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The Life Experiences of Women with an Intellectual Disability who were Sexually Assaulted

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THE LIFE EXPERIENCES OF WOMEN WITH AN INTELLECTUAL DISABILITY WHO WERE SEXUALLY ASSAULTED

by

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ABSTRACT

The views of those with an intellectual disability (ID) on sexuality is not a topic many are willing to broach. Many challenges exist for those identified with ID when it comes to sexual education, including a lack of appropriate curricula; a lack of trained school personnel; the inability of school, state, and national stakeholders to agree on policy or curriculum content; and the generalizability of the content. These challenges are heightened by an increase in sexual assault of women with ID. To improve sexual assault prevention skills, the researcher conducted a phenomenological study to identify the current status of sexual assault and sexual education, specifically for women with ID. Semi-structured interviews occurred with seven women with ID who were sexually assaulted. The outcome of this dissertation research provides information, derived from these women, as ways to better educate females with ID in relation to sexual education and sexual assault prevention.

This dissertation is dedicated to my mom, Delores Schreffler, who raised me to be the strong, independent woman I have become, has shown me what a true fighter looks like, and inspires me to be better every day. Thank you for always supporting me. I love you and could have never done this without you.

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While I am only one person, I truly believe that great movements begin with a single action. This dissertation will hopefully be that single action to begin a movement to help increase the sexual education and decrease the sexual assault of people with disabilities. Everything I do is to increase awareness and hopefully make the world a safer place.

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CHAPTER ONE: INTRODUCTION

Prologue

Imagine, if you can, a nine-year old girl. You might picture a little girl with pigtails in her hair. You might see a girl going to a friend's house to watch the latest YouTube video. You might picture a girl that does not have any worries in the world. That is the picture society should have of any young girl. Would the picture change if she had an intellectual disability (ID)? Probably not. The same girl is in fourth grade, but instead of living the care-free life she should be, she is worried and confused and hurt because things are happening at home she does not understand. Last night, her mother had to go pick up her father, and she was left in the care of her grandpa. While trying to wait for her parents to get home, she falls asleep in her father's chair. The next thing she knows, her grandfather is waking her. She is confused because her grandfather is showing her his butt and penis. She thinks, "Why is this happening?" He then takes her to the bedroom and proceeds to have sex with her. "I kept on saying yes. And then I said no. I couldn't make up my mind."

This experience is, and should be, uncharted territory for a nine-year old girl. She does not tell her parents about the event. The next day a girl in art class says they had seen her and her grandpa having sex. She denies it. The other girl tells the classroom teacher. She then has to talk to the school counselor. The next thing she knows, it is the very end of the day, and she has to go to the conference room and talk to the police. They take her shorts for evidence.

The Department of Children and Family Services is called. Again, the girl has to tell the story. She finds out that the grandfather did the same thing to her sister. They have to move from their house, but her father gets sick, so they move into their uncle's house until they can find a new place to live.

The move to a new place should be the end of the story, right? The grandfather should have been arrested, and the girl should have been able to focus on recovery. Unfortunately, that did not happen. The grandfather was never arrested for the sexual assault. He continued to assault the girl. She also was sexually assaulted by her cousin and another man in the trailer park until she was 17-years-old. None of the men were arrested for sexual assault.

All the girl can think about is how she wished she had a phone to record when her grandfather started the assault. She felt like no one believed her. She thinks if she had the phone, maybe the other attacks would not have happened. Maybe someone would have believed her. She eventually begins counseling to start her path towards recovery. The girl is 18-years-old now and on track to graduate from high school in May. But, how does someone recover from something so horrific, sustained, and that started at such a young age? Was there anything that could have been done to prevent the assault?

Introduction

Sexual assault of persons with an ID is an epidemic in the United States. Women with ID statistically have a 50-90% chance of sexual assault at some point in their lives depending on the data source (Keilty & Connelly, 2001; Stevens, 2012). Researchers in prior studies have examined the consequences of sexual assault on persons with ID (Antaki, Richardson, Stokoe, & Willott, 2015b; Baladerian, 1991; Balogh et al., 2001; Brown, Stein, & Turk, 1995; Hickson, Khemka, Golden, & Chatzistyli, 2008; Keilty & Connelly, 2001; Nixon, Thomas, Daffern, & Ogloff, 2017); however, research on preventative measures against assault are lacking. Current Federal policies, as noted by Elia and Eliason (2010); Kohler, Manhart, and Lafferty (2008); Pittman and Gahungu (2006); Santelli et al. (2006); and Stanger-Hall and Hall (2011) focus on

"abstinence only" as the core of sex education for students in the U.S., which some researchers believe has led to a general lack of knowledge about issues related to sexuality, including protective strategies (Bridges & Alford, 2010).

As a result, students, and even adults, have had to compensate by learning about sex and sexuality from a variety of other sources in their communities (Gougeon, 2009). These alternative sources, such as peers, social media, and lived experiences, rarely focus on sexual assault or sexual assault prevention (Gougeon, 2009). While this gap in the curriculum is a problem for everyone in the U.S. (Stanger-Hall & Hall, 2011), this lack of assault prevention education is especially dangerous for persons with ID who are at much greater risk for assault compared to the general population (Blanchett & Wolfe, 2002). This gap in both sexual education curriculum and preventative strategies for sexual assault are at the core of the problem addressed in this study. The researcher conducted a phenomenology study to identify, learn about, and make recommendations for both sex education and sexual assault programs for students with ID, with a specific focus on the unique needs of females.

The researcher interviewed women with ID who have been sexually assaulted. Through the phenomenology, the researcher learned of the participants' past sexual education and coded themes about the sexual assault and supports received by the participants. The researcher presents themes across the participants and concludes the study with recommendations for proactive sexual assault education for females with ID.

Statement of the Problem

Worldwide, people with ID have a higher rate of sexual assault than their non-disabled peers (Stevens, 2012). According to Keilty and Connelly (2001), 75% of men and 90% of

women with ID are sexually assaulted at some point in their lives. Even though people with ID are more likely to be sexually assaulted in their lifetimes, research is currently lacking in the area of sexual assault prevention for people with ID (Doughty & Kane, 2010). Cases of sexual assault have emerged as a major social concern with the deinstitutionalization of persons with ID in the 1970's (Balogh et al., 2001).

For many in the general population, sexuality is defined by what teachers, parents, and spiritual leaders say (Cuskelly & Bryde, 2004). Students with ID are no different. These beliefs are further influenced by this population's caregiver ideas if they reside in a residential or group home facility. The views of those with ID on sexuality and abuse is not a topic clearly identified in the literature and may be one researchers are afraid to broach with this population due to a lack of ease for students with ID in acquiring and adapting new knowledge or even understanding complex concepts (Schwartz & Robertson, 2018). Northway et al. (2013) noted those with ID are a vulnerable population and abuse is a sensitive subject because "A failure to enable the voices of people with ID to be heard about issues such as abuse can also become a further form of oppression and abuse" (Northway et al., 2013, p. 363).

The potential outcomes of this research study could provide foundational research to expand the curricula, especially for females with ID, while understanding preventative strategies to support females with ID "to protect themselves from abuse and, if they are abused, to provide them with appropriate support" (Northway et al., 2013, p. 363). Sexual assault of persons with ID not only has an effect on the individuals assaulted, but also a "substantial physical, mental, emotional, and social cost" on the community (Stevens, 2012, p. 169). By analyzing what has happened to women with ID who were sexually assaulted, this study could shed light on the sexual assault prevention needs of those with ID.

Theoretical Framework

The theoretical framework used to guide the analysis of this study is The Socio-Ecological Model (*SEM).* First developed as the ecological model by Bronfenbrenner (1979) and then molded by McLeroy, Bibeau, Steckler, and Glanz (1988) to fit health promotion programs, the *SEM* is used by the World Health Organization (WHO) and the Centers for Disease Control and Prevention (CDC) (Krug & Dahlberg, 2006) as a framework for the prevention of abuse and violence. The theory of an ecological model is to examine the relationship between a person and their environment. A typology of violence created in 1996 divided violence into three categories: self-directed violence (suicide and self-abuse), interpersonal violence (family and intimate partner violence), and collective violence (between unrelated individuals). Furthermore, the typology of violence breaks down the type of violent act: physical, sexual, psychological, and involving deprivation or neglect (see Figure 1).

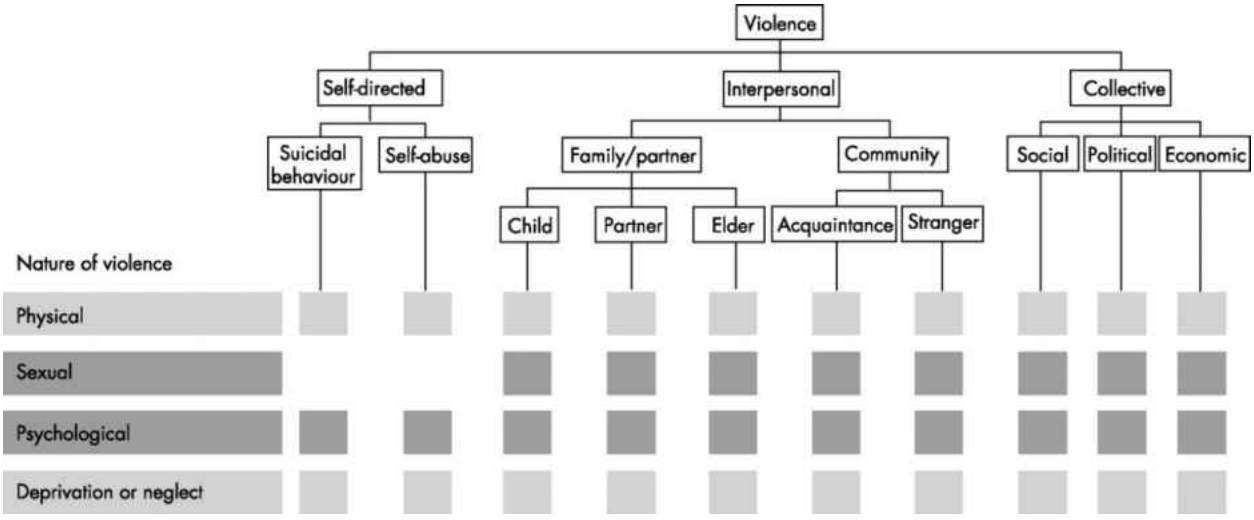


Figure 1 Typology of violence (Krug & Dahlberg, 2006)

Though the researcher will focus only on sexual assault, the *SEM* addresses all four types of violence. Bronfenbrenner (1979), McLeroy et al. (1988) along with Krug and Dahlberg (2006)

all note various levels of a person's life influences his or her behavior and exposure to violence (see Figure 2).

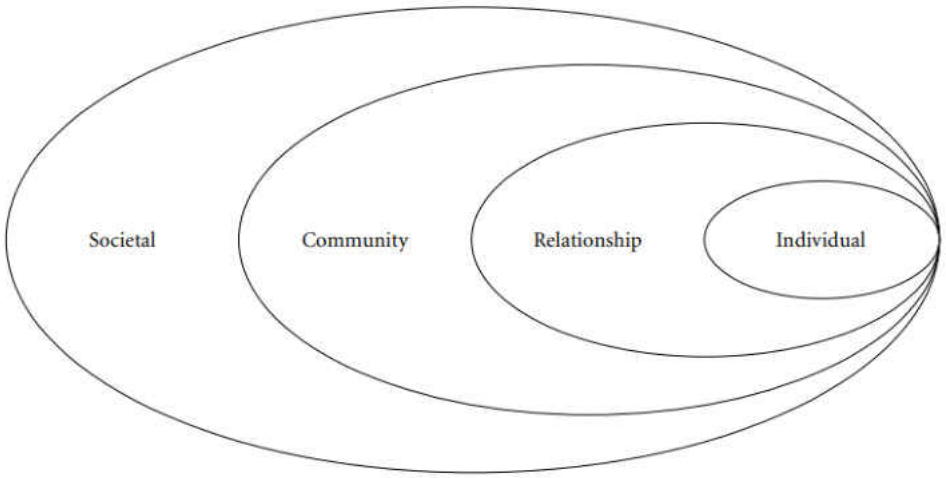


Figure 2 Socio-Ecological Model - Adapted from Bronfenbrenner, 1986

The *SEM* follows four distinct levels of a person's life. The first level is the individual. Through the individual, identification occurs of a person's biological and personal factors from history. These factors may include age, education, income, substance use, or history of abuse, which could possibly increase the person's susceptibility to violence.

The second level examines social relationships within proximity of the person. These relationships could include peers, family, and intimate partners. Each of these relationships increase the possibility and risk for victimization. If living with family or intimate partners who do abuse the person, the risk and likelihood of repeated abuse increases. Relationships with peers, family, and partners all contribute to a person's behavior.

The third level is the context of the community that bounds the relationships. School, work, and the community in which a person lives all contribute to settings prone to violence and where relationships occur. Violence in the context of community is most often found in nomadic

living conditions, heterogeneity with highly diverse populations, and overcrowded areas. Communities with high drug flow, social isolation, and unemployment experience higher-than-average levels of violence, especially when institutional supports are missing.

The fourth level explores the societal factors associated with violence. These factors include disruptions in relationships that drive a wedge between societies, groups, or countries. Krug and Dahlberg (2006) include such societal factors as (a) "cultural norms that support violence as an acceptable way to resolve conflicts, (b) attitudes that regard suicide as a matter of individual choice instead of a preventable act of violence, (c) norms that give priority to parental rights over child welfare, (d) norms that entrench male dominance over women and children, (e) norms that support the use of excessive force by police against citizens, and (f) norms that support political conflict" (p. 287). Beyond basic relational norms in society; educational, health, economic, and social policy also contribute to societal factors.

These four interwoven, but distinct levels in the *SEM* demonstrate how violence can occur across multiple factors affecting a person's life, including the individual factors as they interact with social, cultural, and economic factors. The context of this model is used to understand how to decrease violence through understanding the multiple levels of an individual's life. Most importantly, reductions in violence occur through the complexities within and between these levels (Krug & Dahlberg, 2006). By addressing all four levels of the Socio-Ecological Model in sexual education, the prevention of violence could be reduced (Bronfenbrenner, 1979; Krug & Dahlberg, 2006; McLeroy et al., 1988).

Purpose Statement

The purpose of this study was to use the *SEM* through a qualitative design to analyze the lived experiences of women with ID, who have been sexually assaulted, to understand the individual and interwoven levels of their lives through the analysis of a phenomenological study. As researchers and statistics have proven (Antaki et al., 2015b), people with ID have the highest rate of crime and assault over other types of disabilities (Harrell et al., 2012). The assumption of this researcher is this high rate of assault indicates what is currently being taught, or not taught, in schools in relation to sex education and sexual assault prevention. In this study, the researcher interviewed women with ID who have been assaulted to try and understand their past history prior to or after their assault, regarding their sexual abuse prevention and sexual education, to identify potential connections between assault and education.

Research Questions

The primary question answered in this study is: What are the lived experiences of women with ID who have been sexually assaulted?

Sub-questions

1. What were the experiences of women with ID who were sexually assaulted in relation to sexual education?
2. What were the experiences of women with ID who were sexually assaulted after the assault happened?

3. What are the lived experiences of women with ID who have been sexually assaulted compared to the rates reported in the National Crime Victimization Survey?

Organization of the Study

The researcher interviewed seven women, ages 18-65, with ID, who were sexually assaulted, to discuss their experiences and their perceptions. Through semi-structured interviews with these women, the researcher discussed their experiences surrounding their sexual assault, including their sexual education, the assault itself, and the support they received after the assault. These interviews were analyzed through qualitative methods using *Nvivo for Windows* (QSR International, 2018), a qualitative research analysis software.

Operational Definitions

Advocate

Often, parents lack the knowledge of special education required to help their children navigate the education system, whereas advocates are specially trained in special education law. An advocate supports parents in securing appropriate services for their child or young adult. Under the Individuals with Disabilities Education Act (IDEA), parents and children have the right to work with an advocate who has knowledge of special education law (IDEA of 1990, 1990).

Community

Gusfield (1975) found two segments in the idea of community: geographical and relational. Geographical community includes the neighborhood, town, and city where a person resides. Relational describes the "quality of character of human relationship, without reference to location" (p. 16). Gusfield (1975) claimed geographical and relational are not mutually exclusive. This study will focus on the relational community and the interests and skills the community supports.

Culture

"Complex whole which includes knowledge, beliefs, arts, morals, laws, customs, and any other capabilities and habits acquired by [a human] as a member of society" (UNESCO, 2017, para. 1).

Disability

"A person who has a physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such impairment, or a person who is perceived by others as having such an impairment" (Americans with Disabilities Act, 1990, para 3).

Inclusion

"Inclusion is seen as a process of addressing and responding to the diversity of needs of all learners through increasing participation in learning, cultures and communities, and reducing exclusion within and from education. It involves changes and modifications in content, approaches, structures, and strategies, with a common vision which covers all children of the appropriate age range and a conviction that it is the responsibility of the regular system to educate all children" (UNESCO, 2005, p. 13).

Intellectual Disability

Formerly referred to as mental retardation or MR, intellectual disability (ID) "is a disability characterized by significant limitation in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18" (AAIDD, 2018).

National Sex Education Standards

"The goal of the *National Sexuality Education Standards: Core Content and Skills, K-12* is to provide clear, consistent and straightforward guidance on the *essential minimum, core content* for sexuality education that is developmentally and age-appropriate for students in grades K-12" (Future of Special Education, 2011, p. 6).

Sexual Assault

The Bureau of Justice Statistics (BJS), an entity of the United Stated Department of Justice, defines sexual assault as

> A wide range of victimizations, separate from rape or attempted rape. These crimes include attacks or attempted attacks generally involving unwanted sexual contact between victim and offender. Sexual assaults may or may not involve force and include such things as grabbing or fondling. Sexual assault also includes verbal threats. (Morgan & Kena, 2018, p. 20)

The BJS also defines rape as

> Coerced or forced sexual intercourse. Forced sexual intercourse means vaginal, anal, or oral penetration by the offender(s). This category could include incidents where penetration was from a foreign object such as a bottle. Includes attempted rapes, male and

female victims, and both heterosexual and same-sex rape. Attempted rape includes verbal threats of rape. (Morgan & Kena, 2018, pp. 19–20)

Sexual Education

For the use of participant interviews, sexual education would have been either a class or part of a health class taken where the participants had the opportunity to talk about the changes their body has gone through or having safe sex to prevent getting a sexually transmitted disease, like using a condom or not having sex until they are married. This education most likely occurred in an educational setting, but any type of formalized (not simply parent discussion about the topic) will be considered as sexual education.

Students without Disabilities

For the purpose of this dissertation, a student without a disability (SWOD) is any student that does not have a disclosed disability who is currently or was served with an IEP or 504 plan in the school they attended.

CHAPTER TWO: LITERATURE REVIEW

History of Sexual Education

The history of sexual education for individuals identified as having an intellectual disability (ID) began before the 1880's, in a time when many persons with this label were hidden away in their homes or released to the custody of almshouses or asylums for the blind or insane (Kempton & Kahn, 1991). The identification of a person as ID was believed to be both the result and cause of sexual 'vice" avoided through the 'practice of virtue.'

In 1876, the shift began for inclusion of people identified as ID into society. This shift was marked by the formation of the Association of Medical Officers of American Institutions for Idiotic and Feeble-Minded Persons, with a goal to educate institutions about individuals with ID and reintegrate this population into their home communities as productive members of society. Yet, the Association and its educators battled negative perceptions of individuals with ID, as society continued to perceive these individuals as sexual deviants and feared 'degeneration' on a national scale. This fear led to further institutionalization of many with ID, while producing emerging professions, including social work and an emergent version of special education teachers, to serve those institutionalized (Rafter, 1992).

Despite forward movement for individuals with ID, from 1880 to 1940, the United States and other nations began to see a rise in eugenics, an effort to eliminate persons with ID. As many as 30 states in the U.S., between 1907 and 1931, passed legislation permitting sterilization of criminals, 'degenerates,' and 'imbeciles' (Block, 2000). As people with ID were viewed as sexually promiscuous and thereby criminals, this population was targeted for sterilization to limit overwhelming the larger population (Paul, 1974). Concurrently, research was being conducted to determine the circumstances surrounding 'Deborah Kallikak,' a resident of the Vineland

Training School for Feeble-minded Boys and Girls in Vineland, New Jersey. This research claimed mental deficiency was linked to heredity and criminal behavior (Goddard, 1912), and led to involuntary castrations and ovariectomies. Further, segregation of individuals with ID was justified through administration of intelligence tests, created by Alfred Binet, to criminals, prostitutes, and alcoholics, deeming them 'mentally retarded' (Kempton & Kahn, 1991). In 1927, a legal battle began between the Superintendent of the State Colony of Epileptics and Feeble Minded versus Carrie Buck, a third-generation female deemed feeble-minded. Buck attempted to fight a salpingectomy, which cut out the fallopian tubes. Buck argued she was raped and impregnated by the nephew of her employer's family. The family promoted Buck be put into an institution, under the guise of feeble-mindedness (Block, 2000). Legislators in Virginia passed a sterilization law in 1924, and Buck's case was used to determine the parameters of the law (Smith & Nelson, 1989). The court ruled against Buck, with Supreme Court Justice Holmes stating:

> She may be sexually sterilized without detriment to her general health and that her welfare and that of society will be promoted by her sterilization. We have seen more than once that the public welfare may call upon the best citizens for their lives. It [the state] would be strange if it could not call upon those who already sap the strength of the state for these lesser sacrifices, often not felt to be such by those concerned, in order to prevent our being swamped with incompetence. It is better for all the world if, instead of waiting to execute dangerous degenerate offspring for crimes or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind. The principle that sustains compulsory vaccination is broad enough to cover cutting the

Fallopian tubes…Three generations of imbeciles are enough. (Supreme Court of the United States, 1927, p. 7)

The outcome of Buck's case ushered in further isolation, with a denial of basic sexuality rights for people with ID. These rights were further curbed, with individuals in the 1940's and 50's housed in institutions lacking basic sexual education; residents found persons of the opposite sex were sometimes punished with solitary confinement and a shaved head. This forced homogeneity of populations led to a rise in homosexual behavior, further promoting outside views of sexual deviance in this population. In 1950, with the formation of the Association for Retarded Children (ARC), therapeutic communities and co-ed socializing began. Still, without formal sexual education, this co-mingling lead to a rise in pregnancies. At one institute, for example, couples would engage in sexual activity during social events. Resulting pregnancies led to an increase in what was termed at the time "tunnel babies" (Paul, 1974), those born to institutionalized mothers.

John F. Kennedy created the Presidential Panel on Mental Retardation in 1961, resulting in training and community-based service programs for individuals identified as ID (Bazelon & Boggs, 1963). Kennedy's sister was identified as ID, and this new wave of advocacy at a national level led to increased normalcy and acceptance. This time in the history of ID also brought about a movement of deinstitutionalization. As those with ID started to leave institutions, a theme of "dignity of risk" promoted the opportunity to explore sexuality through experiences, mirroring the typical population (Perske, 1972). Despite an expectation for normalcy for deinstitutionalized individuals with ID, professionals began to recognize a need for increased social skills and sex education, as well as protection from abuse (Kempton & Kahn, 1991).

The initial revolution for sex education in America, while focused on the typical population, did extend to individuals with ID. In 1964, Dr. Mary S. Calderone founded the Sexuality Information and Education Council of the United States (SIECUS) to create sexual education curricula for schools across America. Dr. Calderone worked for Planned Parenthood Federation and was concerned about a lack of materials and information available to young people and adults about sexuality. With the creation of SIECUS, many up-to-date resources became available to educators and parents for the typical population. To this day, SIECUS continues to expand into policy and communities, becoming the national leader in sexuality education (SIECUS, 2018).

Paralleling the work of Calderon in 1964, a small group of researchers began to explore what was occurring for those with ID. Those researchers included:

- Robert Edgerton (1964, 1967) conducted some of the earliest research on individuals with ID about sexuality. He found those who left institutions had no working knowledge of procreation, birth control, and sterilization.
- Marvin Rosen (1970) from the Elwyn Institute was the first to "document applied systematic desensitization and behavior modification techniques" to decrease anxiety about heterosexual relationships and change what was deemed deviant sexual behavior for this population (Kempton & Kahn, 1991, p. 99).
- Warren Johnson (1976) worked at the Health Clinic at the University of Maryland. He focused on counseling parents on their child's sexuality.
- Medora Bass (1963) advocated for the use of effective birth control for those with ID

- Sol Gordon (1978) travelled the country advocating for a change of attitudes toward the sexuality of those with ID.

With the 1970's came a sexual revolution in America (Treas, 2002); Woodstock, in 1969, promoted a sexual freedom many had not experienced (Hodenfield, 1969). Alex Comfort wrote the book, "The Joy of Sex," in 1972, which led the way for other publications and conversations on sexual practice. The Pornography Commission began to allow the sale of sexually explicit materials to adults in 1970, which led to sexual educators and therapists using materials of concrete imagery to promote an understanding of sexual matters (Attorney General, 1986; Commission on Obscenity and Pornography, 1970). The Family Planning Services and Population Research Act of 1970 provided training for family planning clinic personnel, family planning research, and community-based education and outreach. In 1973, Roe v. Wade brought reproduction rights to the forefront of the United States. With the passing of this legislation, women were guaranteed the right to abortion, sterilization laws also came under scrutiny. In 1973, 23 states still allowed involuntary sterilization. Relf v. Weinberger of 1974 prohibited the use of federal funds to sterilize minors or mentally incompetent adults for any reason.

