety skills, had the best outcomes. Few studies have examined the long-term effects of abuse prevention programs. Finkelhor et al. (1995) evaluated the impact of victimization prevention interventions on the strategies that children used in real-life situations to avoid and deal with at-risk situations. A total of 67% of the children in their study had participated in a school-based abuse prevention program. Children who attended more comprehensive programs received higher scores on a test of knowledge of sexual abuse than children who attended less comprehensive programs or who had not attended any abuse prevention program at all (Finkelhor et al., 1995). The programs were considered more comprehensive if they included at least nine of the following twelve components: knowledge of sexual abuse; bullying; good and bad touch; confusing touch; incest; screaming and yelling to attract attention; telling an adult; abuse is not the child's fault; practicing skills in the classroom; information to take home; a meeting for parents; repetition of the material over more than one day (Finkelhor et al., 1995).

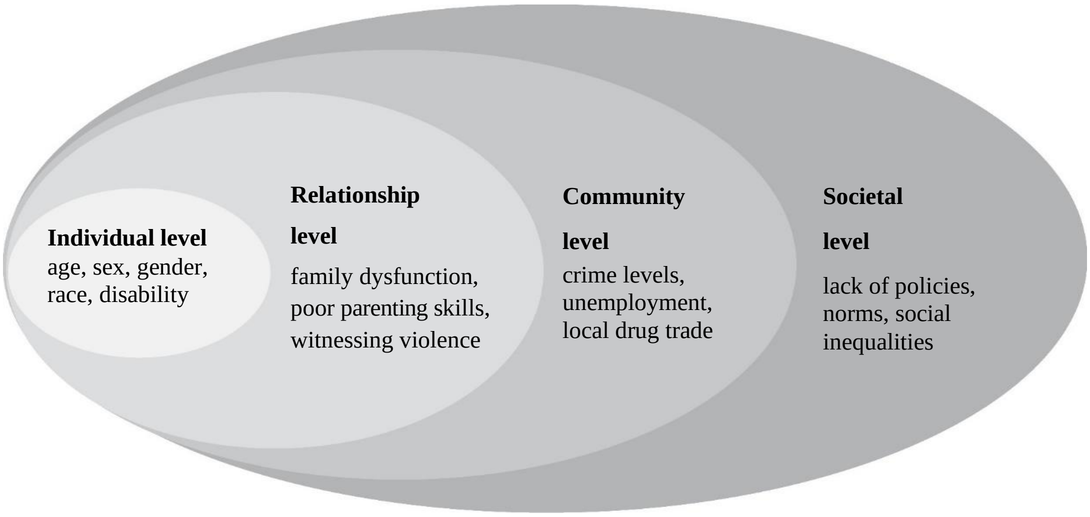
4.3.2. The social-ecological model

Ecological models have increasingly been used in research and practice over the past 30 years (Sallis et al., 2008). These models are centred on the key concept that human behaviour has several different levels of influence and can be used to develop extensive intervention approaches that target all levels (Sallis et al., 2008). For abuse prevention, aspects that are similar to those considered for health promotion need to be considered. In the health field, the social-ecological model is based on several core concepts and principles, namely the following: well-being is influenced by a variety of environmental factors; personal and environmental factors often interact; certain behaviours and roles have an effect on well-being within the community setting; physical and social conditions influence health; interdisciplinary research is vital for developing effective health promotion programs; and interventions need to be developed in response to the unavailability of environmental resources (Stokols, 1996).

Besides using the social-ecological model for developing health promotion interventions, it can also be used to develop abuse prevention programs. The social-ecological model consists of four factors that all influence each other, namely individual factors, relationship factors, community factors and societal factors (Figure 4.2.). In the case of abuse, the model can be used to understand the risk factors for abuse to create programs that effectively operate on all levels and address the root causes of the problem (World Health Organization, 2016). Individual risk factors include, among others, age, sex, gender, race and disability (World Health Organization, 2016). Children with communicative and cognitive disabilities are at increased risk due to their difficulties with communicating and understanding spoken language. Relationship risk factors include dysfunction in the family, poor parenting skills and witnessing violence in the home (World Health Organization, 2016). Community-level risk factors are aspects such as high crime levels, unemployment and local drug trade (World Health Organization, 2016). Society-level risk factors include norms where violence is accepted, where health and social policies are absent or not implemented, and where social inequalities exist (World Health Organization, 2016). The social-ecological model can therefore be used effectively to understand the range of factors that influence the child’s risk of becoming a victim of abuse, and to understand the factors that might protect them from becoming or remaining victims.

Figure 4.2

The Social Ecological Model



4.3.3. The present review

The current scoping review aims to provide an overview of the available research that has been conducted on school-based abuse prevention programs for children 7–12 years old. The focus is on programs that teach prevention of more than one kind of abuse (e.g., sexual, and physical abuse or emotional abuse and neglect) to the children themselves. The review aims to map out the specific components of the programs, the methods of delivery, the measurements used, and the results obtained. To our knowledge, this is the first scoping review with this specific purpose.

The results from the scoping review will ultimately be used to develop a school-based abuse prevention program for children with communicative and/or cognitive disabilities. Since very little research has been published on abuse prevention programs developed for children with communicative and/or cognitive disabilities, disability was not one of the inclusion criteria.

4.3.4. Materials and methods

This review followed the recommendations and guidelines for scoping reviews as proposed by Arksey and O'Malley (2005) and The Joanna Briggs Institute (2015). A scoping review was deemed appropriate for this study, because the purpose was to map out existing research articles on school-based abuse prevention programs and to describe these, regardless of study design and methodology used (Arksey & O'Malley, 2005).

4.3.4.1. Search process

The scoping review included a search of several bibliographic databases, hand searches of specific journals, and the scanning of reference lists of the included articles. The specific search terms were developed by the student and the supervisors together with a research librarian, who conducted the literature search. Several trial searches were conducted by the research librarian and the first author by using different search terms in different combinations, and they then reviewed the results of the searches. The search terms had been piloted in a previous search and were revised according to the findings of the pilot study.

The final search terms used for the PubMed search were the following: Boy OR Boys OR Child OR Children OR Childhood OR Girl OR Girls OR Young kids OR Youngster OR Young person OR Young people AND School* OR Schools (Mesh) AND Abuse* OR Assault* OR Cruelty OR Ill-treat* OR Mistreat* OR Maltreat* OR Molest* OR Oppression OR Child Abuse (Mesh) AND Program* OR Intervention AND Prevention OR Preventing OR Evaluation OR Program evaluation (Mesh) OR School Health Services (Mesh). The same search terms or variations to suit the database in question, were used in all searches. Five databases were searched: PubMed, CINAHL, The Cochrane Library, ERIC and PSYCInfo. The search was limited to the period January 1989 to December 2018. The 1989 starting point was selected as the Convention on the Rights of the Child (United Nations, 1989) was published in 1989, which could have resulted in an increase in the number of abuse prevention efforts. A strict focus was kept on published research articles and therefore grey literature was not searched. In total, 2683 articles were found and after the duplicates were removed, 2047 remained, as shown in the PRIMSA (Preferred Reporting Items for Systematic Review and Meta-Analyses) flowchart in Figure 4.3.

In addition to the database search, the journals *Child Abuse and Neglect* (January 1989 – December 2018) and *Child Abuse* (1996–2018) were hand searched. The hand search produced six articles (Figure 4.3.). The reference lists of the articles that were included in the scoping review were also hand searched, but this search produced no new results. The articles that were obtained through the database search and the hand search were imported into RAYYAN (https://rayyan.qcri.org), a web application for creating and screening systematic reviews, which allows researchers to collaborate on reviews and screen papers independently.

4.3.4.2. Inclusion and exclusion criteria

Inclusion and exclusion criteria were strictly adhered to, see Table 4.1. The criteria were developed using the PIO – Population, Intervention and Outcome – system (Booth et al., 2000). To distinguish between other kinds of abuse programs, for example those aimed specifically at parents or teachers to decrease their abuse of children (e.g., the ACT Training Program (Guttman & Mowder, 2005) and the Good School Toolkit (Devries et al., 2018)), the concept of child involvement in the program was vital. The program had to be delivered in a school setting to children between 7 and 12 years of age and at least teach the children about two forms of abuse, for example physical and sexual abuse, or emotional abuse and neglect.

Articles that labelled the intervention as only a child sexual abuse prevention program were excluded from the review, as several reviews had already been conducted on school- based child sexual abuse programs, including the previously mentioned Cochrane review by Walsh et al. (2015). Articles were included if children who participated in the program were between 7 and 12 years of age, however not all children in the program had to be within that age range. For example, an article could include children who were 7 years old as well as children in other age groups. Effects on children’s self-esteem, safety knowledge and skills or empowerment had to be presented for the article to be included in this scoping review.

Table 4.1

Inclusion and Exclusion Criteria for Stage 1

PIO	Inclusion criteria	Exclusion criteria
Population	Children 7 to 12 years old	Focus only on children younger than 7 or only older than 12
Intervention	School-based abuse prevention program Training/components directed at children Low, middle, and high-income settings Address more than one kind of abuse, i.e., physical abuse and verbal abuse Focus on abuse perpetrated by adults (adults abusing children)	Abuse prevention program in another setting, i.e., community centre, nurses office Aimed only at adults (i.e., teachers, parents) Focus only about one kind of abuse, i.e., child sexual abuse Directed at child-to-child abuse, such as bullying
Outcome	Self-esteem, safety knowledge and skills	

4.3.4.3. Screening

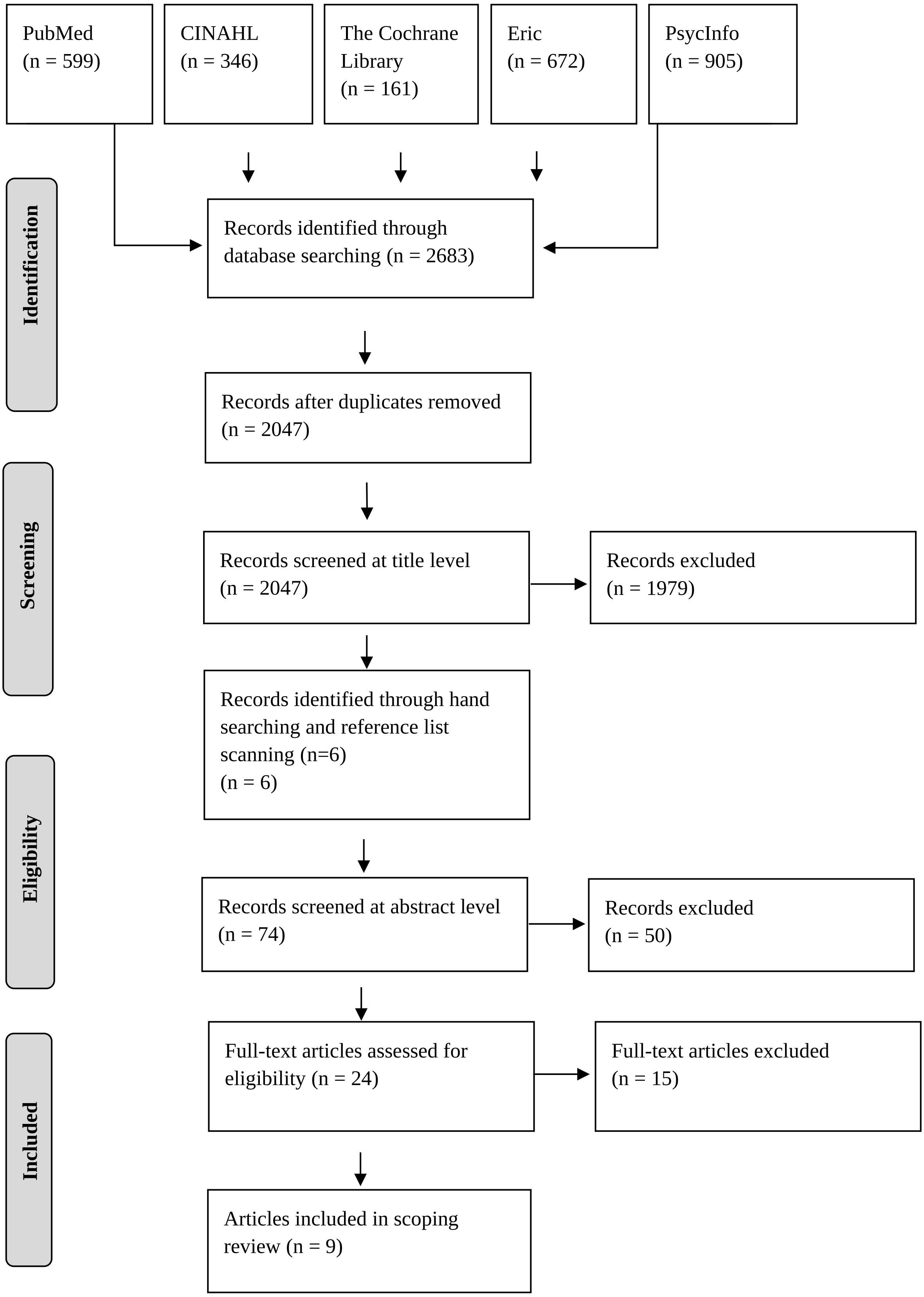
After the database search, which resulted in 2047 articles (2683 articles before duplicates were removed), the articles were screened in several phases. In the first phase, the articles were screened on a title level and 1979 articles were excluded. The screening resulted in 68 articles being included for abstract screening. Another six articles were included from the hand search and reference scanning, which resulted in a total of 74 articles. The articles were subsequently screened by the first and third author independently on an abstract level for suitability and relevance using the PIO (Population, Intervention and Outcome criteria. Any disagreements were discussed and resolved between the three authors. Twenty-four articles were included for full-text screening, which was done by the first, second and third author independently. All disagreements were discussed and resolved. Nine articles were included in the scoping review. Fifteen articles were excluded because they did not describe a specific program (n = 2), used the wrong outcome measure (e.g., disclosure rates, reduction in abuse from teachers to students) (n = 10), were not child focused (n = 1), focused only on child sexual abuse (n = 1) or were an opinion piece (n = 1). The search and selection processes are presented in the PRISMA flow chart shown in Figure 4.3.

4.3.4.4. Data extraction

A preliminary version of the data extraction tool was made using the suggestions from The Joanna Briggs Institute (2015). The data extraction tool was extensive and allowed for detailed information about the articles to be completed, including information about the components and length of the programs, the research design and measurements used, and the outcomes of the article. The preliminary version was presented to and critiqued by an expert panel and revisions were made accordingly. A pilot test of the data extraction tool was done using three articles that had been included for full-text screening, and revisions were made accordingly. Data were extracted by the first, second and third author independently and compared and combined to minimise errors and to ensure that rich data were extracted from the articles Figure 4.3.

Figure 4.3

PRISMA (Preferred Reporting Items for Systematic Review and Meta-Analyses) Flowchart of Search process and Article Selection



4.3.5. Results

Table 4.2. shows an overview of the nine programs that were included in the review. Most of the programs, eight out of nine, originated in high-income countries, with four of these originating from the United States. Only one of the programs came from a low- or middle-income country, Sri Lanka. The articles were published between 1992 and 2018. Four of the articles included children only as participants and five included a combination of children, parents and/or teachers or other school staff. All programs were taught to children by adults. The duration of the programs varied from one session to twenty sessions and from one week to 12 weeks. A positive result, as noted in Table 4.2., signifies that the outcomes of the programs were positive.

Apart from the mapping of the programs, additional analyses were conducted to address the key components and frequency of those components (Figure 4.4.), the methods of instruction and frequency of those methods (Figure 4.5.), the measurements used and the outcomes of the articles. Figure 4.4. and Figure 4.5. include the components and methods of instruction that were used in more than one of the programs. They also report the results in terms of the eight programs that are presented in the nine articles included in this scoping review – one program (Learn to BE SAFE with Emmy™) is used in two articles. Components or methods of delivery that were used in just one of the programs are not presented in Figure 4.4. and Figure 4.5. A decision to include all articles, irrespective of research quality, was made so as not to reduce the number of articles further.

4.3.5.1. Outcome measures

The nine articles that were included in the review included 4135 children, 1841 parents, 16 teachers and two school counsellors.

i) Safety Skills

All the programs measured the concept of safety and/or safety skills. White et al. (2018) and Dale et al. (2016) used several instruments to measure children's self-report of safety skills. For example, they used the Protective Behaviours Questionnaire (ProBeQ), which includes items measuring important protective components such as private and public body parts and unsafe secrets. Dale et al. (2016) also used the Application of Protective Behaviours Test (APBT) (White et al., (2018) used the APBT-revised), which presents children with pictures of four scenarios and asks how they would engage in the situation – providing one safe and three unsafe options for each situation. White et al., (2018) included The Observed Protective Behaviours Test (OPBT), which is a 2-part in-vivo situation designed to assess children's ability to implement safety skills. In addition to the child-reported measurements, parents were asked to rate children's understanding of protective behaviours using the Parent Protective Behaviours Checklist (PPBC).

Lam et al. (2018) used a child's sense of safety as the outcome measure and obtained results through asking parents to complete a custom-designed questionnaire, including questions about program exposure and perceptions of program outcomes. Moreno-Manso et al. (2014) likewise developed a custom-designed questionnaire that included several hypothetical situations of abuse, based on items concerning knowledge of different kinds of abuse, exploitation and children's rights. Leihua (1997) used interviews with children to assess safety skills and perceived competence regarding personal safety. Similar to Leihua, Warden et al. (1997) used interviews with black-and-white drawings depicting different safety situations and asked children to make decisions about safety by judging if a situation was dangerous, safe or uncertain. The answers were rated by a panel of experts using a five-point scale of how safe a child would be, depending on their response to that situation. Oldfield et al. (1996) used The Children's Knowledge of Abuse Questionnaire-Revised (CKAQ), which assesses children’s knowledge of abuse prevention concepts. Dhooper and Schneider (1995) constructed a questionnaire that included questions about children’s general understanding of child abuse, their ability to discriminate between discipline and child abuse, the difference between appropriate and inappropriate touch, and a proper response to situations of physical and sexual abuse.

Kraizer (1991) included several instruments to measure safety skills and developed the Children Need to Know Knowledge/Attitude Test that measures cognitive awareness, understanding and attitudes towards issues that she concluded to be generally associated with risk. Simulations and roleplay were used to measure actual behavioural change. Kraizer (1991) also subjected 16 children to behavioural simulations to assess their real-life response to potentially dangerous situations. Parents were interviewed by telephone to determine the actual rates and patterns of self-care of the children included in the article.

Table 4.2

Overview of Programs in Chronological Order

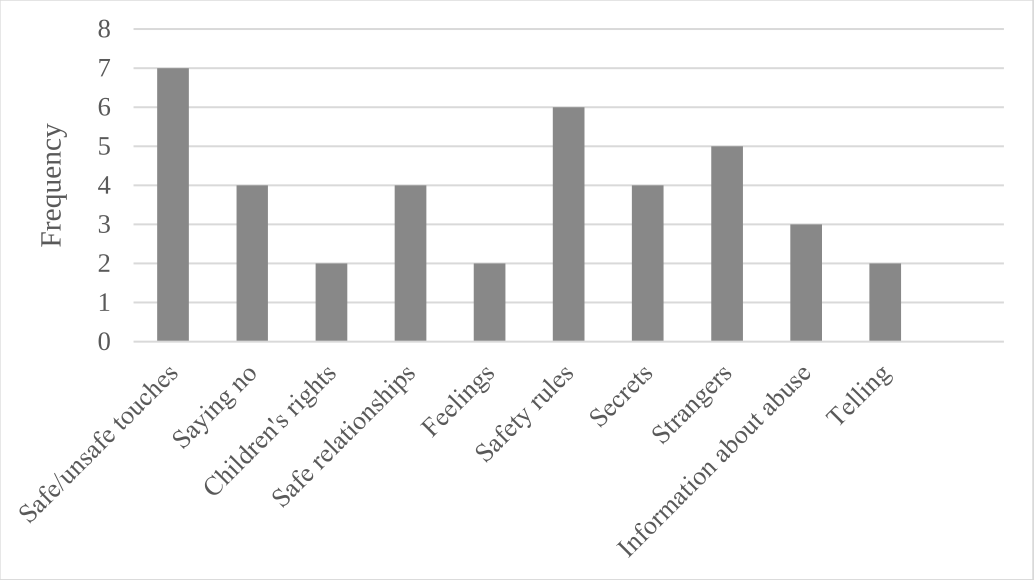
Authors	Program	Aim	Research design	Participants	Key components	Duration	Method of delivery	Results
White et al., (2018)	Learn to BE SAFE With Emmy ™	To build resilience and coping skills. To teach children prevention strategies	Cluster-randomized controlled trial with pretest-posttest design including 6-month follow-up	Children 5-7 yrs.: n= 611 Parents: n= 357	Secrets Strangers Body parts Safe relationships Safe/unsafe touches Feelings Safety rules Personal space Safe/unsafe situations	5 weeks (once per week)	Roleplay Discussion Modelling Skills practice Simulated scenarios	Positive
Lam et al., (2018)	Be Safe	To prevent sexual abuse and to teach safety skills related to other kinds of abuse	Cross sectional retrospective approach	Children: 5–9 yrs.: number not disclosed Parents: n= 835	Safe/unsafe touches Children’s rights Saying no Safe relationships Safety rules Adults’ responsibilities to protect children	10–12 weeks, 10-20 min sessions	Songs/music Role play Storytelling Posters Games Lesson cards Booklets Bookmarks Leaflets for parents	Positive
Dale et al., (2016)	Learn to BE SAFE With Emmy ™	To build resilience and coping skills. To teach children prevention strategies	Randomized controlled trial with pretest-posttest design and 6-month follow-up	Children 5–7 yrs.: n = 245 Parents, T1: n = 117 T2: n = 85 Teachers: n = 6	Secrets Strangers Body parts Safe relationships Safe/unsafe touches Feelings Safety rules Personal space Safe/unsafe situations	5 weeks (once per week)	Role play Discussion Modelling Skills practice Simulated scenarios	Positive

Authors	Program	Aim	Research design	Participants	Key components	Duration	Method of delivery	Results
Moreno-Manso et al. (2014)	The prevention program	To improve children’s capacity to handle threatening situations. Includes physical abuse, sexual abuse, emotional abuse and neglect	Pretest-posttest design with control group and 6-month follow-up	Children 9-10 yrs.: n= 317	Children’s rights Feelings Safety rules Information about abuse Empathy Healthy eating and basic needs Distinguishing between respect and extreme obedience and presents and bribes	12 weeks with one two-hour session per week	Songs/music Role play Storytelling Drawing/painting Tutorial action Physical exercises Clay	Positive
Leihua, (1997)	Talking about touching	To teach personal safety skills	Pretest-posttest design without random assignation	Children 3-9 yrs.: n = 133 Teachers n = 10 School counsellors n = 2	Safe/unsafe touches Safety rules Strangers Assertiveness Safety rules for other situations (e.g., riding in a car and responding to a fire)	6-8 weeks, 10-20-minute sessions	Work sheets Video Audio Discussion Posters Skills practice Home activities	Positive
Warden et al., (1997)	Kidscape	To increase children's ability to deal with being bullied; being approached by a stranger; receiving inappropriate intimacy (with secrecy).	Pretest- posttest design with 2-month follow-up.	Children 6 and 10 yrs.: n = 120	Safe/unsafe touches Saying no Safety rules Secrets Strangers Coping with bullies	Weeks 10-20 sessions	Work sheets Role play Storytelling Discussion Drawing/painting Posters Story writing	Mixed

Authors	Program	Aim	Research design	Participants	Key components	Duration	Method of delivery	Results
Oldfield et al. (1996)	Project Trust/ TOUCH	To understand sexual abuse (mainly), but also physical abuse and other related topics	Posttest only, control group design with random assignation	Children 6-12 yrs.: n= 1269.	Safe/unsafe touches Saying no Safe relationships Secrets Strangers Safe/unsafe adults The right to question touch	One session, 45-60 minutes	Play performed by trained high-school students	Positive
Dhooper & Schneider (1995)	School-Based Child Abuse Prevention Program	To increase children's understanding and recognition of abuse (physical and sexual) and to interrupt or avoid abusive situations	Pretest-posttest design with control group, but without random assignation	Children 8-11 yrs.: n= 796	Safe/unsafe touches Information about abuse Telling Discriminating between abuse and normal discipline	One session	Puppet show Workbooks Songs/music Skits (a short comedy sketch) Question and answers session Writing letters to the puppets	Positive
Kraizer (1991)	The Safe Child Program	To teach children about sexual abuse, prevention of abuse and abduction by strangers, prevention of physical and emotional abuse and safety for children in self-care	Pretest-posttest design with experimental and control group, using two intervention periods	Children 3-10 yr: n= 644 Parents: n= 447 Teachers: not reported	Safe/unsafe touches Saying no Safety rules Secrets Strangers Information about abuse Telling about abuse	5-10 days	Videos Role play	Positive

Figure 4.4

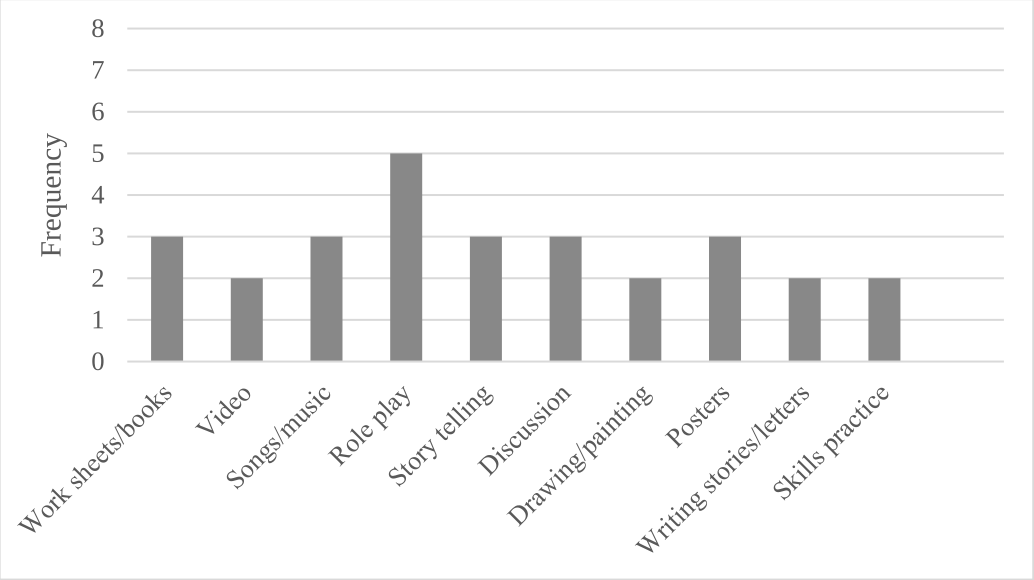
Frequency of Key Components Included in the Eight Programs (n = 9)



Note: Components that are only used in one program are not shown in this figure

Figure 4.5

Frequency of Instruction Methods Employed in the Eight Programs (n = 9)



Note: Methods that are only used in one program are not shown in this figure

ii) Anxiety, self-esteem and locus of control

Five articles used instruments to measure anxiety, including the Revised Children's Manifest Anxiety Scale 2nd Edition (RCMAS-2 Short Form) (Dale et al., 2016; White et al., 2018). Oldfield et al. (1996) used an older version of the same instrument, the Revised Children's Manifest Anxiety Scale (RCMAS) and The State-Trait Anxiety Inventory for Children (STAI- CH). Leihua (1997) assessed anxiety as part of the pre-test post-test interviews that were conducted to assess safety skills. Only one article (Kraizer, 1991) measured self-esteem by using Battle's Culture-Free Self-Esteem Inventory, and locus of control by using the Children's Nowicki-Strickland Internal-External Locus of Control Inventory.

iii) Program satisfaction/evaluation

Some of the articles measured program satisfaction, usually with questionnaires that had been tailor-made for the specific article. White et al. (2018) and Dale et al. (2016) measured parental satisfaction with the program, and Dale et al. (2016) also measured teacher satisfaction. Leihua (1997) let teachers complete a 6-point Likert scale to assess each lesson in terms of ease of use; importance for children; effectiveness in teaching concepts and skills; utility of supplementary activities; comfort level with teaching lesson; children's comfort level; interest, and comprehension. In the article by Warden et al. (1997), teachers completed a follow-up questionnaire designed to assess possible differences in the presentation of the Kidscape program. The questionnaire included questions on teachers' preparation and training prior to Kidscape; training in delivering Kidscape; ease or unease with topic; timescale of the teaching of the program; teaching methods used; additional training on child safety, and children's responses to the program. At the end of the final post-test roleplay, Kraizer (1991) interviewed each child about their views of the program. Teachers completed the Teacher

Knowledge/ Attitudes questionnaire, which included 19 items assessing understanding, awareness and attitudes about child abuse. They also completed a demographics sheet that was used to determine differences between teachers' responses to the training program and if their difference in skills affected children's results.

4.3.5.2. Outcomes

Eight articles reported positive results and one article reported mixed results. White et al. (2018) and Dale et al. (2016) both reported positive results, concluding that Learn to BE SAFE with Emmy™ seems to be an effective intervention for increasing children's knowledge of protective skills and behaviours. The results were maintained at follow-up and children's anxiety did not increase as a result of their participation in the program. Children's confidence in disclosure was reported to be increased in the article by White et al. (2018). There were no significant differences between the experimental and control groups in terms of application of protective behaviours in the article by Dale et al. (2016). Parents (Dale et al., 2016; White et al., 2018) and teachers (Dale et al., 2016) were satisfied with the program. Results in the article by Lam et al. (2018) were positive, and an increase in exposure to the program was associated with improvements in the perceived safety of the child in school as well as in the community. However, exposure was relatively low and low correlations were found.

Moreno-Manso et al. (2014) found that children increased their knowledge of abuse and safety skills and that much of the results were maintained at the 6-month follow-up. They then concluded that stories proved to be an effective method of instruction and that schools must be involved in primary prevention.

A significant improvement of children's safety knowledge and skills for all grades was reported by Leihua (1997). The children did not experience increased anxiety due to their participation in the program and teachers were satisfied with the program. Warden et al. (1997) reported mixed results, as they found that although children in the experimental group provided more cautious and thoughtful responses to safety situations after training, similar changes were seen in the control group. The authors' hypothesised that this could be due to the evaluation process that acted as a priming effect (Molden, 2014), since the number of correct responses increased further from post-test to the follow-up two months later. The results from the teacher questionnaire also showed that the program had been taught differently by different teachers (Warden et al., 1997). Oldfield et al. (1996) found that children in the experimental group showed significantly greater knowledge of abuse prevention information, including concepts that are difficult to acquire (e.g., saying 'no' to persons of authority), than did children in the control group. This knowledge was retained at follow-up. There was a higher incidence of disclosure of abuse in the experimental group than in the control group, but there were no differences in anxiety levels between the experimental and the control group.

In the article by Dhooper and Schneider (1995), children who attended the prevention program had a significantly higher understanding of child abuse than those who did not attend, and their results increased from pre-test to post-test. The control group also showed improvement from pre-test to post-test, but the increase was smaller. Younger children learned more than older children – an effect that the authors suggest might be because the older children already had some knowledge of abuse. Children trained in smaller groups benefited more, with 40 being the optimum group size. Kraizer (1991) reported that the element of the program identified as being primarily responsible for producing the desired prevention skills was classroom roleplay following the video demonstrations. There were no negative side-effects of the program and fear levels of the children were reduced by 10%. A predictive correlation between self-esteem and behavioural change was associated with a reduction in risk of abuse. Explicit information about child abuse was not necessary to achieve the desired level of prevention skills. Preschool and kindergarten age children learned the skills most effectively. The skill of individual teachers did not affect the results of the children and results were retained at 6-month follow-up. Two out of 16 children performed well on the telephone part of the stranger simulation, but none of the children performed well on the simulated package delivery activity.

4.3.6. Discussion

The aim of the present scoping review was to review school-based abuse prevention programs for children 7–12 years of age. To be included in the review, the programs had to teach at least two different kinds of abuse, be directed at children, and include safety knowledge and skills, empowerment or self-esteem as the outcome. After applying the inclusion and exclusion criteria to the potential articles, only nine articles remained. This shows that even though many abuse prevention programs have been developed for this particular age group, most focus on sexual abuse and only a few teach about abuse in a broader sense, such as emotional abuse and neglect. The abuse prevention programs included in this scoping review all received positive results, except for one program (Kidscape) that reported mixed results. The scientific quality of the evaluations varied greatly, from randomised-controlled trials with pre-test–post-test designs and 6-month follow-up, to post-test-only designs. All of the included articles used safety skills and knowledge as an outcome measure. Only one of the articles measured self-esteem or resilience (Kraizer, 1991) although some programs (e.g., Learn to BE SAFE with Emmy^{TM}) focused on these qualities when teaching children skills. Many programs included the same key components, for example safe/unsafe touches, safety rules, saying no, secrets and strangers. These components are also common in school-based child sexual abuse prevention programs (Walsh et al., 2015). Active participation by the children (such as roleplay, discussions, skills practice and work sheets) was used in several of the programs and has been highlighted as successful methods of instruction (Brassard & Fiorvanti, 2015).

Even though the articles that were included reported positive results in terms of gained safety skills in children as a result of participation in the program, the question remains as to whether the knowledge gained by the children was retained over longer periods of time. Most articles included some form of follow-up, but none of them tracked the results for longer than six months. The included articles all operated on the individual and relationship level of the social-ecological model. Few articles had a holistic focus and included teacher or parent training, even though articles like Moreno-Manso et al. (2014) suggested that future research need to include parent involvement. The social-ecological model assumes that all levels influence and relate to each other, and therefore an extensive abuse prevention program would need to operate on all levels – including the community and societal levels – to further strengthen the program (Figure 4.2). None of the published programs had the latter two as focus. None of the articles in this scoping review included children with disabilities. This is concerning, considering that children with disabilities are not only three to five times more likely to be victims of violence and abuse than children without disabilities, but they are also more likely to be repeat victims of violence (Fluke et al., 2008; Jones et al., 2012; Krnjacki et al., 2018). Children with disabilities may well lack the skills to protect themselves from abuse and might not even be aware that they are being victimised, due to not knowing or understanding their rights (Wilczynski et al., 2015). They may never have received instructions on how to protect themselves against abuse, making it difficult to report possible abuse. Moreover, they could well have communication difficulties (Wilczynski et al., 2015).

Helton et al. (2017) found that cognitive disabilities were associated with a risk of sexual abuse and therefore prevention efforts need to be adapted to cater for specific language and communication deficits. Other studies on abuse prevention programs such as the IMPACT: Ability (Dryden et al., 2017) (excluded from this review because it is aimed at teenagers) and the Good School Toolkit (Devries et al., 2018) (excluded from this review because of the outcome measures) have successfully included children and youths with disabilities. Wilczynski et al. (2015) propose that sexuality education for children and youths with disabilities have to include teaching them how to recognise abuse, how to say no to a perpetrator, how to get away from dangerous situations and how to disclose abuse in an appropriate way. Similar tactics need to be considered for both sexual abuse and other kinds of abuse such as physical or emotional abuse. According to Lund (2011), there is some evidence that both cognitive and behavioural interventions could be effective in teaching persons with intellectual disabilities safety skills. However, the published studies on this topic are few and have small sample sizes, leading to poor generalisability (Lund, 2011). In an article by Hasan et al. (2014) it was found that women with disabilities have low help-seeking behaviour, making prevention very important. To make abuse prevention programs available for children with communicative and/or cognitive disabilities, these programs need to be accessible and understandable. Abuse prevention programs that are used for adults with intellectual disabilities often include some sort of simulation or practising of skills in a hands-on way (Dryden et al., 2017; Lund, 2011). The importance of adaptation of abuse prevention programs in terms of language and communication for persons with cognitive disabilities has also been noted by Helton et al. (2017). There is an urgent need for abuse prevention programs developed or adapted for children with disabilities, especially for those with communicative and/or cognitive disabilities.

4.3.7. Limitations of the present review

Although this review aimed to conduct a thorough review of articles on school-based abuse prevention programs for children 7–12 years old, the inclusion criteria that were used (i.e., articles that address more than one kind of abuse) could have resulted in the exclusion of some potentially relevant program. For example, articles that focused on sexual abuse but also included other prevention concepts that were not clearly alluded to in the abstract, could have been excluded. The review was also limited in terms of the search terms used. After several trial searches, the term ‘violence’ was excluded because it did not provide relevant results. To avoid excluding potentially relevant articles in this way, the first author screened the articles excluded after the trial search on a title level. Moreover, the articles included in this review focused on a linear view of causality, whereas the social-ecological model also looks at the process and the interaction between the different levels, assuming a more complex systemic relationship. This explains why none of the articles included a measurement for long-term improvement of the children’s quality of life and why the results might not necessarily be generalisable and sustainable in real-world situations. Lastly, the outcomes of the review had to include children’s self-esteem, safety skills and knowledge or empowerment (as per the inclusion criteria), which also narrowed the number of articles. These outcome measures were chosen to reflect the more long-term benefits of the programs, as opposed to only looking at the short-term gains such as satisfaction with or enjoyment of a program.

4.3.8. Suggestions for further research

As demonstrated by the results that emerged from this review, research on school-based abuse prevention programs for children 7–12 years old that include several forms of abuse and measure self-esteem, safety skills and knowledge or empowerment is limited. More research is needed in terms of successful program components, teaching methods and the success factors that can be pinpointed for abuse prevention programs to achieve positive outcomes. The use of several methods of instruction also have to be incorporated into abuse prevention programs, as it has been identified as a success factor (Brassard & Fiorvanti, 2015). Long-term follow-up beyond six months post-test is lacking for abuse prevention programs in general, including the articles in this review. This issue must be addressed in future research to draw conclusions about the long-term effects of participation in abuse prevention programs. Research is severely lacking on inclusive abuse prevention programs for school-aged children with disabilities, even though they are particularly vulnerable to being victims of abuse. It is possible that children with disabilities are among the participants in the articles included in this scoping review, but their disabilities have not been identified and described. This ought to be considered when planning research studies on school-based abuse prevention programs. Future research need to develop or adapt abuse prevention programs so that all children, including children with disabilities, can participate in them. Research also ought to provide for data collection methods that allow children with disabilities to participate in surveys or interviews.

This is the end of the excerpt of the pre-print version of "*School-based Abuse Prevention Programs for Children: A Scoping Review*" by Nyberg et al. (2021a).

4.3.9. Conclusion of Phase 1.1

Phase 1.1 of the thesis focused on exploring key components, outcome measures and evaluation methods of school-based abuse prevention programs for 7–12-year-old children in the published literature.

The nine articles that met the stringent inclusion criteria and were included in the scoping review all included safety skills as an outcome measure and the majority of the studies reported positive results. Safety skills and the demonstration of safety skills could be included as a suggested outcome measure in the guidelines in the present study. However, the way in which safety skills are evaluated needs to be adjusted to suit children with communicative and/or cognitive disabilities. Furthermore, program satisfaction was measured in several studies, and it reiterated that satisfaction measures can provide valuable insights to continuous adaptations needed in an abuse prevention program for children with communicative and/or cognitive disabilities.

Key components and methods varied across studies, but some components and methods were included in several studies, such as safe/unsafe touches, good and bad secrets, strangers, role play and discussion. As similar components are used in many programs with successful outcomes, they could also be valuable in guidelines of school-based abuse prevention programs aimed at children with communicative and/or cognitive disabilities. Additionally, other specific components and methods to address the lives and unique situations of this population should also be included, such as adapting teaching methods and materials used in such programs. Finally, the fact that few programs were found that teach children about several different kinds of abuse, demonstrates the need for providing broad knowledge about abuse to children with communicative and/or cognitive disabilities. The programs included in the study focused on efforts situated at the individual and relationship (local) level of the social-ecological model and none focused on the broader aspects of the community level or the social level. Thus, none of the programs included teacher training or community collaboration.

The social-ecological model (Stokols, 1996) was used to discuss the risks relating to child abuse as well as the results of this phase. After reviewing the results of Phase 1.1, a decision was made to use the BEM as part of the theoretical framework of the study. The BEM was chosen as it is a similar ecological model but with an increased focus on learning principles (Hovell et al., 2009; Richard et al., 2011) which was seen as vital for this study given the focus on the school context.

4.4. Phase 1. 2: School-based abuse prevention programs for children with disability: A qualitative study of components and methods

In order to address sub-aims ii), iii), and iv), a qualitative study of components and methods linked to school-based abuse prevention programs for children with communicative and/or cognitive disabilities was conducted to identify the target populations' needs, risk behaviours and situations and the differences between the risk factors and protective factors between the original and the target population, identify the capacity in the community and organization around this population and conduct a needs assessment with the stakeholders in keeping with the conceptual framework. Additionally, the relevance of characteristics, themes, methods, goals and outcomes of school-based abuse prevention programs was explored, and stakeholders were consulted with regards to the specific components that were needed based on the needs of the target population, the level of adaptation that was needed as well as strategies linked to implementation (Table 3.2).

Several of the following paragraphs were adapted from an excerpt of the pre-print version of "*School-based abuse prevention programs for children with disability: A qualitative study of components and methods*" by Nyberg et al. (2021b) which was published in the Australasian Journal of Special and Inclusive Education (Appendix C1). Permission was obtained from the publisher to include this paper as part of the present study (Appendix C2).

4.4.1. Introduction

Child abuse is a pervasive global challenge affecting all children, irrespective of age, sex, race, religion, or ability. The World Health Organization (1999) defines it as

> *"all forms of physical and/or emotional ill-treatment, sexual abuse, neglect or negligent treatment or commercial or other exploitation, resulting in actual or potential harm to the child's health, survival, development or dignity in the context of a relationship of responsibility, trust or power."* (pp. 15)

Children with developmental disabilities (e.g., cerebral palsy, Down syndrome, Autism Spectrum Disorder) are three to five times more likely of being victims of abuse than their typically developing peers (Jones et al., 2012), and are over-represented in involvement with child protection services for all kinds of abuse (Dion et al., 2018). They are also more likely to be victims of more serious and more frequent sexual abuse (Soylu et al., 2013).

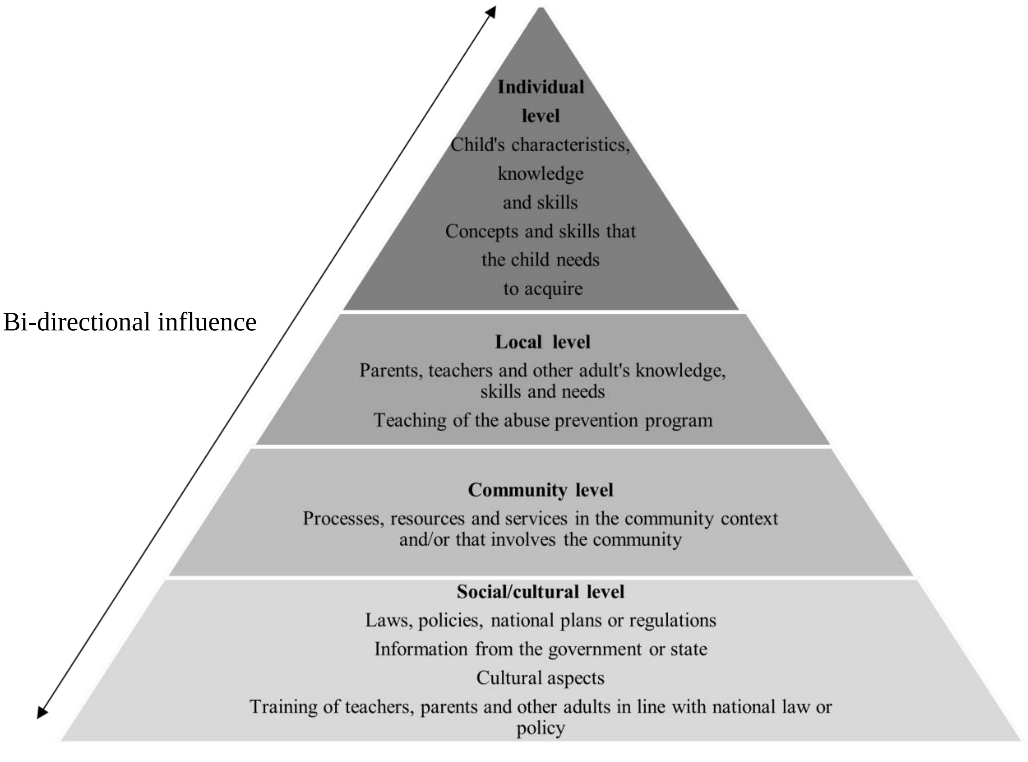
These children may also experience complex communication needs, which manifest as difficulties with producing and/or understanding spoken language. Although no large epidemiological studies have been conducted on children with complex communication needs, smaller studies suggest that they are particularly vulnerable as they cannot rely on traditional communication modes, such as speech for help (Devries et al., 2018). Augmentative and alternative communication (AAC) offers many of these children an effective way of interaction, which could include disclosing abuse. AAC includes all forms of communication that are used to express and complement expression of thoughts, emotions and needs (Beukelman & Light, 2020). It can also be used to enhance understanding (i.e., strengthening receptive language) and for creating structure, e.g., when using visual schedules. Many children with complex communication needs are students in special schools (also known as "schools for specific purposes" or "specialised schools"). The definition of special schools differs between countries, but in this study special schools refer to segregated schools - that can be situated on the same premises as mainstream schools – specifically for children with intellectual disabilities.

Abuse prevention is an important strategy to decrease child abuse (World Health Organization, 2016). However, there appears to be a lack of research on school-based abuse prevention programs, that address different types of abuse aimed at both children with and without disabilities. All children need access to appropriate, accurate and accessible information that is informed by evidence about life-skills, rights, specific risks (e.g., the Internet and social media) and self-protection (e.g., developing positive peer relationships) (Mikton et al., 2016; United Nations, 2011). Abuse prevention programs should thus be developed to suit the needs of all children, regardless of (dis)abilities, by employing the seven universal design principles, namely: equitable use, flexibility in use, simple and intuitive use, perceptible information, tolerance for error, low physical effort and size and space for use (Johnson & Muzata, 2019).

The Behavioural Ecological Model (BEM) holds promise for unpacking what a school-based prevention program should entail. It states that physiological responses can be learned (respondent conditioning) and can be reinforced or extinguished depending on contingencies of past responses (operant conditioning). Furthermore, it explains that learning occurs in a social context where the person, environment and behaviour interacts and influence each other (social cognitive theory) (Hovell et al., 2009). The BEM assumes that behaviour is shaped through four levels of influence (individual, local, community and social/cultural level) that interact, see Figure 4.6. It has been used successfully for developing health promotion interventions and has also been adapted for public health research relating to tobacco use (Rovniak et al., 2006), research on sustainability practices of universities (Brennan et al., 2015) and in developing anti-bullying school-based interventions (Dresler-Hawke & Whitehead, 2009). In the latter study, the importance of involvement of individuals and institutions from all levels of the model is emphasized in order to decrease bullying (Dresler-Hawke & Whitehead, 2009). These principles can also be assumed for abuse prevention, which is similar to bullying in that it includes emotional or physical abuse. Therefore, the BEM could provide a framework for the current study.

Figure 4.6

The Behavioural Ecological Model for School-based Abuse Prevention Programs



Source: Adapted from Hovell et al. (2002)

On the one hand, there is a paucity on abuse prevention programs that have been developed for children with disabilities (Nyberg et al., 2021a). On the other hand, established abuse prevention programs developed for children without disabilities, such as Staying Safe with Emmy and Friends (Dale et al., 2016; White et al., 2018), are not adapted to the specific needs of children with communicative and/or intellectual disabilities. Furthermore, the specific components taught in these programs might differ according to the child’s (dis)ability and specific needs. For example, children who are in a wheelchair may be more exposed to potentially abusive situations while visiting the bathroom or showering, while children with challenging behaviour might be exposed to abuse as a response to their own problem behaviour. Not only have abuse prevention programs specifically aimed at children with disabilities thus been under-researched, but research on adapting existing programs to better fit the needs of children with communicative and/or intellectual disabilities is scant.

The aim of this study is therefore to explore the views of three stakeholder groups, namely teachers in special education, practitioners working with children with disabilities who had been victims of abuse, and parents of children with communicative and/or intellectual disabilities, regarding the key components and methods they considered as important for consideration when developing a school-based abuse prevention program.

4.4.2. Materials and methods

4.4.2.1. Research design

A qualitative approach was used to obtain in-depth information on the development of a school-based abuse prevention program for children with communicative and/or intellectual disabilities. Two focus groups and six semi-structured interviews were conducted.

4.4.2.2. Participants

Three different stakeholder groups were included: Group 1 (teachers working in special education with children 7-12 years of age); Group 2 (practitioners experienced in working with children with disabilities who had been victims of violence, such as child investigators, nurses and psychologists) and Group 3 (six parents of children with communicative and/or intellectual disabilities 7-12 years of age), described in Table 4.3.

Parents participated in one-on-one interviews, rather than focus groups due to the ethical implications of discussing abuse in a group setting.

Table 4.3

Participant Description

Sex	Age	Profession	Years in profession	Experience with children with disability	Experience with AAC
Group 1: Teachers (n = 7)					
F	56 yrs.	Teacher	>20yr	>20yr	>20yr
F	57 yrs.	Teacher	>20yr	15-20yr	15-20yr
F	41 yrs.	Special education teacher	15-20yr	15-20yr	15-20yr
F	41 yrs.	Teacher	0-5yr	10-15yr	0-5yr
F	38 yrs.	Teacher	10-15yr	10-15yr	10-15yr
F	38 yrs.	Special education teacher	0 -5yr	5-10yr	0-5yr
F	49 yrs.	Special education teacher	5-10yr	5-10yr	5-10yr
Group 2 = Practitioners (n = 5)					
F	47 yrs.	Child coordinator	5-10yr	5-10yr	5-10yr
M	52 yrs.	Psychologist	15-20yr	15-20yr	0-5yr
F	49 yrs.	Specialist child/youth nurse	10-15yr	5-10yr	None
F	35 yrs.	Child investigator	0-5yr	0-5yr	0-5yr
F	32 yrs.	Psychologist	0-5yr	0-5yr	None

4.4.2.3. Data collection

Before recruiting participants to the study, ethics permission was obtained through the Ethical Vetting Board at the University of Gothenburg (Appendix A1).

i) Focus groups with teachers and practitioners

The focus group with seven teachers (Group 1) was conducted at a central, convenient location for them. All had been recruited through a post on the Facebook page of a centre for AAC and assistive technology. All participants received written information about the study after expressing initial interest to participate. They completed a consent form and a biographical questionnaire before the focus group started. The first author acted as the moderator for the focus group. A research assistant was responsible for notetaking and summarized the discussion at the end to ensure the accuracy of the notes and facilitate member checking.

The focus group with the practitioners (Group 2) was conducted at a venue where most of them worked. They were recruited using a snowball technique and after the initial contact was made, they received written information about the study. They signed informed consent forms and completed biographical questionnaires before the focus group commenced. Despite their different professional backgrounds, they were co-workers and thus knew each other. Once again, the first author was the moderator of the group and she was assisted by a research assistant.

Both focus groups 1 and 2 used the same interview guide to ensure comparability and increase procedural integrity. The following five questions were asked: 1) What experiences do you have of children with disabilities who have been victims of abuse? 2) If you were to design a program for children with communicative and/or intellectual disabilities aimed at preventing abuse, what would you include? 3) Which questions are important to ask during the evaluation of the program? 4) In your opinion, what is the key element/most important element in an abuse prevention program for children with communicative and/or intellectual disabilities and 5) Which difficulties with implementing an abuse prevention program do you foresee? The focus groups were audio recorded and transcribed verbatim by the first author. The transcriptions were checked and corrected for accuracy by the third author.

ii) Semi-structured interviews with parents

Six semi-structured interviews were conducted with parents (Group 3) at a location they chose, using an interview guide that started with the initial five questions included in the focus groups. Five further questions were added after reviewing focus group results, namely: 1) Do you think that parents want to know more about child abuse and abuse prevention programs? 2) How can parents be involved in an abuse prevention program at school? 3) What is important to consider when teaching children with communicative and/or intellectual disabilities about abuse? 4) In your opinion, how could the program be adapted for children with different disabilities? and 5) How can you retain the children's knowledge about abuse that they received during the program? The interviews were audio recorded.

4.4.2.4. Data analysis

The data from the three stakeholder groups were collapsed to form one corpus which was analysed with Atlas.ti 8. Braun and Clarke's (2006) six steps for thematic analysis was employed, namely 1) Familiarization with the data by reading and rereading the transcripts; 2) Generating initial codes; 3) Searching for themes; 4) Reviewing themes and codes through re-coding and refinement; 5) Defining and naming themes and 6) Constructing a code book with themes, codes and definitions of the codes. The code book included four main themes, namely teaching methods and components (with 27 different codes), implementation (with 14 different codes), difficulties (with 19 different codes) and evaluation (with 10 different codes). The coding was validated by the second author who subsequently reviewed 20% of the data. She was blinded to the code assigned but had knowledge of the theme to provide context. Interrater reliability of 78% was achieved after the review. After a consensus discussion, full agreement was achieved. Each code was reviewed and plotted onto a level of the BEM framework.

