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Sexual Violence Prevention Education for Individuals with Intellectual Disabilities: The Social Validity and Effect of Disability Impact on Parent Perception

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A thesis submitted to the faculty of
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ABSTRACT

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Children and adolescents with intellectual disabilities are sexually abused or assaulted at a rate seven times greater than those without disabilities (Shapiro, 2018). There is a lack of education and prevention programs specifically for this vulnerable population. The purpose of this study was to explore parental perceptions about the need for sexual violence prevention education, based on their child's disability type, severity, and communication level. A 33-item online survey was completed by parents of children with intellectual disabilities (n=61). The majority of parents valued the social validity of providing sexual violence prevention education. A child's disability type did not impact their parent's perception of the need for education. As the severity of a child's disability increased, parents indicated that their child was lacking adequate knowledge about sexual violence prevention. Children with lower levels of communication fluency did not understand sexual abuse and assault prevention. Common parental themes of fears about their child's involvement in sexual violence prevention education included their child's inability to understand or curriculum content and the manner in which education would be provided. Findings inform care providers about the importance of including all children with disabilities in sexual violence prevention education.

Keywords: sexual abuse, sexual assault, sexual violence, intellectual disabilities, prevention

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Description of Thesis Structure

Sexual Violence Prevention Education for Individuals with Intellectual Disabilities: The Social Validity and Effect of Disability Impact on Parent Perception is written in a hybrid format. The hybrid format combines university thesis requirements with modern journal publication configuration. Figures and tables are embedded within the journal-ready article. The literature review is included in Appendix A and the survey in this study is found in Appendix

Introduction

In October 2017, the social media hashtag "#MeToo" swept the United States and launched the Me Too movement, revealing how widespread sexual assault and abuse are in our communities, calling for immediate action to stop sexual violence from happening for good. The Me Too movement highlighted the prevalence of sexual violence and issues surrounding it and put this terrible crime in the necessary public spotlight (Zacharek, Dockterman, & Edwards, 2017).

The terms *sexual abuse* and *sexual assault* are often used interchangeably when they describe very different criminal acts. *Sexual abuse* usually describes unwanted sexual activity towards children and includes touching in a sexual manner or forcing a victim to touch the perpetrator in a sexual way (American Psychological Association [APA], 2019). According to the United States Department of Justice Office on Violence Against Women (2019), the term *sexual assault* means any nonconsensual sexual act prohibited by law, including when the victim lacks capacity to consent. Sexual assault is a criminal act and includes unwanted touching and kissing, rubbing, groping or forcing the victim to touch the perpetrator in sexual ways (United States Department of Justice Office on Violence Against Women, 2019). Both types are traumatic and harmful to the victim. Since the population of interest for this study is persons with intellectual disabilities age 21 and under that are serviced by the public-school system, the term *sexual violence* will be used since it captures both the child and adult population.

Child and adolescent populations are known to be vulnerable to sexual assault (Trotman, Young-Anderson & Deye, 2016). Female adolescents (aged 12 to 17) account for one in five sexual assault reports, and those aged 16 to19 are four times more likely than any other group to be a victim of sexual assault (Danielson & Holmes, 2004). One in four girls and one in six boys

will be sexually abused before they turn 18 years old (Finkelhor, Hotaling, Lewis, & Smith, 1990). The true incidence of sexual violence is unknown because between 50% (Trotman et al., 2016) to 63% (Rennison, 2002) of all sexual assault cases are not reported.

Nearly one in five people living in the world has a disability (Brault, 2012). The term *disability* includes a wide range of limitations from cognitive, sensory (vision and hearing), and mobility limitations (U.S. Department of Justice, 2011). Under the Individuals with Disabilities Education Act (IDEA) of 2004, an intellectual disability is defined as a "significantly subaverage general intellectual functioning, existing concurrently with deficits in adaptive behavior and manifested during the developmental period, that adversely affects a child's educational performance" (IDEA, 2004).

Children with disabilities are more likely to be victims of physical and sexual violence (Jones et al., 2012) than the rest of the population (U.S. Department of Justice, 2011). There is a wide variance of reported prevalent sexual violence rates, ranging from 14% within the population of individuals with disabilities (Balogh et al., 2001) to 61% for women and 25% for men (McCarthy & Thompson, 1997). Euser, Alink, Tharner, Ijzendoom, and Bakermans-Kranenburg, (2015) found that children with intellectual disabilities receiving out-of-home care had 9.8 sexual assault occurrences per 1000 children, which was significantly higher than neurotypical children in similar living situations.

There is a lack of current research about sexual violence in the adolescent population with intellectual disabilities. Lumley, Miltenberger, Long, Rapp, and Roberts (1998) found that 25% of adolescent females with intellectual disabilities had experienced some form of sexual assault, while Sobsey and Varnhagen (1998) found that 54% of sexual assault victims had

intellectual disabilities. Even though this literature is older, it highlights that sexual violence has been a long-standing issue in the child and adolescent populations with intellectual disabilities.

A large meta-analysis by Jones et al. (2012) identified a lack of well-designed research studies and poor standards of measurement of disability and violence. A recent report found that individuals with intellectual disabilities are sexually assaulted at a rate that is seven times higher than those who do not have disabilities (Shapiro, 2018). Again, this rate accounts only for reported sexual assaults and does not capture the true rate because not all sexual assault cases are reported (Trotman et al., 2016; Rennison, 2002).

Persons with intellectual disabilities usually have more exposure to persons responsible for their care (e.g., teachers, peer tutors, doctors, classroom aides). Most victims know their assailant and the perpetrators use force, make threats or take advantage of victims unable to give consent (APA, 2019; Greenfield, 1997). Researchers found that 50% of sexual abuse victims with intellectual disabilities were abused by a member of their family (Balogh et al., 2001).

While reducing sexual violence in the general population is a difficult issue, decreasing incidences among those with intellectual disabilities is more complex. This paper will focus only on one aspect of a reduction strategy: sexual violence prevention education. One reason that individuals with special needs are abused at higher rates than those without may be the fact that individuals with significant cognitive or intellectual disabilities generally have not been educated on important sex education topics, such as determining appropriate and inappropriate boundaries, identifying situations where they may be at higher risk, and defending themselves in the event of being victimized (Shapiro, 2018).

In addition to their child's lack of education, parents are often not aware of the higher risk that their child may be assaulted or abused. If they are aware, parents often do not take the

time to educate their child about what to do in a dangerous situation. Sex education and sexual violence prevention may be uncomfortable topics to discuss with children or adolescents, especially for parents of individuals with intellectual disabilities. A survey of (n=530) neurotypical male and female students found 59% of participants reported never had a meaningful discussion about sex with either of their parents with the most common Reasons cited being embarrassment and that "sex was an unacceptable topic to discuss in the home" (Smith, 2008).

Effective sex education is an important part of an individual's life and leads to healthy sexual development (Yildiz & Cavkaytar, 2016). A lack of proper sex education for individuals with special needs can lead to various inappropriate behaviors, (i.e., indecent exposure or public masturbation) exclusion from society, or vulnerability to sexual violence (Yildiz & Cavkaytar, 2016). Educating people with disabilities is an effective way to prevent sexual violence from happening (Miltenberger et al., 1999).