After the 1970's, sexual education of people with ID was mainstreamed. Many with ID tried to lead a typical lifestyle, and sexual education became available to everyone. The 1980's brought a new fear to sexuality; Acquired Immune Deficiency Syndrome (AIDS) and reported sexual abuse became more prevalent because of a new level of openness to discussions about sexuality in society. Emerging researchers reported 80-95% of persons with disabilities were victimized sometime in their life (Craft & Craft, 1983). The times of sexual freedom and the 'free love' of the 70's came to an end. Also, during this time, the first African American woman surgeon general, Joycelyn Elders, was fired for encouraging the practice of masturbation at a

high school (Jehl, 1994). The topic of sex became a taboo subject to the general public once more. However, because of the AIDS epidemic, the creation of sexual education curriculum emerged and began to be required in schools across the nation (Stiggall, 1988). The fear of sexually transmitted diseases (STDs) created a division in sexual education between abstinence-only education or a more comprehensive approach. A plethora of new curricula with more of a generic approach to the topic of sexuality were created and with a clear focus on the typical population, with little variance for students with disabilities (Blanchett & Wolfe, 2002).

Sexual Education Curricula

School, State, National Policy.

The outcome of mandated curricula and sexual education created a new debate at all levels of government in the field of sexual education over two different types of sexual education curricula: abstinence-only-until-marriage and comprehensive sex education (Advocates for Youth, 2009). Today, abstinence-only-until-marriage (AOUM) programs teach abstinence as the only socially acceptable way of sexual expression for students. The AOUM curriculum does not provide in-depth teachings on contraception and condoms for the prevention of STDs and pregnancy (Kohler et al., 2008; Santelli et al., 2006; Stanger-Hall & Hall, 2011). Comprehensive sex education curriculum used today teaches that abstinence is the best way to prevent unwanted pregnancy and STDs; however, it also teaches about contraception, condoms, and STDs including HIV (Pittman & Gahungu, 2006). A comprehensive sex education curriculum is supposed to help young people explore their own values, goals, and options through interpersonal and communication skills. At this time, only 24 states and the District of Columbia

require public schools to teach sex education. Many states only require one semester of health education, including sex education for students in both general and special education settings (Guttmacher Institute, 2016). Current AOUM programs are federally funded, but not comprehensive sex education. Researchers have proven AOUM programs are not an effective way to teach sex education; however, because federal funds only support this area of curriculum use in schools, this model is the predominate instruction occurring (Bridges & Alford, 2010; Elia & Eliason, 2010b; Kohler et al., 2008; Pittman & Gahungu, 2006; Santelli et al., 2006; Stanger-Hall & Hall, 2011).

Challenges of Sexual Education curricula for those with ID.

The issues of sex education curricula for individuals with ID face two challenges. The first is the acceptance this population should even be taught about sexuality. The second is where these students are educated, which is mainly in self-contained settings. The year 1975 saw the first teachers in the general education setting prepared to teach sex education. At the same time, with the passage of IDEA and the concept of a free and public education (FAPE) emerging, students with ID in public schools were mainstreamed more than ever before. Despite their presence, questions of if this population should even be educated on this topic continued, and often times students with ID were removed from the general setting where this education occurred (Blanchett & Wolfe, 2002). These same issues identified in the 1970's continue today for students with ID who are still often served in restrictive settings with teachers who lack adequate preparation and accessible materials to teach critical, sexual education concepts (McDaniels & Fleming, 2016).

Why this educational revolution is still not occurring for those with ID is the inability of school, state, and national organizations and policy-makers to agree on what should be taught (Pittman & Gahungu, 2006), and people with ID struggle with the ability to generalize skills taught in the classroom. This lack of consensus on content and access to appropriate curricula is a particular problem in sex education, and the status quo of doing nothing continues to have a devastating impact on this population with regard to high rates of sexual assault (Egemo-Helm et al., 2007).

Sexual Education Curricula

Throughout history when sex education is discussed, students with disabilities often are left out of the conversation (Gougeon, 2009) until they are of age to become sexually active (Boehning, 2006). Gougeon (2009) found the following on the adverse effects of leaving students with disabilities out of the decision making when it comes to sex education:

> The consequences of adopting a reactive approach for students are the increased likelihood of their being uninformed or misinformed, being at an increased risk of abuse or exploitation, increasing the risk of contracting a sexually transmitted disease (STD), compromised self-advocacy skills, inappropriate socio-sexual behaviours [sic], and, ultimately, social exclusion and isolation. (p. 283)

As school, state, and national policy makers are waging a war on the type of sexual education students should be receiving, advocates note decision-makers lose sight of what matters most: the students (Advocates for Youth, 2009; McDaniels & Fleming, 2016). Curricula needs to be developed for all students with the research and input from all people (Blanchett & Wolfe, 2002;

Gougeon, 2009; D. Schaafsma, Kok, Stoffelen, & Curfs, 2017). Inclusion in the design of a curricula should guarantee the curricula is adaptable to all students (Blanchett & Wolfe, 2002).

In an inclusive setting, curriculum should address the needs of all students in the classroom. Blanchett and Wolfe (2002) reviewed 12 curricula recommended by SEICUS. Each curriculum was said to be adaptable for students with ID; however, only four were listed as targeting that specific audience. Gougeon (2009) incorporated the idea of "critical pedagogy" into her research on the ways to teach sex education to all students. Critical pedagogy was adapted from the works of Henry Giroux (1999) and Peter McLaren (2007). This method of teaching is

> diverse; seeks interdisciplinary knowledge; rejects the distinction between high and low culture, therefore allowing the curriculum to be responsive to peoples' actual lived experiences; shows the ethics behind language used by educators and how they influence behaviour [sic]; and questions power relations in school/history and uses this questioning to redefine and re-situate identities. (p. 285)

Based on this method, sex education should be a "lived curriculum" that accounts for a student's lived experiences in the day-to-day teachings (Gougeon, 2009, p. 285). Sex education should be comprehensive, and teachers need to have a comprehensive knowledge of what their students know and understand before they begin to teach the content. This content typically includes the concepts included in the Circles of Sexuality in Figure 3. Once educators have a firm grasp on content, they then have the opportunity to create their lessons and adapt the curriculum to meet the needs of all of their students (Duffy, Fotinatos, Smith, & Burke, 2013). It is then that all students will have the opportunity to be educated with a curriculum that will work.

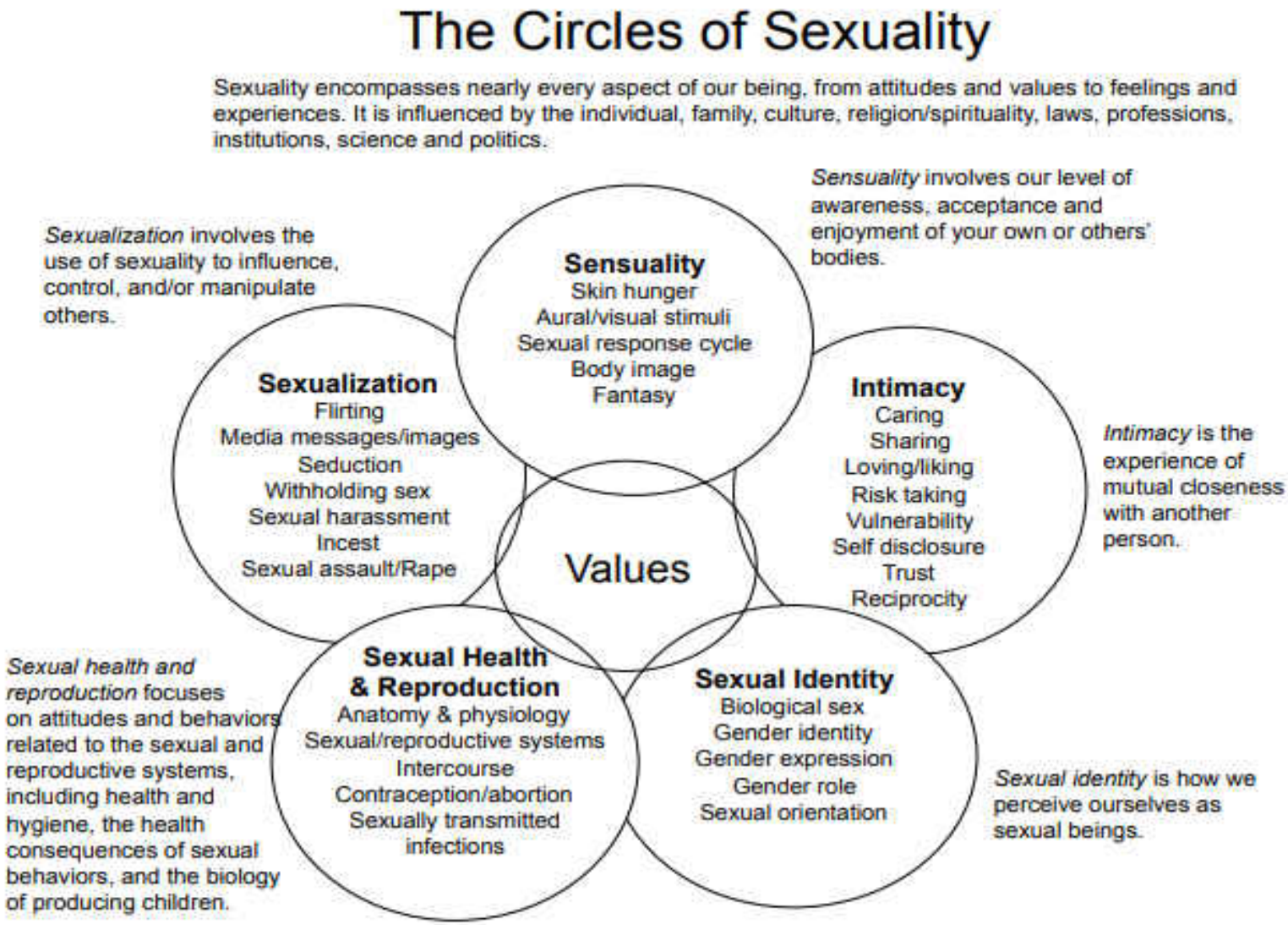


Figure 3 Circles of Sexuality, adapted from Life Planning Education, 1995, Advocates for Youth, Washington D.C. Adapted with permission from Advocates for Youth

Sex Education of Students with ID

Creating sexual education curricula that benefits all students could help include those with ID. According to the National Longitudinal Transition Study – 2 (SRI International, 2002) only 43% of students with and without ID receive sex education. Additionally, only 16.2% of those students with moderate to profound ID are likely to receive sex education. Many teachers surveyed claimed sex education would benefit only those students without ID or with mild ID. Only 25% of teachers surveyed thought students with moderate to severe ID would benefit from sex education. Unfortunately, after the NLTS2 research, limited research exists delving into the perspectives of teachers and administrators on the sex education of students with ID. Yet, knowing the administrators and school officials' thoughts on this topic is essential as they are the ones who, along with state curriculum guidelines, provide the sex education curriculum and standards to teachers.

Trained Personnel and Materials.

This lack of agreed upon curriculum, paired with sexual educators not prepared to work with students with disabilities, are interrelated issues. Oftentimes, teachers continue their instruction at the same pace they would if they did not have a student with a disability in their class (Walker-Hirsch, 2007). Researchers have shown students with ID need more time to comprehend content taught in the classroom (Browder, Spooner, & Meier, 2011; Kurth, Morningstar, & Kozleski, 2014; McDonnell, Johnson, Polychronis, & Riesen, 2002). If a teacher does not slow down their instruction and provide more examples for the students with ID, they may not retain and generalize the information (Egemo-Helm et al., 2007). Additionally, Wolfe

and Blanchett (1997) found a lack of sex education curricula being created to help students with ID. A study conducted by Wolfe and Blanchett (2002) was based on twelve programs recommended by the Sexuality Information Education Center of the United States (SIECUS). While there were positives and negatives in all programs, none were perfect. This finding shows teachers need to pick and choose the best content and modify the current sex education programs to fit the needs of their students. In order for these modifications to be made, teachers need preparation in sex education (Blanchett & Wolfe, 2002).

In order to increase the number of both general and special education teachers qualified to teach sex education, the creation of professional development is needed. Teachers need practice and guidance on the topic of sexual education to ensure they have a level of comfort for this sometimes, difficult topic. Teachers need a support system to openly ask their own questions and address their own concerns. They also need a curriculum that addresses all the students they have in their classroom, including those with learning, intellectual, and physical disabilities. Each school district or county needs to provide teachers the opportunity to learn and stay up-to-date on current teachings and policies as it relates to sex education (Barnard-Brak, Schmidt, Chesnut, Wei, & Richman, 2014).

Limitations of Current Curricula

One of the difficulties surrounding sex education of students with ID is their struggle to generalize information taught to them in a classroom setting (Egemo-Helm et al., 2007). Students may be able to explain what a condom is and properly put it on a banana, but then may be unable to generalize its use on a human penis in a sexual encounter (Schaafsma et al., 2017). Limitations in many studies on the effectiveness of sexual education curricula is a lack of generalization

skills when taught to students with ID. When skills are assessed, role-play is the chosen method of assessment; unfortunately, many role-play activities use people familiar to the students, and they do not receive realistic opportunities to apply the information provided. Egemo-Helm et al. (2007) conducted a study using *in situ* training sessions after sex education content had been taught in a classroom. The participants did not know they were still being assessed in the real world, though the researcher controlled the situations to prevent harm to the participants. Results of the study showed an increase in generalization skills when instruction could occur directly after an *in situ* situation.

As shown by the Egemo-Helm et al. (2007) study, generalization is a skill important to the success of sexual education of students with ID. In addition to providing opportunities for students to practice their skills outside of the classroom but within a safe environment, students also need access to various instructional materials (books, videos, models), various instructional strategies (role-play, demonstrations), and various ways to show comprehension (surveys, demonstrations, concept identification; Wolfe & Blanchett, 1997). Ragg and Rowe (1991) studied the effect of using group activities in teaching sex education to those with ID. They recommend using activities such as role-play, gender reversal, and guided imagery to promote a deeper understanding of the content which leads to better generalization of the material. These activities can help both students with disabilities and students without disabilities.

Sexual Assault Prevention Literature Review

Most research in sexual assault prevention for those with ID is not being conducted in the United States. No matter the country, limited researched on the sexual assault of women with ID is available. A literature review was conducted to investigate what research has occurred to

decrease the high rates of sexual assault for those with ID. While the proposed study examines the sexual assault of women with ID, articles gathered for the review of literature include both male and female participants. The researcher reports current research on both sexes, but then focuses on what the women with ID experienced. Twelve articles were found within the last 18 years. Eight out of 12 articles came from the United States, with many written by the same authors. Other articles came from Australia, the United Kingdom, and Italy. Research has shown a higher occurrence of sexual assault in those with ID (Balogh et al., 2001; Bureau of Justice Statistics, 2017; Keilty & Connelly, 2001; Northway, Davies, Jenkins, & Mansell, 2005). These high reported rates of sexual assault lead to the purpose of this study.

Research Questions

The current status of sexual assault/abuse for students with ID is important to understand because the history of sexuality for this population has been slow to evolve while the rate of abuse is 57% higher than the general population for women (Bureau of Justice Statistics, 2017). Therefore, a systematic review of the literature was conducted on sexual assault, specifically on women with ID, to determine the current state in the field of education. This review is driven by the following research questions:

Research Question: To what extent is sexual assault represented in the literature on women with ID?

Sub-question 1: What empirical literature is available about the sexual assault of women with ID?

Sub-question 2: What empirical literature is available about sexual assault prevention for women with ID?

Methods

Criteria

The criteria used for the analysis of literature included in this selection were articles published as empirical studies in peer-reviewed journals, containing the search terms "intellectual disability" or "mental retardation"; "sexual assault" or "sexual abuse"; and "women" or "female." Both qualitative and quantitative studies were included. The time frame the search covered included articles dating back to the year 2000 due to the lack of research in the field of sexual assault and ID. Next, articles were hand-coded to exclude the following fields: (a) duplicates from other search terms or search engines, (b) not empirical (i.e. brief reports, program, or curricula descriptions), (c) did not include women, (d) did not include the topic of sexual assault, and (e) did not include ID. These criteria were chosen for the purpose of determining women with IDs' perspectives on sexual assault prevention methods, sexual education, and sexuality.

Data Sources

The search began by using the University of Central Florida's Library System. Education-specific databases included Education Resources Information Center (ERIC), ProQuest Education Journals, and Science Direct. Other databases included Criminal Justice Databases: ProQuest Social Sciences Premium Collection, Social Work: ProQuest Sociology, and Psychology: PsycArticles and PsycINFO.

Search Procedures and Study Selection

Searches were conducted using the following search terms: (a) “intellectual disability” AND/OR “mental retardation”, (b) “sexual assault” AND/OR “sexual abuse”, and (c) “women” AND/OR “female.” Table 1 includes the total number of articles located after all the inclusion criteria were analyzed. After the initial and hand-coding phase, a total of 12 articles met the criteria for inclusion in the review.

Results

The researcher, through a systematic literature review, identified the existing literature on sexual assault and prevention for women with ID.

Table 1 Systematic Review of Literature Results

Database	ERIC	PsycINFO	ProQuest Education Journals	Science Direct	ProQuest Social Sciences	ProQuest Sociology	PsycArticles
Phase 1: Initial Search	33	110	561	141	159	74	2
Phase 2: Excluded duplicates and studies not in English					981		
Phase 3: Excluded studies that were not empirical					564		
Phase 4: Excluded studies that did not have women					378		
Phase 5: Excluded studies that did not have an intellectual disability					16		
Phase 6: Excluded studies that did not have sexual assault					12		

Study Selection

During this literature review, six phases were conducted. Phase 1 of the search included key search terms in multiple search fields using Boolean terms. Phase 2 removed any duplicate studies from the databases and articles not written in English. Phase 3 included the removal of studies that were not empirical. Phase 4, 5, and 6 excluded studies that did not include women, ID, or sexual assault. A summary of the results is provided in Table 2.

Table 2. Qualitative and Quantitative Articles on the Prevention and Sexual Abuse of Persons with an Intellectual Disability

Article	Country of Origin	Population	Design	Comparison	Outcome
(Eastgate, Driel, Lennox, & Scheermeyer, 2011)	Australia	9 women with mild ID	Semi-structured interviews		Themes: sexual knowledge and sources of knowledge; negotiating sexual relationships; declining unwanted sexual contact; self-protection strategies; sexual abuse experiences; and sequelae of sexual abuse
(Egemo-Helm et al., 2007)	USA	7 women with mild to moderate ID, 4 actually completed the study	Self-report, role-play, and *in situ* assessments Multiple baseline across subjects		Participants showed increase in ability to say no or verbally refuse, leave the situation, and report abuse. *In situ* situations did not score as high.
(Fisher, Burke, & Griffin, 2013)	USA	5 young adults with ID; 4 males and 1 female; age range 20-23	Multiple baseline across participants using safety ratings Classroom behavior skills training and *in situ* training		Participants acquired skills during behavior skills training in the classroom. They did not generalize the skills to the *in situ* assessments.
(Hickson et al., 2008)	USA	36 women with ID, IQ 35-75, age 22-55, in residential placement	The Decision-Making Video Scale The Stress Management Survey-Revised	Women with documented history of abuse vs. women	The women with a documented history of abuse differed from those with no documented history of abuse in the extent to which they employed passive/avoidant strategies in response to decision-

Article	Country of Origin	Population	Design	Comparison	Outcome
			The Coping Strategy Scale-Revised The Support Systems Scale Risk Indicator Survey	without a documented history of abuse	making vignettes depicting situations of abuse.
(Hickson, Khemka, Golden, & Chatzistyli, 2015)	USA	58 women and men identified with intellectual and developmental disability	*ESCAPE-DD* curriculum, *Decision-Making Scale* (DMS)	Control Group: Voluntary access to existing personal safety and abuse prevention services offered by the agency.	Participants in the intervention group showed increased application of effective decision-making skills in response to scenarios involving sexual, physical, and verbal abuse. Participants showed no increase in the ability to understand potential harm or danger in abuse situations.
(Khemka, 2000)	USA	45 women with mild to moderate ID, age range 21-40	Pretest-posttest control group design Two training conditions and a control condition (decision-making training, self-directed decision-making training, no training)	Control group with no training	The self-directed decision-making training increased skills for more effective handling of abuse situation more than the decision-making training. Both trainings showed improvement over the control group.

Article	Country of Origin	Population	Design	Comparison	Outcome
(Khemka & Hickson, 2000)	USA	90 adults with mild ID 45 men, 45 women	Social Interpersonal Decision Making Video Scale		45% suggested resisting or stopping the occurrence of abuse. 20% suggested seeking social support or help from authority 35% failed to suggest a prevention-focused decision
(Khemka, Hickson, & Reynolds, 2005)	USA	49 women with mild or moderate ID Age range 22-55	Pretest-posttest control group design ESCAPE curriculum Decision-Making Video Scale Knowledge of Abuse Concepts Scale Empowerment Scale Stress Management Survey Self Decision-Making Scale	Control group with no training	Women in the treatment group performed better in the areas of knowledge of abuse concepts, feelings of empowerment, and independent, prevention-focused decision making. No differences were recorded for the stress management measure between groups.
(Kucuk, Platin, & Erdem, 2017)	Turkey	15 children with mild ID Ages 10-14 Nine girls, six boys	Pretest-posttest semi-experimental design Story Map Method Parent opinions and Child Interview Forms		Knowledge scores increased following lessons in the areas of special body parts, good-bad touch and saying 'no,' establishing safe boundaries with strangers, and reporting cases of abuse.

Article	Country of Origin	Population	Design	Comparison	Outcome
(Murphy & O'Callaghan, 2004)	UK	60 people with ID, 60 young people with average IQs	SexKen-ID (McCabe, 1994) two measures of the understanding of abuse, developed especially for the study		The evidence from the Sex-K-ID suggested the levels of sexual knowledge for people with ID were far lower than for non-disabled 16- to 17-years old.
(Northway et al., 2013)	UK	47 PWID in focus groups, 14 PWID individually interviewed	Focus groups and interviews		Themes: severity of abuse, emotions and feelings, and what should happen to abusers?
(Ward, Atkinson, Smith, & Windsor, 2013)	USA	31 adults with ID 14 women and 17 men	Friendships and Dating Program (FDP) Process Evaluation Model Social Networks Measure Interpersonal Violence Interview		The FDP had results that increased social networks and decreased the number of incidents of interpersonal violence for participants.

Results of Individual Studies

Twelve articles were reviewed. Each article dealt with the sexual assault of females with ID, and some included males. After reviewing the articles, five themes emerged: (a) sexuality and abuse, (b) *in situ* training to prevent abuse, (c) decision-making skills, (d) increasing awareness, and (e) consent.

Interviews on sexuality and sexual abuse

Eastgate, Driel, Lennox, and Scheermeyer (2011) conducted a study using semi-structured interviews to delve into the sexual and relationship experiences of women with ID in New South Wales, Australia. Additionally, they researched sexual knowledge, relationship experience, and self-protection skills. Their participants were women with ID, older than 18, that could participate in the consent process independently. Total participants included two women aged 20-29, four women aged 30-39, and three participants aged 40-49. Interviews were between 45-75 minutes using an interview outline to prompt discussions. Several themes emerged from the interviews including sexual knowledge and sources of sexual knowledge, negotiating sexual relationships, declining unwanted sex within a relationship, declining unwanted sexual advances from non-partners, accounts of sexual abuse, disclosure of abuse, and sequelae of abuse.

Knowledge of the participants on sexual intercourse ranged from "when you haven't got any clothes on and the person lies on top of you" to "In a girl, I think that every couple months or something there is an egg release…and the guy's sperm basically goes up them into the girl's eggs and basically makes a baby…the guy ejaculates his semen into the girl's vagina" (Eastgate et al., 2011, p. 227). When asked how they learned about sex, one participant stated, "We did not

talk about anything about sex at school cos I think we couldn't, I dunno was it illegal for us to talk about it?" (p. 227). Another participant stated, "We had to learn how to put a condom on, so we basically do it on a banana or a zucchini" (p. 227). One woman stated she learned about sex "Because I was raped" (p. 227). When it came to declining unwanted sex within a relationship, one participant stated, "I knew it was wrong to hit me [but] I actually didn't know that him forcing me to have sex was wrong" (p. 228). Participants had various ways of dealing with unwanted sexual advances from non-partners, including calling the police and stopping the action. One participant, however, found it more difficult to decline the unwanted attention stating, "[A friend] just woke me up in the middle of the night wanting to have sex, and I just didn't really want it, and in the end I enjoyed it, I shouldn't have, it was a bad mistake" (p. 228). Another participant stated she had sex with friends because she was lonely.

Many participants relayed stories of sexual abuse by familial abusers, such as a grandfather, uncle, or brother. All described abuse as 'wrong' or 'bad,' though they had different experiences when disclosing their abuse; one participant described being called a liar by her family, while another discussed the idea of her word against the attacker's. Others had positive experiences when disclosing their abuse; a female victim described disclosing to her parents, who then involved law enforcement – thus receiving needed help. Long-term impacts of abuse ranged from an inability to have sexual intercourse, to fear and avoidance of relationships.