4.4.3. Findings

The findings are presented according to the four levels of the BEM. The themes and codes linked to each level of the BEM is shown in Table 4.4.

Table 4.4

Themes and Codes Related to the Different Levels of the BEM

Social-cultural level	Community level	Local level	Individual level
Teaching methods and components			
• Involve parents • Use videos • Use role play • Use case studies • Train face-to-face • Adapt training material for children • Knowledge: types and signs of abuse • Knowledge: disability and treatment • Knowledge: how to report • Create opportunities to practice skills • Address attitudes		• Use play • Use stories • Use videos • Use role play • Check comprehension • Listen-and-believe • Include AAC methods	• Empowerment and children's rights • Distinguish wrong/right • Identify and name abuse • Say "*no*" • Identify dangerous situations • Unmask deceitful behaviour • Disclose abuse • Understand sexuality • Show integrity • Understand and identify emotions • Understand behavioural consequences
Implementation			
• Ensure parental support • Make mandatory	• Dedicated budget • Shared values • Collaboration • Adaptation of context • Community relevance	• Who teaches? • Support from management • Adaptations: teaching methods • Adaptations: teaching material	• Retaining knowledge • Screening • Adaptation of program to different disabilities
Difficulties			
• Lack of knowledge: abuse • Lack of knowledge: disability • Cultural aspects • (Over) protecting children • Child's rights	• Social services	• Bulldozing • Staff resistance • Time constraints • Fear: adults • Despair: parents • Concern: effect of training • Decision-making: teachers	• Communication and cognitive challenges • Poor generalization skills • Disclosure/ failure to disclose • Docility • Dependency • (re)Traumatization • Challenging behaviour
Evaluation			

Social-cultural level	Community level	Local level	Individual level
• Employ different evaluation methods	• Disclosure as outcome measure • Abuse as outcome measure	• Expert panel review • View adult's role • View multiple role players • Consider context • Did it work?	• Children understanding key components (receptive) • Children using key components (expressive)

4.4.3.1. Social/cultural level

The social/cultural level of the BEM refers to laws, policies, national plans or regulations, information from the government or state, cultural aspects and training of teachers, parents and other adults. Four themes were related to this level, namely teaching methods and components, implementation, difficulties and evaluation (Table 4.4.).

Eleven codes linked to teaching methods and components, namely i) involve parents, ii) use videos, iii) use role play, iv) use case studies, v) train face-to-face, vi) adapt training material for children, vii) knowledge: types and signs of abuse related to teaching, viii) knowledge: disability and treatment, ix) knowledge: how to report, x) create opportunities to practice skills and xi) address attitudes were delineated on the social/cultural level. All three stakeholder groups reiterated the importance of involving parents in abuse prevention programs. Videos and role play were suggested teaching methods as was the use of case studies to facilitate discussion: *"Well, when we worked with the case studies, there was really good discussions and it's an angle of approach that doesn't single out anyone".* Some participants preferred face-to-face training over online methods. They also suggested that the training material (including a training manual) should be in an accessible format for children, so that the adults would not need to adapt it themselves. Regarding the content, participants suggested that the overall aim of abuse prevention training should be to increase the adult's general knowledge of both abuse and disability, and the intersection of the two.

> "*To make it visible earlier on a group level, because then it might be easier if you see that one of your children's friends are being treated badly or is not doing well, or it might be easier to do something about that if there is a focus on it. For everybody*."

Adults need to know about different types of abuse and how to identify possible signs of abuse, since this can be especially difficult with children with communicative and intellectual disabilities: *"But it is really hard to tell, so therefore a lot of the children who are victims of abuse are not detected".* Participants discussed being trained on how to report suspected abuse: *"One shouldn't be put in a position where you ask the questions [about abuse] and don't really know, what do I do with this?"* Knowing about available treatment options, was also discussed. Participants also identified the attitude towards disabilities and abuse component, and that it should be included in training. Opportunities should also be created for using the skills acquired during training.

Five codes, namely i) lack of knowledge: abuse, ii) lack of knowledge: disability, iii) cultural aspects, iv) (over)protecting children and v) child's rights linked to difficulties related to the social/cultural level were identified. The lack of knowledge (related to disability and to abuse) was discussed at length, as highlighted by a practitioner: *"I think overall that when we are addressing schools, teachers sometimes have alarmingly little knowledge about abused children"*. Some participants said that the rights of children with disabilities should be known and respected by society but that is not always the case. Participants also discussed the risk of over-protecting adolescents with disabilities by denying them access to alcohol, romantic partners or the broad freedoms enjoyed by peers without disabilities:

"One difficulty is when do you start to talk about what? Age-wise, when is a student mature enough to start to talk about sexual abuse? I think that's really difficult with our students, when they get to puberty. So, you don't kind of start something that can turn out wrong. To know when do I start talking about this. They aren't really the age that they are".

Some participants also highlighted cultural aspects related to disability and abuse as potential difficulties that trainers should be aware of.

Two codes, namely i) ensure parental support and ii) make mandatory related to implementation emerged. Parental support as a critical element of successful implementation of the abuse prevention program was underscored, as children with disabilities sometimes exhibit challenging behaviour which increases the caregiving burden, and which might in turn act as a trigger for abuse.

> "*Describing that it is normal to feel frustration as a parent. And despair, sadness and anger - anger is contagious. Talking about these feelings. If you have a child with behaviour issues then that is extremely challenging parenting. Without talking about the child as being difficult, but rather talking about challenging parenting instead."*

Some participants thought that the program needed to be mandatory (e.g., included in the school plans and regulations).

Only one code relating to evaluation was linked to this level, namely the need for proper evaluation methods that are adapted for all children:

> *"It's an extensive task, it's not just sitting down with a questionnaire, that's not possible. But it's rather observations over time, and then to capture the correct results."*

Methods such as Talking Mats™ (Murphy & Cameron, 2008) were mentioned, as well as using interviews or questions before and after the implementation of the program.

4.4.3.2. Community level

The community level refers to processes, resources and services in the community context and/or that involves the community. Three different themes, namely implementation, difficulties and evaluation were related to this level, as shown in Table 4.4.

Five implementation codes, namely i) dedicated budget, ii) shared values, iii) collaboration, iv) adaptation of context and v) community relevance were delineated. Firstly, the importance of a dedicated budget for the implementation of the program was discussed. Sharing the same values in terms of rights of individuals with disabilities and what constitutes abuse was suggested as an important factor. Schools, parents, therapeutic and other services need to collaborate and share important information: "*There has to be communication between the home and the school. Because these children have especially big difficulties to understand that there can be different rules in different places".* The context where the program is implemented (e.g., school), needs to be adapted to meet all children's needs. The context can also facilitate knowledge and understanding: *"The child will be dependent on the knowledge in a given context".* Participants also discussed that the program ought to be relevant for the community at large.

Evaluation yielded two codes linked to this level. Firstly, using disclosure as an outcome measure (e.g., disclosing to the school nurse). Secondly, using abuse as an outcome measure (e.g., using the number of reports made to social services, the number of police reports or the numbers of police investigations that go to court).

Only one code, social services, related to difficulties was reported. Participants identified social services practitioners as important collaborators, while also noting their lack of knowledge regarding how to communicate with children with communicative and/or intellectual disabilities: "*We did contact social services to consult them, but they didn't have any knowledge whatsoever"* as well as a lack of transparency in the processes and actions of social services: *"We talked quite a lot about this issue with the confidentiality, that it could be… well it makes it difficult sometimes".*

4.4.3.3. Local level

The local level includes the knowledge, skills and need for training for parents, teachers and other adults as well as the actual teaching of the abuse prevention program. The codes related to this level belonged to all four themes, namely teaching methods and components, implementation, difficulties, and evaluation (Table 4.4.).

Seven codes, namely i) use play, ii) use stories, iii) use videos, iv) use role play, v) check comprehension, vi) listen-and-believe, and vii) include AAC methods relating to teaching methods for children with disabilities were linked to this level. Play and stories were described as methods for ensuring understanding of key components, as well as using videos and roleplay:

> *"I'm thinking that you would need to replay things, kind of. Either using role play, or dolls or something. That you create something other than just… well of course teach, but also something more experience based, I think is needed."*

Evaluating the children's comprehension was suggested to ensure that they grasped the intended information. Participants also discussed that adults should listen to and believe children when they speak out:

> "*I'm also thinking about this thing that we discussed quite a lot when we did our questionnaires, which is feedback to the student. I have listened to you, I understand you, I want to help you".*

Finally, different AAC-methods (e.g., Talking Mats™, communication boards and manual signs) was seen as crucial to enable children with communicative and/or intellectual disabilities to understand the key components taught in the program. The need for AAC customization for individual children was also mentioned.

Seven codes related to difficulties, namely i) bulldozing, ii) staff resistance, iii) time constraints, iv) fear: adults, v) despair: parents, vi) concern: effect of training and vii) decision-making: teachers were mentioned. “Bulldozing” entails violating children’s rights, and not respecting children when they say no, e.g., if a child does not want to participate in certain compulsory school activities, and says no, it could create a potentially problematic situation in terms of respecting the child’s decision. Some children are more inclined to respond with a “no” to any inquiry that involves something unfamiliar:

> *“I feel like we need to include the concept of ‘I don’t want to’. I mean we work a lot with that… how do I put this. We’re struggling to get our students to try things, and then they can say ‘I don’t want to’, but we still drag them along to things.”*

Also discussed as a potential difficulty was resistance from staff to implement the abuse prevention program due to different reasons (e.g., lack of knowledge or resources, time constraints, fear):

> *“One thing I’ve been struck by over the years, is that one quite often meet staff at schools and preschools that are too afraid to report [abuse] or to take it further and discuss the matter even though they’ve seen indications of abuse. Today we are starting to give better information and education to them also. But it’s so easy for them to say, ‘I don’t want to be that child’s safe person because imagine if I have to stand and talk to that angry dad later.’ And then you have to talk to that person from our perspective and say that well, the child is going home to that dad, you can choose not to do that.”*

Abuse can stem from a sense of despair that parents can experience when dealing with children with challenging behaviour as described by a police officer:

> *“I often meet children with different kinds of neuropsychiatric disabilities. And when you talk to those parents, they often say that they kind of snapped…. They’ve coped with so much and then they ran out of energy. Patience, energy, perseverance, everything ran out. And then, then there was only violence left.”*

Parents' concern that their child will be abused or traumatized when participating in an abuse prevention program, can also influence their willingness to allow their child to participate in such a program. One parent mentioned that teachers need to be in charge in their classrooms and make decisions and rules, without having to consider parental preferences.

Five codes relating to evaluation were delineated, namely i) expert panel review, ii) view adults' role, iii) view multiple role players, iv) consider context and v) did it work. The code "Did it work" refers to evaluating whether the abuse prevention was effective (i.e., did it produce the desired outcomes) without suggesting any method. Adults' understanding of their responsibility and the need for adaptations such as using AAC, was suggested by a parent as an important aspect to evaluate. Evaluating the effect of the program by asking about the context was also suggested: "*I think what could also be evaluated, is the environment at the school. Is the school calmer after the program?"* Participants thought that it was important to ask questions to children, to parents and to teachers when evaluating the program. One participant suggested that a first version of the program could be reviewed by an expert panel to verify the contents and methods of the program.

Four codes relating to implementation were identified, namely i) who teaches, ii) support from management, iii) adaptations: teaching methods and iv) adaptations: teaching material. Participants discussed that the program trainer should be somebody with appropriate skills whom the children trust. The teachers especially highlighted that teachers need support from principals and the school management to enable them to implement the program. Furthermore, participants felt strongly that the program should be adapted to children with communicative and/or intellectual disabilities. This adaptation needs to be done in terms of the methods used in the program (e.g., how questions are asked, how information is provided and in what group setting it is taught). Moreover, these adaptations should be done for individual children and for the group: *"I can imagine that some might find it difficult to deal* *with it in a group and for some it'll be an advantage to do it in a group".* The program also needs to be adapted in terms of the materials used (e.g., using pictures and AAC-methods to enhance understanding). Participants suggested using a basic manual to start, which could then be adapted for individual children.

4.4.3.4. Individual level

The individual level refers to the child's characteristics, knowledge and skills as well as concepts and skills that need to be acquired. The codes that were related to the individual level came from four different themes, namely teaching methods and components, implementation, difficulties and evaluation as shown in Table 4.4.

Key components refer to the concepts that should be taught to children with communicative and/or intellectual disabilities as part of the program. Eleven codes were identified, namely i) empowerment and children's rights, ii) distinguish wrong/right, iii) identify and name abuse, iv) say "no", v) identify dangerous situations, vi) unmask deceitful behaviour, vii) disclose abuse, viii) understand sexuality, ix) show integrity, x) understand and identify emotions, and xi) understand behavioural consequences. Empowering children by teaching them about their rights and learning what is right and wrong were highlighted in all three groups: *"But my idea with this kind of [abuse prevention] program is also to help children with disabilities to have agency in their own well-being in some way".* Participants also suggested that children's rights could be linked to the Convention on the Rights of the Child (United Nations, 1989).

The need for children with communicative and/or intellectual disabilities to be able to speak up about abuse, to understand what constitutes abuse and know how to say no, to learn about specific situations that could be associated with risk (such as being alone in a taxi with a taxi driver) as well as unmasking deceitful behaviour (such as adult's posing as children online) were discussed in all groups. Disclosing abuse could present some challenges. A parent said:

> "*We need to strengthen children from within, so that they dare to talk about it. And give the right prerequisites. If that child has had a different experience or has difficulties with expressing themselves, then we need to face that at the same time".*

Children with communicative and/or intellectual disabilities also need to be taught about sexuality, integrity, feelings and how their behaviour affects others. One practitioner had experienced the consequences of a lack of teaching young adults with intellectual disabilities about sexuality:

> *"It was kind of a topic that was just left there… and at the same time everybody was ... well …aware that many of them had sexual relationships. This concept of, what are we protecting them from, and not? Should you protect children, or adults, from their own sexuality? That doesn't turn out well."*

Seven codes relating to difficulties were noted: i) communication and cognitive challenges ii) poor generalization skills iii) disclosure/failure to disclose, iv) docility, v) dependency, vi) (re)traumatization and viii) challenging behaviour. Challenges related to communication and intellectual difficulties were frequently discussed and concerns were raised in terms of both general understanding and understanding specific concepts such as abuse and the ability to express themselves. One teacher said: "*It is really us who control the words that they can give us, because we might not give them these words or objects to talk about"*. A parent expressed concern about their child's ability to disclose abuse: "*To express something by herself about what she experienced, I don't think that she could do that"*. Generalization of concepts was described as difficult for children with communicative and intellectual disabilities, and participants expressed concerns about how to compensate for that in abuse prevention: "*It might be OK for Mum and Dad to do something, but it might not be*

OK if school staff does roughly the same thing, or something that can be perceived as the same thing." Difficulties related to communication and cognition was also linked to disclosure, including both actual disclosure and failure to disclose. The participants envisaged potential problems related to disclosure not only in terms of having access to the appropriate vocabulary, but also who to disclose to and at what time.

> "*And they [children with communication difficulties] don't come to the police either, because they haven't been able to disclose about abuse or vulnerability from the beginning, to anyone around them. In situations where for example the person that you could disclose to, like an assistant or something like that, if that person is the abuser… then it becomes difficult."*

Docility refers to children with communicative and/or intellectual disabilities answering questions in the way that they think that the person asking the question wants them to answer, rather than telling the truth. Many children with disabilities are dependent on caregivers and staff for many areas of daily life. This could affect their ability to disclose abuse, to say no to risky situations or actual abuse and to remove themselves from the abuser:

> "*I'm thinking dependency on usually a lot of different persons and that can be a lifelong dependency in many ways. Maybe not on the level that you need help in every situation, with dressing and so on, but to get a functioning home situation when you start to become an adult, to gain some more freedom…this differs so much when you might not have the prerequisites yourself to live it."*

Traumatization or re-traumatization was a risk linked to the abuse prevention program as alluded to by some participants. Talking about abuse, naming abuse and speaking about sexuality and integrity creates a potential risk that some children will be affected, especially if they have previously been victims of abuse, a fact which might not be known:

> “*There’s also a risk, I think, to scare children from intimacy. You need to think about how you talk about sexual abuse and consent. That at the core intimacy and physical closeness is something nice and cosy. I think that adults talk about it in a way that it almost scares children away from that. We shouldn’t do that. But rather teach the children how it [intimacy] can be safe.”*

Behavioural difficulties in children with communicative and/or intellectual disabilities was discussed by several participants in terms of the challenges related to this when implementing an abuse prevention program:

> “*I can’t demand from him that he should totally know what is right and wrong in all situations. He has for example shoplifted. It is very wrong. You can’t do that. He knows that. But he doesn’t know that when he is doing it. Because he forgets it.*”

Three codes relating to implementation were identified, namely i) retaining knowledge, ii) screening and iii) adaptation of program to different disabilities. Retaining the knowledge gained from participation in the abuse prevention program was thought to be done mainly by repetition: “*Repeating the information many times”; “Continuously as the child ages it changes and then you need to carry on. It is not like it is a one-time event”.* The idea of screening children for experience of abuse while offering the abuse prevention program at the same time was mentioned by one participant. Adapting the program to children’s (dis)abilities was seen as essential to enable as many children as possible to participate and benefit from the program. However, some participants also saw this as the greatest potential challenge to the successful implementation of the program. A teacher explained: “*I still think [the biggest challenge] is getting through to all groups of students. The ones who have the most difficulties and have severe intellectual disabilities*”. Some participants proposed solutions for this, such as:

> “*I think it would be good to have a class that is put together depending on the difficulties. And then you need sort of a toolbox with different exercises, and then you can use the ones that fit for this particular group”.*

Two codes, namely i) children understanding key components (receptive) and ii) children using key components (expressive) belong to the evaluation construct. Children’s understanding of the topic was suggested as a possible way to evaluate the effectiveness of the program: “*I think you need to ask the children what they learned. So, some sort of evaluation with the children”.*

4.4.4. Discussion

Our study shows the depth and complexity of developing and implementing a school-based abuse prevention program for children with communicative and/or intellectual disabilities. These children are particularly vulnerable to abuse and need to be involved in abuse prevention themselves. Furthermore, the involvement of parents and teachers was also reported as being crucial to ensure successful implementation. The number of focus groups and interviews were limited, as well as the number of participants. The results presented in the study should be viewed as preliminary and an addition to the limited knowledge base on school-based abuse prevention programs for children with disabilities.

The adapted version of the BEM employed in this study, is proposed as a valid framework for developing school-based abuse prevention programs. The analysis of the present study’s data reveals that the findings are assigned to all the levels of the BEM.

The results linked to the social/cultural level were mainly related to teaching adults about abuse and identifying signs of abuse in order to provide support to children and prevent abuse and neglect. A general lack of knowledge of abuse was raised as a concern, which is consistent with a Swedish report that showed that 35% of universities did not include child abuse in teacher training for younger children, and that the existing training was limited (Inkinen, 2015). Noticing signs of abuse in children with disabilities can be challenging as some of the common signs of abuse or neglect might not be relevant for children with disabilities, e.g., changes in behaviour or frequent absence from school. These behaviours might be linked to the child’s disability and not abuse. Drawing from the results of the present study, describing the signs of abuse children with disabilities exhibit is needed, but to our knowledge, no tool currently exists for this purpose.

Beyond identifying and describing abuse, teachers also need to feel confident in reporting abuse. Most child abuse and neglect is never reported, as demonstrated by the discrepancy between the number of reports to child protection services versus the frequency of abuse found in surveys distributed to adults and children (Gilbert et al., 2009). In a study in Sweden of general practitioners, 20% had suspected child abuse but not reported it despite mandatory reporting laws (Talsma et al., 2015). The underlying reasons for lack of reporting can include limited knowledge about the signs of abuse, routines for reporting as well as fears about damaging the relationship with the family.

Supporting parents of children with communicative and/or intellectual disabilities to navigate some of the challenges of parenting a child with a disability was highlighted. Parents and other familiar caregivers are often the main perpetrators of child abuse and neglect (Hurren et al., 2018; Stöckl et al., 2017), emphasising that parental support to cope with the increased caregiving burden of children with disability, should never be underestimated. Parenting programs to decrease abuse have been found to have moderate yet significant effectiveness on re-occurrence of child abuse and should therefore be considered in situations of known abuse (Vlahovicova et al., 2017).

Despite relatively few themes linked to the community level in our study, the involvement of the community in abuse prevention is important. The community’s role becomes evident in the concept of shared values of rights and risks for all children - including children with disability. Shared values can be achieved through training both teachers and parents to ensure that both groups receive the same information. Collaboration is also important for children, as they benefit from consistency in the information given and the attitudes towards abuse amongst the important adults in their lives.

Social services are an important collaborator for both schools and families, and the difficulties described by the teachers in the present study in relation to social services is troubling. A lack of written policy on how to serve children with disabilities could contribute to each case being handled on individual basis, which could influence the quality and consistency of the service negatively (Lightfoot & LaLiberte, 2006). Furthermore, social worker's knowledge of disability and AAC may be limited.

Unintentional abuse can stem from trying to convince children to do things that they don't want to do, or to challenge them to push beyond their capability. Respecting their rights and opinions, while at the same time making sure that they participate in activities needs to be discussed within the scope of an abuse prevention program. Lack of information to teachers and parents can create challenges, such as parents not wanting their child to participate in the abuse prevention program or teachers being reluctant to teach the program.

Research has highlighted active participation by children as a vital component in school-based abuse prevention (Brassard & Fiorvanti, 2015). Interactive teaching methods such as role play, videos and discussions could potentially increase understanding and facilitate learning in children with communicative and/or intellectual disabilities and make the program accessible and appealing to them. Video modelling has also been used effectively to teach children with various disabilities about social skills (Gül, 2016) and could likewise be used to teach abuse prevention. The use of AAC-materials, in particular pictorial support, based on universal design principles will ensure that the program is accessible for all children.

Furthermore, learning also depends on the person teaching the program, their knowledge of the children and their ability to adapt the program. The teacher's skill and experience are thus crucial in the adaptation process.

The complexity of learning, understanding and being able to express oneself as a child with communicative and/or intellectual disabilities, was discussed in-depth. The main message from these discussions was the need for adaptation to meet the individual child's needs, using universal design principles (Johnson & Muzata, 2019). Flexibility, also a universal design principle, emphasises that programs ought to have room and suggestions for adaptations for children with different skills, as outlined earlier. Likewise, the principle of perceptible information, was addressed by the participants in terms of the need for adapting the program for children with intellectual disabilities. These adaptations should be included in the program, with suggestions of different approaches to accommodate different types of disabilities.

Children with communicative and/or intellectual disabilities need knowledge on a vast array of topics within the scope of abuse prevention. To provide a common ground, knowledge on feelings, sexuality and children's rights needs to be established before teaching about abuse and neglect. All information should be age- and disability appropriate and children with communication disabilities should be given access to the appropriate vocabulary to disclose abuse (Kim, 2010). As many children with communicative and/or intellectual disabilities experience difficulties with generalization, the key components of the program should be repeated over time.

Children with communicative and/or intellectual disabilities are dependent on their caregivers and are often trained to be compliant. This poses a challenge in view of abuse prevention. Therefore, children's empowerment should be central to an abuse prevention program highlighting that their voices need to be heard (United Nations, 2011).

4.4.5. Conclusion

Several challenges but also possibilities with implementing a school-based abuse prevention program were identified in the present study. The findings reported can be used to navigate the challenges of program development and implementation. Future studies should include a larger sample size to draw further conclusions on this important topic. Some difficulties that were mentioned by all three stakeholder groups concerned limited knowledge, time, resources and support. In order to implement an abuse prevention program, it is imperative to first ensure that the needed factors are in place. If not, the program is bound to fail.

This is the end of the excerpt of the pre-print version of "*School-based abuse prevention programs for children with disability: A qualitative study of components and methods*" by Nyberg et al. (2021b).

4.4.6. Conclusions of Phase 1.2

Phase 1.2 focused on identifying key components, teaching methods, adaptations, and challenges to implementation of school-based abuse prevention programs for 7–12-year-old children with communicative and/or cognitive disabilities as well as parent's roles in such programs, as perceived by stakeholders.

The results from both the focus groups and the interviews, show that several adaptations in terms of the methods, key components, and materials are needed to teach school-based abuse prevention programs to children with communicative and/or cognitive disabilities. The adaptations should be incorporated at all four levels of the BEM and should address the specific challenges that children with communicative and/or cognitive disabilities face.

Interactive teaching methods such as using roleplay and discussions were suggested as well as incorporating other mediums for conveying content, such as videos. The importance of providing AAC-materials and adapting the materials and methods to suit the needs of individual children was highlighted by participants. Teachers and parents' involvement was regarded as crucial components of primary abuse prevention programs. Training of teachers and providing supporting information to parents should be an essential part of school-based abuse prevention programs for children with communicative and/or cognitive disabilities. Therefore, guidelines for adapting programs should mention these aspects.

Additionally, the need for resources and support to teachers to enable implementation of school-based abuse prevention programs was reinforced. The findings from Phase 1.2 highlight the principal's crucial role in supporting the implementation of school-based abuse prevention programs, thus underscoring the need for guidelines to be aimed at both teachers and principals.

4.5. Phase 1. 3: Signs of abuse in children with disabilities: A rapid review with a social validation component

In order to address the last sub-aim of this phase, a rapid review of signs of abuse in children with disabilities followed by social validation by an expert panel was conducted. The needs, risk behaviours and specific situations, the specific components (namely signs of abuse) related to the target population that should be included in the program and the level of adaptation (by assessing accuracy of signs of abuse) was explored as per the conceptual framework (Table 3.2).

Several of the following paragraphs were adapted from an excerpt of the pre-print version of "*Signs of abuse in children with disabilities: A rapid review with expert panel social validation*" by Nyberg et al. (2021c) published in the Journal of Intellectual and

Developmental Disability (Appendix D1). Permission was obtained from the publisher to include this paper as part of the present study (Appendix D2).

4.5.1. Introduction

Children with disabilities are three to five times more likely of being victims of abuse than their peers without disability (Jones et al., 2012). Children with intellectual disabilities have been found to be more likely to experience several occasions of maltreatment (Dion et al., 2018).

An intersectional perspective is helpful for understanding this elevated risk as disability itself is a risk factor for different forms of abuse, including any form of physical and emotional ill-treatment, sexual abuse, neglect, and exploitation that results harm to the child's health, development or dignity (Winters et al., 2017). Social disadvantage, type of impairment, gender, communication difficulties, dependency on social support systems, lack of resources and social support for parents of children with disabilities as well as parental stress can be potential factors linked to abuse of children with disabilities (Flynn, 2020). Children with complex communication needs (which manifests as difficulties with understanding language and/or with producing spoken language) may, for example, face additional barriers to disclosing abuse (Flynn & McGregor, 2017) and could thus be at higher risk of experiencing abuse and victimization due to their communication difficulties (Flynn, 2020; Goldberg Edelson, 2010).

Identifying and understanding signs of abuse in children with disabilities is crucial to end ongoing abuse and enable rehabilitation and support. Despite limited studies focused on the signs of abuse, results indicate similarities between children with and without disabilities (Debelle, 2012; Reinke, 2005) identifying behaviour problems as the most common sign of abuse (Reinke, 2005). However, interpreting and understanding these signs can be compounded by the fact that behavioural and emotional signs can also be attributed to the disability rather than to underlying trauma or co-morbid disorders (Vervoort-Schel et al., 2018). In addition to this, a child's intellectual and language development can impact their reaction to traumatic experiences such as abuse (McCarthy, 2001; Vervoort-Schel et al., 2018). Post-traumatic stress disorder (PTSD), for example, has been described as more difficult to identify in persons with intellectual disabilities or autistic people as the symptoms can be interpreted as being linked to the disability rather than to abuse (Kildahl et al., 2019, 2020). This paucity of research regarding the signs of abuse may possibly be attributed to beliefs about abuse risk for children with disabilities (Miller & Brown, 2014).

Practitioners who work with children with disabilities often lack knowledge about abuse and signs of abuse and the topic of abuse is often not included in professional training (Franklin & Smeaton, 2017; Inkinen, 2015) even though the potential risk of abuse should necessitate awareness and vigilance (Flynn, 2020). Similarly, primary caregivers (including parents) and other family members can be unaware of how to detect and interpret signs of abuse in children with disabilities and typically lack knowledge for considering trauma or abuse as underlying reasons for the manifested behavioural or emotional symptoms (Kildahl et al., 2020). Consequently, this can result in abuse not being detected. Therefore, it is vital that key stakeholders such as parents, teachers and other adults in these children's social networks become aware of potential signs of abuse in children with disabilities as a first step in preventing abuse. Subsequently, a rapid review of publications describing signs of abuse in children with disabilities was carried out in this study.

Social validation is defined as judging the social significance, appropriateness and importance of goals, procedures and results (Wolf, 1978). Wolf specifies three dimensions of the social validity concept for the applied behaviour analysis field, namely (1) social importance of goals, (2) social acceptability of procedures and (3) social importance of the outcomes (Wolf, 1978). Carter and Wheeler (2019) agree, stating that acceptability is a vital component of social validity defining it as judgments of treatments by stakeholders or potential consumers. Despite agreement on the importance of social validity, guidelines for reporting and assessing it is lacking (Park & Blair, 2019). When it is incorporated into a study, it is often done by asking those who implement, receive or consent to a treatment or intervention about their opinions (Carter & Wheeler, 2019). Several different methods can be used to do so, of which using a survey or a rating scale constructed for the specific purpose of socially validating the study in question is the most common (Carter & Wheeler, 2019). The application of social validity measurements in the child abuse prevention research field is seemingly scarce. As in other research fields, the component of social validity is often an "afterthought" and is not described in detail in publications (Carter & Wheeler, 2019).

The overall aim of this study was to identify signs of abuse in children with disabilities by firstly conducting a rapid review to describe the extant literature and secondly to confirm the results by employing a custom-designed social validation questionnaire completed by an international expert group.

4.5.2. Method

The study employs a two-phase mixed-method sequential research design (Creswell & Creswell, 2018) commencing with a rapid review followed by a survey including both quantitative and qualitative questions. The study was approved by the Ethical Committee at the Faculty of Humanities, University of Pretoria (reference number GW0180828HS).

4.5.2.1. Rapid review

Rapid reviews are used for compiling and synthesising knowledge in a simplified manner, using parts of the systematic review process (Tricco et al., 2015). The purpose of a rapid review is to make results available to stakeholders in a timely manner using resources effectively (Hamel et al., 2021). As the intent of the present study was to enhance the results from the review with a social validation component, a rapid review was deemed appropriate for the purpose of this study. Rapid review methodology varies across studies, but ways to streamline the process is to limit the search to published literature and limiting the search in regards to language and date (Tricco et al., 2015), which were both employed in the present study. Furthermore, using only one reviewer to screen title, abstract and full text has been found to be a common approach in rapid reviews (Tricco et al., 2016). This process was enhanced in the present study by using one reviewer for the title and abstract screening, but three researchers in total working independently for the full-text screening and data extraction. All three researchers had a good understanding of the topic and used the same screening and data extraction criteria and tools and followed instructions drafted by the first author to ensure consistency in the screening and data extraction process.

The search was performed in October 2019 by a research librarian well experienced in conducting database searches, using the following databases: PubMed (1022 references), PsycINFO (548 references) and Cinahl (647 references). Articles between 1989 and 2019 that were written in English, Swedish, Norwegian and Danish were searched. The additional languages (beside English) were added as the first and second authors can read and understand these languages. The search terms used were: Disabled Persons OR Intellectual Disability OR disabled OR intellectual disabilit* AND Contusions OR Signs and Symptoms OR Diagnostic Screening Program OR bruise*OR manifestation* OR sign OR signs OR symptom* OR clinical effect* OR mark OR clinical finding*OR behavioural issue*OR screening OR assault* AND abuse OR neglect OR maltreatment OR violence OR assault* OR cruelty OR ill-treatment OR mistreat* OR molest* OR oppression OR violent OR violently. Boolean operators were included, and only published literature was searched.

The search resulted in 1797 records after duplicates (n = 420) were removed, as shown in the PRISMA (Preferred Reporting Items for Systematic Review and Meta-analysis) (Page et al., 2021) in Figure 4.7.

4.5.2.2. Screening

The first author screened all studies on a title level using the PEO-criteria (Table 4.5). After this initial screening, 471 studies were reviewed on an abstract level by the first author. Subsequently, 42 studies were deemed appropriate for full-text screening. The full text screening was carried out by three reviewers independently. The first author read all 42 studies, while the second and third author each read 21 studies. In case of disagreement, discussions were had until consensus was reached. After reviewing the full text articles, 23 studies were included for data extraction (Figure 4.7) (Akbas et al., 2009; Berg, 2014; Berg et al., 2015; Debelle, 2012; Dion et al., 2018; Elvik et al., 1990; Firth et al., 2001; Hayes, 2009; Kildahl et al., 2019; Koppenhaver, 1995; Martorell & Tsakanikos, 2008; Nowak, 2015; Reinke, 2005, 2006; Sequeira & Hollins, 2003; Shabalala & Jasson, 2011; Soylu et al., 2013; Strickler, 2001; Sullivan & Knutson, 1998; van der Put et al., 2014; Verdugo et al., 1995; Walters et al., 1995; Wissink et al., 2018).

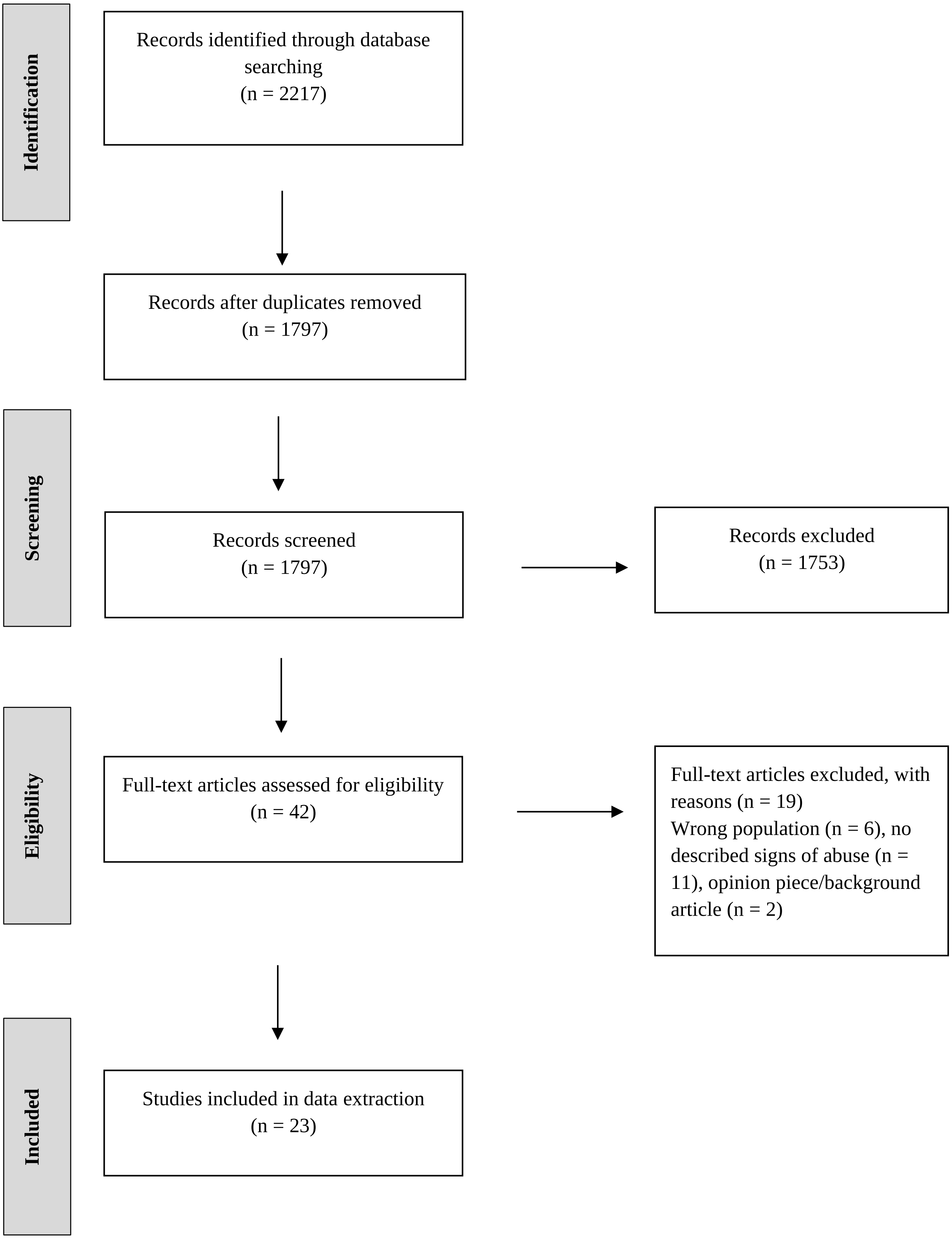
Table 4.5

PEO-Criteria of the Current Study

	Inclusion	Exclusion
Population	• Children with disabilities (18 years of age and younger)	• Persons without disabilities • Only adults with disabilities
Exposure	• Victim of any of: - Sexual abuse - Physical abuse - Neglect - Financial abuse - Exploitation - Emotional abuse	• Primary substance abuse or alcohol abuse • Gun violence
Outcomes	• Signs of abuse (behavioural, emotional)	• Medical examination

Figure 4.7

PRISMA-chart of Current Study



4.5.2.3. Data extraction

A custom-designed data extraction tool was developed, and pilot tested by a practitioner peer-group prior to data extraction. This group consisted of 10 PhD-candidates, who were trained professionals in the disciplines of speech-language pathology, psychology (educational or clinical), education and occupational therapy. The data extraction tool contained six types of abuse, 15 behavioural signs of abuse and 19 physical signs of abuse. This practitioner group was asked to use two key references and complete the data extraction tool and provide feedback on its applicability and useability. Minor changes were suggested and made, prior to the data extraction. Data extraction was carried out independently by all three authors. The data extraction was complicated by the fact that publications used different labels for the same signs of abuse (e.g., “aggression” and “violent behaviour”) and that there was a general lack of definition of concepts. This resulted in moderate interrater reliability, with Cohen’s kappa of 0.75 between the first and second authors (McHugh, 2012)

The quantitative data on signs of abuse was summarised and calculated for frequency. As each extracted sign could be noted down two times for each article (one for each reviewer), a level of at least five notations (meaning that the sign of abuse was mentioned in more than two articles) was selected. The rationale for this approach is that the purpose of the study was to identify signs of abuse in children with disabilities that had a higher frequency and that would therefore be expected and seen more probably.

The qualitative descriptions of signs of abuse (e.g., signs that were written in the “other column”) were listed, refined (e.g., by grouping synonyms) and followed with a frequency count. Similar to the quantitative data, only signs with at least five notations were added to the final list. The frequency of the behavioural and physical signs of abuse, using both the qualitative and quantitative data was counted and summarised. This resulted in a final list that contained 28 items.

4.5.2.4. Social validation

i) Participants and sampling

Participants were selected for the social validation phase of the study using a multiple-method sampling approach. This specific aim necessitated “expert participants” who were well versed in both disability and in abuse research. Due to the cross-disciplinary nature of the topic, the pool of potential participants was small. Four different groups of participants were primarily invited to participate in the survey, (1) authors of research studies included in the abstract review stage of the rapid review conducted in phase 1of this study; (2) authors of research studies included in a previously conducted scoping review by the authors of the present study with a related focus (Nyberg et al., 2021a) (3) personal contacts with suitable clinical or research background linked to the topic and (4) members of international organizations targeted at preventing violence and abuse towards children with/without disabilities or international disability alliances. All invited participants were asked to further snowball the invitation to other suitable possible participants in their own professional networks (Sue & Ritter, 2012). As the sample was based on a snowball technique, sampling error estimates and target sample size cannot be calculated (Sue & Ritter, 2012). Item nonresponse in the present study consisted of participants quitting the survey before finishing (n = 4), as responses could not be skipped without an answer being given. This resulted in a total of 39 completed surveys from participants.

Due to the global recruitment process and online data collection, participants represented different countries, namely Sweden (n = 14), South Africa (n = 7), Norway (n = 3), The United Kingdom (n = 3), Australia (n = 3), Turkey (n = 2), The United States (n = 2), The Netherlands (n = 2), Iceland (n = 1), Spain (n = 1) and Denmark (n = 1). Their first languages reflected the countries that they lived in. The years of experience in working in their current profession ranged from 0 to 5 years to over 20 years, with 49% of the participants having worked in their current profession for more than 20 years. The majority of the participants had completed postgraduate studies, with 41% having earned their PhDs and 46% having received a Master’s degree. Academic knowledge is viewed as an essential part of the definition of an expert (King et al., 2008). Their job descriptions, which were provided in free text and thus could include several professions for each person, included psychologists (n = 11), professors (n = 7), associate professors/researchers/lecturer (n = 6), managers of units (n = 5), physicians (n = 2), child psychiatrists (n = 2), consultants/experts on abuse/disability (n = 4), unnamed occupations (n = 2) and retired (n = 1). Other biographic data is shown in Table 4.6.

Table 4.6

Biographical Information of Participants (n = 39)

Sex		
Female: 24 (62%)	Male: 15 (38%)	
Age: Seniority in career and age is highly linked, with increased age implying increased seniority for researchers (Over, 1988)		
31-40 y: 7 (18%)	41-50 y: 7 (18%)	51-60 y: 12 (31%)
61-70 y: 9 (23%)	71 y +: 4 (10%)	
Workplace (multi-choice question)		
Government: 5 (13%)	University: 16 (41%)	Healthcare: 16 (41%)
Non-profit organization: 6 (15%)	Other: 6 (15%) (This included community practice, children’s advocacy center, NGO/INGO, retired)	
Main area of expertise relevant to the study (multi- choice)		
Children with disabilities: 20 (51%)	Child abuse: 30 (77%)	Other: 10 (26%) (This included adult abuse survivors, forensic psychiatry, police psychology, disability inequalities, parent-child relationships, child health care, child protection).

<table>
<tr><td colspan="3">Years of clinical experience in your main area of expertise relevant to the study: Participants with many years of experience in the profession can be viewed as experts, although years of work experience alone does not guarantee expertise (Shanteau et al., 2002).</td></tr>
<tr><td>1-5 years: 4 (10%)</td><td>6-10 y: 7 (18%)</td><td>11-20 y: 10 (26%)</td></tr>
<tr><td>More than 20 y: 15 (38%)</td><td>None: 3 (8%)</td><td></td></tr>
<tr><td colspan="3">Estimated number of cases of known abuse against children with disabilities involved in: Case-based reasoning (e.g., basing your judgement on previous cases) can be a component of expertise (Hoffman, 1998). This is highly relevant in this study as the participants rating of the accuracy of each sign of abuse must be weighed against their familiarity with the topic.</td></tr>
<tr><td>1-5 cases: 4 (10%)</td><td>6-10 cases: 4 (10%)</td><td>11-20 cases: 7 (18%)</td></tr>
<tr><td>More than 20 cases: 23 (59%)</td><td>Other: 1 (3%)</td><td></td></tr>
<tr><td colspan="3">Number of published studies authored in areas relevant to the study: This can be used to assess performance in the research field (Abramo et al., 2015).</td></tr>
<tr><td>1-5 published studies: 12 (31%)</td><td>6-10 published studies: 3 (8%)</td><td>11-20 published studies: 3 (8%)</td></tr>
<tr><td>>20 published studies: 6 (15%)</td><td>None: 15 (38%)</td><td></td></tr>
</table>

4.5.2.5. Material

An online survey was constructed in Qualtrics, a digital platform for constructing surveys (https://www. qualtrics.com/uk/). The system was set up so that each participant had to provide written consent before being able to continue with the survey. After written consent had been provided by the participant, a biographical information section followed, as described in Table 4.6.

After completing the biographical portion of the survey, participants were asked to rate signs of abuse in children with disabilities on an ordinal 7-point Likert scale (1 = Very accurate; 2 = Moderately accurate; 3 = Slightly accurate; 4 = Neither accurate nor inaccurate; 5 = Slightly inaccurate; 6 = Moderately inaccurate; 7 = Very inaccurate). A 7-point Likert scale was deemed appropriate as the population were experts in the field and could be expected to want to express a nuanced opinion (Chyung et al., 2017). Definitions for each sign of abuse were provided in the survey. Additionally, the participants were asked to volunteer and rate signs of abuse that they had encountered in children with disabilities in their research or clinical work. Participants were also able to provide a free-text comment at the end of the survey. The survey was pilot tested using a group of five professionals, namely two clinical psychologists, two PhD- candidates who were also trained as speech-language therapists and one specialised occupational therapist with a PhD in medicine. The pilot group were asked to complete the survey using the online link using a custom-designed questionnaire for evaluating their experience of the survey, including components such as usability and clarity of definitions and signs of abuse. Subsequent changes were made according to their feedback and the survey was re-tested by one of the participants to ensure that the suggested changes had been carried out to satisfaction.

4.5.2.6. Procedure

A quantitative description of the empirical accuracy of different signs of abuse in children with disabilities was deemed suitable for the purpose of the study (Creswell & Creswell, 2018), as the researchers wanted to collect data over a time-limited period (20 days). Data was collected using an online survey which was distributed through email containing the link to the survey (Sue & Ritter, 2012). This method of distribution was considered appropriate for the sample population as they are active in clinical work or research and thus are used to using emails as a method of communication. Potential participants were informed on the nature of the survey, the identity of the researchers and organization, how data would be used and that they would remain anonymous in both completing the survey and when the results were reported, the average length of the survey (20–30 min) and that there were no risks associated with part-taking in the survey (Sue & Ritter, 2012).

4.5.3. *Results*

In total 35 full responses and four partial responses were recorded. Participants rated each of the 28 signs of abuse independently on a 7-point Likert-scale (1 = Very Accurate; 7 = Very inaccurate). Thus, the lower the score, the higher the perceived accuracy of the sign of abuse (Table 4.7). The survey results were analysed with SPSS, reporting means, range and standard deviation (Table 4.7).

Table 4.7

Numbers, Range, Mean and Standard Deviation for the Rating of Signs of Abuse

	Sign of abuse	N	Range	Min	Max	Mean	Std. Deviation
1	PTSD	36	2	1	3	1.75	.692
2	Poor self-esteem	37	3	1	4	1.81	.908
3	Withdrawal	37	3	1	4	1.86	.948
4	Anxiety	36	3	1	4	1.94	.955
5	Signs of penetration	36	6	1	7	2.06	1.472
6	Nightmares	37	3	1	4	2.08	.983
7	Depression	36	4	1	5	2.14	1.018
8	Self-harm	36	3	1	4	2.17	.811
9	Acting out	36	4	1	5	2.19	1.037
10	Emotional problems	35	3	1	4	2.20	.994
11	Bruising	36	5	1	6	2.22	1.098
12	Inappropriate sexual behaviour	37	5	1	6	2.27	.962
13	Inappropriate anger	38	5	1	6	2.34	1.169
14	Behavioural problems	36	5	1	6	2.36	1.125
15	Aggressive behaviour	39	6	1	7	2.38	1.388
16	Suicidal thoughts	36	5	1	6	2.42	1.079
17	Burns or trauma	36	6	1	7	2.50	1.558
18	Irregular school attendance	36	5	1	6	2.61	1.076
19	Eating/appetite disturbance	35	5	1	6	2.63	1.087
20	Victimizing	36	6	1	7	2.67	1.242
21	Suicide attempt	36	4	1	5	2.69	1.142
22	Non-compliance	36	4	1	5	2.83	1.134
23	Running away from home	36	5	1	6	2.94	1.393
24	Negative peer involvement	35	5	1	6	2.97	1.150
25	Crying	35	5	1	6	3.09	1.269
26	Substance abuse	36	5	1	6	3.44	1.182
27	Alcohol abuse	36	5	1	6	3.53	1.134
28	Dominant behaviour	39	6	1	7	3.67	1.493

Statistically significant differences were not seen between each item as the differences and the sample size were too small, but a significance level of $p < .05$ was reached for the differences between the 10 signs rated as most accurate versus the 10 signs rated as least accurate (Table 4.8). The calculation was done by conducting a paired samples t-test of item 10 (Emotional problems) and item 19 (Eating/appetite disturbance) in SPSS.

Table 4.8

P-value for Differences Between Item 10 and Item 19

Item and Item number	**Mean**	**Std Dev**	**Std Error Mean**	**Lower**	**Upper**	**T**	**Df**	**Sign 2-tailed**
Emotional problems (#10) Eating/appetite disturbance (#19)	-.429	.739	.125	-.682	-.175	-3.431	34	.002

4.5.3.1. Group differences

Ratings were compiled into different groups to compare the results between groups. Comparisons were made between the participants who had published in their main area of expertise relevant to the study (n = 21) and missing data (n = 3) and the participants who had no publications in their main area of expertise relevant to the study (n = 14) and missing data (n = 1) using an independent samples t-test. The participants with no publications rated inappropriate sexual behaviour, alcohol abuse, substance abuse, signs of penetration and running away from home as significantly less accurate as signs of abuse in children with disabilities than did the group with at least one publication, whereas they rated poor self-esteem, eating/appetite disturbance and emotional problems as significantly more relevant than did the participants who had published in their main area of expertise relevant to the study. For the other signs of abuse (n = 20), no significant differences were seen between the two groups. Only the significant results are presented in Table 4.9 (n = 8).

A second group comparison was carried out using an independent samples t-test, comparing participants with experience from more than 20 known cases of abuse against children with disabilities (n = 22) missing data (n = 1) and participants with experience from less than 20 known cases of abuse (n = 13), missing data (n = 3). For these two groups, smaller differences in mean ratings were found, producing no significant differences in ratings for any of the signs of abuse.

Table 4.9

Group Comparison Using Independent Samples T-test in SPSS

Sign of abuse	**Participant group**	**N**	**Mean**	**Std. Dev.**	**Df**	**T**	**Sign (*p*<0.05)**
Poor self-esteem	No publ. Publ.	14 23	1.43 2.04	.646 .976	35	-2.1	.044
Inappropriate sexual behaviour	No publ. Publ.	14 23	2.79 1.96	1.188 .638	35	2.8	.009
Alcohol abuse	No publ. Publ.	14 22	4.14 3.14	.959 1.082	34	2.8	.007
Substance abuse	No publ. Publ.	14 22	4.07 3.05	.997 1.133	34	2.8	.009
Signs of penetration	No publ. Publ.	14 22	2.79 1.59	1.805 1.008	19,22	2.3	.036
Running away from home	No publ. Publ.	14 22	3.64 2.50	1.646 1.012	19,31	2.3	.031
Eating/appetite disturbance	No publ. Publ.	14 21	2.14 2.95	.949 1.071	33	-2.3	.029
Emotional problems	No publ. Publ.	14 21	1.71 2.52	.914 .928	33	2.5	.016

4.5.3.2. Ratings of additional signs of abuse

In the last section of the survey, participants were invited to add and rate additional signs of abuse in children with disabilities that they had encountered in their clinical work or research, using the same 7-point Likert scale (Table 6). Eleven participants provided 40 additional behavioural signs and 10 additional physical signs, all rated as accurate, ranging from 1 = Very accurate to 3 = Slightly accurate. The signs of abuse were analysed using a deductive analysis. Initially, signs that had been volunteered by participants that were synonymous with signs that were already included the survey and had thus already been rated by the participants were removed. Secondly, similar signs of abuse that had been volunteered by different participants were combined with each other. The process was carried out using a consensus discussion between the three authors. After these two steps, 23 signs of abuse volunteered by participants remained. The signs are presented in Table 4.10 with the number of entries and mean rating. The signs provided by the participants in free text were compared to the signs extracted from the rapid review that were not included in the survey, as they had less than five notations. Sixteen of the 23 signs that were provided by the participants had also been extracted from the publications in the rapid review and are marked with cursive font in Table 4.10. However, only seven of the signs were provided more than once (and none more than by three participants), confirming that they were considered as more unusual signs of abuse in children with disabilities.