Sexual violence prevention programs are rarely empirically evaluated, making it difficult researchers to measure performance and generalization of a specific skill instead of mere knowledge acquisition. Lumley et al. (1998) found that in a group of six adult women with intellectual disabilities who were trained in sexual abuse prevention methods, each woman learned the skills and knowledge but were unable "to exhibit them to criterion during the probes (p. 91-101)." In addition to teaching prevention, it is also vital that sexual assault prevention advocates work together to ensure that their programs/the programs they teach are evidence based in order to meet the needs of those with disabilities (Barger, Wacker, Macy, & Parish, 2009). In order to develop an effective sexual violence prevention education curriculum, it is important to address the barriers and stigma surrounding sex education and effective abuse

prevention strategies and to look at the social validity of the program. social validity as a way to measure subjective experiences for recipients of behavior treatments. Montrose Wolf (1978) argued in a seminal paper on social validity that there are three levels needed in order to objectively measure a subjective behavior: (a) social significance of a goal (Is the goal a desired outcome?), (b) social appropriateness of a procedure (Is the treatment or procedure acceptable?), and (c) social importance of the effects (Is everyone satisfied with all outcomes?). All these questions comprise social validity and allow researchers to objectively measure behaviors or opportunities that may be otherwise difficult to measure (Wolf, 1978). The social validity of a sexual violence prevention curriculum is imperative because it shows whether or not a curriculum produces a desired outcome, is age and level appropriate for the students involved, and parents or other caregivers are satisfied with the curriculum and what is being taught.

Prevention of sexual violence for individuals with disabilities is a significant issue that needs to be understood and addressed on a larger scale. While there are many aspects of the problem, one of the first steps that needs to be addressed involves parental perceptions, fears, and barriers to having their child receive sexual violence prevention education. Involving parents in the learning process is critical in maximizing the effectiveness of a sexual violence prevention curriculum. Davis and Gidycz (2000) found that a child's age did not impact how much information they were able to learn when it came to an abuse prevention curriculum designed specifically for children with a typical development. They found that the most effective form of prevention education was through long-term, active programs, regardless of a child's age. Further, the best chance at helping decrease the number of victims of sexual violence within this population is to push sexual violence prevention education programs for individuals with special needs along with their families (Eastgate, VanDriel, Lennox, & Scheermeyer, 2011; Murphy &

O'Callaghan, 2004; Rape Crisis Network Ireland (RCNI), 2011) and to provide education programs targeting the general population regarding sexual violence and intellectual disability (Edwards, Harold, & Kilcommins, 2012; McGilloway, Smith, & Galvin, 2018; Suarez & Gadalla, 2010). The ultimate goal is to prevent the sexual victimization of those with intellectual disabilities.

Statement of the Problem

School-age children (under 21) with intellectual disabilities experience sexual violence at higher rates than the general population. Although the limited statistics in existence vary, all of them indicate that this population is more vulnerable to sexual violence than those without disabilities. A key component of prevention is providing education. Currently, there are many sex education curricula directed at children and young adults who are normal developmentally. However, resources and adapted educational material is lacking for those with special needs. An important factor in providing sexual violence prevention education is parental involvement. Little is known about how parents of children with intellectual disabilities perceive this the importance of sexual violence prevention education.

Statement of the Purpose

The purpose of this study was to explore variables that may impact a parent's perception of the need to provide their child with sexual violence prevention education based on their child's disability type, severity of disability, communication level, and risk factors that may increase the child's vulnerability. Additionally, it was important to identify parental fears and beliefs that could impact their support and willingness to have their child participate in sexual violence prevention education.

Research Questions

This study addressed the following:

1. What effect does a child's disability have on parent-rated social validity of the need for sexual violence prevention curriculum?
2. Does the severity of a child's communicative abilities impact parental perception of the need for sexual violence prevention curriculum?
3. Does the level of severity of a child's disability (mild, moderate, and severe) impact parental perception of the need for sexual violence prevention curriculum?
4. Does the type of a child's disability (Down syndrome, Autism, and other intellectual disabilities) and prevalence of risky behaviors impact parental perception of the need for sexual violence education?
5. What are the most common parental fears and beliefs about barriers in providing sexual violence prevention education?

Method

This study was approved by the Brigham Young University Institutional Board Review (IRB). Four local organizations in one western state in the United States for parents of children with special needs were contacted to request participation in an online Qualtrics survey. A representative from each organization volunteered to facilitate parent participation in the survey. The survey link was sent to parents via email or social media (e.g., Autism Council of Utah Facebook page).

Participants

Participants (n=79) were residents of the western state and parents of either a biological or adopted child with an intellectual disability under age 21. The majority of participants in the

survey were white (88.89%), female (88.61%), and identified their religious preference as Christians (82.25%). The mean age was 46.25 (SD=10.2). The participants were predominantly married or in a domestic partnership (84.62%) and had a higher socioeconomic status, $100,000+ household income (see table 1). According to an estimated update from the 2010 U.S. Census (United States Census Bureau, 2018) 50.7% of the U.S. population is female, and 76.6% is white. In the survey sample, there was a higher representation of female participants compared to the U.S. general population. Additionally, there was overrepresentation of Christian participants (82.25%) in the survey compared to the U.S. general (73.7%) population (Newport, 2016).

Table 1

Participant Demographics

Factor	Group	*N*	Percentage
Gender	Female	70	88.61%
	Male	7	8.86%
	Other	2	2.53%
Race	White	72	88.89%
	Asian	1	1.23%%
	Black or African American	0	0%
	Native American or Alaska Native	1	1.23%
	Native Hawaiian or other Pacific Islander	0	0%
	Latino or Hispanic American	5	6.17%
	Other	2	2.47%
Age	Year range born/Age range		
	1950 or earlier/69+	2	3%
	1951-1960/59-68	11	14%
	1961-1970/49-58	17	21%
	1971-1980/39-48	31	39%
	1981-1990/29-38	16	20%
	1991-2000/19-28	2	3%
Yearly Household Income	less than $20,000	6	7.59%
	$20,000-$34,999	3	3.80%
	$35,000-$49,999	6	7.59%
	$50,000-$74,999	17	21.52%
	$75,000-$99,999	13	16.46%
	$100,000+	34	43.04%
Religious Preference	Non-denominational Christian	7	8.86%
	Protestant Christian	1	1.27%
	Latter-Day Saint	60	75.95%
	Catholic	4	5.06%
	Atheist	1	1.27%
	Agnostic	1	1.27%
	None	4	5.06%
	Other	1	1.27%
Marital Status	Single (never married)	5	6.41%
	Married or domestic partnership	66	84.62%
	Widowed	0	0%
	Divorced	7	8.97%
	Separated	0	0%

Instruments

The research team developed the survey from outcome measures in the Prevent Child Abuse Utah sexual abuse prevention curriculum (Prevent Child Abuse Utah, 2016) and added demographic items. Each of the 33 items of the survey was reviewed by the research team. Survey questions were entered into a Qualtrics survey tool. The research team consisted of a university faculty member who is a Board-Certified Behavior Analyst, two licensed special education teachers of students with severe disabilities, and a graduate student whose research specialty is on preventing sexual abuse within the special needs population. After the survey tool was developed, each item was reviewed by a representative of a partner organization focusing on preventing child abuse and the requested changes were made.