In situ Training

Egemo-Helm et al. (2007) studied the effects of *in situ* training to teach women with ID sexual abuse prevention skills. The results of this study were promising, except for the fact the women in the study struggled to generalize the skills taught in a classroom or role-play setting to

the real world. Seven women participants with mild to moderate ID participated in this study. Ages of the participants ranged from 28-47-years-old, and the participants were referred to the study by their case managers at a local agency. Scoring for the training was on a 4-point scale, with participants earning one point for each of the following: "(a) did not agree to engage in, or begin to comply with, the requested behavior; (b) said 'No' or otherwise verbally refused; (c) left the situation or told staff to leave; and (d) reported the incident to a staff person" (Egemo-Helm et al., 2007, p. 103). Additionally, assessments on prevention skills included self-report, role-play, and *in situ* assessments.

Participants were paired together for three, one-hour training sessions. During their instruction time, participants were taught sex education and sexual abuse prevention skills, and they participated in 10 role play scenarios in a variety of locations. The trainings continued until the participants were fluent in all aspects of the abuse prevention skills. One week after the training sessions ended, researchers began the *in situ* assessments. If a participant scored lower than four on the *in situ* assessment, a training session began right away.

Out of the seven participants that started the study, only four completed it. Each participant who completed the study required *in situ* trainings during the *in situ* assessment phase. One participant required at least 12 *in situ* trainings and never made the final criterion for the study. The other three participants eventually reached the criterion of earning four points during *in situ* assessments, three consecutive times. This study was the first with maintenance checks at one and three months after the study. Three out of the four participants maintained their abuse prevention skills after one month, and two out of four participants maintained their skills after three months.

Egemo-Helm et al., (2007) showed that women with ID were able to learn the skills necessary to prevent sexual abuse. However, they also demonstrated, with their maintenance checks, that women with ID needed a continual reinforcement of skills to prevent loss. Further research is needed to determine if skills can be generalized if repeated refresher trainings need to occur for each participant.

Responding to Lures

Fisher, Burke, and Griffin (2013) studied how to teach young adults with ID to respond appropriately to lures from strangers. The study included five young adults (4 males and 1 female), aged 20-23, with IQs ranging from 46-68. The researchers utilized a multiple baseline across participants design with an intervention of behavior skills training and *in situ* assessments using confederate strangers (people known by the researchers but not the participants). Parents participated in the behavior skills training (BST) along with the participant and the trainer. The trainer used role play in the BST with continued instruction if the participant did not respond appropriately. *In situ* training occurred within one week of completing the BST. Social validity was determined by interviews of the participants and a survey completed by the parents.

During baseline, only one participant walked away from the confederate. It took participants 3-4 days to complete the BST. Following the training, all participants met the *in situ* performance criterion within three days. After the *in situ* training, a maintenance period was recorded. The first participant, the female, met the criterion all five times; the second met the criterion two out of four times; the third participant met the criterion all three times; the fourth participant met the criterion two out of three times; and the fifth participant met the criterion one

out of two times. The researchers showed, while the participants met all the criteria in the BST, the training did not generalize to the *in situ* and maintenance periods.

Decision-Making Skills

Khemka and Hickson are two researchers who have conducted extensive research in the area of decision-making skills of women with ID. The following, five studies show the collective results of their work.

Profiles of Women with ID

Hickson, Khemka, Golden, and Chatzistyli (2008) analyzed the profiles of women with and without a documented history of abuse. Participants included 36 women with ID, with an IQ range of 35-75, and an age range of 22-55. All participants lived in a residential setting. Of the 36 participants, 21 had a past with documented abuse while 15 had no documented abuse within the past five years before the study began. Researchers used the Decision-Making Video Scale to assess the participants' ability to make decisions *in situ*ations of abuse (sexual, physical, and verbal). Also used was the Stress Management Survey-Revised, the Coping Strategy Scale-Revised, and the Support Systems Scale.

Each participant was given a survey with three types of measures: "(a) a measure of comprehension and decision-making performance in response to video clips depicting abuse situations; (b) self-report measures of stress, coping, and social support; and (c) several indicators of social/psychological status as reported by each participant's case manager" (Hickson et al., 2008, p. 135). The authors found women who were abused became more passive/avoidant in response to situations of abuse.

ESCAPE-DD curriculum

Hickson, Khemka, Golden, and Chatzistyli (2015) studied the impact of the *ESCAPE-DD* curriculum on the decision-making skills of women and men with intellectual and developmental disability (IDD) *in situ*ations of abuse. Participants were 60 women (n=30) and men (n=30) with mild to moderate IDD. Participants were recruited from seven adult day programs in New York City. Participants were then randomly assigned to either the treatment or control group. Researchers used the Decision-Making Scale as the pretest-posttest instrument to measure the participant's ability to make appropriate decisions in scenarios involving sexual, physical, or verbal abuse.

Participants in the treatment group received instruction from the *ESCAPE-DD* curriculum, a curriculum modified for both men and women from the original *ESCAPE* curriculum, specifically for women. Design of the curriculum was meant to incorporate "interplay among the (a) cognitive (e.g., distinctions between abusive and healthy relationships and acquisition of a stepwise strategy), (b) motivational (e.g. goal processes and personal agency beliefs), and (c) emotional (e.g., awareness of feelings and emotion regulation) processes involved in effective decision making" (Hickson et al., 2015, p. 495). The researcher found an increase in effective decision-making skills in reference to scenarios involving sexual, physical, and verbal abuse. In comparison with the control group, participants in the treatment group were able to recommend effective decision-making 84% of the time while participants in the control group were only able to recommend strategies 63% of the time. The researchers also demonstrated the participants struggled to understand the danger or harm associated with the abuse situations.

Simulated Interpersonal Situations of Abuse

Khemka (2000) studied the effectiveness of two, decision-making training approaches. The study included 36 women with mild ID, with an IQ range of 50-70, in the 21-40 age range. Khemka (2000) utilized a pretest-posttest control group design using the Social Interpersonal Decision-Making Video Scale, the Self Social Interpersonal Decision-Making Scale, and the Nowicki-Strickland Internal-External Scale. Training for the treatment groups consisted of small groups of 2-3 participants, though some training sessions were individualized. Participants attended 10 sessions over several weeks. Those in the control group did not receive any training, but they still had access to the agency's regular social skills or sex education curricula.

The researchers showed the effectiveness of the decision-making training over the control group who received no training. The self-control decision-making training was more effective than the decision-making training. This finding could have occurred because the self-control decision-making training focused on both the cognitive and motivational aspects of decision-making while the decision-making training focused solely on the cognitive aspects. Participants in the self-control training also were able to generalize their decision-making better than those in the decision-making training and the control group.

Decision-Making in Simulated Situations

Khemka and Hickson (2000) conducted a study to research the decision-making abilities of adults with ID as it relates to social interpersonal situations involving abuse. The study included 90 adults with ID, 45 women with a mean IQ of 61.02 and a mean age of 35.15, and 45 men with a mean IQ of 60.11 and mean age of 36.42. The instrument used was the Social Interpersonal Decision Making Video Scale. No intervention was used for this study. The Scale

consisted of three different variables: (a) recognition of the problem, (b) definition of the problem, and (c) a recommended decision. The recommended decision section also was split into three categories: (a) direct prevention-focused, (b) other-dependent prevention-focused, and (c) nonprevention-focused. Each category and variable were aggregated by physical, sexual, and verbal abuse. The Scale was given over two settings, using both Form A and B of the instrument. In the first session, the narratives were given in either a male or female voice using one form. The second session use the opposite voice and the second form of the instrument.

All participants recognized situations involving abuse as a problem situation. Participants only offered a direct prevention-focused decision to stop the abuse 45% of the time. Only 20% of the time, participants suggested seeking help from an authority figure. "Participants failed to suggest a prevention-focused decision 35% of the time, which raises concerns about their own ability to act independently in a timely manner to resist social pressure and coercion and protect themselves in interpersonal situations involving abuse" (Khemka & Hickson, 2000, p. 22). Women in the study engaged in more reporting-type behaviors focused on other-dependent prevention-focused responses.

Decision-Making Curriculum to Resist Abuse

Khemka, Hickson, and Reynolds (2005) studied the impact of the ESCAPE curriculum on 36 women with ID. The mean age of the participants was 34.31, and their mean IQ was 55.92. The researchers utilized a pretest-posttest control group design using the Decision-Making Video Scale as a pretest screening measure, the Knowledge of Abuse Concepts Scale as a cognitive measure on knowledge of abuse concepts, the Empowerment Scale to assess perceptions of control and self-efficacy, the Stress Management Survey to measure self-reported stress levels,

and the Self Decision-Making Scale to measure self-protective decisions in relation to scenarios of sexual, physical, and verbal abuse. The intervention consisted of the ESCAPE curriculum designed to help women with ID resist sexual, physical, and verbal abuse. Intervention sessions occurred once or twice a week for 40-50 minutes over a 6-12 week period. Sessions were small groups consisting of three women. The ESCAPE curriculum has 12 lessons and six support group sessions. The curriculum covers three board units: (a) knowledge of abuse and empowerment, (b) decision-making strategy training, and (c) structured support groups. Women in the control group, while not having access to the treatment, still had access to their regular abuse treatment and prevention services.

Khemka and colleagues (2005) found women in the intervention group outperformed those in the control group in the areas of knowledge of abuse concepts; feelings of empowerment; and independent, prevention-focused decision making. The category of stress management did not show a difference between the intervention and control group. The intervention group also scored higher on providing high-quality definitions of sexual abuse, physical abuse, and rape compared to the control group. Both groups struggled to provide a definition for verbal abuse and consent.

Increasing Awareness of Protection

Kucuk, Platin, and Erdem (2017) conducted a study in the Central Anatolian region of Turkey to research how much children with ID could learn about self-protection using the Story Map Method. Participants in the study were 15 children: 9 girls and 6 boys, between the ages of 10-14. The study utilized a pretest-posttest semi-experimental design without a control group. The Story Map Method used a series of stories created and illustrated for the purpose of this

study. Each story was leveled in accordance with the participants cognitive and intelligence levels, and the content was about protecting children from sexual abuse.

Results of the study showed an increase in the children's knowledge scores on special body parts, good-bad touch and saying 'no,' and establishing safe boundaries with strangers and reporting cases of abuse. Parents of the children in the study had favorable reactions to what the children learned and how it transferred to their everyday lives.

"…After you told these special body parts she show breast and special body parts and say 'they say nobody could not see these places,'" mother of 4th child (Kucuk, 2017, p. 155)

"…When her big brother wants to touch her she says 'shame shame don't touch.' My big brother says I am your brother, it is not shame for me. 'No' says 'don't touch.' Now, since he learned these, when his uncle come he never lets him touch his head and another areas also" mother of 6th child (p. 156).

"…While she was coming back from school, one man wanted to ask her something. She didn't speak to him, her big brother told me. She said 'I don't want to speak, go'…" mother of 7th child (p. 156).

Children also became more aware of occurrences they needed to report.

"…Last week she get off the school bus by crying. I asked what happened she said 'my friend touched my leg'…" mother of 13th child (p. 157)

"…from the special class her friend named O…first touched her legs and then wanted her to touch his special body part. My child came and told me…" mother of 4th child (Kucukk, 2017, p. 157).

Capacity to Consent

Murphy and O'Callaghan (2004) studied the capacity of adults with ID to consent to sexual relationships. They used the SexKen-ID developed specifically for the study to measure the understanding of abuse. The researchers also used the Social Network Map and the Test of Interpersonal Competence and Personal Vulnerability (TICPV). Participants included 60 adults with ID (30 males and 30 females) with mean ages of 37.6 years and a mean IQ of 59.8. Additionally, 60 young people without disabilities (30 males and 30 females) also were recruited with a mean age of 16.6. It was assumed those without disabilities had IQs in the average range. Participants without disabilities took the survey on their own while participants with ID had the survey read to them with researchers checking understanding along the way.

Their results showed adults with ID had a significantly lower understanding of all things sexual and were more vulnerable to abuse. The adults with ID scored significantly lower in the areas of pregnancy, masturbation, contraception, birth control, STDs, types of sexual relationships, and legal aspects of sex. The adults with ID also showed a limited understanding of consent and often considered a consenting situation as 'wrong.' They also showed limited understanding in situations that would be considered abusive. No significant gender differences were found in scores for any of the assessments (Murphy & O'Callaghan, 2004).

Northway et al. (2013) conducted a study to find the views of people with ID on abuse. The significance of this research is the potential support of people with ID "to protect themselves from abuse and, if they are abused, to provide them with appropriate support" (Northway et al., 2013, p. 363). The research used in the article was part of a 3-year research study. Norway and colleagues (2013) collected their data through focus groups and individual interviews. People with ID helped develop the entire research study, including the research questions, the

application for funding for the project, and helped with data collection, dissemination, and implementation of services based on the finding of the research. For the study, a partnership was formed between the University of South Wales, Rhondda Cynon Taff People First (an advocacy organization), and New Pathways (a counselling program for post-sexual abuse). Training for the study consisted of formal teaching sessions and times to practice their skills and apply the knowledge gained in the teaching sessions.

Forty-seven people with ID participated in the study, all between the ages of 18-65. All 47 participated in the focus groups; however, only 14 participated in the individual interviews. 19 participants were women, 27 were men, all with mild or moderate ID. Living situations ranged from independent living, living with partners, family, or in a supported living setting. The focus groups and interviews all took place at a three-day residential event held at a hotel. The rationale for the location was that after speaking about abuse, the participants were not to be left alone, and support and counseling services were available for those who required them.

Training sessions also were provided to all who were dealing with the data analysis part of the project. In this study, three themes emerged from the data: severity of abuse; emotions and feelings; and what should happen to abusers. Under severity of abuse, while most participants stated sexual abuse would be the worst type of abuse, one of the participants had a very insightful answer.

> "Well, that depends on the individual because what can be abuse to you might not be abuse to me" (Northway et al., 2013, p. 367).

Under emotions and feelings, the authors found a range of feelings: "anger, fear, bitter, disgust, upset and paranoid…and embarrassment" (Northway et al., 2013, p. 368). One participant talked about how he felt he could not change the abuse,

"I just feel it shouldn't happen, but it does. And there's nothing you can actually do about it, it just happens…makes me feel angry, it's such against, it's actually abusing your human rights basically, and we all have human rights" (p. 368).

At least five participants discussed feelings of taking one's life and a hopelessness to their situation.

"…it's well not very nice. It makes you feel – sometimes it makes you feel, it's like is life worth living for?" (p. 369).

The response to what should happen to those who abuse people was mixed. Some participants thought the abusers should be punished for their acts, others thought they should be educated to not do it again.

"I think they should see how we are treated and see how they feel" (p. 370).

"I think you should treat people the way you want to be treated. So if you don't want to be abused, don't abuse other people" (p. 370)

"I want them to understand how they feel about it. And why do you want to do it 'cos it's not fair" (p. 370).

Friendships and Dating Program

Ward, Atkinson, Smith, and Windsor (2013) evaluated the Friendships and Dating Program (FDP) developed at the University of Alaska Anchorage Center for Human Development. The program was developed to teach social skills necessary for healthy relationships and to prevent violence for those with an intellectual and developmental disability. The program included 20 sessions taught over 10 weeks in small, coed groups. Participants for the study were 31 adults with ID (14 women and 17 men). Small groups had three to seven

participants. Researchers used the Social Networks Measure and the Interpersonal Violence Interview to assess outcomes of the program in a pretest-posttest design.

Participants had a statistically significant change to their Social Networks Measure scores between pre and post testing, which shows the FDP allowed participants to identify more people in their social networks. Participants also showed a statistically significant decrease in their scores on the Interpersonal Violence Interview. Teaching abuse-prevention skills in combination with sociosexual relationship skills significantly decreased the participant's number of interpersonal violence. Interpersonal violence consisted of abuse such as physical, sexual, emotional, financial, neglect, and exploitation. Participants answered "yes", "no", "don't know", refused to answer, or "not applicable" to questions such as "Has anyone you know held or tied you down so you could not get away?" and "Has anyone you know made you have sex with her/him when you did not want to?" (Ward et al., 2013, p. 26).

Views of Those with ID on Sex and Sex Education.

In addition to articles found in the literature review on research about women with ID and sexual assault, a number of researchers discussed women's perceptions of sexuality. While the research did not include sexual assault, the thoughts of women with ID on sexuality were included as a way to build upon their ability to educate, understand, and protect themselves from what is considered 'right' and 'wrong.' Table 3 shows the breakdown of the four articles found on women with ID talking about sexuality.

Table 3 Articles on Women with IDs' Perceptions of Sexuality

Article	Country of Origin	Population	Design	Themes
(Azzopardi-Lane & Callus, 2015)	Malta	40 men and women with ID Ages early 20s to late 50s	Group interviews After 2 meetings, groups were split by gender	Negative social attitudes and restrictive social perspectives Denial of sexual maturity Internalization of stereotypical attitudes
(Bernert & Ogletree, 2013)	USA	14 women with ID Ages 18-89	Ethnography Formal and informal observations and interviews over 2 years	How disability influenced women's sexuality How the women expressed their sexuality How the women learned about sexuality
(Fitzgerald & Withers, 2013)	UK	10 women with ID Ages 19-64	Semi-structured interviews	Sex and sexuality Regulated beings Women with ID
(Schaafsma et al., 2017)	The Netherlands	20 participants with ID 10 men and 10 women Ages 15-52	Exploratory needs assessment Semi-structured interviews	Sex education Topics and knowledge Homosexuality Relationships Sex Parenthood Internet/social media Negative experiences and sexual abuse Support/environment Advice for sex education by participants themselves

Azzopardi-Lane and Callus (2015) conducted group interviews with 40 men and women with ID in Malta, a country in Europe. Participants were part of a self-advocacy group called the Consultative Committee of Persons with Intellectual Disability (KCC), which holds regular support meetings. After two meetings for the research project, the researchers decided to split the groups by gender to increase the level of comfort in talking about sensitive subjects. Themes that arose from the interviews included negative social attitudes and restrictive social perspectives, denial of sexual maturity, and internalization of stereotypical attitudes.

Negative attitudes included perspectives of others when addressing their sexuality.

"It doesn't mean that because you have a disability you cannot have a relationship" (Azzopardi-Lane & Callus, 2015, p. 35)

"They would scold me if they found out I was dating a young man" (p. 35)

"Once I did that [kiss in public] and people started staring. I don't do that in front of people anymore" (p. 35)

Other views that emerged from the study included thoughts on sexual maturity and what it would mean to be sexually active.

"Parents need to trust us, we are old enough to be in a relationship" (p. 36).

"…they have every right to have sex" (p. 36).

"…a girl is worse than a boy…when you've got a daughter, it's easy that she brings home a baby" (p. 36).

Bernert and Ogletree (2013) conducted a study on women with ID's perceptions of sex. Participants included 14 women with ID, ranging in age from 18-89 years old. The authors conducted an ethnography over two years using formal and informal observation and interviews.

They found three themes arose after their interviews were completed: how disability influenced the women's sexuality, how the women expressed their sexuality, and how the women learned about sexuality. The authors also found three, underlying themes for how women expressed their sexuality: "First, most of the women had some, but very limited sexual experiences given their ages. Second, the women described various conditions or criteria for sex when communicating their meaning of 'sex.' Third, most of the women expressed negative perceptions of sex, regardless if they had actually engaged in sex or anticipated first intercourse" (Bernert & Ogletree, 2013, p. 243).

Many women in this study were practicing abstinence out of fear instead of an informed decision based on facts.

> "I don't like it no more. I never do like it. I'm happy with the way I am" (p. 243).
>
> "The way society's goin' now days, I don't think that many people really practice it [abstinence]" (p. 244).

The participants worried about pregnancy and contracting sexually transmitted diseases and reported using condoms and birth control.

> "They do it kind a stupid. [Sexual partners] could have somethin' that you never know, which you could get it too" (p. 244).
>
> "Sex might make 'probly some, but not all people happy if they're ready to, uh, the main one I think is they're ready to have a kid" (p. 244).

Many sexual education courses in the United States practice abstinence-only, which could discourage young adults from having sex by showing them worst case scenarios. One issue found in this study was all but one of the participants could actually explain what intercourse was, instead giving "criteria or conditions for the context of sex" (Bernert & Ogletree, 2013, p.

245). Another issue is "only two out of the fourteen participants associated pleasure with sex" (Bernert & Ogletree, 2013, p. 244). Many had negative perceptions of sex.

> "…sickening. That's how I think of it anymore. It's disgustingly gross" (p. 244).
>
> "All [he] wanted was sex but I didn't like havin' it all sex, all the time. I wasn't too thrilled about it" (p. 245)
>
> "[People] think they like [sex]. People love it, but not me. I'm not that crazy. I used to be, but I ain't no more. See, you're 16, you're not ready. If you're not ready, then what's the sense of you doin' it? You're not ready for the responsibility of having a baby and having AIDS because that's gonna kill you anyway" (p. 245).
>
> "It probably would be scared for me. I mean, you know, because it would be the first time. Uh, you know, what's going, you know, what's gonna happen to my body after sex" (p. 245).

Without the proper guidance, women with ID may lack the self-efficacy skills necessary to talk to their partners about what they need to promote pleasure in their sexual encounters. Additionally, without proper guidance, those with ID are open to more sexual abuse than those without disabilities.

Fitzgerald and Withers (2013) conducted a study in the United Kingdom, using interviews, to discuss sex and sexuality with women with ID. Participants were 10 women with ID with ages ranging from 19-64 years old. Semi-structured interviews were conducted to explore how the women felt as sexual beings. Themes of the study included sex and sexuality, regulated beings, and women with ID.

Eight of the 10 women thought sex was not something to be discussed. One participant claimed having sex would "make me go sick" (p. 7). Others held similar, negative opinions on sex:

> "Like every time he used to knock on the door, oh do you want to have sex, aww no I can't be bothered tonight and that, he just like get his pants down and start doing it and I were like get off me" (p. 8).
>
> "'Cos of all the pain we get, it's horrible, men don't get half of the things we get…We have to go through all the pregnancies, periods, and you know when we have to go for tests and stuff, (whispered) smear tests and all that, I don't like those" (p. 8).

Many women discussed having to hide their sexuality. One participant talked about staff members at her home not allowing them to do more than 'kiss and cuddle' while another participant talked about how her mother influenced her decisions on sex:

> "My mother said never do it…She said it's alright to have a cuddle and then leave it at that and a kiss but that's all, not more than that" (p. 9)

Schaafsma et al. (2017) conducted a study in the Netherlands where they conducted semi-structured interviews with 20 people with ID (10 males and 10 females) on the topic of sexual education. The average age of participants was 28.9 with a range from 15-52. Considered a needs assessment and using Step One of the Intervention Mapping protocol, topics in the interviews were: sex education, relationships, sex, social media, parenthood, and support.

Results of the interviews showed 19 out of the 20 participants received sexual education of some kind (e.g., school, staff member, parent, reading a book). One participant started the conversation with his parents first,

> "uhm, I started and I found it very pleasant. They were really glad that I started talking about it" (Schaafsma et al., 2017, p. 25).
>
> "I received sex education last year, but if you would ask me questions about it I wouldn't know what to say" female, age <20 (p. 25).

When asked about sexually transmitted diseases, all participant knew that safe sex is when they use a condom. A majority of the participants (11), when asked to name sexually transmitted diseases, were able to name HIV and AIDS.

> "AIDS, and uhm, HIV. But also other genital diseases that can make your genitals smell bad and stuff" (p. 26).
>
> "But the disease can only occur when the girl has slept with several boys" (p. 26).

Four out of the 20 participants disclosed some type of sexual abuse in the interviews. Out of the four participants, three were females.

> "I was sexually abused there (boarding school) for 7 years by another boy. He put a knife to my throat and a gun against my head. I went to the staff, but they did nothing. I also went to the police, but they collaborated with the boarding school, and they did nothing as well. I was thinking what now? I was powerless." (p. 29).

Summary of Evidence

The results of this systematic literature review support further research on the sexual education of women with ID. People with ID are more likely to become victims of sexual assault than their non-disabled peers. While studies have shown a gradually more positive attitude toward the sexuality of persons with ID (Azzopardi-Lane & Callus, 2015; Bernert & Ogletree, 2013; Fitzgerald & Withers, 2013; D. Schaafsma et al., 2017), a missing piece is the prevention

of sexual assault. Most research in the area of sexual assault of persons with ID is coming from Australia and the UK (Eastgate et al., 2011; Fitzgerald & Withers, 2013; Murphy & O'Callaghan, 2004; Northway et al., 2013; D. Schaafsma et al., 2017). Research in the United States is not current and rarely includes prevention strategies for persons with ID. Research is needed to find a balance between early sexual education and prevention education. If research is focused on finding strategies that work to prevent the sexual abuse of persons with ID, the statistics of 90% and 75% will hopefully be a thing of the past. This study is being conducted to hear the voices of females with ID to potentially identify ways to lower, and perhaps someday, to eradicate this issue.