Table 4.10

Signs of Abuse and Rating Provided by the Participants

Nr	Sign of abuse	Rating (mean)	Nr of entries
	Behavioural signs		
1	*Hypervigilant, guarded/insecure behaviour*	1.7	3
2	Anxiety or reluctance to be in the presence of or be left alone with a particular person or to go to a particular place/room, behavioural avoidance	1.7	3
3	*Inappropriate laughter, grimacing or unusual smile, problems with emotion regulation*	2	3
4	*Child expressing fear of parent/other, fear of specific caregiver*	1.5	2
5	Change in child’s behaviour without any other explanation, sudden change in behaviour	1.5	2
6	*Problems developing friendships with others, lack of social skills*	1.5	2
7	*Child describing parent/other in ONLY positive ways (overcompensating), odd interaction patterns with parent*	2	2

Nr	Sign of abuse	Rating (mean)	Nr of entries
8	*Schoolastic difficulties*	1	1
9	*Attachment disorder*	1	1
10	*Loss of earlier abilities*	1	1
11	*Somatisation (complaints about body pains)*	2	1
12	*Uncritical behaviour amongst strangers*	2	1
13	*Dissociation*	2	1
14	Problems with emotion regulation	2	1
15	Non-independent behaviour, attachment disorder	2	1
16	*Selective mutism*	3	1
17	*Restlessness, increased motor activity*	3	
	Physical signs		
18	*Enuresis, encopresis*	2.7	3
19	Discharge from vagina or penis	1	1
20	Venereal disease	1	1
21	*Pregnancy*	1	1
22	*Bite marks and sucking marks on child's body and neck*	2	1
23	Frequent bladder infections in females	2	1

4.5.3.3. Comments on the survey

Twenty participants chose to give free-text comments at the end of the survey. Comments that were just complimentary were removed and the remaining comments were analysed using thematic analysis. Four themes were identified, namely (1) Methodological considerations; (2) Children with disabilities; (3) Signs of abuse and (4) Preventing abuse.

The "Methodological considerations" theme included three codes: methodological considerations/age (n = 5), methodological considerations/type of disability (n = 5), methodological considerations/lack of context (n = 3). Comments regarding methodological considerations/age included referring to participants experience as an influence on their rating of signs, or suggesting that rating could have been improved if the population had been divided into different age groups. The code methodological considerations/type of disability included comments wanting more clarity on the types of disabilities referred to in the survey or suggesting that the population were divided into different disabilities as a way of enhancing the rating. Methodological considerations/lack of context referred to the fact that the signs of abuse and the definitions were presented without any contextual information such as disability or environment of the child. One participant wished to be able to leave comments on each rated sign of abuse, to provide context to the rating.

The theme "Children with disabilities" contained five codes, namely communication implications (n = 4), caregiver considerations (n = 3), increased vulnerability (n = 3), type of disability affects the accuracy of signs/ symptoms (n = 4) and gullibility (n = 1). Communication difficulties referred to the fact that children with disabilities can have difficulties with communicating about abuse, understanding that they have been abused and understanding different types of abuse. Caregiver considerations refer to both their unique position in being able to understand the child, especially if there are communication difficulties, as well as the need for professionals to analyse the interaction of the child and caregivers to gain more insight into the relationship and potential abuse. The code increased vulnerability included comments that children with disabilities, due to physical and/or cognitive restraints, are more vulnerable of becoming victims of abuse. The code gullibility refers to a comment saying that children with disabilities might be more easily deceived into not telling about abuse or believing when being told that the abuse isn't harmful. The final code in this theme consists of comments from participants stating that different disabilities present with different signs of abuse, and that a behaviour (e.g., aggressive behaviour) could be interpreted as typical behaviour for children with specific types of disabilities, but concerning and as a potential sign of abuse in children with other types of disabilities.

The theme "Signs of abuse" contained six codes, unspecific signs (n = 5), specific signs (n = 5), not decisive signs (n = 7), same signs (n = 1), no signs (n = 2) and types of abuse (n = 1). Unspecific signs referred to comments saying that many different signs or symptoms could be seen as signs of abuse, and that they could be very unspecific. Specific signs included participants providing signs that they thought were accurate as signs of abuse in children with disabilities, such as behaviour changes, PTSD, aggression and bruising in specific locations. Several participants commented that the signs of abuse presented in the survey was not decisive and could not be used in isolation as definite signs of abuse as they could well also be present without any abuse history. Two participants said that children with disabilities often display the same signs as children without disabilities, whereas two comments wanted to bring attention to the fact that many children with disabilities do not present with any signs at all, even though they have been victims of abuse. Lastly, one participant stated that the different types of abuse (e.g., sexual abuse or physical abuse) are linked to specific signs.

The theme “Preventing abuse” contained four codes, namely investigation (n = 1), specific abuse prevention strategies (n = 3), case history (n = 1) and listening and believing (n = 1). Investigation refers to the need to investigate suspected abuse thoroughly without scaring the child. The code abuse prevention included comments that claimed that the most important thing for this population was using individualised abuse prevention methods that are specifically adapted for children with disabilities. The importance of getting a case history to be able to detect abuse was highlighted in one comment. Another comment stated the need for persons such as teachers to be attentive and not discounting reports of abuse from children with disabilities.

4.5.4. Discussion

The purpose of the present study was to identify and socially validate signs of abuse in children with disabilities using a two-phase study. None of the signs included in the present study received an overall mean value that indicated them as inaccurate as signs of abuse in children with disabilities. The lowest rating of the included signs of abuse in the study had a mean value of 3.67 (dominant behaviour), indicating a level of neither accurate nor inaccurate–slightly accurate. These results were expected as the signs were derived from published literature on the topic. However, results from the social validation phase of the study suggest that the perceived accuracy of signs of abuse in children with disabilities differ between signs. The top 10 rated signs were perceived as significantly more accurate as signs of abuse in children with disabilities than the bottom 10 rated signs. The sign with the highest perceived accuracy was PTSD, which is interesting as it is has been described as potentially challenging to diagnose in persons with disabilities (Kildahl et al., 2020). Poor self-esteem, withdrawal and anxiety were similarly rated as moderately accurate- very accurate, although the differences between each sign were small.

The differences in ratings between the participants with no publications and the participants who had published in their main area of expertise relevant to the study could be regarded as a potential difference between participants who were primarily clinicians or primarily researchers (with some exceptions). It is possible that the difference in rating was linked to the signs of abuse that children with disabilities present within the clinical world in contrast to the signs of abuse that are most often described in research on the topic. For example, alcohol abuse and substance abuse in individuals with intellectual disabilities have been explored in research (Carroll Chapman & Wu, 2012) as well as signs of penetration as a sign of abuse in children with disabilities (Akbas et al., 2009; Wissink et al., 2018) However, these signs might not be the most typical sign that children present within a clinical setting, if one is not conducting a forensic examination (in the case of signs of penetration) or working with older children/teenagers (in the case of alcohol abuse and substance abuse). In contrast, symptoms such as poor self-esteem, eating disturbances and emotional problems may more frequently be present and observable in a clinical setting.

Participants were given the opportunity to provide signs of abuse and rate them towards the end of the survey. These signs were seemingly based more on the specific nature of the participants’ clinical work or research practice. None of these signs were mentioned more than three times, even though 23 different signs were described, pointing to the plethora of possibilities. Many of the signs had also been extracted during the rapid review but not included in the survey as they had too few notations, and thus were deemed less common. The additional signs of abuse provided by the participants reflect the difficulty that is inherent with analysing and understanding signs of abuse in children with disabilities, namely the unspecific nature of the signs of abuse and the fact that some children with disabilities present no signs of abuse at all. This was also mentioned by some participants in the comment section of the survey.

Hypervigilance, insecure behaviour and changes in behaviour were mentioned several times as a strong potential indicator of abuse. This includes a change in behaviour towards a certain person or situation, or a general behaviour change or avoidance. Careful enquiry and observation of the child’s behavioural history and current behaviour could be important ways to detect potential abuse. Difficulties with relationships or anxiety revolving around specific individuals or situations were also mentioned and could be important factors when reviewing case history.

All of the signs included in the present study can also be linked to other causes than abuse, as pointed out by some participants. This is in itself a risk, as attributing potential signs of abuse to the child’s disability, without further investigation, could lead to abuse going undetected (Miller & Brown, 2014). Disablist attitudes and beliefs regarding children with disabilities capabilities and quality of life (Miller & Brown, 2014) as well as beliefs that children with disabilities are not abused (Stalker et al., 2010) can further increase the risk of both experiencing abuse, and that the abuse goes undetected (Franklin & Smeaton, 2017). Additionally, disempowerment, over protection, social isolation and a lack of education regarding sexuality and relationships can make children with disabilities more susceptible to experiencing abuse (Franklin & Smeaton, 2017).

Comments on the survey suggested that many different behavioural signs or physical signs could be signs of abuse, but that abuse could manifest differently in different children and that some children might not show any of the mentioned signs, even though they had been abused. To further complicate matters, some signs of abuse presented in this study could also be potential risk factors for abuse, such as low self-esteem, which could in turn be an effect of disablist attitudes. This bi-directional influence of attitudes, risk factors and potential signs of abuse complicates the detection and hindering of abuse. These comments underpin the need for a holistic view and assessment of signs of abuse as well as the need for skilled professionals with knowledge and understanding of abuse, trained at making judgments about the presence of abuse in children with disabilities (Franklin & Smeaton, 2017; Hernon et al., 2014; Miller & Brown, 2014). The importance of empowering children, believing children who disclose abuse and taking action should be highlighted in the training of professionals (Franklin & Smeaton, 2017). Additionally, caregivers and individuals close to the child who know them well play an important role in recognising and spotting potential signs of abuse (Hernon et al., 2014).

4.5.5. Methodological considerations

Participants provided comments at the end of the survey linking to methodological considerations for the study. Some participants felt that the rating process was difficult, as the signs of abuse lacked context such as age of the child or the specific disability of the child. This lack of context could have influenced their rating of the signs of abuse. The lack of context was an intentional choice when constructing the survey, as providing context for each sign of abuse would limit the rating to just that specific situation/disability, when the researchers wanted to rather produce a general rating of commonly described signs of abuse in children with disabilities. Additionally, the option to provide comments to each rated sign of abuse was considered during the development process but was deemed unsuitable as it could potentially narrow the results to the specific context that participants described. However, these suggestions could be considered for future studies within this field.

4.5.6. Limitations of the study

Although a concerted effort was made to recruit experts in the field who would have knowledge on this complex topic, the number of participants was limited. The intersection of the topics of disability and child abuse is not well researched and consequently, few professionals or researchers can claim expertise in this area. However, when considering the participant description, it is clear that many prominent scholars in the field participated. As the rapid review methodology is not as theoretically sound as the more extensive systematic review methodology (Khangura et al., 2012), social validation was used to enhance the process by confirming the results of the rapid review. Several participants highlighted that "children with disabilities" is a large and heterogeneous group, which includes babies, toddlers, middle-schoolers, and teens as well as different disabilities such as autism, cerebral palsy and Down's syndrome, and that the signs of abuse were presented in the survey without context, making the rating process more difficult.

4.5.7. Conclusions

Findings from the study conclude that an international expert panel rated signs of abuse in children with disabilities derived from a rapid review on the topic as accurate. The perceived level of accuracy was significantly different between the 10 signs that were rated the highest, compared to then 10 lowest rated signs. The results should not be used as a checklist, but rather as guidance for clinicians, teachers, and parents in which signs could present in a child with disability that have been abused. The results should be viewed as preliminary due to the small sample size and the sensitive nature of the topic and should be used with caution. However, the prevailing problem we stand before today is not that abuse against children and adults with disabilities is being over-reported, but rather under-reported (Hernon et al., 2014; Nareadi, 2013; Willott et al., 2020). Thus, this paper could provide some insight into which signs of abuse appear to be most accurate for this population.

This is the end of the excerpt of the pre-print version of "*Signs of abuse in children with disabilities: A rapid review with expert panel social validation*" by Nyberg et al. (2021c).

4.5.8. Conclusion of Phase 1.3

Phase 1.3 focused on identifying and describing potential signs of abuse in children with disabilities by conducting a rapid review of the extant literature, extracting signs of abuse in children with disabilities and subsequently socially validating them by using an expert panel. The results show that all the signs of abuse extracted from the review were perceived as accurate, thereby confirming the results from the rapid review, however, the level of accuracy differed between the signs. The 10 most accurate signs were rated as significantly more accurate than the 10 lowest rated signs. The highest rated sign was PTSD, and the lowest rated sign was dominant behaviour. Furthermore, participants commented that the behavioural and physical signs that were included in the survey could also be linked to other causes, and that some children with disabilities who had been abused might not show any signs of abuse. They also highlighted the importance of interpreting potential signs of abuse within the context of the child and that child's disability.

4.6. Conclusions of Phase 1

As is typical in the first phase of sequential mixed method designs (Creswell & Creswell, 2018), this phase of the study consisted of rich, qualitative and quantitative data from three sources, namely a scoping review, focus groups and interviews, and a rapid review followed by social validation. As described in the conceptual framework, Phase 1 focused on assessing the current situation, reviewing, and exploring existing programs, selecting programs, consulting with stakeholders and experts and exploring the level of adaptation of selected programs that would be required to suit the needs of the target population (children with communicative and/or cognitive disabilities) (Table 3.2).

Results from Phase 1 provided information on the key components, outcome measures and evaluation methods used in school-based abuse prevention programs for 7–12-year-old children as well as the key components, teaching methods and adaptations that should be included in such a program. Additionally, the results highlight the potential challenges to the implementation of such programs as well as the role that parents can take on in school-based abuse prevention programs. Furthermore, stakeholder's knowledge of signs of abuse in children with disabilities is important to prevent and detect abuse. Information on the relevance and accuracy of signs of abuse in children with disabilities was provided in the third and last stage of this phase.

4.7. Implications for Phase 2

The results from Phase 1 suggest the need for developing guidelines of school-based abuse prevention programs to suit the specific needs of 7–12-year-old children with communicative and/or cognitive disabilities. These suggested adaptations include changes to both the content and the teaching methods used, as well as training teachers in abuse and abuse prevention and involving parents in school-based abuse prevention programs. Furthermore, it is suggested that signs of abuse in children with disabilities should be included in such guidelines to help further teachers' knowledge on this complex topic. There are research-based school-based abuse prevention programs for primary school aged children available, and different programs are already established and used in different schools, contexts, and countries. Therefore, developing guidelines of school-based abuse prevention programs for children with communicative and/or cognitive disabilities was viewed as a more beneficial and cost-effective (financially and human resources) research strategy than developing a new program.

4.8. Summary

This chapter focused on Phase 1 of the study which included three diverse data sources spread across different sub-phases. Phase 1.1 included a scoping review of school-based abuse prevention programs for 7–12-year-old children and showed that similar components and methods were used in many of the included nine studies with safety skills included in all as an outcome measure.

Phase 1.2 incorporated qualitative methods (i.e., focus groups and interviews) to explore the perceptions of stakeholders regarding the topic at hand. Findings suggested that several adaptations in both the teaching methods and materials are required to enable successful participation from children with communicative and/or cognitive disabilities. The importance of training teachers and giving information to parents regarding child abuse, and specifically about abuse against children with disabilities, was highlighted.

Phase 1.3 included a rapid review followed by a social validation of the results from the rapid review by means of a survey. Participants rated signs of abuse according to the perceived level of accuracy and could also provide additional signs. Results show that all included signs of abuse were perceived as potentially accurate, but a significant difference in perceived accuracy was found between the lowest rated signs and the highest rated signs. The results highlight the need for teachers and parents to be aware of potential signs of abuse in children with disabilities, to prevent ongoing abuse from continuing.

CHAPTER 5

PHASE 2: DEVELOPMENT PHASE

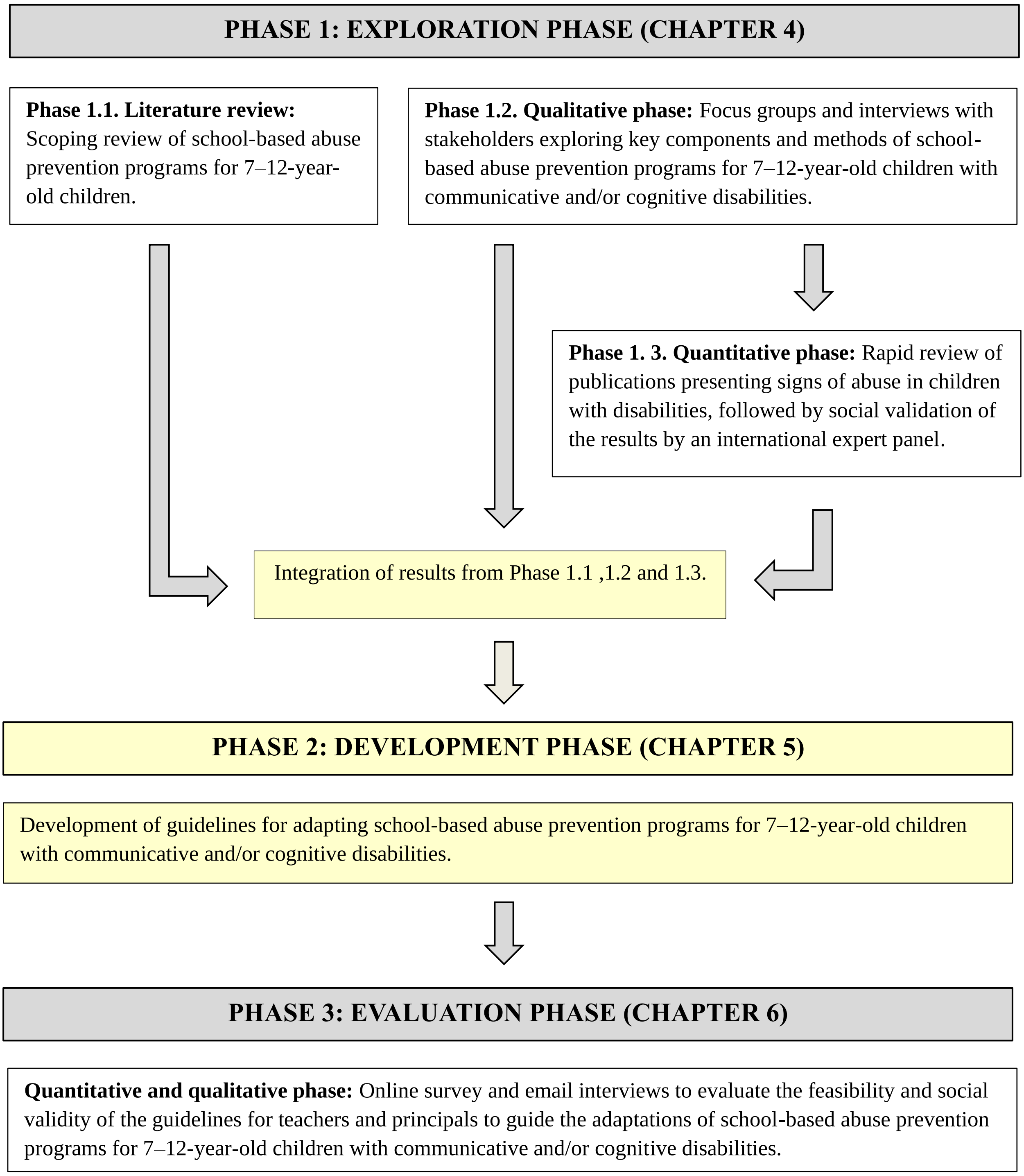
Research methodology and results

5.1. Introduction

This chapter describes Phase 2 of the study and focuses on the development of the guidelines for teachers on how to adapt school-based abuse prevention programs for 7–12-year-old children with communicative and/or cognitive disabilities. This was done by using integrated data from Phases 1.1, 1.2 and 1.3 as was described in Chapter 4. Chapter 5 begins with the main aim as well as the sub-aims for Phase 2, as highlighted in Figure 5.1, and then goes on to describe the research methodology and results of this phase (i.e., the guidelines) before concluding with a summary. The preceding chapter (Chapter 4), the current chapter and the following chapter (Chapter 6) should thus be read in conjunction as outlined in Figure 5.1.

Figure 5.1

Three-phase Exploratory Sequential Mixed Methods Design with Current Phase Highlighted



PHASE 1: EXPLORATION PHASE (CHAPTER 4)

Phase 1.1. Literature review: Scoping review of school-based abuse prevention programs for 7–12-year-old children.

Phase 1.2. Qualitative phase: Focus groups and interviews with stakeholders exploring key components and methods of school-based abuse prevention programs for 7–12-year-old children with communicative and/or cognitive disabilities.

Phase 1. 3. Quantitative phase: Rapid review of publications presenting signs of abuse in children with disabilities, followed by social validation of the results by an international expert panel.

Integration of results from Phase 1.1 ,1.2 and 1.3.

PHASE 2: DEVELOPMENT PHASE (CHAPTER 5)

Development of guidelines for adapting school-based abuse prevention programs for 7–12-year-old children with communicative and/or cognitive disabilities.

PHASE 3: EVALUATION PHASE (CHAPTER 6)

Quantitative and qualitative phase: Online survey and email interviews to evaluate the feasibility and social validity of the guidelines for teachers and principals to guide the adaptations of school-based abuse prevention programs for 7–12-year-old children with communicative and/or cognitive disabilities.

5.2. Aims

The main aim and sub-aims for Phase 2 are presented below.

5.2.1. Main aim: Phase 2

The main aim of Phase 2 is to integrate data from Phase 1 using a recursive abstractive thematic analysis approach to allow for the development of guidelines that could be used by teachers with the support of principals to adapt existing school-based abuse prevention programs for 7–12-year-old children with communicative and/or cognitive disabilities.

5.2.2. Sub-aims

The following specific sub-aims were identified in order to achieve the main aim for this phase:

i) To integrate the results from Phases 1.1 to 1.3 using a recursive abstractive thematic analysis approach focused on recommendations for adapting school-based abuse prevention programs for 7–12-year-old children with communicative and/or cognitive disabilities.

ii) To develop the content of the guidelines aimed at teachers and principals based on the integrated results.

iii) To design the guidelines by including considerations regarding language, layout, structure, and formatting, according to the methodology described in this chapter.

5.3. Research process

Guidelines can be defined as a document with recommendations pertaining to a certain field or disciplinary area (Wang et al., 2018) – in this case education and more specifically, the education of children with communicative and/or cognitive disabilities. Practice guidelines in particular, are aimed at influencing the decision-making process of service providers in the field (i.e., in medicine, practice guidelines are directed towards healthcare practitioners and in education towards teachers and principals) (Tetreault et al., 2019). Therefore, it is important that guidelines are perceived by stakeholders as being trustworthy and in order for this to transpire, guidelines should reflect a strong evidence-base and be developed using a structured and explicit process (Shalala et al., 2011).

In the report "Clinical practice guidelines we can trust" (Institute of Medicine (US), 2011, p. 25), clinical practice guidelines are defined as, "…statements that include recommendations intended to optimize patient care. They are informed by a systematic review of evidence and an assessment of the benefits and harms of alternative care options". Although the guidelines produced in this PhD-study are not aimed at healthcare practice per se, but focuses on the school context, these guidelines are informed by a recursive abstractive thematic analysis review of the evidence (in this case three different data collections methods) and aim to benefit the intended target population, namely children with communicative and/or cognitive disabilities. Extensive research has been conducted on how best to develop (clinical) practice guidelines and several reports (Institute of Medicine (US), 2011; World Health Organization, 2014) have been published on the topic, thereby providing a well-researched foundation for guideline development. Thus, it was deemed suitable to use a modified version of the suggested development process for clinical practice guidelines in the present study.

As abuse against children is considered a significant public health issue worldwide (Djeddah et al., 2000) which not only impacts children's mental health and well-being immediately after the abuse, but also in the long-term (Shaw & De Jong, 2012), the guidelines have been developed to minimise the impact of abuse against children with disabilities as a public health issue by facilitating adaptations and implementations of school-based abuse prevention programs for children with communicative and/or cognitive disabilities by teachers and principals.

5.4. Guideline development

Shekelle et al. (1999) originally described the guideline development process as identifying and refining the topic of a guideline, gathering, and running a guideline development group, assessing the evidence, translating the evidence into recommendations, and externally reviewing the guidelines. Twenty years later, Tetreault et al. (2019) presented similar steps to the development of clinical practice guidelines. The first step is identifying the critical knowledge gaps in the field and defining the clinical problem. The second step includes developing a systematic review and clinical practice guidelines and assessing benefits and harms, acceptability and feasibility, impact and use of resources of the intervention and thereafter developing and rating the recommendations. The third and final step includes developing (clinical) knowledge through the assessment of barriers to implementation, monitoring the use of the recommendations, evaluating the outcomes and updating the guidelines (Tetreault et al., 2019). In addition, The Institute of Medicine (US) (2011) describes the criteria to ensure trustworthiness in guidelines as follows:

i) being based on a systematic review of the existing evidence;
ii) being developed by a well-informed multi-disciplinary panel of experts and representatives from the patient groups;
iii) considering patients' perspectives;
iv) being grounded in a clear, transparent and un-biased process;
v) providing a clear description between treatment options and health outcomes;
vi) providing ratings of the strength of the recommendations as well as the quality of evidence; and

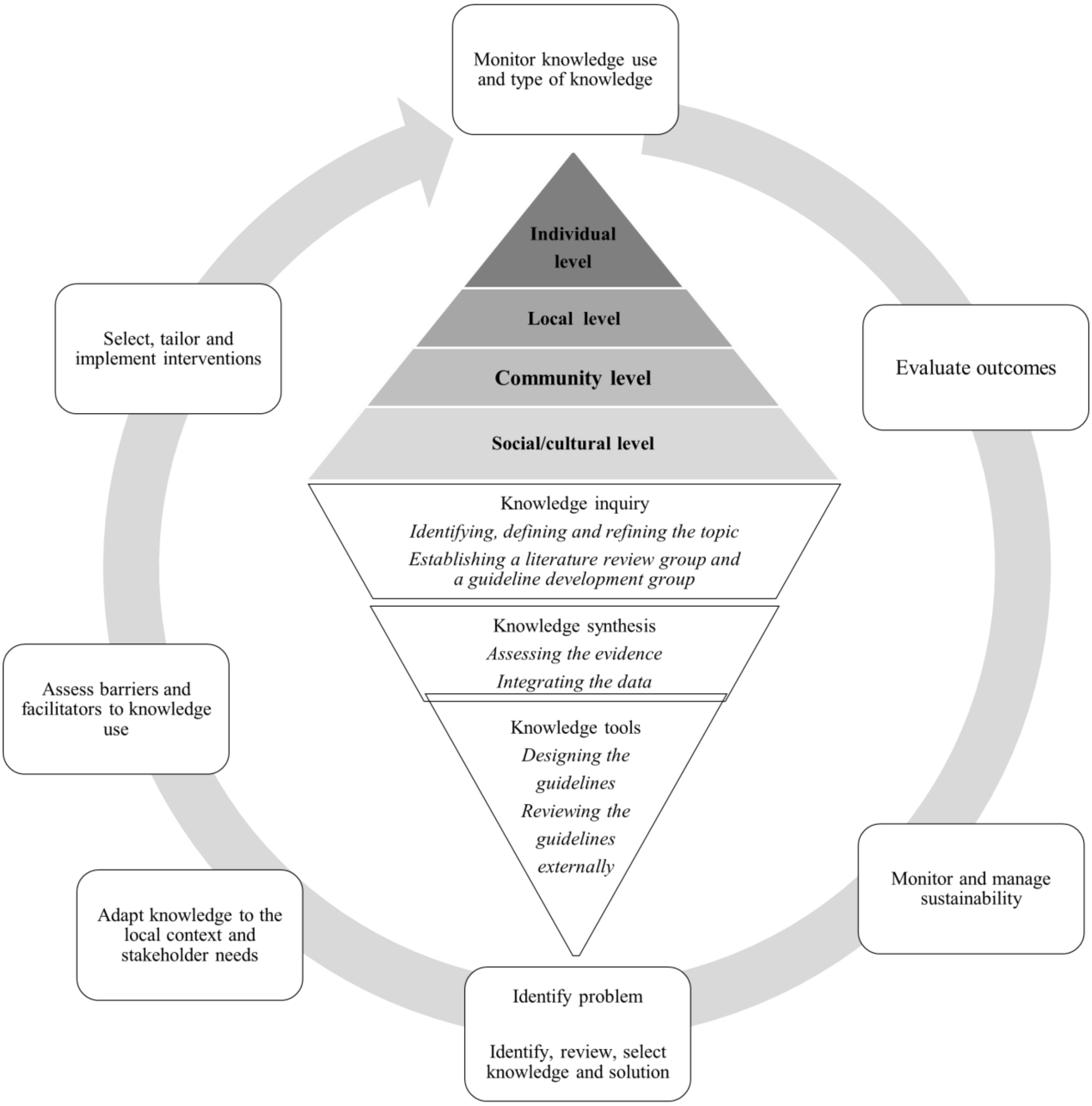
vii) being appropriately revised when new evidence surfaces.

As these described processes for guideline development are similar, a combination of the steps using the theoretical framework described in Chapter 2 was used and applied in this study to develop guidelines for adapting school-based abuse prevention program for primary school aged children with communicative and/or cognitive disabilities.

The following steps of the conceptual framework also guided and informed the guideline development process: identifying barriers and concerns in the original programs related to the target population and implementation as well as differences in risks and protective factors in original population and target population, identifying the need for adaptations while retaining core elements, developing an adaptation plan, maintaining key components, constructing adaptations to suit the target population, considering relevant local and cultural adaptations, including stakeholder advice in the guidelines, providing recommendations for stakeholders, producing the guidelines, and including recommendations for stakeholder training, implementation, and evaluation (Table 3.2). The guideline development process is outlined in Figure 5.2 and subsequently described in depth in this chapter.

Figure 5.2

Outline of Guideline Development Process in the Present Study



5.4.1. Development of the content of the guidelines

In order to realise the second sub-aim of Phase 2, knowledge was created through the knowledge funnel which in this phase included knowledge inquiry by identifying, defining and refining the topic and establishing a literature review group and a guideline development group, a knowledge synthesis by assessing the evidence and integrating the data and the development of knowledge tools by designing the guidelines and reviewing them externally (Figure 5.2).

5.4.2. Knowledge inquiry

This step includes identifying, defining, and refining the topic at hand as well as establishing both a literature review group and a guideline development group.

5.4.2.1. Identifying, defining, and refining the topic

The initial step of developing practice guidelines is to define and identify the scope of the problem and to investigate the need and feasibility of developing guidelines for the topic at hand (Shekelle et al., 1999; Tetreault et al., 2019; World Health Organization, 2014). The development of practice guidelines should be considered high priority if there is a notable burden as a result of the topic (i.e., child abuse in this case), uncertainty on the topic and a potential to improve quality of life (Shekelle et al., 1999; Tetreault et al., 2019), as is the case of abuse against children with disabilities and abuse prevention methods aimed at this population. Although there are several available school-based abuse prevention programs targeting children, these programs have not been adapted for children with disabilities and particularly not for children with communicative and/or cognitive disabilities, as established in Phase 1. Due to their unique needs and challenges, these children would require a program that address difficulties relating to both communication and intellectual functioning, such as problems with expressive language (i.e., verbally expressing oneself), receptive language (i.e., understanding language) or both. To avoid the development of yet another abuse prevention program which is costly both in terms of financial and human resources, an alternative route, such as the development of guidelines that recommend adaptations that can be applied to any existing school-based abuse prevention program, was considered appropriate. This approach also enables the further strengthening of the existing evidence-base of already established programs as they can be adapted and tried for new populations. As have been demonstrated in previous chapters in this thesis, abuse against children with disabilities is a worldwide concern affecting millions of children resulting in severe consequences such as low quality of life (Afifi et al., 2007), poor health (Leeb et al., 2011), substance abuse issues and mental health problems (Strathearn et al., 2020), as well as economic challenges (Currie & Widom, 2010). Furthermore, implementing abuse prevention programs with children at a young age might minimise the risk of being abused during pre-adolescent years, when the risk of sexual abuse could be increased (Chen et al., 2010). Therefore, the need for the development of guidelines of school-based abuse prevention programs for 7–12-year-old children with communicative and/or cognitive disabilities should be considered as being a high priority.

5.4.2.2. Establishing a literature review group

The proposed literature review group should be multi-disciplinary in nature and include research experts (Tetreault et al., 2019). The literature review group in the present study consisted of the student, the study supervisors and a research librarian supported by a peer-group of 13 fellow PhD-students with varying professional disciplinary backgrounds, including speech-language therapy, clinical psychology, education, and occupational therapy. Each person has practical experience related to their respective disciplines of working in the field of disability. Furthermore, both literature reviews conducted as part of the study (Phase 1.1 and 1.3) were published in international, peer-reviewed accredited journals, implying that they had undergone a stringent peer-review process.

The overall purpose of a literature review, irrespective of the specific typology, is to identify gaps in the research evidence and analyse and describe those gaps (Munn et al., 2018). For the specific purpose of Phase 1.1 of the current study, a scoping review rather than a systematic review was considered to be appropriate as the purpose was to identify and map the available research evidence on the topic (Arksey & O'Malley, 2005). The review specifically aimed to identify key characteristics relating to school-based abuse prevention programs (Munn et al., 2018) as well as to identify barriers and concerns linked to the target population which were included in the review. The outcome of this study pointed to a need for adaptations to be developed.

For Phase 1.3, a rapid review was conducted using a streamlined version of a systematic review protocol (Tricco et al., 2015). Its specific aim was to identify signs of abuse in children with disabilities which were described in the research literature and evaluate the social validity of those signs. The outcome of the rapid review highlighted that there was a difference in the perceived accuracy of signs of abuse in children with disabilities and that signs of abuse should be viewed in context.

In the steps related to the review of the literature, it is recommended to follow a systematic review process by including the following ten steps:

i) registering the protocol;
ii) developing the clinical question/problem;
iii) outlining detailed inclusion and exclusion criteria;
iv) determining databases to be searched;
v) developing the search strategy;
vi) reviewing studies according to inclusion and exclusion criteria;
vii) extracting relevant data;
viii) assessing risk of bias of each study;

ix) summarising findings; and

x) evaluating the risk of bias across the studies (Tetreault et al., 2019).

For both reviews conducted in the study, steps ii) to vii) and step ix) were followed in the exact same manner, however, steps i), viii), and x) differed as the protocol was not registered and the risk for bias was not assessed. The purpose of both the scoping review and the rapid review was not to assess the quality or the overall results of the studies included in the review, but rather to map the evidence and extract data on specific components (e.g., key components, outcome measures and evaluation methods, as well as signs of abuse), thus an assessment of bias or a quality assurance measure of the studies was not included.

5.4.2.3. Establishing a guideline development group

It is recommended that the guideline development group include relevant stakeholders with diverse occupations and backgrounds, including specialists on the topic, stakeholders, caregivers, and researchers (Institute of Medicine (US), 2011; Qaseem et al., 2012; Tetreault et al., 2019). The inclusion of stakeholders is important as they can bring new perspectives and assist in re-focusing the guideline development to those who are affected by the implementation of the guidelines (Institute of Medicine (US), 2011; World Health Organization, 2014). In the present study, the guideline development group consisted of the participants in Phase 1.2 (i.e., teachers in special schools, parents of children with disabilities, psychologists, child interrogators, and forensic nurses working with abused children with disabilities) and in Phase 1.3 (i.e., researchers and clinicians working in the field of child abuse, or in disability, or in both) and the core research group (the student and supervisors).

The overarching purpose of the guideline development group is to review and translate the existing evidence into unbiased practice guidelines (Qaseem et al., 2012). The group should have a leader who is experienced in facilitating discussion and encouraging positive group dynamics, and who will remain neutral during the discussions. Additionally, a vice-chair who can ensure that all stakeholder groups are adequately represented should be included (Tetreault et al., 2019). During the focus groups and interviews, the student acted as the group leader (moderator), facilitating group interactions and discussions whilst remaining neutral. The supervisors acted as the vice-chairs for the entirety of Phase 1, guiding stakeholder representation (participant selection), data collection methods, and the analysis processes.

The process of data collection in the form of focus groups and in-depth individual interviews (Phase 1.2), as well as an online survey (Phase 1.3), allowed participants to express their views on key components, teaching methods and adaptations that should be included in an abuse prevention program for children with communicative and/or cognitive disabilities (Phase 1.2) as well as the social validity of signs of abuse in children with disabilities (Phase 1.3). This data thus provided expert and stakeholder knowledge and views to inform the guideline development (Table 3.2).

In contrast to the typical guideline development process, the final guideline development was conducted by the student and the supervisors. However, member-checking was conducted as participants who were included in Phase 1.2 were given the opportunity to check their answers for accuracy and input on the synthesised results. Additionally, the guidelines that were developed were subsequently evaluated in terms of feasibility and social validity in Phase 3 by employing three stakeholder groups (teachers, principals, and content experts) (Chapter 6).

5.4.3. Knowledge synthesis

This step includes assessing the available evidence and integrating the data from Phase 1.

5.4.3.1. Assessing the evidence

The research evidence that was collected during Phase 1 was assessed in three ways:

i) through peer review and publication in accredited journals (Phase 1.1, 1.2, and 1.3);
ii) through data saturation during focus groups and interviews (Phase 1.2); and
iii) through social validation by an expert panel (Phase 1.3).

Furthermore, the study employed both data source triangulation and methods triangulation as described in Chapter 3 (Table 3.1), further strengthening the evidence, and ensuring diversification. Diversification is a preferred approach when developing guidelines, as the relevance of a study cannot rely on the design alone, but also depends on the ability of the design to answer the research questions linked to the guideline development (Beauchamp et al., 2015). In addition to diversifying the data sources, the diversification of the types of data that are included in the guidelines has also been advocated, namely scientific data, contextual data, and experiential data (Beauchamp et al., 2015).

Scientific data (i.e., research evidence) is used when developing practice guidelines, by synthesising results from a systematic review into practice recommendations (Tetreault et al., 2019). In the present study, scientific data was collected through the scoping review on school-based abuse prevention programs for 7–12-year-old children (Phase 1.1) and through the rapid review on signs of abuse in children with disabilities (Phase 1.3).

Contextual data (i.e., the specific conditions surrounding an intervention, such as the setting, the surrounding environment, governmental or institutional policies, relationships between professionals and clients and caregivers) was also employed to further strengthen the quality of the guidelines (Beauchamp et al., 2015). In the present study, contextual data was collected during focus groups and interviews with stakeholders (Phase 1.2).

Lastly, experiential data (i.e., the experiences and views of stakeholders on a topic) is collected from stakeholders and should be used to inform recommendations for a specific setting, such as special schools (Beauchamp et al., 2015). The purpose of the experiential data is to expand on the scientific and contextual data, but not to replace it. It can therefore be used to gather information about potential hurdles in terms of implementation or harm of an intervention and is typically gathered through interviews or group discussions. In the present study, experiential data was collected in focus groups and interviews (Phase 1.2) as well as during social validation with an expert panel through an online survey (Phase 1.3). As the validity of this data could be compromised due to bias, it is important to employ a transparent and structured process as was done in the present study (Beauchamp et al., 2015).

5.4.3.2. Integration of data

Data on different aspects of guidelines of abuse prevention programs for children with communicative and/or cognitive disabilities was gathered in Phase 1, using three different data sources as explained earlier. The three sources each feed into different aspects of the guideline development adaptations, as per the conceptual framework.

The integration of data was conducted using a recursive abstractive thematic analysis process (Table 5.1). It started with recursive abstraction - a six-step method that is useful for analysing interview data (Polkinghorne & Arnold, 2014). Interesting data is highlighted and extracted into a table (Step 1 and 2), data is then paraphrased (Step 3), grouped into themes (Step 4), coded (Step 5), checked for accuracy, patterns are identified and recommendations are formulated (Step 6) (Polkinghorne & Arnold, 2014). However, as the recursive abstraction methodology currently still has a limited research-base, it was supplemented by the more well-known and commonly used reflexive thematic analysis (Braun & Clarke, 2006). Thematic analysis is a method used for identifying patterns within data as well as analysing and reporting those patterns by also using a six-step process including: familiarising oneself with the data, generating initial codes, searching for themes, reviewing themes and codes, defining and naming themes and constructing a code book (Braun & Clarke, 2006).

As the integration of the data highlighted teachers as the key implementors of school-based abuse prevention programs and principals as the facilitators for the implementation, in line with the results that were found when reviewing the literature (Chapter 2), a decision was made to let these results guide the focus of the guidelines, thus aiming the guidelines at those two groups. For a comprehensive account of all the data that was integrated, please see Appendix E.

Table 5.1

Recursive Abstractive Thematic Analysis Process used in the Integration of Data

Step	Method	Description
1	Recursive abstractive process	Findings from Phases 1.1, 1.2, and 1.3 were reviewed. Each publication was read twice, then interesting data and key findings were highlighted. Subsequently, the highlights were checked and expanded/retracted if necessary (Polkinghorne & Taylor, 2022).
2	Recursive abstractive process/ Thematic analysis	The highlighted quotes/sections were transferred to a separate table and re-worded and grouped into themes (Polkinghorne & Taylor, 2022). This was carried out through an iterative process, which entailed re-visiting the data and asking the three questions: *What are the data telling me?*; *What is it that I want to know?* and *What is the dialectical relationship between what the data are telling me and what I want to know*? (Srivastava & Hopwood, 2009). Initial themes were suggested (Braun & Clarke, 2006).
3	Thematic analysis	The initial themes were refined and grouped into guideline themes (Braun & Clarke, 2006).
4	Thematic analysis	Recommendations were gathered according to themes and further edited and condensed using an iterative process (Srivastava & Hopwood, 2009). As providing guidelines for school-based abuse prevention programs aimed at teachers and principals was the focus, information and recommendations that pertained to other organizations (e.g., government and policy development departments) and stakeholders (e.g., healthcare professionals) was removed.
5	Recursive abstractive process	Recommendations were re-visited/reviewed and edited for clarity (Polkinghorne & Taylor, 2022).

Step	Method	Description
6	Thematic analysis	Each overarching theme was explained and detailed, using Braun and Clarke's (2006) recommended steps. Themes were also labelled to show which study the expanded recommendation/suggestion was derived from and linked to the BEM (for analysis purposes).

The integrated data, including the themes and quotes, was used to formulate recommendations that would provide the guidelines for adaptations, in accordance with both the theoretical and the conceptual frameworks of this thesis. Core elements of school-based abuse prevention programs were maintained, and recommendations for staff training, parental involvement, adaptations for the local context, implementation and evaluation were included (Table 3.2).

Additionally, practical applications of each recommendation were constructed using the integrated results from Phase 1 as well as the clinical experience of the student to increase the applicability of the recommendations. Subsequently, the guidelines were reviewed and revised by the student in conjunction with the supervisors.

5.4.4. *Knowledge tools*

This step included the design of the guidelines and the external review of the guidelines.

5.4.4.1. *Designing the guidelines*

The design and structure can influence the level of implementation of guidelines (Kastner et al., 2015). In order to address the third sub-aim of this phase, specific considerations were made when designing the guidelines, namely the use of clear language, layout, structure, and formatting to achieve well-developed effective guidelines (Panteli et al., 2019).

To ensure that the guidelines are well accepted and clear, language that is vague and unspecific should be avoided, as this can reflect a limited knowledge base on the topic (Institute of Medicine (US), 2011). The language used should be clear and simple (Kastner et al., 2015) and not include semantic or syntactic ambiguity (Gupta et al., 2016) or ‘disciplinary jargon’. The guidelines should be written in a precise form and include information on the action that is recommended, and under which circumstances that action is recommended (Institute of Medicine (US), 2011). Limited research evidence can affect the ability to make precise recommendations as the evidence might not speak in favour of any particular approach or method (Institute of Medicine (US), 2011). These aspects were all considered in the development of the guidelines, and clear language using appropriate terms and clearly explained concepts was strived for.

In terms of the specific words used to convey the strength of the recommendation, ‘must’ has been found to suggest the highest level of obligation, whereas ‘may’ and ‘may consider’ was found to suggest the lowest level of obligation in clinical practice guidelines (Lomotan et al., 2010). Given the evidence-base of the guidelines produced in the present study, which is limited due to the scope of the available research and the limitations inherent to a PhD-study, specific but non-obligatory language was considered appropriate as the guidelines should be viewed as recommendations, not as conclusive evidence.

A lack of understandable layout and structure has been found to be a barrier to implementation of guidelines (Cochrane et al., 2007). Factors that facilitate the implementation of guidelines that were employed in the guidelines included grouping information according to themes, using a clear and user-friendly layout to decrease the length of the document, making deliberate choices in terms of the placement of visuals, and considering how information should be presented (Gupta et al., 2016). In addition, key recommendations were clearly highlighted and links to additional information were provided

(Kastner et al., 2015). The guidelines included sub-headings and sections, such as introduction, purpose, and recommendations as well as clear information on who the stakeholders were (teachers supported by principals). All of these strategies that were considered during the design and layout of the guidelines have been found to be effective strategies to facilitate implementation of (clinical) practice guidelines (Kastner et al., 2015).

The key information in the guidelines were formatted according to three design principles, namely making it vivid (prominent and standing out), intuitive (matching to the information the stakeholders expectations), and visual (using pictures, figures and other alternatives to text) (Versloot et al., 2015). In accordance with the principle to make key information vivid, the guidelines produced in this study used bold font and capital letters for the first and second-level headings, bold and large font on third level headings, bold font on recommendations, and italics on suggestions for practical applications (Versloot et al., 2015). Additionally, the use of colour coding of themes and the use of bulleting and boxes were strategies employed to make important information stand out and be easy to find in the guidelines (Versloot et al., 2,015). To make the guidelines intuitive, the use of a step-by-step approach, dividing information into clearly outlined steps in a logical approach was used (Versloot et al., 2015). Additionally, headings were used to group information and to increase readability and accessibility (Versloot et al., 2015). Furthermore, numbered pages and an outline of content was used to make the information easy and intuitive to find (Versloot et al., 2015). Finally, information was made visual by including a figure detailing the data sources used to develop the guidelines, placed on the left hand side to facilitate recall (Silayoi & Speece, 2007) as well as an image used as an example of pictorial support for talking about abuse (Versloot et al., 2015).

5.4.4.2. External review of the guidelines

Guidelines should be externally reviewed by stakeholders to ensure that they are applicable, valid, and clear (Qaseem et al., 2012; Shekelle et al., 1999). Potential stakeholders can be experts in methodological content and procedures as well as potential stakeholders of the guidelines (Qaseem et al., 2012; Shekelle et al., 1999; World Health Organization, 2014). The guidelines should be reviewed by individuals or organizations who can be expected to be critical towards the guidelines, such as schools in the present study, as they can draw attention to bias or methodological flaws and provide suggestions on how to improve the messages conveyed in the guidelines (Institute of Medicine (US), 2011). The external review group should be diverse in gender, location and background to bring diverse perspectives to the review of the guidelines (World Health Organization, 2014). If there is a lack of diversity or perspectives in the guideline development group or if key stakeholders are missing in that group, they should be added to the external review group (World Health Organization, 2014). The external reviewers should concentrate on the entirety of the research evidence that was reviewed during the guideline development, the rationale for the recommendations made in the guidelines and how they relate to the evidence-base and the applicability of the guidelines to the setting in which they will be implemented (Institute of Medicine (US), 2011).

In addition to the diversity of both the literature review group and the guideline development group, a diverse panel was selected to review the feasibility and social validity of the guidelines. Two of the members included in this panel had been involved in Phase 1.3. No other members included in the panel had been involved in any of the preceding groups. Particular attention was given to ensure that the school context was represented in the external review group given the focus on school-based abuse prevention in the guidelines. The participants, data collection, analysis, and results of this external review are described in Chapter 6.

5.5. Results

The guidelines commenced with an introduction of the topic, the purpose of the guidelines and the research that the guidelines are based on. Subsequently, the structure of the guidelines was described, and an outline of the content was given. The guidelines comprised of two parts, one which was aimed at principals, and one aimed at teachers. Each section included a theme under which recommendations were derived from the integration of the data from Phase 1.1 to 1.3 and was presented. Themes that were included in the guidelines were linked to the corresponding level of the BEM which informed the theoretical framework for the study. This information was, however, not included in the guidelines provided to the participants in Phase 3 as it was deemed unnecessary and potentially confusing – given the practical focus of Phase 3.

Three themes were aimed at principals, namely:

i) Resources, policies, and collaboration (Community level of the BEM).
ii) Evaluation with teachers (Social/cultural level of the BEM).
iii) Teacher training (Social/cultural level of the BEM).

Five themes were aimed at teachers, namely:

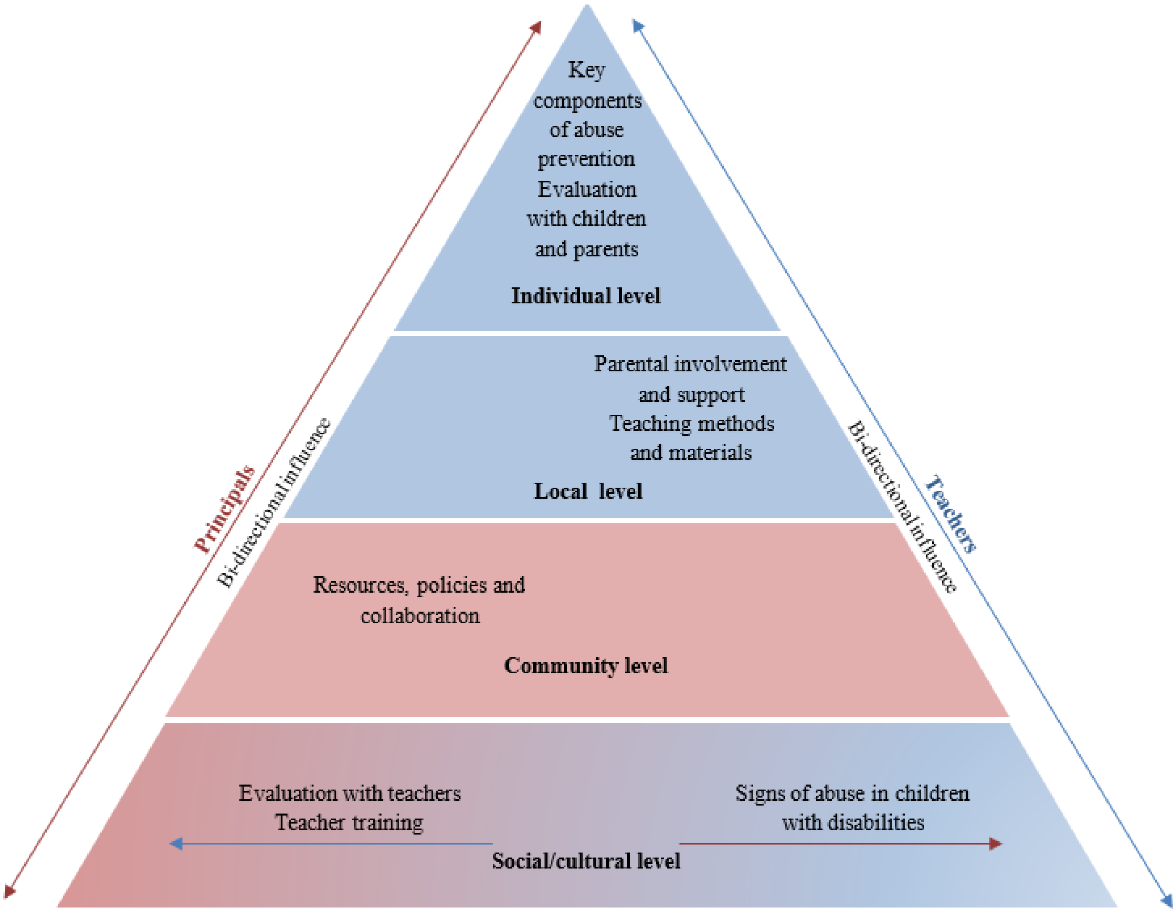
i) Parental involvement and support (Local level of the BEM).
ii) Signs of abuse in children with disabilities (Social/cultural level of the BEM).
iii) Key components of abuse prevention (Individual level of the BEM).
iv) Teaching methods and materials (Local level of the BEM).
v) Evaluation with children and parents (Individual level of the BEM).

Figure 5.3 includes a graphic representation of the themes according to the BEM. From this figure it becomes clear that at the broadest level (i.e., the social/cultural level) there are themes related to both the principals and the teachers. This ensures that the adaptations have a broad and solid base. The themes related to the principals follow next (i.e., resources, policies, and collaboration) which are linked to the community level, while the final two levels of the BEM specifically focus on teachers, with the themes parental involvement and support and teaching methods and materials focused on the local level. Lastly, key components of abuse prevention and evaluation with children and parents pertain to the individual level.

This multi-level approach is considered as best practice approach when addressing multi-systemic challenges (VanderKaay et al., 2021), such as child abuse. Collaborative partnerships between stakeholders with a common understanding of the problem, who share the same vision and follow clear procedures, result in collective capacity building and authentic, functional problem-solving. Not one level of the BEM is more important than another – all four levels are needed to ensure a common understanding across all levels. However, collaboration is a central component of successful multi-level approaches, and therefore, developing a common understanding (e.g., by providing clear guidelines) within and across levels is essential.

Figure 5.3

Guideline Themes According to the Levels of the BEM



Under each recommendation, suggestions of how to realise the recommendations were given. As alluded to earlier, these suggestions were derived from three sources, namely the scoping review on school-based abuse prevention programs (Phase 1.1), the focus groups and interviews with stakeholders (Phase 1.2), the rapid review and social validation of signs of abuse in children with disabilities (Phase 1.3), and lastly, the student's clinical experience as a speech-language therapist with experience in the field of AAC (Chapter 3, Section 3.4.). The guidelines in Section 5.6 show the guidelines exactly as they were provided to participants. Please note that hyperlinks have not been included in this version (due to PNG-format), but the participants in Phase 3 had access to clickable links.

