TABOO IN THE CLASSROOM: SEX EDUCATION EXPERIENCES OF 4 ADULTS HAVING INTELLECTUAL DISABLITIES

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by

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Accepted by the faculty of the College of Education, Morehead State University, in partial fulfillment of the requirements for the Master of Arts degree.

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Sex education is widely recognized as essential programming for persons with moderate to severe intellectual disabilities. Research dating back 30 years indicates that without comprehensive and systematic sex education, people with moderate to severe intellectual disabilities are placed at heightened risk for sexual abuse and exploitation. With this in mind, the problem examined in this study is one of limited programming and accessibility issues related to the sex education of persons with moderate to severe intellectual disabilities. The researcher examined available literature along with the perceptions of 4 individuals who have moderate to severe intellectual disabilities in regards to the sex education program they received during their high school education. The researcher utilized methods from the qualitative research tradition, namely the unstructured interview and the field, formal technique to accomplish this task. In analyzing the verbatim transcriptions from the interviews of the participants, the researcher ascertained many findings, 2 of which were significant: 1) that among this group of participants, sex education was not among their educational experience, and 2) that the participants articulated an emphasis on sex education being no more than education in human growth and development. Based upon these significant findings, the researcher concludes that: 1) persons with moderate to severe intellectual disabilities absolutely need comprehensive sex education

programming; and 2) this programming should be presented in a systematic fashion, using real life depictions, repeated over time.

Accepted by: _____, Chair

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Dedication

I wish to dedicate this thesis to my family who has supported every one of my academic endeavors with enough enthusiasm to sustain me. My mom, dad, and sister Melanie have helped me grow from an uninspired youth to a determined young woman. I also would like to dedicate the work on this thesis to my fiancé, David, who offered words of encouragement when I have found myself in desperation. Thanks to the love and support of my family and of David, I have completed a hurdle in my life that at times I was unsure would come.

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I would like to acknowledge the support of Dr. April Miller and Dr. Jody Fernandez. Drs. Miller and Fernandez agreed to serve on my thesis committee, taking time from their busy teaching schedules. I appreciate very much their commitment to me as a student and their guidance on this research.

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grateful for the special relationships with many of the faculty members of the Department of Curriculum and Instruction where I was fortunate enough to receive a graduate assistantship.

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Chapter 1

INTRODUCTION

Statement of the problem:

Sex education programs are commonly found in the curriculums of middle and high schools across America. Experts contend that sex education programs inform students about dangerous situations and to self- advocate for their sexuality (Lumley & Scotti, 2001; Grieveo, McLaren, & Lindsay, 2006; May & Kundert, 1996; Canham, 2006; Martorella & Portugues, 1998; Walcott, 1997; Cuskelly & Byrde, 2004; Drew & Hardman, 2007). Furthermore, experts suggest that teens need to have accurate and comprehensive information on how to prevent teen pregnancies and sexually transmitted infections (Denehy, 2007). Ivinson (2007) opined that existing sexuality programs aid in the prevention of risky behaviors and also aid in the prevention of social injustice and sexual oppression. The special population of teens with moderate to severe intellectual disabilities is particularly vulnerable to social injustice, sexual oppression, and unwanted physical consequences. Because of these vulnerabilities, sex education for adolescents with intellectual disabilities is essential. Failure to recognize the importance of sex education can result in this population being abused and exploited (May & Kundert, 1996).

Social injustice and sexual oppression are common experiences for people who have intellectual disabilities. Much available research agrees that the attitude the general public has regarding the sexuality of people who have intellectual disabilities

is not favorable (Hilton, 2007; May & Kundert, 1996; Canham, 2006; Martorella & Portugues, 1998; Cuskelly & Bryde, 2004; McCabe, 1999; Lumley & Scotti, 2001; Wehmeyer, 2002). This research also suggests that the public exhibits a less than favorable attitude regarding the sexual behaviors of the intellectually disabled as well as their freedom to marry and parent (Cuskelly & Bryde, 2004). With this research in mind, sex education programs that are in existence often are not intended for, nor meet the needs of people who have intellectual disabilities.

While sex education is rather common in some form in most middle and secondary schools, many curriculums and programs demonstrate a disparity in accessible sex education and related services for students with intellectual disabilities (Lumley & Scotti, 2001). McCabe (1999) found that roughly 50% of people having disabilities did not receive any form of formal sex education (McCabe, 1999). Even more alarmingly, May and Kundert 1996 noted "…that only 7% of students with disabilities had received any form of sex education in school" (May & Kundert, 1996, p.434). Through research, it has been determined that formal sex education classes in the traditional sense are not effective for people who have intellectual disabilities (McCabe, 1999, Hilton, 2007, May & Kundert 1996). This is why sex education needs to be modified and offered in a way that those who have such disabilities can learn valuable information that pertains specifically to them and that they can retain over a period of time.

Purpose of the study:

The purpose of this study is to examine the perceptions of individuals who have moderate to severe intellectual disabilities in regards to the sex education program they received during their high school education. The researcher will provide an opportunity for individuals with intellectual disabilities to share their thoughts, attitudes, and feelings about the programs they were offered in school. Specifically, the study will investigate the perceptions of 4 individuals and how they thought their sex education impacted their lives. This will be achieved by querying each participant about their experiences, attitudes, and how their sex education influenced their current lives. A corollary purpose of the study will be to determine whether sex education programs were made available to the participants and the degree to which they met their needs.

Need for the study:

Available literature on best practice for sex education for people who have moderate to severe intellectual disabilities is somewhat limited. Many studies have been conducted on the need for sex education for people who have intellectual limitations (Lumley & Scotti, 2001; Grieveo, McLaren, & Lindsay, 2006; May & Kundert, 1996; Canham, 2006; Martorella & Portugues, 1998; Walcott, 1997; Cuskelly & Byrde, 2004). Also, studies exist that examine the lack of available appropriate sex education programs for people with intellectual disabilities (Lumley

& Scotti, 2001). The quandary is that there is little research that examines the attitudes and perceptions of the actual population of people who have these intellectual disabilities. Much of the information that exists follows the same pattern. It interviews the caregivers, parents, and teachers of this special population (Martorella & Portugues, 1998, Cuskelly and Byrde (2004). A major limitation in the available research shows little information that actually represents the thoughts and desires of the people it claims to address. In any other field of study, the population represented would play a crucial part in gathering data and drawing conclusions. However, in much research, which focuses on individuals who have moderate to severe intellectual disabilities, they are usually considered incapable of expressing their own opinion. Interestingly, the last 20 years has seen a burgeoning in literature and an increased curricular focus on the development of critical self advocacy and self-determination skills among all individuals with intellectual disabilities (Wehman, 2006). In spite of this change in consciousness, the misconceptions about the self advocacy skills of people with intellectual disabilities continues to predominate the perspective of many educators, and is reflected in the sex education literature that perpetuates the very problem this study addresses.

Assumptions:

The direction of this study was determined initially by an observation made by the researcher in the field. The students receiving services in the special education classroom for the majority of the school day in this particular school were not offered

to participate in the sex education program that was being provided to their same age peers. Not only were they not offered participation, they were actually prevented from participating in the program. It was observed, by the researcher that the students who were prevented from the sex education program would have benefited from such a program just as their same age peers were assumed to benefit. The researcher has developed the following assumptions about the availability of sex education programs for adolescents who have intellectual disabilities and the effectiveness of available programs:

- For various reasons, teaching staff or school administration prevents students with intellectual disabilities from participating in the available sex education programs offered to non-disabled students;
- Special education teachers fail to offer modified sex education curriculums for their students due to limited understanding of the sexuality needs of the students, denial of people who have intellectual disabilities as sexual beings, limited parental support or involvement in sex education, and poor attitudes regarding the sexual behavior and development of this special population;
- And, the limited available programs are not designed with best practice in mind for students who have intellectual disabilities. They do not meet the need for systematic instruction as well as multiple representations of content.

Summary:

The researcher noted that available literature suggests that persons with moderate to severe intellectual disabilities are placed at heightened risk for sexual abuse and exploitation. Due to these risks, experts in the field of special education widely agree that comprehensive and systematic sex education programming is an essential element of education for persons with moderate to severe intellectual disabilities. The researcher identified the problem addressed in this study during field observation which involved limited programming and access to sex education for students with moderate to severe intellectual disabilities. In the following chapter, Literature Review, the researcher will provide evidence of the necessity for and availability of sex education programs for persons with intellectual disabilities.

Chapter 2

LITERATURE REVIEW

The term sex education as used in this study and defined by Ivinson (2007) refers to the purposeful education of youth in the areas of:

- the act of sex between two people;
- reproduction;
- sexual orientation;
- eroticism;
- and, morality issues regarding family values and gender relations.

Furthermore, the available research identifies commonly accepted curriculum suggestions for sex education from the primary grades through the secondary years. During primary schooling, children are generally taught to be confident communicative partners in expressing their thoughts about feelings and relationships. It is during these primary years that children are expected to know the appropriate names of the parts of their bodies. They should be capable to describe how their bodies work. Children at this age should be taught to protect themselves from dangerous situations and how to get help if needed. A final objective of educators in the primary grades is to prepare their students for the impending onset of puberty (Warwick, Aggleton, & Rivers, 2005). Warwick, Aggleton, and Rivers (2005) make further suggestions for the sex education objectives of secondary students. Students

in their secondary schooling years are expected to develop values and morals surrounding their sexual judgment. They should be aware of human sexuality, both theirs and others'. They should have a basis for assimilating the arguments of delaying engagement in sexual activities and how to protect themselves if they do choose to engage in such activities. It is at this time in students' lives when they should be developing confidence and self esteem related to respect for themselves and others in relationships. A final objective that Warwick, Aggleton, and Rivers (2005) identify for secondary students is to understand how the law regulates sexual behavior.

The subjects in the available literature examined for this research as well as the actual participants used in this research all have intellectual disabilities. Sometimes referred to as cognitive impairments, mental retardation, or mental disabilities/handicaps, this research will use the people-first language, intellectual disability. The term intellectual disability, formerly mental retardation, has been most recently identified as being the preferred term by the professional community associated with research in this area (AAIDD, 2008). The American Association on Intellectual and Developmental Disabilities (AAIDD), formerly the American Association on Mental Retardation (AAMR) defines intellectual disabilities as:

> "… a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before the age of 18" (http://www.aamr.org/content_100.cfm?navID=21).