CHAPTER THREE: METHODOLOGY

Introduction

The purpose of this qualitative study is to explore the sexual education and sexual assault of women with ID. Between the years 2011-2015, females with ID had the highest rate of violent victimization out of any other disability (Harrell, 2017). The Bureau of Justice Statistics (BJS), an entity of the United Stated Department of Justice, defines sexual assault as

> A wide range of victimizations, separate from rape or attempted rape. These crimes include attacks or attempted attacks generally involving unwanted sexual contact between victim and offender. Sexual assaults may or may not involve force and include such things as grabbing or fondling. Sexual assault also includes verbal threats. (Morgan & Kena, 2018, p. 20)

The BJS also defines rape as

> Coerced or forced sexual intercourse. Forced sexual intercourse means vaginal, anal, or oral penetration by the offender(s). This category could include incidents where penetration was from a foreign object such as a bottle. Includes attempted rapes, male and female victims, and both heterosexual and same-sex rape. Attempted rape includes verbal threats of rape. (Morgan & Kena, 2018, pp. 19–20)

Each state, however, has its own definitions and penalties for sex-related crimes. These variations in definitions and who defines these acts have created issues at the local, state, and national levels in the accuracy of reporting sexual assault (Keilty & Connelly, 2001). Despite this lack of clarity in both use of terms and what is or is not reported, current data clearly portrays a rate of sexual assault for individuals with ID exceeding the national average. The rate of reported assault of women without disabilities is at 33% (Smith et al., 2017) while women with ID are

57% more likely to be sexually assaulted than a women without a disability (a rate reported as high as 90%) (Bureau of Justice Statistics, 2017; Keilty & Connelly, 2001).

For the semi-structured interviews of the study the researcher relied upon the definition of ID provided by the Individuals with Disabilities Education Act (IDEA) and the American Psychiatric Association (APA) to identify female participants. Both the definition of sexual assault and the definition of ID guided the researcher in identifying the population to interview for the study and in the creation of the interview protocol. Knowing the statistics of sexual assault of women with ID, the researcher determined this population to be of the greatest need, though also recognizes there are many other populations that require support as well.

Purpose Statement

The purpose of this study was to use qualitative methodology to analyze the lived experiences of women with ID, who have been sexually assaulted, to understand the individual and interwoven levels of their lives through a phenomenological study. As research and statistics have proven (Antaki et al., 2015b), people with ID have the highest rate of crime and assault over other types of disabilities (Harrell et al., 2012). This study will seek to understand how sexual education and sexual assault prevention curricula impacted women with ID who were sexually assaulted. In this study, the researcher interviewed seven women with ID who have been assaulted to try and understand their past history prior to, or after, their assault, regarding their sexual abuse prevention and sexual education.

Research Questions

The primary question answered in this study is: What are the lived experiences of women with ID who have been sexually assaulted?

Sub-questions

1. What were the experiences of women with ID who were sexually assaulted in relation to sexual education?
2. What were the experiences of women with ID who were sexually assaulted after the assault happened?
3. What are the lived experiences of women with ID who have been sexually assaulted compared to the rates reported in the National Crime Victimization Survey?

Research Strategy: Appropriateness of Design

Phenomenology

While Edmund Husserl (1859-1938), a German mathematician and philosopher, is considered the father of phenomenology, he was a student of Franz Bretano (1838-1917) who was the first to discuss the idea of the "intentional nature of consciousness" and the "internal experience of being conscious of something" (Holloway, 1997, p. 117). The idea behind phenomenology is to describe the experiences of people involved with the same phenomenon. Phenomenologists seek to leave behind the individual and instead focus on common experiences (Creswell, 2013). Husserl believed in order to understand a common phenomenon, one must

remove all outside experiences and focus strictly on the shared event (Eagleton, 1983). He was the first to use the term 'phenomenology' which was then defined as the science of phenomena (Moustakas, 1994). The researcher in this study sought to understand the phenomenon of sexual assault of women with ID and to describe as accurately as possible the lived experiences of the participants to arrive at the ultimate truth of the phenomenon (Solomon & Higgins, 1996).

While there are many approaches to phenomenology, the researcher followed the procedures for Moustakas's (1994) transcendental phenomenology. Through a transcendental phenomenology, the researcher removes all prior knowledge and prejudices by a process called 'bracketing'. Based on the stages for transcendental phenomenology, the researcher first determined a phenomenon to study (sexual assault), then went through the process of bracketing out any personal experiences had with the phenomenon (Creswell, 2013; Moustakas, 1994). The researcher was then able to conduct the interviews and analyze the data without any preconceived notions clouding the data.

During the phenomenological study, seven women with ID who were sexually assaulted were interviewed using semi-structured interviews. The researcher followed Colaizzi's (1978) qualitative data analysis procedures in collecting data through interviewing, followed by coding and analyses based on a phenomenological study (Colaizzi, 1978; Sanders, 2003). Interview questions used to gather data about this phenomenon can be found in Appendix A. Analyses of the phenomenological themes derived from the interviews were compared to data collected from the National Crime Victimization Survey of women who were sexually assaulted and were not identified as ID from a prior study (Schreffler, 2019).

Participants

This researcher gathered data from seven women, ages 18-65 years old, with mild to moderate ID who were sexually assaulted. Participants were women from within the continental United States. In order to participate in the study, the participants must have been (a) age 18 or older, (b) female, (c) have mild to moderate ID (IQ between 36-70) (d) have verbal communication skills to have a conversation, and (e) have been sexually assaulted after the age of 15. The researcher used social media and email to contact organizations that work with people with ID and rape crisis centers. Through the search, seven women were identified to participate. Verbal consent was received from either the participant, if they did not have a guardian, or the guardian. Demographic data for the participants can be found in Table 4.

Table 4 *Participant Interview Demographic Data*

	Pseudonym	Age	Race	High School (public/private)	Inclusion or Pull-out	Year Graduated
1	Donna	55	African American	Public	Inclusion	1982
2	Sarah	18	White	Public 2 years Private 2 years	Inclusion then Pull-out	May 2019
3	Betsy	48	White	Public	Inclusion	1990
4	Angelica	38	White	Public 2 years Private 1 ½ years	Inclusion then Pull-out	1999
5	Samantha	59	White	Public	Pull-out	1978
6	Cheryl	65	White	Public for 1 year	Inclusion	GED in 1972
7	Amy	61	White	Private	Pull-out	1977

Throughout the interview, participants were asked about their background in sexual education. Cheryl was kicked out of her public school as a freshman and did not transfer to another school,

instead earning her GED in 1972, and Amy went to a private Catholic school. These unique instances may have affected the level of sexual education the participants received. Topics discussed during each participant's education can be found in Chapter 4.

Settings

Because sexual assault is a sensitive topic to be discussed, interviews took place at centers closest to the participants. Each interview was conducted in a private room where no other person could hear the discussion. Counselors were on site if the participants required extra support during or after the interviews. In several interviews, the participants felt more comfortable with the counselors in the room, which was allowed if a participant made such a request.

Instrumentation

The researcher used semi-structured interview protocols (see appendix A) for interviewing the women with ID who have been sexually assaulted. Questions for the interview protocol were carefully selected based on a review of the literature and in discussions with experts in the field of special education and sexual assault of persons with ID. Experts included those highly regarded in the field of qualitative research and those highly qualified in the field of sexual education for students with disabilities. The questions in the interview protocol were aligned to the Socio-Ecological framework. The interview protocol for this study was validated through a pilot study, where the researcher tested the questions to analyze the content received from participants' answers. Once the interviews were completed and transcribed, the researcher

removed all sensitive information from the transcriptions and used *Nvivo for Windows* (QSR International, 2018) to analyze emerging themes.

Researcher as an Instrument

I have been a special education teacher for 10 years. I received my undergraduate degree in elementary and early childhood education and my masters in special education. Working with students with disabilities has been a passion of mine for many years. Reflecting on my experiences working with students with disabilities, I have both positive and negative views. I have seen the great improvements students can make when included in the general education population, but I have also had to advocate strongly to make sure students had the same education as their typically developing peers. I am currently working toward my Ph.D. in special education, and my research has impacted my views as well.

Working with the Down Syndrome Foundation on parent and student sexuality education has led me further into the belief that sex education and sexual assault prevention is a community effort. I have conducted research in collaboration with Advocates for Youth on preparing middle and high school health teachers to create inclusive, LGBT classrooms. This research opened my eyes to the high probability of women with ID being sexually assaulted. It also made me realize many health teachers do not have the professional development needed to teach sexual education to those with ID. Additionally, the curricula used by many health teachers is not appropriate for students with ID. My research also has shown sexual assault prevention is lacking for those with ID. Both my teaching and research experiences have impacted my views as a researcher.

Procedure

The researcher received IRB approval in September of 2018 with revisions accepted in November 2018. Recruitment of the seven women with ID, who have been sexually assaulted at least once since the age of 15, was completed in February 2019. The researcher worked with local counselors to set up dates and times for participant interviews. Interviews took place at organization centers or counseling centers close to the participants. Counselors were available at all times during the interviews at all locations. During each interview, the researcher began with non-invasive questions to build a rapport with the participant. Participants had the option of not answering questions they deemed too intrusive or if they started to feel anxious or uncomfortable. See Appendix A for the questions asked of the participants, and how each question aligns with the Socio-Ecological framework.

All interviews were audio recorded and transcribed through Rev.com. A client non-disclosure agreement was signed with Rev.com due to the sensitive nature of the interviews. After the interviews were transcribed, the researcher met with the participants to review their answers for member checking either in person or over the phone. During this follow-up meeting, the participant was able to correct anything she thought was misconstrued or elaborated on any questions and answers. Transcribed interviews and interviewer notes were uploaded into *Nvivo for Windows* (QSR International, 2018) using a coded number for each participant to protect their identity for further data analyses.

National Crime Victimization Survey

Data collected during the interview process was compared to data collected in a prior study that analyzed the National Crime Victimization Survey (NCVS) (Schreffler, 2019). The

use of the NCVS started in 1973 and is the primary source of criminal victimization for the nation (United States Department of Justice & Bureau of Justice Statistics, 2015). The survey is derived from a sample taken from 135,000 households, 225,000 persons, representing the nation's population, which specifically includes those with disabilities. Data collected on sexual assault victims includes the frequency, characteristics, and consequences of crime victimization in the United States. The survey is collected via in person interviews, with subsequent interviews occurring over the phone or in person. The youngest age of participants in the database is 12-years-old, though data for this survey will only include participants over the age of 18. Data from the NCVS came from an analysis of the 2016 database. The researcher analyzed the data using descriptive statistics about women with a cognitive disability (from this point forward termed ID for purposes of this study) who have been sexually assaulted.

Using the categories 'cognitive disability' as ID is defined in the NCVS, the variable of sexual assault of females was analyzed. Further analyses of the data occurred to determine any differences that exist between females with ID and those considered for this study not disabled (exclusion of all female participants who checked any of the disability categories in the NCVS database). The researcher utilized SPSS for the data analysis process. Similarities and differences between the NCVS data and the data collected by participant interviews were analyzed based on descriptive statistics.

Method of Analysis

The researcher followed Colaizzi's method of analysis for a phenomenological study (Colaizzi, 1978; Sanders, 2003). The participants' interviews were analyzed using the seven steps in the process: (a) acquiring a sense of each transcript, (b) extracting significant statements,

(c) formulating meaning, (d) organizing formulated meanings into clusters of themes, (e) exhaustively describing the investigated phenomena, (f) describing the fundamental structure of the phenomena, and (g) returning to the participants. Themes were derived from each step of the process.

The first step conducted by the researcher occurred after interviews were transcribed to acquire a sense of each transcript. The researcher began by reading through each transcript once in order to gain a rudimentary understanding of the interviews. The researcher then read through each transcript twice more before moving onto the second step.

The second step was to extract significant statements from the transcripts. The researcher used the software *Nvivo for Windows* (QSR International, 2018) to highlight statements significantly related to the research questions. During step three, the researcher read through significant statements twice and organized those ideas based on the meaning the researcher derived from the statements. Based on the meanings derived from step three, the researcher extracted key words and phrases from the statements to formulate clusters of themes, which corresponded with step four. These ideas extracted at step three became the main and secondary themes for each research question. For step five, the researcher then proceeded to write a detailed, exhaustive description of the phenomenon found in step four. The data were then condensed into a summary during step six.

Step seven required the researcher to return to the participants to seek validity of the writing of the researcher. Due to the sensitivity of the data collected in interviews, this step was completed out of order. The researcher transcribed the interviews immediately after the interview and went back for member checking the next day. The researcher went over the verbatim transcripts with the participants. The participants were able to provide feedback and clarification

on the accuracy of the interview. While out of order, this satisfied the description of step seven and was critical to ensure victims did not have to talk about the issue outside of the IRB approved setting with a certified counselor available.

Trustworthiness

Member Checking

Member checking is when data gleaned from interviews is shared with the participants to ensure their thoughts were captured accurately (Creswell, 2013). After the interviews were transcribed, the researcher met again with the participants, either in person or over the phone, and reviewed the answers to their questions. Changes or discrepancies were noted and changes made in the final transcripts analyzed.

Coding the Data using *Nvivo for Windows*

Steps two through four in Colaizzi's methods (1978) of analysis require the researcher to code significant statements from the research. The researcher used *Nvivo for Windows* (QSR International, 2018) to complete steps two through four in coding the data. Significant statements found in the transcripts were divided into themes based on each of the research questions in *Nvivo for Windows*.

Inter-Coder Agreement

Reliability of the data were completed using inter-coder agreement. According to Creswell (2007), inter-coder agreement can be used when multiple people code and analyze the data. The second coder was a graduate from the Exceptional Education program at the University of Central Florida. A rate of 90% was the agreed upon rate to establish reliability. The final rate of inter-coder agreement was 93%.

CHAPTER FOUR: RESULTS

Introduction

The purpose of this study was to investigate the lived experiences of women with ID who have been sexually assaulted and to understand how their sexual education may have impacted their ability to protect themselves. The study utilized a phenomenological research design to explore the phenomenon of the sexual assault. An analysis of seven interviews was performed using Colaizzi's method (1978) of analysis for qualitative studies. Themes were derived from the data and used to help answer the research questions. The primary question answered in this study is: What are the lived experiences of women with ID who have been sexually assaulted?

Sub-questions

1. What were the experiences of women with ID who were sexually assaulted in relation to sexual education?
2. What were the experiences of women with ID who were sexually assaulted after the assault happened?
3. What are the lived experiences of women with ID who have been sexually assaulted compared to the rates reported in the National Crime Victimization Survey?

The researcher in this chapter presents the participants' stories, the interview process, the analysis of the data collected, themes and meanings derived from the data, and how these themes did or did not align with the NCVS data set.

Participant Stories

The concept of a phenomenological study is to explore the lived experiences of the participants who share in a common phenomenon. By recoding their experiences, researchers are able to draw meaning from these common experiences. The extraordinary women in this study were willing to share their experiences, though it may have caused them pain and sadness. Before the researcher is able to share the data and break apart the experiences of the women with ID interviewed, the participant's stories are shared to be understood and heard as a whole. The following are the stories of the sexual assault of the women interviewed. Sarah's story is the prologue found in Chapter 1.

Donna

Donna is a 55-year-old woman. While she currently uses a wheelchair, that was not always the case. Donna has had several experiences with sexual assault. When she was 11, she was walking down an alley with a friend in a major metropolitan area. A man in a mask started to chase her and her friend. She told her friend to run, knowing her friend was faster than she was. Donna ran for her life, but the masked assailant caught her and raped her. Sometime during the act, she had the wherewithal to remove the mask on her assailant. She was able to go to the police and identify her attacker because of this action. Unfortunately, it did not stop her from becoming pregnant and losing a baby at the age of 11. It also did not stop her from being sexually assaulted at the ages of 14, 18, and 24. While Donna did not address her assaults from when she was 14 and 18, she did talk about the time when she was 24.

At the age of 24, her boyfriend at the time verbally and sexually assaulted her. There was a time on a bus he put a gun to her head, and she begged him to shoot her in front of all the

witnesses. He continued to verbally and sexually assault her until she had the strength to call her family to come and get her.

Betsy

Betsy is a 48-year-old woman from a rural area. She was sexually assaulted when she was 19-years-old. She was home and recalls it was a church day. Her mom had gone to church with her step-mom and step-dad. Betsy stayed home to watch the crock-pot because they were supposed to have company for dinner, and her mom was not sure if the food was going to need more water or not. She did not want to leave it on and have it burn. Betsy's mom also told her to do the dishes and have the house picked up before they got back. Betsy had finished all of her chores when her mom's boyfriend came over. He was not expected and was not supposed to be there because they were expecting company. Betsy recalls him sitting on the couch, drinking and getting high. The next thing she knew, he had thrown her on the bed, tied her up, and raped her.

Betsy told her mother what happened, but she did not believe her. She then told her step-dad who took her to the emergency room. The hospital did a rape kit. The police came, and Betsy filed a report. The police arrested the boyfriend, and he spent the rest of his life in prison.

Angelica

Angelica is a 38-year-old woman who grew up in a rural area. During the interview, she did not want to go into detail about her sexual assault. "I've come a long way and I don't want to go back. If I talk about it, I'm afraid I'm going to go back. And I don't want to go back." Angelica did know her assailant. She did talk to the police after the assault, and they did a rape kit. Her assailant was not arrested.

Samantha

Samantha is a 59-year-old woman who lived in a rural area her whole life. She was sexually assaulted when she was 44-years-old. Samantha had gone to church and was returning on a church bus when the assailant hid himself in the group to gain access to the apartment building, which is normally secure to outsiders. The assailant knocked on Samantha's door and asked to use her telephone. He attacked her, took her pants off, and raped her on the bed. She started bleeding, and she told her building manager what had happened. The manager called the cops and an ambulance came to take her to the hospital. She had to have surgery that night because the assailant tore her inside. After she got out of the hospital, she stayed at a shelter until she felt safe to return to her home. Samantha met with the police and gave a description of the assailant. That, combined with the DNA evidence from the surgery at the hospital, allowed the police to arrest him. He was sentenced to 60 years in prison.

Cheryl

Cheryl is a 65-year-old woman who was sexually assaulted when she was 58-years-old. She worked with the man who assaulted her. One time, he asked her to go into the men's room, but she refused. She told her supervisor, and he told her "Don't you do that." The supervisor took no action beyond the verbal warning to not do what the co-worker asked. Cheryl had heard other girls who worked with the man talking about how he had sexually assaulted them as well, but they were too scared to do anything about it. One warm February night, Cheryl took a walk down her street. She saw construction happening on a house that someone was trying to turn into a restaurant. The workers were on the street, and the assailant told Cheryl he wanted to show her the place. Once inside the house, Cheryl was dragged into the bathroom and sexually assaulted.

She recalls it was a Sunday night. She talked to her neighbor about what happened, but they did nothing. The next day, she called an organization that helps people with ID, and they immediately put her in contact with someone at a rape crisis center.

Cheryl talked with the police, who had trouble finding her assailant. Finally, when they did find him, he lied to the detective. He was never arrested.

Amy

Amy is a 61-year-old woman who was sexually assaulted when she was younger. When she was 10 or 11, her brother started to sexually assault her. It happened every time her parents went out, to the point she never wanted them to leave because she knew what would happen. It also happened when her parents were asleep. The sexual assault continued until Amy was 15. She never told anyone about it until she was 55-years-old because she was afraid no one would believe her. She still has limited contact with her brother, but only when other people are around.

Data Analysis Results

Participant interviews ranged in length from 21 minutes to 44 minutes, with the average time being 30 minutes. Across all seven participants, 3 hours and 32 minutes of interview data were recorded, transcribed, and analyzed. The results include 610 significant statements relating to the research questions. At the beginning of the data analysis, 323 Units of Relevant Meaning were identified (Colaizzi Step 4) with 68 statements Describing the Phenomenon (Colaizzi Step 5). Based on the data, three main themes arose with 13 secondary themes. These three themes, constructed through the Describing of the Fundamental Structure of the Phenomenon (Colaizzi

Step 6), included: (a) descriptions of the actual assault; (b) participant education; (c) support received after the assault.

In order to gain a deeper understanding of the data, the researcher employed a variation of the Consensual Qualitative Research (CQR) first used by Hill, Thompson, and Williams (1997). Nelson, Englar-Carlson, Tierney, and Hau (2006) used this method to explore not only their primary themes, but also secondary and tertiary themes as well. This method allows the researcher the opportunity to dig deeper into the experiences of the participants (Hill et al., 1997; Hill et al., 2005). Based on the organization of Nelson et al. (2006), primary and secondary themes were analyzed based on frequency. Categories included *typical* if the experience was mentioned by 6-7 participants, *frequent* if mentioned by 3-5 participants, and *variant* if mentioned by 1-2 participants (Nelson et al., 2006). The data are displayed in Table 6 to provide a succinct presentation to allow the reader a deeper understanding of the information gathered from the participants' lived experiences.

Data from this study also were compared to data collected from the National Crime Victimization Survey (NCVS) where possible (Schreffler, 2019). Included in Table 5 is a column indicating the themes related to the NCVS. In the supporting data section for each secondary theme, a separate section is included analyzing the similarities and differences between the data collected in this survey and the national database.

Table 5 Frequency of Participant Experiences by Themes and Secondary Themes

Research Question	Theme	Secondary Theme	Typical	Frequent	Variant	RQ3 NCVS
RQ1	*Participant Education*	Classes Taken		X		
		Classroom Type	X			
		Lessons Learned After Assault	X			
		Other Sources of Education	X			X
		Sexual Education	X			
		Topics Covered	X			
RQ2	*Description of Assault*	Location	X			X
		Assailant	X			X
		Protection of Self			X	X
RQ2	*Support After Assault*	Other People Believing Participant		X		
		Counseling	X			X
		Helping Others		X		
		Police	X			X

Note: Typical = 6-7 participants; Frequent = 3-5 participants; Variant = 1-2 participants

Research Sub-Question One

The first research sub-question was, "What were the experiences of women who were sexually assaulted in relation to sexual education?" Each participant had some type of sexual education, whether it was comprehensive or abstinence-only, at school, through an organization, or with a family friend. Information on the type of education they received can be found in Table 5 in Chapter 3. Data from this study suggests what the participants learned in school did not help prevent their sexual assault. The participants in this study also stated they had learned important lessons from their experiences, ones they wish they could share with younger people.

Research Sub-Question One: Supporting Data

Theme One: Participant Education

While the phenomenon studied was the sexual assault of women with ID, a recurring theme found was participant education. This theme included both sexual education and general education. Each participant came from states where sexual education is not mandatory, but health education is required while providing medically accurate information in public schools. Six of the seven participants had experience in public school, Amy went to a private school, Sarah and Angelica started in public school and transferred to a private school after two years, and Cheryl was expelled from her high school as a freshman. The type of school participants went to and the type of classes they were in (i.e. inclusion or pull-out) could have affected the type of sexual education they received. Secondary themes found under participant education

included: (a) general education classes taken; (b) classroom type; (c) sexual education; (d) topics covered; (e) other sources of sexual education; and (f) lessons learned after assault.

Secondary Theme 1: General Education Classes Taken

One common theme the participants discussed was their favorite classes they took while in high school. Five out of seven participants talked about the classes they had with their general education peers. Donna took a psychology class in high school, and when asked why that was her favorite, stated: "It was my favorite because I love talking to people and understanding them. I took math. That's my favorite subject. I took typing, and Spanish."

Sarah discussed her reading class, stating they used Read 180, which was her favorite because she is currently reading a book on rainforests. Sarah also enjoyed physical education (P.E.) because they had to be bused to a different school (her school did not have a gym).

Betsy had a unique experience in school. Her school offered classes many schools do not these days. Betsy's school had "auto body shop, they have wood shop. Oh yeah, they got into all sorts of stuff."

Participants who discussed their general education classes also mentioned P.E. (or gym), math, science, social studies, and home arts. The researcher had to inquire about home arts, as that was not a class she was familiar with in general. For Angelica, home arts (or home economics) was where she learned about healthy eating and the food pyramid, while others learned those topics in their health class.

In 1970, there were some mainframes and minicomputers used in schools, but not many. In 1975, Apple donated some Apple 1 PCs to schools (Molnar, 1997). Samantha, who graduated in 1978, had a computer class while she was in high school.

Out of the seven participants, five discussed classes they took outside of health or sexual education. Because of the age differences in the participants, each one had a unique experience with the classes they were able to take.

Secondary Theme 2: Classroom Type

While the Individuals with Disabilities Education Act of 1990 brought about the idea of the least restrictive environment (LRE), inclusion for students with ID was not a foreign concept (IDEA, 1990) before 1990. The perception presented about their inclusive experiences varied. Out of the seven participants interviewed, five were included with their general education peers. Sarah and Angelica transferred to a private school after two years of public school. While they were included with their general education peers in the public school, they were placed in pull-out classes in their private schools. Sarah talked about the size of the classes she had at each school: "It was included with all the other students over at (public school), because it was a bigger class over at (public school), but now it's a small class over here at (private school)."

Donna enjoyed being with her general education peers, and felt she was accepted at least by the teachers: "No, I was included with other students. They accepted me. The teachers, they loved me. I got all A's and a student told me, 'You're a teacher's pet.'"

While Cheryl left high school during her freshman year, she recalled being bullied in elementary school when she was included with her general education peers: "That's why they beat me up in school. They called me cootie bug because they said I was always touching people."

Most of the participants were included with their non-disabled peers for at least part of their day. As the data shows, they had different experiences with their non-disabled peers with Donna enjoying her time in the classroom and Cheryl being bullied.

Secondary Themes 3 and 4: Sexual Education and Topics Covered

Participants in this study first talked about if they received sexual education and how long it occurred. They also talked about the topics covered. The researcher merged these two themes because while they were different, they had many similarities. Six out of the seven participants had some type of sexual education in high school, whether it was covered in health class or an actual sexual education class.

