SUPPORT PERSONS’ KNOWLEDGE IN COMPARISON WITH CONSUMERS’
SEXUAL KNOWLEDGE

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General-Experimental

by

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DEDICATION

This thesis is dedicated to the children and adults with developmental and physical disabilities I have been fortunate to have met and worked with in previous years. Individuals with developmental disabilities are capable of being active participants in society, have the same needs and desires as other typically developing individuals.
ACKNOWLEDGMENT

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ABSTRACT

SUPPORT PERSONS SEXUAL KNOWLEDGE IN COMPARISON TO CONSUMER SEXUAL KNOWLEDGE

by

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Master of Arts in Psychology

General-Experimental

Individuals with developmental disabilities are vulnerable and at-risk for sexual exploitation and abuse due to limitation in sexual education. Past research demonstrates individuals with disabilities are sexually active regardless or not if they have sexual knowledge. The purpose of this study was to examine the overall sexual knowledge of the support person in comparison to the individual with developmental disability (consumer). Two hundred and seventy one support persons and consumers were given surveys to measure their overall sexual knowledge and subscales. Support persons’ overall sexual knowledge was positively correlated with consumers’ overall knowledge. Consumers’ age and intelligence quotients (IQ) were significantly correlated to sexual knowledge. Consumers living independently had higher sexual knowledge in comparison to those living in residential or with family members. Sexuality is an important part of life for consumers, just as it is for most people, and they search to gain accurate sexual information from support persons. Further study in the area of support persons’ attitudes, education, and program evaluation will increase safe practices, decrease inappropriate sexual behaviors, and enhance the lives of individuals with developmental disabilities.
CHAPTER I
INTRODUCTION

Individuals with developmental disabilities are often seen as childlike due to their dependability and reliance on others (Lesseliers & Van Hove, 2002). Individuals with developmental disabilities often rely on others for support (e.g., family, paid service providers, staff) and care in daily living and look to other individuals for decision-making. Similar to typically developed individuals, people with developmental disabilities have sexual needs and desires regardless of perceptions and beliefs of others. This can, at times, be misinterpreted as inappropriate sexual behaviors and/or can lead to victimization.

Formal sex education is limited to high school years and is not always presented in the most appropriate manner for individuals with developmental disabilities. Sexuality education opportunities are reduced following high school and are virtually non-existent later in adult life. It is likely that the knowledge of the support persons regarding disabilities and sexuality can influence the sexual knowledge of the person with developmental disabilities.

Statement of the Problem

Individuals with developmental disabilities are vulnerable and at-risk for sexual exploitation and abuse due to limitations in sexuality education (Modella & Mak, 2008; Sobsey, 1994). Minimal and inadequate research has been done to find appropriate types of programs and services necessary to better meet the needs of individuals with developmental disabilities. Exploring the knowledge level and understanding of these individuals will be highly beneficial to minimize the risk of inappropriate and offensive
sexual behaviors as well as enrich lives of those with disabilities. Understanding which factors relate to the sexual knowledge of individuals with developmental disabilities can allow for customization of sexuality programs for these individuals.

**Purpose**

The purpose of this study is to examine the relation between the support persons’ overall knowledge of sexuality and developmental disabilities in relation to the sexual knowledge of the individual with developmental disabilities (i.e., consumer). It is likely that the support persons’ sexuality and disability knowledge will influence the sexual knowledge of the individual with developmental disabilities. The other purpose of this study is to examine whether the living arrangement of the individual with developmental disabilities will be related to his/her sexual knowledge. In addition, various individual qualities of the consumers may relate to their sexual knowledge, such as age, gender, and intelligence quotients (IQ). Thus, these qualities will be examined as potential control variables in relation to sexual knowledge.

The support person’s role is essential to meeting the needs of the individual with a developmental disability and providing the individual with accurate knowledge. The results of this thesis can potentially guide prevention and intervention programs designed to enhance the knowledge of support persons as well as the individual with developmental disabilities. Thus, sexuality educators as well as helping professionals working with individuals with developmental disabilities can potentially benefit from the findings.

**Definitions**

The following definitions are provided to ensure shared meaning between the
author of this thesis and the readers of the thesis.

- **Developmental disabilities**, according to The Developmental Disabilities Assistance and Bill of a Rights Act of 2000, means a severe chronic disability of an individual that: (a) is attributable to mental and physical impairment or combination of mental and physical impairments; (b) appears before the individual turns age 22; (c) is likely to persist throughout life; (d) reduces functional abilities in three or more of the following areas (i.e., self-direction, capacity for impendent living, receptive and expressive language, learning mobility, self-care, and economic self-sufficiency); and (e) results in individualized supports, special interdisciplinary services, and other forms of assistance that are for extended duration or lifelong.

- **Consumer** is a person with developmental disabilities who is eligible to receive services from programs targeted to individuals with developmental disabilities. In the case of this thesis, the consumers are individuals who agreed to attend the *Responsible Choices Program* training with their support person and to participate in the research.

- **Sexuality** refers to all aspects related to a person’s sexual behavior, sexual feelings, and sexual character (www.dictionary.com). In this thesis, the terms “sexual” and “sexuality” will be used synonymously.

- **Support person** includes a professional caregiver and/or a family caregiver. For the purposes of this thesis, a support person is any caregiver who (a) is selected by the consumer to participate in the *Responsible Choices Program*, (b) agrees to attend the *Responsible Choices Program* training with the consumer, and (c) agrees to participate in the research study.
Hypotheses

Research Hypotheses

Based on the review of literature in Chapter 2, the following research hypotheses were developed.