AAIDD also defines a classification system which refers to the intensity of the disability. This system of classification is divided into four levels of support: intermittent, limited, extensive, and pervasive (Beirne-Smith, Patton, & Kim, 2006). Specifically this study focused on the thoughts and attitudes of adults with moderate to severe intellectual disabilities. AAIDD makes a concerted effort to de-emphasize the single factor of IQ score when determining a level of disability. They instead refer to these levels of support which an individual would need to be successful or independent. While AAIDD uses this level of support classification system, often the public will request a more specific or measurable identification tool such as an intelligence quotient (IQ) score. IQ scores can be loosely aligned with the AAIDD support classification although this is not the preferred method of severity classification. The American Psychological Association (APA) defines of mental retardation as recently as 2006 and uses IQ scores to classify severity of intellectual disability. These scores classify this rating system into four levels of severity (Beirne-Smith, Patton, & Kim, 2006):

- Mild mental retardation is warranted by an IQ score of 70-55;
- Moderate mental retardation is warranted by an IQ score of 55-40;
- Severe mental retardation is warranted by an IQ score of 40-25;
- And, profound mental retardation is warranted from an IQ score of 25 and below.

Generally, the population under consideration for this research has a representative IQ score of 55-25 on a standard IQ test. By and large, the specified participants as well as previous subjects identified in available literature are educated primarily outside of the general education classroom. These individuals often spend the majority of the school day in self contained classrooms, identified to meet the specific educational needs of students with intellectual disabilities.

In America today, many sex education programs that are in existence are geared toward an abstinence-only education (Denehy, 2007). The term abstinence education refers to a program geared towards teaching "…students that the only surefire way to prevent STDs [sexually transmitted infection] and pregnancy is to be abstinent…" (Denehy, 2007, p. 245). Since 1996, federal funding has increased dramatically for abstinence-only education (Duberstein-Lindberg, Santelli & Singh, 2006). Denehy (2007) contends that the reason for abstinence-only education is that educators feel that teaching students about sexual behavior, pregnancy preventatives, and options to protect against STDs will encourage students to participate in sexual activity they may not otherwise participate in having received an abstinence-only education. In a study done by Duberstein-Lindberg, Santelli, & Singh (2006) on the changes in sex education from 1995 to 2002, it was determined that most males begin receiving abstinence education at 11.4 years of age while females begin at 12.4 years of age. A more comprehensive approach to sex education, including birth control education for both males and females was initiated about 2 years after the dates of the abstinence program (Duberstein-Lindberg, Santelli & Singh, 2006). It should be

noted that Denehy (2007) cites research that indeed does not support the claims of proponents of abstinence only programs. This research indicates that by providing students with only information about abstaining from sex, teachers are ignoring the plausible fact that large numbers of teens will become sexually active before adulthood (Denehy, 2007; Starkman & Rajani, 2002).

Due to mounting evidence that adolescents in America are likely candidates to become sexually active during their school age years, opponents of abstinence only sex education propose a comprehensive sex education program (Denehy, 2007). In a comprehensive sex education program students are taught "…complete and accurate information about sexuality, contraception, and confidential reproductive health services" (Denehy, 2007, p. 245). In other words, comprehensive sex education is "…teaching that provides balanced and accurate information on both abstinence and birth control…" (Duberstein-Lindberg, Santelli & Singh, 2006, p. 182). Specific research in the field of comprehensive sex education by Starkman and Rajani (2002) states that, "students who have had comprehensive sex education use contraception and practice safer sex more consistently when they become sexually active" (p.314). The conversation that is taking place among experts in the field of sex education generally agrees that comprehensive sex education that includes information on abstinence but also birth control methods is more effective in preventing STD's and pregnancy than abstinence only programs (Denehy, 2007, Duberstein-Lindberg, Santelli & Singh, 2006; Starkman & Rajani, 2002). Denehy (2007) goes further to demand that all teens receive information on comprehensive sex education and that

they receive it at a young age. Denehy (2007) further suggests that this type of programming be taught before teens become sexually active as young as at the age of middle school. Leading organizations in the health field including, American Medical Association, the American Academy of Pediatrics, the American College of Obstetricians and Gynecologists, the American Nurses Association, and the American Public Health Association all support the implementation of comprehensive sex education programming (Starkman & Rajani, 2002).

Alarmingly, 15-24 year olds represent 25% of the sexually active population in the United States. This group of young people acquires nearly half of all new incidences of STDs (http://www.cdc.gov/std/stats06/toc2006.htm, 2006). Data collected in 2005 from Youth Risk Behavior Surveillance indicates that 63.1% of high school seniors surveyed report being sexually active during adolescence (Denehy, 2007). Denehy (2007) reports that each year teens in the United States face about 800,000 pregnancies. The American Medical Association (AMA) states that over 90% of teen pregnancies are unintentional (AMA). As abstinence-only education became more prevalent with increased federal funding between 1995 and 2002 the percentages of students who received any instruction on birth control fell from 81% to 66% for males and from 87% to 70% for females (Duberstein-Lindberg, Santelli & Singh, 2006). Duberstein et al. (2006) notes that by the year 2002, "one-third of adolescents of each gender had not received any instruction about birth control methods" (p. 184).

A study done by May and Kundert (1996) determined that most students' Individualized Education Programs (IEP) do not address their sexuality needs. In fact, May and Kundert (1996) found that, "only 7% of students with disabilities had received any form of sex education in schools" (p. 434). Similar statisitcs regarding the number of special education teachers teaching sex education report that only 10% address any topic related to sexual behavior (Canham, 2006). Research conducted by Macdougall and Morin concluded that 50% of their adult respondents with intellectual diabilites have had sexual experinece duing their lives (Macdougall & Morin, 1979 as cited in McCabe, 1999). This statistic alone indicates that there is a direct need for formal sex education for people with intellectual disabilites because they indeed are sexual beings and sexually active (Wehmeyer, Sands, Knowlton & Kozleski, 2002). From the research noted ealier, it can be determined that comprehensive sex education is vital to any population of people who are or may be sexually active (Denehy, 2007; Duberstein-Lindberg, Santelli & Singh (2006); Starkman & Rajani, 2002). The research noted in this review on comprehensive sex education was more specific to adolescents as a whole; one can deduce that adolescents with intellectual disabilities are an especially critical population within this population.

People with intellectual disabilities are an especially vulnerable population. It was until the 1970's that several states were still allowed and in some cases mandated the sterilization of people with intellectual disabilities (Lumley & Scotti, 2001). In fact, sterilization is still a legal procedure in the United States but requires that a court

establish the individual is incompetent to make their own decisions and unable to successfully parent offspring (Drew & Hardman, 2007). Individuals with intellectual disabilities are at a heightened risk for sexual abuse (Canham, 2006; Cuskelly & Byrde, 2004; Grieveo, McLaren, & Lindsay, 2006; Lumley & Scotti, 2001; Martorella & Portugues, 1998; May & Kundert, 1996; Walcott, 1997). The percentage of people with intellectual disabilities who have been exposed to sexual abuse ranges between 25-80% (Lumley & Scotti, 2001). A possible reason for this compromised position many people with intellectual disabilities find themselves in, can be attributed to the disposition of these individuals who have been conditioned to comply and depend upon others (Lumley & Scotti, 2001). Also, according to Lumley and Scotti (2001) people with intellectual disabilities exercise reduced social skills and judgment and have been exposed to a limited amount of sex education. Similarly, Grieveo, McLaren, & Lindsay (2006) state in their research that people with learning disabilites show a "lack of sexual knowledge, physical and emotional dependancy on caregivers, multiple care giving and limited communication" (p. 31). As the severity of the intellecual disability increases or the level of support needed increases, the risk of sexual abuse also comparatively increases (Grieveo, McLaren, & Lindsay, 2006). The lack of sexual knowledge attained and retained by people with intellectual disabilites is addressed in research done by Talbot and Langdon (2006). This research suggests that people with intellectual disabilites possess considerably less sexual knowledge information than do their non-disabled counterparts. This lack of knowledge can be attributed to, "...difficulties with the

learning and retaining of information, inadequate sex education training, and inadequate information regarding the emotional and psychological aspects of intimate relationships" (Talbot & Langdon, 2006, p. 523-524). A comprehensive sex education program designed specifically for the individual needs of persons with intellectual disabilites is appropriate and necessary for successful retention of such information needed to guard oneself against abuse, disease, and unwanted pregnancy (McCabe, 1999).

The type of sex education programming for individuals with intellectual disabilties most commonly recommended by the available research is a comprehensive program (Lumley & Scotti, 2001; McCabe, 1999; Snell & Brown, 2006). The literature suggests that the comprehensive program not only cover traditional subject matter such as "anatomy, puberty, intercourse, masturbation, venereal disease, birth control, pregnancy, and childbirth" (Lumley & Scotti, 1999, p.110), but also social relationships and self esteem (McCabe, 1999). Additonal material encourages that people who have intellectual diabilties need programming on informed consent and promoting self detemination (Drew & Hardman, 2007; Wehmeyer, Sands, Knowlton & Kozleski, 2002). A comprehensive listing of the essential components of a sex education curriculum specifically for individuals who have intellectual disabilites designed by Whitehouse and McCabe includes (Wehmeyer, et al., 2002, p. 212-213):

- Distinguishing body parts and reposriduction organs;

- Family life skills;
- Self-care skills;
- Social manners and social interactions;
- Interpersonal relationships;
- Nutrition;
- Puberty;
- Attitudes about sexuality;
- Physical and emotional components of sexual realtionships;
- Sexual and relationship vocabulary;
- Masturbation and sexual intercourse;
- Reproductive health;
- Menstrual management;
- Breast self-examinations and other physical examinations;
- Sexual abuse avoidance;
- Birth control and abstinence;
- And, prevention of sexually transmitted diseases.

This list can be further expounded upon and broken into age-specific objectives and curriculm suggestions by Snell and Brown (2006). Between ages 3-9, children need to be taught the differences between boys and girls, body names and functions, public and private places, modesty, and how babies are born. At ages 9-15, associated with puberty, children need to be taught about hygiene, physical changes, menstruation, nocturnal emisions, inappropriate touching and saying "no," social boundaries and manners, sexual feelings, and how babies are made. Finally, during the young adult-to-adult years of 16 and up, individuals need to be taught dating preparation, relationships (love vs. sex), handeling sexual/emotional feelings, laws and concequences for inappropriate touching, sexual intercourse and other sex acts, pregnancy prevention, STD prevention, marriage, and parenting (Snell & Brown, 2006).