Procedure

Four local parent organizations were contacted and a representative for each organization was identified to promote and facilitate survey participation through email or social media with direct links to the survey. The representative from each organization was vital in promoting the survey because he or she was already in a trusted position with the potential parent participants.

After opening the survey through the direct link, interested participants were asked to give consent before answering any questions and were notified that it would take approximately 20 to 30 minutes to complete. The first question in the survey asked parents to consent or not. If parents chose not to consent, the survey was finished and parents could exit out of the program. Participants had the option to skip questions if they did not wish to answer and could exit the survey at any time. Average survey completion time was 11 minutes. A total of 120 surveys were sent out. Seventy-nine surveys were started with n=61 fully completed.

Measures

The mixed method 33-item survey included the following quantitative measures: (a) demographics (parental and child), (b) child's current level of functioning, and (c) child sexual behaviors. Qualitative measures included open-ended questions regarding parental concerns about sex abuse prevention education, parental fears and perceived barriers, and their child's current extent of knowledge about sexual abuse prevention.

Social validity measures were addressed in the survey by questions about who and where abuse prevention should be taught and what the program outcomes should be.

Sexual Abuse Prevention Program

Currently, there are no evidence-based sexual abuse prevention curricula for either typically developing children or children with special needs. Prevent Child Abuse Utah's (PCAU) program was designed to be taught in public elementary schools to children with typical development and is delivered in a one-day 30-minute session. This pre-existing program, although not evidence based, was selected because of its age appropriate-curriculum's wide use in Utah elementary schools and acceptability in the public-school system. The research team felt that the six main objectives would be suitable for the special needs population.

The first objective is that students understand that everyone has a right to protect his or her body. This means that each individual is the "boss" of their body and that they are in charge of who or what touches them. The second objective addresses the concept that when someone hurts a child on purpose, it is not the child's fault. The fault is always on the perpetrator, not the victim. The third objective involves teaching a child about inappropriate behaviors that include physical (e.g., hurting another individual), emotional (e.g., bullying), and sexual abuse (e.g., inappropriate touch). Recognizing the difference between good and bad secrets is the fourth

objective and teaches children to be able to identify a bad secret (e.g., an adult is inappropriately touching a child). Teaching the child to tell the bad secret to an adult is an important outcome of this element. The fifth objective involves teaching three safety rules for protection: 1) Being able to identify a gut feeling that something is wrong; 2) Saying "no" and telling an adult; and 3) Identifying three safe adults a child can tell. The curriculum emphasizes the importance of having multiple people in the child's mind so that if a child is not believed or the perpetrator is one of the listed safe adults, the child has others that he or she can tell. See Table 2.

Table 2

Prevent Child Abuse Utah's Sexual Abuse Prevention Education Outcomes

1. Understand everyone has a right to protect his/her body
2. Realize that when someone hurts a child on purpose, it is not the child's fault
3. Describe appropriate versus inappropriate behaviors relative to:
    a. Physical abuse and emotional abuse
    b. Sexual abuse
4. Recognize differences between good and bad secrets
5. Learn the "Three Safety Rules" for protecting themselves
6. Specify three people they could tell if someone was hurting them and they needed help.

Research Design

This study utilized a mixed quantitative and qualitative survey research design. Independent variables included disability type (e.g., Down Syndrome, Autism and other Intellectual and Developmental Disabilities (IDD); severity of the disability (e.g., mild, moderate, severe); and communication level (e.g., nonverbal, one-two word phrases, simple sentences, and fluent). Dependent variables were parent perceptions of the need for sexual violence education.

Data Analysis

Qualtrics survey responses were transferred to the Statistical Package for Social Sciences (SPSS) for data analysis. Descriptive data were analyzed using means and percentages. All statistics, including Chi Square and *t*-test, were calculated using SPSS 25.

Three question items utilized a Likert scale to measure parents' perception and opinion on the importance of topics surrounding sex education (e.g., anatomy and physiology, pregnancy and reproduction) and the outcomes of a sex abuse prevention curriculum (i.e., PCAU's sexual abuse prevention education outcomes). Responses ranged on a scale from 1=not at all important to 5=very important.

Qualitative analysis was completed on four survey items where respondents were able to provide free response answers regarding parental fears and barriers about providing basic sexual functioning knowledge and sexual abuse prevention education. Open-ended responses were analyzed for prominent themes using a three-step content analysis process. (Neuendorf, 2002).

Results

Overall, 79 surveys were started by parent participants, with n=61 fully completed surveys. Results were analyzed to address each of the four research questions.

Social Validity

Participants were asked to rate their opinion about importance of the need for inclusion of six specific identified sexual violence prevention outcomes. Responses were broken into two groups based on the parent's report of their child's diagnosis: Down syndrome (n=40) and other IDD (n=14). Other diagnoses did not have a large enough sample size for analysis. None of the parents ranked any of the program elements lower than a four (1-5 Likert scale). See Table 3 for overall means of each element. Statistical analysis by *t*-test determined if the two types of

disability samples were statistically different from each other (the null hypothesis is true). Only two elements were statistically significant: resisting abusive situations and the difference between a good and a bad secret.

Table 3

Mean Ratings of Program Elements

Program Elements	Down Syndrome (n=40)	Other IDD (n=14)	Overall Mean	*t*-Test
Recognizing abusive situations	4.85	4.71	4.81	NS
Resisting abusive situations	4.90	5.00	4.93	0.04
Reporting abusive situations	4.97	5.00	4.98	NS
When an adult hurts a child, it is never the child's fault	4.88	4.93	4.89	NS
The difference between a good and bad secret	4.81	5.00	4.86	0.038
Appropriate vs. inappropriate sexual behaviors	4.88	4.86	4.87	NS

*NS=Not Significant

Communication Level

Each of the parent participants provided demographic information about their child's current communication level (nonverbal, one-to-two-word phrases, simple sentences, and speaking fluently). Each child's communication level was compared to parent's opinion as to whether the child had adequate knowledge about sexual violence prevention. Only six parents of communication-fluent children felt that their child had adequate knowledge. Additionally, 10 parents of communication-fluent children were unsure about the extent of their child's knowledge, while five parents felt that their child did not have any knowledge. Only one child who could speak in simple sentences had adequate knowledge while the remainder were unsure or felt that their child had no knowledge. For the majority of children communicating through one-to-two-word phrases, parents did not believe their child had adequate knowledge. Overall,

nonverbal children did not have any knowledge about sexual violence prevention (see Figure 1). In summary, the severity of the child's communication abilities impacted parental perception. As communication fluency of the child decreased, parental perception of the need for sexual violence prevention curriculum increased.