1. The support persons’ level of sexual knowledge and disability knowledge will be significantly correlated to the consumers’ sexual knowledge.

2. The consumers’ living situations will be related to their sexual knowledge. Specifically, those consumers living independently and in supported-living residences will have significantly higher levels of sexual knowledge compared to those consumers who live with family members.

3. Older consumers will have significantly more sexual knowledge than younger consumers.

4. Male consumers will have significantly more sexual knowledge than female consumers.

5. Consumers with higher IQs will have significantly more sexual knowledge than consumers with lower IQs.

Assumptions

This research study was created based upon certain assumptions. First, it was assumed that support persons and consumers answered the items on the questionnaires completely and honesty. Next, it was assumed that consumers had an adequate understanding of the questions in the interview, and that the questions were accurately answered. This assumption was made because of the intense training of the individuals who conducted the interviews with the consumers.
Also, it was assumed that participation in the research was made without
d Pressures from researchers, support persons, and/or agency staff. Participation in the
research was not a prerequisite for participation in the Responsible Choices program. In
addition, it was assumed that no errors were made in the data collection, data coding, and
data entry; again, because of the training given to the researchers and staff. And finally, it
was assumed that the data analyses were conducted accurately since the primary author
of the thesis worked closely with the chair on the analyses.
CHAPTER II
REVIEW OF LITERATURE

Developmental Disability Defined

The American with Disabilities Act (ADA) recently celebrated its 20th anniversary and its mission to provide individuals with disabilities with equal opportunities to lead productive lives. According to The Developmental Disabilities Assistance and Bill of Rights Act (DDABRA) of 2000, it is estimated that 1.2 to 1.65 percent of the United States population is comprised of individuals with developmental disabilities. Developmental disability is defined as a severe, chronic disability of an individual that is attributable to a mental or physical impairment or combination of mental and physical impairments (DDABRA, 2000). Developmental disabilities generally manifest before age 22, are expected to continue indefinitely, and infer that a person has functional limitations in three or more of the following areas of life activity: (1) self-care, (2) receptive and expressive language, (3) learning, (4) mobility, (5) self-direction, (6) capacity for independent living, and/or (7) economic self-sufficiency (DDABRA, 2000).

Individuals with intellectual disabilities have below average scores on intelligence tests, resulting in limited cognitive functioning and adaptive skills (National Center on Birth Defects and Developmental Disabilities [NCBDDDD], n.d.). Intellectual disability is sometimes referred to as mental retardation. Individuals with developmental disabilities can be diagnosed as mild, moderate, or severe depending on the individual’s support needs.

Types of developmental disabilities include intellectual disabilities, Cerebral...
Palsy, Down syndrome, Fragile X syndrome, and Autism Spectrum disorders. Cerebral Palsy results in brain abnormalities and physical limitations that occur before, during, or after birth, or in early child development (NCBDDD, n.d.). Down syndrome and Fragile X are genetic disorders that cause developmental delays and impairments. Autism spectrum disorder refers to a group of developmental disabilities that have limitations in social interactions and communication as well as occurrences of behavioral challenges (NCBDDD, 2011).

**Individuals with Developmental Disabilities At-Risk**

**Increased Risk of Victimization**

Individuals with developmental disabilities are at a higher risk of victimization than the general population. According to some estimates, individuals with developmental disabilities are 4 to 10 times more likely to be victims of crimes such as abuse or sexual assault in comparison to individuals without a disability (Modella & Mak, 2008; Sobsey, 1994). With limitations in physical and cognitive functioning, individuals with developmental disabilities are prone to be victims of abuse, neglect, and exploitation. Estimates suggest that 99% of victimization occurs with people the individuals with developmental disabilities knows (Baladerian, 1991), likely due to their over-reliance on their support persons (Petersilia, 2001) and the lack of personal boundaries established between individuals with developmental disabilities and their associates.

One reason for the likelihood of individuals with developmental disabilities being victimized is the underreporting of cases (Petersilia, 2001). Studies show hate crimes toward individuals with developmental disabilities are often dealt with among institutions
or residential homes that individuals reside in instead of reporting to authorities. Thus, institutional staff can perpetrate with little threat of serious consequence.

Sherry (2010) illustrated in his work that when individuals with disabilities are victims of sexual abuse, it is often labeled a “crime” instead of “abuse” (cited in Gill, 2010). Petersilia (2001) demonstrated that even when crimes are reported to the police, there are often various barriers to the investigation. One barrier is the individual’s limited communication skills and comprehension. Petersilia described instances when investigators asked individuals with developmental disabilities to describe events, yet the possibility of confusion often created a stress level that led to misunderstandings. This confusion and lack of communication can also result in the police officers perceiving the individual with the disability as not being credible or reliable (Petersilia, 2001). In most cases, police officers are placed in compelling situations in which they are unclear about how to most effectively work with the individuals with developmental disabilities (Modell & Mak, 2008).

There are many factors that might lead to an individual with a developmental disability not reporting instances of abuse, including the fear of upsetting others or being placed in restrictive settings by the primary caregivers when the individual attempts to report abuse (Sobsey & Doe, 1991). Sobsey and Doe surveyed 166 people with disabilities and found that they did not report abuse for fear of punishment from the offender and the belief that it would not make a difference to report.

People with developmental disabilities are often reliant on others, especially when one is dependent on financial or physical assistance (Petersilia, 2001). Thus, the individual with developmental disability may be less inclined to make a report.
Additionally, the lack of sexuality education and misinterpretation of social cues of others can lead the individual with a developmental disability to be vulnerable to victimization (Petersilia, 2001).