Traditional techniques for teaching sex education generally includes a great deal of fact teaching and may be ineffective for the target population (Lumley & Scotti, 2001). A traditional sex education program offered to people with intellectual disabilties is taught in a whole group atmosphere and the focus is on the biological functions of the human body (Lumley & Scotti, 2001). These techniques leave special needs learners ill-equipped to deal with real life sexual situations. In order for a comprehensive sex education program to be effective in changing the behavior of the individual with an intellectual disability, it must be taught with a great deal of involvement from the individual as well as the important people in their lives such a parents, caregivers, or significant others (Lumley & Scotti, 2001; Wehmeyer, 2002).

Often times, it is the attitudes and feelings of these important members in a person's life that determines the programming sought and provided to individuals with intellectual disabilites.

Many researchers have attempted to determine society's percpetions and attitudes about the sexuality of persons with intellectual disabilites (Canham, 2006; Cuskelly & Bryde, 2004; Hilton, 2007; Lumley & Scotti, 2001; Martorella & Portugues, 1998; May & Kundert, 1996; McCabe, 1999; Wehmeyer, 2002). The thought of indivuduals with intellectual disabilities as sexual beings has for a long time been disregarded (May & Kundert, 1996). It is common that people who have intellectual disabilites are only thought of in regards to predatory or abusive actions against them (Wehmeyer, 2002). Research done with parents of people with intellectual disabilites shows that parents equate the right to sexuality with the severity or type of specific disability (Martorella & Portugues, 1998). This information is supported by research done by Cuskelly and Byrde (2004), showing that studies conducted with staff members caring for individuals with intellectual disabilties link the severity of the disability with appropriate response to sexual activity. Masturbation is one such sexual activity. Martorella and Portugues (1998) found that although parents agreed that masturbation was healthy and natural, they did not want their children with intellectual disabiltiies engaging in it. An overwhelming theme throughout Martorella and Portugues' (1998) research was that the parents of children with intellectual disabilites felt their children may not have had the same rights as others in regards to human sexuality because they equated sex

directly with reproduction. Further, these parents felt that reproduction was not an appropriate avenue for their children with intellectual disabilites (Martorella & Portugues, 1998). This is obviously problematic as it is commonly recognized that all people have sexuality needs (Drew & Hardin, 2007; Wehmeyer, 2002).

Advocates in the field of intellectual disabilities have a difficult time reconciling this population's sexuality needs and even their marriage and reproduction rights (Cuskelly & Bryde, 2004). "Researchers have shown that displays of affection and sexual behaviors shown by individuals with mental retardation are seen as less acceptable than the same behaviors shown by persons without disabilities" (Lumley & Scotti, 2001, p.109). Along with a societal misconception about the basic human needs of individuals with intellectual disabilities, teachers and parents are sometimes reluctant to help these adolescents gain access to appropriate education and resources (Canham, 2006).

There has been relatively little research done which directly involved the actual population of people who have intellectual disabilities. However, the research that has been done with the actual population concludes that because of the negative societal attitudes and limited sexual education experience, people who have intellectual disabilties are left with negative opinions of sex and their own sexuality (McCabe, 1999). This research shows that people who have intellectual disabilities may associate sexuality with embarassment and/or guilt. McCabe (1999) opined that they express a negative attitude toward masturbation, oral sex, and homosexuality. Snell and Brown (2006) further suggested that adults with intellectual disabilties

consider sex as "dirty" and "bad". These negitive viewpoints by adults with intellectual disabilties reflects the assimilation of negative societal attitudes. Possibly worse, guilt about sexual feelings may lead individuals to inappropriate behaviors that put them at risk for sexual abuse and exploitation (Snell & Brown, 2006; Collins, 2007).

Teachers may be ill-equipped to help their students realize the full potential of a healthy sexual identity. Related to this, pre-service preparation has been shown to be insufficient for special educators' sex education training. Directors of 258 special education pre-service preparation programs responded that 41% did not offer coursework in sex education to their students (May & Kundert, 1996). Of the directors that responded in the affirmative, the average for the amount of time this subject was covered was 3.6 hours of time in class (May & Kundert, 1996). Even more alarming, a recent study done by Canham (2006) indicated that 93% of baccalaureate-prepared special educators had received no pre-service, professional education about teaching sex education to students having intellectual disabilities. Warwick, Aggleton, and Rivers (2005) support the current research that sex education training is lacking in teacher preparation programs across the United States.

Students with intellectual disabilties who have not been taught about their own sexuality may not understand the social context of when it is okay to act upon sexual feelings. Therefore, a student may physically act upon his/her own sexual feelings in school or public in an inappropriate manner such as public masturbation (Snell & Brown, 2006). Students who have a difficult time navigating social context

may be prone to making sexual advances toward a person who is an inappropriate partner (Snell & Brown, 2006). Often, sex education or the topics of sex and sexuality are not addressed until this inappropriate behavior manifests itself (Wehmeyer, 2002). Inappropriate behavior can be avoided by addressing sex and sexuality before a situation is likely to occur. As mentioned previously in curriculm suggestions, some topics such as puberty should be addressed as early as in the primary grades while more explicit sex topics such as masturbation and intimate relations should be addressed in middle and high schools (Snell & Brown, 2006).

Summary:

In summary, the literature examined suggests that sex education is a vital toolkit for individuals who have intellectual disabilities. These individuals are placed at a heightened risk for sexual abuse and exploitation and therefore desperately need a comprehensive and systematic sex education program. As little as 7% of persons who have intellectual disabilities have received appropriate sex education programming (May & Kundert, 1996). This statistic of 7% is quite alarming but can be tempered with a more recent statistic by McCabe (1999), that 50% of people who have intellectual disabilities do not receive any form of formal sex education. With these two recent studies' results combined, one can reasonably predict that persons with intellectual disabilities are an underserved population with regard to sex education opportunities in high school.

In addition, there is a prevailing societal attitude that views sexuality of individuals with intellectual disabilities unfavorably (Cuskelly & Byrde, 2004). This may add to the limited research on the topic as well as the limited availability of programming to meet the sexuality needs of this population. There is an extreme history of injustice regarding the sexuality of persons with intellectual disabilities that not only includes exclusion from sex education, but radical measures such as forced sterilization practices (Lumley & Scotti, 2001). While research is limited that examines the actual attitudes of the population themselves, there is literature that overwhelmingly concludes that sex education is a vital necessity to the well being of persons with intellectual disabilities. This literature advocating for sex education of person with intellectual disabilities dates back thirty years and professionals in the field of special education agree that persons with intellectual disabilities are capable learners of sex education and can greatly benefit from successful and systematic programming in sex education.

Chapter 3

METHODOLOGY

The purpose of this study is to examine the perceptions of individuals who have moderate to severe intellectual disabilities in regards to the sex education program they received during their high school education. Specifically, the study investigated the perceptions of 4 individuals and how they thought their sex education impacted their lives. A corollary purpose of the study was to determine whether sex education programs were made available to the participants and the degree to which they met their needs.

The available literature examined in the previous chapter suggested that people with intellectual disabilities, specifically those with moderate to severe intellectual disabilities are at heightened risk for sexual abuse and exploitation. It also suggested that they are in need of a comprehensive program taught in a direct and systematic fashion that is tailored to teaching safety, self determination, and healthy decision making. In light of the findings of the literature review this study focused on the following overarching questions:

- Based on the personal experiences of 4 persons who have moderate to severe intellectual disabilities, did their high schools allow them to participate in sex education?

- If the above is true, what did these 4 adults remember being covered in sex education, and was it responsive to their needs?

- Also, based on the same 4 persons' personal sex education experiences, what instructional methods did they say they preferred to learn sex education content?

There is an extremely small body of literature that exists which actually provides a voice for persons with intellectual disabilities. Historically, experts in the field of intellectual disability, teachers, and caregivers have made decisions for people having intellectual disabilities. Often times, these decisions greatly impact the lives of persons with intellectual disabilities and they are made without the consultation of the individual themselves. Because the experts and caretakers ignore the individuals' voices, implications for happiness and quality of life can be dubious. The only other group in which experts and caregivers intervene on life altering decisions is children. Obviously, there is a substantial difference between decisions made for children and decisions made for adults with intellectual disabilities. This present research attempts to draw attention to this problem because the population in question appears to have little voice in the decisions affecting their quality of life.

There is no one better equipped to answer the researcher's overarching questions than the adults illustrative of this population. By examining the attitudes and perceptions of persons with moderate to severe intellectual disabilities on the sex education services they either did or did not receive in high school, the researcher will attempt to give a voice to an often ignored and unheard population. The researcher

accomplished this task through face to face interviews and word for word transcriptions. The researcher describes each of these processes in the section below.

Design:

The researcher employed methodologies from the qualitative research tradition. The research design was intended to be flexible and less formal than a traditional quantitative inquiry. The researcher intended to get inside the backgrounds of 4 participants in a non-threatening, informal environment. Their recollections of sex education in high school may or may not be true of their peers having similar backgrounds and educational experiences. Thus, the methodologies the researcher employed were based upon explorations of ideas, attitudes, and perceptions.

In order to accomplish this task and to establish rigor in the data collection process the researcher employed 2 related qualitative methodologies: the unstructured interview and the field, formal interview technique (Denzin & Lincoln, 2000). The field, formal interview technique is a subset of an unstructured interview style (Denzin & Lincoln, 2000). According to the unstructured interview style, "...[it] is structured to some degree- that is, there is a setting, there are identified informants, and the respondents are clearly discernible" (Denzin & Lincoln, 2000, p.653). Further, the field, formal style has a preset location that must be in the field, the interviewer is somewhat directive in his/her questioning technique, and the questions are semi-structured (Denzin & Lincoln, 2000).

The researcher interviewed 4 adults who have moderate to severe intellectual disabilities. The researcher conducted these interviews using an unstructured interview style, namely the field, formal style (Denzin & Lincoln, pp. 653, 2000). As part of this semi-structured methodology the researcher included an introductory type interview to establish rapport between the researcher and the participant. During this rapport-building exercise, the researcher determined the participants' unique communication attributes and adjusted questioning accordingly. The researcher also gathered background information on the participants' demographics such as their age, place of residence, and caregiver roles.

