EFFECTS OF SEXUAL EDUCATION ON THE SEXUAL KNOWLEDGE OF ADULTS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

A DISSERTATION

SUBMITTED TO THE FACULTY

OF

THE SCHOOL OF PROFESSIONAL PSYCHOLOGY

SPALDING UNIVERSITY

BY

CLAIRE HORTON BANIAK

IN PARTIAL FULFILLMENT OF THE

REQUIREMENTS FOR THE DEGREE

OF

DOCTOR OF PSYCHOLOGY

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LOUISVILLE, KENTUCKY

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ABSTRACT

People with intellectual and developmental disabilities (ID/DD) are often believed to be incapable and unintelligible. This is particularly relevant in regard to their sexuality. Due to strong biases and misconceptions held by many in society, people with ID/DD are often believed to be asexual, hypersexual, or child-like, and, as such, are not believed to understand sexuality or require support to learn more about sexual expression. Unfortunately, these beliefs put this population at risk of sexual abuse and exploitation. Further, people with ID/DD desire sexual knowledge and experience. In fact, sexuality education programs have been shown to increase sexual knowledge for people with ID/DD. By increasing sexual knowledge, sexual attitudes become more positive, sexual experiences and needs are met, and the risk of sexual abuse and exploitation decreases. The present study sought to provide a sexuality education program to eight adults with ID/DD with the expectation that their sexual knowledge will increase and the greatest knowledge gains will relate to boundaries and consent, sexually transmitted diseases, and contraception. The Sexual Knowledge, Experience, Feelings, and Needs Scale for People with Intellectual Disability (SexKen-ID; McCabe, 1994) was utilized as a pre- and post-measure of the sexual knowledge of participants. Participants engaged in nine one-hour sessions focusing on friendships, dating and marriage, anatomy, masturbation, sexual interactions and behaviors, boundaries and consent, contraception, sexually transmitted infections, and menstruation and pregnancy. Results indicated increases in sexual knowledge across all areas measured by the SexKen-ID, with the exception of the Dating subtest on which knowledge was maintained. Further, boundaries and consent, sexually transmitted diseases, and contraception were not found to show the greatest increases in sexual knowledge; however, this is likely due to inflated scores among other subtests. Additionally, knowledge growth pertaining to sexually transmitted infections was minimal and may be impacted by longstanding, false beliefs about AIDS provided by parents, caregivers, and others who likely seek to protect their children from harm. Overall, the findings are consistent with previous studies on the effect of sexuality education on the sexual knowledge of people with ID/DD and provide further support for the importance of sexuality education for this population.

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CHAPTER 1

INTRODUCTION

People with intellectual and developmental disabilities (ID/DD) are often perceived as beneath and less than people who are typically developing. Societal stigma and biases against differences lead to the belief in many myths and falsities that have a strongly negative impact on the lives of people with ID/DD (Basile, Breiding, & Smith, 2016; DiGiulio, 2003; Franco, Cardoso, & Neto, 2012; Gomez, 2012; Hingsburger & Tough, 2002; Irvine, 2005; McCabe, 1993; Pownall, Jahoda, & Hastings, 2012; Saxe & Flanagan, 2014). Many misconceptions surround the sexuality of people with ID/DD, which limits their access to appropriate sexual knowledge and ability to engage in appropriate sexual expression (Azzopardi-Lane & Callus, 2014; DiGiulio, 2003; Gomez, 2012; Healy, McGuire, Evans, & Carley, 2009; Irvine, 2005) and increases their risk of contracting diseases and being sexually exploited (Barnard-Brak, Schmidt, Chesnut, Wei, & Richman, 2014; Basile et al., 2016; Irvine, 2005; Mahoney & Polling, 2011; McCabe, 1993; McGillivray, 1999; Murphy & O'Callaghan, 2004; Saxe &

Flanagan; Swango-Wilson, 2011). Sexual knowledge acquired through sexuality education programs can increase the likelihood that people with ID/DD engage in safe sexual practices (Barnard-Brak, Schmidt, Chesnut, Wei, & Richman, 2014; Caspar & Glidden, 2001; Dukes & McGuire, 2009; Edmonson, McCombs, & Wish, 1979; Lunsky, Straiko, & Armstrong, 2003; Penny & Chataway, 1982; Saxe & Flanagan, 2014).

The present study sought to provide a nine-week sexuality education program to adults with ID/DD in order to increase their sexual knowledge and ability to engage in safe sexual practices. Sexual knowledge was measured by the Sexual Knowledge, Attitudes, Experiences, and Needs Scale for People with Intellectual Disability (SexKen-ID; McCabe, 1994). The SexKen-ID is an interview-based measure that was administered as a pre- and post-assessment of participants’ sexual knowledge.

Myths and Misconceptions

Historically, the sexuality of people with intellectual disabilities (ID) was looked upon as pathological in nature. Many believed that men with ID were aggressors and women with ID were victims. To manage the sexuality of people with ID, many were sterilized and/or placed in gendered institutions (Friedman, Arnold, Owen, & Sandman, 2014). By separating and sterilizing people with ID, the belief, stemming from the early 1900s eugenics movement, was that ID would not spread among society (Friedman et al., 2014; Gomez, 2012).

Prevailing myths and misconceptions stem from early beliefs and treatment of people with ID/DD. The most common misconceptions are that people with ID/DD are asexual, hypersexual, and/or child-like (Azzopardi-Lane & Callus, 2014; DiGiulio, 2003; Franco et al., 2012; Gomez, 2012; Irvine, 2005; Saxe & Flanagan, 2014). Misconceptions about their sexuality impact the way people with ID/DD are treated both in their daily life and in regard to their sexuality. Further, the people with whom this population spends the most time – parents, caregivers, teachers, and support workers – often hold some of the strongest misconceptions (Barnard-Brak et al., 2014; Pownall et al., 2012; Schaafsma, Kok, Stoffelen, van Doorn, & Curfs, 2014; Swango-Wilson, 2008; Szollos & McCabe, 1995; Wilkenfeld & Ballan, 2011; Wolfe, 1997).

Misconceptions and Beliefs of Parents and Caregivers

Parents and caregivers of people with ID/DD hold many false beliefs about the abilities of their dependents in numerous areas of functioning. In relation to sexuality, Szollos and McCabe (1995) assessed the perceptions of caregivers of people with ID regarding the sexuality of people with ID as a part of a larger study on sexual knowledge, attitudes, experiences, and needs of people with ID. Twenty-five participants with ID who were recently mainstreamed into community-based services completed the Measure to Assess Sexual and Relational Knowledge, Experience, Feelings, and Needs (McCabe & Schreck, 1992) interview, and ten caregivers who previously cared for the twenty-five participants with ID in an institutional setting completed the Measure to Assess Caregiver and Parental Perceptions of Sexual and Relational Knowledge, Experience, Feelings, and Needs interview. When compared to the results of the participants with ID, caregivers were found to significantly overestimate the knowledge, attitudes, experiences, and needs of people with ID. Caregivers significantly overestimated the knowledge of people with ID pertaining to masturbation, marriage, homosexuality, sexual interaction, and dating and intimacy. That is, people with ID indicated significantly less knowledge of masturbation, marriage, homosexuality, sexual interaction, and dating and intimacy than indicated and perceived by caregivers. Regarding attitudes and experiences, caregivers significantly overestimated the attitudes and experiences of people with ID related to current relationships, sexually transmitted diseases, masturbation, sexual interaction, and sexual abuse. In terms of need, caregivers significantly overestimated the need of people with ID to know more about pregnancy, childbirth, abortion, masturbation, sexual interaction, and dating and intimacy. That is, people with ID indicated a significantly lesser need to learn more about pregnancy, childbirth, abortion, masturbation, sexual interaction, and dating and intimacy. Rather, female participants with ID indicated a need to learn more about marriage, and male participants with ID indicated a need to learn more about current relationships and menstruation (Szollos & McCabe, 1995). Therefore, it appears that parents and caregivers may not discuss sexuality with their dependents (Brantlinger, 1985; McCabe, 1993; Oladunni, 2012) because they may believe their dependents are already knowledgeable.

Another cause is likely related to the discomfort parents and caregivers have with discussing sexuality with their dependents who have ID/DD (McCabe, 1993). Many parents and caregivers support sexuality education for people with ID/DD (Lofgren-Martenson, Sorbring, & Molin, 2015; Pownall et al., 2012; Swango-Wilson, 2008) but feel uncomfortable or uncertain about providing sexuality education themselves (Lofgren-Martenson et al., 2015; McCabe, 1993; Swango-Wilson, 2008).

Swango-Wilson (2008) assessed the perceptions of 85 caregivers of adults with ID related to the sexuality and ability of the adults with ID to participate in sex education classes. Caregivers were found to support the idea of sex education classes; however, they were uncertain of the usefulness, effectiveness, and appropriateness of such classes. Further, Pownall and colleagues (2012) evaluated the attitudes, experiences, and needs of mothers of adolescents and young adults with and without ID in relation to sexuality. Thirty mothers of adolescents and young adults with ID and thirty mothers of adolescents and young adults without ID completed a series of questionnaires pertaining to their beliefs and attitudes about the sexuality of their children and the support they receive in educating their children about sexuality. Results indicated that mothers of people with ID discussed fewer sexuality-related topics, in less detail, and at a later age than mothers of people without ID. They focused primarily on safety issues in order to protect their children from exploitation and abuse. Mothers of people with ID held more cautious attitudes and beliefs, believing their children were not interested in sexual relationships, did not have sexual feelings, and/or did not understand the concept of sexuality. Moreover, mothers' occupations were found to impact their attitudes and beliefs about their children's sexuality, with mothers who held unskilled positions holding more conservative views about their children's sexuality and engaging in less detailed discussions about sexuality with their children. Pownall and colleagues (2012) found that mothers of people with ID often only provide sexuality education to their children that aligns with their personal biases about their children's abilities and interests. That is, mothers of people with ID who believe their children do not have the same sexual feelings or interests as people without ID are less likely to discuss important sexuality topics such as contraception with their children. The impact of the mothers' biases appears to directly impact the sexuality education provided to their children with ID, which may put people with ID at risk for engaging in sexually inappropriate behaviors and/or being sexually exploited (Pownall et. al, 2012).

The beliefs of parents and caregivers largely impact the beliefs of their dependents with ID/DD (Crockett, Raffaelli, & Moilanen, 2003; Garwood & McCabe 2000; Pownall et al., 2012). When parents and caregivers hold negative attitudes toward the sexuality of their dependents with ID/DD, the dependents often become anxious, confused, and fearful of their sexuality, as indicated by results of the SexKen-ID (Garwood & McCabe, 2000). However, people with ID/DD still experience the sexual motives and drives that people without ID/DD experience. When they feel uncomfortable exploring their sexuality in person, they may utilize other resources, such as the internet, to learn how to engage in sexuality-related behaviors, such as sexual behaviors or dating.

Lofgren-Martenson and colleagues (2015) utilized focus groups consisting of parents and teachers of young adults with ID to examine perceptions of internet use among young adults with ID related to love and sexuality. Seven teachers and five parents participated in focus groups lasting up to an hour. Teachers and parents noted that individuals with ID are often lonely and the internet provides them with a way to develop connections and relationships with others. However, a concern was raised regarding their ability to read the body language of others and understand the feelings and needs of others when using the internet to communicate. As such, there is a greater risk that relationships formed and sustained through the internet can lead to disappointment, frustration, and conflict. Further, appropriate behavior on the internet may differ from appropriate behavior in face-to-face relationships. Many people with ID may not understand appropriate behavior and boundaries when using the internet. Additionally, parents raised a concern about their dependents finding websites related to sexuality, believing their dependents are too immature for the content on such websites. Parents also indicated the belief that teachers should be the ones who teach people with ID about safe internet practices in order to prevent sexual abuse and risks online (Logren-Martenson et al., 2015). Despite parents' good intentions, their struggle to discuss sexuality with their children with ID/DD may backfire. A lack of information about sexuality is associated with a higher risk of sexual exploitation and abuse (Lofgren-Martenson et al., 2015; Pownall et al., 2012).

Misconceptions and Beliefs of Teachers

Teachers of students with ID/DD hold mixed views about the appropriateness of sexual expression and sexuality education for their students. Some teachers believe that sexuality education is appropriate for students with mild ID but inappropriate for students with moderate to profound ID (Barnard-Brak et al., 2014). This was the case in a study conducted by Barnard-Brak and colleagues (2014) in which the perceptions of teachers regarding the benefit of sexuality education for students with ID were examined as part of a larger project. The teachers evaluated in the study appeared to associate students' level of expressive communication with their level of receptive communication, despite significant research showing that receptive communication is often more advanced than expressive communication. As a result of such beliefs, teachers often did not believe that students with ID could benefit from sex education. This belief is also contradicted by research suggesting students with ID and lower expressive communication skills can benefit from sex education programs and curricula adapted for their level of functioning (Barnard-Brak et al., 2014). The perceptions of teachers and educators clearly impacts their understanding of their students and their ability to learn, as well as students' access to sexuality education.

Wolfe (1997) examined the thoughts and opinions of teachers and administrators related to the sexuality of students with ID. Teachers and administrators completed 19-question surveys. A total of 98 surveys were returned, 37% of which were from teachers and 63% of which were from administrators. The majority of participants acknowledged that students with ID displayed sexual behavior, with teachers reporting significantly more sexual behaviors than administrators. Of the sexual behavior observed, the most frequent was masturbation; however, participants also noted students with disabilities touched others inappropriately, kissed, hugged, showed interest in sexual activity, and engaged in some sexual intercourse, homosexual activity, rubbing, and exhibitionism. These sexual behaviors were reported to cause problems in the school setting, specifically regarding recognition of appropriate and inappropriate times to engage in sexual behaviors and recognition of consent of others (Wolfe, 1997).

Participants supported general, appropriate sexual expression by students with ID that consisted of hugging, kissing, hand holding, masturbation, and interest in others (Wolfe, 1997). Over half supported kissing between two people with ID, while the rest of participants said they would feel uncomfortable and/or that the action was inappropriate. The majority of participants believed oral and anal sex, viewing of pornography, and homosexuality were inappropriate for students with ID. Regarding relationships, all participants believed friendship was appropriate for students with ID; however, participants were mixed about other types of relationships. The majority of participants supported sterilization of people with ID. Overall results of the study indicate the impact of the personal views and beliefs of teachers and administrators on the types of appropriate sexual practices of people with ID. The personal values of teachers and administrators pertaining to appropriate sexual expression for people with ID is important, as sex education and inappropriate sexual expression of people with ID often occurs at school when they are surrounded by similar-aged peers (Wolfe, 1997). Wolfe’s (1997) conclusion aligns with the impact of the beliefs of parents and caregivers on the sexuality people with ID (Crockett et al., 2003; Garwood & McCabe 2000; Pownall et al., 2012), as well as the continued beliefs of educators as their students age.