5.6. Guidelines of school-based abuse prevention programs for 7–12-year-old children with communicative and/or cognitive disabilities

GUIDELINES FOR ADAPTATIONS OF SCHOOL-BASED ABUSE PREVENTION PROGRAMS FOR CHILDREN WITH COMMUNICATIVE AND/OR COGNITIVE DISABILITIES

Abuse against children is a prevalent issue all over the world, including children with communicative and/or cognitive disabilities. A variety of school-based abuse prevention programs are available, but there are limited programs available for children with communicative and/or cognitive disabilities. Therefore, these guidelines aim to facilitate the adaptation of existing school-based abuse prevention programs to suit the needs of children with communicative and/or cognitive disabilities. The guidelines are intended for teachers and principals working both in inclusive and special education settings.

INTRODUCTION

Having a disability is a risk factor for different types of abuse (Winters et al., 2017) and research shows that children with disabilities are 3-5 times more likely of being abused than children without disabilities (Jones et al., 2012). Communication difficulties and lack of social support for parents of children with disabilities have been linked to abuse (Flynn, 2020) which suggests that children with communicative and/or cognitive disabilities might be at even higher risk of being abused. Additionally, these children are often not provided with knowledge about abuse and how to handle risky situations linked to abuse, and can lack the necessary vocabulary to communicate about abuse, further hindering detection and disclosure of abuse (Bryen et al., 2003; Oosterhoorn & Kendrick, 2001; White et al., 2015).

Communicative and/or cognitive disabilities can manifest as difficulties with understanding language, producing language (e.g., speaking or writing) and as limitations in intellectual functioning and result from various diagnoses, such as intellectual disability, cerebral palsy, autism spectrum disorder (ASD) and attention-deficit/hyperactivity disorder (ADHD).

School-based abuse prevention programs are used to decrease the risk of children being abused and are currently available in most parts of the world. These programs often consist of lessons focused on preventing one or several types of abuse (such as sexual, physical and emotional abuse) by teaching children concepts such as good and bad secrets, appropriate and inappropriate touch, private parts of the body and safety rules. However, most of these programs have not been developed for children with communicative and/or cognitive disabilities, and therefore do not address the specific adaptations that these children might need to allow them to benefit and learn. Teachers and parents should be involved in these adaptations as as they are key role players in teaching and supporting children about abuse prevention (Mcelearney et al., 2021). Using the principles of Augmentative and Alternative Communication (AAC) has also been reported to be effective. The guidelines in this document have been developed to address these needs for adaptations of school-based abuse prevention programs for children with communicative and/or cognitive disabilities. The main focus of the guidelines is to prevent children from being abused by adults or older children. As such, it does not focus on bullying by same-aged peers.

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White, R., Bornman, J., & Johnson, E. (2015). *Testifying in court as a victim of crime for persons with little or no functional speech : vocabulary implications*. Child Abuse Research in South Africa, 16(1), 1–14. https://doi.org/10.10520/EJC171281

Examples of school-based abuse prevention programs

Learn to be safe with Emmy and friends (Australia)

Keeping Safe (Northern Ireland/UK)

Play it Safe (United States of America)

Did you know?

When the text looks like this there is a link that you can click.

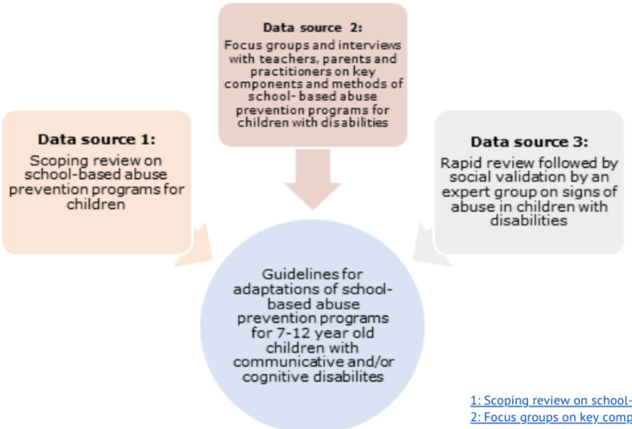
GUIDELINES FOR ADAPTATIONS OF SCHOOL-BASED ABUSE PREVENTION PROGRAMS FOR CHILDREN WITH COMMUNICATIVE AND/OR COGNITIVE DISABILITIES

PURPOSE

These guidelines describe adaptations for school-based abuse prevention programs to suit the needs of primary school age children with communicative and/or cognitive disabilities (i.e., 7-12 years of age). These adaptations can be applied to an already existing school-based abuse prevention program and can also be used to help choose a program for implementation.

The guidelines are intended for teachers and principals who work with children with communicative and/or cognitive disabilities, in an inclusive or special education setting. The guidelines assumes that teachers will be the primary persons teaching the program to the children, as is typical in most school-based abuse prevention programs.

The guidelines are based on the results from three different data sources. Additional results can be accessed by clicking the links provided below.



Data source 2: Focus groups and interviews with teachers, parents and practitioners on key components and methods of school- based abuse prevention programs for children with disabilities

Data source 1: Scoping review on school-based abuse prevention programs for children

Data source 3: Rapid review followed by social validation by an expert group on signs of abuse in children with disabilities

Guidelines for adaptations of school-based abuse prevention programs for 7-12 year old children with communicative and/or cognitive disabilites

STRUCTURE OF THE GUIDELINES

The guidelines are structured according to seven overarching themes. Three themes are directed at principals, whereas five themes are directed at teachers. Under each theme, key findings are presented. After each key finding a number corresponding to the number of the data source is provided in parentheses, as such (#1, #2, #3).

Suggestions for practical applications are provided under each key finding (apart from in the theme “Signs of abuse in children with disabilities”) using an *italics* font. The practical applications are based on the clinical experiences of the researchers and should not be viewed as research-based recommendations. The practical applications include links to resources in both English and Swedish, to enable use of the guidelines in both international and Swedish schools.

OUTLINE OF CONTENTS

3) Principals: Resources policies and collaboration, Evaluation with teachers and Teacher training

4) Teachers: Parental involvement and support and Signs of abuse in children with disabilities

5) Teachers: Key components

6) Teachers: Teaching methods and materials and Evaluation with children and parents

1: Scoping review on school-based abuse prevention programs for children
2: Focus groups on key components and methods of school- based abuse prevention programs for children with disabilities
3: Rapid review followed by social validation on signs of abuse in children with disabilities (under publication)

Development of the guidelines

These guidelines have been developed using the results from three data sources that collectively formed part of a PhD-project which was conducted at the Centre for Augmentative and Alternative Communication at the University of Pretoria, South Africa.

The three data sources included:

1. Scoping review
2. Focus groups and interviews:
   - Teachers working in special education with children with communicative and/or cognitive disabilities 7-12 years of age
   - Parents of children with communicative and/or cognitive disabilities 7-12 years of age
   - Practitioners working with children with disabilities who have been abused (including psychologists, forensic nurses, child interrogators and social workers)
3. **Rapid review followed by social validation**
   - Experienced professionals working with either children with disability, child abuse or both (including researchers, professionals, physicians, child psychiatrists, managers of health care units and consultants on abuse or disability)

The researcher and the supervisors have no personal or professional affiliations to any organization with financial interest in the content of these guidelines and there were no competing interests in the development of these guidelines.

GUIDELINES FOR ADAPTATIONS OF SCHOOL-BASED ABUSE PREVENTION PROGRAMS
PRINCIPALS

RESOURCES, POLICIES AND COLLABORATION

Activities that may facilitate the implementation of school-based abuse prevention programs for children with communicative and/or cognitive disabilities include:

- **Provide support to teachers and sufficient funding to enable implementation of the abuse prevention program (#2)**

Consider allocating time for preparation, training, and practice to teachers as well as funds for hiring substitute teachers and for producing materials. Support such as professional counselling, providing a mentor or professional courses to teachers who are expected to implement the program, is also needed.

- **Provide opportunities and venues for collaboration and community involvement (#2)**

Consider inviting collaborators such as practitioners in health care and social services to a meeting before the implementation of the school-based abuse prevention program, to inform them about the purpose of the program and discuss how they might get involved in the program mission. Consider involving collaborators in the process of adapting the school-based abuse prevention program.

EVALUATION WITH TEACHERS

Strategies for evaluating school-based abuse prevention programs for children with communicative and/or cognitive disabilities may include:

- **Assess teacher's knowledge of and attitudes towards abuse against children, satisfaction with the program or perceived impact of the program on the children that participated (#1)**

Consider using evaluation tools that are suggested in the abuse prevention program that has been chosen for adaptation. Interviews or surveys before and after the program can be used to evaluate differences in knowledge and attitudes. Interviews with teachers after the program can be used to assess program satisfaction as well as the perceived impact on children.

TEACHER TRAINING

Strategies that may increase teacher's knowledge of abuse and facilitate their implementation of school-based abuse prevention programs for children with communicative and/or cognitive disabilities are:

- **Provide information about abuse against children with communicative and/or cognitive disabilities including different types of abuse and their increased risk of being abused (#2, #3)**

Consider professional courses or workshops for teachers to participate in, inviting experts on the topic to speak at teacher conferences and creating study groups for teachers using online resources. An overall comprehensive handbook on school-based abuse prevention (including the role of teachers) has been produced by the World Health Organisation and information in Swedish about abuse against children with disabilities is available through Stiftelsen Allmänna Barnhuset.

- **Provide information about how to ask questions about abuse, handle disclosure and report abuse as well as the different treatment options available for children with communicative and/or cognitive disabilities who have been abused (#2)**

Consider inviting police officers, social workers, or members of local child protection teams to provide information on the topic and to describe the process from disclosure of abuse to action. Information about how to handle disclosure of abuse is available through Childhelp and information about treatment options linked to child abuse can be accessed from the Child Welfare Information Gateway.

- **Provide information on myths around disability and abuse (such as the myth that children with disabilities aren't abused) and negative attitudes towards children with disabilities (2)**

Consider facilitating discussions about the myths, negative attitudes and stigmas surrounding disability and abuse that are prevalent in society. Training material on myths and facts around sexual violence and persons with disabilities have been produced by, for example, the Nevada Coalition to END Domestic and Sexual Violence.

- **Provide information on children's rights and disability rights (#2)**

Consider providing training to teachers on the Convention on the Rights of the Child (CRC) and the Convention on the Rights of Persons with Disabilities (CRPD). Training materials can be found through the United Nations Human rights office.

- **Facilitate discussion on the dependency and need for compliance that children with communicative and/or cognitive disabilities may experience and how that can affect their ability to speak up against abuse and remove themselves from risky situations (#2)**

Consider asking teachers to provide examples of such situations in the school setting and discuss how best to deal with such situations.

- **Work towards shared values at the school level on abuse prevention and children's rights (#2)**

Consider creating a school policy regarding values, attitudes and behaviours related to abuse prevention. Establish the policy with all employees and communicate the contents of the policy to children and parents. Regularly re-visit the policy during staff meetings and professional development meetings. Examples of what could be included in such a policy can be accessed through Nidirect.

- **Use strategies such as videos, role play, case studies and skills practice (in online or in face-to-face format) to conduct the teacher training depending on the needs and preferences of the teachers who are participating in the training (#2)**

Consider using online resources such as the ones linked above to find training materials. Videos on abuse against persons with disabilities are available in Swedish through Dart (Sahlgrenska University Hospital)

GUIDELINES FOR ADAPTATIONS OF SCHOOL-BASED ABUSE PREVENTION PROGRAMS
TEACHERS

PARENTAL INVOLVEMENT AND SUPPORT

Strategies that may increase parent's knowledge of abuse and facilitate their involvement in school-based abuse prevention programs for children with communicative and/or cognitive disabilities are:

- **Provide parents with information about abuse and different types of abuse against children with communicative and/or cognitive disabilities (#2)**

Consider providing parents with written information about abuse against children with communicative and/or cognitive disabilities. Examples of information aimed at parents can be found at the Centers for Disease Control and Prevention.

- **Provide parents with information about the abuse prevention program to strenghten their ability to support their children throughout the program and decrease their concerns that their child might risk being traumatized by participating in the program (#2)**

Consider inviting parents to meetings before, during and after the program to give information on the school-based abuse prevention program and provide them with written information about the program's purpose and expected outcomes.

- **Provide parents with information about support available in society regarding challenging behaviours in their children to reduce the caregiving burden and thereby decrease the potential risk of abuse (#2)**

Consider providing parents with written information about volunteer organisations, health care, social services or other institutions working with parents of children with disabilities in the community. Consider inviting such support organisations to speak at open lectures at the school that all parents are invited to.

SIGNS OF ABUSE IN CHILDREN WITH DISABILITIES

Information that may facilitate the detection and recognition of signs of abuse in children with communicative and/or cognitive disabilities include:

- **Know how to identify potential signs of abuse in children with disabilities and being attentive to such signs (#2, #3)**
- **Understand that potential signs of abuse should not be interpreted in isolation as indicating abuse (#3)**
- **Know that signs of abuse can be very unspecific (#3)**
- **Be aware that some children who have been abused might not show any signs of abuse (#3)**
- **Be aware that symptoms that are typical for one type of disability (e.g., angry outbursts) can be potential signs of abuse in another type of disability and that symptoms/signs must always be viewed in a context (#3)**
- **Be aware that sudden changes in behaviour may be a sign of abuse (#3)**
- **Know that children with disabilities may present with the same signs of abuse as children without disabilities (#3)**
- **Know that some signs of abuse may be more commonly linked to specific types of abuse (e.g., bruising on the arm could be linked to physical abuse) (#3)**

The following behavioural and physical signs of potential abuse in children with disabilities have been derived from the rapid review and social validation of signs of abuse in children with disabilities that formed data source #3. It should be noted that all the symptoms presented below **can be signs of abuse but can also be present in children that have not been abused. Therefore, these signs are not decisive in determining abuse.** The potential signs of abuse are arranged below according to perceived accuracy, ranging from very accurate to slightly accurate.

Please note that this list is not exhaustive and the presence of one or several of these symptoms does not equal the presence of abuse.

1) Post-traumatic stress disorder
2) Poor self-esteem
3) Withdrawal
4) Anxiety
5) Signs of penetration
6) Nightmares
7) Depression
8) Self-harm
9) Acting out
10) Emotional problems
11) Bruising
12) Inappropriate sexual behaviour
13) Inappropriate anger
14) Behavioural problems
15) Aggressive behaviour
16) Suicidal thoughts
17) Burns or trauma
18) Irregular school attendance
19) Eating/appetite disturbance
20) Victimizing other children
21) Suicide attempts
22) Non-compliance
23) Running away from home
24) Negative peer involvement
25) Crying
26) Substance abuse
27) Alcohol abuse
28) Dominant behaviour

GUIDELINES FOR ADAPTATIONS OF SCHOOL-BASED ABUSE PREVENTION PROGRAMS
TEACHERS

KEY COMPONENTS

Key components that may be included in school-based abuse prevention programs for children with communicative and/or cognitive disabilities are:

- **Provide information about abuse, including different types of abuse such as sexual, physical and emotional abuse, neglect and exploitation (#1, #2, #3)**

Consider naming abuse with the correct terms and emphasising that abuse should be taken seriously. Information about abuse adapted for children with disabilities can be found in Swedish through Dart (Sahlgrenska University Hospital)

- **Provide information about children's rights, encouraging children to express themselves and conducting exercises designed to help build children's self-esteem. Empowering and listening to children may be linked to a decreased risk of abuse and may help children talk about abuse (#1, #2)**

Consider focusing on empowerment throughout the school-based abuse prevention program to strengthen self-esteem. Child-friendly materials on children's rights are available through UNICEF and can be adapted by adding additional pictorial support, which can be found through the pictorial support resource Bildstöd. Consider involving the school psychologist for ideas on how to develop and strengthen self-esteem in children.

- **Know how to disclose abuse (telling), to whom and at what time (#1, #2)**

Consider inviting a police officer or social worker to talk about abuse against children and how the police and social services can help children if they have been abused. Materials for asking children with communicative and/or cognitive disabilities about abuse in several languages are available through the CAAC (University of Pretoria). Materials in Swedish for asking children with disabilities about abuse are available through Dart (Sahlgrenska University Hospital).

- **Know how to say "No!" and speak up against abuse (#1, #2, #3)**

Consider modelling specific methods of saying no that are adapted to the children who are included in the program, such as holding out your hand to signal "Stop!" or pressing a "No" button on a speech generating device.

- **Provide information about safe and unsafe touches and private and public body parts (#1, #2)**

Consider using pictures of bodies to model safe and unsafe touches and private and public body parts. Pictures of bodies can be found through Bildstöd.

- **Provide information about good and bad secrets (#1)**

Consider contextualising good/bad secrets to relate to children's lives and give examples that they can relate to. Examples of lessons on good and bad secrets can be found through Keeping Safe.

- **Provide information about positive and safe relationships and sexuality (#1, #2)**

Consider including age appropriate sexuality education. Information about disability and sexuality can be found through Center for Parent Information & Resources.

- **Provide information about risky situations specifically linked to children's everyday lives (#1, #2)**

Consider focusing on situations where the child is potentially alone with an adult, and which strategies children can use if they feel that the situation is uncomfortable or scary, such as screaming, saying no, leaving (if possible) or honking the horn on their electric wheelchair.

- **Provide information about safety rules and strangers, including adults posing as children online (#1, #2)**

Consider teaching children about strangers and risky situations particularly about situations that occur online. Explain that not everyone tells the truth about who they are online. Emphasize specific safety rules such as never meeting anyone in person alone that they "met" online, not turning on their webcam if the other person doesn't do it first and never sharing their home address and telephone number. Encourage children to discuss situations that feel uncomfortable or strange with trusted adults for guidance. Information about online abuse can be found in English by accessing Cerebra and in Swedish through Nätkoll.

- **Provide information about feelings, including the effect of negative behaviours on people around you (#1, #2)**

Consider using pictorial support to talk about feelings and how feelings and behaviours can affect family and friends. Pictures with faces of children conveying different feelings can be found through Bildstöd.

- **Accomodate the differences in individual abilities and the need for different types of support and adaptations for each child to show respect for the child and encourage understanding (#2)**

Consider encouraging discussion between children about their differences, their strengths and positive traits to facilitate mutual respect and increased self-esteem.

Examples of pictorial support about abuse

Communication boards for talking about abuse in 21 languages (CAAC, UP)

Pictorial support for preventing, discovering, and dealing with abuse in Swedish (Dart, Sahlgrenska University Hospital)

Communication boards and teaching tools about abuse in English (Speak Up and be Safe from Abuse-project)

If this document is printed, it is advised to print the links as well.

GUIDELINES FOR ADAPTATIONS OF SCHOOL-BASED ABUSE PREVENTION PROGRAMS
TEACHERS

TEACHING METHODS AND MATERIALS

Strategies that may be used to teach school-based abuse prevention programs to children with communicative and/or cognitive disabilities are:

- **Use interactive teaching methods such as storytelling, role play, videos, play and skills practice to facilitate understanding of key concepts (#1, #2)**

Consider using materials that include children with similar disabilities as the children participating in the program to facilitate recognition, representation and understanding.

- **Use work sheets and books, songs and music, discussions, posters, writing stories and letters, drawing and painting to teach key components (#1)**

Consider adapting the materials to each child's abilities to enable them to participate in the activities as independently as possible. Consider using stories and pictures that include children with similar disabilities as the children participating in the program.

- **Repeat key components and increase the exposure of the program to facilitate remembering, as generalisation of learned concepts can be difficult for children with communicative and/or cognitive disabilities (#1, #2)**

Consider strategies such as selecting key components to be repeated throughout the school year, teaching the program over a longer period or repeating the program each year to create opportunities for generalisation and recall of learned knowledge and skills.

- **Adapt the language, vocabulary and the group size depending on the type of disability and level of functioning of the children who are participating in the program (#2)**

Consider being flexible in terms of the group size, ranging from just one child to a whole class, depending on the individual needs of the children. Adapt the vocabulary and the language used to suit the needs of the children in the group.

- **Incorporate strategies to check comprehension of the key concepts taught in the program (#2)**

Consider checking comprehension by asking children to summarise the discussions or by asking wrong or right questions.

- **Use a teacher who is trusted and known by the specific children in the group to teach the abuse prevention program (#2)**

Consider being flexible with schedules and tasks to ensure that the most suitable person for teaching the program is made available. If needed, enlist the help of principals to make schedule changes or bring in substitute teachers.

- **Be aware of the potential risk of traumatization or re-traumatization of children participating in the school-based abuse prevention program, particularly if they have been abused, which might not be known by teachers or parents (#2)**

Consider involving the school psychologist in the implementation of the abuse prevention program to assist with issues regarding potential traumatisation or re-traumatisation. Consider adapting contents in the abuse prevention program to children's cognitive abilities and level of maturity.

- **Use AAC-materials and strategies, such as communication boards and books, manual signs, and point-talking to children with communicative and/or cognitive disabilities to provide vocabulary to facilitate understanding of and talking about abuse (#2, #3)**

Consider providing AAC-materials using appropriate symbol systems (e.g., PCS, Bliss-symbols, manual signs) for each child to take home. Topics could include different types of abuse, prevention strategies for both parents and children that adress how to report abuse. Include written information about how the pictorial support should be used.

- **Create a "toolbox" with different methods and materials that teachers can use to tailor the delivery of the program (#2)**

Consider including different AAC-materials, pictures, objects, books, and toys in the "toolbox".

EVALUATION WITH CHILDREN AND PARENTS

Strategies for evaluating school-based abuse prevention programs for children with communicative and/or cognitive disabilities may include:

- **Assess children's satisfaction with the program (#1)**

Consider using interviews with Talking Mats or supplementing surveys that are included in the chosen program with pictorial support to facilitate understanding.

- **Assess children's safety skills and understanding of key components by using methods that are adapted to suit each child, such as Talking Mats, interviews, questions before and after the program, role play, simulations or scenarios depicting risky situations (#1, #2)**

Consider adapting instruments that are available or suggested in the chosen program. For examples of such instruments, please refer to White et. al. (2018). Use pictorial support to facilitate understanding of the chosen instrument.

- **Assess children's anxiety levels, self-esteem, or locus of control before and after the program (#1)**

Consider creating custom-made interview questions using strategies such as Talking Mats to ask children about these topics. Consult with the school psychologist to develop appropriate questions for assessment.

- **Assess parent's satisfaction with the program (#1)**

Consider using instruments that are available or suggested in the abuse prevention program that has been chosen for adaptation. Interviews or surveys after the program can be used to assess program satisfaction and impact.

- **Assess children's safety skills by asking parents to rate children's understanding of protective behaviours or general sense of safety (#1)**

Consider using instruments that are available or suggested in the chosen program. For examples of such instruments, please refer to White et al. (2018).

If this document is printed, it is advised to print the links as well.

5.7. Conclusions of Phase 2

During this phase a detailed process was used to develop and design the guidelines of school-based abuse prevention programs for 7–12-year-old children with communicative and/or cognitive disabilities, based on both the theoretical and conceptual frameworks of the study as well as research literature on guideline development and design. A recursive abstractive thematic analysis process was used to integrate the results from Phase 1 to provide the recommendations that are included in the guidelines. The resulting guidelines are aimed at teachers and principals and are meant to be implemented in a school context with children with communicative and/or cognitive disabilities. The last step of the guideline development process, namely the external review of the guidelines by stakeholders, will be executed in Phase 3 of the study.

5.8. Summary

Chapter 5 focused on the development of the guidelines for teachers and principals to guide the adaptation of school-based abuse prevention programs for 7–12-year-old children with communicative and/or cognitive disabilities.

The chapter began with a description of the steps used in the guideline development process, including identifying, defining, and refining the topic, establishing a literature review group and a guideline development group, and assessing the evidence. Subsequently, the process of designing the guidelines was described, including considerations in terms of language, layout, structure, and formatting. Furthermore, the recursive abstractive thematic analysis process of integrating the results from the three data sources that form Phase 1 of the study to form the guidelines was detailed and the developed guidelines were presented. The guidelines included three themes aimed at principals and five themes aimed at teachers and contained actionable recommendations as well as suggestions for practical applications.

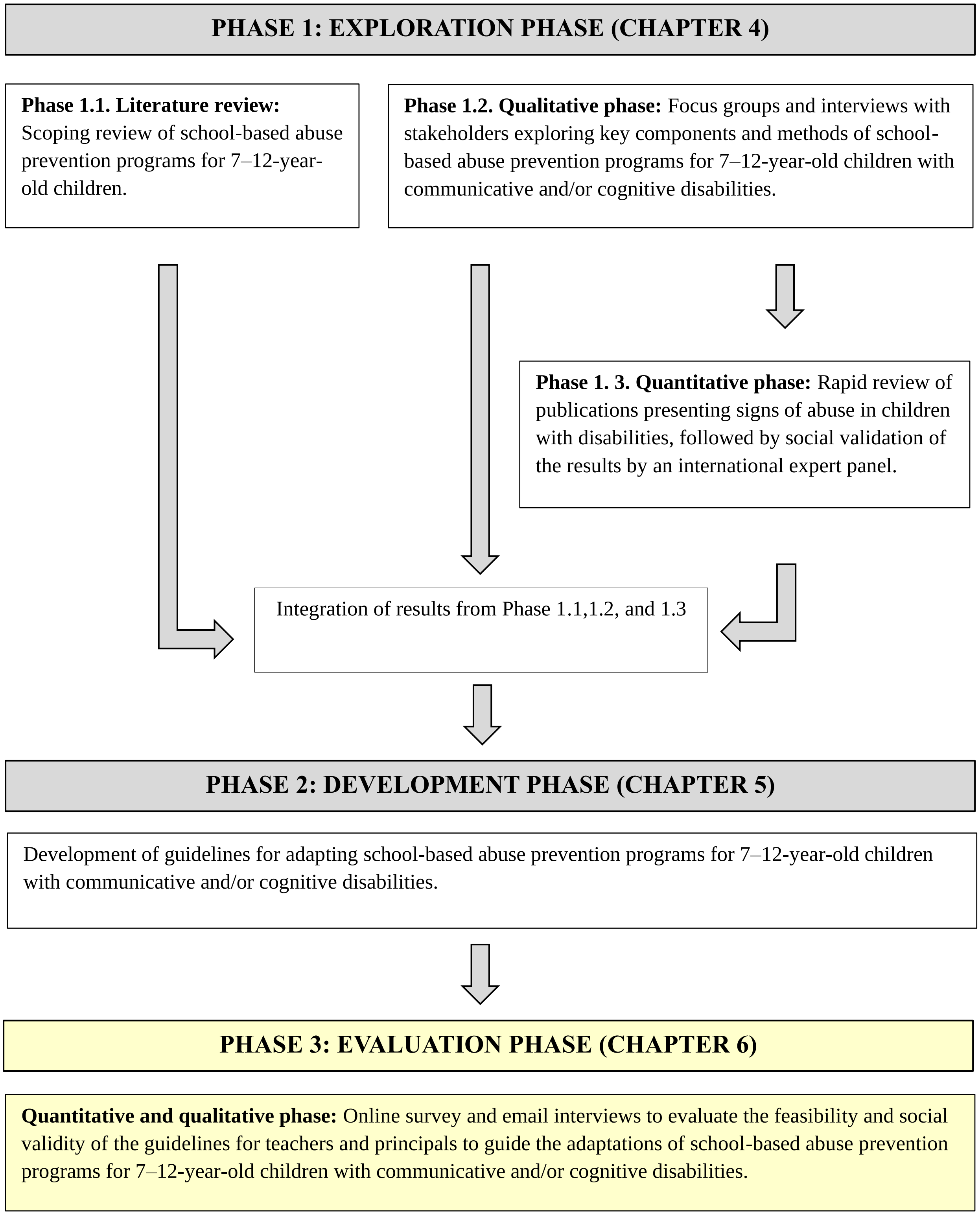
CHAPTER 6
PHASE 3: EVALUATION PHASE
Research methodology, results, and discussion

6.1. Introduction

This chapter describes Phase 3 of the study which focuses on evaluating the feasibility and social validity of the guidelines suggested for teachers and principals regarding school-based abuse prevention programs for 7–12-year-old children with communicative and/or cognitive disabilities which was developed during Phase 2 of the present study. This is the final chapter of three chapters that focus on the different phases of the exploratory sequential mixed methods design which was used in this research study. Chapters 4, 5, and 6 should thus be read in conjunction as shown in Figure 6.1.

Figure 6.1

Three-phase Exploratory Sequential Mixed Methods Design with Current Phase Highlighted



PHASE 1: EXPLORATION PHASE (CHAPTER 4)

Phase 1.1. Literature review: Scoping review of school-based abuse prevention programs for 7–12-year-old children.

Phase 1.2. Qualitative phase: Focus groups and interviews with stakeholders exploring key components and methods of school-based abuse prevention programs for 7–12-year-old children with communicative and/or cognitive disabilities.

Phase 1. 3. Quantitative phase: Rapid review of publications presenting signs of abuse in children with disabilities, followed by social validation of the results by an international expert panel.

Integration of results from Phase 1.1,1.2, and 1.3

PHASE 2: DEVELOPMENT PHASE (CHAPTER 5)

Development of guidelines for adapting school-based abuse prevention programs for 7–12-year-old children with communicative and/or cognitive disabilities.

PHASE 3: EVALUATION PHASE (CHAPTER 6)

Quantitative and qualitative phase: Online survey and email interviews to evaluate the feasibility and social validity of the guidelines for teachers and principals to guide the adaptations of school-based abuse prevention programs for 7–12-year-old children with communicative and/or cognitive disabilities.

Chapter 6 commences with the main aim for Phase 3 as well as the delineated sub-aims and then goes on to describe the research methodology and results of the entire phase. The methodology and results are summarised at the end of the chapter.

6.2. Aims

The main aim and sub-aims for Phase 3 are presented below.

6.2.1. Main aim: Phase 3

The main aim of Phase 3 was to explore the feasibility and social validity of the proposed guidelines of school-based abuse prevention programs for 7–12-year-old children with communicative and/or cognitive disabilities using qualitative and quantitative indicators.

6.2.2. Sub-aims

Three sub-aims were delineated to address the main aim of Phase 3:

i) To develop a suitable tool to explore and describe the feasibility and social validity of the newly developed guidelines.

ii) To explore the feasibility (conceptualised as clarity of scope and purpose, level of stakeholder involvement, rigour of development, clarity of presentation, applicability, editorial independence, and overall quality) of the newly developed guidelines.

iii) To explore the social validity (conceptualised as social relevance, social acceptability, and social importance) of the guidelines.

6.3. Research design

Exploring the feasibility of guidelines can be conducted in several ways. Some researchers use the terms ‘feasibility study’ and ‘pilot study’ interchangeably, whilst others argue that there are distinct differences between the two (Whitehead et al., 2014). This study agrees with the latter and regards a feasibility study as a study that focuses on whether or not something should be done, if it should be proceeded with, and if so, how it should be done (Eldridge et al., 2016). In contrast to a pilot study, a feasibility study does not necessarily implement something on a small scale in the same way as a large scale future study would be implemented (Eldridge et al., 2016). Applied to the present study, the feasibility of the newly developed guidelines for the adaptation of school-based abuse prevention programs for children with communicative and/or cognitive disabilities was explored by focusing on the perceived feasibility and social validity.

The purpose of social validity assessment has been described as gaining an understanding of which interventions, such as the guidelines in the present study, are liked or disliked by stakeholder groups and why this is the case (Schwartz & Baer, 1991). It should be noted that social validity is a construct with many dimensions and an intervention cannot be simply characterised as being ‘socially valid’ or not, in other words with a clear distinction between the presence or absence of social validity but rather as a continuum (Foster & Mash, 1999).

When measuring social validity, three areas are typically considered: The goals of the intervention (i.e., the guidelines), both in terms of its importance and acceptability; the acceptability of the intervention; as well as the social importance of the outcomes of the intervention (Wolf, 1978). The assessment of social validity can occur at different times during the process of an intervention, including the feasibility stage (Foster & Mash, 1999), as was done during this PhD study. Social validity measures applied to the present study included exploring stakeholders’ perceptions on the social importance and relevance of the goals of the guidelines and the social and general acceptability of the guidelines as well as the social importance of the outcomes of the guidelines (Carter & Wheeler, 2019; Wolf, 1978).

The evaluation of the feasibility and the social validity of the guidelines was conducted by eliciting both quantitative and qualitative data. A quantitative data collection method, namely an online survey, was chosen to obtain information on the variables relating to quality that were quantifiable (Creswell & Creswell, 2018). One advantage of the online survey was that it offered a convenient option for the participants, allowing them to submit their answers at a time that was suitable to them (Evans & Mathur, 2005; Sue & Ritter, 2012). Furthermore, the online survey option also facilitated the inclusion of international participants as this method does not require postage or mailing services allowing immediate access to the answers provided by the participants (Evans & Mathur, 2005). The online format also made it easy to gather results and follow-up thereon, thereby allowing the survey to be designed so that answers to each question was required to ensure complete data (Evans & Mathur, 2005; Sue & Ritter, 2012). Furthermore, due to the Covid-19 pandemic, online methods were preferred to limit physical contact.

However, online surveys have the disadvantage of requiring computer and internet access, but as the participants were all working professionals and were approached for participation in the study in their professional capacity, internet and computer access was not considered a challenge (Sue & Ritter, 2012). Additionally, many professionals had gained experience of using online methods during the pandemic.

A qualitative data collection method, namely email interviews, was used to obtain in-depth information of the participants' perceptions on constructs linked to the feasibility and social validity of the guidelines. Email interviews were selected as it is a method for assessing social validity that generates large amounts of data in a short period of time (Carter & Wheeler, 2019). To ensure that specific and comparable data was gathered across participants, a semi-structured interview format was used rather than an unstructured interview (Carter & Wheeler, 2019). As the Swedish participants were spread across the country and the international participants resided in different countries, some form of distance interviewing was deemed appropriate. Video or telephone interviews could have been utilised for this purpose, but its synchronous nature would require scheduling a specific time and date. Email interviews enable asynchronous interviews, making scheduling easier (especially in cases where time zones differ) which in turn provides greater access to participants (Hawkins, 2018). Furthermore, the written format can provide participants with the opportunity to think through and clarify their answers in text which can result in rich and accurate data while also allowing opportunities for several exchanges over a longer period of time compared to face-to-face, video, or telephone interviews (Hawkins, 2018). However, using email interviews might be more time consuming for participants as they need to write down their answers, which might deter from participation (Fritz & Vandermause, 2018; Hawkins, 2018). There is also a risk of participants providing short and brief answers (Hawkins, 2018) which increases the need for probing and expanding follow-up questions which were utilised in the present study.

Ogilvie and McCrudden (2017) recommend using an online survey complimented by another data collection method (in this case email interviews) to evaluate the acceptability of a specific intervention, as surveys by nature are limited to short answers and do not assist in providing in-depth knowledge on a topic. By combining methods, the participant’s view on acceptability and its justification (i.e., why the intervention, program or guideline is deemed acceptable or not) is enhanced (Ogilvie & McCrudden, 2017). Interviews can be a particularly useful way of gaining more knowledge on why interventions are viewed favourably or not (Ogilvie & McCrudden, 2017). Therefore, a combination of the two data collection methods was selected purposefully to explore and evaluate the feasibility and social validity of the guidelines. Additionally, this phase contained the following steps from the theoretical and conceptual frameworks: consulting with experts and stakeholders on specific components related to the target population that should be included in the program and evaluating the feasibility of the guidelines, including the suggested methods for implementation and evaluation (Table 3.2).

6.4. Ethical considerations

A detailed account of the ethical considerations of the study was provided in Chapter 3. In addition to those principles, it should also be reiterated that the participants in Phase 3 all participated in the study voluntarily and in their professional capacity. They were not coerced or in any other way forced to participate and no incentives were given to any of the participants. All participants provided written consent by clicking on a link, before they were able to access the online survey which allowed them to participate in the study. As the data was collected through online methods, the participants' names and contact details were only known by the student. Names were replaced with a numeric code before the analysis of the results and all data was stored in a de-identified manner on a password protected computer.

6.5. Participants

The participants in this phase represented three distinct groups. Group 1 consisted of teachers with experience in working with children with communicative and/or cognitive disabilities in special schools or in inclusive settings in Sweden. Group 2 consisted of principals with experience in working with children with communicative and/or cognitive disabilities in special schools or in inclusive school settings in Sweden. These principals did not work at the same schools as the teachers referred to in Group 1. Group 3 consisted of content (topic) experts, with extensive clinical experience working with childhood disability, child abuse or school-based abuse prevention, or extensive research experience in any of these topics. Some of these experts worked in Sweden while others were internationally based.

Participants from all three groups were purposively selected to review the content of the guidelines and to explore the capacity of schools to implement the adaptations, in keeping with the theoretical and conceptual frameworks of the study.

6.5.1. Participant recruitment

Participants for Phase 3 were selected using a non-probability sampling approach (Taherdoost, 2016). Snowball sampling, in which a few persons are used to encourage peers to take part of the study, was utilised to recruit potential participants for Group 1 and 2 (teachers and principals) (Taherdoost, 2016). Eligible participants in Group 1 and 2 were asked to name other potential participants whom they thought would be suitable for participation in the study.

For the third participant group (content experts), purposive sampling was used in which particular persons are selected for inclusion, based on the personal networks of the student and supervisors, in order to provide important information that is specific to those participants (Taherdoost, 2016).

All potential participants for Group 1, 2, and 3 were contacted directly by the student to recruit them for the study if they met the inclusion criteria.

6.5.2. Participant selection

Selection criteria for the participants for all three groups included in Phase 3 is presented in Table 6.1.

Table 6.1

Selection Criteria of Participants for Phase 3

Group 1 **Teachers**	**Group 2** **Principals**	**Group 3** **Content experts**	**Theoretical justification**
Working in a special education or inclusive setting.	Working in a special education or inclusive setting.	Working as clinicians or researchers within either field of disability, child abuse, or school-based abuse prevention.	The external review group should have diverse backgrounds and should consist of experts in content as well as potential end-users of the guidelines to bring diverse perspectives to the review of the guidelines (Qaseem et al., 2012; Shekelle et al., 1999; World Health Organization, 2014).
Experience working with children with communicative and/or cognitive disabilities.	Experience working with children with communicative and/or cognitive disabilities.	Experience working with children with communicative and/or cognitive disabilities.	Experience of the target population (i.e., children with communicative and/or cognitive disabilities) was deemed as necessary to ensure that the participants were able to review the feasibility and social validity of the guidelines.

6.5.3. Participant description

In total 25 potential participants were identified, of whom all 25 expressed an interest to participate. Of these, six participants (five teachers and one principal) withdrew from the study after they received the e-mail containing the letter of informed consent, the guidelines, link to the online survey and interview questions. Five of them cited a heavy workload as the reason for withdrawal while one participant did not respond at all, despite repeated reminders. Nineteen participants completed the survey and email interview, comprising of six teachers (Group 1), three principals (Group 2) and ten content experts (Group 3).

6.5.3.1. Group 1: Teachers (n = 6)

The teachers were specifically targeted due to their experience working with children with communicative and/or cognitive disabilities. Six teachers participated in the study. Their job descriptions included special education, working with children with mild—severe intellectual disabilities and communication pedagogues, working with AAC, tutoring staff, and adapting materials. For more biographical information about the participants, see Table 6.2.

6.5.3.2. Group 2: Principals (n = 3)

The principals were targeted because of their experience working as principals in schools with children with communicative and/or cognitive disabilities in attendance, such as special schools. The participants job descriptions included head of education, operations manager for the student healthcare and principal. Their biographical information is included in Table 6.2.

6.5.3.3. Group 3: Content experts (n = 10)

The group included 10 participants with varying job descriptions such as researchers, consultants, and content writers (focused on child protection, child rights, school-based protective education behaviour programs, disability, and AAC), psychologists/psychotherapists (who work in the field of trauma, abuse, child advocacy programs), senior clinicians, and lecturers/assistant professors (in nursing and in speech-language therapy and AAC). Their biographical information is provided in Table 6.2.

6.6. Material

The online survey, information about the study and consent letter (Appendix B5) as well as the interview questions were available in both English and Swedish depending on the participants' preference.

6.6.1. *Letter of informed consent*

After expressing interest to participate in the study, all participants were sent letters of informed consent. These letters contained information about the background and aim of the study, what would be expected of them during the study, their right to withdraw at any time, information about confidentiality and data storage as well as contact details of the student and main supervisor.

6.6.2. *Online survey*

An online survey was designed using Qualtrics XM. The online survey comprised of two sections: the first section was to obtain the biographic information and the second focused on the feasibility and social validity of the newly designed guidelines. Qualtrics XM is a website that can be used for building online surveys, collect data and conduct data analysis (www.qualtrics.com) which is often used by academic researchers (Weber, 2021). The 10 biographic questions were asked first, as described in Table 6.2.

Table 6.2

Biographical Information of the Participants Included in Phase 3

	Group 1: Teachers (n = 6)	**Group 2: Principals (n = 3)**	**Group 3: Content experts (n = 10)**
Sex			
Participants should be diverse in gender to bring diverse perspectives to the review and appraisal of the guidelines (World Health Organization, 2014).			
Female	6	3	8
Male			2
Age			
Seniority in career and age is related. Increased age implies an increased level of seniority for researchers. (Over, 1988).			
31–40 years	2	1	3
41–50 years	3		4
51–60 years	1	2	1
61–70 years			1
>71 years			1
First language			
Descriptive information			

	Group 1: Teachers (n = 6)	**Group 2: Principals (n = 3)**	**Group 3: Content experts (n = 10)**
Swedish	6	3	4
English			4
Other			1 - Italian 1 - British Sign Language
Country of residence			
Descriptive information			
Sweden	6	3	4
United Kingdom			3
Other			1 - Germany 1 - South Africa 1 - Australia
Workplace (multi-choice)			
Establishing a diversity in the participant group in terms of their backgrounds is considered important to obtain a comprehensive evaluation of the guidelines (World Health Oganization, 2014).			
Education (school)	5	3	
Higher education (university)			3
Healthcare			2
Non-profit organization			4
Workers union	1		
Self-employed (e.g., consultant)			3
Number of years worked in current profession			
Establishing a diversity in how many years the participants had worked in their profession, as the guidelines were meant to be applicable and understandable for both early career (novice) as well as more experienced teachers and principals. Furthermore, many years working in the same profession can indicate expertise, although it does not guarantee it (Shanteau et al., 2002).			
0–5 years	2	3	2
6–10 years	1		3
11–20 years	3		3
>20 years			2
Highest qualification			
Participants should be able to provide feedback based on scientific and clinical knowledge (Qaseem et al., 2012). *It is plausible that scientific knowledge increases with research training.*			
Bachelor's degree	3	2	
Honours degree			1
Master's degree	2		4
PhD			5
Other (e.g., in-service training requirements)	1	1	

For the feasibility and social validation section of the online survey, a rating task consisting of 11 statements were included (Table 6.3, Column 4). Participants were asked to rate each statement on a 7-point Likert scale ranging from 1 = Strongly disagree to 7 = Strongly agree. Sensitive scales, such as a 7-point Likert scale are ideally suited for this purpose as the participants were stakeholders and experts in topics linked to school-based abuse prevention, thus wanting to express nuanced opinions on the topic (Chyung et al., 2017). Participants were also able to leave a comment at the end of the survey.

The statements used in the rating task were derived from the AGREE II tool - an updated version of the original AGREE - which was developed for the healthcare context to appraise and evaluate clinical practice guidelines (Brouwers et al., 2010; Terrace, 2003). As the adaption guidelines in this study were developed using the steps for clinical guideline development and aim to minimise the effect of a public health issue, namely abuse against children with disabilities, the AGREE II tool was deemed applicable to capture the feasibility of the guidelines. The AGREE II is comprised of 23 items, of which 15 were used in this study, spanning over six domains, and includes two overall items directed towards the quality of the guidelines as a whole, which were included in the study (Brouwers et al., 2010). The six domains include:

i) Scope and purpose
ii) Stakeholder involvement
iv) Rigour of development
v) Clarity of presentation
vi) Applicability, and
vii) Editorial independence.

Items from all six domains were used to capture the feasibility of the guidelines, as well as the overall quality appraisal of the guidelines. This was combined with the three main constructs of social validity (social acceptability, social importance and the purpose and goals of the intervention) and synthesised to form a custom-made evaluation tool which was used to inform the online survey and the email interview questions (Table 6.3).

Table 6.3

Evaluation Tool used in the Study, Including the Online Survey and Email Interview Questions

1. Theoretical foundation	2. Theoretical justification	3. Semi-structured interview questions used in email interview	4. Online survey questions *Rating task on a scale from 7-point scale (1 = Strongly disagree, 7 = Strongly agree)*
Constructs: Scope and purpose (criteria for high quality clinical practice guidelines include specific statements about the purpose and clinical questions of the guidelines and details the target populations (Terrace, 2003)**).**			
AGREE II Items: • The overall objective(s) of the guideline is (are) specifically described. • The health question(s) covered by the guideline is (are) specifically described.	The purpose of the guidelines, why this specific topic is important and what the expected impact of the guidelines are, should be clear, logical and self-evident (Kish, 2001).	1) How would you describe the purpose and main goals of the guidelines?	
AGREE II Item: • The population (patients, public, etc.) to whom the guideline is meant to apply to is specifically described.	The target population should be clearly specified and age, sex, and other factors that could affect the recommendations regarding the guidelines should be taken into consideration (Kish, 2001).		1) The target population for whom the guidelines had been developed is specifically specified.
Construct: Stakeholder involvement (criteria for high quality clinical practice guidelines include information about the expertise and composition of the guideline development group and involvement of patients, as well as being piloted before publication (Terrace, 2003)**).**			
AGREE II Item: • The guideline development group includes individuals from all relevant professional groups.	Multiple disciplines and participants from groups who would be included in the guidelines are important to involve in the guideline development group to facilitate discussion in the development process and thus create more balanced guidelines (Shekelle et al., 1999).		2) The guideline development group (participants in the three data sources) includes all relevant professional groups.
AGREE II Item:			

1. Theoretical foundation	**2. Theoretical justification**	**3. Semi-structured interview questions used in email interview**	**4. Online survey questions** *Rating task on a scale from 7-point scale (1 = Strongly disagree, 7 = Strongly agree)*
• The views and preferences of the target population (patients, public, etc.) have been sought.	The inclusion of the patients and caregivers can provide additional perspectives and keep a patient-centred focus throughout the guideline development (Institute of Medicine (US), 2011).		3) The target population has been asked about their views and preferences on the topic.
AGREE II Item: • The target users of the guidelines are clearly defined.	The target users of the guidelines should be clearly described at the beginning of the guidelines (Kish, 2001).		4) It is clearly defined who the target users of the guidelines are (i.e., responsible for implementing the guidelines).
Construct: Rigour of development (criteria for high quality clinical practice guidelines include information about search strategy, inclusion/exclusion criteria, methods for formulating the guidelines, explicit linking between the evidence and the guidelines, discussion of benefits and risks as well as external review and a procedure for conducting updates (Terrace, 2003)**).**			
AGREE II Item: • The methods for formulating the recommendations are clearly described.	The process of gathering evidence and expert opinions and translating it into guidelines should be described (Shekelle et al., 1999) as this process can be prone to bias if the guideline developers do not use a systematic approach (Grimshaw et al., 1995).		5) The methods used for formulating the guidelines are clearly described.
AGREE II Item: • There is an explicit link between the recommendations and the supporting evidence.	The guidelines should clearly state the research evidence that the recommendations are based on and should provide enough information for users to determine the validity and reliability of the guidelines (Grimshaw et al., 1995).		6) The link between the guidelines and the data sources is clear.
Construct: Clarity of presentation (criteria for high quality clinical practice guidelines include specific recommendations and potential other options being described, key recommendations being easily found and the provision of a summary and patient leaflets (Terrace, 2003)**).**			
AGREE II Item:			

1. Theoretical foundation	**2. Theoretical justification**	**3. Semi-structured interview questions used in email interview**	**4. Online survey questions** *Rating task on a scale from 7-point scale (1 = Strongly disagree, 7 = Strongly agree)*
• The recommendations are specific and unambiguous. • Key recommendations are easily identifiable.	The recommendations should be as specific and clear as possible (Kish, 2001; Qaseem et al., 2012) and the key recommendations should be highlighted in the guidelines and be clear and precise (Institute of Medicine (US), 2011).	2) How do you perceive the structure and presentation of the guidelines?	7) The guidelines are clear and specific.
Construct: Applicability (criteria for high quality clinical practice guidelines include discussions on potential organizational changes and resource implications linked to the implementation and information on the monitoring of the guidelines (Terrace, 2003)**).**			
AGREE II Item: • The guideline provides advice and/or tools on how the recommendations can be put into practice.	The recommendations provided in the guidelines should be actionable (Qaseem et al., 2012) and should describe exactly what the recommended action is and when it should be carried out (Institute of Medicine (US), 2011).		8) The guidelines provide advice and/or tools on how the guidelines can be put into practice.
Social validity: • What are the participants perceptions on the acceptability of the guidelines?	Social acceptability or appropriateness is a key component of social validity and can been defined as judgements by target users or consumers on the treatment (in this study the guidelines) (Kazdin, 1980).	3) How do you think that implementing these guidelines in a school setting would work?	
AGREE II Item: • The potential resource implications of applying the recommendations have been considered.	Guidelines should take into account the potential resource implications of implementation of the recommendations and whether those costs or resources are reasonable (Grimshaw et al., 1995; Shekelle et al., 1999).		9) The potential resources needed to implement the guidelines are clearly described.
AGREE II Item: • The guideline describes facilitators and barriers to its application.	Guidelines should consider issues related to feasibility including time, skill, necessary staff		10) The facilitators and barriers to the implementation of the

1. Theoretical foundation	2. Theoretical justification	3. Semi-structured interview questions used in email interview	4. Online survey questions *Rating task on a scale from 7-point scale (1 = Strongly disagree, 7 = Strongly agree)*
	and ability to apply the guidelines (Shekelle et al., 1999).		guidelines are clearly described.
Social validity: • What are the participants perceptions on the social importance of the guideline outcomes? • What are the participants perceptions of the goals of the guidelines?	The relevance of the goals of the guidelines and the validity and social importance of the intervention for the stakeholders and population should be explored in social validity (Wolf, 1978).	4) How do you perceive the relevance and importance of the guidelines for the target population?	
Construct: Editorial independence (criteria for high quality clinical practice guidelines include a statement about conflicting interests and interests of the funding body (Terrace, 2003)**).**			
AGREE II Item: • The views of the funding body have not influenced the content of the guideline. • Competing interests of guideline development group members have been recorded and addressed.	Guideline groups should strive to minimise conflict of interests, and financial conflict of interest should be adequately reported and managed (Shekelle, 2018).		11) The information about competing interests of the researchers and influence on the guidelines from a funding source is clearly stated.
Construct: Overall quality of the guidelines.			
AGREE II Item: • Rate the overall quality of the guidelines (1= Lowest possible quality; 7= Highest possible quality).	The perceived overall quality of the guidelines is based on the perceptions of the construct described above.	5) Please rate the overall quality of the guidelines, using a scale from 1 = Lowest possible quality to 7 = highest possible quality and motivate your rating.	
AGREE II Item: • I would recommend this guideline for use.	The endorsement of the guidelines is based on	6) Would you recommend the guidelines for use?	

1. Theoretical foundation	**2. Theoretical justification**	**3. Semi-structured interview questions used in email interview**	**4. Online survey questions** *Rating task on a scale from 7-point scale (1 = Strongly disagree, 7 = Strongly agree)*
	the perceptions of the constructs described above.	(Please motivate and describe your answer) 7) Do you have any additional comments or other feedback regarding the guidelines that you have not yet provided?	

Source: Conceptualized from the AGREE II Tool (used to capture the feasibility) (Brouwers et al., 2010; Terrace, 2003) and the main constructs of social validity (Wolf, 1978)

However, as the AGREE II focuses on clinical practice guideline appraisal, eight items from the original AGREE II linked to the domain's rigour of development, clarity of presentation and applicability were not applicable to the present study. These specific items as well as the justification for exclusion are shown in Table 6.4.

Table 6.4

Items from AGREE II that were not Deemed Applicable to be used to Inform the Online Survey and Email Interviews

Items from AGREE II	Justification for exclusion
Rigour of development	
7) Systematic methods were used to search for evidence.	This aspect was evaluated through peer review of the three data sources that were used to formulate the guidelines (Chapter 4).
8) The criteria for selecting the evidence are clearly described. 9) The strengths and limitations of the body of evidence are clearly described.	A review by the participants of the underlying evidence-base was not within the scope of this study, however, the participants were provided with links to the publications that they could read if they wished to.
11) The health benefits, side effects, and risks have been considered in formulating the recommendations.	Not applicable to the present study as no treatments are prescribed.
13) The guideline has been externally reviewed by experts prior to its publication.	This is the focus of this phase (Phase 3).
14) A procedure for updating the guideline is provided.	Not applicable to the present study at this stage as the guidelines are part of a PhD-project and have yet to be published.
Clarity of presentation	
17) The different options for management of the condition or health issue are clearly presented.	Not applicable to the guidelines developed in the present study as abuse is not a medical condition and the guidelines do not speak of management of an existing condition.
Applicability	
21) The guideline presents monitoring and/or auditing criteria.	Not applicable to the present study at this stage as the guidelines are part of a PhD-project and have yet to be published.