The basic series of questions the researcher focused on are located below:

1. When you were in school, did you participate in a sex education class?

    Possible probes may include:

        -Did you learn about sex from your teacher in school?

        -Did you learn about sex in high school?

        -Did you talk about sex with you teacher?

        -Did you talk about your body with your teacher?

2. What types of things did you learn in sex education?

    Possible probes may include:

        -Tell me what you talked about.

        -What do you know from school about sex?

        -Did you learn about your body, puberty, hormones, masturbation, etc.?

-What did they teach you about protection?

-What do you know about getting help if you need it?

3. Did you have any questions about sex that you didn't learn?

Possible probes may include:

-Are there things that you wished you learned about in school but you didn't?

-Were there things that you didn't ask or weren't able to ask? Why?

5. Do you think your sex education class helped you? How?

Possible probes may include:

-Are you glad you took sex education? Or didn't?

-Do you think sex education would have helped you?

-What types of things that you learned in sex education still help you?

6. What types of ways do you think are good to teach you about sex?

-Who do you like to talk to about sex, a girl or a guy?

-Do you like to learn from using books, pictures, or movies?

-Do worksheets help you learn?

-Do you think practicing the same stuff over and over helps you remember it better?

Identification of Participants:

This research pertains to the attitudes and perceptions of 4 adults who have moderate to severe intellectual disabilities. The researcher was able to access this

group by contacting a daytime rehabilitation facility for persons needing extensive to pervasive supports. This facility is not an institutional setting and does not service permanent residents. The facility in question was located in a metropolitan area of Ohio and services approximately 100 adults. The non-residential rehabilitation facility provides clients with daytime programming, vocational rehabilitation services, a sheltered workshop, and therapies such as speech, occupational therapy, physical therapy, and aquatic therapy. Based on the services provided at the targeted facility, the researcher determined that each client was a potential participant for the study and met the AAIDD support classifications. Specifically, based on these levels of supports and comparable IQ scores, the participants in this study have a representative IQ score of 55-25 on a standard IQ test.

Participants' Contextual Features:

The participants in this study all have moderate to severe intellectual disabilities. The researcher was not privileged to the educational records of the participants and therefore assumed that each was classified according to the AAIDD parameters of moderate to severe intellectual disabilities. Evidence of this level of support can also be seen by the fact that the participants are not living independently and that they are relying on support from parents and other family members.

After completion of consent protocols at the cooperating facility, the researcher met with 4 adult male participants. The researcher questioned and ascertained their personal profiles during the rapport building interview. For identity

protection, the researcher will use the names *Participants A, B, C, and D (see Table 1: Summary of Participant Characteristics, p.39).*

Participant A is a 48 year old male who uses a manual wheelchair independently. He lives at home with his mother, father, and sister. Participant A indicated during his interview that he went to a vocational high school. He was able to draw specific conclusions about the difference in the vocational high school as compared to a traditional high school, which he would refer to as "normal." Participant A was very verbal and had a positive attitude while working with the researcher. He seemed very conscious of respecting the feelings of the female researcher by the way he phrased somewhat embarrassing or inappropriate topics. At one point during Participant A's interview he asked for the recording to be stopped and that he have a few moments to gather his thoughts. This is an example of that participant's effort to say things in a sensitive manner to respect the feelings of the female researcher.

Participant B is a 41 year old male. Participant B used a motorized wheelchair and was able to navigate with it independently. He lives at home with his mother. Participant B indicated that he attended a local area traditional high school. He was able to draw very specific conclusions about the programming he received in high school and had a very detailed recollection of those events. Participant B has physical limitations which make him non-ambulatory and also restricts the use of his arms and hands. He has a strained speech pattern due to muscle rigidity in his mouth, face, and neck. The researcher was led to believe that Participant B may have been

placed in special education more so for his physical disability that may have masked his true intellectual capabilities to his teachers.

Participant C was a 47 year old male who attended a traditional high school out of state in the South. He lives at home with his step-mother and father and uses a manual wheelchair for mobility. He relies on others to help him use his wheelchair to reach desired destinations. Participant C had very fond memories of his former home in the South. He indicated that he was able to live much more independently than he is able to now in Ohio. Participant C also indicated that he enjoys working at the facility and would like to continue to learn how to manage money and improve his money management skills as a salesperson for the facility.

Participant D indicated that he is a 26 year old male who lives at home with his mother and father. He is ambulatory and attended a local area, traditional high school. Participant D takes the vocational aspect of his placement in the rehabilitation facility very seriously. He has a very important job at the facility in a janitorial type position and asked to postpone his interview until he had completed a task that he was involved in.

Table 1: Summary of Participant Characteristics

Participant	Age	Living Arrangement	Type of High School	Sex Education Program
A	48	With mother, father, and sister	Vocational	No
B	41	With mother	Traditional	Yes
C	47	With father and step-mother	Traditional	No
D	26	With mother and father	Traditional	No

Access-Permission Protocols:

In order to recruit participants for this study the researcher was obligated to respect the rights of the participants as well as possibly their legal guardian(s). Because of the implicit nature of the participant's intellectual disabilities and the likelihood of risk of coercion, the researcher prepared a three-tiered consent process to ensure informed consent. First, the researcher delivered copies of an initial consent form to the contact person at the facility (See pages 86-87 in appendix). This form explained the basic intent of the study and asked for permission of the participant and their legal guardian to receive an additional letter of consent providing further

information on the study. The researcher addressed the second letter of consent (See pages 88-89 in appendix) again to both the potential participant and their guardian. This letter repeated the basic intent of this study and provided more specific information on the study and requested permission to contact the participant in person to review the third and final letter of consent/assent. The researcher wrote the third and final assent letter (See pages 90-91 in appendix) using simplified language to be first read by or to the participant. Once read, the researcher addressed concerns and questions and asked the participant to orally repeat the consent information. This final task assured the researcher that the participant was free from coercion and understood the study's purpose and was willing to proceed.

Originally, the researcher secured initial consent from 11 participants for the study. However, through the multi-tiered process of consent, at the time of interviews only 4 participants were willing to continue. The researcher did not pursue contact with the individuals as they chose to discontinue participation in the study. Due to possible implications of coercion, the researcher was unable to speak with the participants as they chose to discontinue participation and therefore has no explanation for lack of participation. The researcher adhered strictly to the consent and assent processes outlined in this three-tiered protocol.

Data collection:

The researcher conducted the unstructured, field formal interviews in a private conference room at the daytime rehabilitation facility. The researcher conducted the

interviews on an individual basis and audio recorded them for later transcription. Each interview ranged between 15 and 30 minutes. During the transcription process the researcher word processed verbatim the participants' responses using Microsoft Word and coded for emerging themes.

All raw materials were secured during the course of the research and any originals that can link the participant to their identifying information will be destroyed prior to publication. The confidential nature of this research entails tremendous effort on the part of the researcher to protect the identity of the participants and participating facility.

Analysis:

In the qualitative research tradition, the constant comparative method is employed when the research pertains to multi-data sources (Bogdan & Biklen, 1992). As it did in this study, the transcriptions for 4 separate but related interviews were the aforementioned multi-data sources. The constant comparative method is an analysis method which entails that the researcher identifies key themes in one data collection and then compares it to and either eliminates, confirms, or adds to it by comparing it to the next source of data collection. This continues until all sources have been thoroughly examined and the themes have been fully coded (Bogdan & Biklen, 1992).

To analyze the data the researcher first transcribed each of the audio recordings as precisely as possible. The researcher did not change any of the

participants' words or thoughts thus transcribing each interview verbatim. It was the goal of the researcher to present the thoughts of the individual participants as accurately as possible. Once the transcriptions were completed the researcher reread each of the interviews and coded each statement based on the dominant ideas expressed. Then in rereading, the researcher compared the statements to find individual subjects to identify themes. The researcher coded the themes according to common threads that can be called strands. These strands were analyzed to identify major themes they represented. By comparing the key ideas from one interview to the next, the researcher arrived at common strands and themes. The researcher discusses these themes and strands, citing specific excerpts from each interview as evidence in the following chapter.

Summary:

In summary, chapter 3 provided the reader an overview of the qualitative methodologies the researcher employed. Namely, the researcher employed qualitative methodologies: the unstructured group interview and the field, formal interview techniques in the design of this study. For data collection the researcher used the constant comparative method to code the transcriptions of the interviews and identify major themes and strands. The researcher will discuss the findings from the transcriptions of the interviews in the following chapter, Findings.

Chapter 4

FINDINGS

The purpose of this study was examine the perceptions of individuals who have moderate to severe intellectual disabilities in regards to the sex education program they received during their high school education. Specifically, the study investigated the perceptions of 4 individuals and how they thought their sex education impacted their lives. A corollary purpose of the study was to determine whether sex education programs were made available to the participants and the degree to which they met their needs. The overarching questions which guided this research were:

- Based on the personal experiences of 4 persons who have moderate to severe intellectual disabilities, did their high schools allow them to participate in sex education?
- If the above is true, what did these 4 adults remember being covered in sex education, and was it responsive to their needs?
- Also, based on the same 4 persons' personal sex education experiences, what instructional methods did they say they preferred to learn sex education content?

In order to ascertain these questions, the researcher followed specific protocols to determine the participants for the study. First among these protocols was to gain access to the participants by contacting an Ohio daytime rehabilitation

facility. Second among these protocols was to receive permission to obtain consent from potential participants. This stage of the protocols required 3 tiers of consent from the participants and/or their legal guardians in order to ensure that they understood the research, their role in the research, the nature of the questions to be asked of them, and understood that their privacy and anonymity would be protected. These protocols resulted in 4 male participants whose characteristics matched AAIDD's support classifications.

The researcher audio recorded the participants' interviews. The researcher then transcribed each interview as accurately as possible, making painstaking efforts to capture the true thoughts of each individual. The transcription process was difficult due to unique communication styles of the participants. These communication barriers included stuttering, muscle rigidity of the face and neck, and verbal intonation ability. After careful analysis of the transcriptions, the researcher was able to identify common threads that linked each participant's interview to the next participant's. These threads, called strands, were then classified into major themes. The researcher discusses these findings and elaborates upon them in this chapter.

Themes and Findings:

The researcher uncovered several significant findings which can be classified into 3 broad themes and 8 strands. These themes and strands emerged during the process of semi-structured interview questioning which involved suggestions about

preferred sex education practice. The researcher ascertained the following 3 broad themes and 8 strands:

1) Sex education

    a. Sex education limitations in high school;

    b. Informal sex education exposure;

    c. Limited discussion about sexual protection;

    d. Informed treatment of sexual abuse.