**Increased Risk of Perpetration**

In addition to being the victim of hate crimes and abuse, people with developmental disabilities are also more likely to be a perpetrator and/or to commit non perpetrating sexual offenses (exposing private parts in public). Minimal exposure or lack of sexuality education not only increases the risk of being victimized, but it also contributes to the individual exhibiting inappropriate and offensive sexual behaviors (Ward & Bosek, 2002). Most inappropriate and offensive sexual behaviors are due to cognitive impairments and lack of social skills.

Ward and Bosek (2002) conducted a survey to examine issues and inappropriate behaviors described by community service supporters. They found that service providers reported challenges in dealing with inappropriate and offensive sexual behaviors by individuals with developmental disabilities. For example, service providers reported that individuals in their care commonly exhibited behaviors that were appropriate in private but not in public situations (e.g., masturbation). Next, the service providers reported that individuals with developmental disabilities engaged in behaviors such as grabbing, touching, and/or rubbing others for stimulation. Displaying such inappropriate behaviors in public created the perception that the individual was a sexual perpetrator rather than a person with a disability who lacked appropriate knowledge and social skills (Petersilia, 2001).

Other factors also contribute to the increased likelihood of sexual offending by an
individual with developmental disabilities. For example, minimal relationship skills, insignificant social sexual knowledge, poor impulse control, and susceptibility to the influence of others can also increase the likelihood that an individual with developmental disabilities can be labeled as a perpetrator (Day, 1993; Lindsay, 2002).

**Individuals with Developmental Disabilities and Sexuality**

Many individuals with developmental disabilities lack sexual knowledge; yet, not surprisingly, they find sexual behaviors and interpersonal relationships an important part of life (Siebelink, Jong, Taal, & Roelvink, 2006). Research shows that people with disabilities are sexually active, even with minimal sexual knowledge (Walker-Hirsch, 2007). In Leuter and Mihokovic’s (2007) study, participants with developmental disabilities had some level of sexual knowledge, however, it was insufficient. The participants’ lack of knowledge was mainly in distinguishing gender differences, diseases, and protection from sexually transmitted diseases. Galea, Butler, and Iacono’s (2004) findings are consistent with Leuter and Mihokovic’s, emphasizing the limits of sexual information regarding topics such as safe sex practices, contraception, menstruation, and sexually transmitted diseases. McCabe (1999) indicated that individuals with developmental disabilities had significantly lower sexual knowledge when compared to the physically disabled or the general population.

Healy, McGuire, Evans, and Carley (2009) conducted focus groups with individuals with intellectual disabilities to encourage open discussion about sexuality. The researchers divided the participants into three age groups (i.e., 13-17 years, 18-30 years, and 30+ years) and gender groups (i.e., male and female) to ease discussion among the participants. The researchers found an increase of socio-sexual awareness with age.
Participants did have some accurate knowledge and understanding of interpersonal relationships. Many had some sexuality education in high school, but the information provided was somewhat limited. Traditional sexuality education in schools often covers the biological aspects of sexuality, yet socio-sexual education is frequently forgotten (Lumley & Scotti, 2001).

McCabe (1999) found that half of the participants with disabilities in her study had no prior education on sexuality. It is quite evident that individuals with developmental disabilities have a palpable need for sexual knowledge in order to better meet their needs. According to Swango-Wilson (2009), sexuality education can reduce inappropriate sexual behaviors and minimize vulnerability to sexual abuse and exploitation. Brown and Pirtle (2008) reiterate this when they argue that sexuality education impacts every aspect of an individual’s life, regardless of whether they have a developmental disability or not.

Role of Support Person with Individuals with Developmental Disabilities

Individuals with developmental disabilities often seek assistance from parents, siblings, relatives, teachers, and care providers for their needs and care. The support person can be a professional and/or a family caregiver. Limitations in cognitive abilities leave individuals to rely on others for help with living, social, and financial needs (Petersilia, 2001). Support persons are also the main source of knowledge for individuals with developmental disabilities (Brown & Pirtle, 2008; Swango-Wilson, 2008). Caregivers’ roles in the lives of individuals with disabilities are to teach the difference between inappropriate and appropriate behaviors (e.g., personal space), and they can be essential during the developmental years of sexuality (Brown & Pirtle, 2008; Swango-
Wilson, 2008).

According to Walker-Hirsch (2007), family members are important as they can provide a reliable and safe source of information for individuals with disabilities, as long as they are approachable. However, it is evident that the discussion of sexuality is a difficult topic for parents and family members regardless of the child being disabled or not. Walker-Hirsch strongly advised parents to acknowledge and provide their child with accurate information about sex to enhance the quality of life for the individual. When family members are not the primary caregivers for individuals with developmental disabilities, they may turn to the support and guidance of staff when living in residential care.

Support persons are challenged with providing opportunities for sexual identity development and also to protect individuals with developmental disabilities. Service providers and caregivers are often faced with uncertainty in their rights and responsibilities to the sexuality of individuals they serve (McGuire & Bayley, 2011). Staff members often forget they are responsible “to” instead of responsible “for” the individuals they provide services to (Rowe, 2007). Research indicates that many support persons’ anxiety toward the discussion of sexuality is due to their minimal level of knowledge on the topic and uncertainty of their capabilities to present the information (Evans, McGuire, Healy, & Carley, 2009). Teachers and care providers are often faced with the dilemma of providing sex education to individuals with disabilities, but may be concerned it will conflict with family members’ attitudes and moral beliefs as well as societal norms (Brown & Pirtle, 1998).