6.6.3. Guidelines of school-based abuse prevention programs

The guidelines were written in English, but the Swedish participants were encouraged to contact the student with any questions or need for explanation (or translation if needed) of specific terms. The complete guidelines were shown in Chapter 5 (Section 5.6).

6.6.4. Email interviews with semi-structured questions

In addition to the biographic questions and the AGREE- II items that formed part of the survey, email interviews were conducted. The process of developing the seven questions for the semi-structured email interview was also shown in Table 6.3. As earlier research had suggested that sending less but longer, more complex emails with several questions at once facilitated more detailed responses when compared to more frequent emails each containing a single question, all seven questions were sent in one email (Fritz & Vandermause, 2018). Questions were numbered rather than bulleted as this might assist in ensuring that participants answer all the questions (Fritz & Vandermause, 2018).

6.7. Procedure

Some procedures were related to ethics while the rest were related to data collection. Regarding ethics, prospective participants received an initial email which included information about the study and what was expected of them. After participants had expressed an interest in participating in the study, they were sent an email including information on how to participate in the study, a link to the consent form and online survey, the interview questions, and the guidelines of school-based abuse prevention programs in a PDF-format.

After reading the informed consent letter (Appendix B5), participants provided consent using an online form developed in Qualtrics (www.qualtrics.com). If participants consented to participate in the study, the link connected them to the online survey. If they declined participation, they were thanked for considering participating in the study and the online form was terminated.

Regarding data collection, all participants who consented were given instructions on the process of evaluating the guidelines, namely carefully reading the guidelines, answering the online survey, and answering the interview questions by email. Each participant was given

10 days to complete these tasks. The student was available throughout this time via email or telephone to respond to any possible questions from the participants. After the participants had submitted their answers, they received a response within two days with individual follow-up questions, depending on the direction of the answers given by the participants (Dahlin, 2021). The follow-up questions were asked either to expand or deepen answers and reasoning on a certain topic *("Tell me more about…", What do you think…"*) or to clarify *("Can you please describe…", "Can you give an example of…"*). However, the participants who submitted after the final date for submission (n = 3) were not sent any follow-up questions due to time constraints. A specific time each day was set aside to go through and respond to emails from participants and review the research questions to enable thoughtful and nuanced responses and follow-up questions (Fritz & Vandermause, 2018). After the participants responded to the follow-up questions, further probing questions were asked if needed. Furthermore, the participants were thanked for their participation in the study and informed them that the results would be shared after the analysis had been completed.

6.8. Data analysis

The quantitative data from the rating task linked to AGREE II items was analysed using a descriptive analysis (Creswell & Creswell, 2018). Means, medians, standard deviation and variance were calculated using Qualtrics (www.qualtrics.com) and reported in the results (Creswell & Creswell, 2018). Missing data was not reported as all participants who started the survey also completed it in full.

The qualitative data was prepared for analysis using a process described by Fritz and Vandermause (2018). As using email interviews eliminates the need for transcription (Hawkins, 2018), the data was imported into separate Word documents, one for each participant. Subsequently, the participants names were replaced with a numeric code to de-identify data. The documents were read through to ensure that there were no gaps or missing data before beginning the analysis (Fritz & Vandermause, 2018).

Hereafter, the data was analysed using Atlas.ti9, a software for conducting qualitative thematic analysis (https://atlasti.com/). A reflexive thematic analysis approach was used to analyse the data. Thematic analysis is characterised as a, "… method for identifying, analysing and reporting patterns (themes) within data" (Braun & Clarke, 2006, p. 79). Reflexive thematic analysis is characterised as a contextual reflexive process in which the coding is open and not linked to a specific coding framework, and the theme development and coding process is iterative (Braun & Clarke, 2020). The analysis of the data was not a linear process, hence the movement between the steps during the analysis process (Braun & Clarke, 2006). In reflexive thematic analysis, the subjectivity of the researcher is viewed as an asset and the effect of the researcher in shaping the results is seen as something positive (Braun & Clarke, 2020). Thus, concepts such as inter-rater or inter-coder reliability does not apply to reflexive thematic analysis (Braun & Clarke, 2020). The six steps of thematic analysis and their application to Phase 3 is described in Table 6.5.

Table 6.5

The Six Steps of Thematic Analysis and the Application to the Analysis of the Results of Phase 3

Six steps of analysis	Application to Phase 3
• **Familiarising oneself with the data**	Several readings of the data, note-taking and writing down ideas and thoughts related to emergent codes and themes in the data.
• **Generating initial codes**	Systematic coding of the entire data set, grouping and collecting data into relevant codes.
• **Searching for themes**	Reviewing the coding, grouping the codes into themes, and gathering all the data into themes.
• **Reviewing themes**	Making sure that the themes tie into the coded extracts and the data set, reviewing the grouping of codes in collaboration with the main supervisor.
• **Defining and naming themes**	Producing clear definitions and terms for each theme, reviewing, and refining the themes and the story they tell about the data set.
• **Producing the report**	Selecting and reviewing examples, relating the results back to the research questions and theoretical framework as well as the literature, writing up the results.

Source: Braun and Clarke (2006)

As the data was already in a written format, the starting point for analysis, which is often considered the transcription, was instead the student's immersion in the data set by reading through the material several times, asking questions and taking notes along the way (Braun & Clarke, 2006). Codes and themes were generated which were continuously reviewed as described in Table 6.5. The revision of the themes was done in collaboration with the student and the main supervisor through discussion of each of the themes and codes. All codes and themes were gathered in a code book, together with the description and weight of each of the codes and themes (Appendix F).

6.9. Results

The results from the online survey and the email interviews are presented below.

6.9.1. Online survey/rating task

All 19 participants completed the online survey rating task, including 11 statements that were derived from the AGREE II tool and rated on a 7-point Likert scale (1 = strongly disagree to 7 = strongly agree). The results from this rating are presented in Table 6.6.

Table 6.6

Results from the Online Survey Rating Task

Please rate these statements on a scale from 1 = Strongly disagree to 7 = Strongly agree	**Group1: Teachers**				**Group 2: Principals**				**Group 3: Content experts**				**Total**
	Mean	Med.	SD	Var.	Mean	Med.	SD	Var.	Mean	Med.	SD	Var.	**Mean**
Scope and purpose													
1) The target population for who the guidelines had been developed is specifically described.	5.17	5	1.46	2.14	6.33	6	0.47	0.22	6.10	6	0.70	0.49	**5.87**
Stakeholder involvement													
2) The guideline development group (participants in the three data sources) includes all relevant professional groups.	5.50	6	1.50	2.25	6.67	7	0.47	0.22	5.70	6	1.10	1.21	**5.96**
3) The target population have been asked about their views and preferences on the topic.	3.00	3	1.83	3.33	5.33	5	0.47	0.22	4.60	4.5	1.20	1.44	**4.31**
4) It is clearly defined who the target users of the guidelines are (i.e., responsible for implementing the guidelines).	6.33	6.5	0.75	0.56	6.67	7	0.47	0.22	6.50	6.5	0.50	0.25	**6.50**
Rigour of development													
5) The methods used for formulating the guidelines are clearly described.	5.67	5	0.94	0.89	5.33	6	0.94	0.89	6.10	6	0.54	0.29	**5.70**
6) The link between the guidelines and the data sources is clear.	5.67	7	1.89	3.56	5.33	6	1.70	2.89	6.40	6	0.49	0.24	**5.80**
Clarity of presentation													
7) The guidelines are clear and specific.	6.00	6	1.00	1.00	5.33	6	1.70	2.89	5.40	6	1.28	1.64	**5.58**
Applicability													
8) The guidelines provide advice and/or tools on how the guidelines can be put into practice.	6.50	7	0.76	0.58	6.33	6	0.47	0.22	5.90	6	0.83	0.69	**6.24**
9) The potential resources needed to implement the guidelines are clearly described.	6.67	7	0.47	0.22	6	6	0.82	0.67	5.70	6	0.90	0.81	**6.12**
10) The facilitators and barriers to the implementation of the guidelines are clearly described.	5.67	6	0.47	0.22	5.33	5	0.47	0.22	4.90	5.5	1.22	1.49	**5.30**
Editorial independence													
11) The information about competing interests of the researchers or influence on the guidelines from a funding source is clearly stated.	5.17	6	2.11	4.47	3.33	3	1.25	1.56	5.90	6	0.83	0.69	**4.80**
Please rate the overall quality of the guidelines	**5.58**	**6**			**5.63**	**6**			**5.80**	**6**			**5.67**

Note: Med = Median, SD = Standard deviation, Var. = Variance

6.9.2. Email interviews

The data from the email interviews were collapsed to form one corpus, which was analysed using reflexive thematic analysis (Braun & Clarke, 2006). This was done to enable reflection on the combined answers of the participants. However, the participant groups are reflected in the quotes, as each participant number is added in brackets after each quote and is numbered according to their group. Thus, quotes starting with the number 1 (i.e., {1.1}) came from the teacher group, quotes starting with the number 2 (i.e., {2.1}) came from the principal group and quotes starting with the number 3 (i.e., {3.1}) came from the content expert group.

The analysis resulted in a code book that comprised a total of 24 codes which were grouped into five distinct themes (Appendix F). The themes were:

i) Value
ii) Applicability
iii) Content
iv) Design, and
v) Implementation.

The results are presented according to each theme.

6.9.2.1. Value

This theme pertained to the perceived value of the guidelines, and contained three codes, namely:

i) Importance
ii) Quality, and
iii) Recommendations for use.

i) Importance

This code was used to describe the perceived importance of the guidelines for the target population and stakeholders.

The guidelines were described by the participants as *"Critically important"* {Participant 3.9}, *"Very important and relevant in our context"* {Participant 1.4}, and *"Very important for the target population"* {Participant 2.1}. Participants felt that there was a lack of resources and information relating to the prevention of abuse against children with communicative and/or cognitive disabilities and that the guidelines could help further knowledge on this topic: *"Very important topic that should be given more attention, which these guidelines enable"* {Participant 1.1}.

Furthermore, the guidelines were described as highly relevant for children with communicative and/or cognitive disabilities (the target population), as described by a teacher: *"It is very important for our group of students [children][1]. A very important issue to draw attention to and teach on"* {Participant 1.6}.

The guidelines were also described as highly important and relevant for teachers and principals, both to facilitate the adaptations of school-based abuse prevention programs and to increase knowledge of how to work with abuse prevention in the classroom, but also to increase the knowledge of how to detect abuse.

Additionally, a few participants focused on other staff who interact with children with communicative and/or cognitive disabilities, such as school assistants and care workers. Increasing their knowledge on abuse and abuse prevention, including signs of abuse in children

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[1] Teachers, principals, and some of the content experts used 'students' to describe 'children' or 'learners'.

with disabilities was viewed by these participants as beneficial to preventing abuse and implementing the guidelines in a school context. One content expert commented: *"Care workers and support workers are key players in the lives of children with disabilities, they provide a lot of day-to-day care, so much of the guidance for teachers and parents is very relevant"* {Participant 3.6}.

One participant, a psychologist with extensive experience of working with children who had been abused, commented that despite acknowledging the importance of the guidelines for principals and teachers, these guidelines were also seen to serve a further protective purpose for the children:

> *"I think in general that it is difficult to prevent abuse by having children protect themselves, but to give information can strongly increase the possibility that you say something when something has happened and, in that way, get support and protection"* {Participant 3.8}.

ii) Quality

This code referred to the perceived overall quality of the guidelines. Although participants provided an overall numeric rating of the guidelines (presented in Table 6.6.), they also added a qualitative comment to justify their rating. Overall, the guidelines were rated highly (average score of 5.67 / 7 for the combined group) and participants expressed that they perceived the quality of the guidelines as high: "*These are very good guidelines that apply for all school-based abuse prevention programs, with several guidelines specific to children with communicative and/or cognitive disability"* {Participant 3.10}.

However, several participants felt that the guidelines had room for improvement, particularly regarding aspects such as layout and accessibility which will be discussed in detail below. A content expert commented: *"I would put 6 [with 7 being the maximum score] as there is room for improvement and breaking the guidelines down into a more user-friendly version"* {Participant 3.6}.

iii) Recommendations for use

This comment referred to whether participants would recommend the guidelines for use, a question which they were asked during the interview.

All 19 participants stated that they would recommend the guidelines for use. One participant conditioned their recommendation with saying that guidelines would be recommended if the suggested changes were conducted. However, most participants were clear that they would recommend the guidelines in their current form.

> *"Yes, I would highly recommend these guidelines for use. As mentioned in your introduction, abuse against children with disabilities is still an ongoing human and children's rights issue that needs to be addressed - and these guidelines could assist in this!"* {Participant 3.5}.

6.9.2.2. Applicability

As for the previous theme, three codes were linked to this theme, namely

i) Appropriateness for context

ii) Appropriateness for population, and

iii) Helpful strategies.

i) Appropriateness for context

The code appropriateness for context was used for comments on the usefulness and applicability of the guidelines for the intended context, namely the school setting.

Overall, most participants were positive in terms of the appropriateness of the guidelines for the school context. Two participants thought that the applicability of the guidelines could be enhanced by including a step-by-step plan or similar strategies to highlight the most important and foundational activities that all schools should undertake in terms of abuse prevention. Similarly, two participants suggested adding more concrete strategies and tools for implementation, including ready-made materials and recommendations of specific evaluation tools and discussion prompts.

One participant, experienced in implementing a school-based abuse prevention program, found that the guidelines were quite general and could therefore be used by all schools regardless of whether children with communicative and/or cognitive disabilities were in attendance.

ii) Appropriateness for population

The code appropriateness for population was used for participant quotes which focused on the usefulness and applicability of the guidelines for the intended target population, namely children with communicative and/or cognitive disabilities.

Some teachers viewed the guidelines as applicable in an inclusive setting, or in special education schools for children with less severe intellectual disabilities. However, for children with severe intellectual disabilities, these teachers felt that there were significant challenges, or that it would be impossible to use the guidelines for teaching abuse prevention to this population.

Furthermore, challenges such as children not understanding abstract concepts and difficulties with generalization were mentioned as specific problems relating to having a severe intellectual disability.

> *“But the biggest obstacle is that the students, based on their intellectual disabilities, don’t have the ability to understand and use concepts such as want/don’t want, explaining that you can say no when something doesn’t feel good and so on. Because it doesn’t apply to everything”* {Participant 1.2}.

Several suggestions for modifications as well as thoughts related to applicability for children with more severe intellectual disabilities were provided by the participants. Suggestions included using less text and more pictures, including strategies such as videos adapted for the children’s cognitive level and rather focusing on teachers, parents, and other school staff (e.g., counsellors and school nurses) who work with these children to further their knowledge and thus facilitate the prevention of abuse. One teacher pointed out the need for the teachers who are implementing the guidelines to adapt the recommendations to the children they teach:

> “*Even if the students are 7–12 years, they are not at that age level communicatively and cognitively, and when it comes to for example, ’online’ and talking to strangers online, it is not relevant for my students at the present moment but may be very relevant for another teacher that are reading these guidelines”* {Participant 1.6}.

Participants also commented on the additional risk of abuse that children with communicative and/or cognitive disabilities face, stemming from their dependency on others. Problems relating to abuse disclosure was highlighted, as well as the potential difficulty for children to protect themselves by saying ‘no’ in a specific situation (especially considering their communication difficulties) and that teachers and other stakeholders that implement abuse prevention programs should be aware of this difficulty and its far-reaching consequences.

> *"One of the issues that one comes across frequently that is particularly important in addressing children with disabilities with protective needs, is that the capacity to say 'no' is very limited. Yes, it is a right, but in the actual situation the child may not be able to use this injunction which then compromises recovery once abuse is discovered because the child feels responsible: 'I should have said no'. Their capacity to fully understand their own powerlessness in the situation may not yet be developed. This expectation needs to be fully discussed with educators who present a program. It applies equally to children without disability"* {Participant 3.9}.

One content expert experienced in implementing a school-based abuse prevention program, felt that a lot of the teaching strategies and key components suggested would already be included in existing school-based abuse prevention programs. This expert felt that more specific strategies that are directly applicable to children with communicative and/or cognitive disabilities is needed, and that the recommendations which are directly addressed to this population as being the most useful aspect of the guidelines.

iii) Helpful strategies

This code was used for comments regarding the suggestion of strategies and links that were included in the guidelines which were perceived as helpful to facilitate the implementation.

Many participants found the links to materials, programs, and evaluation strategies to be valuable tools to find further information on the topic and facilitate the implementation of the guidelines. Participants commented: *"It is good, with concrete suggestions of ways of working* *and activities to take on these issues"* {Participant 2.2} and, *"Good, with links so you easily can read more or get material"* {Participant 3.1}.

However, one participant expressed concern as to whether teachers and principals would look at the links and use the additional material provided in the links. Another participant commented that schools might benefit from being provided with more concrete suggestions and materials in the guidelines.

6.9.2.3. Content

This theme was linked to the content of the guidelines, and contained six codes, namely

i) Continued development
ii) Clarity of language
iii) Goals and purpose
iv) Links to research
v) Translation, and
vi) Next steps.

i) Continued development

This code referred to suggestions of further changes to the guidelines that could be considered in the future.

Participants suggested several content changes to improve and further strengthen the guidelines, which were generally already considered favourably. A few participants suggested the addition of readily available materials, such as training materials for teachers, or materials for children that had been adapted to different developmental levels. Additionally, it was suggested that the guidelines should include minimum tasks, easy-to-follow schedules that outline the flow of an abuse prevention process as well as specific lesson plans. Including an introduction which clearly detailed which steps should be taken and in what order, was also suggested by one participant as a potential facilitator for implementation. Additional suggestions included stratifying, simplifying, and condensing the content of the guidelines and adding pictorial support (an AAC method using symbols to facilitate understanding) and/or pictures.

Furthermore, a few participants had suggestions in terms of specific vocabulary or terms used that they felt should be changed or clarified (e.g., replacing ‘signs of abuse’ with ‘indicators of abuse’) and content that should be added, such as examples of myths relating to child abuse.

ii) Clarity of language

This code was used to describe comments regarding the clarity of the language used in the guidelines.

Participants were conflicted in their views on the clarity of the language. Several participants remarked that they found the guidelines clear and descriptive: “*I perceive them as clear and easy to assimilate”*{Participant 1.2} and *“I think these guidelines are structured and well written. They give the impression of being based on existing evidence. The structure makes it easy to find facts in the texts and there are clear recommendations”* {Participant 3.7}.

However, some participants felt that the clarity of the language could be improved, and suggested being more detailed in the ouline of the content and adapting the vocabulary to include less scientific terms: *“Overall, all pages present too much text and very little pictorial support. Some sentences are also too long and complex. The vocabulary is also too complex and* *advanced: for example several terms from research are used without explanation"* {Participant 3.2}.

iii) Goals and purpose

This code referred to the perceived goals and purpose of the guidelines, as identified by the participants.

Most participants had a clear view of what they perceived as the purpose of the guidelines, and several described the goals and purpose as being very clear. However, as participants were asked to describe the goals and purposes, their descriptions differed to some extent. Most participants identified the purpose to be linked to adaptations of school-based abuse prevention programs for children with communicative and/or cognitive disabilities, and some also included a more general sentiment of preventing abuse against children with disabilities or providing schools, teachers, and principals with knowledge on how to prevent abuse. Two participants described the goals and purpose as: *"To describe how to adjust school-based prevention programs so it can fit for children with communicative and/or cognitive disabilities"* {Participant 3.1} and *"The purpose is that at an early stage discover students with disabilities that are victims of abuse, and how you preventatively can work to decrease the abuse"* {Participant 2.3}.

However, a few participants described the purpose differently: one participant had understood that the guidelines focused only on sexual abuse, while another described the guidelines as also including victimization by peers, such as bullying.

iv) Links to research

This code was used for comments on the connection between the recommendations in the guidelines and the research that had previously been conducted and upon which the guidelines were based.

Some participants commented on the fact that the guidelines were research-based and perceived that connection as clear: *"From what I read, the guidelines were developed using evidence from literature, included stakeholder involvement and were transparent in how the guidelines were developed and the processes used"* {Participant 3.5}.

A few of these participants also based their rating of the overall quality of the guidelines on the perceived link to the research. Most of the participants who commented on the solid research foundation were themselves experienced in conducting research.

v) Translation

This code referred to comments on the need for a Swedish translation of the guidelines. Some of the Swedish-speaking participants felt that translation of the guidelines to Swedish would be crucial for implementation in the Swedish school-context. Translation to any other language was not suggested by any of the international participants.

vi) Next steps

This code refers to suggestions for the next steps in evaluating and implementing the guidelines. Suggestions included involving children in the research and asking them about their need for adaptations, for example, by including them in a focus group to discuss their challenges and needs in terms of protection and how they could be involved in the further development of the guidelines. An additional suggestion was to set up a working group of teachers or other professionals to facilitate the implementation of the guidelines.

6.9.2.4. Implementation

This was the largest theme with nine codes delineated from it, namely:

i) Facilitators to implementation
ii) Barriers to implementation
iii) Knowledge and awareness
iv) Resources
v) Management support
vi) Rules, policies, and regulations
vii) Student healthcare
viii) Support/coaching, and
ix) Other persons.

i) Facilitators to implementation

This code was used to describe comments regarding strategies that could facilitate the implementation of a program that has been adapted using the guidelines.

Participants commented that teachers needed to be properly trained to be able to implement an abuse prevention program, and that their ability to teach the concepts included in such a program would be vital for the children's learning. One of the principals commented: *"[I] see that initially a good introduction and training is needed to ensure that the work is being conducted in a safe and secure way in terms of the quality"* {Participant 2.1}.

Additionally, one participant suggested that teachers and principals also need to have a certain level of knowledge regarding communication, communication difficulties, and the use of AAC to facilitate the implementation of the program. They suggested that these skills in terms of communication, should be in place before starting the work with adapting and implementing an abuse prevention program. Other strategies that were mentioned that could facilitate the implementation included collaboration between school staff and arranging information meetings with the creators of the guidelines.

ii) Barriers to implementation

This code was used to describe comments linked to potential barriers to implementing the guidelines that the participants could foresee.

A few participants felt that there was a risk that schools would not use the guidelines and that the guidelines would be forgotten, discarded, or perceived as being too complicated to use.

> *"I feel the guidelines provide a good concise structure, however in terms of practicality I do feel there will be a need for support/facilitation (which is perhaps beyond the scope of the guidelines) to ensure the guidelines don't just get read and cast aside"* {Participant 3.3}.

Two participants voiced concerns that it would take a lot of effort to find the relevant information, and that this could in turn deter teachers and principals from using guidelines.

> *"The links contained in the individual steps to be followed are absolutely useful and interesting. However, they can also be an obstacle to the implementation of the guide. The user has to put a lot of effort into finding the relevant information and this can discourage the use of the guide"* {Participant 3.4}.

The potential lack of enough available teachers trained in abuse and abuse prevention was also brought forward as a potential barrier to implementation. In addition, concerns that implementing the guidelines and teaching an abuse prevention program would increase the workload for trained teachers, which already have a heavy workload and a busy teaching curriculum, were voiced by a few participants.

Furthermore, the fact that abuse and topics associated with abuse prevention, can be difficult subjects to teach to children, especially children with communicative and/or cognitive disabilities was discussed. A certain level of comfort in speaking about these topics would be required from teachers to teach children about such as sexuality and victimization.

> *"A possible obstacle is that many adults fear talking about sexuality with children, maybe especially with children with disabilities. In those cases, a lot of work would have to be done on the preparation side, but I think it is well described in the text how that could be done"* {Participant 3.8}.

iii) Knowledge and awareness

This code was used for comments regarding the need for knowledge and awareness on the topics of abuse and abuse prevention in teachers, principals, and parents.

Overall, participants felt that successful implementation depended on the understanding of abuse and abuse prevention in both teachers and principals. Skills development in teachers was viewed as an important part of the guidelines. Specific knowledge of the increased risk of being abused, and potential difficulties with disclosure was brought forward by a few participants as topics where increased knowledge was needed.

Furthermore, some participants highlighted what they perceived as a general lack of knowledge of abuse and abuse prevention in teachers, principals, and other school staff, suggesting that these topics should be included in the basic training for teachers and special education teachers: *“There is a big knowledge gap on this topic and a lot of education is needed, not least in the basic training for teachers”* {Participant 1.4}.

iv) Resources

This code was used for comments related to the resources needed in the school context to implement the guidelines.

Time constraints were frequently mentioned by the participants, including the necessity of freeing up time for teachers to participate in training, conduct the necessary preparation steps, implement the abuse prevention program with the children and follow-up the implementation: *“I think that the teachers also think that it is important but that they will find it difficult to find the time to work with the material”* {Participant 1.4}.

In addition to time, financial resources were mentioned as a requisite for successful implementation. Financial resources were perceived as important both in terms of being able to provide training to staff, and to hire substitute teachers and other staff to enable increased time to be devoted to teachers implementing the abuse prevention program using the guidelines, as mentioned above. One of the teachers commented: *“My first thought (besides that it would be great to implement all of these) is that it is something that is expensive. Schools would need to focus especially on this (which is also needed)”* {Participant 1.5}.

To facilitate implementation, careful planning in terms of the resources needed was suggested by one principal. This planning strategy was suggested to include utilising team meetings and conferences to conduct training and discussions on how the abuse prevention program could be implemented.

v) Management support

This code referred to the support, knowledge and responsibility of principals and heads of education to facilitate implementation of the guidelines.

Overall, participants felt that the principal's role in the implementation of the guidelines was crucial and could be the determining factor for whether it was possible to implement the guidelines or not. The principals were viewed as being able to provide resources to teachers to implement the guidelines, and to guide the priorities that should be made in the school context. Participants were positive to the principal's role being described in the guidelines and that part of the guidelines were aimed specifically at them: *"One key to successful implementation I think is that the guidelines very clearly include the principals, and the principal's role to ensure success"* {Participant 1.3}.

Furthermore, several participants felt that principals needed to understand the importance of abuse prevention in relation to children with communicative and/or cognitive disabilities as this might result in them being more inclined to devoting resources to implement the guidelines.

Some participants, including principals themselves, suggested that principals should have the overall responsibility of planning and implementing abuse prevention programs, but could enlist the help from healthcare teams concerned with children as well as from dedicated teachers to lead the implementation: *"There are a lot of things to take a stand on before the principal plan for the implementation work"* {Participant 2.2}.

Furthermore, a few participants stressed the need to establish the implementation of the guidelines not only at the principal level, but also at a higher level with the head of education and with the school governing body. A content expert commented: *"The most crucial factor will be the principal level. Therefore, I also miss a level above the principal since I think this work must be strongly anchored and driven by the school or municipal management"* {Participant 3.2}.

vi) Rules, policies, and regulations

This code was used for comments regarding curriculums, school policies, rules, and regulations that were perceived as linked to the implementation of the guidelines.

One participant suggested strengthening the link between the guidelines and national school policies and curriculums to facilitate implementation. Another participant agreed, stating that they had found that programs which were linked to the curriculum, were easier to implement for teachers and principals.

The habilitation services (known as "rehabilitation" services in many countries) were mentioned by two participants as having an important role in providing parents and children with information about abuse prevention. One of the participants elaborated on the difficulty for schools to collaborate with the habilitation services:

> *"Here there are some difficulties, especially as our county council has decided that the habilitation centre's work is only aimed at the home environment. Subsequently, we can't turn to them with questions or wishes as only parents can do that. But maybe if a decision was made at a higher level in both services [school and habilitation centres] about a material that should be worked with and also these guidelines, then you would have the same starting point in conversations with parents"* {Participant 1.2}.

vii) Student healthcare

This code was used for comments on the student healthcare, which are teams of healthcare professionals who are employed by the school and work directly with the children at the school, and their role in implementing the guidelines.

Many of the teachers and principals thought that information on the role of the student healthcare was lacking in the guidelines. The student healthcare team were seen as very important facilitators in the implementation process. One participant in the study suggested that this team could help ease the workload for teachers and principals by taking on most of the responsibility for implementing the guidelines.

> *"I think that it is important that the student healthcare team (psychologist, counsellor, special education teacher) at the school understand and are knowledgeable about guidelines and materials because I think that it will be their task to support teachers in this work, and to raise awareness about the topic"* {Participant 1.1}.

In addition, it was pointed out by participants that the role of the student healthcare team is to work with health promotion and prevention and that the school nurse is in contact with the children during regular health checks, at which abuse could potentially be disclosed. School psychologists were identified as potential resources in implementing the guidelines by some participants. However, one participant pointed out that at the present moment, the school psychologist was not involved at all in abuse prevention or any similar topics (e.g., bullying prevention) at their school.

viii) Support/coaching

This code was used for quotes that mentioned the need for support or coaching in implementing the guidelines.

A few participants suggested that the guidelines themselves could be used as support for teachers in how they could work with abuse prevention in their classroom. Additionally, the need for support and coaching of teachers implementing the program was highlighted by two participants: *"There is a need for coaches who can help, as well as compulsory teaching opportunities"* {Participant 3.7}.

ix) Other persons

This code refers to other persons, apart from teachers, principals, and members of the student healthcare team, that were mentioned by the participants in relation to the implementation of the guidelines.

A content expert with knowledge of the school system in the UK, shared that schools in the UK typically have a safeguarding officer, which could be an important person in implementing a school-based abuse prevention program. Additionally, other staff such as communication support workers and care workers were mentioned as potential important persons in the implementation process.

6.9.2.5. Design

This theme included three codes, namely:

i) Layout/visual presentation

ii) Accessibility, and

iii) Comprehensiveness.

i) Layout/visual presentation

The code layout/visual presentation was used to describe the overall layout and structure of the guidelines as well as the formatting of the guidelines.

Participants had conflicting views on both the layout and structure of the guidelines. Some participants felt that the layout was clear and made the document easy to read, that it was easy to find information in the text, and that the use of formatting strategies was helpful: *"Use of subheadings, explanatory introductory paragraphs, bullet points and bold/italics is useful in differentiating content and presenting information"* {Participant 3.10}.

However, some participants felt that the structure was confusing, difficult to follow and that it contained too much text and too few pictures. They felt that this also impacted the usability and applicability of the content of the guidelines. One of the content experts said: *"The structure should be simplified in its design and presentation. Reading is a bit difficult due to the somewhat confusing formatting of the guide. This unfortunately makes the content difficult to use"* {Participant 3.4}.

ii) Accessibility

This code referred to comments on the accessibility of the guidelines in terms of the readability and use of visuals such as pictures and pictorial support.

Several participants felt that there was a lot of text in the guidelines and that the font used was too small, which affected the readability. Participants suggested adding pictures to make the text easier to read and ease up the density of the text or breaking up the text into smaller sections on more pages: *"Lots of information on few pages, so a bit difficult to read"* {Participant 3.1}.

One participant with extensive experience of working with AAC and universal design, felt that there was a lack of using universal design principles and pictorial support in the guidelines, which could act as a model for readers of how such strategies could be used in implementation.

iii) Comprehensiveness

This code referred to comments on the participants perceptions of how comprehensive the guidelines were.

In general, participants felt that the guidelines were very comprehensive and contained in-depth information on the topic, as expressed by a teacher: *"You have included good and ample information in only a few pages"* {Participant 1.3}.

One principal felt that the information was too in-depth to be implemented in a school environment, whilst one of the teachers felt that guidelines could benefit from more in-depth information on certain topics. The comprehensiveness of the guidelines was also reflected in a comment stating that the guidelines were a bit lengthy.

6.10. Discussion

The aim of this phase of the present study was to explore the feasibility and social validity of the guidelines of school-based abuse prevention programs for 7–12-year-old children which were developed in the preceding phases of the study.

Overall, the results demonstrate that the participants viewed the quality of the guidelines as high as determined by both their qualitative comments on the email interviews as well as by their overall quantitative rating of the quality of the guidelines. Additionally, participants found the guidelines highly important and relevant for the target population (children with communicative and/or cognitive disabilities) and stakeholders (teachers and principals) and would recommend them for use. Most participants felt that the guidelines were applicable to the school context as well as to the population, children with communicative and/or cognitive disabilities, and that the scope and purpose, target population, and stakeholders of the guidelines were clear. Furthermore, participants rated the clarity and specificity of the guidelines highly. The results can thus be interpreted as suggesting that the guidelines were perceived as both feasible and socially valid.

The participants provided interesting reflections on the applicability of the guidelines to children with severe intellectual disabilities, which was not described specifically as the target population but as a group that is included within the larger group of children with communicative and/or cognitive disabilities. It is suspected that this population is especially vulnerable in terms of the risk of being abused (Mahoney & Poling, 2011). However, abuse prevention interventions focused on teaching children with severe intellectual disabilities are incredibly scarce. This is likely due to the fact that many of the existing strategies used to teach children about abuse prevention is not applicable for this population in its current form, due to the difficulties these children experience with communication, receptive and expressive language, and cognitive skills (Mahoney & Poling, 2011), as reflected in the comments made by some of the teachers in this study. One participant also explained that the guidelines were impossible to adapt to children with severe intellectual disabilities. These results represent the inherent challenges relating to the teaching of abuse prevention concepts to children with severe intellectual disabilities. The solution to this problem might be to, rather than focus on teaching children with severe intellectual disabilities about abuse and abuse prevention directly, focus instead on teachers, parents, care workers and other persons who work directly with them (Mahoney & Poling, 2011). This was also suggested by one teacher, who could see that this approach could benefit the children in their class.

Children with and without intellectual disabilities can face challenges in understanding certain concepts and in learning to say ‘no’ to abusive situations, as pointed out by participants. One participant commented on the difficulty of having children protect themselves from abuse by teaching them abuse prevention concepts. It is important that teachers and parents make it clear to children that it is the responsibility of adults, not children, to keep children safe. Children, with and without disabilities, should not be burdened with feeling like they are responsible for their safety on their own, or that they should feel guilty if they are not able to say no or remove themselves from an abusive situation, as mentioned by one of the participants. However, providing strategies that children could use in potentially abusive situations, can also reduce risk and be empowering to children, which is often one of the aims of school-based abuse prevention programs (Lynas & Hawkins, 2017).

In the online survey, participants rated the clarity on how the guidelines could be put into practice very highly which was reflected in the email interviews, where participants gave positive feedback on the inclusion of practical applications of the guidelines which included suggestions of, and links to relevant methods and materials. These practical applications, whilst not based solely on the research from Phase 1, were thus viewed as very beneficial by the participants. This is positive, as the inclusion of links and practical applications was an important consideration when developing the guidelines (Kastner et al., 2015). Some participants asked for the inclusion of more concrete materials, discussion prompts or ready-made resources in the guidelines. This speaks to the time constraints that teachers are experiencing and the perceived amount of time and effort it would take to adapt the recommendations to their school context and to find suitable materials. However, the inclusion of ready-made materials in the guidelines could prove difficult as the goal is for the guidelines to be applicable to all school-based abuse prevention programs. It would be a difficult task to foresee what materials could be needed and how such materials would need to be adapted for optimal use in different contexts. No matter how many materials and strategies are included in the guidelines or similar materials, individual adaptations are always going to be needed due to the varying needs of children with communicative and/or cognitive disabilities in the school context. The need for the adaptation of guidelines is also highlighted in the theoretical framework of this study, where adaptations form part of the action cycle, regarding knowledge to action implementation.

Participants had somewhat differing views on the layout, structure, formatting, and accessibility of the guidelines. It can be hypothesised that perceptions of layout and structure can in part be a matter of personal preferences, such as preferring one graphic design over the other, or not preferring to read documents when the text is presented in a horizontal format. However, when developing guidelines, it should be a matter of importance that the guidelines are read and understood by as many stakeholders (i.e., teachers and principals) as possible and that the guidelines are implemented (Kastner et al., 2015). Thus, comments regarding the accessibility, clarity of language, layout, structure, and formatting should be carefully reviewed to determine whether those comments may enhance the visual appeal of the guidelines and facilitate its ease of use. Making the guidelines vivid, intuitive, and visual as a formatting strategy (Versloot et al., 2015) seemed to have been moderately successful, as participants views on the clarity of the formatting varied. One possible contributor to the negative comments from some participants in terms of the formatting could be that a great effort was made not to make the guidelines too lengthy, as this can also impact the implementation of the guidelines (Gupta et al., 2016). This, however, resulted in a larger amount of text being included on each page. Furthermore, the visual elements included in the guidelines could have been expanded, judging by comments made on the accessibility and layout of the guidelines, in which participants suggested the inclusion of more pictures as well as pictorial support (AAC-materials using symbols) to increase the readability and accessibility of the guidelines. This suggestion can also be interpreted as being in line with the universal design principles.

Overall, the results from the survey indicate that most participants felt that guidelines were clear in terms of most of the statements that they were asked to rate. One difficult question for participants to rate seemed to be the question about whether the target population had been asked about their views on the topic. Some participants scored this item highly, most likely as they were thinking about the stakeholders (the teachers and principals), and others scored it very low, likely because the target population (children with communicative and/or cognitive disabilities) were not asked for their views on the topic. In hindsight, this item should have probably been clarified, but since it was used in the AGREE II-tool and concerns about that item was not voiced in the development process, that issue was not observed earlier.

The clarity of the description of the potential resources needed to implement the guidelines was rated very highly in the online survey, and it was a theme that was also brought forward in the email interviews, which was often linked to time constraints. Experiencing time constraints has been found to be a cause of burnout in teachers (Kokkinos, 2007) and can be a problem for teachers and principals alike. In the present study, participants felt that the principal was responsible for making time for teachers to implement abuse prevention programs. However, principals must act within the financial constraints that the budget for the school represents. Thus, getting creative with the resources available in schools, such as the involvement of the student healthcare team and the utilization of teacher's conferences and meetings to train teachers in abuse prevention, as mentioned by participants in this study, could be valuable strategies to consider, whilst not requiring too many resources.

Increased knowledge in teachers, principals and other staff was suggested as a strategy that could facilitate the successful implementation of the guidelines. Several research studies have shown that teachers knowledge of abuse are often lacking (Abrahams et al., 1992; Márquez-Flores et al., 2016; Rani, 2019). The first step in adapting and implementing an abuse prevention program for children with communicative and/or cognitive disabilities should be to train teachers and provide information to parents about abuse against children with disabilities. This can be achieved by using training programs or resources that are already available, such as the ones suggested in the guidelines, and devoting teacher conferences, parent meetings, or other available venues to this subject. A fear of not having enough time to 'learn it all' should not deter from starting the journey of learning more about this topic. In these cases, principals as well as the student healthcare team can act as facilitators by providing support and time to teachers who are in the process of developing their skills in abuse prevention.

Based on the results of this phase, it is proposed that some minor changes to the guidelines are conducted before evaluating their effectiveness in a potential future intervention study. These changes should include a re-structuring of the layout, formatting, and design of the guidelines, including decreasing the amount of text on each page thereby increasing the readability and including pictures to illustrate and give examples of strategies that are suggested in the guidelines. Universal design principles should be considered when conducting these changes to ensure accessibility. Additionally, a section clarifying the target group of the guidelines- specifically focussing on the potential strategies to use when teaching children with severe intellectual disabilities about abuse prevention, such as focussing on the knowledge and skills development of teachers, parents, and other care givers instead of teaching more complex abuse prevention strategies to these children should be included in the introduction. Furthermore, adding more practical examples of pictorial support or other materials could be considered, as this was requested by some of the participants in this study. However, this must be weighed against the applicability of the guidelines to different contexts, and it should be clearly stated that these materials are only examples which should be adapted to the local environment.

6.11. Summary

This chapter described the evaluation of the feasibility and social validity of the guidelines of school-based abuse prevention programs for 7–12-year-old children with communicative and/or cognitive disabilities which were developed in the study. This was explored by conducting an online survey and email interviews with three participant groups.

Results show that the participants viewed the quality and importance of the guidelines as very high and that they would recommend the guidelines to others for their intended use. Furthermore, results show that participants thought that the guidelines were applicable to the school setting and to children with communicative and/or cognitive disabilities, depending on the children’s specific cognitive (developmental) level. The principal’s role in facilitating the implementation of the guidelines was emphasised. Additionally, participants provided feedback on the design of the guidelines, the implementation of the guidelines as well as suggestions for content and design changes. Lastly, the findings were discussed, and results were found to be indicative of the guidelines being feasible and socially valid.

CHAPTER 7

CONCLUSION

7.1. Introduction

This is the final chapter of the thesis, and it provides a summary of the results of the study, which were obtained using a three-phase mixed method exploratory sequential design. This is followed by the clinical implications of the study and a discussion on the strengths and limitations. Finally, recommendations for further research are presented.

7.2. Summary of the results from the study

A summary of the results from the study is presented below according to the three different phases of the study.

7.2.1. Phase 1

Phase 1 comprised of three separate data collection stages.

In Phase 1.1, a scoping review of school-based abuse prevention programs for 7-12-year-old children was conducted. This review focused on programs that included more than one type of abuse, was conducted by teachers in a school setting and included safety knowledge and skills, empowerment, or self-esteem as the outcome measure. The original search yielded a large number of possible studies (n = 2047), however, only nine studies describing eight programs matched the stringent inclusion criteria and were included in the study. Eight of the included studies reported positive results, whereas one study reported mixed results. The results from the studies were mapped in terms of the key components, instruments, and teaching methods as well as the outcome measures that were used. The review found that many of the programs that were included in the study used similar key components, such as good and bad secrets, strangers, safety rules and saying ‘no’. There was also an overlap in terms of the teaching methods that were used in the programs. Although most programs reported positive results, none reported including children with disabilities and none of the reports included a long-term follow-up beyond six months. The programs operated on the local and individual level of the four-level BEM and lacked focus on the inclusion of teacher and parent training. The programs also did not include suggestions for broader community or social/cultural level-involvement despite acknowledgement in the literature of the importance of a multi-level approach (Hovell et al., 2002).

Subsequently, Phase 1.2 focused on exploring the views of stakeholders and stakeholders on key components and methods that they perceived as important to include in an abuse prevention program for the target population (i.e., 7–12-year-old children with communicative and/or cognitive disabilities). Three different stakeholder groups were included in the study. One group comprised of teachers working in special education with children with communicative and/or cognitive disabilities across the relevant age group (n = 7) and the second group included practitioners working with children with disabilities who have been victims of abuse (n = 5). Participants from these two stakeholder groups participated in focus groups: one for teachers and one for practitioners. The third stakeholder group included six parents of 7–12-year-old children with communicative and/or cognitive disabilities; data was collected from them by means of individual semi-structured interviews. Several adaptations of teaching methods and materials as well as key components were suggested and described by the participants as being necessary for a school-based abuse prevention program to be suitable for children with communicative and/or cognitive disabilities. Participants saw the involvement of teachers and parents in abuse prevention as an important component and highlighted a lack of resources as a barrier to implementing a school-based abuse prevention program. Findings from the study were related to all four levels of the BEM (i.e., social/cultural, community, local, and individual levels). Additionally, a general need for increased knowledge of abuse against children with disabilities was suggested, with a specific focus on detecting and understanding signs of abuse in children with disabilities. This was suggested as participants mentioned that there was a lack of knowledge on the topic and that they found it difficult to know how to interpret potential signs of abuse in children with disabilities, even though they recognised the potential value in being able to do so.

This recommendation led to a third phase (Phase 1.3) which was not originally envisaged, namely a rapid review on possible signs of abuse in children with disability. This review was strengthened by adding an expert panel to socially validate the signs reported in the literature using a custom-designed online survey. The 39 participants included in this phase comprised of an international expert panel, with extensive experience in working with or conducting research on children with disabilities, child abuse or both. The initial search across three databases yielded 1797 potential studies of which 23 studies remained after inclusion criteria had been applied. Signs of abuse were extracted from these studies using a custom-made data extraction tool. This resulted in 28 signs of abuse, which were subsequently imported into an online survey and rated by the participants on a 7-point Likert scale (1 = Very accurate to 7 = Very inaccurate) in terms of being indicative of potential abuse. The participants rated all the signs of abuse as accurate and thereby socially validated the results. There was a significant difference in the rating between the ten highest-rated signs and the ten lowest-rated signs. The single sign of abuse that was rated as being the most accurate was PTSD, followed by other signs such as poor self-esteem, withdrawal, and anxiety while the least accurate signs were dominant behaviour, alcohol abuse, and substance abuse. In addition to the rating task, participants were provided with the opportunity to list additional signs of abuse as well as comments to the survey. None of the additional signs of abuse which were provided were mentioned by more than three participants, indicating that these signs were less common. In the comments left on the survey, participants discussed that the signs described in the survey were not decisive in determining abuse, that such signs of abuse could be unclear or absent, and that the signs should always be interpreted within the context and specific situation of each child.

7.2.1.1. Synthesis of Phase 1

In conclusion, the first phase of the study revealed the school-based abuse prevention programs included in the scoping review had similarities in terms of the key components and teaching methods that were used, as well as the outcome measures. Several adaptations were suggested in terms of the teaching methods, materials, and components to ensure applicability and usefulness for children with communicative and/or cognitive disabilities. The current lack of knowledge regarding specific signs of abuse in children with disabilities was highlighted by the participants as a potential danger zone. A rapid review showed that the potential signs of abuse extracted from research studies were socially valid and that there was a difference in the perceived accuracy of the signs.

7.2.2. Phase 2

This phase focused on developing guidelines of school-based abuse prevention programs for 7–12-year-old children with communicative and/or cognitive disabilities, using a recursive abstractive thematic analysis approach. The theoretical and conceptual frameworks of this study was used in combination with a modified version of the process for clinical guideline development to guide the development of the guidelines through knowledge inquiry, knowledge synthesis and the creation of a knowledge tool (the guidelines).

The integration of the data was done by using a combination of two qualitative data analysis methods, namely recursive abstraction, and thematic analysis. Using this combination of methods, the results from Phases 1.1 to 1.3 were extracted, condensed, and formulated into guidelines of school-based abuse prevention programs, intended for teachers and principals. The recommendations were supplemented with practical suggestions of methods, materials and websites that could help in the adaptation process. The guidelines included eight different themes, three of which were aimed at principals and five of which were aimed at teachers. When linking these guidelines to the BEM, three were related to the broadest level, namely the social/cultural level of which two were related to principals (i.e., evaluation with teachers and teacher training) and one to teachers (i.e., signs of abuse in children with disabilities). On the next level (the community level), the guidelines focused specifically on principals (i.e., resources, policies, and collaboration), while the guidelines for the top two levels (local level and individual level respectively) focused exclusively on teachers with themes such as parental involvement and support, teaching methods and materials, evaluation with children and parents, and key components of abuse prevention.

7.2.3. Phase 3

The last phase of the study comprised of an evaluation of the feasibility and social validity of the guidelines for adapting school-based abuse prevention programs for 7–12-year-old children with communicative and/or cognitive disabilities which was developed during the preceding phases. The evaluation focused on the scope and purpose, stakeholder involvement, rigour of development, clarity of presentation, applicability, and overall quality of the guidelines. A combination of quantitative and qualitative methods was used, namely an online survey and email interviews. Items for both the survey and the interview questions were based on the constructs feasibility and social validity as captured by the AGREE II, which is a guideline assessment tool. Potential participants were recruited from Sweden as well as internationally. Nineteen participants were included in the study, stratified across three groups: teachers, principals, and content experts experienced in working with and/or conducting research on disability or child abuse. All participants had experience working with children with communicative and/or cognitive disabilities in some capacity.

Results from the study showed that participants rated the overall quality of the guidelines as very high, with an average mean rating of 5.67 on a 7-point Likert scale (7 = highest possible quality). Furthermore, results from the items in both the online survey and the email interview questions show that participants felt that the guidelines were highly important and relevant and that they would recommend them for use. Participants also felt that the guidelines were applicable to the context and population but raised some concerns in terms of the applicability of the guidelines for children with severe intellectual disabilities. A lack of resources and the need for both additional time and funding to be able to implement the program was highlighted by some participants, as well as the need for increased knowledge on abuse prevention for teachers, parents, and other adults. Furthermore, participants had conflicting views on the structure, layout, and accessibility of the guidelines, but most participants approved of the overall design of the guidelines. Lastly, participants gave suggestions to the involvement of the student healthcare team as facilitators to implementation as well as specific content changes in the guidelines.

7.3. Clinical implications and scientific contribution of the study

No similar published studies were found in which guidelines for how to adapt school-based abuse prevention programs for children with communicative and/or cognitive disabilities had been developed and evaluated, despite these children's increased risk of being abused. This increased risk of abuse and the paucity of programs for this population, points to the potential importance and clinical implications of the current study. The commitment shown by all participants in this study, their assurance of how important they believe this topic to be, and their continued long-term engagement with the student (communication via email even after data collection) is reason to believe that these guidelines could have a positive impact for children with communicative and/or cognitive disabilities. The clinical implications and contributions are presented according to the levels of the BEM and are linked to both the theoretical and conceptual frameworks of the study. While also acknowledging that this separation into the respective levels is purely an academic exercise, as these implications are intertwined impacting on each other in a transactional manner, it serves the purpose of highlighting the importance of strengthening knowledge, skills, and capacity across the system. Moreover, collaboration is a central component of successful multi-level interventions such as the proposed guidelines, and positively impacts on the sustainability of such initiatives. The scientific contribution of the study is presented after the clinical implications.

7.3.1. *Social/cultural level*

Teachers working with children with communicative and/or cognitive disabilities as well as parents of such children seem to have a lack of knowledge relating to abuse and abuse prevention. This makes the teacher training and parental involvement that is suggested in the guidelines a very important component, one which can be implemented in schools or classrooms catering for children with severe intellectual disabilities who might not be able to participate in abuse prevention programs themselves.

As the guidelines have been written in English, and include international resources, they could be applied to English-speaking contexts internationally. International content experts were included in the evaluation of the feasibility of the guidelines as well as in Phase 1.3, further suggesting the potential for international implementation. Additionally, as guidelines were developed in this study (in lieu of a curriculum-driven program) teachers from all over the world are empowered to make adaptations to suit their specific context and needs. Hence, they can ensure a close alignment to the children's knowledge embedded in their classrooms.

Phase 1.3, which investigated the perceived accuracy of signs of abuse in children with disabilities is, as far as the student is aware, a unique study. The findings from this study could have implications for teacher's vigilance to potential signs of abuse and for detecting abuse. It could be used as a tool to increase the overall awareness of the risk that children with disabilities face of becoming abused which could lead to earlier identification of children who are abused, and therefore reduce the risk of continued abuse, as well as the potential signs that can be seen from abuse. However, it should be noted that those potential signs of abuse can never be seen as decisive and should never be the only deciding aspect which is used for guidance on whether a child had been abused or not.

7.3.2. Community level

The guidelines could be used as a catalyst for collaboration between community stakeholders, such as schools, social services, and health services. As children with communicative and/or cognitive disabilities often have many contacts throughout the community with various care and support services, a shared knowledge and understanding of abuse and abuse prevention could prove vital to decrease the risk of abuse and improve the response from community stakeholders when abuse is suspected. In this context, the guidelines could provide a generic roadmap and be used as a discussion tool while also guiding the knowledge that is needed on this topic.

7.3.3. Local level

The teaching methods suggested in the guidelines could be implemented more widely at schools looking to implement abuse prevention programs, not only linked to children with communicative and/or cognitive disabilities. Many children benefit from the use of interactive teaching methods and methods to facilitate communication, such as using pictorial support. By implementing these strategies when teaching abuse prevention concepts, a more inclusive environment which caters for all children's needs could be achieved, in line with the principles of universal design.

The recommendations in the guidelines, aimed at parental involvement, could also be applied to other caregivers and care workers. As participants in this study highlighted, caregivers and care workers need information about abuse and abuse prevention, as well as how to identify signs of abuse in children with disabilities. As children with communicative and/or cognitive disabilities can spend significant parts of their day in interaction with these persons, their knowledge about abuse and abuse prevention could be very important to minimise the risk of abuse. These guidelines could thus serve to close the knowledge-awareness gap.

7.3.4. Individual level

The guidelines demonstrate the need for teaching children with communicative and/or cognitive disabilities safety skills and empowering them to speak up against abuse, irrespective of the modality that they use. The guidelines could be used to ensure that all necessary adaptations are conducted to cater to the needs of this population, including AAC-materials and adapting key components so that they are relatable and applicable to the lives of children with communicative and/or cognitive disabilities.