2) Human growth and development education

    a. Exposure to puberty education.

3) Preferences in sex education

    a. Preferred instructional materials;

    b. Preferred instructional methods;

    c. Preferred teacher gender in sex education.

The researcher discusses each of these themes and stands and provides specific examples from the interviews in the sections below. Excerpts of the participants' interviews are used to provide evidence of the themes and strands as well as to give the reader an opportunity to hear the thoughts of the participants as accurately as the researcher could transcribe them.

Theme 1: Sex education

The first theme which emerged from the researcher's transcriptions of the interviews was that of sex education. The researcher noticed that the participants' sex education experience varied, one as having a formal sex education program and the other 3 learning about sex through other informal means. Another notable observation about sex education was with regard to sexual protection. Again, 3 participants indicated they had not received formal training on this subject in high school. Yet another observation the researcher made was with regard to sexual abuse in which 3 of the 4 participants indicated they had received instruction. In terms of this first broad theme, the four strands describing these participants' experiences were: a) sex education limitations in high school; b) informal sex education exposure; c) limited discussion about sexual protection; and d) informed treatment of sexual abuse.

Strand a, "Sex education limitations in high school"

The researcher questioned each of the participants about the sex education programs that they may or may not have received during their high school educations. If the participants appeared not to understand the term "sex education," the researcher explained it by asking if they learned about sex or their bodies. Sometimes the researcher used the term puberty and explained its meaning as "changes to your body." Three of the 4 participants responded that they did not participate in any type of formal sex education in high school. One participant stated that he did receive sex

education and had an apparent working memory of the material covered in the class. Participant B (B., henceforth), the individual who stated that he recalled having formal sex education in high school appeared to be fairly specific in his recollections. These recollections included statements such as:

R. (Researcher, henceforth)- "Okay, when you were in high school [B.], did you have a sex education class?"

B.- "Uh we covered a little bit in(inaudible)."

R.- "You covered a little bit in your class?"

B.-" Health."

R.- "In health? In health class. Okay, so in health class did your teacher teach you about sex?"

B.-"Yeah, we just, covered like the g...g...general basics."

R.- "You covered the general basics?"

B.- "Yeah."

R.- "Okay, do you remember what some of those basics were? Can you tell me a little bit?"

B.-" Like...like...things like... chromosomes, and genes, and (inaudible)."

R.- "AIDS?"

B.- "No eggs."

R.- "Age?"

B.- "Eggs!"

R.- "AIDS?"

B.-" E-G-G-S!"

R.- "Eggs? "

B.- "Chromosomes, genes..."

R.- "Genes? Okay..."

B.- "(Response inaudible)"

The 3 participants whose experiences did not include a formal sex education course were very blunt in their responses. When asked about whether they had a sex education course in high school they simply responded with "no," but that was after the researcher clarified the meaning of sex education for them. In the exchange below, the researcher provided 4 questions in order to help Participant C (C., henceforth), understand the original question:

R.- "Okay. Well [C.], when you were in high school, did you take a sex education class?"

C.- "Well I took a science class."

R.- "You took a science class? Did you learn about sex in your science class?"

C.- "Well, no. Uh, I learned about Black history."

R.- "Black history?"

C.- "Yeah."

R.- "Uh huh. Did you have any classes where you learned about sex?"

C.- "Like when people get on top of each other, sex?"

R.- "Right, or about, you know your body or puberty?"

C.- "No."

Participant A, (A., henceforth) and participant D (D., henceforth), also recalled having no formal sex education during high school. The researcher provided similar clarifications for them as were provided for C. However, A. and D. consistently responded bluntly and with one word, "no." The exchange below involving D. is illustrative of the definitive nature of his recollection:

> R.- "Okay, Alright. So [D.], when you were in high school did you have a class about sex education?"
>
> *D.- "No."*
>
> R.- "No? Did your teacher talk to you about sex?"
>
> *D.- "About sex? No."*

Of the same 3 participants that did not receive sex education services, 2 of them indicated that they previously had and presently have no desire for sex education. Again, the exchange below involving A. illustrates this lack of interest in sex education:

> R.- "Well, do you think it would have helped you if you had stayed long and maybe learned about sex a little bit or learned about your body more? Would that help you, or you don't care?"
>
> *A.- "I don't care."*
>
> R.- "Okay. Do you have any questions about sex that you haven't learned or you are afraid to ask?"
>
> *A.- "No."*
>
> R.- "Okay. Do you wish that you had taken a class in sex ed?"
>
> *A.- "No."*

In summarizing theme 1, "sex education," strand a, "sex education limitations in high school," one participant, B., had formal sex education during high school, while his counterparts A., C., and D. did not. Their recollections regarding sex education limitations were varied and required considerable clarification by the researcher. In the next strand, the researcher will discuss "informal sex education exposure."

Strand b, "Informal sex education exposure"

Of the 3 participants whose experiences did not include formal sex education during high school, they also indicated they learned about sex from sources outside their teachers. Participant A demonstrated this finding when he discussed inappropriate sexual exploration amongst classmates with or without teacher knowledge. Evidence of this type of "experiential learning," is illustrated in A.'s elaborations below:

R.- "Did you learn about sex at all in high school?"

A.- "No."

R.- "Have you learned about sex since you've left high school?"

A.- "Well (long pause)... we had something... to that effect that's what your talking about, but it wasn't the real thing."

R.- "Okay. Can you describe it to me a little bit?"

A.- "(Long pause)...I don't know what to say to that. Can you stop and let me get my things together?"

R.- "Sure can. We are going to pause. (stopped recording for a few minutes)"

R.- "Go ahead."

A.- "There was...after our lunch hour...this is why...this is why...this is why I told you, I tell you that [school name] was not a school."

R. "Okay?"

A.- "Okay. One classroom they had dark out, they had the lights turned out..."

R.- "Umm hmm?"

A.- "Draw, draw...the shades drawn."

R.- "Umm hmm?"

A.- "And stuff like that. They had it turned into a kissing room."

R.- "Were the teachers aware of this room? Did the teachers know about it?"

A.- "And...not...uh...I think they did... I think they did. But they didn't stop it."

R.- "Okay. So did your teachers ever talk to you about kissing? Did they ever teach you about kissing?"

A.- "Yeah."

R.- "What did they say about that?"

A.- "I known about that...I known about that part."

R.- "Yeah, you knew about it, but did your teachers talk to you about it? When it is good, when it may be bad? Did they tell you any of those kinds of things?"

A.- "No."

When questioned about informal sex education from sources other than teachers, Participant C indicated that he learned about sex from, "a guy." Participant D indicated that he too learned about sex from sources other than his teacher but unlike

Participants A and C, D indicated that he was taught by his father. The following exchange is an example of C. learning about sex from other sources:

> *C.- "We couldn't learn that uh type of, learning in school about sex, some people got to know what sex means by going to the bathroom and getting on top of each other or laying down with somebody."*
>
> R.- "Uh huh."
>
> *C.- "Get on top of."*
>
> R.- "That's right. So you didn't learn about that in school?"
>
> *C.- "Yeah, that's how I learned how to, when people, tell you, like a girl come in and get on top of you."*
>
> R.- "Uh huh."
>
> *C.- "And then you get frustrated."*

A common thread uniting the recollections of participants A., C., and D. is that each of them indicated through discussion a very limited or ill-formed conception of sex, sexual intercourse, or sexual relationships.

Strand c, "Limited discussion about sexual protection"

When the researcher questioned each participant about sexual protection, such as condoms and oral contraceptives, 3 of the 4 said they did not learn about sexual protection in high school at all. Participant C. indicated that he learned about sexual protection from outside sources although the transcription of his exchange was unclear as to the source. The exchange did indicate that C. was taught outdated and archaic approaches to protection. For example, this participant responded that in order to protect yourself from pregnancy you must, "get your tubes tied," and "tap

your kidneys." When probed further on these preventative measures, C. did not appear to have a working knowledge of the procedures he referenced but was adamant about their essentiality to pregnancy prevention as seen below:

R.- "Right. Do you know what ways you can protect yourself so you don't have a baby?"

C.- "Get your tubes tied."

R.- "Get your tubes tied? Okay. Are there any other ways?"

C.- "Tap your kidneys, I mean your kidneys."

R.- "Do what?"

C.- "Uh, your kidneys."

R.- "Your kidneys?"

C.- "I mean your privates."

R.- "Your privates?"

C.- "Yeah."

R.- "Do what to your privates?"

C.- "Get your tubes tied."

As in strand a, "sex education limitations in high school," participants A and D gave blunt and definitive "no" responses when asked specifically about their recollections of sexual protection education. Participant B who was the only one to have recalled sex education during high school stated that he did not learn about sexual protection. In a way related to this strand, the following strand discusses the manner by which the participants learned about protecting themselves from sexual abuse.

Strand d, "Informed treatment of sexual abuse"

The fourth and final strand of the theme, "sex education," concerned the participants' recollections of sexual abuse and how to protect themselves. Three of the 4 participants expressed fairly vivid recollections of learning about what to do when placed in a compromising sexual situation and who to inform in an instance of sexual abuse. Most notably, participant A gave an explicit example of an event where he felt he needed to report sexual impropriety and did so by alerting his father. In the exchange below the participant is speaking of a place he referred to as "the kissing room":

> *A.- "I didn't go...I didn't go to...I didn't go to even...I didn't go to that school that long even to find out...I just...Mom and Dad...when I told mom and Dad what that school was like..."*
>
> R.- "Umm hmm?"
>
> *A.- "They pulled me from it. They waited until something happened along the way, and then when that happened, they pulled me out of there."*
>
> R.- "Okay."
>
> *A.- "So I didn't even find out...stick around to find out."*

Here participant A is recalling an event where he felt sexually compromised at his school and he knew to alert his father for help. When the researcher asked a similar question to Participant B, he responded that he would alert a "doctor or relatives," if ever placed in a compromising situation. Comparable to participants A and B, participant C indicated that he would alert a family member, namely his "daddy." His response is noted below:

R.- "Okay, so did you learn about getting help if something were to happen to you, sexually?"

C.-"Well I got help, I got my daddy."

R.- "Well if somebody did something to your body that you don't like, do you know how to get help?"

C.- "Yeah, call 9-1-1."