Further, the views of educators extend past the school setting and into adult day service programs, where the importance of sexuality education is stressed in relation to appropriate sexual expression during adulthood for adults with ID/DD. Wilkenfeld and Ballan (2011) interviewed ten teachers and instructors in school programs and adult day service programs for people with DD to determine the attitudes and beliefs of educators related to the sexuality of people with disabilities. The researchers also sought to determine differences in the attitudes and beliefs of teachers in school programs and instructors in adult day service programs and appropriate methodology for the delivery of sexuality education to people with DD. Results were qualitatively analyzed and yielded three main themes: sexuality is a basic human right, capacity to consent is important and necessary, and sexuality education is needed. Educators stressed the importance of autonomy for people with DD, as well as the normalcy of sexual expression. Regarding capacity to consent, educators noted concerns about the ability of this population to understand and handle the emotional aspects of sexual intimacy. They also raised awareness of the need to consider facilitation of sexual activity for those with physical disabilities and challenges, as they might need assistance in preparing for sexual intimacy, such as assistance removing their clothes or positioning themselves. Despite concerns about consent and facilitation, educators supported sexual intercourse and marriage for people with DD but did not support pregnancy due to the potential health concerns for people with disabilities as well as questions about their ability to care for a child. Lastly, educators stressed the importance of sexuality education for people with DD in order to promote education about safe and socially appropriate relationships and experiences and reduce risk of abuse and exploitation. They also suggested multisensory approaches to teaching sexuality education to promote comprehension with this population. However, teachers in the school program did not believe it was their role to provide sexuality education to students; rather, they believed that was the role of the parents. Instructors at the adult day services program were open and willing to educate their students on sexuality. Overall, educators strongly support sexuality education for people with disabilities (Wilkenfeld & Ballan, 2011). Despite support for sexuality education by educators, teachers in the school program believed it was the duty of parents and caregivers to provide sexuality education for people with ID/DD. This contradicts the view of parents and caregivers that teachers should provide sexuality education to people with ID/DD (Lofgren-Martenson et al., 2015). If parents, caregivers, and teachers cannot agree on the source of sexuality information for their independents with ID/DD, often the last resort are support workers, who may or may not feel comfortable or have the knowledge and understanding to provide sexuality education to people with ID/DD.

Misconceptions and Beliefs of Support Workers

Support workers for people with ID/DD support their clients' rights to sexual expression (Saxe & Flanagan, 2014). However, caregivers often do not feel comfortable providing sexuality education to clients with ID/DD due to a lack of education and training (Wilson & Frawley, 2016). When they do have to provide sexuality education, it is almost always in response to an inappropriate sexual incident by a client with ID/DD (Gourgeon, 2009; Huntley & Benner, 1993; McCabe & Schreck, 1992; Schaafsma et al., 2014). However, those teaching sexuality education often do not believe their clients need or understand the information (Schaafsma et al., 2014). Just as the beliefs of parents, caregivers, and teachers impact their dependents' beliefs and education about sexuality, the same may be true for support workers.

Effects of Misconceptions and Beliefs on People with ID/DD

Misconceptions lead to a variety of detrimental effects for people with ID/DD. Irvine (2005) addressed common myths and misconceptions about the sexuality of people with intellectual and developmental disabilities, as well as the consequences to these styles of thinking. People with disabilities are often kept from engaging in sexuality and related behaviors due to parental fears; the belief that people with disabilities are asexual and, therefore, have no interest in sexual behaviors; and the idea that people with disabilities are like children.

Additionally, people with disabilities often lack access to accurate and appropriate information about sexuality, and information they gain is often false. However, by not providing people with disabilities education about their sexuality, numerous risks arise. If people with disabilities do not understand appropriate and inappropriate sexual behaviors, they will likely not recognize if they are being sexually abused or sexually abusing others (Irvine, 2005). Further, lack of understanding and knowledge can cause people with ID/DD to be more susceptible to the biases and misconceptions of others (Hingsburger & Tough, 2002).

Hingsburger and Tough (2002) also explained how peoples' biases impact those with intellectual and developmental disabilities, particularly when the biases surround sexuality. Numerous accounts of parents, physicians, and other trusted care workers purposefully providing misinformation about sexuality to people with disabilities were recounted. Further, the authors addressed the lack of privacy received by people with disabilities, stating, "For people with disabilities, private business becomes public news" (Hingsburger & Tough, 2002, p. 9). To combat misinformation and lack of privacy, Hingsburger and Tough (2002) detailed the importance of agency policies about sexuality and self-advocacy by people with disabilities noting that self-advocacy had a positive effect on the receipt of appropriate and accurate information about sexuality.

Relatedly, members of a self-advocacy group for people with ID/DD yearned for more opportunities to socialize with same-age peers, as opposed to spending their free time with family (Azzopardi-Lane & Callus, 2014), as they are often supervised by others (Azzopardi-Lane, & Callus, 2014; DiGiulio, 2003; Gomez, 2012; Irvine, 2005). People with disabilities are also permitted little privacy to explore their sexuality or the ability to meet potential sexual partners, as other people are often around them (Irvine, 2005). Without privacy, people with ID/DD are limited in their ability to explore their sexuality.

DiGiulio (2003) reviewed numerous issues contributing to the sexual expression, knowledge, and attitudes of people with physical and developmental disabilities. Diagnostic and societal views greatly impact access to sex education for people with disabilities. Diagnostically, Masters and Johnson’s Sexual Response Model provides the basis for appropriate and impaired/disabled sexual functioning. This model served as the basis for the Diagnostic and Statistical Manual of Mental Disorders’ definition of sexual dysfunction. People with disabilities are often labeled as having a sexual dysfunction without consideration for the impact of their disabilities. People with disabilities often attempt to adapt their sexual lives to promote healthy sexual responses that fit with their abilities; however, due to the nature of their sexual responses and activity, their adaptations are labeled as dysfunctional. Further, societal and familial beliefs that people with disabilities are asexual, hypersexual, and/or unable to experience sexual pleasure are barriers for people with disabilities. People with disabilities often rely on family and friends for assistance meaning they spend much more time with close relatives and friends than alone. This leads to difficulties with accessing resources about sex education and sexual health as well as privacy to explore appropriate sexual activities. Further, a lack of privacy often leads people to explore sexual activities in inappropriate places, such as public restrooms or parks (DiGiulio, 2003). These instances often reinforce societal and familial beliefs that people with disabilities are hypersexual and inappropriate, when in actuality the activities themselves are appropriate, but the individuals lack privacy and education about personal exploration of sexual pleasure and functioning (DiGiulio, 2003; Gomez, 2012).

In addition to being denied the opportunity for physical sexual pleasure, people with disabilities are often denied opportunities for love, affection, and interpersonal relationships for a variety of reasons (DiGiulio, 2003). Families may lack awareness that their loved ones with disabilities are interested in intimacy and relationships just as people without disabilities. Additionally, families and friends may provide the wrong information to people with disabilities in order to prevent them from becoming intimate or sexually active or due to their own lack of knowledge about the topic and/or its importance (DiGiulio, 2003; Hingsburger & Tough, 2002). This lack of knowledge and experience puts people with disabilities at a greater risk of contracting HIV/AIDS, becoming victims of sexual abuse, and making inappropriate relational and sexual choices (Azzopardi-Lane & Callus, 2014; Barnard-Brak, et al., 2014; Basile et al., 2016; DiGiulio, 2003; Gomez, 2012; Healy et al., 2009; Irvine, 2005; Mahoney & Polling, 2011; McCabe, 1993; McGillivray, 1999; Murphy & O'Callaghan, 2004; Saxe & Flanagan; Swango-Wilson, 2011). Further, sex education that is provided to people with disabilities often does not take into consideration the challenges this population faces physically, cognitively, and socially. Thus, those who do receive education may not understand what they are learning and continue to lack access to appropriate education on sexual health and functioning (DiGiulio, 2003).

In addition to a lack of appropriate education from parents, caregivers, educations, and support workers, people with ID/DD also face barriers to sexuality education from their physicians. Physicians often do not encourage patients with disabilities to receive appropriate sexual health care and screenings. Physicians may not think to provide sex education to people with disabilities due to beliefs that people with disabilities do not experience sexual feelings or engage in sexual activities (DiGiulio, 2003). Brantlinger (1985) joins the chorus voices that point out the negative effects of a lack for sex education, including engagement in risky sexual behaviors.

Access to Sexuality Education

Misconceptions, false beliefs, and discomfort of parents, caregivers, teachers, and support workers directly impacts the access of people with ID/DD to sexuality education. Barnard-Brak and colleagues (2014) conducted a study to explore access of children with ID in public schools to sex education. More specifically, researchers evaluated the frequency of receiving sex education based on students’ level of functioning, the perceptions of teachers regarding the benefit of sex education for students not currently receiving sex education, and categorization of the predictors of receiving sex education based on the level of intellectual deficit. The sample consisted of 5,070 participants obtained from the National Longitudinal Transition Study-2, which consists of data of thousands of adolescents with disabilities across the United States. The average age of the sample was 15.7 years old. Regarding level of functioning, 11.6% were classified as mild ID, 13.0% as moderate to profound ID, and 75.4% as no ID according to their Individualized Education Plans. The disabilities of adolescents classified with no ID was unclear. Results indicated that students without ID were more likely to receive sex education than students with mild ID, and students with mild ID were significantly more likely to receive sex education than students with moderate to profound ID. Barnard-Brak (2014) also found that more teachers thought students with no ID or mild ID would better benefit from sex education than students with moderate to profound ID. Finally, predictors of the receipt of sex education varied based on level of ID. Students without ID were more likely to receive sex education if they were already receiving physical education. Students with mild ID were more likely to receive sex education based on higher levels of expressive communication and social skills. Access to sex education for students with moderate to profound ID was found to be predicted by household income, level of expressive communication, and physical education. In other words, students with a higher socioeconomic status background, who had high levels of expressive communication, and who were taking a physical education class were significantly more likely to receive sexuality education. Overall, students with ID were found to be significantly less likely to receive sex education than students without ID, primarily based on the perceptions of teachers related to levels of expressive and receptive communication and the appropriateness of sexuality education for students with ID, as discussed previously (Barnard-Brak et al., 2014). However, it is important to note when generalizing the results of Barnard-Brak and colleagues' (2014) study that the participant information utilized was obtained through a national database and the research questions were developed after the data was collected. Therefore, additional variables that may have impacted the results were not capable of being used due to the archival nature of the data.

Misconceptions and lack of access to sexuality education for people with ID/DD is not just an American phenomenon. In Nigeria, many adolescents with disabilities are at an increased risk of engaging in unsafe sexual behaviors that often result in contracting sexually transmitted infections, sexual exploitation, or teenage pregnancy (Oladunni, 2012). This is further complicated by misconceptions, such as the belief that HIV is transmitted through the sharing of utensils with people who have HIV. Moreover, teachers and parents often do not discuss sexuality with adolescents who have disabilities, leading adolescents to learn from their peers, who may be misinformed. Nigeria has attempted to promote sexuality education in schools through the National Curriculum for teaching Sexuality and Family Life Education; however, the curriculum does not address the sexuality needs for adolescents with disabilities, who compose approximately 10% of the Nigerian population (Oladunni, 2012).

Oladunni (2012) explored the access of adolescents with disabilities to sexuality education and information in Osun State. Through a cross-sectional study and random sampling, he surveyed 140 adolescents with disabilities across four schools. The survey was adapted from the World Health Organization's questionnaire about adolescent reproductive and sexual knowledge and behavior. Results indicated that adolescents with disabilities often receive sexuality knowledge from peers, followed by their mothers and teachers. Further, 110 out of 140 participants reported never attending sexuality education classes. Teachers were also surveyed, and their responses indicated support for sexuality education for students with disabilities. However, teachers also reported a need for education in the curricula, as well as access to resources in order to provide sexuality education to students with disabilities. Oladunni (2012) concluded that adolescents with disabilities receive most of their information about sexuality from peers mainly because they receive so little information from teachers and parents. Oladunni (2012) concluded that teacher and parent education, as well as appropriate curricula and teaching materials, would promote sexuality education for people with ID/DD and might increase access to appropriate and comprehensive sexuality education.

Access to sexuality education for people with ID/DD is clearly impacted by the beliefs, biases, and misconceptions held by parents, caregivers, teachers, support workers, and society as a whole. Moreover, these biases also influence the sexual beliefs and experiences of people with ID/DD.

Beliefs and Experiences of People with ID/DD

As stated previously, the beliefs and experiences of people with ID/DD are impacted by the beliefs and misconceptions held by their parents, caregivers, teachers, and support workers. Brantlinger (1985) conducted a naturalistic study with thirteen high schoolers with mild ID. The students were in special education classes from elementary through high school. Students were interviewed about their sexual knowledge using a 31-item questionnaire with a section composed of 21 words to assess understanding of casual and formal terminology related to sex. Results indicated that students felt uncomfortable talking about sex, as most were raised in homes where sex was not dicussed or had parents who were perceived as extremely anxious when talking about sex with their children, as noted by descriptions such as, “When my dad tries to talk to me he shakes like a leaf” (Brantlinger, 1985, p. 106). Students expressed feeling uncomfortable discussing sex and sexuality with their parents, siblings, and peers, and noted they would feel most comfortable receiving sex education from a teacher. Students’ understanding of sexual maturity, puberty, and birth control was considerably low. Further, many students held significant misconceptions about birth control and pregnancy, such as the belief that condoms were used to get women pregnant and a towel wrapped around a penis works as an appropriate form of contraception, which could lead to risky behavior in the future if sex education was not provided (Brantlinger, 1985). Similar beliefs are held for other adolescents and adults with ID/DD.

Lunsky and Konstantareas (1998) assessed sexual attitudes of people with ID compared to sexual attitudes of people without disabilities to determine if sexual attitudes of people with ID are more accepting than sexual attitudes of people without disabilities. Participants consisted of 16 adolescents and adults with mental retardation, 15 adolescents and adults with autism, 25 undergraduate students without disabilities from a Canadian college, and 28 American undergraduate students without disabilities. The Canadian and American college students without disabilities were matched by the researchers for gender and age to the adolescents and adults with mental retardation and autism. Each participant completed the Socio-Sexual Knowledge and Attitudes Test (SSKAT). Visuals were used to assist people with mental retardation and people with autism when completing the assessment.

Findings indicated that people with mental retardation engage in significantly fewer sexual activities than the other three groups. Additionally, people with autism reported engaging in statistically less sexual activities than American college students who were matched for age and gender to the groups of people with mental retardation or autism. Further, people with mental retardation have less accepting attitudes pertaining to sexual behaviors such as dating, masturbation, and homosexuality, relative to the other three samples (Lunsky & Konstantareas, 1998). Less accepting sexual attitudes are associated with low sexual knowledge, meaning that when people with ID/DD gain sexual knowledge, their sexual attitudes tend to improve (McCabe, 1999). However, due to the biases of caregivers and other prominent support workers in the lives of people with ID/DD, sexual knowledge is often not available. As a result, people with ID/DD may adopt the beliefs and misconceptions of those by whom they are surrounded; however, this is not always the case.

Despite the impact of negative beliefs and misconceptions on the beliefs and attitudes of some people with ID/DD, many hold strong, personal beliefs about their sexual rights and abilities and are aware of the negative and biased perceptions of others. More positive self-views regarding sexuality appear to have become more common within the last two decades, with people with ID/DD becoming more frustrated about their lack of rights and privacy and displaying a desire to express the same sexual needs, wants, and desires as people without ID/DD (Saxe & Flanagan, 2014). Azzopardi-Lane and Callus (2014) worked with an ID self-advocacy group in Malta consisting of 20 adults ages 20-50 with ID. The focus of the study was on the expression of sexuality. Members of the advocacy group elected a small committee of their peers to plan and lead their meetings with assistance from the researchers. Meetings were separated by gender due to a level of discomfort seen in female members when male issues were discussed and in male members when female issues were discussed. The gender separation of the groups promoted better discussion of sexuality and relationships. Azzopardi-Lane and Callus (2014) also utilized pictures, stories, and videos to guide and assist the discussion. Members addressed the importance of sexuality to themselves, as well as feelings of self-consciousness about the lack of autonomy provided by their families and friends. More specifically, members noted a lack of privacy, restricted funds, reliance on others for transportation, and parental control over their relationships and sexual expression. Parental limits on sexual expression and relationships were further complicated by the strong influence of religion, primarily Catholicism, on the members. As a result, members received little exposure to the topic of sexuality and therefore behaved age-inappropriately during parts of the discussions (i.e., laughing at pictures of hugging and kissing). Further, due to the level of influence of others on their sexuality, members felt unsure of when or how to express their sexuality (Azzopardi-Lane & Callus, 2014).