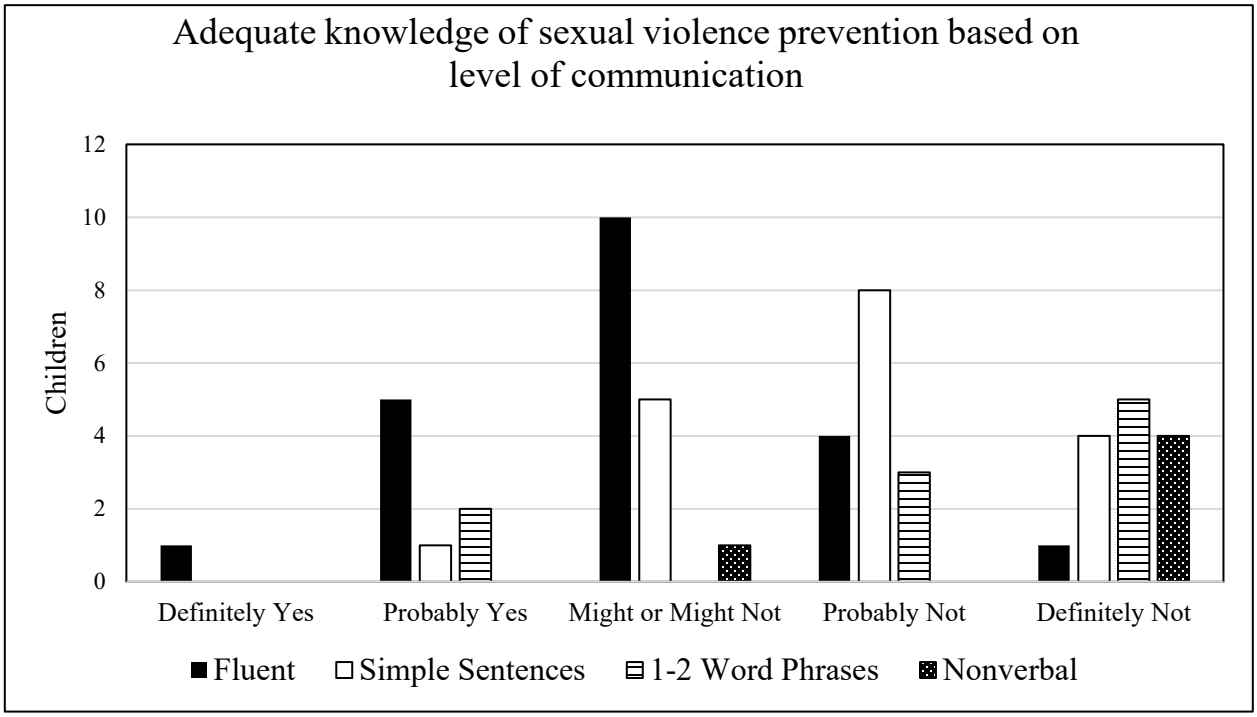

Figure 1. Adequate knowledge of sexual violence prevention based on level of communication.

Severity of Disability

Parents provided information about the severity of their child's disability (mild, moderate, severe) and their perception about the need for sexual violence prevention education for their child. Four parents of children with a mild intellectual disability felt that their child had adequate knowledge about sexual violence prevention while seven were unsure and four identified that their child did not have adequate knowledge (see Figure 2). A definite shift of inadequate knowledge was noticed for children with moderate and severe disabilities. The

child's level of disability severity impacts parental perception of the need for sexual abuse prevention education with moderate and severe populations having inadequate knowledge.

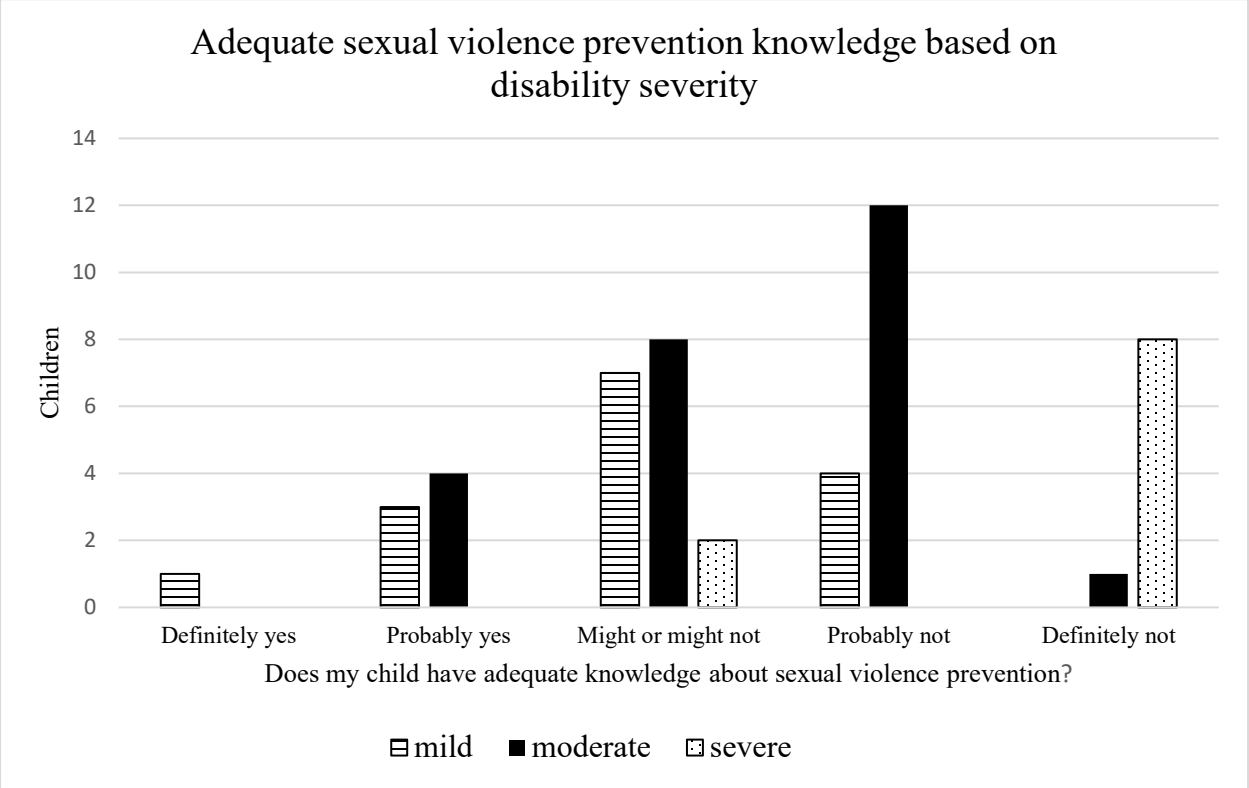

Figure 2. *Adequate sexual violence prevention knowledge based on disability severity*

Disability Type and Risk Behaviors

Parents reported information about their child's disability type. The majority of children had Down syndrome (75%) while the remaining 25% had other IDD, such as Autism and Angelman syndrome. Only six parents of children with Down syndrome felt that their child had adequate knowledge about sexual violence prevention, with the majority reporting they believed their child most likely did not. For parents of other IDD children, only two reported that their child possessed adequate knowledge, while the majority did not (see Figure 3).