Support persons have the power to make socio-sexual and reproductive decisions
that can impact the experiences that individuals with disabilities encounter (Stinson, Christian, & Dotson, 2002). The support person’s uncertainty of the consumer’s ability to consent to sexual decisions often powers them to make such decisions (Stinson et al., 2002; Wolfe, 1997). Hingsburger and Tough (2002) acknowledge that parental and agency power can hinder healthy sexual and relationship development. Denial of sexual acts and relationships can impact how individuals with disabilities respond to support persons when they are fearful of the consequences they receive from their support persons (Lesseliers & Van Hove, 2002).

Individuals with intellectual disabilities have conveyed visitation restrictions and reprimands they face when involved in appropriate sexual behaviors (Bernert, 2011; Lesseliers & Van Hove, 2002). Many individuals with intellectual disabilities express the lack of privacy they encounter when they seek out appropriate sexual opportunities (Lesseliers & Van Hove, 2002; McGuire & Bayley, 2011). Participants also acknowledge staff presence during intimate encounters, and they have discussed how social opportunities limit their ability to be expressive of their sexuality (Lesseliers & Van Hove, 2002). This results in many individuals feeling frustration and disappointment (Bernert, 2011; Grieve, McLaren, Lindsay, & Culling, 2008). Research indicates support persons’ attitudes towards sexuality and sexual expression can be reflected in the sexual attitudes and expression of individuals with developmental disabilities (Siebelink, Jong, Taal, & Roelvink, 2006).

**Support Persons’ Attitudes about Developmental Disabilities and Sexuality**

Family and professional caregivers are important components in the lives of individuals with developmental disabilities, and caregivers can provide an abundance of
support. However, support persons’ attitudes towards sexuality for individuals with developmental disabilities can hinder healthy sexuality development and can be differentiated based on their relationship with the consumer. For example, parents’ personal discomfort regarding sexuality often leads to avoidance of the discussion with their children (Lesseliers & Van Hove, 2002; Stinson, Christian, & Dotson, 2002). According to Lesseliers and Van Hove, parents of a child with a disability are more likely to avoid the discussion of sexuality, preventing the child with the disability from obtaining valuable and necessary information.

According to Lesseliers and Van Hove (2002), parents often are unable to see their child as an adult, setting limitations to their sexual development. Denekens (1992) argued that only a few parents found sexuality an important component to the development of their child with a developmental disability (cited in Lesseliers & Van Hove, 2002). Some caregivers will acknowledge that individuals with developmental disabilities have sexual needs, yet the caregivers’ actions tend not to support this view (Swango-Wilson, 2008).

Parents have much power over decisions about the individual’s sexuality and sexual reproduction (Stinson et al., 2002). McCarthy (1998) asked 15 women with intellectual disabilities regarding decisions about contraception and those involved in the decision-making. Fourteen out of the fifteen women noted that their doctor or parents made the decision on the type of contraception to use. Only one individual made the decision herself. One of the women was not even aware she had an IUD since this information was not shared.

Evans, McGuire, Healy, and Carly (2009) asked families and staff caregivers
about their involvement in decision making when it comes to relationships, and there were differences of opinion. Staff caregivers believed that consumers (79%), family (73%), and staff (70%) should be involved in the decision making of types of relationships appropriate for the individual with the disability. However, family caregivers believed a smaller proportion of staff (58%) and consumers (20%) should be involved in making relationship decisions (Evans et al., 2009). This reflects the differences in opinion and the decision power that families can have on the sexuality of individuals with disabilities. Evans et al. (2009) also found that staff caregivers were more likely to speak with consumers regarding sexuality compared to family members. Specifically, 53% of staff discussed sexuality in comparison to 29% of family caregivers. Both family and staff caregivers agreed that individuals with disabilities should be and are capable of engaging in friendships and non-intimate relationships. There were differences in opinion on the types of relationships individuals with intellectual disabilities should have. Specifically, a greater number of staff agreed that individuals with intellectual disabilities should have intimate relationships, compared with family caregivers who were less likely to believe their family member with intellectual disabilities should have an intimate relationship (Evans et al., 2009).

Other studies have also found that family caregivers are more likely to constrain sexual behaviors by individuals with developmental disabilities than other support persons. For example, McGuire and Bayley (2011) found four out of five parents showed a preference for low levels of intimacy in comparison with paid caregivers. One explanation for the difference is that parents of individuals with developmental disabilities may have more traditional attitudes regarding sexuality than support persons.
who chose to work in the field. In support of this explanation, Cuskelly and Bryde (2004) found that parents of children with intellectual disabilities held more conservative attitudes towards the sexuality of adults with intellectual disabilities compared to staff and a community sample.

Stinson et al. (2002) found that caregivers’ personal beliefs can dictate what information is provided in sex education for individuals with disabilities. For example, Swango-Wilson (2008) found that support persons’ attitudes interfere with the development of the individual’s sexual identity and intervene into sexual activities that the support person might not agree to be healthy (e.g., homosexual relations). Thus, more traditional and/or conservative attitudes might result in the development and expression of sexuality by individuals with developmental disabilities.

Individual characteristics of the support persons can also relate to sexuality attitudes. For example, Cuskelly and Bryde (2004) found that younger caregivers were more accepting than older caregivers of individuals with developmental disabilities engaging in sexual behaviors. Swango-Wilson (2008) also found a significant relationship between the age of the caregiver and the perception of sexual behavior for individuals with intellectual disabilities. Specifically, they found that younger caregivers were more accepting of sexual behaviors by individuals with intellectual disabilities than older caregivers.