Azzopardi-Lane and Callus' (2014) use of visual supports likely helped participants understand topics addressed in the discussion groups. Additionally, the separation of groups by gender indicates the researchers were attuned to the needs of the participants. Moreover, the success of the gender-based group format for discussing sexual knowledge, attitudes, experiences, and needs suggests that a gender-based group format for providing sexuality education is successful, as it provides more opportunity for group discussion and experiential learning, especially in instances where group members show discomfort when discussing sexual topics with members of the opposite sex.

As support and advocacy for sexual expression for people with ID/DD has grown, the values and desires of this population for sexuality education curricula has become of great interest to many researchers and educators. Swango-Wilson (2009) surveyed 12 people with ID/DD, as well as caregivers, professionals, healthcare professionals who work with this population to assess their perceptions of sex education for people with ID/DD. Participants were separated into four groups, each consisting of three people. Results indicated themes of denial and fear from parents of individuals with ID/DD. Professionals were concerned with safety and legal ramifications, while the main concern of healthcare professionals were health-related issues. Participants with ID/DD shared concerns about relationship and practical knowledge pertaining to sexuality. All participants believed that caregivers should be involved in the creation of a sex education program to create learning opportunities in the community.

Later, Swango-Wilson (2011) sought to determine what topics people with ID/DD would like covered in a sex education program, with the intent of using this information to develop a sex education program sensitive to the needs of this population. She surveyed people with ID/DD from the People First self-advocacy group in Alaska, as well as their parents and the professionals who worked with them. Participants were selected based on their ability to provide information about sexuality, communicate verbally, and engage in a question-and-answer communication format. The one-hour interviews consisted of open-ended questions in order to avoid influencing responses. The results were analyzed qualitatively and revealed three main themes: friendships, long-term relationships and marriage, and safe intimacy. Participants also provided feedback regarding useful methodology for sex education programs, which included videos, discussion, guest speakers, demonstrations, mixed gender classes, and homework. Some participants also requested a caregiver sex education program that focuses on appropriate sex education for people with ID/DD (Swango-Wilson, 2011).

Despite the existence of sexuality education programs and curricula marketed for people with ID/DD, few, if any, considered the existing sexual knowledge and attitudes of people with ID/DD when designing the programs. Consideration of the sexual knowledge and attitudes of people with ID/DD can lead to the design of an appropriate, comprehensive sexuality education program for people with ID/DD. Healy and colleagues (2009) conducted a series of focus groups with adolescents and adults with ID in

Ireland. The purpose of the study was to determine the sexual knowledge, experiences, and attitudes of people with ID. Participants were placed in one of five groups, which were separated based on age and then again by gender. No female adolescents participated due to a lack of consent. The gender of the group facilitator matched the gender of the focus group. Open-ended and probe questions were created prior to the discussions in order to maintain the discussion. The discussion of each focus group revolved around participants' general views of sexual experiences and relationships of people with ID, as well as participants' experiences with aspirations regarding sexuality and relationships. Five main themes developed out of the discussions: "general views of sexuality and relationships, personal relationships and the views of relatives, relationships within the [community-based] service, sex and related issues, and the future" (Healy et al., 2009, p. 907). Most participants expressed an interest in both friendships and dating relationships. Those who were in dating relationships partook in activities such as going to dinner or the movie theater with their significant others. Some older participants who were in intimate relationships noted they engaged in personal and physical intimacy with their significant others, such as holding hands or kissing. Most participants did not understand why people with ID are often prevented from having relationships and believed relationships were an individual choice and not the choice of others. Oftentimes, however, relatives influence and prevent the participants from having relationships with others. As a result, participants admitted to hiding their relationships from their relatives. Participants also believed that their community-based service providers kept them from engaging in relationships and/or impacted their privacy. Participants described a strong desire to have their privacy and entitlements respected. Additionally, participants believed the rules and policies of their community-based services did not consider the needs of the participants (Healy et al., 2009).

In regard to sex and sexual issues, most participants had very little knowledge of masturbation, but believed they should be allowed to engage in the act in private (Healy et al., 2009). Many adolescent participants were not open to the idea of sexual intercourse, believing it was forbidden. However, most participants received sexual education through formal sex education programs or vicariously, such as by watching the television. Despite receiving sex education, knowledge of condoms, contraceptives, and sexually transmitted diseases was poor for adolescents with ID. Additionally, participants over the age of 30 had more awareness and understanding of sexually transmitted diseases and the importance of condoms than those ages 15-29. Healy and colleagues' (2009) work is important because participants with ID were provided a nonjudgmental and understanding environment to communicate their sexual knowledge, experiences, and attitudes.

Szollos and McCabe (1995) also evaluated the sexuality of people with ID in what has become a seminal article in the research on the sexuality of people with ID/DD. The sexuality of people with ID were compared with the perceptions of caregivers of the sexuality of people with and without ID/DD. Participants consisted of 25 adults with ID, 10 caregivers, and 39 adults without ID. Adults with ID were administered the Measure to Assess Sexual and Relational Knowledge, Experience, Feelings, and Needs (later known as the Sexual Knowledge, Experience, Feelings, and Needs Scale). Caregivers were administered the caregiver version of this measure and adults without ID were administered the general population version of this measure. All measures were administered as interviews (Szollos & McCabe, 1995).

Overall, women with ID were found to have higher levels of sexual knowledge than men with ID. Women with ID had significantly greater knowledge pertaining to menstruation and marriage than men. Women with ID also had more sexual experience than men with ID, with masturbation being the greatest sexual experience scores for both men and women. The contraceptive experience of women with ID was statistically greater than that of men, likely because many of the women used contraceptive pills. Additionally, women with ID had a statistically higher level of sexual abuse than men with ID. Regarding feelings, few differences arose with the exception of women with ID having a significantly more positive attitude toward marriage than men with ID. Lastly, men with ID reported more sexual needs than women with ID. More specifically, men with ID reported a significantly greater need to understand current relationships and menstruation (Szollos & McCabe, 1995).

As previously stated, caregivers' results indicated significant overestimation of the knowledge, attitudes, experiences, and needs of people with ID. That is, caregivers perceived adults with ID as having more sexual knowledge, more positive sexual attitudes, a greater number of sexual experiences, and more sexual needs than adults with ID reported on the Measure to Assess Sexual and Relational Knowledge, Experience, Feelings, and Needs. Additionally, adults without ID had statistically greater sexual knowledge than adults with ID with the exception of knowledge pertaining to anatomy, dating, and intimacy, meaning that adults with and without ID have similar understandings of anatomy, dating, and intimacy. Adults without ID also had significantly more positive attitudes and significantly more sexual experiences than adults with ID. However, no significant differences were found in sexual experiences related to current relationships, masturbation, and homosexuality, indicating that adults with and without ID have similar sexual experiences related to these areas. Regarding abuse, people with ID had a significantly higher experience with sexual abuse. Lastly, when compared with people without ID, people with ID reported a significantly greater need to know more about menstruation, contraception, masturbation, marriage, homosexuality, and dating and intimacy and significantly less need to know more about sex and sexuality, pregnancy and childbirth, and sexually transmitted diseases (Szollos & McCabe, 1995). Proposed factors that likely impacted the results of this study are the inability of people with ID to engage in sexual expression due to lack of privacy and constant supervision and deficits in social communication and interpersonal relationships (Szollos & McCabe, 1995). Szollos and McCabe’s (1995) seminal study brings to light the significance of the biases and beliefs of caregivers of people with ID related to sexuality. People with ID have less sexual knowledge than caregivers believe, which impacts the information and education about sexuality provided by caregivers and can put people with ID at a greater risk for risky sexual behaviors and sexual exploitation. Therefore, formal sexuality education programs are needed to improve the sexual knowledge, and ultimately the sexual safety, of people with ID.

The beliefs and experiences of people with ID/DD makes it clear that sexuality education is both necessary and desired. Sexuality education can increase the sexual knowledge of people with ID/DD (Bennett, Vockell, & Vockell, 1972; Caspar & Glidden, 2001; Hayashi, Arakida, & Ohashi, 2011; Lindsay, Bellshaw, Culross, Staines, & Michie, 1992; Lindsay, Michie, Staines, Bellshaw, & Culross, 1994; Lunsky, Straiko, & Armstrong, 2003; Penny and Chataway, 1982; Robinson, 1984; Saxe & Flanagan, 2014; Shapiro & Sheridan, 1985) and reduce their risk of sexual abuse and exploitation (Dukes & McGuire, 2009; Gomez, 2012; Irvine, 2005; McDaniels & Fleming, 2016; Swango-Wilson, 2011), which is one of the most common fears of parents and caregivers (Swango-Wilson, 2009). The plethora of cited studies above will be discussed at length in the next section.

Sexual Knowledge of People with ID/DD

Due the misconceptions held by many related to the sexuality of people with ID/DD, it is important to understand the impact societal biases have on the sexual knowledge of this population. People with ID/DD engage in sexual behaviors and have sexual needs similar to those of people without ID/DD (DiGiulio, 2003). However, despite increased awareness of the poor sexual knowledge of people with ID/DD over the past four decades, little has been done to increase this deficit in knowledge (Azzopardi-Lane & Callus, 2014; Gomez, 2012). People with ID/DD continue to hold little knowledge and understanding about important aspects of sexuality, including but not limited to contraception, sexually transmitted diseases, masturbation, and sexual intercourse (Edmonson et al., 1979; Saxe & Flanagan, 2014).

The sources from which people with ID/DD gain information about sexuality is largely influenced by societal biases. Due to the lack of appropriate sexuality education, people with ID/DD must seek information from other sources. Jahoda and Pownall (2014) explored the differences between 30 Scottish adolescents and young adults with ID and 30 Scottish adolescents and young adults without ID in regard to their sexual knowledge and source of sexual information. They also examined gender differences in sexual knowledge and social networking habits, as much sexual knowledge can be gleaned from peers. Jahoda and Pownall (2014) utilized components of the Sexual Knowledge, Feelings, Experiences, and Needs Scale for People with Intellectual Disability (SexKen-ID; McCabe, 1994), among other assessments to develop their own assessment of sexual knowledge that addressed puberty, reproduction, contraception, and sexually transmitted diseases. The assessment measure consisted of a variety of question formats and utilized colorful illustrations and pictures to further understanding. The assessments were conducted individually with one of the authors and were structured in such a way that the assessment began with more direct questions before more open-ended and indirect questions were asked (Jahoda & Pownall, 2014).

Results indicated that people without ID have significantly more sexual knowledge than people with ID (Jahoda & Pownall, 2014). A trend was evidenced in the gender differences among people with ID: across scales and sub-scales of the assessment, men with ID scored significantly higher on knowledge of sexuality than women with ID. The opposite was found to be true for people who do not have disabilities. Women without disabilities scored significantly higher on knowledge of sexuality than men without disabilities. Increased sexual knowledge of women without disabilities may be the result of seeking out knowledge and information to prevent pregnancy should they decide to become sexually active. In contrast, lower levels of sexual knowledge in women with ID is likely the result of limited autonomy and access to sexual knowledge by caregivers who may believe the best way to protect their daughters from sexual harm is through limiting information. Further, many misunderstandings related to sexual intercourse, contraception, and sexually transmitted diseases were noted through open-ended responses. Regarding social networks, people without ID were found to utilize more sources for gaining information about sexuality, while people with ID primarily sought information from their family members, likely due to smaller social networks than their typically developing peers (Jahoda & Pownall, 2014).

Sexual knowledge is clearly influenced by the source from which it is gained. However, sources of sexual knowledge play a much larger role in sexual understanding, as research shows that sexual knowledge directly impacts sexual attitudes, experiences, and needs (McCabe, 1999). McCabe (1999) assessed the sexual knowledge, attitudes, experiences, and needs of people with ID and people with physical disabilities in relation to people in the general population. Participants consisted of 60 adults with ID, 60 adults with physical disabilities, and 100 adults in the general population. All participants lived independently. Approximately half of participants with disabilities and the majority of participants from the general population had received sexuality education prior to the study. People with ID completed the Sexual Knowledge, Experiences, Feelings, and Needs Scale for People with Intellectual Disability (SexKen-ID), which is formatted as a three-part interview. People with physical disabilities completed the Sexual Knowledge, Experiences, Feelings, and Needs Scale for People with Physical Disability (SexKen-PD), which is formatted as a questionnaire and has questions pertaining to the nature, duration, and severity of the physical disability. Finally, people from the general population completed the Sexual Knowledge, Experiences, Feelings, and Needs Scale for the General Population (SexKen-GP), which is also formatted as a questionnaire.

Results indicated that participants from the general population had the highest level of sexual knowledge, followed by participants with physical disabilities (McCabe, 1999). Participants with ID had the least sexual knowledge. People with ID are more likely to receive sexual knowledge from the media or formal sex education courses that may not fit their needs or be attuned to their level of functioning and understanding. This contrasts to the sources from which people in the general population receive sexual knowledge. People in the general population often receive sexual knowledge from family and friends and are able to discuss questions and concerns about sexuality with others. People with disabilities are often not afforded this opportunity due to stigma and biases held by parents, caregivers, and society. This likely contributes to the low attitudes toward sexuality and limited sexual experiences of people with ID indicated in the results of McCabe’s (1999) study. More specifically, people with disabilities reported discomfort with any form of sexual expression, including hand holding. However, people with disabilities reported higher levels of masturbation and levels of tolerance for homosexual expression than were found in people from the general population. McCabe (1999) concluded that the sexual needs of people with disabilities are not being met, as evidenced by limited sexual knowledge and experience and negative attitudes toward sexuality.

Limited sexual knowledge, negative attitudes, and lack of ability to engage in sexual experiences impacts the level of sexual needs of people with ID/DD. When sexual needs are high and are not being met, people with ID/DD might act out sexually in an attempt to meet their sexual needs. Lockhart, Guerin, Shanahan, and Coyle (2010) examined the sexual knowledge, experiences, and needs of people with ID who had sexually challenging behavior, non-sexually challenging behavior, and no challenging behavior. The purpose of the study was to determine the impact of sexual knowledge on sexually challenging behavior in adults with ID. Twenty-four adults with ID were separated across the three groups (sexually challenging behavior, non-sexually challenging behavior, and no challenging behavior). Participants engaged in a series of 40-minute interviews during which the researchers administered the SSKAT – Revised (SSKAT-R), the SexKen-ID, and the AAMR Adaptive Behavior Scale – Residential & Community: Second Edition. Results indicated that sexual knowledge and sexual experiences were consistent across the groups. However, sexual needs, specifically dating and intimacy needs, were statistically higher for people with ID who display sexually challenging behaviors relative to their peers who engage in non-sexually challenging behaviors or no challenging behaviors. Further, when adaptive behavior was controlled for, people with ID who display sexually challenging behaviors were found to have statistically greater total sexual knowledge scores, as well as statistically higher knowledge related to boundaries, contraception, and sexually transmitted diseases than their peers who engage in non-sexually challenging behaviors or no challenging behaviors. In other words, people with sexually challenging behaviors have a greater understanding of sexuality than people with non-sexually challenging behaviors or no challenging behaviors. Lastly, no relationship was found between sexual knowledge and adaptive behaviors, which indicates that although higher adaptive behaviors are associated with sexual knowledge, adaptive behaviors may not play a role in gaining sexual experiences (Lockhart et al., 2010).

Although adaptive behaviors may not directly impact sexual experiences, Lockhart and colleagues' (2010) study demonstrates that sexual knowledge and experiences impact sexual needs and the process through which those needs are met. When needs are unmet, the likelihood that people with ID/DD engage in sexually challenging and inappropriate behaviors increases, which in turn increases their risk for sexual exploitation and abuse.