R.- "Umm hmm, call 9-1-1? Did you learn about that in school?"

C.- "Yeah."

As with other questions, participant D responded with blunt and definitive "no's," as the following exchange illustrates:

R.- "Okay. Did you learn about getting help if something bad happens to your body?"

D.- "No."

"Informed treatment of sexual abuse," is the concluding strand from the broad theme, "Sex education." Moving forward, the researcher will examine the findings from the following theme, "Human growth and development education."

Theme 2: Human growth and development education

The second theme to emerge from the researcher's transcriptions of the interviews was that of human growth and development education. The researcher noticed that 3 of the 4 participants responded affirmatively when asked about receiving human growth and development education in high school. In regards to this

second broad theme, the researcher noted only one strand which is particularly relevant: a) exposure to puberty education.

Strand a, "Exposure to puberty education"

As mentioned previously, the researcher learned that 3 of the participants had no formal sex education in high school and 1 indicated that he had some recollection of a sex education program in health class. Three of the participants responded affirmatively when probed about their education experience of puberty/human growth and development related items. They spoke about personal hygiene and personal hygiene care procedures during puberty. The exchanges below between the researcher and participants C and D are indicators of their experiences in human growth and development education:

R.- "Uh huh. Okay, so when you were learning about sex, did you learn about your body or puberty?"

C.- "Umm hmm."

R.- "What did you learn about that?"

C.- "'Bout keeping your body clean."

R.- "That's right."

C.- "Wa-wash soap and water."

R.- "Right."

C.- "Perfume, deodorant."

The researcher found a similar response from participant D. He too spoke of personal hygiene skills much like participant C, as shown in the following exchange:

R.- [D.], did you learn about puberty in school?

D.- Yeah.

R.- Who taught you about that, your teacher?

D.- Yeah.

R.- What did they teach you about?

D.- What did they teach me?

R.- Umm hmm.

D.- Like some math, math and umm math and reading.

R.- Math and reading? Did they teach you about your body?

D.- No. [participant nods]

R.- They did, did they teach about how to be safe with your body?

D.- Yeah.

R.- "What did they teach you about that?"

D.- "Well, body."

R.- "Umm hmm. Did they teach you about washing, taking a shower?"

D. "Yeah."

R. "Yeah? Did they teach you about things that happen between a boy and a girl? "

D..- "Yeah."

R.- "What did they teach you about that?"

D.- "Like, so smell good."

R.- "So that you smell good?"

D.- "Yeah."

R.- "What else?"

D.- "Uh, smell good everyday. And wash your teeth if they are dirty."

R.- "Uh huh. So you have to take a shower everyday, you have to brush your teeth everyday? Anything else you learned about?"

D.- "Smell good everyday."

The vivid recollections of both men suggested that their high school experience had placed a high priority on personal care. Neither of the men, shown in the examples above, indicated they had received formal sex education in high school, yet were very specific in personal care procedures that they remember being taught.

Theme 3: Preferences in sex education

The third and final theme to emerge from the researcher's transcriptions regarded the participants' preferences in learning sex education. The transcription excerpts that are relevant to this theme show that the researcher made suggestions for certain sex education materials and methods. The researcher asked the participants to identify their preferred sex education materials and methods. The researcher's final probe regarding their sex education preferences was related to the gender of a sex education teacher. Here, the researcher was in quest to determine whether a male or female teacher of sex education made a difference to the participants. In terms of this third broad theme, 3 strands emerged: a) preferred instructional materials; b) preferred instructional methods; and c) preferred teacher gender in sex education.

Strand a, "Preferred instructional materials"

The researcher asked each participant about certain materials used to teach sex education that would be most beneficial to their learning. The researcher provided them with 3 materials suggestions and 2 follow up materials options. Books, pictures, and movies were the first 3 suggestions made by the researcher. From these suggestions, all 4 participants indicated that they would learn best from movies. One participant indicated that he would also like to use books and another indicated that he would also like to use pictures. The researcher notes evidence of this finding in the exchange involving participant A:

R.- "Do you like to learn from books, pictures, or movies?"

A.- "Well back then they had, like...movies, filmstrips, stuff like that."

R.- "Okay, is that how you like it or do you like books, pictures, workbooks?"

A.- "Uh, movies is good."

Similar to the comments made by participant A, participant D gave the following response when asked about instructional materials:

R.- "Okay? Umm, do you think that if the guy teacher used books, pictures, or movies, which of those would be good?"

D.- "Movies."

R.- "What's that?"

D.- "Movies."

R.- "Movies? Okay, so movies are better than books and pictures?"

D.- "Yeah."

The next grouping of materials that the researcher was interested in was workbooks or worksheets. Two of the participants said "no," they would not be helpful and 2 indicated that "yes," they would be helpful. The researcher provides one example of an affirmative exchange and one example of an exchange with a participant who disaffirms the use of worksheets/workbooks. In the following excerpt, the researcher will first illustrate an example of participant A with concerns about the use of workbooks/worksheets:

R.- "Do you like to learn from books, pictures, or movies?"

A.- "Well back then they had, like...movies, filmstrips, stuff like that."

R.- "Okay, is that Movies are good? Do worksheets help you?"

A.- "(No response.)"

R.- "Writing things?"

A.- "I can't under...I don't understand it, but...but... on paper, you know?"

R.- "How you like it or do you like books, pictures, workbooks?"

A.- "Uh, movies is good."

Along with participant A's concerns about comprehension of written language, participant B expressed that he is an auditory learner. The exchange below illustrates evidence of this finding:

R.- "A girl teacher? Okay. Do you like to learn from books or pictures or movies?"

B.- "Videos."

R.- "Videos? Do worksheets and workbooks help?"

B.- "Well...I do better if I hear it."

For different but related reasons, participants A and B indicated strong preferences for materials that they could listen to or see. Participants C and D responded that they do like the use of workbooks/worksheets with simplistic answers as shown in the following excerpt from participant C:

R.- "A guy? Do you like to learn from books, pictures, or movies?"

C.- "Uhh, pictures."

R.- "Pictures? Do movies help you? Videos?"

C.- "Yeah, yeah."

R.- "Yeah? Do you like to use worksheets and workbooks?"

C.- "Yeah."

While there was a strong response in favor of the use of instructional movies above pictures and books, there was a mixed response on the preference of the use of workbooks and worksheets in sex education instruction. The next section, which discusses the preferences of the 4 participants on instructional methods in sex education, is closely associated to the findings regarding preferred materials in sex education instruction.

Strand b, "Preferred instructional methods"

All of the participants showed a strong favor towards repetitive learning. Each of the 4 participants indicated that repeating content many times helps them to

retain the information more completely. The following interview excerpt between the researcher and participant B demonstrates this finding;

> R.- "You do better if you hear it? Great. Okay, does hearing it over and over again help you remember it?"
>
> B- "Yeah."
>
> R.- "Yeah? So, you need to hear it, um, frequently to refresh your memory?"
>
> B.- "Yeah."

At this point in the interview, Participant B has indicated that he does not prefer the use of workbooks and/or worksheets because he has a difficult time writing and recording his thoughts. Due to physical limitations, he indicated that he prefers to hear things in order to commit them to memory. All participants indicated a strong preference for the use of instructional movies in sex education and 2 of the participants indicted that they like the use of workbooks/worksheets in sex education instruction. All participants also indicated that they rely on repetition to commit content to memory. Next, the researcher will highlight the participants' preferences regarding the gender of the sex education teacher.

Strand c, "Preferred teacher gender in sex education"

The researcher noted that the participants in this study overall did not indicate a unanimous preference in gender for the teacher who provides sex education to them. All of the participants used in this study were male and when each were asked if they would like to learn sex education concepts from a male teacher or female, one participant said, "it doesn't matter," another said that he would like to learn from a

female teacher, and the last 2 indicated they preferred a male teacher. The following portion of the interview with participant A is illustrative of his non-preference of a gender specific educator:

> R.- "If you were going to learn about sex, how would you like to learn about it? Would you like to talk to a girl or a guy?"
>
> *A.- "They had girls in there. Uh (long pause)...they talked about it a little bit over there...back then, but they're not going all the way into it."*
>
> R.- "Okay, if they were going to teach you all the way about it, do you want a boy teacher or a girl teacher?"
>
> *A.- "It doesn't matter."*

The researcher noted in the transcriptions that the other participants did indicate a gender preference but were not in agreement on the specific gender. Participant B indicated that he preferred learning sex education concepts from a female teacher, noted in the following exchange:

> R.- "You forget some of them? Okay. So, what ways are good ways to teach about sex ed? Do you like to learn from a girl or a boy teacher?"
>
> *B.- "Girl."*

While participant B made a clear indication that he preferred a female sex education teacher, participants C and D showed preference to a male teacher. Participant C made 2 separate references to a male teacher in his interview with the researcher, as noted in the following exchange:

> R.- "What are some good ways to teach people about sex? Do you like to learn from a girl teacher or a guy teacher?"

C.- "Well, I really not learned about sex at all til the teacher tell me I cant use that word."

R.- "So you didn't learn from a teacher, you learned from maybe like…"

C.- "A guy."

R.- "A guy, some friends?"

C.- "Yeah."

R.- "Some other kids in school, when you were in school?"

C.- "Umm hmm."

R.- "Okay. Do you think it is better to learn from a girl or a guy? Who helps you learn better?"

C.- "A guy."

In terms of theme 3, "preferences in sex education," strand c, "preferred teacher gender in sex education," the participants' preferences did not indicate unanimity for a gender specific teacher. The researcher determined that half of them preferred the same gender as themselves while the other half was split between no preference and gender-opposite.