Bazzo, Nota, Sores, Ferran, and Minnes (2007) surveyed social service providers on attitudes toward sexuality and individuals with intellectual disabilities. They found outpatient treatment centers were the most positive and liberal when asked about sexual rights compared with closed institutions and day centers. Furthermore, Grieve and
colleagues (2008) examined the differences in attitude among three types of care providers: small residential community setting, large nursing home, and in-patient hospital settings. Liberal attitudes about sexuality were more significant in community settings compared to nursing homes (Grieve et al., 2008). Care providers in nursing home settings held more conservative attitudes which can be related to the long-term care, level of disability, and experiences staff encounter (Grieve et al., 2008). This study found contradictory results in conservative attitudes among those with the highest level of training and education.

Findings from Wolfe (1997) demonstrated that teachers and special education administrators held more positive attitudes towards individuals with moderate disabilities compared to severe disabilities to engage in sexual behaviors. The majority of special education teachers and administrators encouraged sterilization as an option for severely disabled individuals (Wolfe, 1997).

**Gender, IQ, and Age in Relation to Consumers’ Sexual Knowledge**

Besides the support persons’ knowledge and attitude, it is likely that characteristics of the consumers can also influence their level of sexual knowledge. Specifically, three variables were examined as potential control variables: gender, IQ, and age.

**Gender.** Stinson and colleagues (2002) demonstrated that sexuality education materials presented to women with disabilities might be limited to what parents, caregivers, and professionals find of importance. This, however, can limit women with disabilities to make healthy sexuality decisions (Stinson et al., 2002). Negative attitudes can also influence how society views women with disabilities and sexuality and
contribute to how women experience and view themselves with having a disability and sexuality (Stinson et al., 2002). Women with developmental disabilities might be viewed with stereotypical attitudes that may limit their opportunities to explore sexuality and engage in sexual acts.

According to Stinson and colleagues (2002), stereotypical views can lead to ignoring or suppressing women’s sexual expression. One example might be the limited knowledge about masturbation that women with disabilities might have, leading to minimal experience in masturbation. Caregivers and support persons might also be quick to correct women that exhibit sexual acts in comparison with men with disabilities since societal views may find it more acceptable for men to engage in masturbation compared to women (Stinson et al., 2002). Lesseliers and Van Hove (2002) found only a few female participants with developmental disabilities knew what masturbation was, and many avoided the subject.

Women are also believed to have fewer sexual needs and experiences when compared with men, which are reflected from societal misconceptions (Konstantareas & Lunsky, 1997; Siebelink, 2006). In addition, parents and service providers can be distressed with the immense responsibilities they might endure with women with developmental disabilities and sexuality (e.g., pregnancy, sexually transmitted diseases), being more cautious of the information and opportunity permitted (Bernert, 2011). Given these differences, it is hypothesized that male consumers will have significantly more sexual knowledge than female consumers.

IQ. Intelligence quotient (IQ) is a label used to describe an individual’s level of intelligence. IQ can be measured with a variety of standardized assessments. IQ is often
used as an indicator of functioning level, with individuals who score under 70 being considered to have intellectual disabilities.

Individuals with higher IQ are more likely to have better understanding and comprehension of sexual knowledge. According to Wolfe (1997), teachers and administrative staff stated those with lower IQ’s should not engage in sexual behaviors. Thus, support persons are more likely to believe that individuals with lower IQ scores should be limited in their sexual experiences.

Also, those with lower IQ may be viewed as having less ability to give consent to sexual behavior. Uncertainty of consumer ability to consent to sexual decisions often leads support persons to make decisions for the consumer (Lesseliers & Van Hove, 2002; Stinson, Christian, & Dotson, 2002; Wolfe, 1997). Caregivers’ attitudes and beliefs based on individuals’ IQ can also determine the amount of opportunities the consumer has for sex education (Stinson et al., 2002). Given this rationale, it is hypothesized that consumers with higher IQ will have significantly more sexual knowledge than consumers with lower IQ.

**Age.** As individuals with developmental disabilities age they are more likely to have more experiences with sexual knowledge than younger individuals. Also, older individuals may be less likely to be restricted by caregivers and to have more opportunity for sexuality education. Based on this premises by the author, it is hypothesized that older consumers will have significantly more sexual knowledge than younger consumers.

**Overview of the Responsible Choices Program**

*Responsible Choices* for sexuality is a proactive, socio-educational human sexuality program targeted toward individuals with developmental disabilities (i.e.
consumers) funded by the state in which the program exists (Plunkett, Longmore, Neal, & Sanchez, 2002). The program is based on the belief that persons with developmental disabilities are sexual beings and deserve to be empowered with accurate knowledge and skills to assist them in their natural sexual development and to avoid victimization and perpetration (Plunkett et al., 2002). In addition, the Responsible Choices program provides family and support persons the knowledge to assist and guide the individual with developmental disability in relationship and sexuality development. For more information on the program, go to http://www.ejhs.org/volume5/plunkett/rc.html
CHAPTER III

METHODOLOGY

Procedures

Participation in the Responsible Choices Program was chosen by application. All applicants were given a pre-program assessment. Pre-program assessment consisted of a one-on-one interview with the Responsible Choices educator to determine if the applicant (i.e., consumer) was appropriate for the program based on the necessary documentation: (a) application, (b) individual’s and/or family’s request and specific need for the training, (c) reason for referral, (d) adaptive functioning, (e) intellectual functioning, (f) behavior support plan/behavior strategy, (g) sexual history, (h) knowledge base pre-test, (i) participation and confidentiality agreement, and (j) informed consent and information release agreement (Plunkett, Longmore, Neal, & Sanchez, 2002). The pre-program assessment allowed the educator to place the consumer in appropriate groups based on: (1) sexual knowledge, (2) sexual experience, and (3) level of development. The pre-program assessment was orally administered (1-3 hours) to consumers prior to the program. Presenters were Responsible Choices educators who received extensive training in sexuality education and who had extensive background working with individuals with developmental disabilities.