7.3.5. Scientific contribution

The study utilised a novel theoretical approach to the adaptation of public health interventions and evidence-based programs for new populations, by employing the BEM supplemented by the KTA as the theoretical framework. The theoretical framework guided the analysis of the study and provided a lens for interpreting and understanding the findings. This approach provides valuable insights into the applicability and suitability of using the BEM, supplemented by the KTA, as a theoretical framework for developing adaptations of evidence-based programs and public health interventions, such as school-based abuse prevention programs for children with communicative and/or cognitive disabilities.

The customized framework for adaptations which was developed in the study and used to guide the development of the guidelines, resulted in guidelines which were linked to all levels of the BEM. Furthermore, the guidelines were considered feasible and socially valid by participants who took part in the evaluation. These results suggest that the customized framework could be used as a tool for developing adaptations of evidence-based programs and public health interventions.

7.4. Evaluation

This section provides an evaluation of both the strengths and the limitations of the study.

7.4.1. Strengths of the study

A comprehensive and diligent research evidence-based guideline development process was followed to address the research gap that is evident when it comes to abuse prevention aimed at children with communicative and/or cognitive disabilities. It included a scoping review on school-based abuse prevention programs for children, two qualitative focus groups and six qualitative interviews on adaptations of abuse prevention programs for children with communicative and/or cognitive disabilities and a rapid review. This was followed by social validation using an online quantitative survey with qualitative components on signs of abuse on children with disabilities, guideline development as well as an evaluation thereof focused on feasibility and social validity using both qualitative and quantitative methods.

The study used a three-phase exploratory sequential design with three different data collection methods used in the first phase, which resulted in rich data that could be employed to develop the guidelines of school-based abuse prevention programs. The scoping review revealed a lack of abuse prevention programs for children with communicative and/or cognitive disabilities, but also pointed to the similarities in terms of the key components, teaching methods and outcome measures used in abuse prevention programs. By conducting the scoping review, the use of the BEM supplemented by the KTA as critical components in the theoretical framework of this study was solidified, as results showed a lack of focus on the social and community level. A further understanding of the importance of adaptations of school-based abuse prevention programs for children with communicative and/or cognitive disabilities was gained as well as insight into how the adaptations could be carried out from the participants in the focus groups and interviews. During this data collection, another gap in the research was identified, namely knowledge on signs of abuse in children with disabilities.

A rigorous approach was used when conducting both the scoping review and the rapid review, following the same steps as are recommended for a systematic review, excluding the appraisal of the evidence but then opting to include a social validation phase. The rapid review demonstrated that whilst potential signs of abuse in children with disabilities that have possibly been abused have been described in the research literature, these signs have not been described in terms of their accuracy which was thus explored in the social validation component. Although the survey topic was complex and intersectional in its nature, 39 international experts volunteered to participate. The survey results show a difference in the perceived accuracy between the ten highest rated signs and the ten lowest rated signs, indicating that there are certain behavioural or physical signs of abuse that are important to be aware of in children with disabilities.

The guidelines that were developed in the present study were based on the data that had previously been collected in the study. A customised framework for adaptations was developed and served as the conceptual framework, guiding all the steps that were taken which were in keeping with the suggested development process for clinical guidelines. Furthermore, the integration of the data from Phase 1 was carried out in six steps, employing a recursive abstraction process combined with a thematic analysis.

The results from the evaluation of the feasibility and social validity of the guidelines of school-based abuse prevention programs for 7–12-year-old children that was conducted in Phase 3 are promising. The data collection was carried out using both quantitative and qualitative methods, thus strengthening the results. The 19 participants all stated that the overall quality of the guidelines was very high and that they were substantially important for both children with communicative and/or cognitive disabilities as well as the stakeholders (teachers and principals). Furthermore, the participants agreed that they would recommend the guidelines for use.

7.4.2. Limitations of the study

The proposed guidelines developed in this study have been evaluated in terms of their feasibility and social validity. However, the effectiveness of the guidelines have not been evaluated in an implementation study, which is a limitation of the present study. Future research studies on the proposed guidelines are needed to evaluate the effectiveness in adapting school-based abuse prevention programs for 7–12-year-old children with communicative and/or cognitive disabilities.

In Phase 1.1, fairly limiting inclusion criteria were used to review the school-based abuse prevention programs that would address the research questions which were asked. For example, only studies that included at least two types of abuse were included, which means that programs focusing on only one type of abuse, such as sexual abuse, were excluded. Furthermore, only abuse perpetrated by adults was focused on, thereby not including peer-to-peer abuse such as bullying. This limited the number of programs which were included but ensured that they were relevant to the purpose. Additionally, by choosing to conduct a scoping review rather than a systematic review, the publications were not appraised in terms of the quality of the methodologies that were used.

In Phase 1.2, a relatively small sample size was used for the focus groups and interviews (n = 19) which was due to the difficulty of recruiting participants from groups such as teachers and parents of children with disabilities, who are already burdened with heavy workloads and responsibilities. Additionally, one of the most common perpetrators of child abuse (particularly of children with disabilities) are parents. This fact could in part explain the difficulty in recruiting persons from this particular group. These difficulties with recruiting participants might have impacted the results that were obtained, as additional perspectives could have been provided if the number of participants had been increased. Additionally, it is recommended that focus groups are conducted several times with the same groups of participants. This was not done in the present study. This could have had a negative effect on the level of data saturation, even though it was perceived that data saturation was achieved in the study. During the analysis of the data from the focus groups and interviews, the results from the three groups were collapsed to form one corpus. This approach facilitated the analysis on a group level but impacted the ability to highlight findings from specific sub-groups, such as teachers or parents. As only teachers who worked in special schools were included in the teacher focus group, perspectives from inclusive school settings were not obtained.

In Phase 1.3, some methodological limitations were uncovered. The signs that could indicate potential abuse that were presented in the survey were not presented within a context (such as the situation that the sign was discovered in, or the disability type of the child displaying the sign), which some participants thought made the rating of the signs more difficult. This was a deliberate strategy, as the intention was to create a ‘baseline’ for the accuracy of potential signs of abuse in children with disabilities, as no similar study had been found when reviewing the research literature. Participants also highlighted that it could have been helpful to add comments to each rated sign of abuse, as opposed to only a comment section towards the end of the survey. By applying this strategy, it could have put the ratings into context and could have served as an explanation for the ratings. Furthermore, the number of participants in the study was relatively limited (n = 39) even though much effort was put into recruiting participants. As signs of abuse in children with disabilities is a complex topic, and the aim was to get experts with substantial knowledge on the topic to participate, this number was still deemed to be sufficient. In the statistical analysis, post hoc analysis were conducted to include a comparison on the ten highest rated signs of abuse to the ten lowest rated signs and to conduct a group comparison between participants. Using a post hoc analysis increased the risk for Type 1 error, which could lead to false positives in the findings. However, these findings were not the main findings of this phase and thus did not impact the results which were used in the development of the guidelines. PTSD was highlighted as being perceived as the most accurate sign of abuse by the participants in this phase. However, PTSD is a clinical diagnosis which constitutes of several potential indicators of abuse, such as severe anxiety and flashbacks. The term PTSD was used in this study as it was frequently described as a sign of abuse in the publications that were included in the rapid review. However, future research on signs of abuse in children with disabilities would benefit to consider using the symptoms of PTSD as indicators of abuse instead of the diagnostic term.

In Phase 3 of the study, a limited sample size was included (n = 19). Initially, the aim was to include 25 participants who had all agreed to participate in the study. However, six participants dropped out of the study when receiving the instructions for the study, citing a heavy workload. Due to a late submission by three participants, there was not enough time to ask follow-up questions to those participants which could have further deepened the knowledge on the topic. Additional perspectives could have been obtained on the feasibility and social validity of the guidelines by including parents of children with communicative and/or cognitive disabilities, as they were one of the key stakeholder groups in Phase 1.2. Their perspectives should be sought in future studies with the aim of implementing the guidelines.

Certain stakeholder groups were chosen for inclusion in this study due to their experience and knowledge on the topic. However, children with communicative and/or cognitive disabilities were not included. They could have contributed with valuable information in terms of their preferences in how abuse prevention programs should be conducted and what their needs were in terms of how the program was taught. However, this was a conscious choice by the student due to the ethical implications of including children with communicative and/or cognitive disabilities during this early stage of research on this topic.

7.5. Recommendations for future research

School-based abuse prevention programs should be adapted and implemented for children with communicative and/or cognitive disabilities, as they are a population group that are particularly at risk of being abused. In the present thesis, the focus was on the knowledge creation part of the theoretical framework. As a knowledge tool, namely the guidelines developed in this study, has been developed and evaluated, there is a need to shift the focus to the action cycle and further adapt and implement the guidelines. This could include applying the guidelines to a school-based abuse prevention program and carrying out the adaptations. The adapted prevention program could subsequently be implemented in a special school or in an inclusive setting during a pilot study. The adapted prevention program could be evaluated using pre- and post-test measurements of knowledge of abuse in both teachers and children. The evaluation could be carried out using a survey format for the teachers and Talking Mats™-interviews for the children, conducted both before and after the intervention as well as six months after the intervention to measure the long-term effects.

After a pilot study has been conducted, the guidelines could be tested on a larger scale in an intervention study, utilising both an experimental and a control group, and including more participants, preferably in several different schools and different age levels. Again, a pre-test-post-test design could be used, and measurements could include knowledge of abuse in teachers and children, program satisfaction in teachers, children and parents, and safety skills in children. Additionally, as many abuse prevention programs claim to aim for feelings of empowerment in children, a measurement which could capture feelings of empowerment before and after the program would be very beneficial. It would be important to include long-term follow-up, preferably at least at six months and again at 12 months after the implementation of the program. Relating to the difficulties that children with cognitive disabilities can face in terms of generalization of learned concepts, using both identical, and similar situations, but not identical to those situations taught in the program during the evaluation of safety skills, would be interesting to gain further understanding into the generalization of the learned abuse prevention concepts.

Another valuable direction for further research on this topic would be to include children with communicative and/or cognitive disabilities in the further development of the guidelines. This could be done through focus groups or interviews, asking children about their preferences and needs in terms of how abuse prevention programs should be taught. Additionally, children with disabilities could be employed as co-researchers in the pilot implementation of an adapted abuse prevention program. It is likely that children's views on this topic will vary significantly compared to adult's views, and children's views would be valuable in furthering the knowledge of what is crucial to include in a school-based abuse prevention program for children with communicative and/or cognitive disabilities.

As the focus of this study was on the educational context and not in the context of healthcare, the need for support which parents of children with disabilities may experience was not explored further. Parents of children with disabilities can have disabilities themselves, potentially complicating the involvement in abuse prevention programs and increasing the risk of becoming a perpetrator of abuse. As discussed earlier, families of children with disabilities also face additional challenges contributing to a higher risk of child abuse, such as poverty and social isolation. Therefore, a study exploring the support needed for parents with disabilities or parents with socio-economic problems to be able to be involved in abuse prevention programs and to support their children with disabilities in learning abuse prevention concepts, would be a valuable addition to this research field.

As a lack of resources has been brought up frequently in this study as a potential barrier to implementation of school-based abuse prevention programs for children with communicative and/or cognitive disabilities, a study exploring the minimal amount of effort and training for the maximal amount of output would be interesting. This study could also consider the aspects of teacher workload by evaluating whether this type of program increases teacher's feelings of stress and being over-worked, or their experience of self-efficacy and the effect of these constructs. This could be done by dividing participants into different groups and conducting the training using the same abuse prevention program, however, in different versions, such as a full version and a slimmed down version containing only the essentials and minimal amounts of materials and preparations. The time and resources for the teachers to implement each version of the program should be carefully monitored and compared to the end results. As the workload and teaching demands continue to increase, innovative ways of conducting research on program implementations should be explored to ensure that the time spent teaching a program is necessary.

The current study demonstrated satisfaction with the guidelines for school-based abuse prevention programs. As children with disabilities are also at a high risk of being subjected to peer-to-peer abuse, such as bullying, a future study could explore the possibility of further developing the guidelines for school-based bullying prevention programs, to benefit the inclusion of children with communicative and/or cognitive disabilities in such programs.

The theoretical and conceptual frameworks which were used in this study highlight the value of customization for conducting adaptations. These frameworks could be further developed and evaluated by using them to adapt programs and interventions in other fields, such as the prevention of bullying, as mentioned above.

Finally, the survey on the perceived accuracy of signs of abuse in children with disabilities in the present study could be built upon by conducting a larger scale study to develop a screening tool for signs of abuse in children with disabilities. However, that kind of screening tool should only be developed for- and used by practitioners experienced in working with children who have been abused and should not be used in a school setting.

7.6. Summary

This chapter discussed the conclusions that were drawn from the results of this study. A summary of the three different phases and the key findings per phase were provided. The clinical implications of the guidelines of school-based abuse prevention programs for 7–12-year-old children were discussed, and the study was evaluated in terms of its overall strengths and limitations. Finally, recommendations for future research linked to school-based abuse prevention for children with communicative and/or cognitive disabilities are provided.

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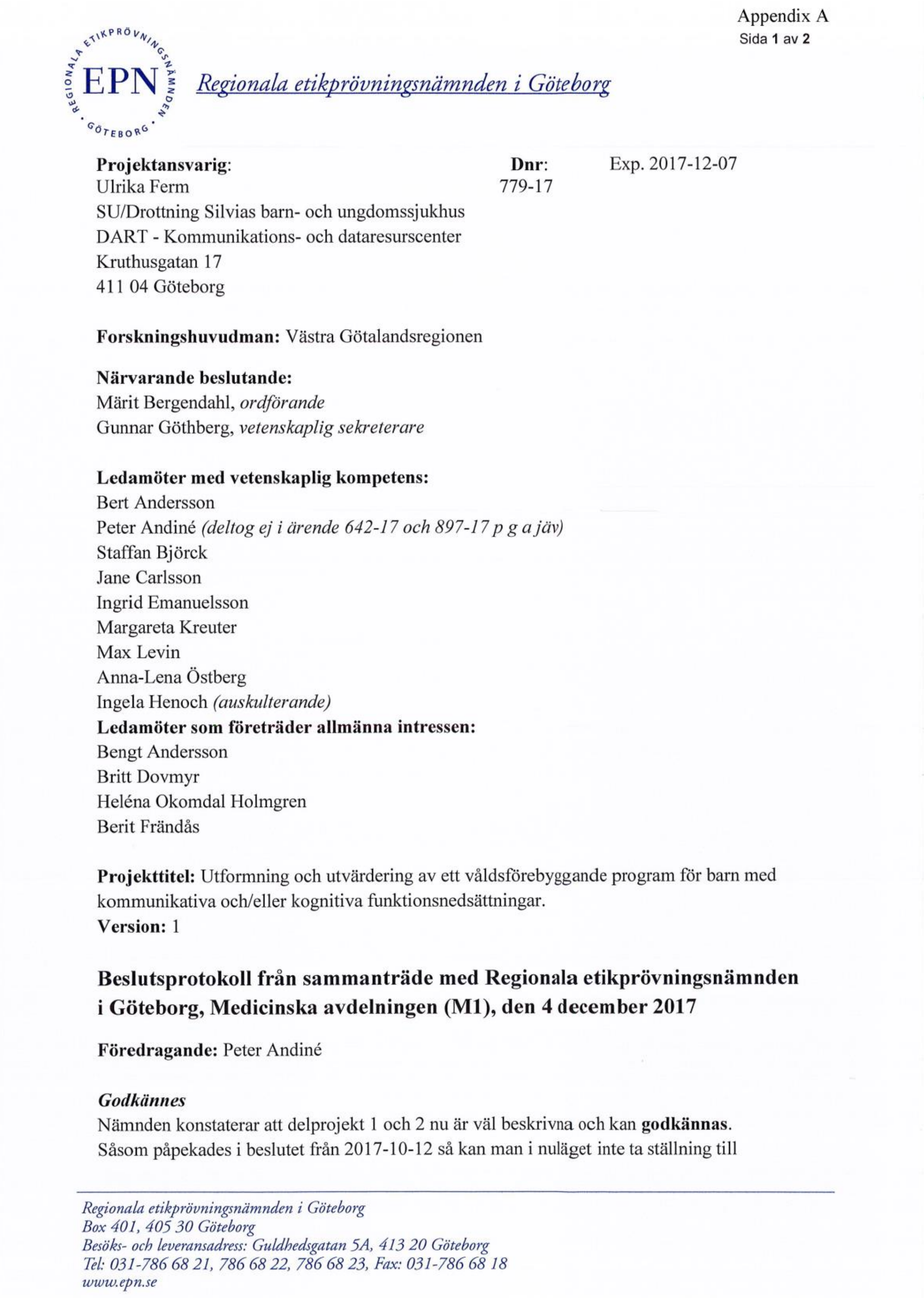
APPENDICES

Appendix A1: Ethics approval from the University of Gothenburg



Appendix A
Sida **1** av **2**

Regionala etikprövningsnämnden i Göteborg

Projektansvarig:
Ulrika Ferm
SU/Drottning Silvias barn- och ungdomssjukhus
DART - Kommunikations- och dataresurscenter
Kruthusgatan 17
411 04 Göteborg

Dnr: 779-17

Exp. 2017-12-07

Forskningshuvudman: Västra Götalandsregionen

Närvarande beslutande:
Märit Bergendahl, *ordförande*
Gunnar Göthberg, *vetenskaplig sekreterare*

Ledamöter med vetenskaplig kompetens:
Bert Andersson
Peter Andiné *(deltog ej i ärende 642-17 och 897-17 p g a jäv)*
Staffan Björck
Jane Carlsson
Ingrid Emanuelsson
Margareta Kreuter
Max Levin
Anna-Lena Östberg
Ingela Henoch *(auskulterande)*
Ledamöter som företräder allmänna intressen:
Bengt Andersson
Britt Dovmyr
Heléna Okomdal Holmgren
Berit Frändås

Projekttitel: Utformning och utvärdering av ett våldsförebyggande program för barn med kommunikativa och/eller kognitiva funktionsnedsättningar.
Version: 1

Beslutsprotokoll från sammanträde med Regionala etikprövningsnämnden i Göteborg, Medicinska avdelningen (M1), den 4 december 2017

Föredragande: Peter Andiné

Godkännes
Nämnden konstaterar att delprojekt 1 och 2 nu är väl beskrivna och kan **godkännas**. Såsom påpekades i beslutet från 2017-10-12 så kan man i nuläget inte ta ställning till

Regionala etikprövningsnämnden i Göteborg
Box 401, 405 30 Göteborg
Besöks- och leveransadress: Guldhedsgatan 5A, 413 20 Göteborg
Tel: 031-786 68 21, 786 68 22, 786 68 23, Fax: 031-786 68 18
www.epn.se

fortsättningsprojekten del 3 och 4. Dessa projekt behöver beskrivas med större tydlighet när resultaten från delstudie 1 och 2 är klara, och som nämnden påpekar bör man då involvera psykolog och/eller psykiatrisk kompetens.

Att denna avskrift i transumt överensstämmer med originalet intygar
Anna Fredriksson
Anna Fredriksson, administrativ sekreterare

Appendix A2: Ethics approval from the University of Pretoria

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Fakulteit Geesteswetenskappe
Lefapha la Bomotho

Humanities 100.
Since 1919

16 February 2021

Dear Mrs EAE Nyberg

Project Title:	Developing and evaluating a maltreatment prevention programme for children with communicative and/or cognitive disabilities
Researcher:	Mrs EAE Nyberg
Supervisor(s):	Prof JJ Bornman
Department:	CAAC
Reference number:	17388602 (GW0180828HS) (Amendment)
Degree:	Doctoral

Thank you for the application to amend the existing protocol that was previously approved by the Committee.

The revised / additional documents were reviewed and **approved** on 16 February 2021 along these guidelines, further data collection may therefore commence (where necessary).

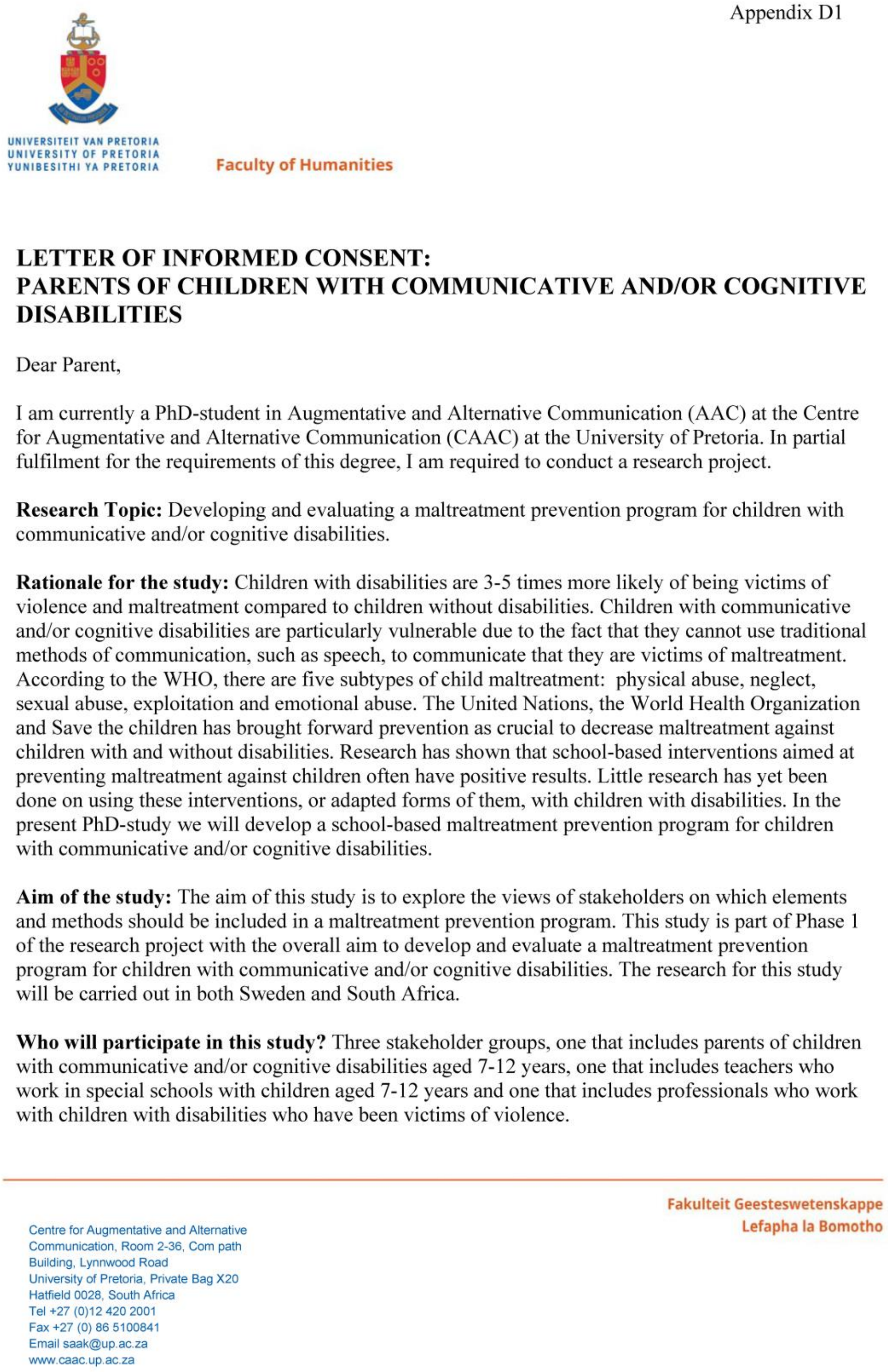
Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the amended proposal. Should your actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

We wish you success with the project.

Sincerely,

Prof Innocent Pikirayi
Deputy Dean: Postgraduate Studies and Research Ethics
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail:PGHumanities@up.ac.za

Appendix B1: Letter of informed consent for parents in Phase 1.2



Appendix D1

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities

LETTER OF INFORMED CONSENT: PARENTS OF CHILDREN WITH COMMUNICATIVE AND/OR COGNITIVE DISABILITIES

Dear Parent,

I am currently a PhD-student in Augmentative and Alternative Communication (AAC) at the Centre for Augmentative and Alternative Communication (CAAC) at the University of Pretoria. In partial fulfilment for the requirements of this degree, I am required to conduct a research project.

Research Topic: Developing and evaluating a maltreatment prevention program for children with communicative and/or cognitive disabilities.

Rationale for the study: Children with disabilities are 3-5 times more likely of being victims of violence and maltreatment compared to children without disabilities. Children with communicative and/or cognitive disabilities are particularly vulnerable due to the fact that they cannot use traditional methods of communication, such as speech, to communicate that they are victims of maltreatment. According to the WHO, there are five subtypes of child maltreatment: physical abuse, neglect, sexual abuse, exploitation and emotional abuse. The United Nations, the World Health Organization and Save the children has brought forward prevention as crucial to decrease maltreatment against children with and without disabilities. Research has shown that school-based interventions aimed at preventing maltreatment against children often have positive results. Little research has yet been done on using these interventions, or adapted forms of them, with children with disabilities. In the present PhD-study we will develop a school-based maltreatment prevention program for children with communicative and/or cognitive disabilities.

Aim of the study: The aim of this study is to explore the views of stakeholders on which elements and methods should be included in a maltreatment prevention program. This study is part of Phase 1 of the research project with the overall aim to develop and evaluate a maltreatment prevention program for children with communicative and/or cognitive disabilities. The research for this study will be carried out in both Sweden and South Africa.

Who will participate in this study? Three stakeholder groups, one that includes parents of children with communicative and/or cognitive disabilities aged 7-12 years, one that includes teachers who work in special schools with children aged 7-12 years and one that includes professionals who work with children with disabilities who have been victims of violence.

Fakulteit Geesteswetenskappe
Lefapha la Bomotho

Centre for Augmentative and Alternative
Communication, Room 2-36, Com path
Building, Lynnwood Road
University of Pretoria, Private Bag X20
Hatfield 0028, South Africa
Tel +27 (0)12 420 2001
Fax +27 (0) 86 5100841
Email saak@up.ac.za
www.caac.up.ac.za

What will be expected of you? You will participate in one focus group to share your knowledge and opinions on the elements and methods that could be included in a maltreatment prevention program for children with communicative and/or cognitive disabilities. It is estimated that the group sessions will last between 60-120 minutes. You will be asked to arrive 30 minutes before the starting time of the focus group. When you arrive, you will be asked to fill out a biographical questionnaire and hand in your filled-out consent form. After you have completed the questionnaire you will be provided with coffee/tea and cake. Stimulus material will be presented at the beginning of the focus group. This material includes definitions of key concepts that will be used during the focus group as well as examples of AAC-materials that have been developed for talking about violence and maltreatment. The focus groups will be audio recorded and the recorded material will be transcribed and analyzed.

What are the risks and benefits? Participation in the study is voluntary and you will receive no incentives for your participation. You may withdraw at any time from the study without any negative consequences. You will at no stage during the focus group be exposed to harm or risk. As some participants may find the topic of conversation (maltreatment against children with communicative and/or cognitive disabilities) uncomfortable, all participants who express the need, will be given the opportunity to engage in a debriefing session with a psychologist after the focus group. It is hoped that you will find it enriching to share your views on the development of a maltreatment prevention program during the focus group.

Confidentiality: When you agree to participate, consent is given that the focus group will be audio recorded and all answers written down. Please respect your fellow focus group member by not disclosing their identity or what they said in the discussion outside of the focus group. Only the researcher and the supervisors will have access to the recordings and written materials. No personal identifying information of any participant or participating organization (or school) will be included when the data is reported. The identity of the participants will be coded. The coding sheet will only be available to researchers working directly with the study. Results from this study will be used to write a thesis, for conference presentations, journal articles and for future research. The recordings, coding sheet, transcripts as well as the raw data will be kept in hard copy and electronic format at a safe place at the Centre for AAC for 15 years for archival and further research purposes.

Proposed date of study: It is proposed that the study will take place in January - March 2019.

If you wish to give your consent for participation in a focus group, please sign the attached consent form and submit to the researcher before the start of the group. We trust that you will agree on the importance of this study to help develop a maltreatment prevention program for children with communicative and/or cognitive disabilities. We would appreciate your willingness to participate in this study.

For further information, please contact researcher: Mrs Amanda Nyberg (speech-language therapist)
Email: amanda.nyberg@vgregion.se Tel No: 004631 342 08 10

Kind regards,

Amanda Nyberg

Mrs Amanda Nyberg
Researcher and SLT

Prof Juan Bornman
Supervisor

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UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities

PARTICIPANT CONSENT FORM:
PARENTS OF CHILDREN WITH COMMUNICATIVE AND/OR COGNITIVE DISABILITIES

Research Topic: Developing and evaluating a maltreatment prevention program for children with communicative and/or cognitive disabilities.

By participating in this study, I agree that:

- I will voluntarily participate in the study as outlined above and that I have the freedom of choice to participate or not
- I understand that I will at no stage during the research process be exposed to any harmful situations
- I have the right to withdraw from this study should I wish to do so for any reason whatsoever without providing any explanation or without any negative consequences
- I understand that there is no direct benefit or financial gain when participating in this study. Information gained in the study will be used to develop a maltreatment prevention program which hopes to benefit children with communicative and/or cognitive disabilities
- I understand that my answers in the focus group will be documented through audio recording and writing
- I understand that the content of the data will be handled with confidentiality and used to write a thesis, for conference presentations, journal articles and for future research
- I understand that no identifying information will be given and that the data will be stored in hard copy and electronic format for a period of 15 years in a safe place at the CAAC, University Pretoria for archival and further research purposes.

I hereby give consent:

Signature:____

Date:________________

Contact information:

Name____

Tel No: ____

Email: ____

Fakulteit Geesteswetenskappe
Lefapha la Bomotho

Centre for Augmentative and Alternative
Communication, Room 2-36, Com path
Building, Lynnwood Road
University of Pretoria, Private Bag X20
Hatfield 0028, South Africa
Tel +27 (0)12 420 2001
Fax +27 (0) 86 5100841
Email saak@up.ac.za
www.caac.up.ac.za

Appendix B2: Letter of informed consent for teachers in Phase 1.2

Appendix D2

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities

LETTER OF INFORMED CONSENT: TEACHERS IN SPECIAL SCHOOLS

Dear Teacher,

I am currently a PhD-student in Augmentative and Alternative Communication (AAC) at the Centre for Augmentative and Alternative Communication (CAAC) at the University of Pretoria. In partial fulfilment for the requirements of this degree, I am required to conduct a research project.

Research Topic: Development and evaluation of a maltreatment prevention program for children with communicative and/or cognitive disabilities.

Rationale for the study: Children with disabilities are 3-5 times more likely of being victims of violence and maltreatment compared to children without disabilities. Children with communicative and/or cognitive disabilities are particularly vulnerable due to the fact that they cannot use traditional methods of communication, such as speech, to communicate that they are victims of maltreatment. According to the WHO, there are five subtypes of child maltreatment: physical abuse, neglect, sexual abuse, exploitation and emotional abuse. The United Nations, the World Health Organization and Save the children has brought forward prevention as crucial to decrease maltreatment against children with and without disabilities. Research has shown that school-based interventions aimed at preventing maltreatment against children often have positive results. Little research has yet been done on using these interventions, or adapted forms of them, with children with disabilities. In the present PhD-study we will develop a school-based maltreatment prevention program for children with communicative and/or cognitive disabilities.

Aim of the study: The aim of this study is to explore the views of stakeholders on which elements and methods should be included in a maltreatment prevention program. This study is part of Phase 1 of the research project with the overall aim to develop and evaluate a maltreatment prevention program for children with communicative and/or cognitive disabilities. The research for this study will be carried out in both Sweden and South Africa.

Who will participate in this study? Three stakeholder groups, one that includes parents of children with communicative and/or cognitive disabilities aged 7-12 years, one that includes teachers who work in special schools with children aged 7-12 years and one that includes professionals who work with children with disabilities who have been victims of violence.

What will be expected of you? You will participate in one focus group to share your knowledge and opinions on the elements and methods that could be included in a maltreatment prevention program for children with communicative and/or cognitive disabilities. It is estimated that the group sessions will last between 60-120 minutes. You will be asked to arrive 30 minutes before the starting time of the focus group. When you arrive, you will be asked to fill out a biographical questionnaire and hand in your filled-out consent form. After you have completed the questionnaire you will be provided with coffee/tea and cake. Stimulus material will be presented at the beginning of the focus group. This material includes definitions of key concepts that will be used during the focus group as well as examples of AAC-materials that have been developed for talking about violence and maltreatment. The focus groups will be audio recorded and the recorded material will be transcribed and analyzed.

In addition to your participation in the focus group, we will ask you to identify parents that could be suitable for participation in the study. Parents must have a child between 7-12 years of age who go to a special school. Parents must also be fluent in English.

What are the risks and benefits? Participation in the study is voluntary and you will receive no incentives for your participation. You may withdraw at any time from the study without any negative consequences. You will at no stage during the focus group be exposed to harm or risk. As some participants may find the topic of conversation (maltreatment against children with communicative and/or cognitive disabilities) uncomfortable, all participants who express the need, will be given the opportunity to engage in a debriefing session with a psychologist after the focus group. It is hoped that you will find it enriching to share your views on the development of a maltreatment prevention program during the focus group.

Confidentiality: When you agree to participate, consent is given that the focus group will be audio recorded and all answers written down. Please respect your fellow focus group member by not disclosing their identity or what they said in the discussion outside of the focus group. Only the researcher and the supervisors will have access to the recordings and written materials. No personal identifying information of any participant or participating organization (or school) will be included when the data is reported. The identity of the participants will be coded. The coding sheet will only be available to researchers working directly with the study. Results from this study will be used to write a thesis, for conference presentations, journal articles and for future research. The recordings, coding sheet, transcripts as well as the raw data will be kept in hard copy and electronic format at a safe place at the Centre for AAC for 15 years for archival and further research purposes.

Proposed date of study: It is proposed that the study will take place in January - March 2019. If you wish to give your consent for participation in a focus group, please sign the attached consent form and submit to the researcher before the start of the group.We trust that you will agree on the importance of this study to help develop a maltreatment prevention program for children with communicative and/or cognitive disabilities. We would appreciate your willingness to participate in this study.

For further information, please contact researcher: Mrs Amanda Nyberg (speech-language therapist)
Email: amanda.nyberg@vgregion.se Tel No: 004631 342 08 10

Kind regards,

Amanda Nyberg

Bornman

Mrs Amanda Nyberg
Researcher and SLT

Prof Juan Bornman
Supervisor

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UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities

PARTICIPANT CONSENT FORM:
TEACHERS IN SPECIAL SCHOOLS

Research Topic: Developing and evaluating a maltreatment prevention program for children with communicative and/or cognitive disabilities.

By participating in this study, I agree that:

- I will voluntarily participate in the study as outlined above and that I have the freedom of choice to participate or not
- I understand that I will at no stage during the research process be exposed to any harmful situations
- I have the right to withdraw from this study should I wish to do so for any reason whatsoever without providing any explanation or without any negative consequences
- I understand that there is no direct benefit or financial gain when participating in this study. Information gained in the study will be used to develop a maltreatment prevention program which hopes to benefit children with communicative and/or cognitive disabilities
- I understand that my answers in the focus group will be documented through audio recording and writing
- I understand that the content of the data will be handled with confidentiality and used to write a thesis, for conference presentations, journal articles and for future research
- I understand that no identifying information will be given and that the data will be stored in hard copy and electronic format for a period of 15 years in a safe place at the CAAC, University Pretoria for archival and further research purposes.

I hereby give consent:

Signature:____

Date:______________

Contact information:

Name:____

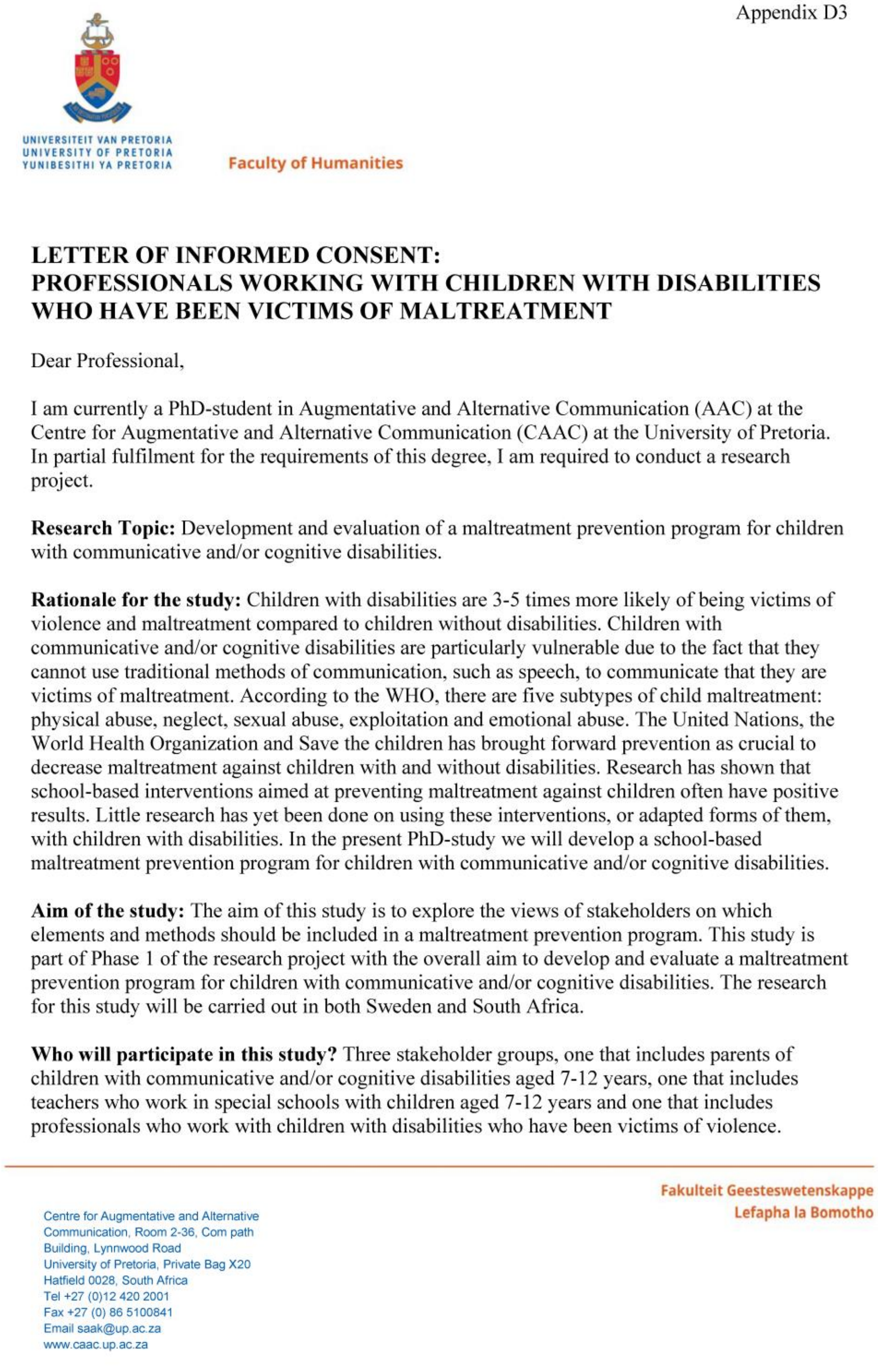
Tel No: ____

Email: ____

Centre for Augmentative and Alternative
Communication, Room 2-36, Com path
Building, Lynnwood Road
University of Pretoria, Private Bag X20
Hatfield 0028, South Africa
Tel +27 (0)12 420 2001
Fax +27 (0) 86 5100841
Email saak@up.ac.za
wwwcaac.up.ac.za

Fakulteit Geesteswetenskappe
Lefapha la Bomotho

Appendix B3: Letter of informed consent for professionals in Phase 1.2



Appendix D3

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities

LETTER OF INFORMED CONSENT: PROFESSIONALS WORKING WITH CHILDREN WITH DISABILITIES WHO HAVE BEEN VICTIMS OF MALTREATMENT

Dear Professional,

I am currently a PhD-student in Augmentative and Alternative Communication (AAC) at the Centre for Augmentative and Alternative Communication (CAAC) at the University of Pretoria. In partial fulfilment for the requirements of this degree, I am required to conduct a research project.

Research Topic: Development and evaluation of a maltreatment prevention program for children with communicative and/or cognitive disabilities.

Rationale for the study: Children with disabilities are 3-5 times more likely of being victims of violence and maltreatment compared to children without disabilities. Children with communicative and/or cognitive disabilities are particularly vulnerable due to the fact that they cannot use traditional methods of communication, such as speech, to communicate that they are victims of maltreatment. According to the WHO, there are five subtypes of child maltreatment: physical abuse, neglect, sexual abuse, exploitation and emotional abuse. The United Nations, the World Health Organization and Save the children has brought forward prevention as crucial to decrease maltreatment against children with and without disabilities. Research has shown that school-based interventions aimed at preventing maltreatment against children often have positive results. Little research has yet been done on using these interventions, or adapted forms of them, with children with disabilities. In the present PhD-study we will develop a school-based maltreatment prevention program for children with communicative and/or cognitive disabilities.

Aim of the study: The aim of this study is to explore the views of stakeholders on which elements and methods should be included in a maltreatment prevention program. This study is part of Phase 1 of the research project with the overall aim to develop and evaluate a maltreatment prevention program for children with communicative and/or cognitive disabilities. The research for this study will be carried out in both Sweden and South Africa.

Who will participate in this study? Three stakeholder groups, one that includes parents of children with communicative and/or cognitive disabilities aged 7-12 years, one that includes teachers who work in special schools with children aged 7-12 years and one that includes professionals who work with children with disabilities who have been victims of violence.

What will be expected of you? You will participate in one focus group to share your knowledge and opinions on the elements and methods that could be included in a maltreatment prevention program for children with communicative and/or cognitive disabilities. It is estimated that the group sessions will last between 60-120 minutes. You will be asked to arrive 30 minutes before the starting time of the focus group. When you arrive, you will be asked to fill out a biographical questionnaire and hand in your filled-out consent form. After you have completed the questionnaire you will be provided with coffee/tea and cake. Stimulus material will be presented at the beginning of the focus group. This material includes definitions of key concepts that will be used during the focus group as well as examples of AAC-materials that have been developed for talking about violence and maltreatment. The focus groups will be audio recorded and the recorded material will be transcribed and analyzed. We also ask you to help name other professionals working with children with disabilities who have been victims of maltreatment that could be suitable for inclusion in the study. Professionals must have at least two years of experience of working with children with communicative/and or cognitive disabilities who have been victims of maltreatment and be fluent in English.

What are the risks and benefits? Participation in the study is voluntary and you will receive no incentives for your participation. You may withdraw at any time from the study without any negative consequences. You will at no stage during the focus group be exposed to harm or risk. As some participants may find the topic of conversation (maltreatment against children with communicative and/or cognitive disabilities) uncomfortable, all participants who express the need, will be given the opportunity to engage in a debriefing session with a psychologist after the focus group. It is hoped that you will find it enriching to share your views on the development of a maltreatment prevention program during the focus group.

Confidentiality: When you agree to participate, consent is given that the focus group will be audio recorded and all answers written down. Please respect your fellow focus group member by not disclosing their identity or what they said in the discussion outside of the focus group. Only the researcher and the supervisors will have access to the recordings and written materials. No personal identifying information of any participant or participating organization (or school) will be included when the data is reported. The identity of the participants will be coded. The coding sheet will only be available to researchers working directly with the study. Results from this study will be used to write a thesis, for conference presentations, journal articles and for future research. The recordings, coding sheet, transcripts as well as the raw data will be kept in hard copy and electronic format at a safe place at the Centre for AAC for 15 years for archival and further research purposes.

Proposed date of study: It is proposed that the study will take place in January - March 2019. If you wish to give your consent for participation in a focus group, please sign the attached consent form and submit to the researcher before the start of the group. We trust that you will agree on the importance of this study to help develop a maltreatment prevention program for children with communicative and/or cognitive disabilities. We would appreciate your willingness to participate in this study. For further information, please contact researcher: Mrs Amanda Nyberg (speech-language therapist) Email: amanda.nyberg@vgregion.se Tel No: 004631 342 08 10.
Kind regards,

Amanda Nyberg

Mrs Amanda Nyberg **Researcher and SLT**	**Prof Juan Bornman** **Supervisor**

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UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA
Faculty of Humanities

PARTICIPANT CONSENT FORM: PROFESSIONALS WORKING WITH CHILDREN WITH DISABILITIES WHO HAVE BEEN VICTIMS OF MALTREATMENT

Research Topic: Developing and evaluating a maltreatment prevention program for children with communicative and/or cognitive disabilities.

By participating in this study, I agree that:

- I will voluntarily participate in the study as outlined above and that I have the freedom of choice to participate or not
- I understand that I will at no stage during the research process be exposed to any harmful situations
- I have the right to withdraw from this study should I wish to do so for any reason whatsoever without providing any explanation or without any negative consequences
- I understand that there is no direct benefit or financial gain when participating in this study. Information gained in the study will be used to develop a maltreatment prevention program which hopes to benefit children with communicative and/or cognitive disabilities
- I understand that my answers in the focus group will be documented through audio recording and writing
- I understand that the content of the data will be handled with confidentiality and used to write a thesis, for conference presentations, journal articles and for future research
- I understand that no identifying information will be given and that the data will be stored in hard copy and electronic format for a period of 15 years in a safe place at the CAAC, University Pretoria for archival and further research purposes.

I hereby give consent:

Signature:____

Date:________________

Contact information:

Name____

Tel No: ____

Email: ____

Fakulteit Geesteswetenskappe
Lefapha la Bomotho

Centre for Augmentative and Alternative
Communication, Room 2-36, Com path
Building, Lynnwood Road
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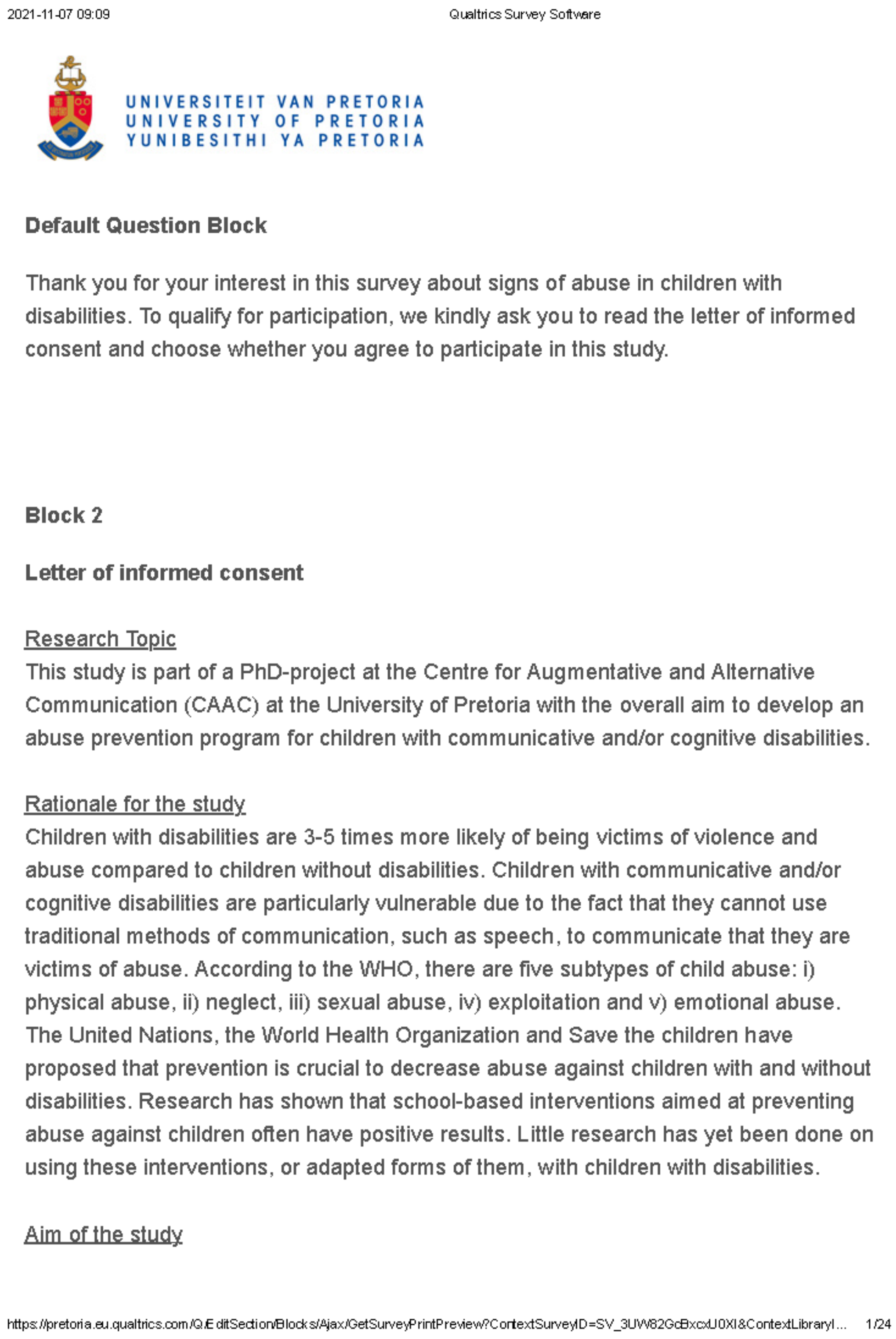
Hatfield 0028, South Africa
Tel +27 (0)12 420 2001
Fax +27 (0) 86 5100841
Email saak@up.ac.za
www.caac.up.ac.za

Appendix B4: Letter of informed consent for Phase 1.3



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YUNIBESITHI YA PRETORIA

Default Question Block

Thank you for your interest in this survey about signs of abuse in children with disabilities. To qualify for participation, we kindly ask you to read the letter of informed consent and choose whether you agree to participate in this study.

Block 2

Letter of informed consent

Research Topic
This study is part of a PhD-project at the Centre for Augmentative and Alternative Communication (CAAC) at the University of Pretoria with the overall aim to develop an abuse prevention program for children with communicative and/or cognitive disabilities.

Rationale for the study
Children with disabilities are 3-5 times more likely of being victims of violence and abuse compared to children without disabilities. Children with communicative and/or cognitive disabilities are particularly vulnerable due to the fact that they cannot use traditional methods of communication, such as speech, to communicate that they are victims of abuse. According to the WHO, there are five subtypes of child abuse: i) physical abuse, ii) neglect, iii) sexual abuse, iv) exploitation and v) emotional abuse. The United Nations, the World Health Organization and Save the children have proposed that prevention is crucial to decrease abuse against children with and without disabilities. Research has shown that school-based interventions aimed at preventing abuse against children often have positive results. Little research has yet been done on using these interventions, or adapted forms of them, with children with disabilities.

Aim of the study

The aim of this study is to explore the views of experts on signs of abuse in children with disabilities. Signs of abuse in children with disabilities have been gathered from published research articles and analyzed in the first stage of the present study. As an expert you will be asked to rate these signs according to their accuracy in detecting abuse in children with disabilities. The results from this study will not be used as a screening tool, but rather as part of an abuse prevention program to raise awareness of abuse against children with disabilities.

Who will participate in this study?

Clinicians and researchers with experience in working with children with disabilities, child abuse or both.

What will be expected of you?

We will ask you to complete a survey where you will rate items (signs of abuse in children with disabilities) derived from published research. To perform this task, you will use your expertise and experience in the field. Additionally, you will be asked to complete a biographical questionnaire which will be used to divide the participants into different groups. The survey takes approximately 20-30 minutes to complete.

What are the risks and benefits?

Participation in the study is voluntary and you will receive no incentives for your participation. You may withdraw from the study at any time without any negative consequences. At no stage during the survey will you be exposed to harm or risk. The rating process of the signs can be percieved as challenging due to the fact that no contextual informaton is given, but we believe that it is the best way to achieve further knowledge of this topic. It is hoped that you find this opportunity enriching as it may further knowledge on signs of abuse in children with disabilities.

Confidentiality

When you agree to participate, consent is given that your answers will be saved and used for research. Only the researcher and the supervisors will have access to the responses of the survey. No personal identifying information of any participant or participating organization will be included when the data is reported. You will not be asked to state your name in the survey. Results from this study will be used to write a thesis, for conference presentations, journal articles and for future research. The raw data will be kept in hard copy and electronic format at a safe place at the Centre for AAC, University of Pretoria for 15 years for archival and further research purposes.

We trust that you will agree on the importance of this study to help develop an abuse prevention program for children with communicative and/or cognitive disabilities. We would appreciate your willingness to participate in this study.

For further information, please contact researcher: Mrs Amanda Nyberg (speech-language therapist) Email: amanda.nybe@gmail.com Tel No: 0046707 277202

Consent text

Research Topic

Developing an abuse prevention program for children with communicative and/or cognitive disabilities.