Sarah had sexual education combined with her health class. This combined class lasted an entire school year. Betsy also had sexual education in health class but only for two out of the four semesters during her freshman year of high school. Amy, Samantha, and Angelica had a health class only focused on abstinence education. Some of the topics reported by the participants covered in the sexual education or health classes included healthy relationships, AIDS, sexually transmitted infections (STIs), condoms, birth control, and abstinence. Table 6 details the topics reported by the participants covered for each of the participants.

Table 6 Participant Sexual Education Data

	Pseudonym	Source of Sexual Education	Topics Discussed in Education[1]						
			Healthy Relationships	AIDS/ STIs	Condoms	Birth Control	Abstinence	Consent	Sexual Assault Prevention
1	Donna	School	Yes		Yes			No	
2	Sarah	School	Yes	Yes	Yes	Yes		No	No
3	Betsy	School	Yes	Yes	Yes	Yes		Yes	No
4	Angelica	Only Health	No	No	No	No	Yes	No	No
		Organization	Yes	Yes	Yes			Yes	Yes
5	Samantha	Only Health		No	No	No	Yes	No	No
6	Cheryl	Family Friend	Yes	No				No	Yes
7	Amy	Only Health	No	No	No	No	Yes	No	No
		Organization	Yes	Yes	Yes	Yes		No	Yes

[1]Categories left blank indicate topic was not discussed in interview

Donna discussed what and who taught her about sexual education:

> Donna: "They taught about healthy relationships."
>
> Interviewer: "How to protect yourself during sex?"
>
> Donna: "Yeah. I learned a lot of things. They were telling me, they were, the teacher explained it, everything to us, about sex education."

When asked about consent, Donna didn't know what the word meant. After the researcher explained the definition, Donna had this to say: "If that person don't stop it, keep doing it, that means he raped me, and if you don't know what no means, I feel sorry for that person."

Sarah had mixed experiences with sexual education. At her public school, she learned about healthy relationships. However, at her private school: "But over here they just give us a packet and just tells us about our body parts like our nervous systems and all that."

When asked about consent, Sarah didn't know what the word meant. After it was explained to her, her response was: "There's stuff that the school should teach us."

Angelica only had health in school, but she also had education from a D.A.R.E. program, which promotes violence prevention.

> "Well, I had this sex ed class here, down the hall it was in …hmmm, I think it was (name) old room. Because when (name) when he was here. It had females down here, and boys in science. I had sex education here. I remember about how the baby grows inside you. And how the first two or three months the woman don't know she's pregnant until later on. Till the baby starts kicking or something like that. So, the baby moves or something."

Angelica also was the only participant that knew about consent. When asked about the word consent, she couldn't explain what it meant. Once it was explained to her, she understood:

Angelica: “Oh, I see that. It’s permission.”

Interviewer: “So did they talk to you about that, in any of your classes?”

Angelica: “Yeah they taught me that. They said that if it’s not consent, its sexual assault. I mean if they’re doing it, its rape.”

Interviewer: “And what is rape?”

Angelica: “Forced sex.”

Each participant had a unique experience in their schools for sexual education, but others had the opportunity to learn about sexual education from other sources.

Secondary Theme 5: Other Sources of Sexual Education

Another theme that arose in participant education was the idea of learning about sexual education from sources other than a health or sexual education class at school. All seven participants discussed outside sources; however, only five were actually taught about sexual education from someone other than their school. Both Donna and Sarah did not have the opportunity to learn from any source outside of school. Donna stated:

> “I don't know about sex education, 'cause I didn't want to learn from nobody else. I didn't want to learn from my mama, or from school, really from my mother. But I didn't get a chance to learn at all. I had to find out the hard way. That really hurt me, ‘cause I got a baby. And that really hurt me.”

While Sarah did not have a chance to talk to her mother because she passed away, Betsy was able to talk to her mom about sex. Betsy felt comfortable asking her mom questions, though she may not have been ready for the answers.

> “Well, I knew before I even went into high school, because my mom and I would sit

down and talk. Me and my mom are close, and my mom ... I said, 'Mom,' I said, 'I have a stupid question,' and she goes, 'Okay, what's your stupid question?' I said, 'How did you make me when ...' she explained how it happened, I was like, 'Okay, I don't want to know no more. That's enough.'"

Betsy, however, talked about how her mother was the only one she could talk to: "No. My family, you don't talk that way with my family except my mom."

Samantha also talked to her mom about the "birds and the bees," though she said she also learned a lot from her friends and from watching TV.

Angelica and Amy took classes from outside organizations on sexual education. While Angelica never talked to friends or family about sex, she learned about sexual education from the D.A.R.E. program. Angelica had access to the D.A.R.E program through an organization for people with disabilities. She was taught sexual assault prevention, how to protect herself (though she was unable to recall how) and "About how people get, just how if you don't watch out, you can get AIDS and all these sexual diseases and stuff."

Amy took a four-week class on healthy relationships through her local ARC, a national organization that supports people with intellectual and developmental disabilities. She learned from the ARC course about safe sex, condoms, AIDS/STIs, birth control, and sexual assault prevention.

Secondary Theme 6: Lessons Learned after the Assault

Each participant was able to look back on their assault and take a lesson from their experiences. Secondary theme six included the lessons they learned from their ordeal. This theme included lessons they felt they should have learned in school, or lessons they wanted to

pass on to others; each participant had thoughts on what they thought of their assault. Donna talked about how she wished she would have listened to her mother.

> "And I'd say to myself, I said, 'Listen to my mama.' I did a bad thing. I didn't go living to my mama. Well, sometimes when we're young, we think we know better. Right. You gotta learn the hard way. I should've stayed with my family. I shouldn't have did what I did at all. Running off, would've just stayed. I should've stayed home."

Sarah discussed having either something to record the assault so people would believe her or being able to run out of the house.

The idea of fault came up with three participants: Betsy, Angelica, and Samantha. Betsy discussed the blame she felt after her assault and coming to the realization that it was not her fault.

> "I wish I never dressed the way I dressed. I had a pair of shorts on and a pajama top, because that's what ... I was going to wait to get my shower when my mom got home, because we didn't know what time our company was going to be, and I was going to get in the bathtub after my mom got home, so my mom could help me wash my hair and I just wish I didn't have that on. I blamed myself for the longest time, because I thought I was dressing inappropriately."

Angelica wished she could go back and talk to herself the night of the assault.

> "Well, 'Cheer up honey, it's gonna get better.' And if she's like, 'No, it won't,' I'm like, 'Yes, it will. And, you know, you'll get the counseling' and stuff like that. Probably something like that. I don't even know what I mean. (laughs) And that it's not her fault. I look back. I know it's not my fault. Mm-hmm (affirmative). It's their faults."

Samantha also talked about how she knew it wasn't her fault. "I got people telling me how could

it be my fault if the guy got me? It's not my fault any ways. If people want to blame me okay, no it's not my fault, he just got me on my bed."

Four of the seven participants discussed what they thought should be taught in school to protect people from assault. Betsy talked about the idea of trust and what a safe person is.

> "I hope the schools, and I'm not saying this to be smart. They need to teach the kids who to be around and who not to be around. They need to teach them a safe person and not a safe person. They need to teach them to look, listen, and get to know the person, or at least get to ... least if you think the person, you're getting to know this person isn't who he thinks he is, then don't go around him, stay away. Get yourself away from that issue, or you're going to get hurt and that's what I want. I want schools to teach the girls that, and the guys, because there's guys and girls."

Samantha discussed the idea of being cognizant of what is around you. "I would look behind me all the time, see who's behind me, I look behind me a lot. Daytime I look around. Being aware of your surroundings."

Cheryl has learned since her attack three steps she wished she had known before. "Stop, I don't like that. Number two, run away and [three] tell somebody."

Amy, who waited 40 years after her assault to talk to someone about it, learned the power of talking to someone. "I kind of learned that I could have told somebody instead of keeping it inside of me." All participants echoed Amy's thoughts when she stated she wished she could "just say 'no' more and tell them that she was going to tell her parents."

Each participant was able to walk away from their experience and learn something from what happened to them. Three of the participants had to learn that what happened was not their fault. Four participants discussed the need for sexual assault prevention and sexual education in

school. As the data suggests, lessons can be learned from others experiences to help prevent future assaults.

Research Sub-Question Two

The second research question was, "What were the experiences of women with ID who were sexually assaulted after the assault happened?" Two themes emerged in this research question. In order to understand the experiences after the assault, each of the women first described the assault. This description became the second theme of the study. Within the second theme, three secondary themes emerged: (a) knowledge of their assailant; (b) location of the assault; and (c) protection of self. Each woman received some type of support after the assault. Descriptions of the types of support each woman received after their assault were found during the interview process. Secondary themes that arose included (a) police support; (b) the belief of others about the assault; (c) counseling; and (d) helping others. Supporting statements from each participant and a summary of themes are provided.

Research Sub-Question Two: Supporting Data

Theme Two: Description of the Assault

Each participant, with the exception of one, went through the ordeal of describing their assault in detail. Themes that emerged from their descriptions included: (a) knowledge of their assailant; (b) location of the assault; and (c) protection of self. Each woman handled telling their stories in different ways. Before they began to talk, the interviewer made sure they knew if they needed to stop or take a break at any time, they could. Donna was eager to speak. "I won't be

afraid," she said. Some participants preferred to tell the story on their own, while others preferred a question/answer style. Angelica was the only participant who did not want to talk about their assault:

> "I mean, I really don't know what to talk about that anymore. 'Cause I don't think about that anymore. I mean, I just want to leave that part alone, for real. I've just totally moved on, and I don't want bad memories come about and stuff like that."

Secondary Theme 1: Knowledge of Assailant

Statistically, 19.5% of rapes are committed by a stranger, 39% are committed by an acquaintance, 33% are committed by a current or former spouse, boyfriend, or girlfriend, 6% are committed by more than one person or the victim cannot remember, and 2.5% are committed by a non-spouse relative (Bureau of Justice Statistics, 2000; RAINN, 2018). Out of seven participants, two did not know their assailant. Donna was one of the participants who did not know her assailant; however, she has been sexually assaulted more than once. While the first assailant was a stranger, she knew her other assailants. When she was 24, she was sexually assaulted by her boyfriend. The assault in the relationship, Donna said:

> "I couldn't take it no more. 'Cause if I stayed more long, I'd be one dead duck. I remember when he held a gun against my forehead on the bus. He couldn't shoot me in front of everyone. There was a lot of witness. Oh, a lot of witnesses. He didn't. I even told him, 'Could you do it in front of everybody. Everybody's looking. They'll know who did it. They might don't know your name, but they can identify you because they looked into your face.' I think whoever get in a relationship like this, got to be crazy. I started talking to other people about it."

Cheryl was assaulted by a co-worker at her job. Betsy was sexually assaulted by her mom's boyfriend. She recalls:

> "My mom's boyfriend come over, she wasn't even expecting him to come, because he wasn't supposed to be there, because we was supposed to have company come over."

Samantha was sexually assaulted by a stranger.

> "I went to church and he was standing at the bus stop, and I tried to get in the apartment, and he followed me upstairs to my apartment."

Amy recalls being sexually assaulted by her brother:

> "My mom and dad went out, my brother, I never wanted my mom and dad to go out because I knew what my brother was going to do. He kept telling me to go upstairs and stuff like that, and I kept saying 'no' and he kept on saying 'it's just for a little bit just for a little bit' and he kept on talking me into it, and I kept on saying 'no' but he still did it."

As the data shows, most sexual assaults are committed by people known to the victim. In this study, five of the participants were sexually assaulted by someone they knew.

Secondary Theme 2: Location of Assault

Most sexual assaults occur at or near a victim's home. From 2005-2015, 55% of sexual assaults occurred at or near the victim's home (Planty, Langton, Krebs, Berzofsky, & Smiley-McDonald, 2013). Additionally, 48% occurred while the victim was sleeping or doing other activities at home. In this study, four out of six participants were sexually assaulted in their home (the seventh participant did not say where she was assaulted). Donna, who was sexually assaulted by a stranger, was assaulted in an alley. She recalls:

"Me and my friend were walking, we were walking an alley. We're walking in an alley and I told her she can run…But then I was trying to run for my life. But he caught me. But here's what I did, I took the mask off his face."

Sarah was sexually assaulted in both homes she lived. "But the very first time I got sexually assaulted when I was living at (home address)." After that assault, Sarah's family was moved by DCFS. However, the people who assaulted her, her grandfather and cousin, were not arrested so she continued to be assaulted in her new home.

"We went to go stay my uncle apartment for a little bit until we got the trailer. Then when we got the trailer, my dad was better by then. Then we lived in the trailer until my mom died and my cousin came over a couple times. He sexually assaulted me there too."

Betsy was home alone when she was assaulted.

"I was home, it was a church day. My mom had went to church with my step-mom and my step-dad. I stayed home to help my mom. We were supposed to have company for dinner and I was watching the Crock-Pot, because my mom didn't know if it was going to need more water or not. She didn't want to leave it on all day and it would burn…Well, I had everything done before she even got home. Well, my mom's boyfriend come over. She wasn't even expecting him."

Samantha, who was sexually assaulted by a stranger, talked about how he got into her apartment.

Samantha: "He followed me to my apartment and then he wanted to use my telephone and then he attacked me and had my clothes off."

Interviewer: "So he asked you to use your telephone?"

Samantha: "Yes."

Cheryl was assaulted by a co-worker, but the assault did not take place at work or at home. Instead, she recalls:

> "And one warm, February night, it was warm and I walked down the street. Him and his helper were working on the house. And he sees me, and thinks I haven't worked at the courthouse for a while, so he thought I had not seen him. And I didn't remember who he was. So, he ended up seeing me and he was standing there in the doorway. And right after I go in the back right by him, he said ... he wanted to show me the place that he was making the building into a restaurant. Which he could not. And I mean then, invites me in, and went to feel my breast, and drags me into the bathroom. It was a Sunday night."

Amy, who was assaulted by her brother, was assaulted in her home whenever her parents were away. She never told her parents about the assault.

The data collected by the participants in this study correlate with the national data. Four out of seven participants were sexually assaulted at or near their home.

Secondary Theme 3: Protection of Self

In the 2016 data from the NCVS, only 45% of women took self-protective measures during their assault (Schreffler, 2019). Self-protective measures could include yelling, turning on the lights, running away, threatening, screaming, trying to get attention, calling the police, and/or complying with the offender. In this study each woman reacted in their own way. Three women talked about how they tried to defend themselves.

Donna tried to run from her first assailant, and when that did not work, she unmasked him.

"I was trying to run for my life. But he caught me. But here's what I did, I took the mask off his face."

Sarah tried to say no, but she was so confused by the experience, she did not know what to do:

"He took me into his bedroom and he started trying to have sex with me, and I kept on saying yes. And then I said no. I couldn't make up my mind."

Amy kept trying to say no to her brother:

"He kept telling me to go upstairs and stuff like that and I kept saying 'no' and he kept on saying 'it's just for a little bit just for a little bit' and he kept on talking me into it, and I kept on saying 'no' but he still did it."

This theme mirrors the theme on lessons learned after the participant's assault. One theme found there was the lack of sexual assault prevention education. In the theme, protection of self, three women discussed ways they tried to defend themselves, but none of them had the assault prevention education that may have helped them in their experiences.

Theme Three: Support after the Assault

One overarching theme found in the interview data was the amount of support each participant received after their assault. Part of the healing process was being able to do something about the assault and talk to others to prevent it from happening again or to others. The support they received afforded them the courage to talk to the researcher and tell their story. As Betsy stated:

"My friend (name), I talk to her up to this day. Me and her are still real close. We have a Facebook, and we talk. She's asked me how I been doing. I told her, I said, 'Seeing a counselor.' I told her about the interview day, I said, 'Guess what? You're going to be

proud of me, I'm doing an interview today.' She goes, 'About what?' I told her and she's like, 'Are you sure you're ready for this?' I'm like, 'I'm more than ready.' I want to get my story out there. I want girls to know they don't have to be afraid to tell anybody. If this happens, they need to go and say something right then and there. Don't let it go past the day that it happens. Go right then and there and tell. Don't hold it in."

The theme *Support after the Assault* included five secondary themes: (a) police involvement; (b) other people believing the participant; (d) counseling; (e) helping others.

Secondary Theme 1: Police Involvement

Six out of the seven participants dealt with the police after their assault. Some had positive experiences, while others felt the police did not do enough to help them in their situation. Only three of the participants had positive interactions with the police. Interest in finding the assailant was evident in police asking for a description of the attacker. Donna had a unique situation when the police asked her to come in and look at mug shots of possible suspects.

"Because they had me looking at some books. Yeah, like mugshots or whatever? Yeah. I said, 'Now there he go! Right there!' There he is right there. He just walked in. And they said, 'Where?' I said, 'Right there, he come in!'" While looking at the mug shots, her attacker walked into the police station. The police had been looking for him for other crimes not related to Donna's attack. He was charged with multiple offenses and sentenced to life in prison. To this day, Donna is not sure what made him walk into the police station of his own will, "Maybe he had a guilty conscience and he just walked in, or something."

Samantha also was one of several participants asked to provide a detailed description of her attacker. Based on her description, the police were able to identify a suspect. As Samantha

explained:

> "But we had no idea where to find him, so it was months and months, long time later, (name) saw him on the news and called their emergency hotline and said here's the guy, here's the guys, here's the guy. Then they matched that up with the description that [I] gave, identical."

Based on the description Samantha gave, the police were able to find the assailant and bring him in for identification. They asked Samantha to come in to see pictures of possible suspects. She was able to identify her assailant through the photographs. "We had DNA evidence for the hospital from surgery and so then everything changed cause then we knew who it was." Samantha was able to go to court and do her part in putting her assailant in jail.

> "Yeah, he raped this other woman, but they were scared. I testified, I was kinda sad you know, I saw him up there and I'm like aw, you know I saw him at court. So, it was several months. Then went to sentence, December, and we went there, he said, sentence him for 60 years. It was December, but I can't remember what year it was? We went to the court to sentence him and got him and I think it was Judge, (name) somebody, the Judge was. He sentence him for 60 years, I said right on."

The police in Betsy's case also were able to arrest her assailant based on DNA evidence collected using a rape kit suggested when she went to the hospital. "They took my statement, they took pictures. At the hospital, they did a rape kit and they said, 'Yeah, she had been raped.'" Betsy's assailant died in prison.

Unfortunately, not all participants had positive experiences with police. Sarah, who was assaulted by three different men and had multiple encounters with the police, did not have a good experience. The first negative encounter was at the school, after she was assaulted the first time

by her grandfather. The police got the Department of Children and Family Services involved, but did no investigation of their own. After Sarah moved to the trailer, her father called the police after she told him about the continued abuse.

Sarah: "And we called the cops, and the cops took my shorts for evidence."

Researcher: "Did they do anything?"

Sarah: "Not really."

Researcher: "No? Did you have to make a statement? You told them what happened?"

Sarah: "Yeah. Multiple times with the same person, and they were aware each time. And nothing was done."

Sarah was one of four participants who did not see their assailant arrested. Angelica, who did not want to talk about her actual assault, did state that the police did a rape kit, but her assailants were never arrested. Amy never told anyone about her assault until she entered therapy years later. Cheryl made a statement to the police, and they eventually found the assailant:

> "But then, the police could not find him for about over two weeks. A detective that they put on that case ended up off work for a week, so he didn't even get ... nobody even looked for him for over a week. And they still tried, go back there and try to find him. They never found him. And finally, they find him, and he just lies to the detective and gets away with it. Yes. It ended up, (name) here, and two people from (organization), went with me over to the courthouse where I explained to the judge what all happened. All they gave it was a three-day order of protection, I think, three month I mean. Three months. It was a civil no contact order."

Cheryl's assailant was never arrested.

As the data shows, only three out of seven women had positive experiences with law

enforcement. Four of the participants wished more could have been done to put their assailants in prison. Amy, who did not speak to the police, stated, "I kind of learned that I could have told somebody instead of keeping it inside of me."

Secondary Theme 2: Other People Believing the Participant

A common theme across the participants in the study was the idea people did not or would not believe them about their assault. Three out of the seven participants talked about family members not believing them about their assaults. Two out of the seven discussed law enforcement officers not believing them. Each participant had a person in their lives not believe them, and they all talked about not understanding how someone would not believe them. The idea they would lie about their situation was a foreign concept in their discussion with the researcher.

Sarah, who was assaulted by her grandfather, cousin, and neighbor, talked about how she wished she would have had a camera to record her grandfather:

> "I wish I would've had a camera. Or a phone with me so I could've recorded that. Or I wish my grandma could've come out of the bathroom right away. To see that. To see what my grandpa was doing."

Amy waited 40 years before she told anyone about her assault "Because I was afraid they wouldn't believe me." Betsy told her mom first about her assault, but her mom did not believe her. She then told her step-dad, who took her to the emergency room. Betsy did, however, have family members and a boyfriend who did believe her:

> "'Why doesn't she believe me then?' I said, 'I'm not lying about me being raped, why doesn't she ... ' Then after I told her when I was raped, when I was ... after I turned 20, I

told her, and she's like, ‘No you weren't, you're lying.’ She didn't even believe me, but my great aunt (name), she knew I was telling the truth. My friend (name) knew I was telling the truth, because I was crying. I was just a mess. When I met my boyfriend, he's like, ‘(aunt), (participant) been raped. She doesn't like me hugging her without even asking me, I can't even kiss her without asking,’ he goes, ‘She's been raped.’ He goes, ‘This is not funny. You've got to take her by her word.’"

It took hearing a guilty verdict from the court system for Betsy’s mom to finally believe her:

> “She still wouldn't take me at my word, until the court ... Until I had the ... My aunt (name) took me to court today, I had to go to court and they, my mom had went, she had come in the court room, and when she heard them say he was guilty, mom knew I wasn't lying then. Mom had to apologize to me.”

Two out of the seven participants found family members did believe them. A common thread was how scared the women were to talk about what happened. As Cheryl stated:

> “It was mainly I was scared to tell my mother. Mother was really worried about me. Did she believe you? I think she did, I think I was mainly scared even to tell her.”

Both Samantha and Cheryl talked about their interactions with police officers. Samantha’s first encounter with police involved an officer who did not believe her. She eventually met an officer who did believe her:

> “I told them I got attacked, I said ‘If you don't believe me, cut me’ The one cop didn't believe me, okay, if you don't believe me put me in jail because I'm bleeding, I'm not going to jail. He didn't believe me and this other cop in court, but the first one didn't believe me. I mean I guess the other cop believed me.”

Having people believe what the women said was a theme found across five of the participants.

Many of the women echoed Betsy, when she realized that it did not matter who believed her, she knew her own truth:

> "My immediate family, my grandma, my aunt, I didn't think they would turn against me, but they did, so you know what? I didn't care. I knew I wasn't lying. I knew I was telling the truth. I had nothing to hide."

Five out of seven participants had experiences with people not believing their stories. As the data shows, each woman's experience was different, but they each had to explain or deal with those who did not believe them.

Secondary Theme 3: Counseling

Another theme that emerged as part of receiving support after the assault was the concept of counseling. As part of the recovery process, six out of the seven women talked about receiving counseling as part of their healing. Some went straight into counseling after their assaults, while others, like Amy, waited longer to talk to someone. Most had positive encounters with their counselors. Betsy was the only participant that had to change counselors because of a comment made by her counselor:

> "I was seeing a counselor from (school), but I didn't like who I was seeing, so I quit going, because I couldn't handle it, because she was like, 'Well,' she's like, 'You're still young, maybe you did something and you didn't realize it.' She wasn't the greatest counselor."

After that encounter, Betsy first talked to a DCFS worker and found out her options for support and someone new to talk to about her assault. She eventually moved on to a different counselor. She was able to receive the help she needed from this counselor:

> "If it hadn't been for (3 names), I don't know where I would be today, because (organization) helped me tremendously. They got me medicine, they got me the things I needed when I thought I was pregnant and I wasn't, because I was sick. I don't know where I would be today if it hadn't been for them."

Other participants had similar, positive experiences with their counselors. Samantha discussed the benefits of using Sand Tray Therapy to help her work through her emotions: "I look at them, I put the good and bad and I put a lot of things in there. It made me feel good, yeah know…I did a good job." Cheryl received counseling for eight months after her attack, while Amy had counseling for six years, though it did not start until 40 years after her attack. She did not know she could get help for what happened to her. Many of the women took what they learned from their counseling and used it to help others. As Betsy stated:

> "The counseling is helping tremendously. Well, I've had a couple of bad dreams, but other than that, it's been safe sailing. I can actually sit down and talk to girls like (name), who's 19, and let them know, 'Hey, you don't need to go through this. This is not what you ... wait until you're older, wait until you're married.'"

Six out of the seven participants in this study sought counseling after their assaults. Most had positive experiences, with the exception of Betsy's first counselor. The support the participants received from counseling allowed them to start the healing process.

Secondary Theme 4: Helping Others

One common theme that came out of the interviews was the idea of taking what had happened to the participants and using it to help others. Five out of the seven participants are currently helping other women who may be in similar situations. They also are using their

experiences to warn others of the potential danger of sexual assault. Cheryl worked with her organization to talk to kids in school:

> "I was, for a long time, (name) had got grants from the state where we went out to the schools and talked to them, to the schools and other places, to try and prevent them from getting sexually abused."