Consumers’ participation in the program was also determined by the participation of a support person. The support persons were given a paper/pencil survey prior to a four-hour orientation. Orientation covered the information to be covered with the consumer and the role of the support person when promoting the positive sexual development of his/her consumer. Both support person and consumer turned in written consents to
participate.

The data collected were entered into a database by trained Responsible Choices staff as well as researchers from two different universities (California State University Northridge and Oklahoma State University). Data were spot-checked for accuracy. Data for this thesis were retrieved from archival data without any identifying information and included the pretest from both the support person and consumer.

Sample

Two hundred and seventy one (271) consumers (46.7% female and 53.3% male) volunteered to participate in the program and research. Consumers ranged in age from 18-68 years (mean age = 35.5 years, standard deviation = 11.2). Consumers’ IQ ranged from 20-97, with a mean average of 54.4 ($SD = 15$). The racial/ethnic background of the consumers follow: 83.3% White, 7.0% American Indian, 7.9% African American, .9% Hispanic, .4% Asian, and .4% other.

All consumers selected a support person to accompany them to the program. The support person’s relationship to the consumer was categorized into three categories: (1) 12.2% independent living, (2) 71.2% supported living, and (3) 16.6% family member. No other demographic information was collected on the support person.

Measurement

Demographic characteristics of the consumers were measured with standard items on the consumers’ sexual knowledge survey. The other measures used in the study are outlined below.

Support Person Survey

Support persons (i.e., staff or family caregiver) were given a 20-item, True/False,
questionnaire in regards to their knowledge of sexuality and disabilities (see Appendix 1). The questionnaire was administered before the Responsible Choices program.

Items on the questionnaire covered common misconceptions of sexuality and individuals with developmental disabilities. Items were coded “0” for an incorrect response, and a “1” was given for a correct response. A total score was computed by summing the items. Thus, higher scores indicated more knowledge of sexuality and disabilities by the support persons.

**Consumer Sexuality Survey**

Consumers were given a survey by Responsible Choices educators prior to the start of the program (see Appendix 2). The educator presented the questionnaire in various formats based on the individual’s limitations and strengths. The different methods included: oral, sign language, visual methods, or a combination of these methods. The survey consists of 49 questions and items were coded “0” for an incorrect response and a “1” for a correct response. The sexual knowledge of individuals with developmental disabilities were divided into the following nine subscales: (1) personal care, (2) social etiquette, (3) expressing feelings in relationships, (4) safety awareness, (5) individual sexual expression, (6) dating, (7) sexual expression in a relationship, (8) illegal sexual acts, and (9) pregnancy & sexual diseases. The number of correct and incorrect responses for each subscale was recorded.

The pretest survey was developed (1) as part of the assessment of participants, (2) to assess the knowledge of consumers at the pre-test so the program trainer can customize the training session to the needs of the consumers, (3) as a way to make individual placements into the appropriate groups (based on sexual knowledge, sexual experience,
and developmental level) and (4) to determine if significant increases in knowledge occurred from pretest to posttest (Plunkett et al., 2002). However, only data from the pretest were included in this study to assess knowledge of the support persons and consumers prior to any treatment, and to determine whether support persons’ knowledge, living arrangement, gender, IQ, and age were significantly related to the sexual knowledge of the individual with developmental disabilities.
CHAPTER IV
RESULTS

All analyses were conducted using SPSS 19.0 for Macintosh.

Bivariate Correlations

Bivariate correlations (i.e., Pearson correlations) were conducted to examine the direction and the strength of the relationship between variables. The bivariate correlations between all variables are reported in Table 1.