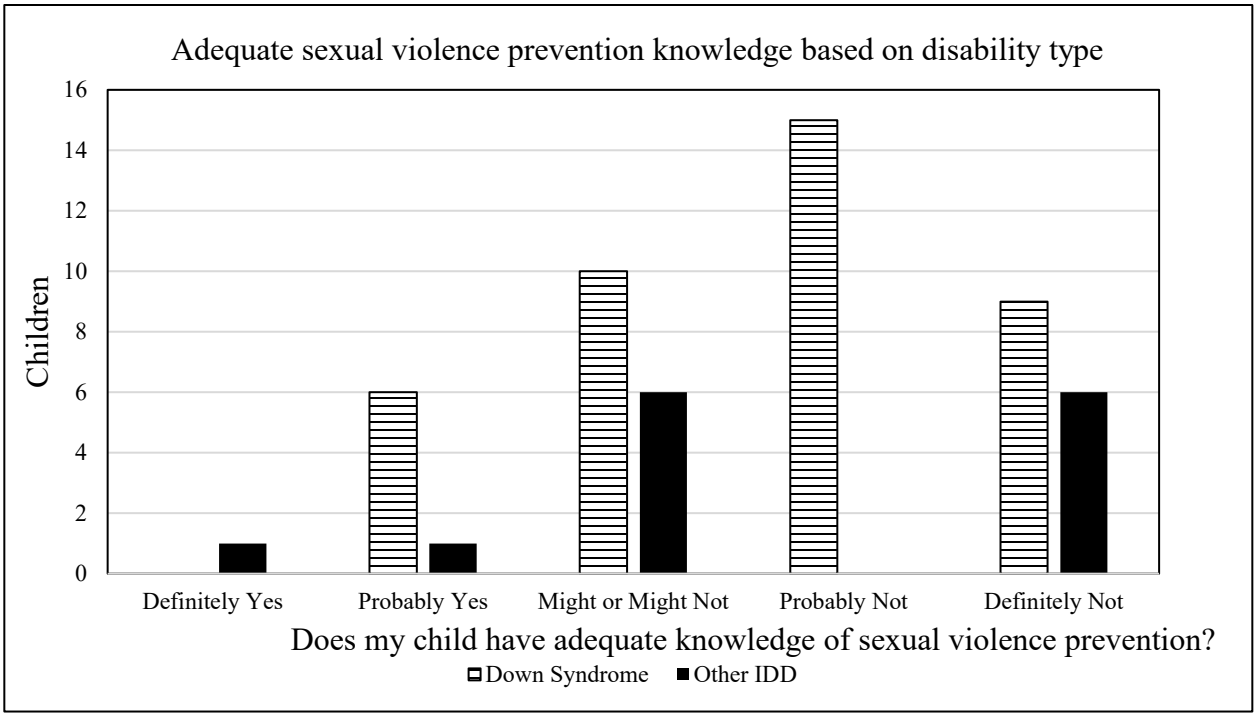

Figure 3. *Adequate sexual violence prevention knowledge based on disability type*

Not every parent who took the survey reported that their child exhibited sexual behaviors. However, 85% of parents reported that their child engaged in masturbation or other self-stimulatory behaviors. For example, parents reported "touching self," or "she puts her hands in her pants sometimes," or "he plays with his genitalia." Other reported behaviors included: inappropriately touching others and a child exposing himself (see Table 4).

Table 4

Sexual Behaviors Reported by Parents

Theme	*N*	Percentage
1. Masturbation/self-stimulatory behaviors	17	85%
2. Inappropriately touching others	2	1%
3. Exposing self	1	0.5%

Several survey questions addressed whether any children demonstrated behaviors that could put them at risk for sexual violence. Statistical analysis found no significance for each of the identified risk behaviors (see Table 5).

Table 5

Prevalence of Risk Behavior in Relation to Disability Type

Risk Behaviors	Down Syndrome	Other IDD	Total	Chi Square
Uninhibited around strangers	44.4%	35.7%	42.4%	NS
Fascination with children	15.6%	7.1%	13.6%	NS
Obsession with boyfriends/girlfriends	22.2%	0.0%	16.9%	NS
Excessive touching others	35.6%	28.6%	33.9%	NS
Excessive flirtation	2.2%	7.1%	3.4%	NS
Other risks	4.4%	14.3%	6.8%	NS

Parental Fears and Beliefs

For quantitative descriptive data, the frequency of each comment was counted along with a list of specific themes. Overall, parents were most concerned with their child's ability to understand or retain complex information (34%). Parents in the survey expressed concerns such as "Can they really understand when I explain what 'inappropriate touch' means?" or "I am afraid she will not be able to understand if she is experiencing sexual abuse." Another parent stated that she had a concern with "[her] child understanding what it is, how to prevent it, and how to report it."

Another theme that emerged was concern about the way sexual violence prevention would be taught (23%). A few parents expressed worry about the fact that it is not always taught in schools. One parent stated, "I personally have been trying to get this information taught in my

school district and the state of Utah as a whole, on a regular basis several times a year, for several years (5th grade to 22 years).” Another parent stated,

> “I am concerned that none of this is taught in the schools or in communities. I actually have a HUGE concern and personal experience with this. I teach my children, but I wish that it was taught and reinforced in the schools since that's where they spend the largest part of their day. My son is very trusting and very physically affectionate but does not have the verbal ability to explain to us if something were to happen--this is really hard for us as parents and we would love to know of any tips or programs that helps with this.”

A third theme that emerged was concern about a child’s well-being if he or she was taught about sexual violence prevention (16%). One worry was “not wanting to inhibit a child’s natural, loving tendency and replacing it with fear.” Some parents were concerned that sexual violence education would scare their children and negatively impact their well-being if not taught properly.

While the study revealed many common themes among parents’ concerns, it is also important to note that 14% of parents did not have any fears regarding sexual violence prevention education itself. Six percent of parents expressed concern that their child may not be able to communicate or participate in learning. Finally, parents (6%) were worried about their child’s ability to generalize new knowledge (see Table 6).

Table 6

Fear/Barrier Themes

Theme	*N*	Percentage
1. Ability to understand/retain information	15	34%
2. How it's taught/it's not taught at school	10	23%
3. Education will scare child/well-being at stake	7	16%
4. No fears/barriers	6	14%
5. Child can't participate/low communication levels	3	6%
6. Child can't generalize what is learned	3	6%

Discussion

Sexual violence can be detrimental to anyone but is especially worrisome among those with intellectual disabilities because of their higher risk rate. The purpose of this study was to address the extent to which parents perceive the need for sexual violence prevention education based on their child's disability type, severity, and communication level. Survey questions also addressed parental fears, beliefs, and barriers to receiving effective education surrounding their child's participation in a sexual violence prevention curriculum.

Every parent in this study rated abuse curriculum elements highly. There was no evidence that disability type had any impact on parents' perception of the need for their child to receive education on specific sexual violence prevention curriculum elements. Interestingly, resisting abusive situations and identifying the difference between good and bad secrets were statistically shown to be the most important curriculum elements to parents.

Results showed a correlation between communication fluency and parent perception on the need for sexual violence prevention education: as fluency decreased, parental perception of

the need for education increased in a linear manner. Parents appeared to recognize the importance of sexual violence prevention education for their limited-communication or nonverbal children.

Overall, as the severity of a child's disability increased to a moderate or severe classification, parental perception of the need for education amplified. This finding strengthens the argument that even the those with severe disabilities needs some type of sexual violence prevention education. Because no evidence-based sexual violence prevention curriculum developed specifically for individuals with moderate to severe intellectual disabilities has been identified, development of such a curriculum could be an area of future research. Furthermore, there remains a need for developmentally appropriate sexual violence prevention curriculum needs for those with mild intellectual disabilities.

There was no significant finding that a child's type of disability had any impact on parental perception. This finding should inform educators and parents that regardless of the disability type, each child needs to participate in sexual violence prevention education. In child specific-risk behaviors, there was no evidence to suggest that disability type or risk behaviors impacted parental perception of the need for education. Further, there was no association between a specific disability type and risky behaviors.