She was able to take what she learned and turn it into three steps to stop assault: "One is Stop, I don't like that. Number two, run away and [three] tell somebody." Angelica became a self-advocate. She would go to meetings and take webinars. The main goal of being a self-advocate was "how we'd get service dogs out there, and the people that need them, and how we can teach the law about people with disabilities, getting sexual assaulted." Donna started talking to other people about her story, hoping others would learn from it. Betsy talks to other girls. She tells them:

> "Just be careful. If your mom's dating someone, I'm not saying it was my fault, but just be careful. Get to know the guy before you trust him, because I trusted him way before I should have. I should have gotten to know him better, and I didn't. I let my guard down. Be careful who you go around. Make sure you get to know the person. If you're dating someone and he pressures you into doing anything, tell him no. Don't let him pressure you. That's not worth it."

Betsy even uses the TV show *Law and Order* to help others. She watches the show with other girls, and they ask her questions because she wants to teach them. Many of the participants thought if they could tell their story, they might be able to help others. As Betsy stated: "I had opened up to her, and I don't want the other girls making the same mistake. I want them to be able to tell. Don't hold it in, go tell, because you don't need the nightmares."

As the data shows, five out of seven participants have turned their experiences into a way to help others. They are able to talk about their ordeal and speak with others about how it might be prevented in the future.

Research Sub-Question Three

Research sub-question three was "what are the lived experiences of women with ID who have been sexually assaulted compared to the rates reported in the National Crime Victimization Survey?*"* The NCVS is a nationwide survey that takes into account all types of crimes, not just sexual assault. No known nationwide survey exists on sexual assault. While the NCVS is a nationwide survey, only 216 women with cognitive disabilities were included and only 20 of those women reported being sexually assaulted. Those 20 respondents within the NCVS were compared to the seven women interviewed for this study. Within this study, six categories emerged that aligned to the NCVS categories: (a) knowing their assailant; (b) location of the assault; (c) protection of self; (d) level of education; (e) police involvement; and (f) support after the assault.

Assailant

Four out of seven (57%) women in this study knew their assailant. Two did not, and one did not state whether she knew them or not. In the NCVS, 14 out of 20 (70%) respondents knew their attacker. Table 7 provides a detailed breakdown of the relationship each participant had to their assailant.

Table 7 Relationship to Assailants

Relationship	Interviews	NCVS
Child or Step-child	0	1
Boy/Girlfriend	0	5
Friend or Ex	0	3
Roommate	0	1
Neighbor	1	1
Customer/Client	0	1
Grandparent	1*	0
Cousin	1*	0
Brother or Sister	1	0
Coworker	1	0
Parent's Boy/Girlfriend	1	0
Stranger	2	6

*Sarah was assaulted by three different people, each reported in this table

Location of Assault

Four out of six participants (67%) were sexually assaulted at home. One participant was sexually assaulted in an alley, while another participant was sexually assaulted at a different location. Angelica did not wish to talk about her assault, so the location of her sexual assault is unknown. According to the NCVS, and similarly to this study, 60% of women with ID were assaulted at home. Table 8 shows the differences between the participants in this study and the women in the NCVS.

Table 8 Location of Assault

Location of Assault	Study Participants	NCVS
Home/next door	4	12
1 mile or less	0	2
5 miles or less	2	3
50 miles or less	0	1
>50 miles	0	1
Don't know	0	1

Protection of Self

In the 2016 data from the NCVS, only 45% of women took self-protective measures during their assault (Schreffler, 2019). Self-protective measures could include yelling, turning on the lights, running away, threatening, screaming, trying to get attention, calling the police, and/or complying with the offender. In this study, three out of six participants (50%) took self-protective actions. Angelica did not talk about her assault, so she is not included in the results.

Table 9 Type of Self-Protection

Type of Self-Protection	Study Participants	NCVS
Defended self	0	3
Yelled, turned on lights	0	4
Cooperated with offender	0	1
Argued, reasoned	2	4
Ran away, hid, locked door	1	2
Called police, guard	0	2
Tried to get attention	0	4
Screamed from pain, fear	0	3

Level of Education

Five out of seven participants in this study completed and earned a high school diploma. One went on to obtain a college degree, and one left high school after ninth grade and received her GED. These demographics are similar to the data collected by the NCVS. However, the NCVS data showed a higher level of education than the participants interviewed in this study. More women in the NCVS had some college than those in the current study. Table 10 shows the similarities and differences in the educational level obtained by participants in this study versus the NCVS.

Table 10 Highest Education Level

Highest Educational Level	Study Participants	NCVS
High School (no diploma)	1 (GED)	2
12th grade (no diploma)	0	1
High School Diploma	5	8
Some College (no degree)	0	6
Associate Degree	0	1
Bachelor Degree	1	2

Police Involvement

While six out of the seven (86%) participants reported their assault to the police in this study, only 8 out of 20 (40%) people with a cognitive disability reported their assault to police in the NCVS. The biggest reason people with cognitive disabilities in the NCVS gave for not reporting their assault to the police was they considered it a personal matter. Other reasons for not reporting in the NCVS included reporting to a different official, not important to the police, police inefficient, protecting the offender, fear of reprisal, and too inconvenient. Reasons given in the NCVS for reporting the assault to police included stopping the incident, prevent future incidents against the respondent, punish the offender, and duty to tell police.

Additionally, of the participants interviewed for this study, three out of seven (43%) were able to see their assailant arrested. Only one out of the 20 (5%) women interviewed for the NCVS saw arrests or charges made in their case.

Level of Support after Assault

It is interesting to note that 100% of the participants interviewed for this study sought counseling after their assault, while only five out of 20 (25%) women who participated in the NCVS went to counseling. One woman (5%) interviewed in the NCVS claimed to seek help from a victim agency. Victim agencies could comprise of rape centers, victim service centers, legal service centers, and other organizations that help after a person has been assaulted. The women interviewed for this study were found through local counseling agencies, which could attribute to the discrepancy in this data.

Overall, an equal number of similarities and differences were observed in relation to the NVCS. The three categories, assailant, location of assault, and protection of self, showed similar findings between the interviews and the NCVS. The categories, level of education, police involvement, and level of support after the assault showed differences. More participants in the NCVS had college experience. Both police involvement and the level of support after the assault were higher in the interviews than in the NCVS.

Triangulation

One issue that arises frequently in qualitative data collection is the idea behind validating the study and the credibility of the data (Creswell & Miller, 2000). Many procedures are recommended, including triangulation, member checking, and peer reviews. The dispute with validity in a phenomenological study is that comparing a personal experience to other data sources could be seen as diminishing the experience of the participants. The researcher of this study understands that experiences in themselves are valid enough. Member checking and peer reviews were conducted to ensure the trustworthiness of the participant interviews. This next

level of analysis, using triangulation to compare the experiences of the women with ID who were sexually assaulted to the National Crime Victimization Survey and the current literature on sexual assault, is provided to identify current gaps across data sets and to garner themes for potential solutions to prevent sexual assault of women with ID.

Based on the overarching research question for this study, "What are the lived experiences of women with ID who have been sexually assaulted?" the researcher learned about participants' education, sexual assault, and the support the women received after their assault. In the current literature, sexual assault prevention programs exist that are designed specifically for women with ID (Egemo-Helm et al., 2007; Fisher et al., 2013; Hickson et al., 2008, 2015; Khemka & Hickson, 2000, 2015; Ward et al., 2013); however, only one participant interviewed said she received any type of sexual assault prevention education. Sexual assault prevention often is not included in sexual education curricula. In an analysis of the studies included in the systematic literature review on sexual assault prevention (Egemo-Helm et al., 2007; Fisher et al., 2013; Hickson et al., 2008, 2015; Khemka, 2000; Khemka et al., 2005; Ward et al., 2013), all participants showed an increase in awareness, ability to say no, and to leave threatening situations. This finding is particularly interesting based on Sarah's experience where she did not know what to say when her grandfather started to sexually assault her. At first, she said no, then yes, and then shared she did not know how to feel. The researchers from systematic literature (Egemo-Helm et al., 2007; Fisher et al., 2013) identified a lack of generalization skills as a theme when the participants were approached outside of the classroom by confederates. The only type of sexual education data gathered by the NCVS research team was the highest level of education for participants. No clear national database identifying the prevalence or lack of education on sexual assault exists, so for women with ID, what is currently known is limited. Future research

needs to consider how to gather the national state of both sexual assault and sexual education of women with ID while also determining the generalizability of sexual assault prevention skills for this population.

When discussing the support the participants received after their assault, many discussed the counseling they received and the support the police provided in finding their assailants. These themes also were reported in the NCVS, but showed different results. More participants in the interviews had experience with the police and counseling than reported by participants in the NCVS (Schreffler, 2019). Researchers have analyzed the various stages people with ID go through after their assault (Antaki et al., 2015b; Antaki, Richardson, Stokoe, & Willott, 2015c, 2015a; Curtice, Mayo, & Crocombe, 2013; Keilty & Connelly, 2001; Murphy & O'Callaghan, 2004) – including talking to the police and receiving support through counseling. These studies, however, were not discussed in the literature review because they dealt with what happens after the assaults, and this theme did not arise until after the interviews. Future research should be conducted to determine how counselors and educators can learn from the experiences of women with ID and what the best options are after their assault to help them both cope with the assault and to prevent future sexual assault. Additionally, research on sexual education and sexual assault prevention for women with ID should be conducted to determine how policy, sexual assault prevention curricula, and sexual education curricula for women with ID can be used to prevent future sexual assaults.

CHAPTER FIVE: DISCUSSION

Introduction

Sexual assault affects between 50-90% of women with an intellectual disability (ID) at some point in their lives (Keilty & Connelly, 2001; Northway et al., 2013) compared to 20% of women without an ID. Both of these statistics are too high, but the rate for women with ID being roughly four to five times higher calls for immediate solutions to the problem. This study was conducted to provide thoughts on potential solutions by examining the lived experiences of women with ID to understand the significance of the life experiences surrounding sexual assault. While the phenomenon studied in this research was based on the sexual assault of women with ID, findings include their experiences with sexual education and the experiences they had after their assault. At the beginning of this study, the researcher sought to determine the impact sexual education and sexual assault prevention had on the prevention of sexual assault for women with ID. However, the lack of sexual assault prevention for the participants led the researcher to examine three different pathways related to their assault; what occurred before, during, and after this unacceptable event in our society. Therefore, the discussion section is divided into these three different sections as a way to potentially help those involved in supporting women with ID to address this issue at the local, state, and national level. The data collected through interviews shows a need for support at each of these levels to better support and protect women with ID.

These three phases are not new in the sexual assault literature for students with ID, but most research to this point has discussed these phases separately. The voices of these women made it clear the issues were intertwined and comprehensive reform is needed before, during, and after assault for this population of students. Before the assault, prior researchers have examined sexual education curricula for those with ID (Blanchett & Wolfe, 2002; Gougeon,

2009; Schaafsma, Stoffelen, Kok, & Curfs, 2013; Swango-Wilson, 2011; Wolfe & Blanchett, 2003). Researchers also have reviewed specific sexual abuse prevention programs for people with ID (Barger, Wacker, Macy, & Parish, 2009; Doughty & Kane, 2010; Egemo-Helm et al., 2007; Hickson, Khemka, Golden, & Chatzistyli, 2013; Hickson et al., 2015; McEachern, 2012; Stevens, 2012; Ward et al., 2013). After the assault, researchers have analyzed the various stages people with ID go through (Antaki et al., 2015b, 2015c, 2015a; Curtice et al., 2013; Keilty & Connelly, 2001; Murphy & O'Callaghan, 2004). What women should do during the assault did emerge in this study, but current practice in both teaching what to do as well as a specific approaches to help victims was not found in the current literature specific to women with ID. What is missing is the integration of the before, during, and after best practices for women with ID. Of course the ideal model would be prevention that would stop assault, but with the current data showing such high rates, that approach alone is not realistic. It is the intersection of the before, during, and after preparation and approach for women with ID that need further investigation and implication in practice to address the current epidemic for this population of student.

The themes that emerged from the data encompass each aspect surrounding the lives of the women with ID who are examined in relation to the phenomenon of sexual assault. The findings from the interviews are reviewed and discussed based on the Socio-Ecological theoretical framework to understand the overall findings in context of society. Study limitations, implications, and recommendations for before, during, and after assault for women with ID are provided both to information of the field and for future research development.

Review of Methodology

Phenomenology research is used to study the lived experiences of a group of people. The researcher used the phenomenological research design to study the sexual assault of women with ID. Through semi-structured interviews, the researcher sought to answer the following research questions. The primary question answered in this study is: What are the lived experiences of women with ID who have been sexually assaulted?

Sub-questions

1. What were the experiences of women with ID who were sexually assaulted in relation to sexual education?
2. What were the experiences of women with ID who were sexually assaulted after the assault happened?
3. What are the lived experiences of women with ID who have been sexually assaulted compared to the rates reported in the National Crime Victimization Survey?

Theoretical Framework: Socio-Ecological Model

The Socio-Ecological Model (*SEM*) was used as a framework for this study. Originating with Bronfenbrenner, the *SEM* focused on multiple environments affecting behavior, specifically targeting the micro-, meso-, exo-, and macrosystems of influence (Bronfenbrenner, 1979, 1986). Each of these levels correlate with levels of engagement. The microsystem deals with face-to-face relations, including family and social networks. The mesosystem includes how settings are interrelated for the participant. This could include work, school, or environments the participants

are in on a regular basis. The exosystem is the larger picture. For example, the exosystem could explain how government policy might affect the person. Finally, the macrosystem is based on values and beliefs instilled in the person. Each layer and system in the model can affect a person's life.

Bronfenbrenner's *SEM* has been used by many since its inception to understand assault and violence and is the tool being used to frame the discussion of assault from the interviews of these seven women with ID. Belsky (1980) used Bronfenbrenner's *SEM* to draw focus on child maltreatment. His work used the *SEM* to show how each individual layer of the *SEM* could contribute to abuse. Belsky (1980) included aspects of Tinbergen's octogenic development to additionally study the history of abusive parents (Belsky, 1980; Tinbergen, 1951). McLeroy et al. (1988) used Bronfenbrenner's *SEM* and translated it to work with health programming. Others have used the model to understand (a) child abuse (Garbarino & Crouter, 1978), (b) youth violence (Garbarino, 1985; Tolan & Guerra, 1994), (c) partner abuse (Chaulk & King, 1998; Heise, 1998), and (d) elder abuse (Carp, 2000; Schiamberg & Gans, 1999). Most recently, the CDC used the model as a framework for the prevention of violence (Krug, Dahlberg, Mercy, Zwi, & Lozano, 2002). In the CDC's *SEM*, there are also four distinct levels that follow Bronfenbrenner's work as seen in Figure 4. These include individual, relationship, community, and societal.

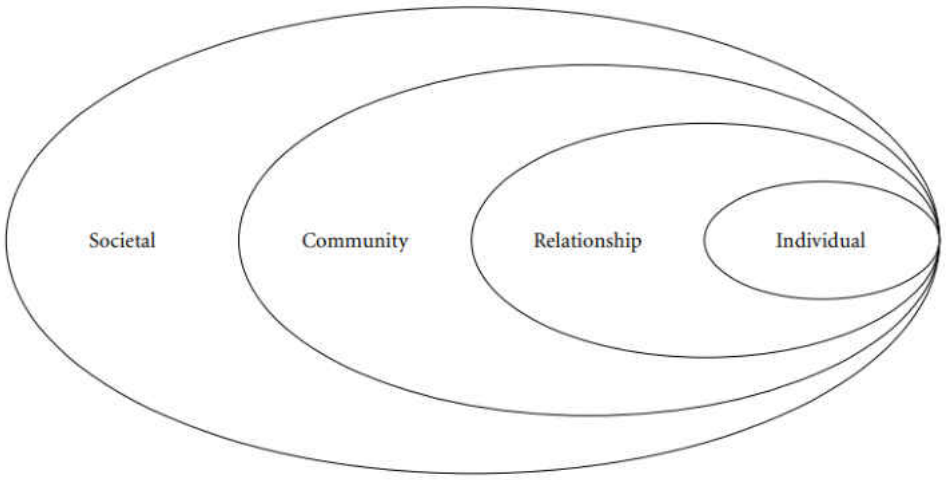


Figure 4 SEM - Adapted from Bronfenbrenner, 1986

Each level of the *SEM* was found in the interviews and themes of this study as shown in Figure 5. The following is a detailed description of how each level was represented and the implications each has aligned with this study.

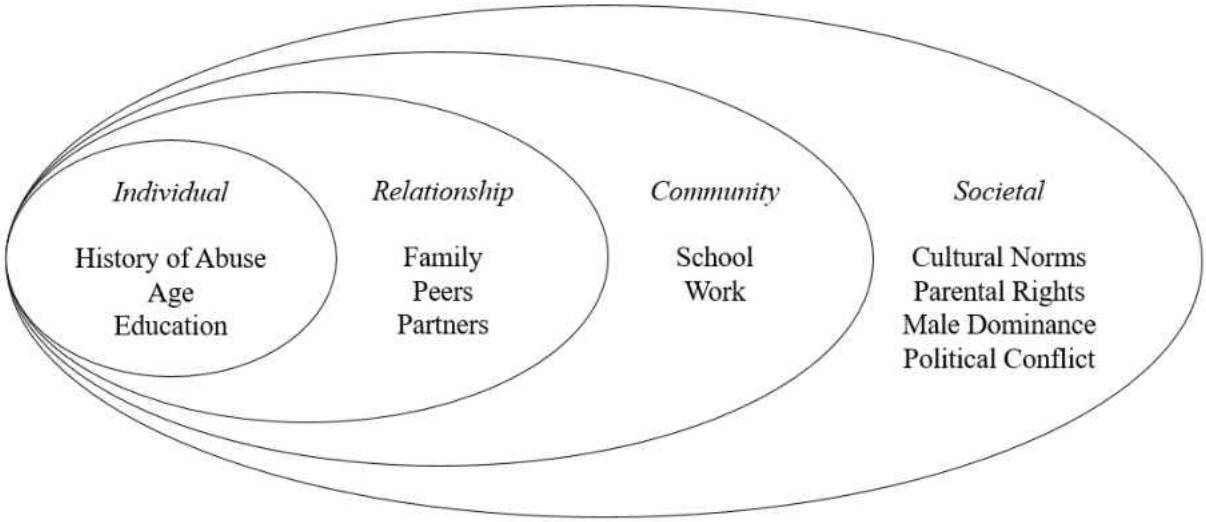


Figure 5 Socio-Ecological Model with connections to themes

Individual

Aspects are considered that relate to the individual, including both biological and personal factors. This relationship could include age, education, substance use, or history of abuse (Bronfenbrenner, 1986; Krug et al., 2002; McLeroy et al., 1988). Factors that were discussed during interviews included a history of abuse, age, and education.

Victims of child sexual abuse are at a greater risk for revictimization, noted by several researchers (Arata, 2002; Cloitre, Tardiff, Marzuk, Leon, & Portera, 1996; Coid et al., 2001; Maker, Kemmelmeir, & Peterson, 2001; Messman & Long, 1996; Schaaf & McCanne, 1998; Spatz Widom, Czaja, & Dutton, 2008; Walsh, Blaustein, Grant Knight, Spinazzola, & van der Kolk, 2007). Arata (2002) reported one-third of child sexual abuse victims experienced repeated victimization. Sexual abuse victims had a two to three times higher rate of revictimization than women without a history of childhood sexual assault (Arata, 2002). Of the seven women interviewed for this study, three were victims of childhood sexual assault (Donna, Sarah, and Amy). Donna and Sarah were revictimized by different assailants while Amy continued to be victimized by the same person.

Age also plays a key factor in the individual level of the *SEM*. Younger women have been found to be more at risk for sexual assault than older women (Acierno, Resnick, Kilpatrick, Saunders, & Best, 1999; Greenfeld, 1997; Heise, 1998; Krug et al., 2002). Approximately one to two-thirds of victims of sexual assault are 15-years-old or less (Greenfeld, 1997; Heise, 1998; Krug et al., 2002). Three of the women in this study were sexually assaulted before the age of 15.

Educational level is the third connection at the individual level in this study. This level has unique properties based on different types of education. Six out of seven of the participants graduated high school with a diploma, with one continuing on to earn a bachelor's degree. One

participant earned her GED. Currently research from the United States is void of a correlation between educational attainment levels and sexual assault. Additionally, the level of educational attainment in sexual education is a factor needing further investigation.

Out of the seven women interviewed for this study, none of them had any type of education in sexual assault prevention in school. Additionally, many were not taught the concepts included in sexuality, which include more than just safe sex. These suggested key concepts in sexual education include sensuality, intimacy, sexual identity, sexual health and reproduction, and sexualization (Advocates for Youth, 1995; Wilson, 2014). Each of these key concepts revolve around a person's values, as shown in Figure 6. The concepts shown in the 'Circles of Sexuality' also pertain to the educational level achievement of the participants in this study. Many missing concepts in their sexual education emerged from the discussion of the participants' phenomenon about sexual education, including the lack of sexual assault prevention provided during their formal and informal education. Informal sexual education includes programs run by outside organizations, such as the ARC and the Down Syndrome Foundation. These programs are a must if students are not receiving the sexual education and prevention education needed at their schools. Additional research needs to be conducted to determine how missing concepts in sexual education, including explicit sexual assault prevention education, is needed for all students but especially for students with ID who are at high risk of assault.

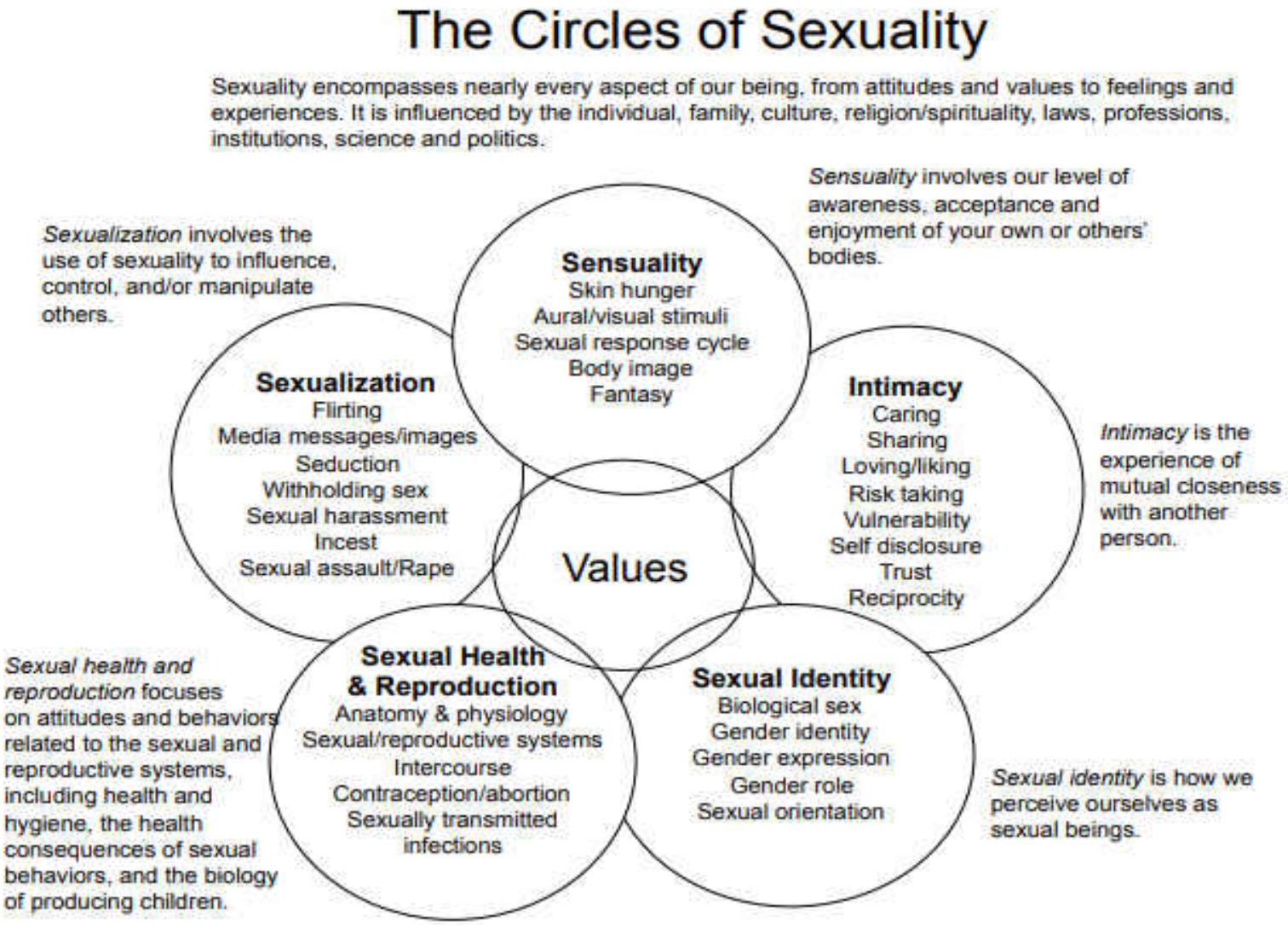


Figure 6 Circles of Sexuality, adapted from *Life Planning Education*, 1995, Advocates for Youth, Washington D.C. Adapted with permission from Advocates for Youth

Relationship

The second level of the *SEM* involves the relationships surrounding the person. Relationships could include peers, family, and/or intimate partners. Throughout the study, each participant was influenced by each of these categories. Donna was assaulted by her boyfriend when she was 24. On the other hand, Betsy had the support of her boyfriend after she had been sexually assaulted. She was able to lean on him, and this support helped her through the healing process.