Murphy and O’Callaghan (2004) evaluated the sexual knowledge, vulnerability, and capacity to consent of adults with ID in England compared to adolescents without ID. By English law, the age of sexual consent is 16 years old. For this study, the authors recruited 16 and 17-year-old adolescents as the comparison group. Sixty adults with ID and sixty adolescents without ID were given a shortened version of McCabe’s (1994) SexKen-ID, the Understanding Consent and Abuse measure, and a series of vignettes to assess understanding of consent. Results indicated adults with ID had significantly less sexual knowledge than adolescents without ID, especially related to pregnancy, masturbation, contraception, sexually transmitted diseases, sexual relationships, and legal aspects of sexual behaviors. Further, adults with ID reported less sexuality education than adolescents. Moreover, results suggested that adults with ID are more vulnerable to sexual abuse due to their lack of understanding of the differences between consenting and nonconsenting situations.

Not only does limited sexual knowledge and experience influence sexual expression and needs, but limited sexual knowledge increases the vulnerability of people with ID/DD to sexual abuse and unsafe sex practices. McGillivray (1999) assessed the knowledge, beliefs, attitudes, and behaviors related to AIDS among people with ID compared to people without ID in Australia. Sixty people with ID and 60 people without ID completed a series of eight assessments that focused on sexual experience, knowledge and attitudes related to AIDS, knowledge and use of condoms, self-efficacy and self-esteem related to safe-sex practices, and sexual behaviors and practices related to safe-sex. Results indicated that people with ID had statistically less sexual experience, knowledge and attitudes related to AIDS, knowledge and use of condoms, self-efficacy, and understanding of safe-sex practices. Overall, participants with ID who were noted to have a high risk for unsafe sexual behaviors or an unknown risk for unsafe sexual behaviors scored significantly lower across the measures compared to participants with ID who had a low risk for unsafe sexual behaviors. No significant differences were found in the self-esteem of people with and without ID, which suggests that all participants had relatively high self-esteem related to sexuality (McGillivray, 1999).

Further, if people with ID/DD do not understand safe sex practices or the warning signs of sexual abuse and exploitation, then they certainly do not understand the laws in place to protect them from abuse. This lack of understanding can put people with ID/DD at a greater risk of being taken advantage of because they do not know that certain sexual behaviors and practices are against the law, nor do they understand their rights.

O'Callaghan and Murphy (2007) expanded upon their previous study (Murphy & O'Callaghan, 2004) to assess how people with ID understand British laws pertaining to sexuality. Sixty adults with ID and sixty adolescents without ID were asked questions about the laws regarding sexuality. Results indicated that adults with ID understood the laws less than the comparison group. More specifically, less than half of the adults with ID knew the age of sexual consent, understood that it was illegal to have sexual relationships with people under the age of 16, and knew about the laws in place to protect people with ID from sexual abuse. Additionally, about half of the adults with ID were not aware that they had a right to sexual relationships or that laws against sexual assault and rape, including protection against sexual relationships with staff at institutions and facilities, applied to people with ID. Further, only two-thirds of participants with ID understood that engaging in sexual relations when being threatened with a knife did not qualify as proper consent. Additionally, only one-third of people with ID knew that they had a right to marry as well as have an abortion if they became pregnant (O'Callaghan & Murphy, 2007).

In order to reduce the risk of sexual abuse and exploitation and improve understanding of legal and personal rights, O'Callaghan and Murphy (2007), as well as other researchers, have noted that people with ID/DD need improvements in their sexual knowledge and attitudes and the opportunity to engage in appropriate sexual expression.

Siebelink, de Jong, Taal, and Roelvink (2006) created an interview measure to assess the sexual knowledge, attitudes, experiences, and needs of people with ID. Participants consisted of 76 adults with ID associated with an agency providing services to people with disabilities in the Netherlands. The questionnaire developed by the researchers consisted of 28 items administered as a structured interview. Results indicated that people with individual disabilities consider sexuality and sexual relationships an important part of their lives. Additionally, male participants indicated significantly greater sexual needs, experiences, and attitudes related to intrapersonal sexual activities such as masturbation and watching adult movies than female participants. Moreover, positive correlations were noted between sexual knowledge and sexual attitudes, as well as sexual attitudes and experiences or needs. Siebelink et al. (2006) indicate that people with more sexual knowledge have more positive attitudes, and, in turn, people with more positive sexual attitudes have more sexual needs and experiences. Such positive results can be gained through sexuality education, from which the increases of sexual knowledge of people with ID/DD are significant regardless of intellectual ability (McDermott, Martin, Weinrich, & Kelly, 1999).

McDermott and colleagues (1999) evaluated the effectiveness of the Family Planning Program provided by the South Carolina Department of Disabilities and Special Needs. Participants consisted of 252 females with ID/DD (average IQ = 59.9, range of IQs >50-75) referred by their county Disability and Special Needs Boards. The Family Planning Program was conducted for one year through personalized, in-home instruction. The curriculum was designed to accommodate individualized levels of support needed by participants, including limited or intermittent support, extensive support, or pervasive support. The curriculum consisted of 13 lessons; however, the lessons taught were based on participant interest and need. Participants also dictated the depth of information learned, meaning if they did not want to learn more about a given topic, they could shift to a different topic. In other words, the curriculum was essentially self-driven in nature, as no topics were required. The most common topics selected were decision making, hygiene, and understanding and use of birth control (McDermott et al., 1999).

The Social Sexual Assessment, a 148-item questionnaire, was used for pre- and post-assessment of sexual knowledge. Results indicated women were more likely to have some sexual knowledge when they took care of their hygiene, had previous sexual experience, and had positive social interactions. General sexual knowledge and hygiene increased significantly as a result of the Family Planning Program. More specifically, results showed that increases in sexual knowledge and hygiene were associated with a greater number of contacts (i.e., meetings with instructors). Women with significant gains in sexual knowledge had 55% more contact with their instructors than their peers with no gains or decreased knowledge. Additionally, women with significant gains in hygiene had three times more contact with their instructors than their peers with no gains or decreased knowledge. Further, when IQ and number of contacts were accounted for, no differences were found in knowledge gains. That is, IQ did not account for the differences in sexual knowledge and hygiene gains across participants (McDermott et al., 1999). Of note is the individualized nature of the program. Adapting the curriculum to meet the needs of participants likely influenced the gains seen in sexual knowledge and hygiene, as the program was likely delivered at a developmentally and intellectually appropriate level. McDermott and colleagues' (1999) study conveys that sexuality curricula are likely more effective in increasing sexual knowledge when they account for the level of intellectual functioning of the audience.

Sexual Knowledge after Sexuality Education

Evaluation of the impact of sexuality education on sexual knowledge of people with ID/DD began decades ago and has yielded consistently positive results. Penny and Chataway (1982) evaluated the gains in sexual knowledge of people with ID prior to and following a sexuality education course. A total of 49 participants divided into eight groups received six 90-minute to two-hour courses on sexuality education across six weeks. The courses covered anatomy, reproduction and conception, sexual relationships and responsibility, gender roles, parenthood, contraception, and sexually transmitted diseases. The courses employed group discussion, life-size models, diagrams, and activities to promote learning and understanding. Participants were administered the Sex Vocabulary Test as a pre-, post-, and two-month follow-up measure. Results indicated that six out of eight groups yielded statistically significant increases in sexual vocabulary between the pre- and post-tests, and two groups had statistically significant differences in their sexual vocabulary between the post-test and the two-month follow-up. A total of 96% of participants showed an increase in sexual vocabulary between the pre- and post-tests, and 76% of participants showed an increase in vocabulary between the post-test and two-month follow-up. Penny and Chataway (1982) suggested that increases in sexual vocabulary likely yield increases in sexual knowledge. Penny and Chataway's (1982) findings are important because the study shows that people with ID can learn and maintain knowledge about sexual terms, which are often unusual terms that are not used in daily life. If people with ID/DD can remember and understand basic sexual terms, they can likely learn and understand broader concepts pertaining to sexuality.

Robinson (1984) evaluated the impact of sex education on the sexual knowledge and attitudes of people with DD, as well as the influence of the place of residence of people with DD on their sexual knowledge and attitudes. The participants consisted of 83 people with DD who resided either in the community or in institutional settings. The SSKAT was administered as a pre- and post-test. The participants engaged in a 10-week sex education course that covered anatomy, sexual behavior, contraception, pregnancy, and sexual relationships. Results indicated a significant increase in sexual knowledge and attitudes upon completion of the sex education course. Additionally, participants who resided in the community were found to have greater sexual knowledge than participants who resided in institutions; however, it is unclear if the IQs of participants were held constant when analyzing Robinson's (1984) findings. This is especially important considering the IQs of participants residing in institutions were found to be statistically significantly lower than the IQs of participants residing in the community (Robinson, 1984). However, Edmonson et al. (1979) noted that IQ does not impede the ability to gain sexual knowledge, meaning that it is likely Robinson's (1984) findings would yield significant results despite holding the IQs of participants constant.

More recent research continues to show significant results not only related to sexual knowledge but also to sexual attitudes, coping skills, and healthy behaviors.

Lunsky et al. (2003) provided a women's health curriculum to women with ID to determine its effectiveness on improving their sexual knowledge, healthy behaviors, and coping skills. Twenty-two women completed pre- and post-assessments of their sexual knowledge, healthy behaviors, and coping skills, as well as follow-up assessments 10 weeks after the post-assessment. They completed an 8-week course with sessions lasting 90 minutes. Results indicated that participants made significant gains in their sexual knowledge and coping skills which were maintained at the 10-week follow-up. They also made significant gains in their healthy behaviors; however, these results were not maintained at the 10-week follow-up, which may be due to the higher pretest scores for healthy behaviors. That is, Lunsky and colleagues (2003) suggested that the difference in the pretest and follow-up scores for healthy behaviors did not significantly differ because the pretest scores for healthy behaviors were higher than other scores (sexual knowledge and coping skills) at the start of the study (Lunsky et al., 2003).

Caspar and Glidden (2001) also assessed the effects of a sexuality education program on the sexual knowledge and attitudes of 12 adults (mean age = 38.7 years) with mild to moderate ID who received residential services. The program consisted of two to three hour sessions. The researchers used a variety of materials to promote learning and understanding, such as overheads, handouts, videos, and tests. To assess knowledge and understanding, Caspar and Glidden (2001) designed two test forms consisting of three sections: true/false objective questions, multiple-choice objective questions, and yes/no subjective questions. The dichotomous subjective questions were designed to assess sexual attitudes of participants.

Prior to receiving sexuality education, half of the participants received Test Form A and half of the participants received Test Form B. Upon completion of the curriculum, the participants who initially received Test Form A received Test Form B and vice versa in order to control for learning from the test forms. Results indicated a significant increase in knowledge between the pre- and posttests, as well as an increase in positive attitudes toward sexuality. Caspar and Glidden (2001) concluded that, despite the small, non-random sample, sexuality education was shown to increase knowledge and acceptance of sex and sexuality.

However, it is important to note that despite improvements in sexual knowledge and attitudes, people with ID/DD continue to be vulnerable to misconceptions. Lindsay et al. (1994) evaluated the knowledge and attitudes of forty-six adults with DD who completed a nine-month sexuality education course. More specifically, participants were surveyed about their knowledge and attitudes pertaining to socio-sexual relationships and homosexuality. Results indicated that there was an overall increase in sexual knowledge upon completion of the course. Additionally, participants' attitudes toward socio-sexual behaviors, such as hand holding on the first date, became less conservative upon completion of the course. However, one concern of note is the common misconception by people with disabilities that if you kiss someone that means you love them. This indicates a level of naiveté that is concerning when taken into context with other misconceptions of sexual knowledge (Brantlinger, 1985; Irvine, 2005). This type of belief could lead to sexual compliance with both familiar people and strangers, which puts people with ID/DD at a greater risk of sexual abuse or exploitation.

Lindsay et al. (1992) conducted a nine-month sexuality course for adults with mild to moderate ID to assess for sexual knowledge and attitudes upon completion of a sexuality education program. The study consisted of two groups. The experimental group consisted of 46 participants, while the control group had 14 participants. Both groups were given pre- and post-tests to assess their sexual knowledge and attitudes, and the experimental group was given the assessment as a three-month follow-up to the course. The questionnaire surveyed several areas of sexuality: anatomy, masturbation, male and female puberty, intercourse, pregnancy, childbirth, birth control, and venereal disease. Results indicated significant increases in all areas of sexual knowledge and attitudes relative to the control group, with significant results maintained at the three-month follow-up. Additionally, the lowest baseline scores were knowledge of birth control and venereal disease, suggesting that sexuality education is especially important for people with ID/DD so they can have the opportunity to learn how to keep themselves safe (Lindsay et al., 1992).

In order to protect people with ID/DD from the risk of sexual abuse and exploitation, improvements in sexual knowledge, social skills, and sexual decision-making are necessary. Hayashi, Arakida, and Ohashi (2011) created an eight-session sex education program for 17 participants who had ID and lived in transitional housing. The purpose of the program was to improve the participants’ social skills, as well as determine the influence of volunteers and training outside the facility on participants' participation in the program. The eight sessions consisted of topics related to anatomy, grooming and hygiene, communication, assertiveness, and problem-solving. A month before and after the eight-week sex education program, participants were administered Kikuchi's Scale of Social Skills (KiSS-18) to assess for baseline and change in social skills. The KiSS-18 consists of 18 Likert-scale questions that measure communication, management (i.e., coping), and problem-solving. Results indicated a significant increase in social skills for people with ID. Additionally, the researchers conducted a brief assessment of enjoyment, difficulty, and usefulness of each session. Results indicated low difficulty across sessions and high enjoyment and usefulness. Enjoyment and usefulness scores were highest in sessions that involved communication practice with people who are typically developing, as well as when sex education training took place outside of the facility, such as at a museum (Hayashi et al., 2011). However, despite the conclusion of Hayashi and colleagues (2011) that participants gained more knowledge on community outings as indicated by their enjoyment and usefulness scores, it may be that the participants simply enjoyed attending an event in the community regardless of the content or purpose.

Further, sexuality education programs can improve sexual decision-making capacity, as evidenced by Dukes and McGuire’s (2009) study in which individualized sex education curricula were provided to four young adults with moderate ID. The purpose of the study was to determine if sex education improves sexuality-related decision-making capacity. The individualized education curricula focused on knowledge in four areas: sexual safety, physical self, sexual functioning, and choices and consequences pertaining to sexual matters. The interventions were provided in 45-minute sessions twice a week. The Sexual Consent and Education Assessment (SCEA) was utilized to measure sexual decision-making capacity in the sample. Components of the SCEA were given pre-intervention, during intervention, and post-intervention in order to track changes in knowledge and decision-making capacity. Results indicated that the four participants showed an increase in their sexual knowledge in all areas. Furthermore, decision-making capacity was found to improve with sexuality education, as higher scores on the SCEA are correlated with improved sexual decision-making capacity. Additionally, six-month follow-up assessments indicated participants maintained knowledge of sexual safety and showed regression in knowledge of general sexuality (i.e., physical self and sexual functioning). However, scores on knowledge of general sexuality were higher at the six-month follow-up than knowledge scores on the pre-intervention assessment. Therefore, providing people with ID with sexuality education can enhance their sexual decision-making capacity (Dukes & McGuire, 2009).