Parents expressed many different fears and concerns about their child receiving sexual violence prevention education. The majority of parents expressed worry about their child's ability to understand content and concepts regarding sexual violence prevention as well as the manner in which it is taught. Teaching a child about sexual violence prevention and sex education in general can be a difficult task for any parent, regardless of their child's ability. When developing a curriculum for sexual violence prevention, it is essential to elicit parental

participation and involvement in the process. This will best ensure that parents not only know what their child is being taught but will also allow them to reinforce the concepts taught in other settings such as in the home or community. It will also allow parents to feel more comfortable and maximize effectiveness in teaching their children. For individuals with special needs, generalization is extremely difficult and if they are able to practice sexual violence prevention skills frequently with a parent or other trusted adult, then they will most likely have a lesser chance of being victimized.

Limitations

A major limitation of this study was the small sample size, consisting mainly of white females who identified with a Christian faith, which is not representative of the U.S. population. Therefore, findings cannot be generalized to other populations. Because the participants were mainly mothers, the study does not account for the potentially differing viewpoints of fathers of children with intellectual disabilities regarding sexual violence prevention education.

Additionally, sampling was limited to parents who participated in support groups excluded those who are not involved in these types of organizations. Parents who were not involved in support groups could also have differing views. Additionally, this study focused only on parents of children with congenital intellectual disabilities, specifically Down syndrome and other IDD, and did not include those with physical disabilities or those suffering from a traumatic brain injury.

Implications for Future Research

Sexual violence prevention education is an important part of human development and safety, regardless of the presence of a disability. Results indicated that most parents of individuals with special needs believe that an abuse prevention curriculum is important, but they

may have concerns about the manner in which it is taught and who would teach it. Future research might consist of a longitudinal study exploring the long-term effects of a sexual violence curriculum for individuals with intellectual disabilities and analyze program effectiveness in reducing incidences of sexual violence. Further research might include studying social and emotional differences between disability types. For example, individuals with Down syndrome are typically perceived as being more socially adept than those with Autism (Fisher, Moskowitz, & Hodapp, 2013), and this could potentially have an effect on vulnerability. Further research could also study if there is a correlation between a child's age and the type of prevention education a parent would want their child to have (e.g., specific content taught, where it is taught, etc.) These implications for future research may inform policy and practice.

Implications for Practitioners

Findings from this study reinforced the importance of sex education and sexual violence prevention to help individuals achieve optimal sexual health, wellness, and safety. Sexual violence prevention education should be administered in a way that best suits the needs of each individual. For example, while individuals with severe disabilities that may have limited communication abilities should still be educated on this topic, it may also be important to educate the caregivers and adults in that individual's life. Added training will allow the individual with a severe disability to have extra protection and safeguards in place to prevent sexual violence (Barger et al., 2009). For individuals who have higher levels of functioning and communication, it is also important not only to train caregivers and adults but to emphasize generalization and practice of the skills taught (Miltenberger et al., 1999). Because individuals with intellectual disabilities are an identified vulnerable population for sexual violence, it is vital

that practitioners take extra measures to accurately and effectively educate people with disabilities and their parents about sexual violence prevention in a safe learning environment.

Conclusion

The purpose of this study was to address the extent to which parents perceive the need for sexual violence prevention education as based on their child's disability type, severity, and communication level. The literature highlights the complexity of preventing sexual violence against people with intellectual disabilities. Because parents are the main caregivers of these individuals, it is vital that parents' fears and beliefs are addressed with any sexual violence prevention program.

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APPENDIX A

Literature Review

In 1978, psychologist Montrose Wolf wrote a seminal paper arguing for the use of social validity as a way to measure subjective experiences for recipients of behavior treatments. Wolf (1978) argued that three levels of social validity are needed in order to objectively measure a subjective behavior: (a) social significance of a goal (Is the goal a desired outcome?), (b) social appropriateness of a procedure (Is the treatment or procedure acceptable?), and (c) social importance of the effects (Is everyone satisfied with all outcomes?). All these questions comprise social validity and allow researchers to objectively measure behaviors or opportunities that may be otherwise difficult to measure (Wolf, 1978).

Children with disabilities are more likely to be victims of physical and sexual violence (Jones et al., 2012) than the rest of the population (U.S. Department of Justice, 2011). There is a wide variance of reported prevalent sexual violence rates, ranging from 14% within the population of individuals with disabilities (Balogh et al., 2001) to 61% for women and 25% for men (McCarthy & Thompson, 1997). Euser, Alink, Tharner, Ijzendoom, and Bakermans-Kranenburg (2015) found that children with intellectual disabilities receiving out-of-home care had 9.8 sexual assault occurrences per 1000 children, which was significantly higher than neurotypical children in similar living situations.

In the adolescent individuals with intellectual disabilities population, Lumley, Miltenberger, Long, Rapp, and Roberts (1998) found that 25% of adolescent females with intellectual disabilities had experienced some form of sexual assault, while Sobsey et al. (1998) found that 54% of sexual assault victims had intellectual disabilities. Even though this literature is dated, it highlights the fact that sexual violence has been a long-standing issue in the child and

adolescent populations with intellectual disabilities and the current data shows that it still is to this day.

Jones et al. (2012) identified a lack of well-designed research studies and poor standards of measurement of disability and violence. A recent report found that individuals with intellectual disabilities are sexually assaulted at a rate that is seven times higher than those who do not have disabilities (Shapiro, 2018). Again, this rate accounts only for reported sexual assaults and does not capture the true rate because not all sexual assault cases are reported, especially with individuals who have low verbal communication skills or are nonverbal altogether (Trotman, Young-Anderson & Deye, 2016; Rennison, 2002).

Davis, Kolinsky, and Sugawara (1986) evaluated the extent to which training parents on sex education changed a mother's perception on talking about sex with her neurotypical child/children. Researchers found mothers who were given proper training on giving sex education to their children felt that they were able to introduce topics surrounding sex to their children at a younger age, give accurate and factual answers to sex-related questions, and were less likely to reprimand sexual actions or language (Davis et al., 1986). While this study dealt with mothers of typically developing children, it demonstrates that education can create a safe place for families to discuss topics surrounding sex. Having education and open discussions are essential for any individual, but especially for those with intellectual disabilities because such spaces allow them to comfortably discuss, learn about, and report sexual abuse or assault (Smith, 2008).

A difficult part of sexual violence prevention education is the need for basic sex education. There is a negative stigma around providing sex education for children and adolescents, especially those with intellectual disabilities. The basis for this stigma "stems from

negative messages concerning sexual health outcomes that have been in use in the U.S. for more than 100 years" (Ford, Barnes, Rompalo, & Hook, 2013, p. 97). Negative stigma surrounding sex education also stems from "other negative, fear-based messages regarding sexual health" (Ford et al., 2013). According to the widely accepted *National Prevention Strategy: Healthy People 2020* United States Department of Health and Human Services, (2019), proper sex *education* allows people to have the greatest chance at achieving sexual health and helps foster an open environment, especially in a medical setting, for people to discuss and receive accurate information about sex, and creates a safe space for people to report about issues that can potentially arise, including abuse and assault (U.S. Department of Health and Human Services, 2019)

Self-Determination Theory

Self-determination Theory is a theory of motivation that states if an individual has three basic needs met: (a) relatedness, (b) competence, and (c) autonomy, then that individual will have self motivation, a strong ability to make decisions on their own, and will generally be able to thrive as a whole. A central focus of self-determination theory is that human nature has positive qualities that benefit personal growth and intrinsic motivation. When relatedness, competence, and autonomy are met, then the ability for personal growth is enhanced. Relatedness is sense of belonging and connecting to others and feeling that you matter to someone else and is optimized by helping others and feeling that you can offer something to another individual. Competence is essential to wellness and involves having a sense of mastery in the things that matter most to an individual. Being able to feel competent boosts self-esteem and gives an individual a feeling of purpose. Finally, autonomy is a behavior that is self-endorsed. Autonomy allows a person to make their own choices and to feel proud of

their accomplishments. This helps to create connectedness with others and within the individual (Van Lange, Kruglanski, & Higgins, 2011).