Family relationships represented for the participants with ID in this study were a mixed bag. Some participants had family members who were extremely supportive before and after their assaults while others faced families that did not believe their stories. The theme of people not believing the experiences of those with ID in sexual assault is a concept not currently documented in literature.

Each participant was supported by peers and went on to become self-advocates. They wanted others to learn from their experiences and went to talk at schools and other organizations to help their peers hopefully prevent an experience like they had encountered. This desire to advocate to prevent assault for other women is a new theme not currently documented in the literature.

The relationships of victims associated with the assailant is another area to consider. Approximately 85-90% of women sexually assaulted know their assailant (National Institute of Justice, 2008). In this study, four out of seven participants (57%) knew their assailant.

Community

The third level of the *SEM* is the person's community. This could include school, work, and other public settings involved in the person's life. Community also includes community beliefs on sexual dominance based on gender and socio-economic levels. Each participant in this study could be classified as a citizen of lower socio-economic status. Studies have shown connections between low socio-economic status and sexual assault (Fergusson, Boden, & Horwood, 2008; Jewkes, 2002; Kimerling & Calhoun, 1994; Koenig, Ahmed, & Hossain, 2003).

The third level of the *SEM* has ties to the individual level for the participants in this study because it also includes the school system. Two of the participants went to private schools, while the rest attended public schools. Each state has its own policy regarding sexual education in the public school system. How individual schools address sexual education can have an impact on students' self-awareness of their own sexuality (Bridges & Alford, 2010; Eisenberg, Madsen, Oliphant, Sieving, & Resnick, 2010; Elia & Eliason, 2010a, 2010b; Linville, 2011; Logue, 2006; Mayo, 2013; McDaniels & Fleming, 2016). Limited knowledge of sexuality and sexual behavior could impact a person with ID's ability to prevent sexual assault (Miller, Pavlik, Kim, & Rogers, 2017). School systems have the ability to choose the sexual education curricula they will use for their students. Finding a sexual education curriculum that includes sexual assault prevention or choosing to add a sexual assault prevention to the student's education could help prevent assaults in the future.

Societal

The societal level includes larger level societies and organizations like government. The factors include social and cultural norms that could increase violence. An example of society in

history could be seen during the rise in eugenics in the United States. People with ID were targeted by a society that considered it inappropriate for people with ID to have children.

In the current society of the United States, the #MeToo movement is bringing to light the amount of sexual harassment and sexual assault seen by all women, including those with ID. With the #MeToo movement, National Public Radio (NPR) conducted a special series, "Abused and Betrayed," that spotlighted the sexual assault of people with ID (National Public Radio, 2018). With this series, society is starting to question the education and protection of people with ID against sexual assault. Since the start of the #MeToo movement, eight states have updated their sexual education standards to include discussion on consent, healthy relationships, inappropriate texting, and online safety (Jones, 2019). An additional seven states have introduced bills to their legislation to update their sexual education policies to include more comprehensive sexual education.

Currently, federal money is used to fund abstinence-only sexual education and not comprehensive sexual education. Policy needs to be challenged to include both a comprehensive sexual education curricula and sexual assault prevention curriculum for all students, including those with ID.

Theory to Practice

In 2004, SIECUS created a tool to analyze sexual education curricula (National Guidelines Task Force, 2004). Each of the four levels of the *SEM* translate to the SIECUS

Guidelines for Comprehensive Sexuality Education as shown in Figure 7.

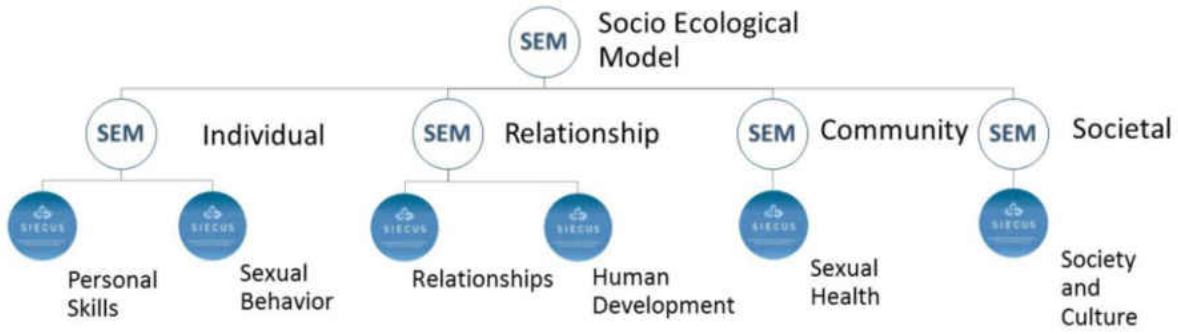


Figure 7 Nested SIECUS concepts in Socio-Ecological Model

Under the first level of the *SEM*, individual, SIECUS represents two key concepts: personal skills and sexual behavior. According to National Guidelines Task Force (2004), which published the guidelines under SIECUS, personal skills encompass the idea that "healthy sexuality requires the development and use of specific personal and interpersonal skills" (p. 15); and sexual behavior includes ideas such as "sexuality is a central part of being human, and individuals express their sexuality in a variety of ways" (p. 15).

The second level of *SEM* includes relationships. Under the SIECUS guidelines, "relationships play a central role throughout our lives" (p. 15); and "human development is characterized by the interrelationship between physical, emotional, social, and intellectual growth" (p. 15).

The third level of the *SEM* includes community. "The promotion of sexual health requires specific information and attitudes to avoid unwanted consequences of sexual behavior" (p. 15). The concept of community includes educators not just in a school, but in the other aspects of a person's life as well. The fourth level, Societal, encompasses SIECUS's key concept of society

and culture. “Society and cultural environments shape the way individuals learn about and express their sexuality” (p. 15).

Part of the issue in research is the research to practice gap. While the SIECUS tool is comprehensive, it is missing sections on sexual assault prevention and adaptation for people with disabilities. A new tool should be created to include these missing parts. The researcher of this study recommends additional research analyzing sexual education curricula through the lens of the *SEM* and the key concepts of the newly created SIECUS tool to analyze curricula. This should include sexual education curricula for both general education courses and sexual education curricula designed for people with ID. Each level of the *SEM* is an important concept that could help improve the sexual knowledge of people with ID and possibly prevent future sexual assault.

Discussion of Findings

In this study, three major themes of the phenomenon of sexual assault of women with ID emerged and were presented in Chapter Four. Each of these themes can be classified into time frames surrounding the assault of women with ID. This discussion will be divided into the following sections: (a) before the assault; (b) during the assault; and (c) after the assault. The themes found during the analyses of the interview data included: (a) participant education; (b) descriptions of the actual assault; and (c) the support the women received after their assaults. In addition to the three major themes, 13 secondary themes emerged, embedded within the major themes. In this section, a brief discussion of themes and secondary themes are provided with connections made to Bronfenbrenner’s Socio-Ecological Model and the outcomes that emerged

from triangulation of the data. Additional discussions are based around the time frame of each theme and the support women with ID needed during that time.

Before the Assault

Data analyzed from the interviews found participant education, or lack thereof, to be the first theme. Their education in many cases did occur in the general education setting where the participants had access to sexual education curriculum or health curriculum. The secondary themes found included general education, type of classrooms (i.e. inclusion or pull-out), sexual education and topics learned, other sources of education, and lessons learned after the assault. In this section will be a brief review of theme one, implications for state and national policy, and implications for sexual education curricula.

Theme 1: Participant Education

The first major theme to emerge was the concept of sexual education for the participants. Evidence from the interviews showed a lack of sexual education as it relates to consent and sexual assault prevention. None of the participants received any education on consent and sexual assault prevention during their school careers. Currently, only 24 states and the District of Columbia require sexual education to be taught in public schools (Guttmacher Institute, 2016). Of those 24 states, only eight require the mention of consent or sexual assault. None of the participants were from states that require consent or sexual assault to be taught.

Similar to the study conducted by Schaafsma et al. (2017) in the Netherlands, topics most mentioned by the participants (number in parenthesis indicates how many received education on this topic) about their sexual education included healthy relationships (6), AIDS/STIs (4),

condoms (5), birth control (3), and abstinence (3). Participants in this study who were taught abstinence-only were not taught any of the other topics mentioned in their school setting.

Participants in this study were from states that did not require sexual education in public schools. If sexual education is taught, two types are typically available: abstinence-only-until-marriage (AOUM) and comprehensive sexual education. Abstinence-only-until-marriage sexual education focuses on abstinence being the only way to prevent pregnancy and STIs (Pittman & Gahungu, 2006). Comprehensive sexual education teaches abstinence as well, but it teaches the best way to prevent pregnancy and STIs, not the only way. Comprehensive sexual education also teaches about other methods of birth control (Pittman & Gahungu, 2006). Only three of the seven participants in this study had access to comprehensive sexual education in their school setting. The others had either AOUM (3) or no sexual education (1) during their tenure in high school. Betsy discussed the lack of sexual assault education during her time at school:

> "I hope the schools, and I'm not saying this to be smart. They need to teach the kids who to be around and who not to be around. They need to teach them a safe person and not a safe person. They need to teach them to look, listen, and get to know the person, or at least get to ... least if you think the person, you're getting to know this person isn't who he thinks he is, then don't go around him, stay away. Get yourself away from that issue, or you're going to get hurt and that's what I want. I want schools to teach the girls that, and the guys, because there's guys and girls."

Betsy's statement aligns with the findings from the Eastgate et al. (2011) study. When asked about their sexual education, one woman stated, "We did not talk about anything about sex at school cos I think we couldn't, I dunno was it illegal for us to talk about it?" (p. 227). Additionally, a participant in the Schaafsma et al. (2017) study reflected on her ability to retain

the information she was taught; “I received sex education last year, but if you would ask me questions about it I would know what to say” (female, age <20) (p. 25).

The themes that emerged for research sub-question one align with current research on sexual education for people with ID. Researchers have shown that sexual education for those with ID is lacking in its content and availability (Blanchett & Wolfe, 2002; Gougeon, 2009; McDaniels & Fleming, 2016; Swango-Wilson, 2011). The themes in this section expand on the needs of women with ID when it comes to sexual education and sexual assault prevention to occur before sexual assault, which did not happen for four of the seven participants in this study.

As noted from triangulation with the NCVS and current literature, women with ID are more likely to not receive sexual education than their non-disabled peers (Barnard-Brak et al., 2014). However, the women with ID interviewed for this study all received some type of sexual education, whether it was abstinence-only sexual education, comprehensive sexual education, or discussed during health class. However, their education did not include pro-active discussions on assault nor did it address the other two areas being discussed; during and after assault.

Implications for State and National Policy

SIECUS publishes an annual report detailing state profiles for sexual education. The report details a mismatch of laws that pertain to sexual education across the United States (SIECUS, 2019b). The following are facts quoted from that report:

- As of 2018, 31 states and the District of Columbia mandate sexual education.
- There is no dedicated federal funding for comprehensive sexual education.
- 4 states require positively affirmed Sexual Orientation, Gender Identity, and Gender Expression (SOGIE) sexual education

- 7 states require teachers to negatively portray or prohibit mentioning LGBTQ people
- 6 states require information on consent to be taught
- 2 states require instruction on sex trafficking
- 32 states require the stress of abstinence in their sexual education programs
- 7 states require culturally appropriate sexual education
- 16 states require instruction on condoms and contraception. (SIECUS, 2019b, p. 1)

These facts are not only for students with disabilities, but all students in the United States attending public schools. As it stands, students with disabilities are less likely to receive sexual education than those without due to exclusion from general health education and the idea that people with disabilities are not sexual beings (Blanchett & Wolfe, 2002; Gougeon, 2009; Schaafsma, Stoffelen, Kok, & Curfs, 2013). Students with mild ID are only 44.12% likely to receive sexual education while those with moderate to severe ID are only 16.18% likely to receive sexual education (Barnard-Brak et al., 2014).

The findings from this study provide a rich description of the educational practices the participants had access to in public schools. Based on the interviews and findings from this study, further research is recommended to determine how state and national policy affects the sexual education of people with disabilities. Based on this study's findings, the researcher recommends the following based on state and national policy.

Due to limitations in this study (i.e. recruitment and homogeneity of the sample), a study should be conducted that includes female participants with ID that were sexually assaulted from all 50 states. Participants from a variety of states that have different sexual education requirements will determine the extent different sexual education programs have on people with disabilities and their abilities to prevent sexual assault.

A study including males with ID could determine differences in sexual education programs and gender. Males with ID should be recruited from each of the 50 states to ensure saturation. A comparison of studies conducted with males and females with ID will determine the effects sexual education has on people with ID.

In order to influence policy, people need to advocate for mandated sexual education for all students. Research has shown comprehensive sexual education is more effective than AOUM sexual education (Elia & Eliason, 2010b; Kohler et al., 2008; Pittman & Gahungu, 2006; Santelli et al., 2006; Stanger-Hall & Hall, 2011). Students with ID need sexual education that explores all avenues of sexuality, including safe sex practices, which are not discussed in abstinence-only education programs. Without a comprehensive sexual education program, students with ID may become more at risk of STIs, unplanned pregnancy, and sexual assault (Swango-Wilson, 2011).

Implications for Sexual Education Curricula

Even though all participants in the study received some type of sexual education, each woman could not recall specifics of the programs or information taught to them. Given the high number of sexual assaults for people with ID, disability should be given a higher priority when it comes to the development of sexual education curricula. In the state profile report by SIECUS, a review of sexual education curricula was conducted based on state reports (SIECUS, 2019a). Programs were categorized into 12 major themes: (a) abstinence-only; (b) sexuality education; (c) healthy relationships; (d) homeless youth; (e) media literacy; (f) medical professionals education; (g) money management; (h) parent education; (i) sexual health; (j) STD and/or HIV prevention; (k) teen pregnancy prevention; and (l) youth development (SIECUS, 2019a). None of the programs reviewed by the SIECUS report were specifically for students with ID.

Recent research has shown Federal policies have driven a focus on "abstinence-only" sexual education for all children in the US, leading to a general ignorance about issues related to sex in the US population (Advocates for Youth, 2009; Bridges & Alford, 2010; Pittman & Gahungu, 2006). Prior researchers have suggested communities hold opposing and antagonistic assumptions about the sexuality of people with an intellectual disability – that they are "forever children" but also hyper-sexual and sexually deviant (Goddard, 1912; Kempton & Kahn, 1991; Pickens, 1967; Smith & Nelson, 1989). As a result, students and adults have had a lack of exposure to quality sex education and sexual assault prevention. According to the National Longitudinal Transition Study – 2 (SRI International, 2002) only 43% of students with and without ID receive sex education. Additionally, only 16.2% of those with moderate to profound ID are likely to receive sex education. While this gap in access to sex education curricula is a problem for everyone in the US, it is especially dangerous for persons with ID who are at much greater risk for sexual assault compared to the general population.

Some research has been done to study sexual education curriculum for students with ID (Blanchett & Wolfe, 2002; Gougeon, 2009; McDaniels & Fleming, 2016; Schaafsma et al., 2013; Schwartz & Robertson, 2018; Swango-Wilson, 2011; Wolfe & Blanchett, 2003). However, the current research does not include how effective the curricula are on the sexual knowledge of those with ID. Additionally, most curricula do not include sexual assault prevention components. For these reasons, the researcher recommends the following:

- A study compiling the effectiveness of sexual education curricula designed for students with ID. Both male and female participants should be included.

- Sexual assault prevention curricula are available outside of sexual education found in schools. A study should be conducted to determine the effectiveness of each prevention curricula to determine if it should be included in school policy on sexual education.
- A study on who provides sexual education in schools should be conducted. Many times, special education teachers are required to teach sexual education when they are not trained in the topic (Girgin-Büyükbayraktar, Konuk-Er, & Kesici, 2017; Hampton, 2017). Professional development should be given to any teacher required to teach sexual education to students with ID.
- A study should be conducted to determine the amount of sexual education knowledge people with ID have after completing sexual education at their high schools. This research could determine the effectiveness of programs across the nation to determine future action in setting policy for sexual education.
- A study should be conducted to determine the skills necessary to prevent sexual assault, especially for those with ID. Once those skills are identified, sexual assault prevention curricula should be identified or created to address sexual assault prevention within the ID population.

During the Assault

The second theme found was the description of the assault for each woman with ID. This included secondary themes on the assailant, the location of the assault, and if the participant used any self-protection measures. This section will give a brief summary of the theme and discuss implications for state and national policy and implications for self-protection.

Theme 2: Description of the Assault

Theme two, descriptions of the assaults, had three different secondary themes. These included location of the assault, participant's knowledge of the assailant, and protection of self. Statistics show most sexual assaults happen at home (Bureau of Justice Statistics, 2000; Planty et al., 2013). Seven women were interviewed for this study, with one choosing to not discuss the actual incident. Of the six that did tell their stories, four were sexually assaulted in their homes. Three of those four were sexually assaulted by people they knew, while one had an intruder in her home.

Additionally, out of the six women who were sexually assaulted that told their stories, four knew their assailant. This matches the current statistics showing only 19.5% of assailants in sexual assault are strangers (Bureau of Justice Statistics, 2000; RAINN, 2018). The two participants assaulted by strangers had different experiences. Donna was walking with a friend in an urban setting while Samantha was at her home. Donna recalled: "Me and my friend were walking, we were walking an alley. We're walking in an alley and I told her she can run…But then I was trying to run for my life. But he caught me."

Samantha's assailant knocked on her door: "He followed me to my apartment and then he wanted to use my telephone and then he attacked me and had my clothes off."

The other women interviewed were assaulted by people they knew. Sarah was assaulted by her grandfather, cousin, and her friend's father. Betsy was sexually assaulted by her mother's boyfriend. Cheryl was assaulted by a co-worker, and Amy was assaulted by her brother. Angelica chose not to tell her story. She did not want to re-live the experience, but she did mention that she sees her assailant sometimes when she walks to work. She would not say if she knew him or not.

"I mean, I really don't know what to talk about that anymore. 'Cause I don't think about that anymore. I mean, I just want to leave that part alone, for real. I've just totally moved on, and I don't want bad memories come about and stuff like that."

The final, secondary theme to emerge when the women talked about the experience with sexual assault was their ability to protect themselves during the assault. As each individual has different reactions to stress and assault, the women interviewed were no different. Three of the women talked about what they tried to do to stop the assault. Sarah and Amy tried to say no, though Sarah admits being confused at first by what was happening. Donna tried to run away, and while her friend was able to run away to safety, Donna was caught and sexually assaulted.

The experiences of the women with ID interviewed for this study reflected the national trends in the NCVS and the current literature. Most of the participants knew their assailant (four out of seven) and the assaults took place at or near the homes of four of the participants. This correlates with national trends of 55% of sexual assaults occurring at or near the victims home (Planty et al., 2013) and 80.5% of victims of sexual assaults knowing their assailant (RAINN, 2018).

Implications for State and National Policy on Sexual Assault

State and national policymakers need to understand what happens during a sexual assault in order to create policy that will help prevent it. By hearing the stories of women with ID who have been sexually assaulted, policymakers will be able to determine what is needed in school and community settings to help prevent sexual assault in the future.

Additional supports can be provided to women with ID in order to teach them skills they might need to access during a sexual assault. This could include self-protection measures and what to do after an assault.

Implications for Self-Protection

Out of the seven participants interviewed for this study, three women talked about how they tried to defend themselves during their assault. One common theme was being aware enough to remember the face of their assailant. Donna even went as far as taking off her assailant's mask so she could remember his face. Women today are taught many different strategies to help them during an assault: keep a key between your fingers, have 911 ready to be dialed on your phone, scream fire if you are grabbed (Nicholls State University, 2019). Strategies to help protect oneself in the event of an assault need to be taught to women with ID. In Donna's case, it allowed her to put her assailant in prison for her assault and may help other women with ID in the future.

After the Assault

The third theme involved support for the participants after the assault. This theme included the secondary themes police involvement, other people's beliefs, counseling support, and helping others. Also discussed in this section will be implications for sexual assault reporting and implications for counselors and law enforcement.

Theme 3: Support after the Assault

The final, major theme found in the data were the discussions of what happened after the sexual assault for each of the participants. In this major theme, four secondary themes were found: (a) police help; (b) other people's belief; (c) counseling support; and (d) helping others. Each woman talked about how these secondary themes supported them through their healing process.

First, the women talked about how the police treated them after they were sexually assaulted. Six out of seven of the women interviewed worked with the police after their assault. Out of those six, only three had positive interactions. From the positive, Donna was asked to look at mug shots when her assailant walked into the police station for some unknown reason. To this day, Donna still does not know why he went to the station; "Maybe he had a guilty conscience and he just walked in, or something." Samantha also provided a description of her assailant to the police; however, it was months before the police were able to arrest anyone. The police in Betsy's case took DNA evidence from her rape kit and were able to arrest her assailant.

Unfortunately, Sarah, Angelica, and Cheryl did not have good results with the police. Sarah, who was sexually assaulted many times by different men and who told the police each time, was unable to see results. The police did nothing to arrest each of the men who sexually assaulted her. Angelica and Cheryl had similar stories. Angelica had a rape kit done and was interviewed by police, but they did not follow through. Cheryl made a statement, the police actually interviewed her assailant, but they did not arrest him.

Another secondary theme found was the idea of other people believing the participants' experiences. Three participants had family member that did not believe they had been sexually assaulted. Two participant talked about the police not believing them. Sarah wished she had a

camera during her first assault so she could have recorded what happened because she felt people did not believe her:

> "I wish I would've had a camera. Or a phone with me so I could've recorded that. Or I wish my grandma could've come out of the bathroom right away. To see that. To see what my grandpa was doing."

Amy waited 40 years to tell someone about her assault. She thought people would not believe her.

Another secondary theme that arose was counseling for the participants after the assault. All seven participants received counseling after their sexual assault. Betsy talked about how her counseling really helped her:

> "If it hadn't been for (3 names) I don't know where I would be today, because (organization) helped me tremendously. They got me medicine, they got me the things I needed when I thought I was pregnant and I wasn't, because I was sick. I don't know where I would be today if it hadn't been for them."

The final, secondary theme found was helping others. Five out of the seven participants were working towards helping others in situations like their own. Cheryl talked about helping out in a school:

> "I was, for a long time, (name) had got grants from the state where we went out to the schools and talked to them, to the schools and other places, to try and prevent them from getting sexually abused."

Betsy wanted to make sure other women knew they should tell someone if something ever happened to them. "I want them to be able to tell. Don't hold it in, go tell, because you don't need the nightmares."

Despite this theme not being identified in the systematic literature review, the findings did not align with past information from the NCVS. All participants in this study sought counseling after their assault while only 25% of the participants in the NCVS had counseling after their assault. Additionally, 86% of the participants in this study worked with the police in comparison to only 40% of the participants in the NCVS. The researcher did not expect to find the level of discussion in this theme, nor the new sub-themes of people believing the participant's story and using the experience to help others. This theme is one the researcher anticipates further in-depth research into this area as a follow-up study.

Implications for Sexual Assault Reporting

In the current political climate, it is necessary to create a system of belief surrounding women who have been sexually assaulted. Counselors and law enforcement officers need to have a positive presence in the lives of women with ID. This could include speaking about sexuality and assault before attempts are made. Creating a welcome environment before assaults occur will encourage women with ID to report assaults after they happen. State and national supports need to include training for service men and women who may come in contact with women with ID who were sexually assaulted. Training in ways to talk to and help those with ID are important factors that impact women with ID's decision to report their assault. With proper training, counselors and law enforcement are able to create a safe environment that is open to all women with ID who were sexually assaulted.

Implications for Counselors and Legal System

All participants in this study sought counseling after their assault; however, not all had great first impressions of their counselors. Additionally, more participants in this study had experiences with the legal system than those in the NCVS. Due to the low N size in the NCVS and in this study, more research is needed. Not all participants had positive experiences with the legal system after their assault. From police not believing their stories to assailants not being held accountable, participants wished the legal system had more training in dealing with situations like their own. The following recommendations could help future victims who are individuals with ID navigate the counseling and legal systems:

- Counselors need to be prepared to work with people with ID. This includes learning about the disability and also how to teach prevention skills to people with ID to prevent sexual assault.
- No national definition of consent exists. Each state has their own laws on consent and can be confusing for people with disabilities. A national definition could solve some of the confusion. Additionally, consent for people with ID may look different than the general population. Those with ID may have less sexual knowledge than the general population (Murphy & O'Callaghan, 2004). These findings raise the question of how much knowledge is "enough" in order to consent to sexual relationships (Curtice et al., 2013; Gill, 2010; Murphy & O'Callaghan, 2004). A study that includes how each state defines consent for people with ID should be conducted. In the study, how consent is defined should be considered for the effect it has on people with ID in relation to sexual assault.
- Training for lawmakers, including police in the criminal justice system, should be given. The use of augmented reality has shown to improve communication and responses in

various populations (Dawson & Lignugaris/Kraft, 2017; Dieker, Hynes, Hughes, Hardin, & Becht, 2015; Judge, Bobzien, Maydosz, Gear, & Katsioloudis, 2013; Straub, Dieker, Hynes, & Hughes, 2014; Vince Garland, Holden, & Garland, 2016). A study could be conducted to determine the effectiveness of using augmented reality as a professional development tool in helping police officers communicate with people with ID. If deemed effective, professional development should be implemented across the United States.