Improvements in the sexual decision-making capacity of people with ID/DD is especially important given the limited understanding of risk by this population. Bennett and colleagues (1972) provided a sex education program for ten “educable mentally retarded” (Bennett et al., 1972, p. 3) females ages 17-23 to evaluate guidelines for future sex education programs. The Sex Information Inventory for Girls was utilized as a pre- and posttest assessment of the participants’ knowledge. The program was delivered in a group format across 12 one-hour sessions. The program covered topics related to menstruation, puberty, reproduction, masturbation, sexual intercourse, contraception, sexually transmitted diseases, and molestation and abuse. A qualitative analysis of the results indicated that the participants demonstrated increased knowledge about sexual terminology, menstruation, sexual intercourse, and birth control at posttest. Additionally, participants were better at distinguishing between sexes upon completion of the program. Further, although participants noted an increased willingness to tell an adult if they were sexually abused, approximately half of the participants indicated they would continue to keep the information to themselves and not tell anyone about potential abuse. The program also resulted in the participants showing increased permissiveness toward premarital sexual intercourse, as well as an increased reluctance to touch the vaginal area even in private spaces. Bennett et al. (1972) noted that more intensive programs might be needed to cover the importance of reporting sexual abuse and molestation. Additionally, participants' permissiveness toward premarital sex was likely impacted by the sexually promiscuous nature of one participant. Lastly, Bennett et al. (1972) believed that participants' reluctance to touch the vaginal area was due to increasing participants' awareness of a problem that had not previously occurred to them.

Finally, in order to promote the most gains in sexual knowledge and, tangentially, in safe sex practices, the sexual knowledge of people with ID/DD prior to completion of sexuality education programs should be utilized to create more individualized programs. Garwood and McCabe (2000) conducted a qualitative study to explore the sexual knowledge and feelings of six male adolescents and men with ID in two sex education programs. The Sex Ken-ID was utilized to assess participants' knowledge, feelings, and experiences. Results indicated that participants gained minimal knowledge in most sexuality areas post-intervention. Moderate increases were seen in areas of friendship, marriage, sex, contraception, homosexuality, pregnancy and childbirth, and STDs. Additionally, positive increases in sexual feelings were seen only in relation to female friendships and hugging someone of the opposite sex. Garwood and McCabe (2000) proposed that the limited influence of the sex education programs on participants' sexual feelings might be due to participants' initial lack of knowledge about sexuality, meaning participants likely did not hold strong attitudes or feelings toward topics of sexuality because they did not have a firm understanding of the topic. More individualized sexuality education curricula might improve the gains in sexual knowledge made by people with ID/DD (Dukes & McGuire, 2009).

Purpose

The purpose of the present study was to assess the sexual knowledge of adults with ID/DD prior to and upon completion of a sexuality education program. The sexual knowledge of adults with ID/DD was expected to increase upon completion of the program. Gains in sexual knowledge for people with ID/DD are especially important given the risk for sexual abuse and exploitation of this population (Barnard-Brak et al., 2014; Basile et al., 2016; Bretherton et al., 2016; Chiesa & Goldson, 2017; Gust, Wang, Grot, Ransom, & Levine, 2003; Hughes et al., 2012; Irvine, 2005; Lund & Vaughn-Jensen, 2012; Mahoney & Polling, 2011; McCabe, 1993; McCarthy & Thompson, 1997; Murphy & O'Callaghan, 2004; Swango-Wilson, 2010; Szollos & McCabe, 1995). People with ID are up to four times more likely to be sexually assaulted than people without ID (Barnard-Brak et al., 2014). People with ID/DD have a higher risk of being sexually abused or exploited due to their lack of understanding of healthy sexual relationships and boundaries. They often do not recognize sexual abuse, and if they do recognize the abuse, they are often discouraged from reporting the abuse (Barnard-Brak et al., 2014; Swango-Wilson, 2010). Additionally, lower levels of expressive communication can make it difficult for people with ID/DD to report the abuse when they do realize it is inappropriate (Barnard-Brak et al., 2014). Sexual abuse impacts people with ID/DD in numerous ways. Females with

ID/DD may become more passive in future sexual relations, make poor decisions regarding relationships, and become more willing to submit to physical, sexual, and emotional abuse. Males with ID/DD may become more aggressive in relationships and potentially engage in aggressive sexual relations with women and children who are more passive (Swango-Wilson, 2010).

People with ID/DD need to understand appropriate and inappropriate sexual behaviors and experiences, as often the abuser is someone with whom they have a close relationship, such as a family member, service provider, or staff at an institution or residential care facility. Although some programs are designed to educate people with mild or moderate DD, no programs are designed to educate people with severe disabilities (Mahoney & Polling, 2011). This is especially important because people with severe disabilities may be at a greater risk of being sexually abused. Additionally, service providers and staff at residential care facilities are often unaware of the risk of sexual abuse for patients with DD or the warning signs when they have been sexually abused (Hingsburger & Tough, 2002; Mahoney & Polling, 2011; Schaafsma et al., 2014). Mahoney and Polling (2011) also argued that the influence of negative societal stereotypes about the sexuality of people with ID/DD increases the likelihood that they will be abused and reduces the likelihood that the perpetrator will be identified or found guilty in a court of law.

Further, people with disabilities are at a greater risk for experiencing discrimination, stereotypes, and abuse. They are especially vulnerable to sexual abuse due to the need for dependence on others and negative beliefs and attitudes about themselves. Basile and colleagues (2016) sought to determine up-to-date statistics about risk of sexual violence for people with disabilities, especially related to men with disabilities and precedence of sexual violence within the past 12 months. The researchers analyzed 2010 data from the National Intimate Partner and Sexual Violence Survey (NISVS), a national, random telephone survey of noninstitutionalized US adults that assesses for "prevalence and characteristics of sexual violence, stalking, and intimate partner violence" (Basile et al., 2016, p. 929). Participants in the 2010 NISVS consisted of 9086 women and 7421 men. The results indicated that 23.8% of women and 20.1% of men have had a disability for over a year. Approximately 1.8% (498,000) of women with a disability reported being raped in the 12 months preceding the survey, relative to the 0.9% (772,000) women without a disability who were raped in the 12 months preceding the survey. This means that 39% of the 1.27 million women who were raped within the 12 months preceding the survey had a disability. Additionally, 6.9% of women (1.9 million) and 6.3% of men (1.44 million) with a disability reported other sexual violence within the 12 months preceding the survey, relative to 5.2% of women (4.70 million) and 5.1% of men (4.56 million) without a disability who reported other sexual violence within the 12 months preceding the survey. This indicates that 29% of the 6.64 million women and 24% of the 6 million men who experienced other sexual violence within the 12 months preceding the survey had a disability (Basile et al., 2016). It is clear that people with disabilities are at an increased risk of sexual violence and abuse. Additionally, those who are thought to be supporters, advocates, and protectors of people with ID/DD often do little to prevent sexual abuse and exploitation of people with ID/DD.

Gust and colleagues (2003) conducted a survey of sexual behavior and associated policies in institutions for people with mental retardation and DD. The institutions were located across the United States, and a total of 115 surveys were returned. The purpose of the surveys was to determine how often patients engaged in consensual and nonconsensual sexual behaviors, the prevalence of pregnancy and reported sexually transmitted diseases among patients, the type of training patients and staff receive related to sexual behavior and recognition and reporting of sexual abuse, the frequency of condom and contraceptive use among patients, institutional policies related to pregnancy, sexual abuse, sexually transmitted diseases, and HIV, and the frequency of sexual abuse. Results indicated that over half of the facilities had policies and procedures in place to address sexual relationships between patients. Additionally, 99% of staff received training for recognition and reporting of sexual abuse. Regarding patient education and training, 100% of facilities offered sex education to patients with mild mental retardation, 84% of facilities offered sex education to patients with moderate mental retardation, and 63% of facilities offered sex education to patients with severe mental retardation. No facility offered sex education to patients with profound mental retardation. Over half of the facilities reported that female patients used contraceptives to prevent pregnancy. Additionally, only six out of the 115 facilities that completed the survey reported one or more instances of a sexually transmitted disease within the last year. Facilities also reported issues with patient-patient and patient-staff sexual relations; however, patient-

patient sexual relationships were of greater concern. Regarding sexual abuse, a total of 110 cases was reported within the year preceding the survey. In 90% of the cases, the perpetrator was a male, and in 65% of the cases the victim was a male. In over half of the cases the perpetrator was a patient. The level of functioning of the victim varied (Gust et al., 2003).

McCarthy and Thompson (1997) analyzed reports of sexual abuse of adults with ID who were referred for sex education in England. A total of 65 women and 120 men with ID were referred. The difference in the percentage of women and men who were sexually abused (61% of women and 25% of men) was statistically significant. Many of the people who experienced sexual abuse were unable to describe the type of abuse that occurred, likely due to a lack of knowledge and understanding of sex and sexuality. For those who were able to describe the abuse, 90% of women reported attempted or actual vaginal penetration, 48% of women reported attempted or actual anal penetration, and 79% of men reported attempted or actual anal penetration. The perpetrators were largely male. Of those who perpetrated women, 98% were men, and of those who perpetrated men, 93% were men. The most common perpetrators were fathers or men with ID who received similar services as the victims. For both men (42%) and women (21%) with ID, the perpetrators were frequently men with ID. Most frequently, the abuse occurred where the victim resided, whether in a home or institution. Additionally, women were found to experience the abuse significantly more negatively than men who often reported mixed feelings about the sexual abuse acts. Moreover, police were only involved in 25% of all of the cases reported in this study. Police involvement is directly related to whether the perpetrator had an ID. That is, police responded less often to incidents in which the perpetrator had an ID relative to cases in which the perpetrator did not have an ID. Additionally, nearly one-third of victims reported in this study received no supports despite reporting the sexual abuse. Most often they were not believed, not considered reliable witnesses, or the incidents were not considered to be significant (McCarthy & Thompson, 1997).

It is important that people with ID/DD are believed when they recognize and report abuse. A meta-analysis of studies conducted between January 1, 1990 and August 17, 2010 provided prevalence estimates of violence against adults with disabilities. The resulting statistics indicated that 24.3% of people with mental illnesses are victims of physical, sexual, or intimate partner violence, followed by 6.1% of people with intellectual impairments, and 3.2% of people with non-specific impairments (Hughes et al., 2012). Additionally, more recent prevalence statistics by Bretherton et al. (2016) indicate that people with disabilities have a 31% risk of being maltreated, with prevalence of physical violence at 20.4% and sexual violence at 13.7%.

By not providing people with disabilities education about their sexuality, it is clear that numerous risks arise. If people with disabilities do not understand appropriate and inappropriate sexual behaviors, they will likely not recognize if they are being sexually abused or sexually abusing others. When sexual abuse does arise, it is often blamed on the individual with a disability (Irvine, 2005). The risk of sexual assault for people with ID may be combated by sexuality education programs that increase the knowledge of sexuality within this population (McCabe, 1993; Whitehouse & McCabe, 1997).

The purpose of this study was to improve the sexual knowledge of adults with ID/DD through a sexuality education program. It was expected that adults with ID/DD would show improvements in sexual knowledge upon completion of the program. Additionally, it was expected that the greatest knowledge gains would be in the areas of boundaries and consent, sexually transmitted diseases, and contraception, as evidenced by the lack of knowledge in these areas in previous studies (Barnard-Brak et al., 2014; Lockhart et al., 2010; Murphy & O’Callaghan, 2004; Swango-Wilson, 2010).

CHAPTER II

METHODS

Participants

Participants were recruited from Cedar Lake Lodge in Louisville, Kentucky. Cedar Lake Lodge provides a variety of community, residential, and employment supports for people with intellectual and developmental disabilities. Participants consisted of 10 adults with suspected mild to moderate intellectual or developmental disabilities; however, one participant did not participate due to difficulties completing the pre-test, and one participant did not attend the sexuality education course. Therefore, pre-test and post-test data was collected for eight participants (female = 3, male = 5). Two participants held individual guardianship and demonstrated an understanding of consent. Six participants did not hold self-guardianship. Their guardians consented to the participation of their dependents in the present study, and the six participants demonstrated an understanding of assent. Participants understood English and had no recent psychosis or trauma.

Sexuality Education Curriculum

The sexuality education curriculum utilized in this study was created by two female doctoral clinical psychology students, one of whom is the present researcher, who received their Masters Degrees in clinical psychology and have many years of experience working with children, adolescents, and adults with ID/DD in a variety of settings. The curriculum was based on two sexuality education curricula for people with ID/DD: *Streetwise to Sexwise: Sexuality Education for High-Risk Youth* (Brown & Taverner, 2001) and *LifeFacts: Sexuality* (Stanfield, 2015). The curriculum consisted of nine group-based lessons lasting 30-60 minutes in length.

Lessons were taught by both doctoral students. Groups consisted of eight participants. Four participants attended all nine sessions, three participants missed two sessions, and one participant missed one session. When a session was missed by a participant, the group reviewed the material from the missed session with the participant in the following session. This served as a way to assess the group’s understanding of the previous lesson’s content, as well as provide the participant with the missed information.

The lessons focused on friendship, dating and marriage, anatomy, masturbation, boundaries and consent, contraception, sexually transmitted infections, and menstruation and pregnancy. These nine topics were selected based on research indicating the most important areas of sexual knowledge gain for people with ID/DD (Azzopardi-Lane & Callus, 2014; Brantlinger, 1985; DiGiulio, 2003; Healy et al., 2009; Jahoda & Pownall, 2014; Lockhart et al., 2010; McCabe, 1999; McCabe & Schreck, 1992; McGillivray, 1999; O'Callaghan & Murphy, 2007; Swango-Wilson 2009, 2011; Szollos & McCabe, 1995).

Several researchers have noted the importance of a variety of methodologies when presenting sexual topics to people with ID/DD (Azzopardi-Lane & Callus; Brown & Taverner, 2001; Caspar & Glidden, 2001; Jahoda & Pownall, 2014; Lunsky & Konstantareas, 1998; McDaniels & Fleming, 2016; Penny & Chataway, 1982; Stanfield, 2015; Swango-Wilson, 2011; Wilkenfeld & Ballan, 2011). The lessons consisted of a variety of methodologies for presenting information, including pictures, stories, videos, role-plays, demonstrations, and group discussions and activities. Swango-Wilson (2011) also noted that mixed-gender groups were preferred by people with ID/DD when learning about sexuality; as such, the present curriculum was designed for use with mixed-gender groups in order to account for the preferences and needs of people with ID/DD.

Survey Instruments

Demographic Questionnaire

Participants completed a demographic questionnaire to gather background information, including age, gender, ethnicity, level of education, and relationship status. In addition, the demographic questionnaire contained questions pertaining to previous experience with sexual education and sources from which participants have sought or received sexual education in the past.

Sexual Knowledge, Experiences, Feelings, and Needs Scale for People with Intellectual Disability (SexKen-ID)

The Sexual Knowledge, Experiences, Feelings, and Needs Scale for People with Intellectual Disabilities (SexKen-ID) was developed by Marita McCabe (1994). The SexKen-ID consists of three one-hour interviews that address sexual knowledge, experiences, feelings, and needs of people with ID across 13 subscales. The assessment consists of 248 open-ended, dichotomous, and 5-point Likert-style questions. The results consist of individual totals for each subscale based on results of the dichotomous and Likert-scale questions and qualitative analysis of open-ended responses (McCabe, 1998).

The reliability of the SexKen-ID was determined by McCabe, Cummins, and Deeks (1999). The researchers conducted discussions with 25 people with intellectual disabilities in groups of five. During this time group members provided feedback about the topics to be covered in an interview-style assessment, as well as the specific nature of the interview. Respondents made clear the need for a series of comprehensive questions that allow for some overlap in order to elicit information in different ways, thereby allowing the opportunity for respondents to communicate their knowledge and understanding as best as possible. Additionally, to minimize the likelihood of acquiescence, questions on the SexKen-ID were developed as a simple variety of yes-no and open-ended questions that allow for multiple correct responses. Pictures were also developed to assist with understanding questions. Further, questions that had the potential to be upsetting were placed in the middle or near the end of sections in order to allow time for the building of rapport between the assessor and respondent.