People with a strong sense of self-determination can also be referred to as a "causal agent", implying that "the person is an actor in his or her own life, instead being acted upon" (Wehmeyer, 1998). For individuals with special needs, a necessity for self-determination exists because it empowers this population to independently make choices and see their self-worth. In regards to sexual violence prevention, having a self-deterministic perspective helps them to see that they have a right to consent or say no, to understand that their bodies develop just as individuals without disabilities do, and that they possess the fundamental human right to protect their body from harm (Walsh & Foshee, 1998).

Barriers

In order to understand the complexity of this issue, it is important to understand existing barriers that individuals with disabilities face when dealing with sexual violence. A systematic literature review about the barriers faced by individuals with disabilities who had been sexually assaulted or abused found three main themes (interpersonal, professional and social context) with eight domains: (a) fear, (b) communication, (c) sexual knowledge and understanding, (d) intellectual disability identification, (e) lack of collaboration between service providers, (f) presumption of capacity/credibility, (g) lack of resources, and (h) myths and misconceptions (McGilloway, Smith, & Galvin, 2018).

Interpersonal context. McGilloway et al. (2018) identified three interpersonal barriers: (a) fear, (b) communication, and (c) sexual knowledge and understanding. Fear is a significant barrier to sexual violence prevention and was primarily dependent on four factors: repercussions from the perpetrator, not being believed, being blamed for the attack, and how disclosure would

impact the rest of the victim's life (McGilloway, et al., 2018). Another factor, communication is a significant barrier because some individuals with disabilities are not able to verbalize their thoughts or emotions. For those that are able to communicate, being interrupted by a supportive adult when reporting caused frustration and may have led to a misunderstanding of the incident (McGilloway et al., 2018). Communication barriers also include power imbalances where a staff member might be able to verbalize their side of a story while the victim might not have the ability to do so (McGilloway et al., 2018).

Finally, direct knowledge regarding sex was also found to be a common barrier to reporting sexual assault (McGilloway et al., 2018) because victims did not know how to explain what happened. It is a tragedy when a victim with an intellectual disability finds out about sex because they were raped (Eastgate, VanDriel, Lennox, & Scheermeyer, 2011). Other studies have shown that a lack of knowledge about sex made individuals with disabilities feel more vulnerable because they did not know how to protect themselves or understand the intentions of others (Eastgate et al., 2011; Hickson, Khemka, Golden, & Chatzistyli, 2013; Hughes et al., 2011; Parley, 2011; RCNI, 2011)

Professional context. Individuals with disabilities usually have several professionals involved in providing their care. McGilloway et al. (2018) identified four professional themes: intellectual disability identification, lack of collaboration between service providers, presumption of capacity or credibility, and lack of resources. Because professionals are often not trained to identify an individual with a disability, this can be a barrier for the individual reporting sexual assault. Professionals may fail to provide special attention to those who may need it (McGilloway et al., 2018). A dissatisfaction with professional services following disclosure directly correlates to professional lack of training because without training, service providers

do not really know how to respond after an individual with a disability discloses an assault (RCNI, 2011).

In addition to training deficiencies, there is an absence of collaboration between service providers (McGilloway et al., 2018). A sexual assault nurse examiner said, “I have no idea where I would send a developmentally disabled client” (Gorden, 2013). Law enforcement agencies reported difficulty receiving support or guidance from outside agencies in handling situations in which an individual with a disability is sexually assaulted by another individual with a disability (Keilty & Connelly, 2001).

Individuals with a disability often have their credibility questioned or are unable to verbalize when reporting a sexual violence incident (McGilloway et al., 2018). According to Dr. Claire Edwards, a disability rights professor in the United Kingdom, “the judicial system is a barrier of itself … you have to be literate; you have to have capacity, you have to be able to prove beyond all reasonable doubt. It's not a system built for people who are vulnerable” ((Edwards, Harold, & Kilcommins, 2012, p. 98). Sadly, the court process is too traumatic for the already traumatized person, which creates another barrier layer to reporting (Keilty & Connelly, 2001).

With the lack of support and resources acting as barriers to reporting abuse or assault, law enforcement has insufficient time to assist individuals with special needs exists (McGilloway, et al., 2018). Law enforcement finds it difficult to keep track of available resources to support victims of sexual assault because “the resources come and go… we'll get comfortable with one, and it disappears on us. And it was doing good, and all of a sudden, bam, it's gone” (Hughes et al., 2011). Additionally, there exists a strong perception that because sexual assault cases involving an individual with a disability will not go to court, there is no need to “waste” valuable

resources (Hughes et al., 2011). These professional barriers further complicate the ability for a victim of sexual violence to report to law enforcement and to be treated appropriately and fairly compared to those without a disability.

Social context. There are many myths and social misconceptions about individuals with special needs, resulting in victim blaming with feelings of shame, perpetrator forgiveness, and justification of an assault (Edwards et al., 2012; McGilloway et al., 2018). One interviewee summed up the social barriers: "We are all human beings, we all have feelings with the lowest or highest IQs and just because of these learning disabilities doesn't mean they are completely alien or live on planet Mars" (Coles & Scior, 2012). Having a preconceived misconception about a person, particularly someone with a disability, can destroy their credibility, dignity, which can create a significant barrier when it comes to reporting and responding to sexual violence allegations.

Davis and Gidycz (2000) found that a child's age did not impact how much information they were able to learn when it came to an abuse prevention curriculum designed specifically for children with a typical development. However, they did find that the most effective form of prevention education would be through long-term, active programs, regardless of a child's age. Further, the best chance we have at combating service disparity with this vulnerable population is to push sexual violence prevention education programs for individuals with special needs and their families (Eastgate et al., 2011; Murphy et al., 2004; RCNI, 2011) and to provide education programs targeting the general population regarding sexual violence and intellectual disability (Edwards et al., 2012; McGilloway et al., 2018; Suarez & Gadalla, 2010).

Education has been found to be the most effective tool in prevention of sexual violence and drastic measures need to be taken in order to ensure that every child, regardless of ability or

disability, is able to participate. Along with education, parental involvement will help maximize effectiveness of a curriculum taught because parents can reinforce learning at home and in other situations. Prevention of sexual violence is a complicated issue and still impacts those with disabilities. This is a significant issue that needs to be understood and addressed on a larger scale.

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APPENDIX B

Parent Perception Survey Questionnaire

Q1 You are invited to take a survey regarding sexual abuse prevention among children and adolescents with intellectual and developmental disabilities.
Participation is voluntary as some of the questions may be sensitive in nature. All information will be kept confidential.