Table 1
Bivariate Correlations

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>11</th>
</tr>
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<tr>
<td>1. Support persons’ knowledge</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Consumers’ Knowledge</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
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<td>2. Sexual knowledge total</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Personal care</td>
<td>.07</td>
<td>.79**</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Social etiquette</td>
<td>.12*</td>
<td>.67**</td>
<td>.46**</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Expressing feelings in relationships</td>
<td>.19**</td>
<td>.86**</td>
<td>.56**</td>
<td>.65**</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Safety awareness</td>
<td>.19**</td>
<td>.56**</td>
<td>.33**</td>
<td>.35**</td>
<td>.51**</td>
<td>1</td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Individual sexual expression</td>
<td>.12*</td>
<td>.71**</td>
<td>.54**</td>
<td>.45**</td>
<td>.53**</td>
<td>.22**</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Dating</td>
<td>.12*</td>
<td>.76**</td>
<td>.48**</td>
<td>.41**</td>
<td>.64**</td>
<td>.31**</td>
<td>.53**</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>9. Sexual expression in a relationship</td>
<td>.15*</td>
<td>.70**</td>
<td>.41**</td>
<td>.42**</td>
<td>.59**</td>
<td>.45**</td>
<td>.39**</td>
<td>.53**</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Illegal sexual acts</td>
<td>.18**</td>
<td>.70**</td>
<td>.41**</td>
<td>.42**</td>
<td>.54**</td>
<td>.35**</td>
<td>.48**</td>
<td>.48**</td>
<td>.49**</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>11. Pregnancy and sexual diseases</td>
<td>.12*</td>
<td>.86**</td>
<td>.57**</td>
<td>.46**</td>
<td>.65**</td>
<td>.41**</td>
<td>.57**</td>
<td>.61**</td>
<td>.58**</td>
<td>.62**</td>
<td>1</td>
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<td>Control Variables</td>
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<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. Age of consumer</td>
<td>-.02</td>
<td>-.12*</td>
<td>-.04</td>
<td>-.11</td>
<td>-.14*</td>
<td>.01</td>
<td>-.12*</td>
<td>-.17**</td>
<td>-.19**</td>
<td>-.09</td>
<td>-.14*</td>
</tr>
<tr>
<td>13. IQ of consumer</td>
<td>.16*</td>
<td>.53**</td>
<td>.42**</td>
<td>.31**</td>
<td>.41**</td>
<td>.42**</td>
<td>.34**</td>
<td>.42**</td>
<td>.46**</td>
<td>.34**</td>
<td>.47**</td>
</tr>
<tr>
<td>14. Gender of consumer\textsuperscript{1}</td>
<td>.03</td>
<td>.02</td>
<td>-.02</td>
<td>-.01</td>
<td>.10</td>
<td>.13*</td>
<td>-.23**</td>
<td>.03</td>
<td>.05</td>
<td>.08</td>
<td>.03</td>
</tr>
</tbody>
</table>

\textsuperscript{1}males = 0, females = 1

**p < .05, **p < .01.

Correlations between Support Persons’ Knowledge and Consumers’ Sexual Knowledge

Support persons’ knowledge was significantly and positively related to overall consumers’ knowledge ($r = .17, p = .005$), social etiquette ($r = .12, p = .034$), expressing feelings in relationships ($r = .19, p = .002$), safety awareness ($r = .19, p = .002$),
individual sexual expression ($r = .12, p = .047$), dating ($r = .12, p = .045$), sexual expression in a relationship ($r = .15, p = .017$), illegal sexual acts ($r = .18, p = .006$), and pregnancy and sexual diseases ($r = .12, p = .047$). Support persons’ knowledge was not significantly related to personal care ($r = .07, p = .150$).

**Correlations between Potential Control Variables and Consumers’ Sexual Knowledge**

First, age of the consumer was examined in relation to the consumers’ sexual knowledge. The correlations indicated that age of the consumers was significantly and negatively correlated to consumers’ overall knowledge ($r = -.12, p = .033$), expressing feelings in relationships ($r = -.14, p = .014$), individual sexual expression ($r = -.12, p = .049$), dating ($r = -.17, p = .010$), sexual expression in a relationship ($r = -.19, p = .005$), and pregnancy and sexual diseases ($r = -.14, p = .032$). Thus, younger individuals had significantly more sexual knowledge in those areas than older individuals. Age was not significantly related to consumers’ personal care ($r = -.04, p = .270$), social etiquette ($r = -.11, p = .055$), safety awareness ($r = .01, p = .442$), and illegal sexual acts ($r = -.09, p = .102$).

The bivariate correlations indicated that consumer’s IQ was significantly and positively related to consumers’ total knowledge ($r = -.53, p < .001$) and each of the subscales ($r$ values ranged from .31 to .47, $p < .001$). Thus, the higher the IQ, the more sexual knowledge the consumer had.

The bivariate correlations indicated that male consumers had significantly higher knowledge about individual sexual expression ($r = -.24, p < .001$) and illegal sexual acts ($r = .13, p = .027$). No other significant correlations were found with gender of the
consumer.

Since the control variables were significantly related to consumers’ sexual knowledge, they were included in subsequent analyses as control variables (described in ANCOVAs below).

**ANOVA**s and **ANCOVA**s

**ANOVA**s Comparing Three Living Situations on Consumers’ Sexual Knowledge

One-way ANOVAs were conducted to examine whether there were significant differences between the three living arrangements (i.e., independent living, supported living, and family member) on the consumers’ level of sexual knowledge total and the various subscales. As shown in Table 2, significant differences were found between the three living arrangements on sexual knowledge total and all of the subscales except for ‘dating’.

Table 2: Results of ANOVAs Comparing Living Arrangement on Level of Sexual Knowledge

<table>
<thead>
<tr>
<th></th>
<th>Independent Living</th>
<th>Supported Living</th>
<th>Family Member</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
<td>M</td>
</tr>
<tr>
<td>Sexual knowledge total</td>
<td>61.8&lt;sup&gt;a&lt;/sup&gt;</td>
<td>12.8</td>
<td>45.3&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td>Personal care</td>
<td>18.9&lt;sup&gt;a&lt;/sup&gt;</td>
<td>3.1</td>
<td>16.4&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td>Social etiquette</td>
<td>1.6&lt;sup&gt;b&lt;/sup&gt;</td>
<td>1.0</td>
<td>1.1</td>
</tr>
<tr>
<td>Expressing feelings in relationships</td>
<td>11.6&lt;sup&gt;a&lt;/sup&gt;</td>
<td>3.9</td>
<td>8.2&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td>Safety awareness</td>
<td>3.7&lt;sup&gt;b&lt;/sup&gt;</td>
<td>1.7</td>
<td>2.4&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td>Individual sexual expression</td>
<td>3.2&lt;sup&gt;b&lt;/sup&gt;</td>
<td>2.0</td>
<td>2.4</td>
</tr>
<tr>
<td>Dating</td>
<td>4.3</td>
<td>1.7</td>
<td>3.3</td>
</tr>
<tr>
<td>Sexual expression in a relationship</td>
<td>3.1&lt;sup&gt;b&lt;/sup&gt;</td>
<td>1.2</td>
<td>2.0&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td>Illegal sexual acts</td>
<td>5.6&lt;sup&gt;a&lt;/sup&gt;</td>
<td>1.5</td>
<td>4.1&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td>Pregnancy and sexual diseases</td>
<td>9.5&lt;sup&gt;b&lt;/sup&gt;</td>
<td>3.7</td>
<td>6.0&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
</tbody>
</table>