Summary:

In summary, chapter 4 discussed the significant findings regarding the perceptions of individuals who have moderate to severe intellectual disabilities in regards to the sex education program they received during their high school education. The researcher used excerpts from the interview transcriptions with 4 male participants as evidence of the findings and classified the findings into 3 broad

themes and 8 strands. The themes are as follows: 1) sex education; 2) human growth and development education; and 3) preferences in sex education. Within these 3 broad themes, the researcher identified 8 related strands. The strands from theme 1, "sex education," were: a) sex education limitations in high school; b) informal sex education exposure; c) limited discussion about sexual protection; and d) informed treatment of sexual abuse. Theme 2, "human growth and development education," had only one strand. The researcher identified this singular strand as, "exposure to puberty education." The researcher reduced the final theme, "preferences in sex education," into 3 strands: a) preferred instructional materials; b) preferred instructional methods; and c) preferred teacher gender in sex education. The significant findings of the themes and strands are as follows:

- 75% of participants did not receive sex education instruction in high school;
- 75% of participants learned sex education concepts from informal sources and had ill formed conceptions about sex, sexual intercourse, and sexual relationships;
- 75% of participants did not learn about sexual protection devices such as condoms or oral contraceptives;
- 75% of participants indicated that they learned how to seek help if placed in a situation of sexual abuse;
- 75% of participants were taught human growth and development concepts;
- 100% of participants indicated that they prefer the use of instructional movies;

- 50% of participants indicated a favorable opinion of the use of worksheet and workbooks, while 50% indicated an unfavorable opinion of the same;
- 100% of participants indicated that repetition is a strategy that helps them retain content;
- And, 50% of participants preferred a gender-like sex education teacher (male) while 25% had no preference and 25% preferred a gender-opposite sex education teacher (female).

Chapter 5, Summary and Conclusions, contains 4 sections: a) limitations; b) discussion; c) implications; d) and recommendations for future research. The first section, limitations, discusses those factors beyond the researcher's control which affected or could have affected the study's outcome. Discussion, the second section in this chapter addresses the significant findings and elaborates upon the participants' stories. The researcher provides some interpretation to those stories for clarification. The third section, implications, explains the relationships of these results to the future of sex education programs for persons who have moderate to severe intellectual disabilities. Final in this chapter, recommendations for future research, the researcher lists possible extensions to this study that should and ought to be pursued by scholars in the field of special education.

Chapter 5

SUMMARY & CONCLUSIONS

The researcher designed and implemented a qualitative study that examined the perceptions of 4 individuals who have moderate to severe intellectual disabilities in regards to the sex education program they received during their high school education. The following sections will summarize the research: a) limitations; b) discussion; c) implications; d) and recommendations for future research. The first section, limitations, discusses those factors beyond the researcher's control which affected or could have affected the study's outcome. Discussion, the second section in this chapter addresses the significant findings and elaborates upon the participants' stories. The researcher provides some interpretation to those stories for clarification. The third section, implications, explains the relationships of these results to the future of sex education programs for person who have moderate to severe intellectual disabilities. Final in this chapter, recommendations for future research, the researcher lists possible extensions to this study that should and ought to be pursued by scholars in the field of special education.

Limitations:

Due to the qualitative nature of this research, the information gathered and gleaned by the researcher is considered to be the most essential and important tool for telling the participants' stories. The researcher developed each of the questions for

the semi-structured interviews, conducted and audio recorded the interviews, and meticulously transcribed the participants' oral exchanges. The researcher avoided changing the participants' thoughts due to unclear speech articulation and thought patterns. The researcher then analyzed and coded each of the interviews and uncovered 3 themes and 8 strands.

Also due to the qualitative nature of this study, the researcher identified several limitations directly related to the participants' backgrounds, particularly the severity of their intellectual disabilities. First among these limitations is the participants' communication attributes. Specifically, the researcher anticipated that any person having moderate to severe disabilities may have unique communicative attributes which could impede the transcription and interpretation processes. The researcher's expectation proved accurate as 3 of the 4 participants in this study exhibited a unique communicative pattern. To summarize these patterns, participant A exhibited a stutter, participant B exhibited extreme muscle rigidity in the face and neck preventing clear speech, and participant C exhibited low speech intonation. Participant D really did not exhibit any extenuating impediments which could have impeded the transcription and interpretation processes. However, the researcher gave careful attention to these speech impediments in order to ensure the accuracy of the transcriptions and the participants' stories.

Second among the limitations is the age of the participants in this study. At the time of this study, the average age of the participants was 40.5. The typical age at which persons having moderate to severe disabilities graduate from high school is 21.

This means that the participants on average had been 19 years removed from their most recent high school experience. Therefore, their recollections of the events that took place in high school may be tainted with other memories. The researcher has no way to ensure that the specific recollections each participant had was that of their actual high school experience and not one before it or after. Also, the amount of time that took place between the actual sex education experience in high school and the interview is great enough for the participants to have had memory regression.

Third among the limitations affecting this research is the researcher's gender as female while each of the participants was male. The researcher anticipated that the gender issue could compromise the participants' comfort level and willingness to share their recollections on such an intimate topic. In order to combat this limitation the researcher attempted to establish rapport with them during the interviews.

Final and perhaps most important among the limitations that affected this study is with regard to the participants' intellectual abilities. According to AAIDD, persons needing extensive to pervasive supports in order to be successful or independent are categorized as having moderate to severe intellectual disabilities. Due to the level of severity of disability suggested by placement in the daytime rehabilitation facility, the researcher carefully developed questions sensitive to the participants' cognitive understanding. The researcher had intentions of providing specific examples of sex education practices and ascertaining the participants' feedback on those specific items. Realizing this could be interpreted as leading the participants to the findings, the researcher made a decision to provide them with

specific examples and get direct feedback on those examples. The researcher deduced examples of sex education practices from available literature on sex education and on education of persons with intellectual disabilities.

Discussion:

To this researcher's knowledge, this is the first study that attempted to uncover the recollections of adults with intellectual disabilities as to their high school sex education experiences. Although the researcher identified several useful themes and strands, the researcher could not help but notice the emphasis these high school experiences seemed to place on personal hygiene as sex education. The findings discussed below all corroborate this finding.

To begin, 3 of the 4 participants indicated to the researcher that they did not participate in formal sex education while in high school. Nearly 20 years after leaving high school, participant B was the only one to be able to recall specific facts from sex education, suggesting he had a meaningful experience. He said that he had received sex education as part of his high school health class. He also indicated to the researcher that he attended an urban, traditional high school. Through conversation with participant B and the 3 other participants, the researcher is led to believe that B was the only participant who had the opportunity to participate somewhat in the general education setting and to have an opportunity to receive a formal sex education.

Related to this finding, the researcher ascertained that 3 of the 4 participants learned about sex education concepts from informal sources such as peers in high school. Each of these participants led the researcher to believe that they learned some sex education concepts through "experiential" learning. Although one participant (B) indicated that he participated in sex education as a part of his health class in high school, the researcher construed that none of them had a functional understanding of the sex education concepts in question.

Interestingly, 2 of the participants who did not receive sex education in high school indicated they had inappropriate sexual encounters during school. This concerned the researcher for 2 reasons: 1) it appears that these participants were segregated from sex education during high school; and 2) their vulnerability exposed them to inappropriate sexual encounters. Thus, the researcher opines that "experiential learning" is dangerous for individuals who may not be fully educated in how to protect themselves sexually and from abuse.

The researcher noted that 3 participants said they had not received education on sexual protection devices and were unaware of condoms and/or birth control measures. Participant C, who had not received formal sex education in high school showed a limited understanding of sexual protection devices. Participant C was able to cite specific measures he believes that one must take in order to protect oneself against pregnancy. The researcher believes that participant C has learned an extreme form of pregnancy prevention, sterilization. Because participant C did not participate in a formal sex education class he appeared to know only one extreme option for

pregnancy prevention. Surprisingly, the participant who had received sex education in high school did not have a recollection of being taught about condoms or birth control. This finding left the researcher to question the curricular effectiveness of his sex education experience and the accommodations he received for understanding and mastery.

As noted earlier in the review of literature, persons who have intellectual disabilities are placed at a heightened risk of being sexually exploited or abused (Canham, 2006; Cuskelly & Byrde, 2004; Grieveo, McLaren, & Lindsay, 2006; Lumley & Scotti, 2001; Martorella & Portugues, 1998; May & Kundert, 1996; Walcott, 1997). The researcher found a reassuring finding from the 4 interviews. Three of the 4 participants indicated that they knew how to seek help if placed in sexual danger. The researcher discovered that participant A actually implemented specific strategies for alerting an instance of possible sexual impropriety. Similarly, the researcher discovered that participants B and C knew to alert their family members in an instance of sexual abuse. Like participant A, B and C articulated steps to take including alerting a family member, calling 9-1-1, or telling a doctor. Again, these findings are especially interesting because participant B was the only one to indicate he had formal sex education in high school. As for the other participants, the researcher was unclear as to how they knew to alert for sexual abuse.

Another finding from the researcher's transcriptions is that 3 of the 4 participants indicated that they had some experience with human growth and development education. Specifically, the researcher found that these 3 participants

were informed on specific procedures dealing with puberty and personal hygiene. Each of the participants who indicated to the researcher that they had been taught human growth and development concepts spoke specifically about hygiene. This personal care technique could have taken place during some sort of sex education programming but likely took place as part of a broader functional skills and functional living curriculum. The researcher is led to believe that these programs only addressed the immediate needs that the faculty and staff experienced on a daily basis, such as body odor and cleanliness of the students. Body odor is indicative of changing hormones during puberty. It is possible to opine based on the stories told by these participants that their teachers did not address the implications of puberty during sex education.

During the analysis of each interview, the researcher focused her questioning on best practice. In reviewing the literature, a comprehensive sex education program is recommended for all adolescents regardless of cognitive ability, specifically for persons who have intellectual disabilities (Lumley & Scotti, 2001; McCabe, 1999; Snell & Brown, 2006). A comprehensive sex education program that covers topics ranging from hygiene to intercourse and sexual relationships is recommended and it is also recommended that best practice for teaching this program be a systematic approach (Lumley & Scotti, 2001, Wehmeyer, 2002). Consistent with this literature, the researcher determined that each of the participants preferred the use of instructional movies to learn sex education concepts. For related reasons, participants A and B indicated that they preferred the use of instructional movies over books or

pictures because they learn better through visual and auditory means. Participant A also indicated to the researcher that for similar reasons, he does not like the use of workbooks and worksheets. Along with specific learning styles that the participants referred to, the researcher is also led to believe that realistic representations of sex concepts are needed and desired for participants to grasp information more fully.

Repetitive learning was a unanimous preferred strategy that the researcher was able to generalize to all 4 participants in this study. The researcher found that when each of the participants was probed about repetitive learning as a strategy to help retain sex education concepts more completely, each of the 4 participants agreed it was important for them to remember content.

Finally, the researcher was unable to determine a gender preference that was generalizable to the whole group of participants. Two of the 4 participants indicated a preference to a gender-like (male) sex education teacher. One participant indicated a preference for a gender-opposite (female) teacher and 1 indicated no preference at all. The researcher is left to question the impact of gender on the responses of the participants and whether gender played any role at all.