- Grants for research should be awarded for studies conducted in the field of special education, sexual education, and sexual assault. The Office of Special Education Programs (OSEP), National Institutes of Health (NIH), and the Institute of Education Sciences (IES) should provide funding to gather more data on the impact sexual education has on those with ID and to determine if a correlation exists between sexuality knowledge and decreased reports of sexual assault.

Study Limitations

No research is without its limitations. While this study was able to achieve saturation with seven participants, there are limitations that must be shared. Limitations in this study include the process of obtaining Internal Review Board (IRB) approval, lack of generalizability which includes recruitment of participants, homogeneity of sample, and guardianship, participant safety, and researcher bias.

The first limitation was obtaining IRB approval. Because of the sensitive nature of the study, the IRB had to go through a full board review. The researcher found this a difficult process because no one on the board was based in special education. The researcher had to

educate those on the board about ID on, for example, how each person is different, discrepancies in IQ, and the communication levels that are apparent in those with ID. This study was the first of its kind going through this school's IRB, and so the board wanted to make sure all persons involved were covered legally. This discussion included getting the school's lawyers involved. Additionally, the IRB full board only met once a month. Therefore, if an issue needed to be resolved, another full month passed before being able to present the new information. Overall, the IRB process took five months to obtain approval for this study, which could have been spent recruiting additional participants.

The second limitation is the lack of generalizability. This includes the recruitment of the participants, participant bias, homogeneity of sample, and guardianship. Each of these items makes it hard to replicate a qualitative study. Given the specific sample of participants needed for this study (i.e. women with ID that have been sexually assaulted), the researcher used snowball sampling (Babie, 1995; Cohen & Arieli, 2011; Crabtree & Miller, 1992) to obtain the number needed for a phenomenology. In order to do this, the researcher contacted organizations that worked with women with ID. From there, the organizations then may have contacted other organizations or individuals for the study. This snowballing may have affected the representation of the participant sample based on who chose or did not choose to refer participants based on personal reasons (Cohen & Arieli, 2011).

Based on the sensitive nature of the study, participant bias was part of the recruitment limitation. Potential participants may have been unwilling to discuss their assault and thus entered participant bias into the study. The lack of willingness to talk about their assault and participate in the study may have limited the perspectives that were included (Groger, Mayberry, & Straker, 1999).

The fourth limitation in this study was the homogeneity of the sample. The researcher chose to only include women with ID in the study because the statistics for this sample were higher than males (Bureau of Justice Statistics, 2017; Northway et al., 2013). The statistics of males with ID being sexually assaulted also are high; however, they were not recruited for this study. In addition to gender, only one participant was African American while the rest were Caucasian.

Guardianship was another limitation of the study. Many people with disabilities do not have their own guardianship; however, a lack of data exists on just how many existing guardianships have been filed in the United States (National Council on Disability, 2018). This study originally had eight participants, but one was unable to participate because her guardian did not give her permission. A pre-screening survey was conducted to determine participants' guardianships. All seven participants had their own guardianship. Potential participants may have been willing to participate in the study, but not having their own guardianship prevented them from being interviewed. Guardianship could have limited the perspectives included in the study (Groger et al., 1999).

Due to the sensitive nature of the study, participant safety became another limitation of the study. The location had to be carefully planned along with having counselors available for the participants in case they became distressed while talking to the interviewer. Several participants chose to have the counselor in the interview, which may have led to participants sharing additional information with the researcher or withholding information they would have otherwise shared. While we tried to hold the interviews in locations the participants were familiar, they may have not been as open because of the location. Participants also may have

been hesitant to share their stories with the researcher, a person they did not meet face-to-face until the interview.

A final limitation of this study is researcher bias, which impacts the reliability of the data analysis. The researcher has done extensive work in the area of sexual education, including workshops with parents on talking about sexuality with their children. Personal opinions on sexual education and sexual assault were put aside for this study; however, the findings are presented with the caveat of representing only one viewpoint, that of the researcher.

Conclusion

The main question answered by this study was, "What are the lived experiences of women with ID who have been sexually assaulted?" The researcher was able to interview seven women with ID who were sexually assaulted. Through this research, evidence of sexual education, stories of sexual assault, and evidence of support after assaults were identified. Additional, secondary themes found were within the context of the main three themes. In education, secondary themes included types of classes taken, classroom type, lessons learned after the assault, other sources of education, sexual education, and topics covered in sexual education. Sexual education became a central theme for this study. Participant's involvement in sexual education was seen in the major education theme, but also when they were discussing their assault and the support they received. Participants talked about their lack of knowledge in how to prevent an assault and what to do while it was happening. Additionally, they talked about how they knew they needed to tell someone about the assault after it happened so they would be able to receive help. Some participants learned to tell someone from programs they had taken outside of school while others learned it during their classes at school.

Secondary themes from the descriptions of the assaults included locations, assailants, and protection of self. The women in this study were extremely brave to tell the story of their assault. Each wanted to share their experiences in the hope of helping others prevent similar assaults. Many were able to recount in detail their assault and how it helped to be able to move past the experience and begin the healing process.

In the theme, support after the assault, secondary themes emerged of other people believing the participant, counseling, helping others, and police involvement. After each woman was assaulted, they were eventually able to receive the help and support they needed to begin to heal from counselors. Through the help of counselors, friends, and family, each participant is at a point in their lives where they are able to tell their story and want to help other women with ID in preventing experiences like their own.

Sexual assault prevention and sex education needs to begin when women with ID are young and before sexual assaults occur. In this study, the youngest victim was 11-years-old. Both general education and special education teachers need to be trained in how to address sexuality with women with ID. Counselors and law enforcement officers need to be available for young females and women with ID to talk to about their sexuality and assault prevention. Knowing that women with ID have a 90% chance of being sexually assaulted at least once in their lifetime, teachers and counselors need to work together to educate family and community members on how to protect women with ID from assault, but also prepare them if they are assaulted with what to do when and after it happens. This education can be achieved by creating partnerships with outside agencies including police, rape crisis centers, and local organizations dedicated to working with people with disabilities to educate families, community members, and

individuals with ID on ways to prevent sexual assault. Above all, a system of belief needs to be created surrounding those with ID. Victims should always be believed.

To achieve the goal of addressing the sexual education needs of people with ID, people need to meet with and contact their local legislators. Only through national policy will the policy on mandated, comprehensive sexual education for all students be changed. Curricula needs to be created and provided to meet the needs of all students. Finally, professional development for all teachers that will teach sexual education needs to be created, using evidence-based practices to prepare teachers to educate all students, including those with ID. Only with education can the prevention of sexual assault begin to be addressed.

Epilogue

Maybe it was when Angelica did not want to talk about her assault because she did not want to relive her nightmare. Or maybe it was when Samantha said she stayed at a shelter after her assault because she did not feel safe in her own home. Or maybe it was Sarah, the youngest of the women interviewed, who colored in a coloring book and needed to take a break during the interview because she was so upset over her story that made me realize the extreme experiences these women had been through. Each made me stop and think and remember why I was asking them to relive these terrible ordeals. Sarah, who was repeatedly raped by her grandfather, cousin, and a man in her neighborhood was brave enough to tell me her story. These women are the reasons this work is so important. These women have been through horrifying experiences. Each one came out the other side of their experiences a stronger woman, more dedicated than ever, to help those like them heal from ordeals such as theirs. Many of these women have gone on to become self-advocates and work daily to improve the sexual education for those with ID as well

as improve the public's knowledge on the sexual assault rates for those with ID. The women in this study are true heroes. One question from this study remains ever present for the field of special education: What will we do collectively, as a community, to help prevent sexual assault of women with ID from happening in the future?

APPENDIX A
INTERVIEW PROTOCOL FOR PARTICIPANTS

Interview Protocol

Thank you so much for taking the time to talk with me. I want this to be as comfortable as possible for you, so please, if at any time you need a break, you don't want to answer a question, or you don't want to continue, let me know.

Before we start, can you tell me what we are going to talk about today, and what you know about why we are talking (Note: If the participant cannot share verbal consent as to why they are in the study, the participant will be dismissed from the study).

We are going to be talking about some sensitive things today- if you feel yourself getting anxious or upset, we have a counselor available for you to speak to. You just need to let me know if you want to talk to her. You will also have time after our conversation to talk with her if you would like.

We will also be talking about some things that might be a little bit embarrassing or uncomfortable. It's ok if you have different reactions. If you don't understand a question or word, it's ok to ask me to explain.

Before we start, do you have any questions for me?

Yes – answer the questions

No – continue to main interview questions

Main interview questions	**Prompts and elicitations**
Where did you go to high school?	Did you always go to the same high school?
Individual and Relationship	
Have you graduated yet?	What year did you graduate? What year will you graduate?
Do you remember the classes you had to take in high school?	Yes – continue on No – give some examples and see if they can name some (e.g., math, reading)
If I say sex education, do you know what I am talking about?	Yes – continue on No – sex education would have either been a class or part of a health class you may have taken where you might have talked about the changes your body went through, or having safe sex to prevent getting a sexually transmitted disease like using a condom, or not having sex till you are married.
When did you have sex education?	What grade were you in?

	If they don't know: was it when you first got to high school or before or later?
Was the class for the whole year? More or less than that?	One semester, one year, less than a semester? Did you only have it once?
Community and Societal	
What were some things you learned in your sex education class?	
Did you learn about sex ed anywhere else?	Did you parents teach you? Did you have a class outside of school? Do you talk about it with your friends?
Were you ever taught how to protect yourself against sexual assault?	Sexual assault will be defined as being forced or coerced to engage in unwanted sexual activity.
Would you be willing to share with me about the time you were sexually assaulted? No pressure, you can break or stop anytime you need to.	Use stems from National Crime Victimization Survey (NCVS) to prompt.
Knowing you went through this event, is there anything you wish you would have learned in your sex education that might have helped you?	Safe sex Sexual assault prevention Healthy vs unhealthy relationships
These are some of the things we learned by looking at a big national survey you and other women took who were sexually assaulted. I would like to ask you what you think about some of the things they learned and see what you think about what other said in the National Crime Victimization Survey. What are your thoughts on each of these things we learned?	Go through statistics found in the NCVS. Does the interviewee relate to any of them? Do they agree/disagree with my findings? Use stems from NCVS.
Is there anything else you would like to tell me, about your schooling, sex education, or anything in general?	

Thank you so much for taking the time to meet with me. After I have collected all of my data, I will be asking to meet with you again. I would like to go over what I have written from talking with you to make sure I am correct.

How are you feeling? As I said before, there is a counselor here for you if you would like to talk with her a bit before you leave. If you don't want to talk with her now, I can give you her information if you ever feel the need to talk about the things we discussed today.

APPENDIX B
IRB APPROVAL FROM THE UNIVERSITY OF CENTRAL FLORIDA

University of Central Florida Institutional Review Board
Office of Research & Commercialization
12201 Research Parkway, Suite 501
Orlando, Florida 32826-3246
Telephone: 407-823-2901 or 407-882-2276
www.research.ucf.edu/compliance/irb.html

Approval of Human Research

From: **UCF Institutional Review Board #1**
FWA00000351, IRB00001138

To: **Jillian Schreffler** and Co-PI: **Lisa A Dieker**

Date: **October 01, 2018**

Dear Researcher:

On 09/26/2018 the IRB approved the following human participant research until 09/25/2019 inclusive:

Type of Review:	UCF Initial Review Submission Form Full Board Review
Project Title:	Sexual Assault of Females with Intellectual Disabilities and Sexual Education
Investigator:	Jillian Schreffler
IRB Number:	SBE-18-14135
Funding Agency:	
Grant Title:	
Research ID:	N/A

The scientific merit of the research was considered during the IRB review. The Continuing Review Application must be submitted 30 days prior to the expiration date for studies that were previously expedited, and 60 days prior to the expiration date for research that was previously reviewed at a convened meeting. Do not make changes to the study (i.e., protocol, methodology, consent form, personnel, site, etc.) before obtaining IRB approval. A Modification Form **cannot** be used to extend the approval period of a study. All forms may be completed and submitted online at https://iris.research.ucf.edu .

If continuing review approval is not granted before the expiration date of 09/25/2019, approval of this research expires on that date. When you have completed your research, please submit a Study Closure request in iRIS so that IRB records will be accurate.

Use of the approved, stamped consent document(s) is required. The new form supersedes all previous versions, which are now invalid for further use. Only approved investigators (or other approved key study personnel) may solicit consent for research participation. Participants or their representatives must receive a copy of the consent form(s).

All data, including signed consent forms if applicable, must be retained and secured per protocol for a minimum of five years (six if HIPAA applies) past the completion of this research. Any links to the identification of participants should be maintained and secured per protocol. Additional requirements may be imposed by your funding agency, your department, or other entities. Access to data is limited to authorized individuals listed as key study personnel.

In the conduct of this research, you are responsible to follow the requirements of the Investigator Manual.

This letter is signed by:

Kiminobu Sugaya, Ph.D.
IRB Chair

APPENDIX C
SURVEY TO DETERMINE ELIBILITY

Survey to determine eligibility

Do you or your parent have guardianship?
Or
Do you have guardianship or does your daughter have her own guardianship?

Participant has own guardianship

Do you classify as a female?
Yes: eligible
No: not eligible
Are you between the ages of 18-21?
Yes: eligible
No: not eligible
Do you have an intellectual disability?
Yes: eligible
No: not eligible
Have you been sexually assaulted in the last 3-5 years?
Yes: eligible
No: not eligible
Are you willing to be audiotaped?
Yes: eligible
No: not eligible

Parent has guardianship over participant

Does your child classify as a female?
Yes: eligible
No: not eligible
Is your child between the ages of 18-21?
Yes: eligible
No: not eligible
Does your child have an intellectual disability?
Yes: eligible
No: not eligible
Has your child been sexually assaulted in the last 3-5 years?
Yes: eligible
No: not eligible
Do not know
Are you willing to be audiotaped?
Yes: eligible
No: not eligible

APPENDIX D
ADULT CONSENT

Title of study: Sexual Assault of Females with Intellectual Disabilities and Sexual Education

Informed Consent

Leader: Jillian Schreffler, doctoral student

Professor: Lisa Dieker, PhD

Where: University of Central Florida, Community Counseling and Center housed in the College of Education building or at a Crisis Center near you

Why am I being invited to take part in a study?

We invite you to take part in a study because you have been identified as having a mild or moderate intellectual disability (IQ range: 36-69), are currently between the age of 18-21, and have a self-identified documented history of being sexual assaulted between the ages of 15-21.

What should I know about a study?

- Someone will explain this study to you.
- Whether or not you take part is up to you.
- You can choose not to take part.
- You can agree to take part and later change your mind.
- Your decision will not be held against you.
- You can ask all the questions you want before you decide.

Who can I talk to?

If you have questions, concerns, or complaints, or think the study has hurt you, talk to the team at University of Central Florida, College of Education and Human Performance. The leader, Jillian Schreffler, may be reached at [redacted]. Dr. Lisa Dieker, Professor, may be reached at [redacted].

This has been reviewed and approved by an Institutional Review Board ("IRB"). You may talk to them at 407-823-2901or irb@ucf.edu if:

- Your questions, concerns, or complaints are not being answered by the team.
- You cannot reach the team.
- You want to talk to someone besides the team.
- You have questions about your rights as a subject.
- You want to get information or provide input about this.

Why is this being done?

There are three reasons this is being done:

1. To relate data from a national survey to your story of sexual assault.
2. To understand if you took a class about sex education in school and what you wish you would have been taught.
3. To try and see if current sex education curriculum needs to be changed.

How long will the study last?

We expect that you will be in this study for one interview lasting from one to two hours. The leader will contact you within 2 weeks for a follow-up meeting where she will meet with you to make sure her findings are what you meant to say. The PI will contact participants by phone the day after the interview to check to see how you are doing.

How many people will be studied?

Up to 25 people will be invited to participate in this study. You will not be in contact with any other participants.

What happens if I say yes, I want to be in this study?

If you say yes to participating in this study, you will be contacted by Jillian Schreffler to schedule a time to interview you. Over the phone you will be asked a few short questions to determine your eligibility for the study. The interview will last between one to two hours and will take place at the University of Central Florida or at a Crisis Center near you. Jillian Schreffler will call you the day after your interview to see how you are doing.

Participant identifiers will be removed before interviews go to the transcriber. Rev.com will be used to transcribe interviews and a non-disclosure agreement will be signed to protect participant identity.

Jillian Schreffler will contact you again to schedule a follow-up meeting within 2 weeks of your first meeting. This meeting is to go over what Jillian Schreffler wrote down from the interview to make sure she is correctly understanding your thoughts and feelings. This would be a time for you to say things such as "That's not what I meant, this is what I mean" or "Yes, that is how I feel." After this second meeting, you are done with the project.

You will be audio recorded during this study. If you do not want to be recorded, you will not be able to be in the study. Discuss this with the leader or a team member. If you are audio recorded, the recording will be kept on a password protected hard drive in a locked, safe place. The recording will be erased or destroyed after it has been written down. Any writing by Jillian Schreffler will have no way to identify you.

What happens if I do not want to be in this study?

Participation is completely voluntary. You can decide to participate or not to participate. If you don't want to participate that is ok and it will not be held against you.

What happens if I say yes, but I change my mind later?

You can leave the study at any time, and it will not be held against you.

Is there any way being in this study could be bad for me?

Topics discussed in these interviews are sensitive. It may be difficult to talk about your sexual assault. Because of the sensitive topics we will discuss, interviews will take place at the University of Central Florida's Community Counseling and Center housed in the College of Education building. **Counselors will available if you want extra support during and after the interview. Counselors will be located in the room next to the interview room. You will also have access to the counseling center after you complete this project if you need it. You may contact the counseling center at (407) 823-2052.**

Family member may have additional psychological risks when the participants are asked to come in for interviews. Counselors will also be available for them if they require additional support.

If the interviews are taking place at a Crisis Center, participants will have access to certified counselors at the center before, during, and after the study. Information on the center will be provided once the local center is identified.

What happens to the information collected for the study?

Efforts will be made to limit the use and disclosure of your personal information, including study, to people who have a need to review this information. We cannot promise complete secrecy. Organizations that may inspect and copy your information include the IRB and other representatives of

this organization. The principal investigator is a mandated reporter. If the guardian is the person that committed the abuse, the principal investigator will speak to the police and rape crisis center to ensure proper reporting has been done. If proper reporting has not be done, the principal investigator will contact the Florida Abuse Hotline.

Document Revision Date: September 26, 2018

APPENDIX E
PARENT CONSENT

Title of research study: Sexual Assault of Females with Intellectual Disabilities and Sexual Education

Informed Consent

Principal Investigator(s): Jillian Schreffler, doctoral student

Faculty Supervisor: Lisa Dieker, PhD

Investigational Site(s): University of Central Florida, Community Counseling and Research Center housed in the College of Education building

How to Return this Consent Form:

You are provided with two copies of this consent form. If you give consent for your young adult to participate in the research, please sign one copy and return it to the researcher and keep the other copy for your records.

Why is my young adult being invited to take part in a research study?

Your young adult is invited to take part in a research study because she has been identified as having a mild or moderate intellectual disability (IQ range: 36-69), is currently between the age of 18-21, and has a self-identified documented history of being sexual assaulted between the ages of 15-21.

What should I know about a research study?

- Someone will explain this research study to you.
- Whether or not your young adult takes part is up to you.
- You can choose not to allow your young adult to take part.
- You can agree to let your young adult take part and later change your mind.
- Your decision will not be held against you or your young adult.
- You can ask all the questions you want before you decide.

Who can I talk to?

If you have questions, concerns, or complaints, or think the research has hurt your young adult, talk to the research team at University of Central Florida, College of Education and Human Performance. The principal investigator, Jillian Schreffler, may be reached at [redacted]. Dr. Lisa Dieker, Faculty Supervisor, may be reached at [redacted].

This research has been reviewed and approved by an Institutional Review Board ("IRB"). You may talk to them at 407-823-2901or irb@mail.ucf.edu.org if:

- Your questions, concerns, or complaints are not being answered by the research team.
- You cannot reach the research team.
- You want to talk to someone besides the research team.
- You have questions about your young adult's rights as a research subject.
- You want to get information or provide input about this research.

Why is this research being done?

There are three reasons this research is being done:

1. To relate data from the National Crime Victimization Survey to personal accounts of sexual assault.
2. To acquire knowledge from women with intellectual disabilities that have been sexually assaulted in relation to their own sex education in school and what they wish they would have been taught.
3. To link the information obtained from reason one and two to current sex education curriculum to see what is available and what may be missing to inform future sex education curriculum.

How long will the research last?

We expect that your young adult will be in this research study for one interview lasting no longer than one to two hours. After the investigator has analyzed the interview transcripts, she will meet with each participant within 2 weeks of the original meeting to validate her findings with the participant. The PI will contact participants by phone the day after the interview to check to see how they are doing.

How many people will be studied?

We expect up to 25 women with intellectual disabilities in this research study. Participants will not have any interactions with each other.

What happens if I say yes, I want my young adult to be in this research?

If you allow your young adult to participate in this research, you will be contacted by Jillian Schreffler to schedule a time to interview your daughter. Over the phone you will be asked a few short questions to determine your daughter's eligibility for the study. Parents will not be allowed in the interview. Information shared in the interview will be confidential and not disclosed to anyone, including the parents. The interview will last no more than one to two hours and will take place on the University of Central Florida campus or at a Crisis Center near you.

Participant identifiers will be removed before interviews go to the transcriber. Rev.com will be used to transcribe interviews and a non-disclosure agreement will be signed to protect participant identity.

Jillian Schreffler will contact you again to schedule a follow-up meeting with your daughter within 2 weeks of the original interview. This meeting is to go over the transcripts of the original interview to make sure we are documenting your daughter's thoughts and feelings correctly. This would be a time for your young adult to say things such as "That's not what I meant, this is what I mean" or "Yes, that is how I feel." After this second meeting, you and your young adult's part are complete in the research project.

Audio or video taping:

Your young adult will be audio recorded during this study. If you do not want your young adult to be audio recorded, your young adult will not be able to be in the study. Discuss this with the researcher or a research team member. If your young adult is audio recorded, the recording will be kept on a password protected computer in a locked, safe place. The recoding will be erased or destroyed after it has been transcribed. All transcriptions will have no identifying information on them.

What happens if I do not want my young adult to be in this research?

Participation in research is completely voluntary. You can decide to allow your young adult to participate or not to participate. There will be no repercussions to you or your young adult if you choose not to participate.

What happens if I say yes, but I change my mind later?

You or your daughter can choose to leave the research at any time it will not be held against you or your young adult. You will need to contact Jillian Schreffler if this is the case. During the first conversation, contact information for Jillian Schreffler will be provided.

Is there any way being in this study could be bad for my young adult?

Topics discussed in these interviews are sensitive in nature. Participants may have an adverse reaction to recounting their sexual assault. Because of the sensitive topics to be discussed, interviews will take place at the University of Central Florida's Community Counseling and Research Center housed in the College of Education building. **Counselors will be on hand if the participant requires extra support during and after the interviews. Counselors will be located in the room next to the interview room. You and your young adult will also have access to the counseling center after you complete this research project to ensure the continued support of your young adult's mental health. You may contact the counseling center at (407) 823-2052.**

Family member may have additional psychological risks when the participants are asked to come in for interviews. Counselors will also be available for them if they require additional support.

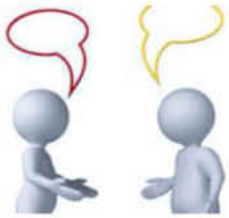
If the interviews are taking place at a Crisis Center, participants will have access to certified counselors at the center before, during, and after the study. Information on the center will be provided once the local center is identified.

What happens to the information collected for the research?

Efforts will be made to limit the use and disclosure of your young adult's personal information, including research study records, to people who have a need to review this information (for example: Principal investigator, faculty supervisor). We cannot promise complete secrecy. Organizations that may inspect and copy your young adult's information include the IRB and other representatives of this organization. The principal investigator is a mandated reporter. If the guardian is the person that committed the abuse, the principal investigator will speak to the police and rape crisis center to ensure proper reporting has been done. If proper reporting has not be done, the principal investigator will contact the Florida Abuse Hotline.

APPENDIX F
ASSENT FORM

Assent Form – Participant Version

Jillian Schreffler and Lisa Dieker want you to be a part of a research study at the University of Central Florida. **We hope to improve sex education for people with intellectual disabilities.** **Your participation is voluntary, and you can stop at any time.**	 UCF College of Education and Human Performance
What you will be asked to do in the study: 1. **Join in an 1-2 hour interview with Jillian Schreffler.** 2. **Go over your interview answers after they have been transcribed to make sure we have what you wanted to say.**	11:00 to 1:00  
During the interview, you will be asked to talk about: 1. **your own sex education in school** 2. **share your story sexual assault** 3. **anything you wish you would have been taught in school that deals with sex education and sexual assault prevention** 4. **You will be asked to relate your story to other stories from a national database.**	 
You will be audio recorded during the study.	
If you have any questions, please contact Jillian Schreffler [redacted]	
Would you like to participate? **Please circle YES or NO**	 

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