Thank you for your time.

- ○ I consent, take me to the survey (1)
- ○ I do not wish to participate (2)

Skip To: End of Survey If You are invited to take a survey regarding sexual abuse prevention among children and adolescents... = I do not wish to participate

Q2 Are you male or female?

- ○ Male (1)
- ○ Female (2)
- ○ Other (please specify) (3) _____

Q3 What year were you born?

▼ 1950 or earlier (1) ... 1995 (46)

Q4 What race do you consider yourself to be? Select one or more of the following:

- ☐ Asian (1)
- ☐ Black or African American (2)
- ☐ White (3)
- ☐ Native American or Alaska Native (4)
- ☐ Native Hawaiian or other Pacific Islander (5)
- ☐ Latino or Hispanic American (6)
- ☐ Other (7)

Q5 What is your household income?

- ○ Less than $20,000 (1)
- ○ $20,000 to $34,999 (2)
- ○ $35,000 to $49,999 (3)
- ○ $50,000 to $74,999 (4)
- ○ $75,000 to $99,999 (5)
- ○ $100,000 or higher (6)

Q6 What is your religious preference?

- ○ Non-denominational Christian (1)
- ○ Protestant Christian (2)
- ○ Latter-Day Saint (3)
- ○ Catholic (4)
- ○ Jehovah's Witness (5)
- ○ Atheist (6)
- ○ Agnostic (7)
- ○ Jewish (8)
- ○ Muslim (9)
- ○ Hindu (10)
- ○ Buddhist (11)
- ○ None (12)
- ○ Other (please specify) (13) _____

Q7 What is your marital status?

- ○ Single (never married) (1)
- ○ Married, or in a domestic partnership (2)
- ○ Widowed (3)
- ○ Divorced (4)
- ○ Separated (5)

Q8 What is your preferred sexual orientation?

- ○ Straight (1)
- ○ Gay (2)
- ○ Lesbian (3)
- ○ Bisexual (4)
- ○ Other (please specify) (5) _____

Q9 How many children with disabilities do you have between the ages of 7-17 whom you would like to consider participating in this study?

- ○ 1 (1)
- ○ 2 (2)

Q10 What is your relationship to the child?

- ○ Mother (1)
- ○ Father (2)
- ○ Other (please specify) (8) _____

Q11 How old is your child?

_____

Q12 What is the nature of your child's disability?

- [ ] Autism (1)
- [ ] Down syndrome (4)
- [ ] Intellectual disability (2)
- [ ] Other (please explain) (3) _____

Q13 What is your child's IQ score (if known)?

- ○ 0-40 (1)
- ○ 40-70 (2)
- ○ 70-85 (3)
- ○ 85+ (4)
- ○ Unknown (5)

Q14 What is the severity of your child's disability?

- ○ Mild (1)
- ○ Moderate (2)
- ○ Severe (3)

Q15 What is the level of your child's communication?

- ○ My child does not communicate verbally (1)
- ○ 1-2 word phrases (2)
- ○ Simple sentences (4)
- ○ Speaks fluently (5)

Q16 Does your child engage in any sexual problem behaviors? (e.g., excessive pornography use, inappropriate touching of self or others, paraphilia's etc.)

- ○ Yes (if yes, description optional) (1) _____
- ○ No (2)

Q17 Who should be teaching sex education? (select all that apply)

- ☐ Home (1)
- ☐ School (2)
- ☐ Other (please specify) (3) _____

Q18 Who should be teaching sexual abuse prevention? (select all that apply)

- ☐ Home (1)
- ☐ School (2)
- ☐ Other (please specify) (3) _____

Q19 Does your child engage in any of the following high risk behaviors? (select all that apply)

- ☐ Uninhibited around strangers (1)
- ☐ Fascination with children (2)
- ☐ Obsession with boyfriends/girlfriends (3)
- ☐ Excessive physical touch (hugging/hand holding, etc.) (4)
- ☐ Excessive flirtatious behavior (5)
- ☐ Other (please specify) (6) _____

Q20 Should sexual abuse prevention be taught as a component of sex education?

- ○ Yes (1)

- ○ No (2)

Q21 When should children begin to learn sex education?

- ○ Pre-school (5)
- ○ Elementary School (1)
- ○ Junior High School (2)
- ○ High School (3)
- ○ Never (4)

Q22 When should children begin to learn sexual abuse prevention?

- ○ Pre-school (5)
- ○ Elementary School (1)
- ○ Junior High School (2)
- ○ High School (3)
- ○ Never (4)

Q23 Has your child ever had sex education or sexual abuse prevention training? (select all that apply)

- ☐ Sex education taught in the home (1)
- ☐ Sex education taught at school (2)
- ☐ Sexual abuse prevention at home (3)
- ☐ Sexual abuse prevention at school (4)

Q24 How important do you believe it is for your child to know the following elements?

	Not at all important (1)	Slightly important (2)	Moderately important (3)	Important (4)	Extremely important (5)
Anatomy and Physiology (1)	☐	☐	☐	☐	☐
Puberty and Adolescent Development (2)	☐	☐	☐	☐	☐
Healthy Relationships (3)	☐	☐	☐	☐	☐
Identity (sexual orientation, behavior, and identity) (4)	☐	☐	☐	☐	☐
Personal Safety (5)	☐	☐	☐	☐	☐
Pregnancy and Reproduction (6)	☐	☐	☐	☐	☐
Sexually Transmitted Diseases (7)	☐	☐	☐	☐	☐

Q25 What fears/barriers do you have regarding sex education?

Q26 What fears/barriers do you have regarding sexual abuse prevention?

Q27 Please explain the extent of your child's knowledge of sexuality below

Q28 Please explain the extent of your child's knowledge of sexual abuse prevention below

Q29 Do you believe your child has adequate knowledge regarding sexuality?

- ○ Definitely yes (1)
- ○ Probably yes (2)
- ○ Might or might not (3)
- ○ Probably not (4)
- ○ Definitely not (5)

Q30 Do you believe your child has adequate knowledge regarding sexual abuse prevention?

- ○ Definitely yes (1)
- ○ Probably yes (2)
- ○ Might or might not (3)
- ○ Probably not (4)
- ○ Definitely not (5)

Q31 How important do you believe it is for your child to know the following elements?

	Not at all important (1)	Slightly important (2)	Moderately important (3)	Important (4)	Very important (5)
Recognizing abusive situations (1)	☐	☐	☐	☐	☐
Resisting abusive situations (2)	☐	☐	☐	☐	☐
Reporting abusive situations (3)	☐	☐	☐	☐	☐
When an adult hurts a child, it is never the child's fault (4)	☐	☐	☐	☐	☐
The difference between a good and bad secret (5)	☐	☐	☐	☐	☐
Appropriate vs. Inappropriate sexual behaviors (6)	☐	☐	☐	☐	☐

Q32 Would you be interested in having your child participate in a 3 session sexual abuse prevention program? (If yes, we will we will contact you with more information. Participation is not mandatory.)

○ Yes (1)

○ No (2)

Q33 If you answered "yes" to the previous question, please provide your contact information:

☐ Name: (1) _____

☐ Phone number: (2) _____

☐ Email: (3) _____