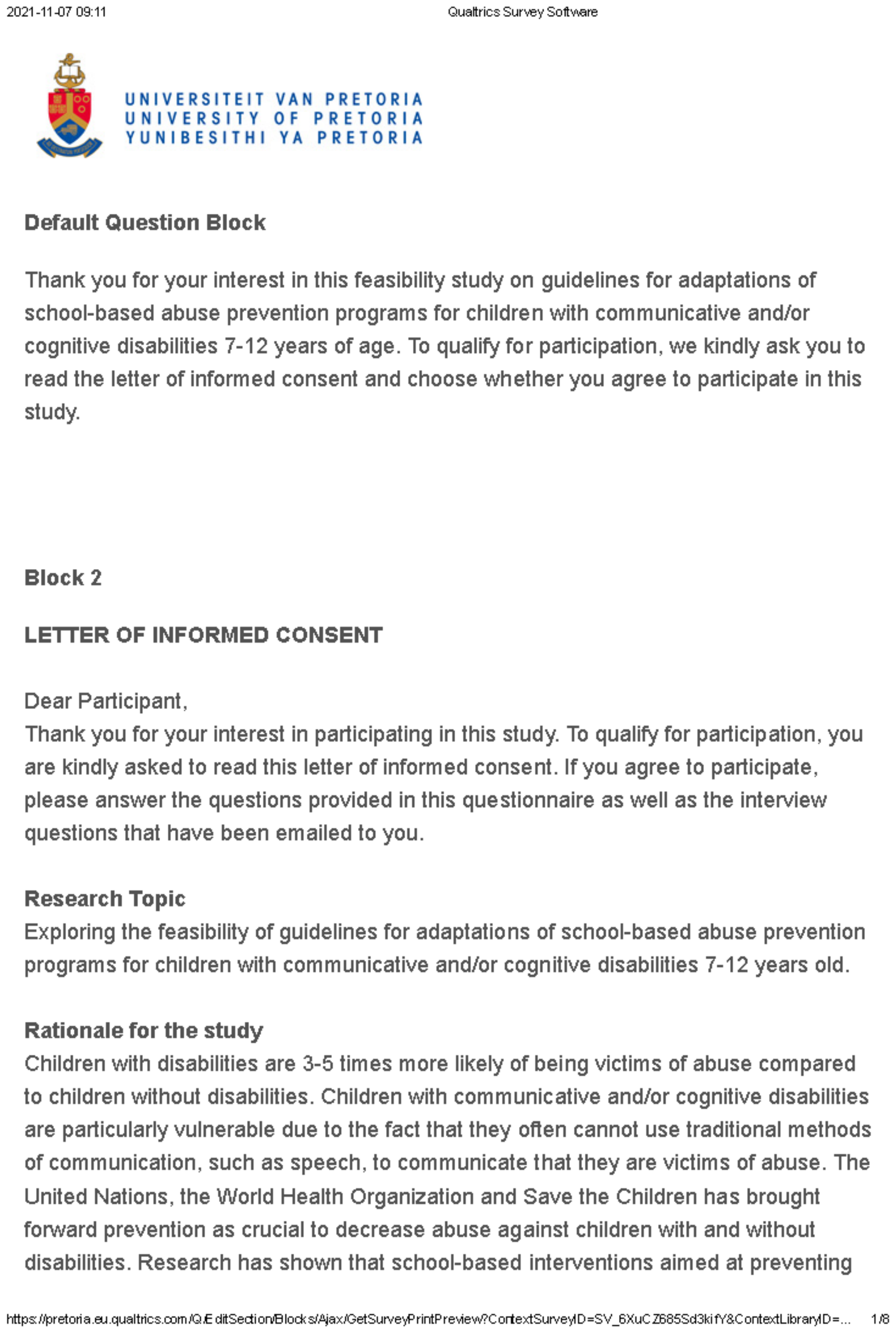
By participating in this study, I agree that:

- I will voluntarily participate in the study as outlined above and that I have the freedom of choice to participate or not
- I understand that I will at no stage during the research process be exposed to any harmful situations
- I have the right to withdraw from this study should I wish to do so for any reason whatsoever without providing any explanation or without any negative consequences
- I understand that there is no direct benefit or financial gain when participating in this study
- I understand that my answers in the survey will be documented
- I understand that the content of the data will be handled with confidentiality and used to write a thesis, for conference presentations, journal articles and for future research
- I understand that no identifying information will be given and that the data will be stored in hard copy and electronic format for a period of 15 years in a safe place at the CAAC, University of Pretoria for archival and further research purposes.

○ Yes, I hereby give consent

○ No, I do not give consent

Appendix B5: Letter of informed consent for participants in Phase 3



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Default Question Block

Thank you for your interest in this feasibility study on guidelines for adaptations of school-based abuse prevention programs for children with communicative and/or cognitive disabilities 7-12 years of age. To qualify for participation, we kindly ask you to read the letter of informed consent and choose whether you agree to participate in this study.

Block 2

LETTER OF INFORMED CONSENT

Dear Participant,
Thank you for your interest in participating in this study. To qualify for participation, you are kindly asked to read this letter of informed consent. If you agree to participate, please answer the questions provided in this questionnaire as well as the interview questions that have been emailed to you.

Research Topic
Exploring the feasibility of guidelines for adaptations of school-based abuse prevention programs for children with communicative and/or cognitive disabilities 7-12 years old.

Rationale for the study
Children with disabilities are 3-5 times more likely of being victims of abuse compared to children without disabilities. Children with communicative and/or cognitive disabilities are particularly vulnerable due to the fact that they often cannot use traditional methods of communication, such as speech, to communicate that they are victims of abuse. The United Nations, the World Health Organization and Save the Children has brought forward prevention as crucial to decrease abuse against children with and without disabilities. Research has shown that school-based interventions aimed at preventing

abuse against children often have positive results. To date, little research has been done on using these interventions, or adapted forms of them, with children with communicative and/or cognitive disabilities.

Aim of the study

The aim of this study is to explore the views of stakeholders on the feasibility of guidelines for adaptations of school-based abuse prevention programs for children with communicative and/or cognitive disabilities. The guidelines have been developed using results from Phase 1 of a PhD-project. You will be asked to review these guidelines and answer the interview questions through email. This study is part of a PhD-project at the Centre for Augmentative and Alternative Communication (CAAC) at the University of Pretoria.

Who will participate in this study?

Teachers, principals and stakeholders with experience of working with/doing research linked to children with disabilities, abuse or AAC.

What will be expected of you?

We will ask you to review guidelines for adaptations of school-based abuse prevention programs for children with communicative and/or cognitive disabilities, after which you will answer the survey and the provided interview questions, using the process that is described in the email that has been sent to you. We expect that this will take you approximately 1-2 hours. We ask you to submit your answers to the interview questions through email within 10 days of receiving the guidelines. After submitting your answers to the interview questions, the researcher will get back to you within two days with follow-up questions.

What are the risks and benefits?

Participation in the study is voluntary and you will receive no incentives for your participation. You may withdraw at any time from the study without any negative consequences. You will at no stage during the study be exposed to harm or risk. It is hoped that you will find it enriching to help further knowledge on adaptations of school-based abuse prevention programs for children with communicative and/or cognitive disabilities.

Confidentiality

When you agree to participate, consent is given that your answers will be saved and used for research. Only the researcher and the supervisors will have access to the

responses. No personal identifying information of any participant or participating organization will be included when the data is reported. Your identity will not be shared with the other participants.
Results from this study will be used to write a thesis, for conference presentations, journal articles and for future research. The raw data will be kept in electronic format at a safe place at the Centre for AAC, University of Pretoria for 15 years for archival and further research purposes.

We trust that you will agree on the importance of this study to help explore the feasibility of guidelines for adaptations of abuse prevention programs for children with communicative and/or cognitive disabilities. We would appreciate your willingness to participate in this study.

For further information, please contact researcher: Mrs Amanda Nyberg (speech-language therapist) Email: amanda.nybe@gmail.com Tel No: 0046707 277202

Consent text

Research Topic

Developing guidelines for adaptations of school-based abuse prevention programs for children with communicative and/or cognitive disabilities 7-12 years of age.

By participating in this study, I agree that:

I will voluntarily participate in the study as outlined above and that I have the freedom of choice to participate or not

I understand that I will at no stage during the research process be exposed to any harmful situations

I have the right to withdraw from this study should I wish to do so for any reason whatsoever without providing any explanation or without any negative consequences

I understand that there is no direct benefit or financial gain when participating in this study

I understand that my answers to the survey and interview questions will be documented

I understand that the content of the data will be handled with confidentiality and used to write a thesis, for conference presentations, journal articles and for future research

I understand that no identifying information will be given and that the data will be stored in hard copy and electronic format for a period of 15 years in a safe place at the CAAC, University of Pretoria for archival and further research purposes.

○ Yes, I hereby give consent
○ No, I do not give consent

Biographical questionnaire

QUESTIONNAIRE
The first part of the questionnaire contains questions including biographical information.
The second part includes a rating task where you will be asked to rate statements about the guidelines. You can read through the guidelines as you are rating the statements.

Name (needed to link your answers on the questionnaire to your answers to the interview questions)

Sex

○ Male
○ Female
○ Other

Appendix C1: School-Based Abuse Prevention Programs for Children with Disabilities: A Qualitative Study of Components and Methods (published in Australasian Journal of Special and Inclusive Education)

Australasian Journal of Special and Inclusive Education (2021), **45**, 252–267
doi:10.1017/jsi.2021.18

CAMBRIDGE
UNIVERSITY PRESS

ORIGINAL ARTICLE

School-Based Abuse Prevention Programs for Children With Disabilities: A Qualitative Study of Components and Methods†

Amanda Nyberg[1], Ulrika Ferm[2] and Juan Bornman[1]*

[1]University of Pretoria, South Africa, and [2]Sahlgrenska University Hospital, Sweden
*Corresponding author. Email: juan.bornman@up.ac.za

(Received 15 October 2020; revised 5 March 2021; accepted 19 April 2021; first published online 13 September 2021)

Abstract
Children with communicative and/or intellectual disabilities are disproportionally affected by abuse when compared to their typically developing peers. In this study, we investigate the key components and teaching methods for abuse prevention programs for use in special schools. The views of parents of children with disabilities were obtained via semistructured individual interviews ($n = 6$), and the views of special education teachers ($n = 7$) and practitioners who work with child victims with disabilities ($n = 5$) via focus groups. Results were coded using thematic analysis and are reported using the behavioural ecological model. Results indicate that children's rights and empowerment were seen as key components. Videos and role-play were reported as effective interactive teaching methods. Using augmentative and alternative communication strategies, such as pictorial support and manual signs, were thought to increase children's understanding and participation. We conclude that teacher involvement in school-based abuse prevention is essential to meet the needs of children with disabilities.

Keywords: abuse; augmentative and alternative communication (AAC); complex communication needs; intellectual disability; prevention; school-based program

Child abuse is a pervasive global challenge affecting all children, irrespective of age, sex, race, religion, or ability. The World Health Organization (1999) defines it as

> *all forms of physical and/or emotional ill-treatment, sexual abuse, neglect or negligent treatment or commercial or other exploitation, resulting in actual or potential harm to the child's health, survival, development or dignity in the context of a relationship of responsibility, trust or power. (p. 15)*

Children with developmental disabilities (e.g., cerebral palsy, Down syndrome, autism spectrum disorder) are 3 to 5 times more likely to be victims of abuse than their typically developing peers (Jones et al., 2012) and are overrepresented in involvement with child protection services for all kinds of abuse (Dion, Paquette, Tremblay, Collin-Vézina, & Chabot, 2018). They are also more likely to be victims of more serious and more frequent sexual abuse (Soylu, Alpaslan, Ayaz, Esenyel, & Oruç, 2013).

These children may also experience complex communication needs, which manifest as difficulties with producing and/or understanding spoken language. Although no large epidemiological studies have been conducted on children with complex communication needs, smaller studies suggest that they are particularly vulnerable, as they cannot rely on traditional communication modes such as

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[†] This manuscript was accepted under the Editorship of Umesh Sharma.

speech for help (Devries et al., 2018). Augmentative and alternative communication (AAC) offers many of these children an effective way of interaction, which could include disclosing abuse. AAC includes all forms of communication that are used to express and complement expression of thoughts, emotions, and needs (Beukelman & Light, 2020). It can also be used to enhance understanding (i.e., strengthening receptive language) and for creating structure (e.g., when using visual schedules). Many children with complex communication needs are students in special schools (also known as 'schools for specific purposes' or 'specialised schools'). The definition of special schools differs between countries, but in this study special schools refer to segregated schools — that can be situated on the same premises as mainstream schools — specifically for children with intellectual disabilities.

Abuse prevention is an important strategy to decrease child abuse (World Health Organization, 2016). However, there appears to be a lack of research on school-based abuse prevention programs that address different types of abuse aimed at both children with and without disabilities. All children need access to appropriate, accurate, and accessible information that is informed by evidence about life skills, rights, specific risks (e.g., the internet and social media), and self-protection (e.g., developing positive peer relationships; Mikton Butchart, Dahlberg, & Krug, 2016; UN Committee on the Rights of the Child, 2011). Abuse prevention programs should thus be developed to suit the needs of all children, regardless of (dis)abilities, by employing the seven universal design principles, namely equitable use, flexibility in use, simple and intuitive use, perceptible information, tolerance for error, low physical effort, and size and space for use (Johnson & Muzata, 2019).

The behavioural ecological model (BEM) holds promise for unpacking what a school-based prevention program should entail. It states that physiological responses can be learned (respondent conditioning) and can be reinforced or extinguished depending on contingencies of past responses (operant conditioning). Furthermore, it explains that learning occurs in a social context where the person, environment, and behaviour interact and influence each other (social cognitive theory; Hovell, Wahlgren, & Adams, 2009). The BEM assumes that behaviour is shaped through four levels of influence (individual, local, community, and social/cultural level) that interact (see Figure 1). It has been used successfully for developing health promotion interventions and has also been adapted for public health research relating to tobacco use (Rovniak, Johnson-Kozlow, & Hovell, 2006), research on sustainability practices of universities (Brennan, Binney, Hall, & Hall, 2015), and in developing anti-bullying school-based interventions (Dresler-Hawke & Whitehead, 2009). In the latter study, the importance of involvement of individuals and institutions from all levels of the model is emphasised in order to decrease bullying (Dresler-Hawke & Whitehead, 2009). These principles can also be assumed for abuse prevention, which is similar to bullying in that it includes emotional or physical abuse. Therefore, the BEM could provide a framework for the current study.

On the one hand, there is a paucity of abuse prevention programs that have been developed for children with disabilities (Nyberg, Ferm, & Bornman, 2021). On the other hand, established abuse prevention programs developed for children without disabilities, such as Staying Safe with Emmy and Friends (Dale et al., 2016; White et al., 2018), are not adapted to the specific needs of children with communicative and/or intellectual disabilities. Furthermore, the specific components taught in these programs might differ according to the child's (dis)ability and specific needs. For example, children who are in a wheelchair may be more exposed to potentially abusive situations while visiting the bathroom or showering, whereas children with challenging behaviour might be exposed to abuse as a response to their own problem behaviour. Not only have abuse prevention programs specifically aimed at children with disabilities thus been underresearched, but also research on adapting existing programs to better fit the needs of children with communicative and/or intellectual disabilities is scant.

The aim of this study is therefore to explore the views of three stakeholder groups, namely teachers in special education, practitioners working with children with disabilities who had been victims of abuse, and parents of children with communicative and/or intellectual disabilities, regarding the key components and methods they considered as important for consideration when developing a school-based abuse prevention program.

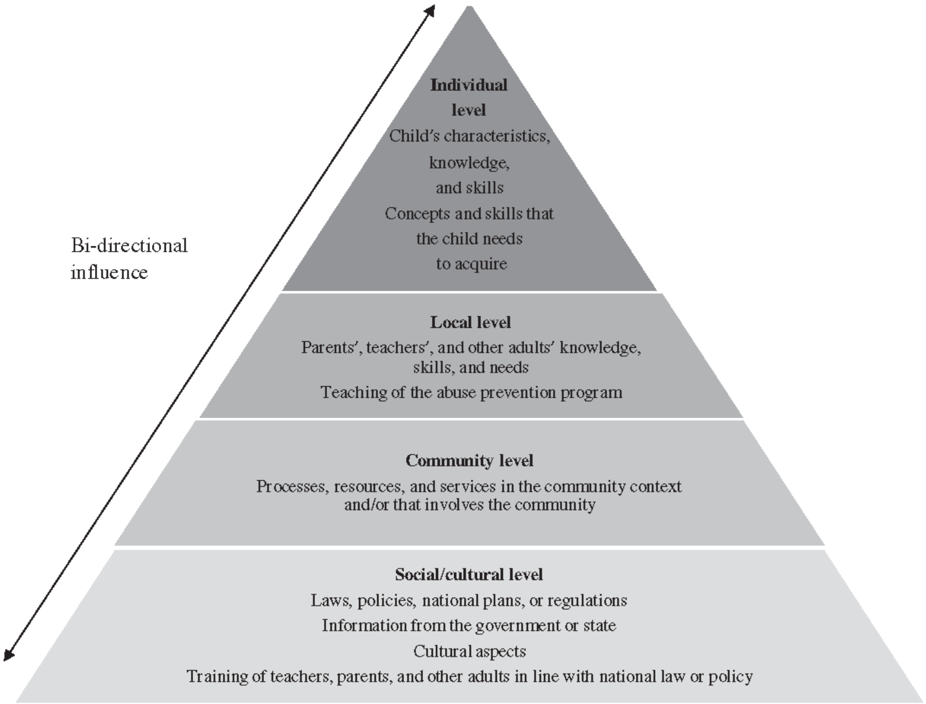

Figure 1. The Behavioural Ecological Model for School-Based Abuse Prevention Programs. Adapted from 'The Behavioral Ecological Model: Integrating Public Health and Behavioural Science', by M. F. Hovell, D. R. Wahlgren, and C. A. Gehrman, in R. J. DiClemente, R. A. Crosby, & M. C. Kegler (Eds.), Emerging Theories in Health Promotion Practice and Research: Strategies for Improving Public Health (pp. 347–385), 2002, San Francisco, CA: Jossey-Bass. Copyright 2002 by John Wiley & Sons, Inc. Adapted with permission.

Materials and Methods

Research Design

A qualitative approach was used to obtain in-depth information on the development of a school-based abuse prevention program for children with communicative and/or intellectual disabilities. Two focus groups and six semistructured interviews were conducted.

Participants

Three different stakeholder groups were included: Group 1 (teachers working in special education with children 7–12 years of age); Group 2 (practitioners experienced in working with children with disabilities who had been victims of violence, such as child investigators, nurses, and psychologists); and Group 3 (six parents of children with communicative and/or intellectual disabilities 7–12 years of age), described in Table 1. Parents participated in one-on-one interviews, rather than focus groups, due to the ethical implications of discussing abuse in a group setting.

Data Collection

Before recruiting participants to the study, ethics permission was obtained through the ethical vetting board at Gothenburg University.

Table 1. Participant Description

Sex	Age in years	Profession	Years in profession	Experience with children with disabilities in years	Experience with augmentative and alternative communication (AAC) in years
Group 1: Teachers ($n = 7$)					
F	56	Teacher	> 20	> 20	> 20
F	57	Teacher	> 20	15–20	15–20
F	41	Special education teacher	15–20	15–20	15–20
F	41	Teacher	0–5	10–15	0–5
F	38	Teacher	10–15	10–15	10–15
F	38	Special education teacher	0–5	5–10	0–5
F	49	Special education teacher	5–10	5–10	5–10
Group 2: Practitioners ($n = 5$)					
F	47	Child coordinator	5–10	5–10	5–10
M	52	Psychologist	15–20	15–20	0–5
F	49	Specialist child nurse	10–15	5–10	None
F	35	Child investigator	0–5	0–5	0–5
F	32	Psychologist	0–5	0–5	None
Group 3: Parents ($n = 6$) comprising 5 mothers and 1 father					
			Child's sex and age	Child's main form of communication	Parent training on abuse?
F	38	Assistant nurse	M 12	Speech	No
F	33	Speech-language therapist	M 9	Speech and AAC (pictures and symbols)	Yes
F	39	Psychologist	F 11	Speech	Yes
F	39	Support teacher	M 1	Speech and AAC (text, pictures, and symbols)	No
M	47	Rehabilitation assistant	M 8	Speech and AAC (text)	No
F	21	Special education teacher	F 7	AAC (manual signs)	No

Focus groups with teachers and practitioners

The focus group with seven teachers (Group 1) was conducted at a central, convenient location for the participants. All had been recruited through a post on the Facebook page of a centre for AAC and assistive technology. All participants received written information about the study after expressing initial interest to participate. They completed a consent form and a biographical questionnaire before the focus group started. The first author acted as the moderator for the focus group. A research assistant was responsible for note-taking and summarised the discussion at the end to ensure the accuracy of the notes and to facilitate member checking.

The focus group with the practitioners (Group 2) was conducted at a venue where most of them worked. They were recruited using a snowball technique, and after the initial contact was made, they received written information about the study. Group 2 participants signed informed consent forms and completed biographical questionnaires before the focus group commenced. Despite their different professional backgrounds, they were co-workers and thus knew each other. Once again, the first author was the moderator of the group and she was assisted by a research assistant.

Both focus groups 1 and 2 used the same interview guide to ensure comparability and increase procedural integrity. The following five questions were asked:

1. What experiences do you have of children with disabilities who have been victims of abuse?
2. If you were to design a program for children with communicative and/or intellectual disabilities aimed at preventing abuse, what would you include?
3. Which questions are important to ask during the evaluation of the program?
4. In your opinion, what is the key element/most important element in an abuse prevention program for children with communicative and/or intellectual disabilities?
5. Which difficulties with implementing an abuse prevention program do you foresee?

The focus groups were audio-recorded and transcribed verbatim by the first author. The transcriptions were checked and corrected for accuracy by the third author.

Semistructured interviews with parents

Six semistructured interviews were conducted with parents (Group 3), at a location they chose, using an interview guide that started with the initial five questions included in the focus groups. A further five questions were added after reviewing focus group results, namely:

1. Do you think that parents want to know more about child abuse and abuse prevention programs?
2. How can parents be involved in an abuse prevention program at school?
3. What is important to consider when teaching children with communicative and/or intellectual disabilities about abuse?
4. In your opinion, how could the program be adapted for children with different disabilities?
5. How can you retain the children's knowledge about abuse that they received during the program?

The interviews were audio-recorded.

Data Analysis

The data from the three stakeholder groups were collapsed to form one corpus, which was analysed with qualitative data analysis software, namely ATLAS.ti 8 (Windows Version 8.4; ATLAS.ti Scientific Software Development GmbH, 2020). Braun and Clarke's (2006) six steps for thematic analysis was employed, namely (a) familiarisation with the data by reading and rereading the transcripts; (b) generating initial codes; (c) searching for themes; (d) reviewing themes and codes through recoding and refinement; (e) defining and naming themes; and (f) constructing a code book with themes, codes, and definitions of the codes. The code book included four main themes, namely teaching methods and components (with 27 different codes), implementation (with 14 different codes), difficulties (with 19 different codes), and evaluation (with 10 different codes). The coding was validated by the second author, who subsequently reviewed 20% of the data. She was blinded to the code assigned but had knowledge of the theme to provide context. Interrater reliability of 78% was achieved after the review. After a consensus discussion, full agreement was achieved. Each code was reviewed and plotted onto a level of the BEM framework.

Findings

The findings are presented according to the four levels of the BEM. The themes and codes linked to each level of the BEM are shown in Table 2.

Social/Cultural Level

The social/cultural level of the BEM refers to laws, policies, national plans, or regulations, information from the government or state, cultural aspects, and training of teachers, parents, and other adults. Four themes were related to this level, namely teaching methods and components, implementation, difficulties, and evaluation (Table 2).

Eleven codes linked to teaching methods and components were delineated on the social/cultural level. These were (a) involve parents, (b) use videos, (c) use role-play, (d) use case studies, (e) train face to face, (f) adapt training material for children, (g) knowledge: types and signs of abuse related to teaching, (h) knowledge: disability and treatment, (i) knowledge: how to report, (j) create opportunities to practise skills, and (k) address attitudes. All three stakeholder groups reiterated the importance of involving parents in abuse prevention programs. Videos and role-play were suggested teaching methods, as was the use of case studies to facilitate discussion: 'Well, when we worked with the case studies, there was really good discussions and it's an angle of approach that doesn't single out anyone'. Some participants preferred face-to-face training over online methods. They also suggested that the training material (including a training manual) should be in an accessible format for children so that the adults would not need to adapt it themselves. Regarding the content, participants suggested that the overall aim of abuse prevention training should be to increase the adults' general knowledge of both abuse and disability, and the intersection of the two:

> *To make it visible earlier on a group level, because then it might be easier if you see that one of your children's friends are being treated badly or is not doing well, or it might be easier to do something about that if there is a focus on it. For everybody.*

Adults need to know about different types of abuse and how to identify possible signs of abuse, as this can be especially difficult with children with communicative and intellectual disabilities: 'But it is really hard to tell, so therefore a lot of the children who are victims of abuse are not detected'. Participants discussed being trained on how to report suspected abuse: 'One shouldn't be put in a position where you ask the questions [about abuse] and don't really know, what do I do with this?' Knowing about available treatment options was also discussed. Participants also identified the attitude towards disabilities and abuse component and that it should be included in training. Opportunities should also be created for using the skills acquired during training.

Two codes related to implementation emerged: (a) ensure parental support and (b) make mandatory. Parental support as a critical element of successful implementation of the abuse prevention program was underscored, as children with disabilities sometimes exhibit challenging behaviour that increases the caregiving burden, which might in turn act as a trigger for abuse:

> *Describing that it is normal to feel frustration as a parent. And despair, sadness and anger — anger is contagious. Talking about these feelings. If you have a child with behaviour issues then that is extremely challenging parenting. Without talking about the child as being difficult, but rather talking about challenging parenting instead.*

Some participants thought that the program needed to be mandatory (e.g., included in the school plans and regulations).

Five codes linked to difficulties related to the social/cultural level were identified: (a) lack of knowledge: abuse, (b) lack of knowledge: disability, (c) cultural aspects, (d) (over)protecting children, and (e) child's rights. The lack of knowledge (related to disability and to abuse) was discussed at length, as highlighted by a practitioner: 'I think overall that when we are addressing schools, teachers sometimes have alarmingly little knowledge about abused children'. Some participants said that the rights of children with disabilities should be known and respected by society, but that is not always the case. Participants also discussed the risk of over-protecting adolescents with disabilities by denying them access to alcohol, romantic partners, or the broad freedoms enjoyed by their peers without disabilities:

> *One difficulty is when do you start to talk about what? Age-wise, when is a student mature enough to start to talk about sexual abuse? I think that's really difficult with our students, when they get to puberty. So, you don't kind of start something that can turn out wrong. To know when do I start talking about this. They aren't really the age that they are.*

Some participants also highlighted cultural aspects related to disability and abuse as potential difficulties that trainers should be aware of.

Only one code relating to evaluation was linked to this level, namely the need to employ different evaluation methods that are adapted for all children:

> *It's an extensive task, it's not just sitting down with a questionnaire, that's not possible. But it's rather observations over time, and then to capture the correct results.*

Methods such as Talking Mats (Murphy & Cameron, 2008) were mentioned, as well as using interviews or questions before and after the implementation of the program.

Community Level

The community level refers to processes, resources, and services in the community context and/or that involves the community. Three different themes — implementation, difficulties, and evaluation — were related to this level, as shown in Table 2.

Five implementation codes were delineated, namely (a) dedicated budget, (b) shared values, (c) collaboration, (d) adaptation of context, and (e) community relevance. First, the importance of a dedicated budget for the implementation of the program was discussed. Sharing the same values in terms of rights of individuals with disabilities and what constitutes abuse was suggested as an important factor. Schools, parents, and therapeutic and other services need to collaborate and share important information: 'There has to be communication between the home and the school. Because these children have especially big difficulties to understand that there can be different rules in different places'. The context where the program is implemented (e.g., school) needs to be adapted to meet all children's needs. The context can also facilitate knowledge and understanding: 'The child will be dependent on the knowledge in a given context'. Participants also discussed that the program ought to be relevant for the community at large.

Only one code, social services, related to difficulties was reported at the community level. Participants identified social services practitioners as important collaborators, while also noting their lack of knowledge regarding how to communicate with children with communicative and/or

Table 2. Themes and Codes Related to the Different Levels of the Behavioural Ecological Model

Social/cultural level	Community level	Local level	Individual level
Teaching methods and components			
Involve parents		Use play	Empowerment and children’s rights
Use videos		Use stories	Distinguish wrong/right
Use role-play		Use videos	Identify and name abuse
Use case studies		Use role-play	Say ‘no’
Train face to face		Check comprehension	Identify dangerous situations
Adapt training material for children		Listen and believe	Unmask deceitful behaviour
Knowledge: types and signs of abuse		Include AAC methods	Disclose abuse
Knowledge: disability and treatment			Understand sexuality
Knowledge: how to report			Show integrity
Create opportunities to practise skills			Understand and identify emotions
Address attitudes			Understand behavioural consequences
Implementation			
Ensure parental support	Dedicated budget	Who teaches?	Retaining knowledge
Make mandatory	Shared values	Support from management	Screening
	Collaboration	Adaptations: teaching methods	Adaptation of program to different disabilities
	Adaptation of context	Adaptations: teaching material	
	Community relevance		
Difficulties			
Lack of knowledge: abuse	Social services	Bulldozing	Communication and cognitive challenges
Lack of knowledge: disability		Staff resistance	Poor generalisation skills
Cultural aspects		Time constraints	Disclosure/failure to disclose
(Over)protecting children		Fear: adults	Docility
Child’s rights		Despair: parents	Dependency
		Concern: effect of training	(re)Traumatisation
		Decision-making: teachers	Challenging behaviour
Evaluation			
Employ different evaluation methods	Disclosure as outcome measure	Expert panel review	Children understanding key components (receptive)
	Abuse as outcome measure	View adults’ role	Children using key components (expressive)
		View multiple role players	
		Consider context	
		Did it work?	

intellectual disabilities ('We did contact social services to consult them, but they didn't have any knowledge whatsoever') as well as a lack of transparency in the processes and actions of social services ('We talked quite a lot about this issue with the confidentiality, that it could be … well it makes it difficult sometimes').

Evaluation yielded two codes aligned to this level, namely (a) using disclosure as an outcome measure (e.g., disclosing to the school nurse), and (b) using abuse as an outcome measure (e.g., using the number of reports made to social services, the number of police reports, or the number of police investigations that go to court).

Local Level

The local level includes the knowledge, skills, and need for training for parents, teachers, and other adults as well as the actual teaching of the abuse prevention program. The codes related to this level belonged to all four themes: teaching methods and components, implementation, difficulties, and evaluation (see Table 2).

Seven codes relating to teaching methods for children with disabilities were linked to this level: (a) use play, (b) use stories, (c) use videos, (d) use role-play, (e) check comprehension, (f) listen and believe, and (g) include AAC methods. Play and stories were described as methods for ensuring understanding of key components, as well as using videos and role-play:

> *I'm thinking that you would need to replay things, kind of. Either using role-play, or dolls or something. That you create something other than just … well of course teach, but also something more experience based, I think, is needed.*

Evaluating the children's comprehension was suggested to ensure that they grasped the intended information. Participants also discussed that adults should listen to and believe children when they speak out:

> *I'm also thinking about this thing that we discussed quite a lot when we did our questionnaires, which is feedback to the student. I have listened to you, I understand you, I want to help you.*

Finally, different AAC methods (e.g., Talking Mats, communication boards, and manual signs) were seen as crucial to enable children with communicative and/or intellectual disabilities to understand the key components taught in the program. The need for AAC customisation for individual children was also mentioned.

Four codes relating to implementation were identified, namely (a) who teaches? (b) support from management, (c) adaptations: teaching methods, and (d) adaptations: teaching material. Participants discussed that the program trainer should be somebody with appropriate skills whom the children trust. The teachers especially highlighted that teachers need support from principals and the school management to enable them to implement the program. Furthermore, participants felt strongly that the program should be adapted to children with communicative and/or intellectual disabilities. This adaptation needs to be done in terms of the methods used in the program (e.g., how questions are asked, how information is provided, and in what group setting it is taught). Moreover, these adaptations should be done for individual children and for the group: 'I can imagine that some might find it difficult to deal with it in a group and for some it'll be an advantage to do it in a group'. The program also needs to be adapted in terms of the materials used (e.g., using pictures and AAC methods to enhance understanding). Participants suggested using a basic manual to start, which could then be adapted for individual children.

Seven codes related to difficulties were mentioned. These were (a) bulldozing, (b) staff resistance, (c) time constraints, (d) fear: adults, (e) despair: parents, (f) concern: effect of training, and (e) decision-making: teachers. 'Bulldozing' entails violating children's rights and not respecting children when they say no; for example, if a child does not want to participate in certain compulsory school activities and says no, it could create a potentially problematic situation in terms of respecting the child's decision. Some children are more inclined to respond with a 'no' to any inquiry that involves something unfamiliar:

> *I feel like we need to include the concept of 'I don't want to'. I mean we work a lot with that … how do I put this. We're struggling to get our students to try things, and then they can say, 'I don't want to', but we still drag them along to things.*

Also discussed as a potential difficulty was resistance from staff to implement the abuse prevention program due to different reasons (e.g., lack of knowledge or resources, time constraints, fear):

> *One thing I've been struck by over the years, is that one quite often meet staff at schools and pre-schools that are too afraid to report [abuse] or to take it further and discuss the matter even though they've seen indications of abuse. Today, we are starting to give better information and education to them also. But it's so easy for them to say, 'I don't want to be that child's safe person because imagine if I have to stand and talk to that angry dad later'. And then you have to talk to that person from our perspective and say that, well, the child is going home to that dad, you can choose not to do that.*

Abuse can stem from a sense of despair that parents can experience when dealing with children with challenging behaviour, as described by a police officer:

> *I often meet children with different kinds of neuropsychiatric disabilities. And when you talk to those parents, they often say that they kind of snapped …. They've coped with so much and then they ran out of energy. Patience, energy, perseverance, everything ran out. And then, then there was only violence left.*

Parents' willingness to allow their child to participate in a prevention program is affected by their being concerned that their child might be abused or traumatised when participating in an abuse prevention program. One parent mentioned that teachers need to be in charge in their classrooms and make decisions and rules without having to consider parental preferences.

Five codes relating to evaluation were delineated, namely (a) expert panel review, (b) view adults' role, (c) view multiple role-players, (iv) consider context, and (v) did it work? The code 'Did it work?' refers to evaluating whether the abuse prevention was effective (i.e., did it produce the desired outcomes) without suggesting any method. Adults' understanding of their responsibility and the need for adaptations, such as using AAC, was suggested by a parent as an important aspect to evaluate. Evaluating the effect of the program by asking about the context was also suggested: 'I think what could also be evaluated is the environment at the school. Is the school calmer after the program?' Participants thought that it was important to ask questions to children, to parents, and to teachers when evaluating the program. One participant suggested that a first version of the program could be reviewed by an expert panel to verify the contents and methods of the program.

Individual Level

The individual level refers to the child's characteristics, knowledge, and skills, as well as concepts and skills that need to be acquired. The codes that were related to the individual level came from four different themes: teaching methods and components, implementation, difficulties, and evaluation, as shown in Table 2.

Key components refer to the concepts that should be taught to children with communicative and/or intellectual disabilities as part of the program. Eleven codes were identified, namely (a) empowerment and children's rights, (b) distinguish wrong/right, (c) identify and name abuse, (d) say 'no', (e) identify dangerous situations, (f) unmask deceitful behaviour, (g) disclose abuse, (h) understand sexuality, (i) show integrity, (j) understand and identify emotions, and (k) understand behavioural consequences. Empowering children by teaching them about their rights and learning what is right and wrong were highlighted in all three groups: 'But my idea with this kind of [abuse prevention] program is also to help children with disabilities to have agency in their own wellbeing in some way'. Participants also suggested that children's rights could be linked to the Convention on the Rights of the Child (United Nations, 1989).

The need for children with communicative and/or intellectual disabilities to be able to speak up about abuse, to understand what constitutes abuse and know how to say no, to learn about specific situations that could be associated with risk (such as being alone in a taxi with a taxi driver), as well as unmasking deceitful behaviour (such as adults posing as children online) were discussed in all groups. Disclosing abuse could present some challenges. A parent said,

> *We need to strengthen children from within, so that they dare to talk about it. And give the right prerequisites. If that child has had a different experience or has difficulties with expressing themselves, then we need to face that at the same time.*

Children with communicative and/or intellectual disabilities also need to be taught about sexuality, integrity, feelings, and how their behaviour affects others. One practitioner had experienced the consequences of a lack of teaching young adults with intellectual disabilities about sexuality:

> *It was kind of a topic that was just left there ... and at the same time everybody was ... well ... aware that many of them had sexual relationships. This concept of, what are we protecting them from, and not? Should you protect children, or adults, from their own sexuality? That doesn't turn out well.*

Three codes relating to implementation were identified, namely (a) retaining knowledge, (b) screening, and (c) adaptation of program to different disabilities. Retaining the knowledge gained from participation in the abuse prevention program was thought to be done mainly by repetition: 'Repeating the information many times'; 'Continuously as the child ages it changes and then you need to carry on. It is not like it is a one-time event'. The idea of screening children for experience of abuse while offering the abuse prevention program at the same time was mentioned by one participant. Adapting the program to children's (dis)abilities was seen as essential to enable as many children as possible to participate and benefit from the program. However, some participants also saw this as the greatest potential challenge to the successful implementation of the program. A teacher explained, 'I still think [the biggest challenge] is getting through to all groups of students. The ones who have the most difficulties and have severe intellectual disabilities'. Some participants proposed solutions for this, such as,

> *I think it would be good to have a class that is put together depending on the difficulties. And then you need sort of a toolbox with different exercises, and then you can use the ones that fit for this particular group.*

Seven codes relating to difficulties were noted: (a) communication and cognitive challenges, (b) poor generalisation skills, (c) disclosure/failure to disclose, (d) docility, (e) dependency, (f) (re)traumatisation, and (g) challenging behaviour. Challenges related to communication and intellectual difficulties were frequently discussed and concerns were raised in terms of both general understanding and understanding specific concepts such as abuse and the ability to express themselves. One teacher said, 'It is really us who control the words that they can give us, because we might not give them these words or objects to talk about'. A parent expressed concern about their child's ability to disclose abuse: 'To express something by herself about what she experienced, I don't think that she could do that'. Generalisation of concepts was described as difficult for children with communicative and intellectual disabilities, and participants expressed concerns about how to compensate for that in abuse prevention: 'It might be OK for Mum and Dad to do something, but it might not be OK if school staff does roughly the same thing, or something that can be perceived as the same thing'. Difficulties related to communication and cognition were also linked to disclosure, including both actual disclosure and failure to disclose. The participants envisaged potential problems related to disclosure in terms of having access to the appropriate vocabulary and also who to disclose to and at what time:

> *And they [children with communication difficulties] don't come to the police either, because they haven't been able to disclose about abuse or vulnerability from the beginning, to anyone around them. In situations where, for example, the person that you could disclose to, like an assistant or something like that, if that person is the abuser … then it becomes difficult.*

Docility refers to children with communicative and/or intellectual disabilities answering questions in the way they think the person asking the question wants them to answer rather than telling the truth. Many children with disabilities are dependent on caregivers and staff for many areas of daily life. This could affect their ability to disclose abuse, to say no to risky situations or actual abuse, and to remove themselves from the abuser:

> *I'm thinking dependency on usually a lot of different persons and that can be a lifelong dependency in many ways. Maybe not on the level that you need help in every situation, with dressing and so on, but to get a functioning home situation when you start to become an adult, to gain some more freedom … this differs so much when you might not have the prerequisites yourself to live it.*

Traumatisation or re-traumatisation was a risk linked to the abuse prevention program, as alluded to by some participants. Talking about abuse, naming abuse, and speaking about sexuality and integrity creates a potential risk that some children will be affected, especially if they have previously been victims of abuse, a fact which might not be known:

> *There's also a risk, I think, to scare children from intimacy. You need to think about how you talk about sexual abuse and consent. That at the core intimacy and physical closeness is something nice and cosy. I think that adults talk about it in a way that it almost scares children away from that. We shouldn't do that. But rather teach the children how it [intimacy] can be safe.*

Challenging behaviour in children with communicative and/or intellectual disabilities were discussed by several participants in terms of the difficulties related to this when implementing an abuse prevention program:

> *I can't demand from him that he should totally know what is right and wrong in all situations. He has, for example, shoplifted. It is very wrong. You can't do that. He knows that. But he doesn't know that when he is doing it. Because he forgets it.*

Two codes belonging to the evaluation construct were noted: (a) children understanding key components (receptive) and (b) children using key components (expressive). Children's understanding of the topic was suggested as a possible way to evaluate the effectiveness of the program: 'I think you need to ask the children what they learned. So, some sort of evaluation with the children'.

Discussion

Our study shows the depth and complexity of developing and implementing a school-based abuse prevention program for children with communicative and/or intellectual disabilities. These children are particularly vulnerable to abuse and need to be involved in abuse prevention themselves. Furthermore, the involvement of parents and teachers was also reported as being crucial to ensure successful implementation. The number of focus groups and interviews were limited, as well as the number of participants. The results presented in the study should be viewed as preliminary and an addition to the limited knowledge base on school-based abuse prevention programs for children with disabilities.

The adapted version of the BEM employed in this study is proposed as a valid framework for developing school-based abuse prevention programs. The analysis of the present study's data reveals that the findings are assigned to all the levels of the BEM.

The results linked to the social/cultural level were mainly related to teaching adults about abuse and identifying signs of abuse in order to provide support to children and prevent abuse and neglect. A general lack of knowledge of abuse was raised as a concern, which is consistent with a Swedish report that showed that 35% of universities did not include child abuse in teacher training for younger children, and that the existing training was limited (Inkinen, 2015). Noticing signs of abuse in children with disabilities can be challenging as some of the common signs of abuse or neglect might not be relevant for children with disabilities (e.g., changes in behaviour or frequent absence from school). These behaviours might be linked to the child's disability and not abuse. Drawing from the results of the present study, describing the signs of abuse children with disabilities exhibit is needed, but to our knowledge, no tool currently exists for this purpose.

Beyond identifying and describing abuse, teachers also need to feel confident in reporting abuse. Most child abuse and neglect is never reported, as demonstrated by the discrepancy between the number of reports to child protection services versus the frequency of abuse found in surveys distributed to adults and children (Gilbert et al., 2009). In a study in Sweden of general practitioners, 20% had suspected child abuse but not reported it despite mandatory reporting laws (Talsma, Bengtsson Boström, & Östberg, 2015). The underlying reasons for lack of reporting can include limited knowledge about the signs of abuse, routines for reporting, as well as fears about damaging the relationship with the family.

Supporting parents of children with communicative and/or intellectual disabilities to navigate some of the challenges of parenting a child with a disability was highlighted. Parents and other familiar caregivers are often the main perpetrators of child abuse and neglect (Hurren et al., 2018; Stöckl, Dekel, Morris-Gehring, Watts, & Abrahams, 2017), emphasising that parental support to cope with the increased caregiving burden of children with disabilities should never be underestimated. Parenting programs to decrease abuse have been found to have moderate yet significant effectiveness on reccurrence of child abuse and should therefore be considered in situations of known abuse (Vlahovicova, Melendez-Torres, Leijten, Knerr, & Gardner, 2017).

Despite relatively few themes linked to the community level in our study, the involvement of the community in abuse prevention is important. The community's role becomes evident in the concept of shared values of rights and risks for all children, including children with disabilities. Shared values can be achieved through training both teachers and parents to ensure that both groups receive the same information. Collaboration is also important for children, as they benefit from consistency in the information given and the attitudes towards abuse among the important adults in their lives.

Social services are an important collaborator for both schools and families, and the difficulties described by the teachers in the present study in relation to social services are troubling. A lack of written policy on how to serve children with disabilities could contribute to each case being handled on an individual basis, which could influence the quality and consistency of the service negatively (Lightfoot & LaLiberte, 2006). Furthermore, social workers' knowledge of disability and AAC may be limited.

Unintentional abuse can stem from trying to convince children to do things they don't want to do, or to challenge them to push beyond their capability. Respecting their rights and opinions, while at the same time making sure that they participate in activities, needs to be discussed within the scope of an abuse prevention program. Lack of information to teachers and parents can create challenges, such as parents not wanting their child to participate in the abuse prevention program or teachers being reluctant to teach the program.

Research has highlighted active participation by children as a vital component in school-based abuse prevention (Brassard & Fiorvanti, 2015). Interactive teaching methods such as role-play, videos, and discussions could potentially increase understanding and facilitate learning in children with communicative and/or intellectual disabilities and make the program accessible and appealing to them. Video modelling has also been used effectively to teach children with various disabilities about social skills (Gül, 2016) and could likewise be used to teach abuse prevention. The use of AAC materials, in particular pictorial support, based on universal design principles, will ensure that the program is accessible for all children. Furthermore, learning also depends on the person teaching the program, their knowledge of the children, and their ability to adapt the program. The teacher's skill and experience are thus crucial in the adaptation process.

The complexity of learning, understanding, and being able to express oneself as a child with communicative and/or intellectual disabilities was discussed in depth. The main message from these discussions was the need for adaptation to meet the individual child's needs, using universal design principles (Johnson & Muzata, 2019). Flexibility, also a universal design principle, emphasises that programs ought to have room and suggestions for adaptations for children with different skills, as outlined earlier. Likewise, the principle of perceptible information was addressed by the participants in terms of the need for adapting the program for children with intellectual disabilities. These adaptations should be included in the program, with suggestions of different approaches to accommodate different types of disabilities.

Children with communicative and/or intellectual disabilities need knowledge on a vast array of topics within the scope of abuse prevention. To provide a common ground, knowledge on feelings, sexuality, and children's rights needs to be established before teaching about abuse and neglect. All information should be age and disability appropriate, and children with communication disabilities should be given access to the appropriate vocabulary to disclose abuse (Kim, 2010). As many children with communicative and/or intellectual disabilities experience difficulties with generalisation, the key components of the program should be repeated over time.

Children with communicative and/or intellectual disabilities are dependent on their caregivers and are often trained to be compliant. This poses a challenge in view of abuse prevention. Therefore, children's empowerment should be central to an abuse prevention program, highlighting that their voices need to be heard (UN Committee on the Rights of the Child, 2011).

Conclusion

Several challenges, but also possibilities, with implementing a school-based abuse prevention program were identified in the present study. The findings reported can be used to navigate the challenges of program development and implementation. Future studies should include a larger sample size to draw further conclusions on this important topic. Some difficulties that were mentioned by all three stakeholder groups concerned limited knowledge, time, resources, and support. In order to implement an abuse prevention program, it is imperative to first ensure that the needed factors are in place. If not, the program is bound to fail.

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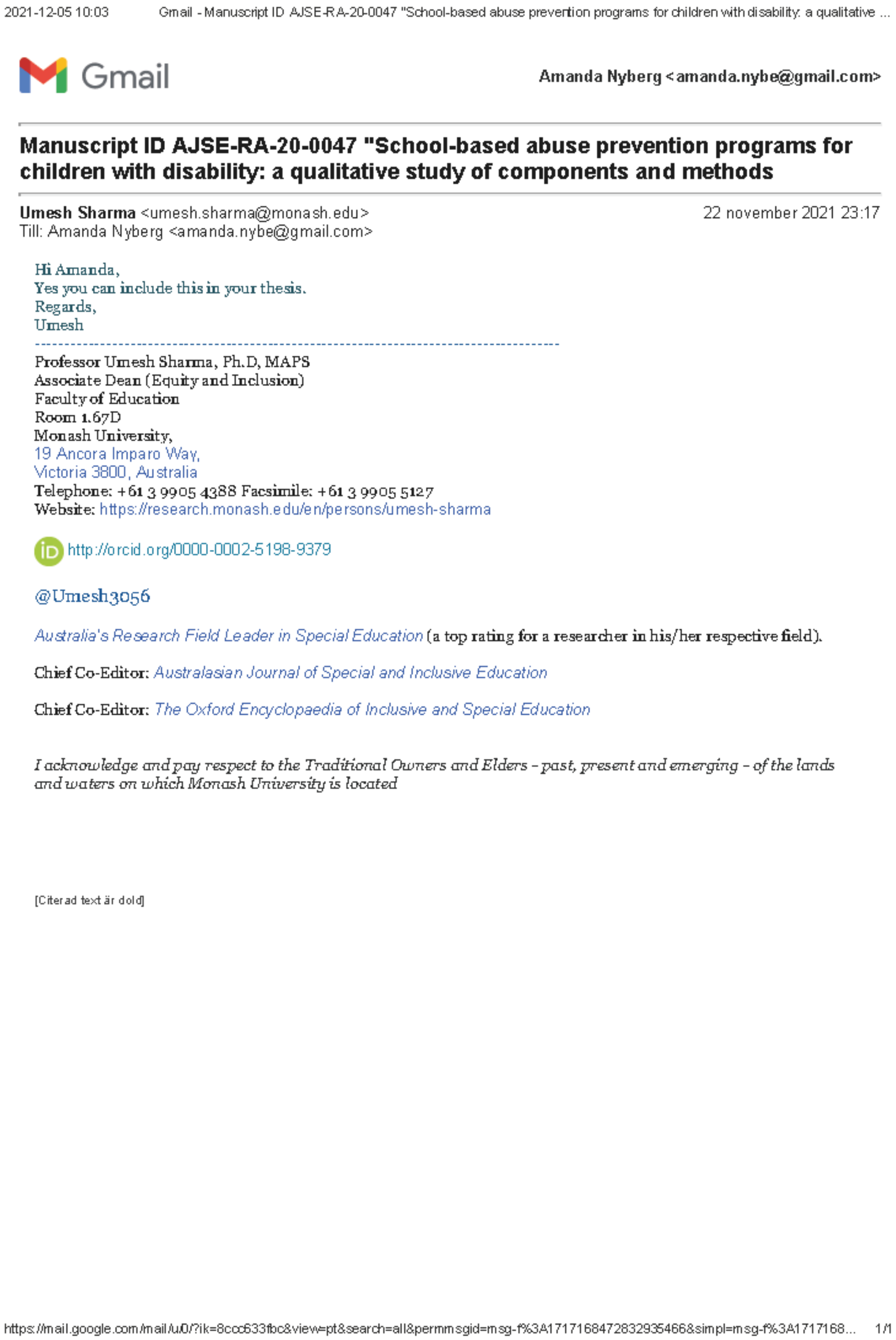
Appendix C2: Permission from Australasian Journal of Special and Inclusive Education



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Amanda Nyberg <amanda.nybe@gmail.com>

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Till: Amanda Nyberg <amanda.nybe@gmail.com>

Hi Amanda,
Yes you can include this in your thesis.
Regards,
Umesh

Professor Umesh Sharma, Ph.D, MAPS
Associate Dean (Equity and Inclusion)
Faculty of Education
Room 1.67D
Monash University,
19 Ancora Imparo Way,
Victoria 3800, Australia
Telephone: +61 3 9905 4388 Facsimile: +61 3 9905 5127
Website: https://research.monash.edu/en/persons/umesh-sharma

http://orcid.org/0000-0002-5198-9379

@Umesh3056

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I acknowledge and pay respect to the Traditional Owners and Elders – past, present and emerging – of the lands and waters on which Monash University is located

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Appendix D1: Signs of abuse in children with disabilities: A rapid review with expert panel social validation (published in Journal of Intellectual and Developmental Disability)

JOURNAL OF INTELLECTUAL & DEVELOPMENTAL DISABILITY
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ORIGINAL ARTICLE

Signs of abuse in children with disabilities: A rapid review with expert panel social validation

Amanda Nyberg[a,c], Ulrika Ferm[b] and Juan Bornman[a]

[a]Centre for Augmentative and Alternative Communication, University of Pretoria, Pretoria, South Africa; [b]Child Neuropsychiatry BNK, Sahlgrenska University Hospital, Gothenburg, Sweden; [c]Department of Research and Development, SV Hospital Group, Alingsås, Angered, Göteborg, Kungälv, Sweden

ABSTRACT

Background: Children with intellectual disabilities are at risk of becoming victims of abuse. However, persons working with this population often lack knowledge on how to interpret signs of abuse. The purpose of this study was to identify and socially validate signs of abuse in children with disabilities.

Method: The study employed a mixed-method sequential design. The first phase consisted of a rapid review of publications that described signs of abuse in children with disabilities ($n = 23$). The second phase included social validation using an online survey. The participants were professionals working with disability and/or child abuse ($n = 39$).

Results: A significant difference between the 10 highest rated signs of abuse compared to the 10 lowest rated signs was found. Group comparisons between participants showed significant differences in the ratings of eight signs.

Conclusions: The results from the study can provide guidance to the accuracy of signs of abuse in children with disabilities.

KEYWORDS
Abuse; children with disabilities; signs of abuse; manifestations of abuse; social validation

Children with disabilities are three to five times more likely of being victims of abuse than their peers without disability (Jones et al., 2012). Children with intellectual disabilities have been found to be more likely to experience several occasions of maltreatment (Dion et al., 2018).