Based on the discussions with the group of people with intellectual disabilities, a draft measure was created. The draft measure was evaluated by eight caregivers of people with intellectual disabilities, four seasoned academics with experience in sex research and therapy, a psychiatrist with experience working with intellectual disabilities, and a clinical psychologist with a specialty in sex research and therapy. The feedback was largely positive and the critiques led to changes in formatting and the result of a three-part interview rather than a single, lengthy interview (McCabe et al., 1999).

The SexKen-ID was then pilot tested with 30 adults with mild intellectual disabilities. The final version is a three-part interview that consists of 248 items. The subscales are organized from least intrusive to most intrusive. Interview 1 consists of the Friendship, Dating and Intimacy, Marriage, and Body Part Identification subscales. Interview 2 consists of the Sex and Sex Education, Menstruation, Sexual Interaction, and Contraception subscales. Interview 3 consists of the Pregnancy, Abortion, and Childbirth, Sexually Transmitted Diseases, Masturbation, and Homosexuality subscales. At the end of the Interviews 1 and 2 are knowledge questions to determine if moving to the next interview is appropriate for the respondent (McCabe, 1994; McCabe et al., 1999).

More specifically, the questions at the end of Interview 1 screen for knowledge about sex, menstruation, sexual interaction, and contraception. Per McCabe (1994), the sections administered in Interview 2 are based on the correct responses provided by respondents in the screening items at the end of Interview 1. For example, if a respondent indicates knowledge about sex, sexual interaction, and contraception but does not indicate knowledge about menstruation on the screening items on Interview 1, then only the items pertaining to sex, sexual interaction, and contraception on Interview 2 would be administered. The items assessing knowledge of menstruation would be scored as “not understanding” or “I don’t know.” The same procedure is utilized for the relationship between the screening items at the end of Interview 2 and the administration of Interview 3 (McCabe, 1994).

To assess the reliability of the SexKen-ID, it was administered to 67 people with intellectual disabilities, and compared to the results of the SexKen-PD, which was given to 60 people with congenital physical disabilities, and the SexKen, which was given to 100 people from the general population. Internal consistency for each dimension of each subscale was determined, with each subscale yielding adequate internal consistency. The Feelings and Needs dimensions of the subscales were found to be less reliable due to the small number of items in these dimensions. In reporting the internal consistency of the dimensions of the subscales, the following abbreviations are used: Knowledge (K), Experiences (E), Feelings (F), and Needs (N). The internal consistency for the subscales are as follows: Friendship Scale E (α = .73), F (α = .34), N (α = .55); Dating and Intimacy Scale K (α = .47), E (α = .72), F (α = .79), N (α = .76); Marriage Scale K (α = .41), F (α = .13); Body Part Scale K (α = .96); Sex/Sex Education Scale E (α = .68), F (α = .72), N (α = .48); Menstruation Scale K (α = .74); Sexual Interaction Scale K (α = .66), E (α = .57), F (α = .60), N (α = .86); Contraception Scale K (α = .83); Pregnancy/Childbirth Scale K (α = .71), F (α = .42), N (α = .77); STD Scale K (α = .71), F (α = .46), N (α = .57); Masturbation Scale K (α = .53), F (α = .66); and Homosexuality Scale F (α = .01; McCabe et al., 1999).

Additionally, test-retest data was collected during a six-week follow-up with 30 participants from each group. The test-retest data indicated stability over time across all three measures as well. In reporting the test-retest correlations of the dimensions of the subscales, the following abbreviations are used: Knowledge (K), Experiences (E), Feelings (F), and Needs (N). The test-retest correlations for the subscales are as follows:

Friendship Scale K (r = .53, p < .01), E (r = .60, p < .01), F (r = .81, p < .001), N (r = .80, p < .001); Dating and Intimacy Scale K (r = .79, p < .05), E (r = .60, p < .01), F (r = .79, p < .001), N (r = .79, p < .001); Marriage Scale K (r = .54, p < .01), F (r = .41, p < .05), N (r = .75, p < .001); Body Part Scale K (r = .79, p < .001); Sex/Sex Education Scale K (r = .23, p > .05), E (r = .77, p < .001), F (r = .87, p < .001), N (r = .71, p < .001); Menstruation Scale K (r = .96, p < .001), F (r = .38, p > .05), N (r = .04, p > .05); Sexual Interaction Scale K (r = .79, p < .001), E (r = .84, p < .001), F (r = .77, p < .001), N (r = .52, p < .05); Contraception Scale K (r = .91, p < .001) F (r = .82, p < .001), N (r = .34, p > .05); Pregnancy/Childbirth Scale K (r = .80, p < .001), F (r = .55, p < .05), N (r = .72, p < .001); STD Scale K (r = .68, p < .01), F (r = .52, p < .05), N (r = .55, p < .05); Masturbation Scale K (r = .78, p < .001), F (r = .85, p < .001), N (r = .95, p < .001); and Homosexuality Scale K (r = .73, p < .001), F (r = .19, p > .05), N (r = .59, p < .01; McCabe et al., 1999).

Although the internal consistency and test-retest reliability statistics vary across subtests, the Knowledge scale consistently holds strong reliability, with the exception of the internal consistency of the Dating and

Intimacy Scale, Marriage Scale, and Masturbation Scale, and the test-retest reliability of the Sex/Sex Education Scale. The reliability of the SexKen-ID would likely increase if the measure was more quantitative than qualitative. However, McCabe (1994) designed the assessment to allow people with ID/DD the opportunity to communicate their understanding as clearly as possible due to expressive communication deficits common in this population (Barnard-Brak et al., 2014). That is, the variety of item types on the SexKen-ID permit people with ID/DD many ways to communicate their knowledge and understanding. Additionally, the open-ended format of qualitative items decreases the chance that researchers' biases impact participants' responses (Healy et al., 2009; Swango-Wilson, 2011). Further, for the present study, the reliability statistics of the SexKen-ID are sufficient, as the researchers sought to allow the participants the ability to communicate their understanding of the material as clearly as possible.

Regarding validity of the SexKen-ID, presently no studies evaluate the validity of this measure. McCabe (1998) states that no comparable assessments evaluate the sexual knowledge, experiences, feelings, and needs of people with ID/DD that are as comprehensive as the SexKen-

ID. However, care was taken to ensure validity of the SexKen-ID during development, as specific and close attention was paid to the working of items based on the work of Sigelman, Budd, Winer, Schoenrock, and Martin (1982, as cited in McCabe, 1998), who evaluated a variety of techniques for questioning people with ID/DD to reduce methodological flaws in assessments.

Procedure

Participants engaged in two 90-minute meetings with the doctoral students, before and after the completion of the sexuality education program. The initial meeting focused on understanding informed consent or informed assent and the completion of the demographic questionnaire and the SexKen-ID, which was administered by the doctoral students. The SexKen-ID served as a pre-assessment of the participants' sexual knowledge. After the initial meeting, participants partook in nine 30-60-minute group sessions at a residence for adults with ID/DD owned by Cedar Lake Lodge during which the doctoral students taught a sexuality education curriculum. Upon completion of the sexuality education program, participants met with the doctoral students to complete the SexKen-ID as a measure of their sexual knowledge after completion of the program.

Lesson 1: Friendship

The goal of the first lesson was for participants to understand how friends differ from dating and sexual partners. At the beginning of the group, the doctoral students introduced themselves to the group and invited the participants to introduce themselves. Then, the group rules were presented. The group rules were 1) Personal stories shared by participants will not be repeated outside of the group, 2) Respect others, 3) Don’t talk over others, 4) If you become uncomfortable, let the researchers know, and 5) You can leave the group at any time.

The researchers guided a discussion about friends: What are friends? Who can be a friend? What do friends do? What do friends not do? How do you know someone is a friend? How are friends different from people you date? How are friends different from sexual partners? The discussion on friendship was aided by a visual aid depicting a multicolored social circle to promote understanding of social networks and circles and appropriate behavior in a given social circle, as well as role-plays for appropriate interactions with people in various social circles.

Lesson 2: Dating and Marriage

The goal of the second lesson was for participants to understand the concept of dating and the responsibility of marriage. The researchers led a discussion on dating, specifically focusing on why people date and of what a date consists. The participants engaged in a series of role-plays with a focus on appropriate times to ask someone on a date. Participants also answered a series of questions about important concepts and ideas when dating. Then, the researchers discussed the concept of engagement, followed by marriage. Responsibilities associated with marriage were covered to stress the significance of marriage. Additionally, the concept of parenting was teased apart from marriage and the differences were discussed with participants. Participants identified differences in healthy and unhealthy relationships with assistance from visual supports and the researchers.

Lesson 3: Anatomy

The goal of the third lesson was for participants to understand and recognize differences in sexual anatomy between males and females. The participants brainstormed differences in physical characteristics of males and females. The researchers then introduced sexual anatomy, as well as differences and changes due to puberty. Sexual anatomy was presented with assistance from visuals, such as anatomical models and pictures. The sexual anatomies and physical differences covered included the vagina, clitoris, internal organs for pregnancy, bigger breasts, less body and facial hair, and smaller frame for females, and the penis, testicles, scrotum, flatter chest, more facial and body hair, and bigger and more musical frame for males. Lastly, participants worked together to identify differences between male and female anatomy as a review of the material covered throughout the lesson.

Lesson 4: Masturbation

The goal of the fourth lesson was for participants to understand appropriate time and place for masturbation. At the beginning of the group, the group rules were reviewed. Then, the researchers led a discussion about masturbation with the assistance of anatomical models, during which basic information about masturbation was shared, as well as appropriate time, place, and safety information. Appropriate time and place were introduced through a sorting activity during which participants sorted images of places under “Okay” or “Not Okay.” At the end of the lesson, the participants worked together to review appropriate time and place for masturbating, as well as safety.

Lesson 5: Sexual Interactions and Behavior

The goal of the fifth lesson was for the participants to understand appropriate sexual behaviors. Then, the participants engaged in a group discussion about their present knowledge about sex. The researchers prompted them with open-ended and closed-ended questions to evaluate for their current level of understanding and knowledge. After the group discussion, the researchers provided information about sexual behaviors related to oral, anal, and penile-vaginal intercourse with assistance from sexual anatomy models. Next, the participants brainstormed times in which people might get in trouble for having sex. The discussion was followed by a discussion about the importance of consent and legal consequences to certain types of sexual behavior. Additionally, participants were provided with worksheets that outline appropriate and inappropriate sexual behaviors, as well as list of scenarios to be identified as appropriate and inappropriate sexual behaviors. Lastly, the researchers led a guided discussion about the reason people have sex.

Lesson 6: Boundaries and Consent

The goal of the sixth lesson was for participants to understand the importance of boundaries and consent, appropriate and inappropriate sexual behaviors and relationships, and what to do if they are uncomfortable with sexual contact and intercourse. Participants brainstormed a list of appropriate and inappropriate touches, identified who is allowed to touch their sexual genitalia, and identified these locations on an outline of the human body. Next, with assistance from the researchers, participants learned about appropriate and inappropriate sexual behaviors. Finally, resources and information were provided about sexual abuse and what do if someone is sexually inappropriate.

Lesson 7: Contraception

The goal of the seventh lesson was for participants to understand the importance of contraception and how to access different types of contraceptives. Participants brainstormed risks to pregnancy, as well as ways to prevent the risks. The researchers then led a discussion about the prevention of pregnancy and sexual infections by talking about contraceptive options. The contraceptives discussion was assisted by use of sexual anatomy models and different types of contraceptives, such as condoms, as well as a demonstration of how to use a condom. Upon completion of the discussion, participants were permitted time to explore the contraceptives and ask questions. Additionally, participants watched the researchers complete a role-play about buying condoms before practicing buying condoms via the role-play themselves.

Lesson 8: Sexually Transmitted Infections

The goal of the eigth lesson was for participants to understand the risks associated with sexually transmitted infections (STIs) and the importance of using contraceptives and seeing the doctor for annual exams or if they suspect they might have an STI. The participants brainstormed diseases that can be obtained from sexual contact. The researchers introduced the concept of STIs with assistance from pictures and images, as well as how people obtain STIs. Participants learned how to prevent an STI and the signs of an STI, as well as what to do if they believe they might have an STI.

Lesson 9: Menstruation and Pregnancy

The goal of the ninth lesson was for participants to understand why menstruation occurs, as well as the process of conception, pregnancy, and labor/delivery of a child. Participants brainstormed what they knew about menstruation. Researchers then provided information about menstruation with assistance from visual aids, social stories, pads and tampons, and a social modeling video about how to change a pad. Participants were permitted the opportunity to explore the pads and tampons, and use of a tampon was modeled with a female genitalia model. The discussion of menstruation was followed by a discussion of sex and conception, as well as the process of pregnancy, labor, and birth. The discussion of pregnancy was aided by a video depicting the growth of a child in the mother's womb and the mother's bodily changes throughout the pregnancy. A review of contraception was covered when discussing how to not get pregnant. The concepts of abortion and adoption were also covered due to their connection with women's option to not want a baby despite being pregnant.

Plan for Potential Participant Discomfort

Based on the content of the study, it was likely participants would experience discomfort discussing sexual content with the female doctoral students. The researchers arranged the opportunity for participants potentially desiring a male instructor to be referred to a male instructor at Cedar Lake Lodge who teaches sexual education classes for Cedar Lake Lodge. Additionally, it was likely participants would experience discomfort or distress due to the content of the SexKen-ID or the group sessions. This occurred several times throughout the administration of the SexKen-ID. When distress was noted in a participant, the doctoral students stopped the assessment and provided the participant with the option for a break, discontinuation of the assessment, or termination of his or her participation in the study. Most participants asked to continue after a short break. One participant asked to terminate her participation in the study. It was also likely that participants would experience discomfort or distress due to the content of the sexuality education course. This occurred several times during the course. When this occurred among the group, the doctoral students paused the lesson and talked with the group about their discomfort. When this occurred with one participant, one doctoral student would talk with him or her briefly and offer a break while the other doctoral student continued with the lesson. Participants typically remained with the group with the exception of one participant who left the group during the lesson on contraception. One doctoral student attempted to talk with him about his discomfort, but he refused. If participants needed further supports to manage their distress, the doctoral students planned to refer them to Cedar Lake Lodge, who had agreed to arrange psychological services for participants should the need arise.

Additionally, although research largely indicates the likelihood of sexual acting out behavior during and after sexuality education is minimal (McCabe, 1993; Whitehouse & McCabe, 1997), the doctoral students arranged for participants to be referred to Cedar Lake Lodge for the arrangement of appropriate psychological services if sexually acting out behaviors arose during the course of the study. No sexual acting out behaviors were observed or reported during the involvement of the doctoral students with participants.

Lastly, due to the nature of the content covered in the study, there was a likelihood that participants would report a history of physical, sexual, and/or psychological abuse or neglect. If reports of abuse or neglect arose, the doctoral students planned to refer participants to Cedar Lake Lodge for the arrangement of appropriate psychological services, as well as report to Adult Protective Services. No history of physical, sexual, and/or psychological abuse or neglect was reported by participants.

CHAPTER III

RESULTS

Demographics

The participants in this study consisted of eight adults with intellectual and developmental disabilities (male = 5, female = 3). Six participants identified as Caucasian and two participants identified as African-American. The ages of participants ranged from 32 years to 65 years, with an average of 50.71 years of age (*SD* = 9.58). Half of participants were in a romantic relationship and half were single. Additionally, three participants endorsed receiving previous sexuality education and five denied receiving previous sexuality education. Of the participants who received sexuality education previously two identified the source of the information as a friend and a parent, repectively. The third participant was unsure of the source of her previous sexuality education.