Implications:

Based on the analysis of the transcribed interviews as well as the review of research the researcher was able to determine the following implications for sex education for persons with moderate to severe intellectual disabilities:

1) Persons with moderate to severe intellectual disabilities absolutely need comprehensive sex education programming;
2) This programming should be presented in a systematic fashion, using real life depictions, repeated over time.

Although the literature is strong in its suggestions that comprehensive sex education be a part of the education of persons with intellectual disabilities, it is clear through the researcher's analysis of the transcriptions of 4 adults who have moderate to severe intellectual disabilities on their perceptions of the sex education experience they had in high school that the actual practice still lags behind. Although the researcher found clear evidence that sex education is not readily a part of most curriculums for persons with intellectual disabilities, there are programs available for commercial purchase that address the needs and the best practice suggestions highlighted in this study. The following programs are examples of curriculum suggestions that are available at this time:

- Hand Made Love: A Guide For Teaching About Male Masturbation, Dave Hingsburger, Diverse City Press Inc.,
    - This is a book and video set that deals with issues of male masturbation and how to effectively share living space with others.
    - This set is both informational to caregivers and teachers as well as appropriate classroom material.

- This set includes graphic real life representation about sexuality concepts.

- Finger Tips: A Guide for Teaching About Female Masturbation, Dave Hingsburger and Sandra Haar, Diverse City Press Inc.,
  - This is a book and video set that deals with issues surrounding female masturbation.
  - This set is both informational to caregivers and teachers as well as appropriate classroom material.
  - This set includes graphic, real life representation about sexuality concepts.
- Under Cover Dick: A Guide For Teaching About Condom Use Through Video And Understanding, Dave Hingsburger, Diverse City Press Inc.,
  - This is a book and video set regarding condom use and sexually transmitted infection prevention.
  - This set is both informational to caregivers and teachers as well as appropriate classroom material.
  - This set includes graphic real life representations about condom use including a step by step guide to successful use of a condom.
- Circles I, II, and III, Leslie Walker-Hirsch and Marklyn P. Champagne, James Stanfield Company Inc.,
  - Circles I includes programming on social boundaries and relationships.

        - This is a 2 part curriculum that deals with social boundaries and relationships.
        - This set includes videos and graphic representations that help students visualize appropriate boundaries to have with different people.
        - Circles I includes materials for both teacher and students.
    - Circles II includes programming on sexual abuse prevention.
        - This is a 2 part curriculum that deals with sexual exploitation and protective behaviors.
        - This set includes video tapes and graphic representations.
    - Circles III includes programming on sexually transmitted disease prevention.
        - This is a 2 part curriculum that deals with communicable disease and sexually transmitted disease prevention.
        - This set includes video tapes intended for both teacher and students.
- Life Horizons I and II, Winifred Kempton, James Stanfield Company Inc.,
    - Life Horizons I includes programming regarding sex education.
        - This is a 5 part curriculum that covers anatomy, puberty, human reproduction, sexual protection, and sexually transmitted disease.

        - Life Horizons I uses slide shows, a teachers script, and a video.
        - This program can be edited to include or exclude sexually explicit materials.
    - Life Horizons II includes curriculum programming on relationships and appropriate sexual behavior.
        - This is a 7 part curriculum that covers self esteem, male/female aspects of sexual behavior, dating, marriage, parenting, and prevention of sexual abuse.
        - This is a slideshow program that includes a teacher's script.
- Sexuality Education for Persons with Severe Developmental Disabilities, James Stanfield Company Inc.,
    - This is a 7 part curriculum that covers anatomy, appropriate social behavior, menstruation, and medical examination.
    - This curriculum is specifically geared toward persons with severe disabilities. It uses a graphic "happy/sad face" to cue appropriate/inappropriate behaviors.
    - This program includes slideshows and a teacher's guide.
- No-Go-Tell!, James Stanfield Company Inc.,
    - This program is geared for a younger audience, 3-7 years old.
    - No-Go-Tell! Uses dolls and graphic representations to inform students about safety, abuse prevention, and abuse reporting.

- Changes in You, James Stanfield Company Inc.,
    - This curriculum addresses the changes associated with puberty.
    - This program is specifically geared towards students aged 4-9 years old.
- Life Facts 1-7, James Stanfield Company Inc.,
    - This comprehensive curriculum has 7 parts.
    - The 7 parts of this program cover basic sexuality, sexual abuse prevention, anti-gullibility training, drug use prevention, AIDS, emotions, and basic physical wellness.
    - This program uses slides, illustrations and prepared lesson plans for teachers.

Recommendations for Future Research:

This study included a very small sample size. In further research, it would be wise to increase the sample size in order to obtain generalizable results. Obviously including both female and male participants would be important in this increased population. While the intimate nature of the study involves the researcher having somewhat of a personal relationship with the participants, it would be important for the researcher to be able to form these bonds quickly and with a number of participants and quite possibly in a panel discussion format.

Based on the findings of this study and the suggestions of these participants in the area of best practice it would be interesting to provide future participants with the

specific representations of best practice recommendations from this study. Having videos that involve real life representation of sex education concepts could be used to evaluate their effectiveness more accurately as the participants would be able to visualize the examples and the concepts and then respond to what works for them and what does not. Also, in further research examples of worksheets and workbooks that may be included as part of a comprehensive program could be evaluated in the same way by future participants. The participants in this study responded that repetition, worksheets, workbooks, and videos all help them learn best. In order to test these recommendations it would be interesting to prepare a curriculum including those materials and strategies and have a sample population test their effectiveness.

Summary:

Sex education for individuals with intellectual disabilities is imperative yet it is not happening nearly enough. Possible reasons to explain the limited programming that is made available to people with intellectual disabilities could include issues of negative societal attitudes regarding the sexuality of this group of people. Also, limited pre-service preparation that teachers receive may play a role in their unwillingness to implement such programs. Lack of community support of such programming may pose problems for those teachers that are willing to implement such programming. Resistance of sexually explicit materials on the part of school administration could pose a barrier to schools having the appropriate graphic representations of sex education concepts that those with intellectual disabilities so require.

In order for sex education to become more available it is important that teachers are trained in method and in theory behind why sex education is such a necessity for students with intellectual disabilities. Also, community support could help gain momentum behind such a movement and in order for such a thing to happen it is important that the community be educated on the necessity. Finally, a positive message about the sexuality of all people, including those with intellectual disabilities is imperative for others to gain and understanding of this type of programming.

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Appendix

Consent Letter 1

Dear [name of facility] Client and/or Guardian,

I am a graduate student at Morehead State University. I am requesting your participation in a research study I am conducting about sexuality education. This study is completely voluntary. You may choose to not participate or end your participation at any time. Also, you may choose to not answer any or all of the questions.

It is my hope that with agreement from you, the participant and/or your legal guardian, I will be able to ask you a series of questions about your experience with sexuality education. Again, it is your choice to participate. You may choose not to at any time.

If you and/or your guardian agree to participate in this study you will receive a second letter, providing you more specific information. Again, you can refuse participation at any point.

The potential benefits from this study are improved sexuality education available for people who have intellectual disabilities. Access to this type of program will also potentially be increased.

I have taken care to ensure that your rights will be protected. By agreeing to this consent, you are only agreeing to receive another letter providing you more information. You may at that point change your mind, and refuse participation. If you agree to the second letter of consent, I will meet with you and discuss the interview further. This is a third opportunity for you to learn about the study. Again, you can refuse participation at this point or any point in the study.

The answers you provide me in the interview will be kept completely confidential. I will ensure that your name is not used. I will be sure that the location of the interviews is not used in any future publication. All of the records of the interview will be kept in a locked location. Once the research is complete the original data linking you to the study will be destroyed.

Please read this information carefully. Ask if you need help to read this. I will be available to answer any questions regarding this study. If you are the guardian, please go over this letter with the adult client in your care. Make sure that you are in agreement with the client about future participation.

Please return this letter signed to [contact name] at [name of facility] by **December 10, 2008**.

Thank you for considering participation in this study.

Name (print):_____

Signiture:_____

Guardian (print):_____

Guardian signature:_____

Date:_____

Contact the researcher at:
Natalie Peterson
Nadz6129@aol.com
937-260-2282

Consent Letter 2

Dear [name of facility] Client and/or Guardian,

Thank you for you interest in participating in my study about sexuality education. This letter will provide you with more specific information about the study. By agreeing to this letter you are giving me permission to meet with you at [facility] to go over further consent information. You may refuse to participate in this study at any point. If this is the case, please return this letter and indicate that you no longer wish you participate.

The interviews will take place at [facility] between you and the researcher, Natalie Peterson. You will be asked if you would like a [facility] staff member to sit in the interview for your comfort. During the interview, you will be asked a series of questions about the sexuality education program you may have received. You can choose to not answer any or all of the questions asked and can choose to end you participation at any point during the interview.

The researcher will audio record all of the interviews and transcribe them. This information will be stored in a locked location. At the completion of this project, the researcher will destroy all original material linking you to this study. Your name will not be used nor will the location of the interviews. Your confidentiality will be protected.

By agreeing to this letter of consent, you are giving me permission to meet with you at URS and obtain a final consent. This consent between the researcher and participant will cover the permission to interview for the last time. You may read the consent form or be read the consent form. Then you may ask any questions you have. Finally, you will repeat the information covered in the form back to the researcher. You may at any point choose not to participate. If you agree, the researcher will schedule another date to conduct the interview.

Please read this information carefully. Ask if you need help to read this. I will be available to answer any questions regarding this study. If you are the guardian, please go over this letter with the adult client of [facility] in your care. Make sure that you are in agreement with the client about future participation.

If you agree to meeting with the researcher to discuss the final letter of consent please indicate so below. If you would like to end your participation please do so below. Thank you for your consideration.

I would like to participate _____

I would not like to participate_____

Name (print):_____

Signiture:_____

Guardian (print):_____

Guardian signature:_____

Contact the researcher at:
Natalie Peterson
Nadz6129@aol.com
937-260-2282

Assent Letter 3

I agree to answer questions about sexuality education.

If I do not want to answer any of the questions, I do not have to.

If I want to stop answering all of the questions, I can.

My name will not be used in the report about my interview.

The name of [facility] will not be used in the report about my interview.

I can change my mind any time I want.

Name (print):_____

Signature:_____

Date:_____