An intersectional perspective is helpful for understanding this elevated risk as disability itself is a risk factor for different forms of abuse, including any form of physical and emotional ill-treatment, sexual abuse, neglect, and exploitation that results harm to the child's health, development or dignity (Winters et al., 2017). Social disadvantage, type of impairment, gender, communication difficulties, dependency on social support systems, lack of resources and social support for parents of children with disabilities as well as parental stress can be potential factors linked to abuse of children with disabilities (Flynn, 2020). Children with complex communication needs (which manifests as difficulties with understanding language and/or with producing spoken language) may, for example, face additional barriers to disclosing abuse (Flynn & McGregor, 2017) and could thus be at higher risk of experiencing abuse and victimisation due to their communication difficulties (Edelson, 2010; Flynn, 2020).

Identifying and understanding signs of abuse in children with disabilities is crucial to end ongoing abuse and enable rehabilitation and support. Despite limited studies focussed on the signs of abuse, results indicate similarities between children with and without disabilities (Debelle, 2012; Reinke, 2005) identifying behaviour problems as the most common sign of abuse (Reinke, 2005). However, interpreting and understanding these signs can be compounded by the fact that behavioural and emotional signs can also be attributed to the disability rather than to underlying trauma or co-morbid disorders (Vervoort-Schel et al., 2018). In addition to this, a child's intellectual and language development can impact their reaction to traumatic experiences such as abuse (McCarthy, 2001; Vervoort-Schel et al., 2018). Post-traumatic stress disorder (PTSD), for example, has been described as more difficult to identify in persons with intellectual disabilities or autistic people as the symptoms can be interpreted as being linked to the disability rather than to abuse (Kildahl et al., 2019, 2020). This paucity of research regarding the signs of abuse may possibly be attributed to beliefs about abuse risk for children with disabilities (Miller & Brown, 2014).

CONTACT Amanda Nyberg ✉ amanda.nybe@gmail.com

Practitioners who work with children with disabilities often lack knowledge about abuse and signs of abuse and the topic of abuse is often not included in professional training (Franklin & Smeaton, 2017; Inkinen, 2015), even though the potential risk of abuse should necessitate awareness and vigilance (Flynn, 2020). Similarly, primary caregivers (including parents) and other family members can be unaware of how to detect and interpret signs of abuse in children with disabilities and typically lack knowledge for considering trauma or abuse as underlying reasons for the manifested behavioural or emotional symptoms (Kildahl et al., 2020). Consequently, this can result in abuse not being detected. Therefore, it is vital that key stakeholders such as parents, teachers and other adults in these children's social networks become aware of potential signs of abuse in children with disabilities as a first step in preventing abuse. Subsequently, a rapid review of publications describing signs of abuse in children with disabilities was carried out in this study.

Social validation

Social validation is defined as judging the social significance, appropriateness and importance of goals, procedures and results (Wolf, 1978). Wolf specifies three dimensions of the social validity concept for the applied behaviour analysis field, namely (1) social importance of goals, (2) social acceptability of procedures and (3) social importance of the outcomes (Wolf, 1978). Carter and Wheeler (2019) agree, stating that acceptability is a vital component of social validity defining it as judgments of treatments by stakeholders or potential consumers. Despite agreement on the importance of social validity, guidelines for reporting and assessing it is lacking (Park & Blair, 2019). When it is incorporated into a study, it is often done by asking those who implement, receive or consent to a treatment or intervention about their opinions (Carter & Wheeler, 2019). Several different methods can be used to do so, of which using a survey or a rating scale constructed for the specific purpose of socially validating the study in question is the most common (Carter & Wheeler, 2019). The application of social validity measurements in the child abuse prevention research field is seemingly scarce. As in other research fields, the component of social validity is often an "afterthought" and is not described in detail in publications (Carter & Wheeler, 2019).

The overall aim of this study was to identify signs of abuse in children with disabilities by firstly conducting a rapid review to describe the extant literature and secondly to confirm the results by employing a custom-designed social validation questionnaire completed by an international expert group.

Method

The study employs a two-phase mixed-method sequential research design (Creswell & Creswell, 2018) commencing with a rapid review followed by a survey including both quantitative and qualitative questions. The study was approved by the Ethical Committee at the Faculty of Humanities, University of Pretoria (reference number GW0180828HS).

Rapid review

Rapid reviews are used for compiling and synthesising knowledge in a simplified manner, using parts of the systematic review process (Tricco et al., 2015). The purpose of a rapid review is to make results available to stakeholders in a timely manner using resources effectively (Hamel et al., 2021). As the intent of the present study was to enhance the results from the review with a social validation component, a rapid review was deemed appropriate for the purpose of this study. Rapid review methodology varies across studies, but ways to streamline the process is to limit the search to published literature and limiting the search in regards to language and date (Tricco et al., 2015), which were both employed in the present study. Furthermore, using only one reviewer to screen title, abstract and full-text has been found to be a common approach in rapid reviews (Tricco et al., 2016). This process was enhanced in the present study by using one reviewer for the title and abstract screening, but three researchers in total working independently for the full-text screening and data extraction. All three researchers had a good understanding of the topic and used the same screening and data extraction criteria and tools and followed instructions drafted by the first author to ensure consistency in the screening and data extraction process.

The search was performed in October 2019 by a research librarian well experienced in conducting database searches, using the following databases: PubMed (1022 references), PsycINFO (548 references) and Cinahl (647 references). Articles between 1989 and 2019 that were written in English, Swedish, Norwegian and Danish were searched. The additional languages (beside English) were added as the first and second authors can read and understand these languages. The search terms used were: Disabled Persons OR Intellectual Disability OR disabled OR intellectual disabilit* AND Contusions OR Signs and Symptoms OR Diagnostic Screening Program OR bruise*OR manifestation* OR sign OR signs OR symptom* OR clinical effect* OR mark OR clinical finding*OR behavioural issue*OR screening OR assault* AND abuse OR neglect OR maltreatment OR violence OR assault* OR cruelty OR ill-treatment OR mistreat* OR molest* OR oppression OR violent OR violently. Boolean operators were included, and only published literature was searched.

The search resulted in 1797 records after duplicates ($n = 420$) were removed, as shown in the PRISMA (Preferred Reporting Items for Systematic Review and Meta-analysis) (Page et al., 2021) in Figure 1.

Screening

The first author screened all studies on a title level using the PEO-criteria (Table 1). After this initial screening, 471 studies were reviewed on an abstract level by the first author. Subsequently, 42 studies were deemed appropriate for full-text screening. The full text screening was carried out by three reviewers independently. The first author read all 42 studies, while the second and third author each read 21 studies. In case of disagreement, discussions were had until consensus was reached. After reviewing the full text articles, 23 studies were included for data extraction (Figure 1) (Akbas et al., 2009; Berg, 2014; Berg et al., 2015; Debelle, 2012; Dion et al., 2018; Elvik et al., 1990; Firth et al., 2001; Hayes, 2009; Kildahl et al., 2019; Koppenhaver, 1994; Martorell & Tsakanikos, 2008; Nowak, 2015; Reinke, 2005, 2006; Sequeira & Hollins, 2003; Shabalala & Jasson, 2011; Soylu et al., 2013; Strickler, 2001; Sullivan & Knutson, 1998; van der Put et al., 2014; Verdugo et al., 1995; Walters et al., 1995; Wissink et al., 2018).

Data extraction

A custom-designed data extraction tool was developed, and pilot tested by a practitioner peer-group prior to data extraction. This group consisted of 10 PhD-candidates, who were trained professionals in the disciplines of speech-language pathology, psychology (educational or clinical), education and occupational therapy. The data extraction tool contained six types of abuse, 15 behavioural signs of abuse and 19 physical signs of abuse. This practitioner group was asked to use two key references and complete the data extraction tool and provide feedback on its applicability and useability. Minor changes were suggested and made, prior to the data extraction. Data extraction was carried out independently by all three authors. The data extraction was complicated by the fact that publications used different labels for the same signs of abuse (e.g., "aggression" and "violent behaviour") and that there was a general lack of definition of concepts. This resulted in moderate interrater reliability, with Cohen's kappa of 0.75 between the first and second authors (McHugh, 2012).

The quantitative data on signs of abuse was summarised and calculated for frequency. As each extracted sign could be noted down two times for each article (one for each reviewer), a level of at least five notations (meaning that the sign of abuse was mentioned in more than two articles) was selected. The rationale for this approach is that the purpose of the study was to identify signs of abuse in children with disabilities that had a higher frequency and that would therefore be expected and seen more probably.

The qualitative descriptions of signs of abuse (e.g., signs that were written in the "other column") were listed, refined (e.g., by grouping synonyms) and followed with a frequency count. Similar to the quantitative data, only signs with at least five notations were added to the final list. The frequency of the behavioural and physical signs of abuse, using both the qualitative and quantitative data was counted and summarised. This resulted in a final list that contained 28 items.

Social validation

Participants and sampling

Participants were selected for the social validation phase of the study using a multiple-method sampling approach. This specific aim necessitated "expert participants" who were well versed in both disability and in abuse research. Due to the cross-disciplinary nature of the topic, the pool of potential participants was small. Four different groups of participants were primarily invited to participate in the survey, (1) authors of research studies included in the abstract review stage of the rapid review conducted in phase 1of this study; (2) authors of research studies included in a previously conducted scoping review by the authors of the present study with a related focus (Nyberg et al., 2021) (3) personal contacts with suitable clinical or research background linked to the topic and (4) members of international organisations targeted at preventing violence and abuse towards children with/without disabilities or international disability alliances. All invited participants were asked to further snowball the invitation to other suitable possible participants in their own professional networks (Sue & Ritter, 2012). As the sample was based on a snowball technique, sampling error estimates and target sample size cannot be calculated (Sue & Ritter, 2012). Item nonresponse in the present study consisted of participants quitting the survey before finishing ($n = 4$), as responses could not be

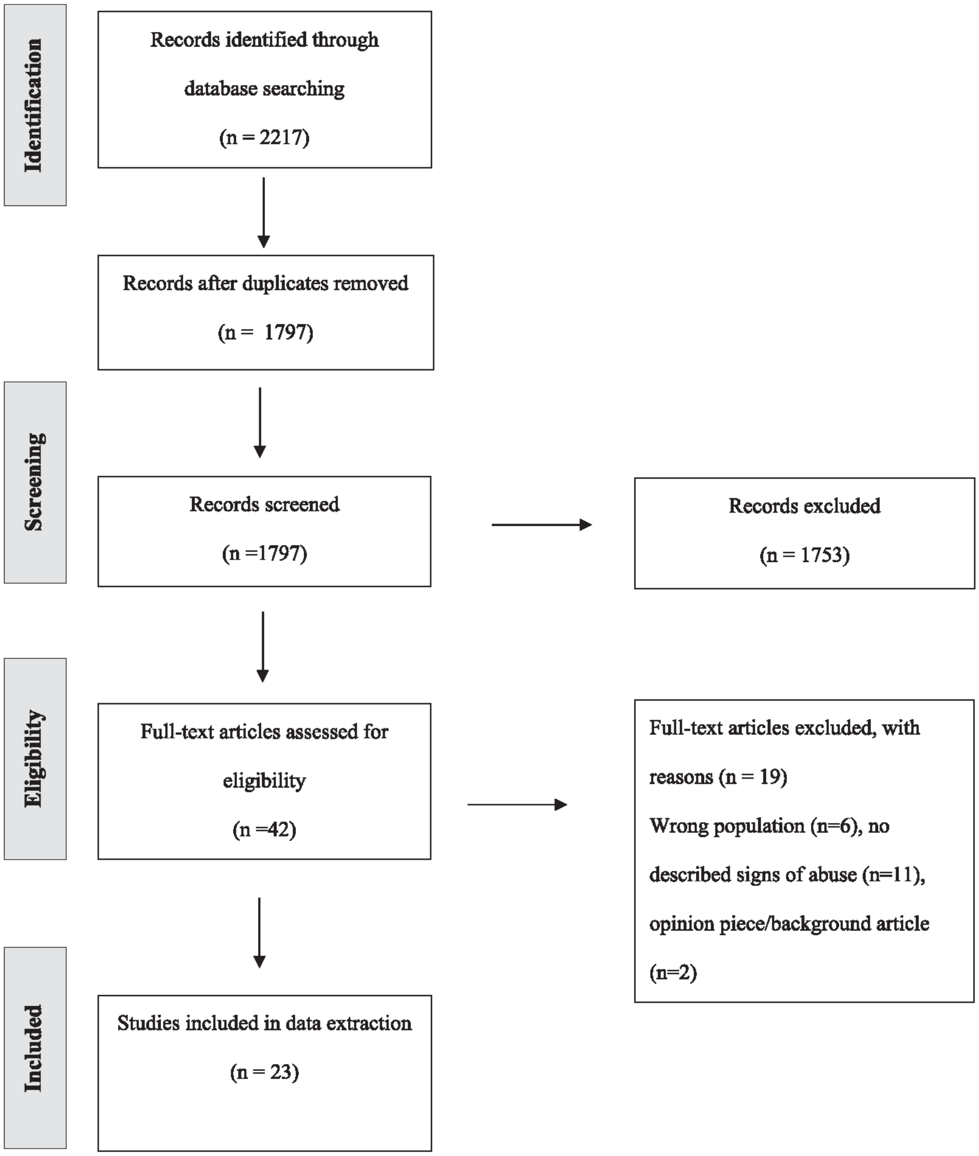

Figure 1. PRISMA – chart of present study.

skipped without an answer being given. This resulted in a total of 39 completed surveys from participants.

Due to the global recruitment process and online data collection, participants represented different countries, namely Sweden (*n* = 14), South Africa (*n* = 7), Norway (*n* = 3), The United Kingdom (*n* = 3), Australia (*n* = 3), Turkey (*n* = 2), The United States (*n* = 2), The Netherlands (*n* = 2), Iceland (*n* = 1), Spain (*n* = 1) and Denmark (*n* = 1). Their first languages reflected the countries that they lived in. The years of experience in working in their current profession ranged from 0 to 5 years to over 20 years, with 49% of

Table 1. PEO-criteria of the present study.

	Inclusion	Exclusion
Population	- Children with disabilities (18 years of age and younger)	- Persons without disabilities - Only adults with disabilities
Exposure	- Victim of any of: ○ Sexual abuse ○ Physical abuse ○ Neglect ○ Financial abuse ○ Exploitation ○ Emotional abuse	- Primary substance abuse or alcohol abuse - Gun violence
Outcomes	- Signs of abuse (behavioural, emotional)	- Medical examination

Table 2. Biographical information of participants ($n = 39$).

Sex		
Female: 24 (62%)	Male: 15 (38%)	
Age: Seniority in career and age is highly linked, with increased age implying increased seniority for researchers (Over, 1988)		
31–40 y: 7 (18%)	41–50 y: 7 (18%)	51–60 y: 12 (31%)
61–70 y: 9 (23%)	71 y +: 4 (10%)	
Workplace (multi-choice question)		
Government: 5 (13%)	University: 16 (41%)	Healthcare: 16 (41%)
Non-profit organisation: 6 (15%)	Other: 6 (15%) (This included community practice, children's advocacy centre, NGO/INGO, retired)	
Main area of expertise relevant to the study (multi- choice)		
Children with disabilities: 20 (51%)	Child abuse: 30 (77%)	Other: 10 (26%) (This included adult abuse survivors, forensic psychiatry, police psychology, disability inequalities, parent-child relationships, child health care, child protection).
Years of clinical experience in your main area of expertise relevant to the study: Participants with many years of experience in the profession can be viewed as experts, although years of work experience alone does not guarantee expertise (Shanteau et al., 2002).		
1–5 years: 4 (10%)	6–10 y: 7 (18%)	11–20 y: 10 (26%)
More than 20 y: 15 (38%)	None: 3 (8%)	
Estimated number of cases of known abuse against children with disabilities involved in: Case-based reasoning (e.g., basing your judgement on previous cases) can be a component of expertise (Hoffman, 1998). This is highly relevant in this study as the participants rating of the accuracy of each sign of abuse must be weighed against their familiarity with the topic.		
1–5 cases: 4 (10%)	6–10 cases: 4 (10%)	11–20 cases: 7 (18%)
More than 20 cases: 23 (59%)	Other: 1 (3%)	
Number of published studies authored in areas relevant to the study: This can be used to assess performance in the research field.		
1–5 published studies: 12 (31%)	6–10 published studies: 3 (8%)	11–20 published studies: 3 (8%)
>20 published studies: 6 (15%)	None: 15 (38%)	

the participants having worked in their current profession for more than 20 years. The majority of the participants had completed postgraduate studies, with 41% having earned their PhDs and 46% having received a Master's degree. Academic knowledge is viewed as an essential part of the definition of an expert (King et al., 2008). Their job descriptions, which were provided in free text and thus could include several professions for each person, included psychologists (n = 11), professors ($n = 7$), associate professors/researchers/lecturer ($n = 6$), managers of units ($n = 5$), physicians ($n = 2$), child psychiatrists ($n = 2$), consultants/experts on abuse/disability ($n = 4$), unnamed occupations ($n = 2$) and retired ($n = 1$). Other biographic data is shown in Table 2.

Material

An online survey was constructed in Qualtrics, a digital platform for constructing surveys (https://www.qualtrics.com/uk/). The system was set up so that each participant had to provide written consent before being able to continue with the survey. After written consent had been provided by the participant, a biographical information section followed, as described in Table 2.

After completing the biographical portion of the survey, participants were asked to rate signs of abuse in children with disabilities on an ordinal 7-point Likert scale (1 = Very accurate; 2 = Moderately accurate; 3 = Slightly accurate; 4 = Neither accurate nor inaccurate; 5 = Slightly inaccurate; 6 = Moderately inaccurate; 7 = Very inaccurate). A 7-point Likert scale was deemed appropriate as the population were experts in the field and could be expected to want to express a nuanced opinion (Chyung et al., 2017). Definitions for each sign of abuse were provided in the survey. Additionally, the participants were asked to volunteer and rate signs of abuse that they had encountered in children with disabilities in their research or clinical work. Participants were also able to provide a free-text comment at the end of the survey. The survey was pilot tested using a group of five professionals, namely two clinical psychologists, two PhD-candidates who were also trained as speech-language therapists and one specialised occupational therapist with a PhD in medicine. The pilot group were asked to complete the survey using the online link using a custom-designed questionnaire for evaluating their experience of the survey, including components such as usability and clarity of definitions and signs of abuse. Subsequent changes were made according to their feedback and the survey was re-tested by one of the participants to ensure that the suggested changes had been carried out to satisfaction.

Procedure

A quantitative description of the empirical accuracy of different signs of abuse in children with disabilities was deemed suitable for the purpose of the study (Creswell & Creswell, 2018), as the researchers wanted to collect data over a time-limited period (20 days). Data was collected using an online survey which was distributed through email containing the link to the survey (Sue & Ritter, 2012). This method of distribution was considered appropriate for the sample population as they are active in clinical work or research and thus are used to using emails as a method of communication. Potential participants were informed on the nature of the survey, the identity of the researchers and organisation, how data would be used and that they would remain anonymous in both completing the survey and when the results were reported, the average length of the survey (20–30 min) and that there were no risks associated with part-taking in the survey (Sue & Ritter, 2012).

Results

In total 35 full responses and four partial responses were recorded. Participants rated each of the 28 signs of abuse independently on a 7-point Likert-scale (1 = Very Accurate; 7 = Very inaccurate). Thus, the lower the score, the higher the perceived accuracy of the sign of abuse (Table 3). The survey results were analysed with SPSS, reporting means, range and standard deviation (Table 3).

Statistically significant differences were not seen between each item as the differences and the sample size were too small, but a significance level of $p < .05$ was reached for the differences between the 10 signs rated as most accurate versus the 10 signs rated as least accurate (Table 4). The calculation was done by conducting a paired samples *t*-test of item 10 (Emotional problems) and item 19 (Eating/appetite disturbance) in SPSS.

Group differences

Ratings were compiled into different groups to compare the results between groups. Comparisons were made between the participants who had published in their main area of expertise relevant to the study ($n = 21$) and missing data ($n = 3$) and the participants who had no publications in their main area of expertise relevant to the study ($n = 14$) and missing data ($n = 1$) using an independent samples *t*-test. The participants with no publications rated inappropriate sexual behaviour, alcohol abuse, substance abuse, signs of penetration and running away from home as significantly less accurate as signs of abuse in children with disabilities than did the group with at least one publication, whereas they rated poor self-esteem, eating/appetite disturbance and emotional problems as significantly more relevant than did the participants who had published in their main area of expertise relevant to the study. For the other signs of abuse ($n = 20$), no significant differences were seen between the two groups. Only the significant results are presented in Table 5 ($n = 8$).

Table 3. Numbers, range, mean and standard deviation for the rating of signs of abuse.

	Sign of abuse	*N*	Range	Min	Max	Mean	Std. Deviation
1	PTSD	36	2	1	3	1.75	0.692
2	Poor self-esteem	37	3	1	4	1.81	0.908
3	Withdrawal	37	3	1	4	1.86	0.948
4	Anxiety	36	3	1	4	1.94	0.955
5	Signs of penetration	36	6	1	7	2.06	1.472
6	Nightmares	37	3	1	4	2.08	0.983
7	Depression	36	4	1	5	2.14	1.018
8	Self-harm	36	3	1	4	2.17	0.811
9	Acting out	36	4	1	5	2.19	1.037
10	Emotional problems	35	3	1	4	2.20	0.994
11	Bruising	36	5	1	6	2.22	1.098
12	Inappropriate sexual behaviour	37	5	1	6	2.27	0.962
13	Inappropriate anger	38	5	1	6	2.34	1.169
14	Behavioural problems	36	5	1	6	2.36	1.125
15	Aggressive behaviour	39	6	1	7	2.38	1.388
16	Suicidal thoughts	36	5	1	6	2.42	1.079
17	Burns or trauma	36	6	1	7	2.50	1.558
18	Irregular school attendance	36	5	1	6	2.61	1.076
19	Eating/appetite disturbance	35	5	1	6	2.63	1.087
20	Victimising	36	6	1	7	2.67	1.242
21	Suicide attempt	36	4	1	5	2.69	1.142
22	Non-compliance	36	4	1	5	2.83	1.134
23	Running away from home	36	5	1	6	2.94	1.393
24	Negative peer involvement	35	5	1	6	2.97	1.150
25	Crying	35	5	1	6	3.09	1.269
26	Substance abuse	36	5	1	6	3.44	1.182
27	Alcohol abuse	36	5	1	6	3.53	1.134
28	Dominant behaviour	39	6	1	7	3.67	1.493

A second group comparison was carried out using an independent samples t-test, comparing participants with experience from more than 20 known cases of abuse against children with disabilities ($n = 22$) missing data ($n = 1$) and participants with experience from less than 20 known cases of abuse ($n = 13$), missing data ($n = 3$). For these two groups, smaller differences in mean ratings were found, producing no significant differences in ratings for any of the signs of abuse.

Rating of additional signs of abuse

In the last section of the survey, participants were invited to add and rate additional signs of abuse in

Table 4. *P*-value for differences between item 10 and item 19.

Item and Item number	Mean	Std dev	Std error mean	Lower	Upper	*T*	Df	Sign 2-tailed
Emotional problems (#10) Eating/appetite disturbance (#19)	−0.429	0.739	0.125	0.125	−0.175	−0.175	34	.002

Table 5. Group comparison using independent samples *t*-test in SPSS.

Sign of abuse	Participant group	*N*	Mean	Std. Dev.	Df	*T*	Sign ($p < .05$)
Poor self-esteem	No publ.	14	1.43	0.646	35	−2.1	.044
	Publ.	23	2.04	0.976			
Inappropriate sexual behaviour	No publ.	14	2.79	1.188	35	2.8	.009
	Publ.	23	1.96	0.638			
Alcohol abuse	No publ.	14	4.14	0.959	34	2.8	.007
	Publ.	22	3.14	1.082			
Substance abuse	No publ.	14	4.07	0.997	34	2.8	.009
	Publ.	22	3.05	1.133			
Signs of penetration	No publ.	14	2.79	1.805	19,22	2.3	.036
	Publ.	22	1.59	1.008			
Running away from home	No publ.	14	3.64	1.646	19,31	2.3	.031
	Publ.	22	2.50	1.012			
Eating/appetite disturbance	No publ.	14	2.14	0.949	33	−2.3	.029
	Publ.	21	2.95	1.071			
Emotional problems	No publ.	14	1.71	0.914	33	2.5	.016
	Publ.	21	2.52	0.928			

children with disabilities that they had encountered in their clinical work or research, using the same 7-point Likert scale (Table 6). Eleven participants provided 40 additional behavioural signs and 10 additional physical signs, all rated as accurate, ranging from 1 = Very accurate to 3 = Slightly accurate. The signs of abuse were analysed using a deductive analysis. Initially, signs that had been volunteered by participants that were synonymous with signs that were already included the survey and had thus already been rated by the participants were removed. Secondly, similar signs of abuse that had been volunteered by different participants were combined with each other. The process was carried out using a consensus discussion between the three authors. After these two steps, 23 signs of abuse volunteered by participants remained. The signs are presented in Table 6 with the number of entries and mean rating. The signs provided by the participants in free text were compared to the signs extracted from the rapid review that were not included in the survey, as they had less than five notations. Sixteen of the 23 signs that were provided by the participants had also been extracted from the publications in the rapid review and are marked with cursive font in Table 6. However, only seven of the signs were provided more than once (and none more than by three participants), confirming that they were considered as more unusual signs of abuse in children with disabilities.

Table 6. Signs of abuse and rating provided by the participants.

No.	Sign of abuse	Rating (mean)	No. of entries
	Behavioural signs		
1	*Hypervigilant, guarded/insecure behaviour*	1.7	3
2	Anxiety or reluctance to be in the presence of or be left alone with a particular person or to go to a particular place/room, behavioural avoidance	1.7	3
3	*Inappropriate laughter, grimacing or unusual smile, problems with emotion regulation*	2	3
4	*Child expressing fear of parent/other, fear of specific caregiver*	1.5	2
5	Change in child's behaviour without any other explanation, sudden change in behaviour	1.5	2
6	*Problems developing friendships with others, lack of social skills*	1.5	2
7	*Child describing parent/other in ONLY positive ways (overcompensating), odd interaction patterns with parent*	2	2
8	*Schoolastic difficulties*	1	1
9	*Attachment disorder*	1	1
10	*Loss of earlier abilities*	1	1
11	*Somatisation (complaints about body pains)*	2	1
12	*Uncritical behaviour among strangers*	2	1
13	*Dissociation*	2	1
14	Problems with emotion regulation	2	1
15	Non-independent behaviour, attachment disorder	2	1
16	*Selective mutism*	3	1
17	*Restlessness, increased motor activity*	3	1
	Physical signs		
18	*Enuresis, encopresis*	2.7	3
19	Discharge from vagina or penis	1	1
20	Venereal disease	1	1
21	*Pregnancy*	1	1
22	*Bite marks and sucking marks on child's body and neck*	2	1
23	Frequent bladder infections in females	2	1

Comments on the survey

Twenty participants chose to give free-text comments at the end of the survey. Comments that were just complimentary were removed and the remaining comments were analysed using thematic analysis. Four themes were identified, namely (1) Methodological considerations; (2) Children with disabilities; (3) Signs of abuse and (4) Preventing abuse.

The "Methodological considerations" theme included three codes: methodological considerations/age ($n = 5$), methodological considerations/type of disability ($n = 5$), methodological considerations/lack of context ($n = 3$). Comments regarding methodological considerations/age included referring to participants experience as an influence on their rating of signs, or suggesting that rating could have been improved if the population had been divided into different age groups. The code methodological considerations/type of disability included comments wanting more clarity on the types of disabilities referred to in the survey or suggesting that the population were divided into different disabilities as a way of enhancing the rating. Methodological considerations/lack of context referred to the fact that the signs of abuse and the definitions were presented without any contextual information such as disability or environment of the child. One participant wished to be able to leave comments on each rated sign of abuse, to provide context to the rating.

The theme "Children with disabilities" contained five codes, namely communication implications ($n = 4$), caregiver considerations ($n = 3$), increased vulnerability ($n = 3$), type of disability affects the accuracy of signs/symptoms ($n = 4$) and gullibility ($n = 1$). Communication difficulties referred to the fact that children with disabilities can have difficulties with communicating about abuse, understanding that they have been abused and understanding different types of abuse. Caregiver considerations refer to both their unique position in being able to understand the child, especially if there are communication difficulties, as well as the need for professionals to analyse the interaction of the child and caregivers to gain more insight into the relationship and potential abuse. The code increased vulnerability included comments that children with disabilities, due to physical and/or cognitive restraints, are more vulnerable of becoming victims of abuse. The code gullibility refers to a comment saying that children with disabilities might be more easily deceived into not telling about abuse or believing when being told that the abuse isn't harmful. The final code in this theme consists of comments from participants stating that different disabilities present with different signs of abuse, and that a behaviour (e.g., aggressive behaviour) could be interpreted as typical behaviour for children with specific types of disabilities, but concerning and as a potential sign of abuse in children with other types of disabilities.

The theme "Signs of abuse" contained six codes, unspecific signs ($n = 5$), specific signs ($n = 5$), not decisive signs ($n = 7$), same signs ($n = 1$), no signs ($n = 2$) and types of abuse ($n = 1$). Unspecific signs referred to comments saying that many different signs or symptoms could be seen as signs of abuse, and that they could be very unspecific. Specific signs included participants providing signs that they thought were accurate as signs of abuse in children with disabilities, such as behaviour changes, PTSD, aggression and bruising in specific locations. Several participants commented that the signs of abuse presented in the survey was not decisive and could not be used in isolation as definite signs of abuse as they could well also be present without any abuse history. Two participants said that children with disabilities often display the same signs as children without disabilities, whereas two comments wanted to bring attention to the fact that many children with disabilities do not present with any signs at all, even though they have been victims of abuse. Lastly, one participant stated that the different types of abuse (e.g., sexual abuse or physical abuse) are linked to specific signs.

The theme "Preventing abuse" contained four codes, namely investigation ($n = 1$), specific abuse prevention strategies ($n = 3$), case history ($n = 1$) and listening and believing ($n = 1$). Investigation refers to the need to investigate suspected abuse thoroughly without scaring the child. The code abuse prevention included comments that claimed that the most important thing for this population was using individualised abuse prevention methods that are specifically adapted for children with disabilities. The importance of getting a case history to be able to detect abuse was highlighted in one comment. Another comment stated the need for persons such as teachers to be attentive and not discounting reports of abuse from children with disabilities.

Discussion

The purpose of the present study was to identify and socially validate signs of abuse in children with disabilities using a two-phase study. None of the signs included in the present study received an overall mean value that indicated them as inaccurate as signs of abuse in children with disabilities. The lowest rating of the included signs of abuse in the study had a mean value of 3.67 (dominant behaviour), indicating a level of neither accurate nor inaccurate–slightly accurate. These results were expected as the signs were derived from published literature on the topic. However, results from the social validation phase of the study suggest that the perceived accuracy of signs of abuse in children with disabilities differ between signs. The top 10 rated signs were perceived as significantly more accurate as signs of abuse in children with disabilities than the bottom 10 rated signs. The sign with the highest perceived accuracy was PTSD, which is interesting as it is has been described as potentially challenging to diagnose in persons with disabilities (Kildahl et al., 2020). Poor self-esteem, withdrawal and anxiety were similarly rated as moderately accurate- very accurate, although the differences between each sign were small.

The differences in ratings between the participants with no publications and the participants who had published in their main area of expertise relevant to the study could be regarded as a potential difference between participants who were primarily clinicians or primarily researchers (with some exceptions). It is possible that the difference in rating was linked to the signs of abuse that children with disabilities present within the clinical world in contrast to the signs of abuse that are most often described in research on the topic. For example, alcohol abuse and substance abuse in individuals with intellectual disabilities have been explored in research (Carroll Chapman & Wu, 2012) as well as signs of penetration as a sign of abuse in children with disabilities (Akbas et al., 2009; Wissink et al., 2018). However, these signs might not be the most typical sign that children present within a clinical setting, if one is not conducting a forensic examination (in the case of signs of penetration) or working with older children/teenagers (in the case of alcohol abuse and substance abuse). In contrast, symptoms such as poor self-esteem, eating disturbances and emotional problems may more frequently be present and observable in a clinical setting.

Participants were given the opportunity to provide signs of abuse and rate them towards the end of the survey. These signs were seemingly based more on the specific nature of the participants' clinical work or research practice. None of these signs were mentioned more than three times, even though 23 different signs were described, pointing to the plethora of possibilities. Many of the signs had also been extracted during the rapid review but not included in the survey as they had too few notations, and thus were deemed less common. The additional signs of abuse provided by the participants reflect the difficulty that is inherent with analysing and understanding signs of abuse in children with disabilities, namely the unspecific nature of the signs of abuse and the fact that some children with disabilities present no signs of abuse at all. This was also mentioned by some participants in the comment section of the survey.

Hypervigilance, insecure behaviour and changes in behaviour were mentioned several times as a strong potential indicator of abuse. This includes a change in behaviour towards a certain person or situation, or a general behaviour change or avoidance. Careful enquiry and observation of the child's behavioural history and current behaviour could be important ways to detect potential abuse. Difficulties with relationships or anxiety revolving around specific individuals or situations were also mentioned and could be important factors when reviewing case history.

All of the signs included in the present study can also be linked to other causes than abuse, as pointed out by some participants. This is in itself a risk, as attributing potential signs of abuse to the child's disability, without further investigation, could lead to abuse going undetected (Miller & Brown, 2014). Disablist attitudes and beliefs regarding children with disabilities capabilities and quality of life (Miller & Brown, 2014) as well as beliefs that children with disabilities are not abused (Stalker et al., 2010) can further increase the risk of both experiencing abuse, and that the abuse goes undetected (Franklin & Smeaton, 2017). Additionally, disempowerment, over protection, social isolation and a lack of education regarding sexuality and relationships can make children with disabilities more susceptible to experiencing abuse (Franklin & Smeaton, 2017).

Comments on the survey suggested that many different behavioural signs or physical signs could be signs of abuse, but that abuse could manifest differently in different children and that some children might not show any of the mentioned signs, even though they had been abused. To further complicate matters, some signs of abuse presented in this study could also be potential risk factors for abuse, such as low self-esteem, which could in turn be an effect of disablist attitudes. This bi-directional influence of attitudes, risk factors and potential signs of abuse complicates the detection and hindering of abuse. These comments underpin the need for a holistic view and assessment of signs of abuse as well as the need for skilled professionals with knowledge and understanding of abuse, trained at making judgments about the presence of abuse in children with disabilities (Franklin & Smeaton, 2017; Hernon et al., 2015; Miller & Brown, 2014). The importance of empowering children, believing children who disclose abuse and taking action should be highlighted in the training of professionals (Franklin & Smeaton, 2017). Additionally, caregivers and individuals close to the child who know them well play an important role in recognising and spotting potential signs of abuse (Hernon et al., 2015).

Methodological considerations

Participants provided comments at the end of the survey linking to methodological considerations for the study. Some participants felt that the rating process was difficult, as the signs of abuse lacked context such as age of the child or the specific disability of the child. This lack of context could have influenced their rating of the signs of abuse. The lack of context was an intentional choice when constructing the survey, as providing context for each sign of abuse would limit the rating to just that specific situation/disability, when the researchers wanted to rather produce a general rating of commonly described signs of abuse in children with disabilities. Additionally, the option to provide comments to each rated sign of abuse was considered during the development process but was deemed unsuitable as it could potentially narrow the results to the specific context that participants described. However, these suggestions could be considered for future studies within this field.

Limitations of the study

Although a concerted effort was made to recruit experts in the field who would have knowledge on this complex topic, the number of participants was limited. The intersection of the topics of disability and child abuse is not well researched and consequently, few professionals or researchers can claim expertise in this area. However, when considering the participant description, it is clear that many prominent scholars in the field participated. As the rapid review methodology is not as theoretically sound as the more extensive systematic review methodology (Khangura et al., 2012), social validation was used to enhance the process by confirming the results of the rapid review. Several participants highlighted that "children with disabilities" is a large and heterogeneous group, which includes babies, toddlers, middle-schoolers, and teens as well as different disabilities such as autism, cerebral palsy and Down's syndrome, and that the signs of abuse were presented in the survey without context, making the rating process more difficult.

Conclusions

Findings from the study conclude that an international expert panel rated signs of abuse in children with disabilities derived from a rapid review on the topic as accurate. The perceived level of accuracy was significantly different between the 10 signs that were rated the highest, compared to then 10 lowest rated signs. The results should not be used as a checklist, but rather as guidance for clinicians, teachers, and parents in which signs could present in a child with disability that have been abused. The results should be viewed as preliminary due to the small sample size and the sensitive nature of the topic and should be used with caution. However, the prevailing problem we stand before today is not that abuse against children and adults with disabilities is being over-reported, but rather under-reported (Hernon et al., 2015; Nareadi, 2013; Willott et al., 2020). Thus, this paper could provide some insight into which signs of abuse appear to be most accurate for this population.

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ORCID

Juan Bornman http://orcid.org/0000-0001-9685-3750

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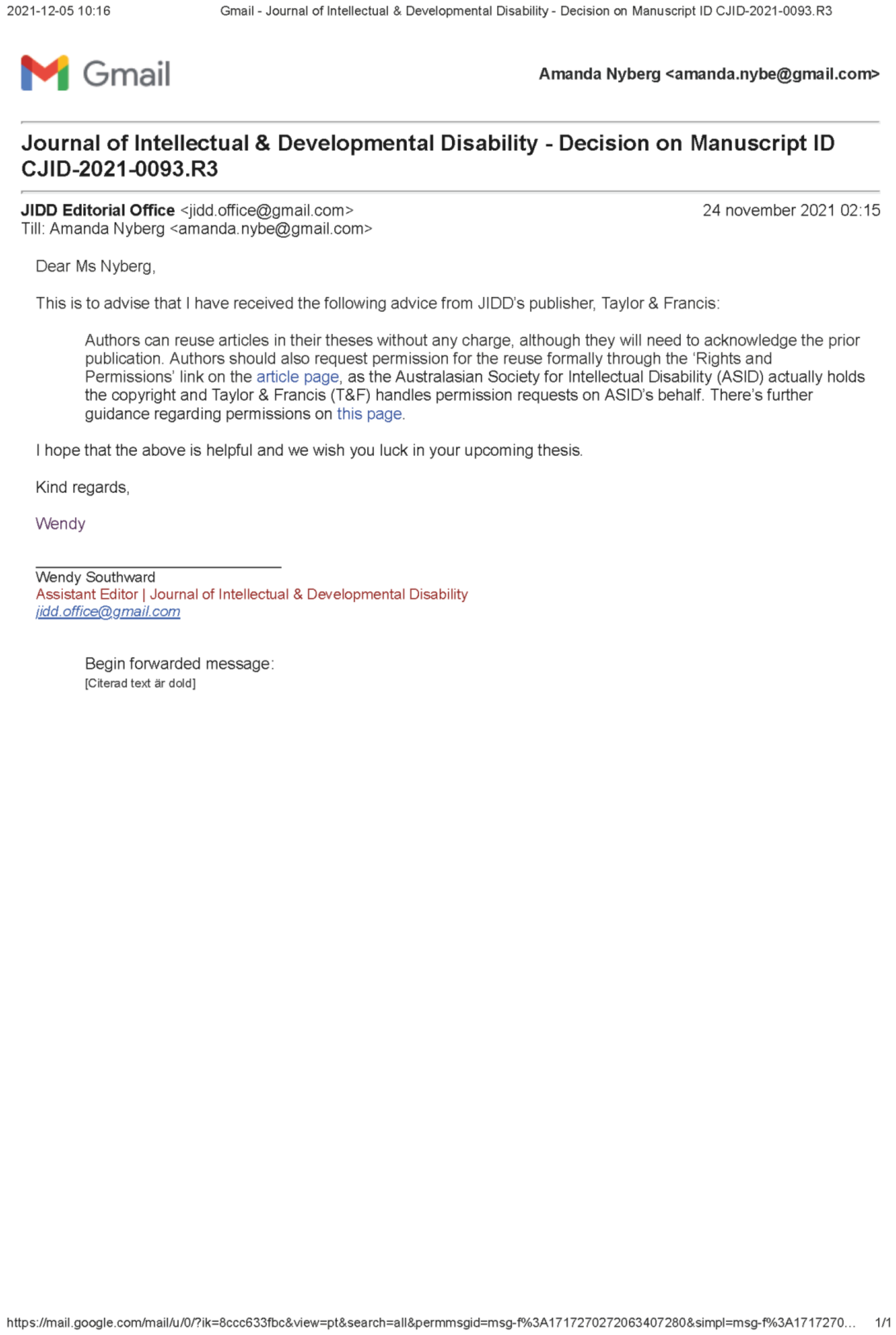

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Appendix E: Information extracted from Phase 1.1.-1.3 for data integration (integration process)

INFORMATION EXTRACTED FROM PHASE 1.1, 1.2, 1.3	**Source**
SOCIAL LEVEL	
Signs of abuse in children with disabilities	
• Teachers should be provided with knowledge on how to identify signs of abuse in children with communicative and/or cognitive disabilities. • Adults need knowledge on how to identify signs of abuse in children with communicative and/or cognitive disabilities.	Focus groups
The accuracy of potential signs of abuse in children with communicative and/or cognitive disabilities can vary significantly, and the potential signs of abuse presented in the guidelines should not be used in isolation to determine abuse.	Rapid review
Stakeholders should be aware that: • Signs of abuse can be very unspecific • Children who have been abused might not show any signs of abuse • The accuracy of signs of abuse may vary depending on the type of disability, as symptoms that are typically part of the disability can be potential signs of abuse in another type of disability • Sudden changes in behaviour, that are not typical for that child may be a sign of abuse. • Children with disabilities may present with the same signs of abuse as children without disabilities • Some signs of abuse may be more commonly linked to specific types of abuse (e.g., bruising on the arm could be linked to physical abuse) • Being attentive to potential signs of abuse could aid in the detection of child abuse	Rapid review
Stakeholder/teacher training	
Stakeholders should be provided with information about abuse against children with communicative and/or cognitive disabilities, different types of abuse and the increased risk of being abused children with communicative and/or cognitive disabilities face.	Focus groups Rapid review
Stakeholder training may include information on: • How to ask questions about and report abuse • Discussions on attitudes towards disabilities and abuse • Treatment options for children with communicative and/or cognitive disabilities who have been abused • Listening to and believing children with communicative and/or cognitive disabilities when they disclose abuse • Discussions around teaching styles and how the program should be taught in the teacher training to ensure coherent teaching styles • Discussion on the increased dependency and therefore need for compliance that is experienced by children with communicative and/or cognitive disabilities and how that affect their ability to speak up against abuse and remove themselves from risky situations • Discussion on the potential for traumatization or re-traumatization for children participating in the abuse prevention program, especially if they have been abused, which might not be known by teachers or parents.	Scoping review Focus groups
Stakeholder training may utilise: • Videos, role play and case studies as teaching methods	Focus groups

INFORMATION EXTRACTED FROM PHASE 1.1, 1.2, 1.3	**Source**
• Online or face-to-face training depending on the needs and preferences of the participants • Skills practice, e.g., conducting “mock lessons” with colleagues	
Teachers should be aware that children with communicative and/or cognitive disabilities can be used to being compliant.	Focus groups
Participation in the abuse prevention program could include the risk of traumatization or re-traumatization for children.	Focus groups
Schools should work to increase the knowledge about children’s rights and disability rights amongst school staff. Knowledge and respect of children’s rights and disability rights can be lacking in society.	Focus groups
Evaluation	
Evaluation of an abuse prevention program may include: • Measuring teacher’s satisfaction with the program • Assessing teacher’s knowledge of and attitudes towards abuse against children • Assessing the general environment at the school before and after the implementation of the program • Exploring teacher’s opinions on the quality and structure of the lessons and the impact that the program has had on the children • Assessing differences in how the program was taught by different teachers by asking them questions about previous knowledge on the topic, training in delivering the program, attitudes towards abuse and disability and the methods used for teaching	Scoping review Focus groups
Teachers implementing the abuse prevention program may benefit from: • Increasing their skill level through training in how to implement an abuse prevention program • Information on the responsibilities inherent to teaching children about abuse including the need to ensure that every child understands the content • Discussing children’s rights contrasted with participation in school activities and when children’s decline to do things can and cannot be respected	Focus groups
Children, parents, and teachers should be included in the evaluation of the program.	Focus groups
An expert panel can be used to audit a preliminary version of an abuse prevention program.	Focus groups
COMMUNITY LEVEL	
Resources, policies, and collaboration	
The implementation of school-based abuse prevention programs may benefit from: • The availability of sufficient funding • Collaboration between schools, parents, health care and social services to facilitate information sharing and developing shared values • Shared values at a school level in regard to abuse, children’s rights, and disability rights • Involving the community in the planning and implementation of the abuse prevention program • Support from principals and school management • Providing training to teachers on abuse prevention • Providing resources and sufficient time to teachers implementing the program • Providing support to teachers implementing the program • Ensuring that the teacher who is teaching abuse prevention to the children is known and trusted by them	Focus groups
Schools should be adapted to meet the needs of every child, as a school environment that is suited for all children may facilitate understanding and knowledge.	Focus groups

INFORMATION EXTRACTED FROM PHASE 1.1, 1.2, 1.3	**Source**
Social service practitioners are important collaborators for teachers but have limited knowledge on how to communicate with children with communicative and/or cognitive disabilities.	Focus groups
It is difficult for teachers to get information about the processes and actions of social services in cases regarding their students.	Focus groups
Evaluation	
The evaluation of an abuse prevention program at the community level may include using number of disclosures of abuse by children with communicative and/or cognitive disabilities (e.g., to school nurse) or number of reports to social services/the police as outcome measures.	Focus groups
A panel can be used to rate children's response to safety skills scenarios or by designing situations to try children's real-life safety skills.	Scoping review
LOCAL LEVEL	
Teaching methods and materials	
Methods and materials used to teach abuse prevention concepts to children with communicative and/or cognitive disabilities in schools may include: • Teaching the program over a longer period to increase exposure and thereby facilitating learning • Using storytelling, role play and videos as teaching methods to facilitate understanding of key components • Using teaching strategies such work sheets/books, songs and music, discussion, posters, writing stories and letters, drawing and painting and skills practice adapted to suit the needs of children with communicative and/or cognitive disabilities • Using play to facilitate the understanding of key components • Encouraging children to express themselves freely by listening to them and believing them as a strategy to develop self-esteem and trust • Repetition of key components to facilitate retention • Adaptations to accommodate for children's disabilities and abilities to facilitate participation in the program and understanding of key components • AAC-materials and strategies, such as communication boards and books, manual signs, and Talking Mats™ • Teaching the program in a small group setting or individually, using simplified language, supplementing the teachings with pictures and objects • Using these guidelines as a manual for the adaptations • Creating a "toolbox" with different methods and materials that teachers can utilise to adapt the program for the group and each individual child • Providing appropriate vocabulary and objects to enable children with communicative and/or cognitive disabilities to understand and talk about abuse • Providing information about abuse in an informative but not overly detailed manner • Situations that are linked to children's lives and that are repeated throughout the abuse prevention program as generalisation of learned concepts can be challenging for children with communicative and/or cognitive disabilities • Different types of materials adapted for different types of disabilities and level of functioning	Scoping review Focus groups
The teacher who is teaching the program should be trusted by the children.	Focus groups
Parental involvement	
• Giving information to parents about the abuse prevention program may decrease the risk of them being worried that their child will be traumatized by participating in the program.	Focus groups

INFORMATION EXTRACTED FROM PHASE 1.1, 1.2, 1.3	**Source**
• Parents can harbour concern that their children will be traumatised or abused by participating in the abuse prevention program.	
Parents shouldn't have the authority to decide over teachings or what happens in the classroom.	Focus groups
Parents should be provided with information about abuse against children with disabilities, including different types of abuse, and should be included in the abuse prevention program	Focus groups
Providing support to parents regarding challenging behaviours in children with communicative and/or cognitive disabilities to reduce the caregiving burden may be an important part of an abuse prevention program to decrease the risk of abuse.	Focus groups
There is a risk of sheltering adolescents with disabilities so much that they are denied the "teenage experience".	Focus groups
INDIVIDUAL LEVEL	
Key components	
Empowering children by increasing their self-esteem and facilitating behaviour change, getting information about their rights and what is wrong/right may be linked to a reduction in risk of abuse and help children talk about abuse. Key components of an abuse prevention program for children with communicative and/or cognitive disabilities may include: • Information about abuse, including different kinds of abuse such as sexual, physical, emotional abuse, neglect, and exploitation • Information about children's rights, potentially by using the Convention on the Rights of the Child • Information about how to disclose abuse (telling), to whom and at what time • Information about how to say no and speak up against abuse • Safe and unsafe touches • Good and bad secrets • Positive and safe relationships, sexuality, integrity, and private and public body parts • Risky situations specifically linked to their life situations • Safety rules • Strangers, including adults posing as children online • Feelings, including the effect of negative behaviours to people around you	Scoping review Focus groups and interviews Rapid review
Challenging behaviour in children needs to be considered in terms of the implementation of the abuse prevention program.	Focus groups
Evaluation	
Evaluation of the abuse prevention program at the individual level may include: • Assessing safety skills by presenting children with scenarios and asking them how they would respond to each situation, interviewing children, or using role play or simulations • Assessing children's anxiety levels, self-esteem, or locus of control before and after the program • Assessing children's understanding of the key components that are taught in the program • Measuring children's safety skills by asking parents to rate children's understanding of protective behaviours or general sense of safety • Measuring parent's and children's satisfaction with the program • Assessing children's satisfaction with the program using interviews	Scoping review Focus groups

INFORMATION EXTRACTED FROM PHASE 1.1, 1.2, 1.3	Source
Evaluation methods that can be adapted to suit each child with communicative and/or cognitive disabilities, such as Talking Mats™, interviews, or questions before and after the program, may be important when evaluating an abuse prevention program.	Focus groups
Children's self-care can be evaluated by interviewing parents.	Scoping review
Children could be screened for abuse whilst teaching the abuse prevention program.	Focus groups

Note: This table shows part of the working process of integrating the data from Phase 1.1-1.3. Thus, formulations and categorisations may have been changed, condensed, or removed in the final guidelines which are presented in Section 5.5.

Appendix F: Code book Phase 3

Code	Description	Theme	Weight
Accessibility	The accessibility of the guidelines in terms of the readability and use of support such as pictures etc.	Design	25
Appropriateness for context	The applicability of the guidelines to the intended context (schools, teachers).	Applicability	23
Appropriateness for population	Appropriateness of the guidelines relating to children with communicative and/or cognitive disabilities and different levels of cognitive functioning and intellectual disability (e.g., mild, moderate, severe) of children with communicative and/or cognitive disabilities.	Applicability	41
Barriers to implementation	Perceived barriers to implementation of the guidelines.	Implementation	38
Clarity of language	Comments regarding the clarity of the content presented in the guidelines (e.g., difficult language, clear explanations of concepts and so on).	Content	21
Comprehensiveness	How comprehensive the information in the guidelines was perceived.	Design	14
Continued development	Suggestions for content changes or adding materials/methods to the guidelines.	Content	39
Facilitators to implementation	Perceived facilitators to implementation of the abuse prevention program.	Implementation	21
Goals and purpose	Perceived goals and purpose of the guidelines.	Content	23
Helpful strategies/usefulness	Suggestions and links that are included in the guidelines and are regarded as beneficial for the implementation of the guidelines.	Applicability	13
Importance	Perceived importance of the guidelines for the target population or stakeholders.	Value	47
Knowledge and awareness	Teachers, principals, other staff, and parents gaining an increased knowledge on the topic of abuse, disability and/or communication.	Implementation	20
Layout/visual presentation	Relating to the overall layout of the guidelines as well as the formatting of the guidelines (e.g., amount of text per page, use of columns etc).	Design	30
Link to research	The link between the research conducted in previous phases of the study and the guidelines.	Content	6
Management support	Support and responsibility of principals and school management, linked to the implementation of the guideline.	Implementation	37
Next steps	Methodological suggestions in terms of the next step in the evaluation process or further development of the guidelines.	Content	3
Other persons	Suggestion of other persons, other than teachers, principals, or student health care team members, could help in implementing the guidelines.	Implementation	6
Quality	Perceived overall quality of the guidelines.	Value	25
Recommendations for use	Comments regarding whether participants would recommend the guidelines for use.	Value	19
Resources	Resources (e.g., time, economic resources) needed to implement the guidelines.	Implementation	23

Code	Description	Theme	Weight
Rules, policies, regulations	School curriculum, syllabus, national school policies or other rules or regulations linking to the implementation of the guidelines.	Implementation	10
Student health care	Mentions of the student health care and their role in implementing the guidelines.	Implementation	26
Support/coaching	Support or coaching provided to teachers and principals responsible for implementing the guidelines.	Implementation	6
Translation	Translation of the guidelines to Swedish.	Content	5