Sexual Knowledge

The SexKen-ID does not provide a total score for sexual knowledge. As such, results are reported on a subtest by subtest basis. The knowledge questions on the Friendship subtest total to 2 points. Participants received an average total of 0.125 on the pretest and 0.375 on the posttest. The difference in pretest and posttest scores is 0.25, which constitutes a 12.50% increase in knowledge related to friendship.

The knowledge questions on the Dating subtest total to 4 points. Participants received an average total of 1.375 on the pretest and 1.375 on the posttest. The difference in pretest and posttest scores is 0, meaning on average participants maintained knowledge related to dating.

The knowledge questions on the Marriage subtest total to 4 points. Participants received an average total of 2.125 on the pretest and 2.75 on the posttest. The difference in pretest and posttest scores is 0.625, which constitutes a 15.63% increase in knowledge related to marriage.

The knowledge questions on the Body Part Identification subtest total to 42 points. Participants received an average total of 30.875 on the pretest and 37.375 on the posttest. The difference in pretest and posttest scores is 6.50, which constitutes a 15.48% increase in knowledge related to anatomy.

The knowledge questions on the Sex and Sex Education subtest total to 2 points. Participants received an average total of 0.00 on the pretest and 0.75 on the posttest. The difference in pretest and posttest scores is 0.75, which constitutes a 37.50% increase in knowledge related to sex and sex education.

The knowledge questions on the Menstruation subtest total to 22 points. Participants received an average total of 5.50 on the pretest and 9.375 on the posttest. The difference in pretest and posttest scores is 3.875, which constitutes a 17.61% increase in knowledge related to menstruation.

The knowledge questions on the Sexual Interaction subtest total to 42 points. Participants received an average total of 15.125 on the pretest and 23.125 on the posttest. The difference in pretest and posttest scores is 8.00, which constitutes a 19.05% increase in knowledge related to sexual interaction.

The knowledge questions on the Contraception subtest total to 18 points. Participants received an average total of 5.125 on the pretest and 9.875 on the posttest. The difference in pretest and posttest scores is 4.75, which constitutes a 26.39% increase in knowledge related to contraception.

The knowledge questions on the Pregnancy, Abortion, and Childbirth subtest total to 30 points. Participants received an average total of 16.75 on the pretest and 21.375 on the posttest. The difference in pretest and posttest scores is 4.625, which constitutes a 15.42% increase in knowledge related to pregnancy, abortion, and childbirth.

The knowledge questions on the Sexually Transmitted Diseases subtest total to 22 points. Participants received an average total of 8.25 on the pretest and 11.00 on the posttest. The difference in pretest and posttest scores is 2.75, which constitutes a 12.50% increase in knowledge related to sexually transmitted infections.

The knowledge questions on the Masturbation subtest total to 6 points. Participants received an average total of 1.625 on the pretest and 3.125 on the posttest. The difference in pretest and posttest scores is 1.50, which constitutes a 25.00% increase in knowledge related to masturbation.

The knowledge questions on the Homosexuality subtest total to 2 points. Participants received an average total of 0.00 on the pretest and 0.75 on the posttest. The difference in pretest and posttest scores is 0.75, which constitutes a 37.50% increase in knowledge related to homosexuality.

Boundaries and Consent

Knowledge items pertaining to boundaries and consent are found in the Sexual Interaction subtest, items 7.43-7.47, and total to 12 points. Participants received an average total of 6.875 on the pretest and 10.125 on the posttest. The difference in pretest and posttest scores is 3.25, which constitutes a 27.08% increase in knowledge related to boundaries and consent.

CHAPTER IV

DISCUSSION

Conclusion

The purpose of this study was to improve the sexual knowledge of adults with ID/DD through a sexuality education program. On average improvement was noted in all areas of knowledge measured by the SexKen-ID with the exception of the Dating subtest. Across the eight participants, six maintained their scores on the knowledge items on the Dating subtest, one showed an increase in knowledge, and one showed a decrease in knowledge. The increase and decrease in knowledge pertaining to dating was reflected on one item: “What is meant by feeling close to someone?” (McCabe, 1994, p. 14; see Table 1). The increase and decrease of two participants’ knowledge on the Dating subtest influenced the average knowledge difference between pretest and posttest and resulted in an overall average maintenance of knowledge related to dating across participants. The results support the first hypothesis that sexual knowledge would increase upon completion of a

Table 1

Response to Item 2.8

Participant 1		Participant 7	
Pretest	Posttest	Pretest	Posttest
Going together	I don't know	I don't know	You really like somebody

Note. Item 2.8 on the SexKen-ID states "What is meant by feeling close to someone?" (McCabe, 1994, p. 14).

sexuality education program with the exception of knowledge related to dating.

The second hypothesis expected the greatest knowledge gains to occur in the areas of boundaries and consent, sexually transmitted diseases, and contraception. This hypothesis was not supported, as the results indicate the greatest knowledge gains occurred on the Sex and Sex Education subtest and the Homosexuality subtest. On average participants demonstrated a 37.50% increase in knowledge on both subtests. However, it is important to note that these subtests were measured out of two total points, which means increases in knowledge on the Sex and Sex Education and Homosexuality subtests are likely inflated. The next two greatest gains in knowledge were in the areas of boundaries and consent and contraception. On average participants demonstrated a 27.08% increase in knowledge related to boundaries and consent and a 26.39% increase in knowledge related to contraception. The Sexually Transmitted Diseases subtest yielded the twelfth highest with an 11.93% knowledge increase. The knowledge gain pertaining to sexually transmitted infections is likely influenced by participants' limited understanding of STDs, as well as their previously held belief that AIDS leads to death. Across the pretest and posttest, no participants indicated an accurate understanding of sexually transmitted diseases or AIDS. On the pretest, four participants believed people die if they get AIDS, two participants indicated people need to go to the doctor or hospital, and two participants did not know what would happens if people get AIDS. On the posttest, two participants believed people die if they get AIDS, two participants indicated people should go to the doctor, two participants did not know, one participant indicated people get sick, and one participant said it "burns when you go to the bathroom." Additionally, regarding the best way to stop getting AIDS, on the pretest three participants did not know, three participants indicated people should stop having sex, one participant believed the person should leave his or her partner alone, and one participant endorsed the use of protection. On the posttest, three participants indicated not having sex, two participants did not know, one participant endorsed use of a condom, one participant believed medicine would prevent AIDS, and one participant said, "…they gave me some medicine for it." Based on research, it is likely that deeply held beliefs that AIDS leads to death and a general misunderstanding of sexually transmitted diseases are the result of the influence of parental, educator, and medical professional attitudes toward sexually transmitted infections and general sexual knowledge for people with ID/DD (DiGiulio, 2003; Gomez, 2012; Hingsburger & Tough, 2002; Szollos & McCabe, 1995).

Implications

The current findings join the chorus of voices that support sexuality education for people with ID/DD. People with ID/DD incur knowledge gains after receiving sexuality education. As research shows, greater sexual knowledge decreases the sexual risk-taking behaviors of people with ID/DD and decreases their chances of becoming a victim of sexual abuse (Barnard-Brak et al., 2014; Basile et al., 2016; Bretherton et al., 2016; Chiesa & Goldson, 2017; Gust, Wang, Grot, Ransom, & Levine, 2003; Hughes et al., 2012; Irvine, 2005; Lund & Vaughn-Jensen, 2012; Mahoney & Polling, 2011; McCabe, 1993; McCarthy & Thompson, 1997; Murphy & O’Callaghan, 2004; Swango-Wilson, 2010; Szollos & McCabe, 1995). Participants in the present study showed an average increase of 27.08% in their knowledge of boundaries and consent, which decreases their likelihood of being victims of sexual violence or abuse and increases their self-advocacy skills.

In addition, improved knowledge of contraception increases the likelihood that participants will engage in safe sex, should they choose to engage in sexual behaviors. However, their limited increase in knowledge of STDS is a concern and suggests the impact of caregiver, educator, and medical professional attitudes, misconceptions, and potential intentional misrepresentation of information strongly impacts the sexual knowledge and understanding of individuals with ID/DD.

Moreover, given the general increase in sexual knowledge as a result of the comprehensive sexuality education curriculum provided, this study joins the increasing literature that strongly supports the effects of comprehensive sex education (CSE) over abstinence-only education (AOE; Gresle-Favier, 2013; Hoefer & Hoefer, 2017; Kirby, 2007; Zanis, 2005). Although research has not addressed the effects of CSE versus AOE as it pertains to people with DD/ID, time and again findings indicate CSE, which teaches abstinence as an option alongside contraception, leads to long-term, safer sex choices and improved sexual decision-making skills and attitudes among adolescents and adults who are typically developing (Gresle-Favier, 2013; Hoefer & Hoefer, 2017; Kirby, 2007; Zanis, 2005).

Limitations

Several limitations were notable throughout the study. First, the limited sample size prevented the use of correlations and other statistical measures to identify statistically significant findings. Additionally, the sample is likely biased as the participants were referred by Cedar Lake Lodge staff who believed the participants would be an appropriate fit for the study.

Further, the resources available to the doctoral students when creating the sexuality education curriculum were limited. The presentation format of the curriculum varied primarily based on readily available and appropriate resources. Despite research supporting a variety of methodologies when teaching people with ID/DD (Azzopardi-Lane & Callus; Brown & Taverner, 2001; Caspar & Glidden, 2001; Jahoda & Pownall, 2014; Lunsky & Konstantareas, 1998; McDaniels & Fleming, 2016; Penny & Chataway, 1982; Stanfield, 2015; Swango-Wilson, 2011; Wilkenfeld & Ballan, 2011), the researchers experienced significant difficulty finding and accessing a variety of appropriate supports. Images and videos were often not developmentally appropriate or not clearly and simply focused on the topics for the purpose of the curriculum and sexuality education group. Further, activities for teaching concepts pertaining to sexuality education were often inappropriate and difficult to adapt while maintaining relevance and integrity. It is possible the limitations in resources impacted the sexual knowledge gains of participants, as the researchers frequently designed their own images or activities due to a lack of appropriate supports.

In addition, some items on the SexKen-ID (McCabe, 1994) appeared difficult for participants to understand, and therefore respond to, as the items in question seem to pertain to abstract concepts. For example, the singular knowledge question on the Friendship subtest is, “What is friendship?” Participants frequently responded with appropriate answers for the question, “What is a friend?” However, since the SexKen-ID item asks about friendship and not friends, participants lost credit.

Additionally, items pertaining to menstruation are likely influenced by the type of birth control female participants use or the age of female participants (e.g., older female participants might have gone through menopause). For example, an item in the Menstruation subtest states, “Do you know when your period is due?” Two female participants no longer menstruate; therefore, their responses were coded as a 0, despite the irrelevant nature of this item for these particular individuals.

Further, although the SexKen-ID (McCabe, 1994) contains items focused on boundaries and consent, this is a complicated concept, especially for people with DD/ID. One item states, “Who should decide whether you have sex?” This was found to be a complicated item through the course of the present study, as some participants were their own guardians while others were not. Additionally, individuals with ID/DD also need to consider the guardianship status of the person with whom they would like to engage in sexual behavior. This is a complex scenario for anyone, but especially for people with ID/DD.

Moreover, the SexKen-ID (McCabe, 1994) involves frequent presentation of drawings of people engaging in social or sexual behaviors and items pertaining to sexual behaviors and sexuality education (e.g., birth control pills, condoms, tampons). These items are used to determine if participants understand what they are seeing. However, the order of items appears to influence participants’ responses to the image of masturbation (e.g., a naked female touching her vagina and a naked male holding his penis). The item before the image identification item is, “What is masturbation?” This may prime participants’ responses to the next item, “What is this a picture of?” Therefore, it is likely that knowledge of masturbation on the SexKen-ID was portrayed as inadvertently higher than participants’ actual knowledge.

Furthermore, participants knew they were participating in a sexuality education program prior to completing the pretest. Therefore, it is possible participants’ sexual knowledge on the pretest is inflated, as participants may have responded with previously heard terms while not actually understanding the concepts.

Directions for Future Research

Future research should consider a variety of topics when expanding research in the area of sexuality among people with ID/DD. Further research with people with ID/DD would benefit from documenting the disabilities of participants, as disability related deficits impact participants’ understanding of material. That is, knowing the disabilities of participants should impact the instructional methods used when teaching sexuality education curricula to people with ID/DD, as there may be differences in the cognitive strengths and deficits associated with different disabilities.

More comprehensive and developmentally appropriate sexuality education curricula is needed for people with ID/DD. Most curricula marketed for this population maintain insufficiencies in content, concepts, and instructional methods (Blanchett & Wolfe, 2002). The curricula referenced by the researchers for the present study are among the most comprehensive and developmentally appropriate sexuality education curricula for people with ID/DD and yet maintain deficits in some areas of content, concepts, and instructional methods (Blancett & Wolfe, 2002; Brown & Taverner, 2001; Stanfield, 2015). Therefore, there is a great need for the modification of existing curricula or development of new curricula that considers research on appropriate content, concepts, and instructional methods pertaining to sexuality education for people with ID/DD. However, it is critical that curricula refrain from teaching abstinence-only sex education, as research consistently indicates a lack of statistical impact on sexual knowledge, attitudes, and behaviors (Gresle-Favier, 2013; Hoefer & Hoefer, 2017; Kirby, 2007; Zanis, 2005).

Additionally, the field is in desperate need of more appropriate resources for people with ID/DD to assist in the understanding of sexuality-related concepts. Resources should consider the research on the cognitive strengths and weaknesses of people with disabilities, as well as evidenced-based instructional methods, such as video modeling, visual supports, and simple, straightforward explanations and activities.

Additionally, in order to better assess the sexual knowledge of people with ID/DD revisions to the SexKen-ID should be considered. Presently, the SexKen-ID items related to sexual knowledge are relatively abstract (e.g., “What is meant by feeling close to someone?”). In addition, some of the items and the scoring does not account for changes in medical knowledge and practice, such as the use of birth control implants. Moreover, the scoring of the measure does not account for items that do not pertain to individuals given their unique circumstances (e.g., birth control implants, menopause). Additionally, items pertaining specifically to males or specifically to females, although labeled and skipped based on the sex of the individual, still influence overall scores. For example, on the Menstruation subtest, females answer all 11 items for a total of 22 potential points; however, males answer seven items, but their responses are still scored out of a total of 22 potential points. Further, the images on the SexKen-ID are difficult to interpret and would benefit from clarity. In addition, the details of images were also difficult for some participants to interpret due to the size of the images. As such, new, larger images on the SexKen-ID would likely influence the understanding and knowledge responses of people with ID/DD.

Lastly, during the course of reviewing literature on the impact of sexuality education on the risk of sexual abuse of people with ID/DD, no studies were found directly correlating increased sexual knowledge with reduced risk of sexual abuse for any population. This is of concern, as many studies and reputable sources (Barnard-Brak et al., 2014; Basile et al., 2016; Bretherton et al., 2016; Chiesa & Goldson, 2017; Gust, Wang, Grot, Ransom, & Levine, 2003; Hughes et al., 2012; Irvine, 2005; Lund & Vaughn-Jensen, 2012; Mahoney & Polling, 2011; McCabe, 1993; McCarthy & Thompson, 1997; Murphy & O'Callaghan, 2004; Swango-Wilson, 2010; Szollos & McCabe, 1995) note the importance of increased sexual knowledge in reducing risk of sexual abuse across populations. Although this may be true, research is desperately needed to provide a foundation for this rationale. Additionally, research support may influence societal discussion and understanding about the importance of encouraging appropriate sexual knowledge among people with ID/DD.

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APPENDIX A

Informed Consent for Participants

Title: Sexual Education for Intellectual and Developmental Disabilities

Investigator: Claire Horton & Autumn Truss

Faculty Advisor: DeDe Wohlfarth, Psy.D.

Dear Potential Research Participant: Our names are Claire Horton and Autumn Truss, and we are students in at Spalding University. We are doing a research project.

Description: We want to see if a sexual education program can help increase your sexual knowledge and attitudes. First, we will ask you some private questions about sexual topics, including Friendship, Dating and Intimacy, Marriage, Body Part Identification, Sex and Sex Education, Menstruation, Sexual Interaction, Contraception, Pregnancy, Abortion and Childbirth, Sexually Transmitted Diseases, Masturbation, and Homosexuality. We will ask questions about what you know about sex, what you have done, and about your feelings. It will take about 1 hour to ask these questions. Next, you will complete 9 sexual education classes. The classes will be 1 hour long. These classes will be led by Ms. Claire and Ms. Autumn. Finally, we will ask you the same questions a final time after you have finished the sexual education classes.

Potential Risks/Benefits: There is little risk if you choose to help with our project. You may become frustrated or upset with a question or with a certain topic. You do not have to answer a question that makes you uncomfortable or upset, and you can stop at any time. If you get upset and do not want to keep working with us, that is OK. If you want to work with Pastor Mark or Tara Clark at Cedar Lake, that is OK too. If you join us in the project, you will get to learn about sexual topics, including: Friendship, Dating and Intimacy, Marriage, Body Part Identification, Sex and Sex Education, Menstruation, Sexual Interaction, Contraception, Pregnancy, Abortion and Childbirth, Sexually Transmitted Diseases, Masturbation, and Homosexuality. You will also be helping us with our research project to find out if sexual education increases your sexual knowledge and attitudes.

If you become very upset, you can call the Centerstone Crisis Hotline: 502-589-4313. They can help you find someone to help you feel better.

Voluntary Participation and Right to Withdraw: The questions we will ask are about very private information.

You can choose if you want to answer these questions. You do not have to answer any of these questions. If you decide not to answer these questions that is OK. If you decide you want to stop the interview at any point that is OK. Just let us know. You may not know the answers to some questions. That is OK. You may not have experienced some things. That is OK too. We just want to know about you. There will be no consequences if you decide to stop at any time.

Confidentiality: We will not let anyone else know what you tell us. The only time we will tell someone is if you tell us about having any sexual experiences that you did not agree to. Then, we will have to tell Mark Whisett and Tara Clark. Additionally, Ms. Claire, Ms. Autumn, Mark Whisett, or Tara Clark will have to contact Adult Protective Services in order to keep you safe. Your name will not be on any of the papers or results of our project. We will use a number instead of your name. The only paper your name will be on is this consent form. No one will know you helped us with our project. We will keep your name and information safe. We will keep everything we use for the project in a filing cabinet that locks so only Ms. Claire and Ms. Autumn can use the information.

Contact Information: Please contact Claire Horton, (chorton01@spalding.edu), Autumn Truss (atruss@spalding.edu) or our faculty advisor, Dr. DeDe Wohlfarth (dwohlfarth@spalding.edu) to request the results of this study or if you have any questions. If you have any questions or concerns about your own rights as a research volunteer, you may contact Dr. Steve Katsikas, Chair of the Spalding University School of Professional Psychology, at skatsikas@spalding.edu.

Consent: I, _____________________, have read this paper and asked questions any questions I have so I can understand it better, and I agree to participate in this research project with Ms. Claire and Ms. Autumn.

_________________________	_________________________
Participant's Name	Participant's Signature

____

Identification Number

APPENDIX B

Information and Consent Form-Guardian Version

Title: Sexual Education for Intellectual and Developmental Disabilities

Investigator: Claire Horton & Autumn Truss

Faculty Advisor: DeDe Wohlfarth, Psy.D.

Dear Potential Research Participant: Our names are Claire Horton and Autumn Truss, and we are students in the Clinical Psychology doctoral program at Spalding University. We are conducting a research study as part of our dissertation research for the completion of our doctorates.

Description: The purpose of the current study is to determine the effectiveness of sexual education programs for adults with developmental and intellectual disabilities. In addition, this study is investigating the effects of sexual education on individual attitudes toward sexually-related topics. This study will involve completing nine one-hour sexual education sessions and completing a

90-minute assessment about sexuality before and after the sexual education course. The assessment addresses topics related to sexual knowledge, attitudes, experiences, and needs and will ask about the participant’s personal experiences with sexuality.

The sexual education sessions will cover body parts and anatomy, sexual interactions and behavior, masturbation, contraception, sexually transmitted diseases, menstruation and pregnancy, friendship, dating and marriage, and boundaries and consent. During the sessions, participants will be shown sexually explicit illustrations and sexual education videos.

Potential Risks/Benefits: The risks of participation within this study are judged to be minimal. There are several potential risks that participants may encounter as a result of the present study. First, participants may become distressed during the assessment due to the sexual topics discussed. If participants become distressed during the assessment, the investigators will stop the assessment and give the participant the option of taking a break or discontinuing the assessment and/or terminating their participation in the study. Participants may also skip any question they do not wish to answer. Additionally, participants may become distressed during the sexuality education sessions due to the sexual content of the sessions. If participants become distressed during the sessions, they will have the opportunity to leave the session early and/or stop participating in the study. If participants require further support, they will be referred to Mark Whisett or Tara Clark at Cedar Lake who will then connect them with appropriate psychological support. Second, participants may begin engaging in sexual acting out behavior due to the content of the material covered in the assessment and sessions led by the investigators. If participants begin engaging in sexual acting out behavior, they will be referred to Mark Whisett and Tara Clark at Cedar Lake who have agreed to arrange psychological services for participants to address these concerns. Finally, due to the content of the assessment and sessions, there is the potential that participants will report a history of physical, sexual, and/or psychological abuse or neglect. If this occurs, participant confidentiality will be broken in order to notify guardians and refer participants to Mark Whisett and Tara Clark at Cedar Lake who have agreed to arrange psychological services for participants to address these concerns further.

Additionally, by law the investigators, Mark Whisett, and Tara Clark are mandated reporters. This means that should abuse or neglect be reported to any of us, we will have to contact Adult Protective Services in order to keep participants safe.

Distressed participants and their caregivers can also access resources through [http://us.reachout. com/get-help/getting-help-in-a-crisis](http://us.reachout.com/get-help/getting-help-in-a-crisis) or the Centerstone Crisis Hotline: 502-589-4313.

The primary benefit of this research is to evaluate current sexual education programs and to contribute to psychological research sexual knowledge and attitudes of individuals with intellectual and developmental disabilities.

Voluntary Participation and Right to Withdraw:

Participation in this study is completely voluntary and you or the participant are free to withdraw from the study at any time. There will be no repercussions if you or the participant decide not to participate or if you or the participant choose to withdraw. Further, your decision for the participant to participate in the study in no way affects services received through Cedar Lake Lodge.

Confidentiality: The results of this study will be analyzed in terms of groups of adults. All information obtained during this study, including the results, will be strictly confidential. The results will only be used for research purposes, but they may be shown to people outside of the research team. However, the results will never be associated with the participant’s name. The participant’s name will only appear on this consent form and will not be identified in any future publication of this study. Instead, the participant will be assigned a participant number, and only the number will appear with the survey responses.

Contact Information: Please contact Claire Horton, (chorton01@spalding.edu), Autumn Truss (atruss@spalding.edu) or our faculty advisor, Dr. DeDe Wohlfarth (dwohlfarth@spalding.edu) to request the results of this study or if you have any questions. If you have any questions or concerns about your own rights or the participant's rights as a research volunteer, you may contact Dr. Steve Katsikas, Chair of the Spalding

University School of Professional Psychology, at skatsikas@spalding.edu.

Consent: I have read this statement and agree to allow ________________________ to participate in the research under the presented conditions.

________________________ ________________________

Guardian’s Name Guardian’s Signature

____

Date

APPENDIX C

Informed Assent for Participants

Title: Sexual Education for Intellectual and Developmental Disabilities

Investigator: Claire Horton & Autumn Truss

Faculty Advisor: DeDe Wohlfarth, Psy.D.

Dear Potential Research Participant: Our names are Claire Horton and Autumn Truss, and we are students in at Spalding University. We are doing a research project.

Description: We want to see if a sexual education program can help increase your sexual knowledge and attitudes. First, we will ask you some private questions about sexual topics, including Friendship, Dating and Intimacy, Marriage, Body Part Identification, Sex and Sex Education, Menstruation, Sexual Interaction, Contraception, Pregnancy, Abortion and Childbirth, Sexually Transmitted Diseases, Masturbation, and Homosexuality. We will ask questions about what you know about sex, what you have done, and about your feelings. It will take about 1.5 hours to ask these questions. Next, you will complete 9 sexual education classes. The classes will be 1 hour long. These classes will be led by Ms. Claire and Ms. Autumn. Finally, we will ask you the same questions a final time after you have finished the sexual education classes.

Potential Risks/Benefits: There is little risk if you choose to help with our project. You may become frustrated or upset with a question or with a certain topic. You do not have to answer a question that makes you uncomfortable or upset, and you can stop at any time. If you get upset and do not want to keep working with us, that is OK. If you want to work with Pastor Mark or Tara Clark at Cedar Lake, that is OK too. If you join us in the project, you will get to learn about sexual topics, including: Friendship, Dating and Intimacy, Marriage, Body Part Identification, Sex and Sex Education, Menstruation, Sexual Interaction, Contraception, Pregnancy, Abortion and Childbirth, Sexually Transmitted Diseases, Masturbation, and Homosexuality. You will also be helping us with our research project to find out if sexual education increases your sexual knowledge and attitudes.

If you become very upset, you can call the Centerstone Crisis Hotline: 502-589-4313. They can help you find someone to help you feel better.

Voluntary Participation and Right to Withdraw: The questions we will ask are about very private information. You can choose if you want to answer these questions. You do not have to answer any of these questions. If you decide not to answer these questions that is OK. If you decide you want to stop the interview at any point that is OK. Just let us know. You may not know the answers to some questions. That is OK. You may not have experienced some things. That is OK too. We just want to know about you. There will be no consequences if you decide to stop at any time.

Confidentiality: We will not let anyone else know what you tell us. The only time we will tell someone is if you tell us about having any sexual experiences that you did not agree to. Then, we will have to tell Mark Whisett, Tara Clark, and your guardian. Additionally, Ms. Claire, Ms. Autumn, Mark Whisett, or Tara Clark will have to contact Adult Protective Services in order to keep you safe. Your name will not be on any of the papers or results of our project. We will use a number instead of your name. The only paper your name will be on is this consent form. No one will know you helped us with our project. We will keep your name and information safe. We will keep everything we use for the project in a filing cabinet that locks so only Ms. Claire and Ms. Autumn can use the information.

Contact Information: Please contact Claire Horton, (chorton01@spalding.edu), Autumn Truss (atruss@spalding.edu) or our faculty advisor, Dr. DeDe Wohlfarth (dwohlfarth@spalding.edu) to request the results of this study or if you have any questions. If you have any questions or concerns about your own rights as a research volunteer, you may contact Dr. Steve Katsikas, Chair of the Spalding University School of Professional Psychology, at skatsikas@spalding.edu.

Consent: I, ______________________________, have read this paper and asked questions any questions I have so I can understand it better, and I agree to participate in this research project with Ms. Claire and Ms. Autumn.

_________________________ _________________________

Participant's Name Participant's Signature

____

Identification Number

APPENDIX D

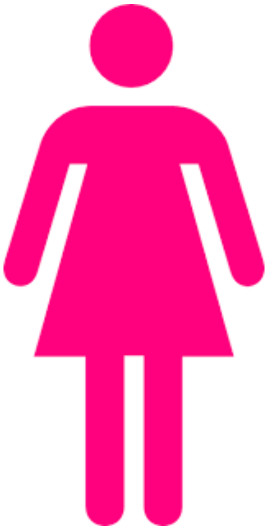
Demographic Questionnaire

ID#: ______________________________

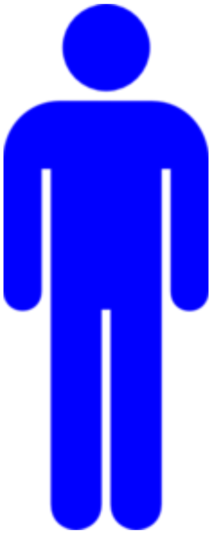
Age: ______________________________

Highest Grade: ________________

Gender



Female



Male

Don’t Know

Ethnicity

White

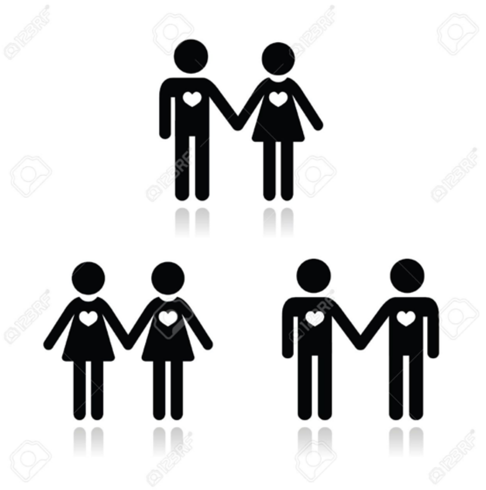
Black

Hispanic

Other

Relationship Status

Single



Relationship

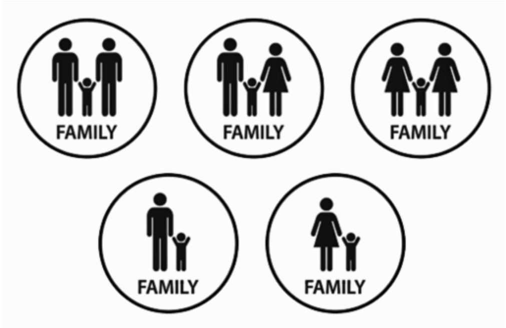
Married

Sexual Status

Have you ever learned about sex?

Yes No ?

Where did you learn about sex?



Parents

Caregiver

T.V.

Computer

Friend

Other__________

APPENDIX E

RESEARCH ETHICS COMMITTEE APPROVAL LETTER

Lead Investigator:

Claire Horton

Faculty Advisor:

DeDe Wohlfarth

Proposal Title:

Effects of Sexual Education on Sexual Knowledge, Attitudes, Experiences, and Needs of Adults with Developmental Disabilities

Greetings,

I am happy to inform you that the proposal you submitted to the Research Ethics Committee at Spalding University has been **approved** following the Expedited Review Procedures as outlined by part §46.110 of the regulatory guidelines of Health and Human Services Codes of Federal Regulations pertaining to the protection of human subjects (Title 45, Part 46).

This approval is for the research protocol described in your application. Please inform the Committee as soon as possible and in writing of any changes you make to the procedure described in your application.

The Committee assumes that you will comply with other requirements established by the site, school, organization or setting within which you conduct your research and that you have or will attain such compliance before conducting your research.

The Committee assumes that you have permission to use any instrument that you have not developed if such permission is required. The Committee assumes that you will comply with the use of published or commercial instruments.

This approval is valid for 12 months and will expire on 7/2/2018. Please update the committee upon the completion of your study (on the REC website), or reapply online to request an extension.

Please also remember that it is your responsibility to notify the Committee immediately of any adverse reactions related to participation in your research study.

Navigate to the REC website if you would like to update/amend your proposal. Click on “Update Proposal” under the left navigation bar and follow the on-screen directions to inform the committee of these changes.

Please check the bottom of this letter for any additional comments made by the committee.

Feel free to ask me any questions with regard to this review and best wishes with your research.

Sincerely,

Stacy Deck, PhD, MSSW
Chair
Research Ethics Committee