Note: Superscripts of the same letter in the same row indicate significant differences (p<.05) in the Tukey post hoc analyses. *p<.05, **p<.01, ***p<.001.

Tukey’s post hoc analyses indicated that consumers living in independent living situations, in comparison to supported living, had higher sexual knowledge total, personal care, expressing feelings in a relationship, safety awareness, sexual expression in a relationship, illegal sexual acts, pregnancy and sexual diseases. Also, consumers living in
independent living situations, in comparison to living with a family member, had higher sexual knowledge total, and social etiquette, expressing feelings in relationships, safety awareness, individual sexual expression, sexual expression in a relationship, illegal sexual acts, and pregnancy and sexual diseases.

**ANCOVAs Comparing Three Living Situations on Consumers’ Sexual Knowledge**

**Controlling for Age, IQ, and Gender**

Next, ANCOVAs were conducted to examine whether there were significant differences between the three living arrangements on the consumers’ level of sexual knowledge after controlling for the consumers’ IQ. As shown in Table 2, IQ was significantly related to the consumers’ knowledge total and each of the subscales. The F values for differences between the living arrangements substantially decreased after controlling for IQ. In four of the subscales, the F value was no longer significant.

Table 3  
*Results of ANCOVAs Comparing Living Arrangement on Level of Sexual Knowledge after controlling for Consumer IQ, Age, and Gender.*

<table>
<thead>
<tr>
<th>Support Person Knowledge</th>
<th>LA</th>
<th>IQ</th>
<th>LA</th>
<th>Age</th>
<th>LA</th>
<th>Gender</th>
<th>LA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sexual knowledge total</td>
<td>8.1*</td>
<td>10.4***</td>
<td>69.5***</td>
<td>4.4*</td>
<td>4.2*</td>
<td>13.2***</td>
<td>.1</td>
</tr>
<tr>
<td>Personal care</td>
<td>1.3</td>
<td>4.0*</td>
<td>41.2***</td>
<td>.3</td>
<td>.4</td>
<td>4.5*</td>
<td>.8</td>
</tr>
<tr>
<td>Social etiquette</td>
<td>2.6</td>
<td>3.6*</td>
<td>18.5***</td>
<td>1.9</td>
<td>4.7*</td>
<td>6.0**</td>
<td>.0</td>
</tr>
<tr>
<td>Expressing feelings in relationships</td>
<td>9.6**</td>
<td>6.6**</td>
<td>33.5***</td>
<td>2.5</td>
<td>5.4*</td>
<td>8.4***</td>
<td>2.1</td>
</tr>
<tr>
<td>Safety awareness</td>
<td>9.2**</td>
<td>9.3***</td>
<td>34.9***</td>
<td>4.1*</td>
<td>.1</td>
<td>12.0***</td>
<td>.5</td>
</tr>
<tr>
<td>Individual sexual expression</td>
<td>3.2</td>
<td>3.2*</td>
<td>18.5***</td>
<td>1.6</td>
<td>5.0*</td>
<td>4.6*</td>
<td>10.9***</td>
</tr>
<tr>
<td>Dating</td>
<td>4.5*</td>
<td>2.4</td>
<td>34.9***</td>
<td>2.2</td>
<td>4.3*</td>
<td>2.6</td>
<td>.1</td>
</tr>
<tr>
<td>Sexual expression in a relationship</td>
<td>4.7*</td>
<td>7.2***</td>
<td>42.5***</td>
<td>3.8*</td>
<td>7.9**</td>
<td>9.7***</td>
<td>.1</td>
</tr>
<tr>
<td>Illegal sexual acts</td>
<td>7.9**</td>
<td>5.1**</td>
<td>17.6***</td>
<td>3.2*</td>
<td>2.1</td>
<td>6.5**</td>
<td>.9</td>
</tr>
<tr>
<td>Pregnancy and sexual diseases</td>
<td>3.2</td>
<td>8.3***</td>
<td>35.6***</td>
<td>5.5*</td>
<td>5.5</td>
<td>12.2***</td>
<td>.0</td>
</tr>
</tbody>
</table>

*CV = covariate in the ANCOVA, LA = living arrangement
*p<.05, **p< .01, ***p< .001.

Next, ANCOVAs were conducted to examine whether there were significant differences between the three living arrangements on the consumers’ level of sexual knowledge after controlling for the consumers’ age. As shown in Table 2, the consumers’
age was significant in relation to total sexual knowledge and six of the subscales.
However, age did not impact substantially the significant differences between living
arrangements on the sexual knowledge.

Next, ANCOVAs were conducted to examine whether there were significant
differences between the three living arrangements on the consumers’ level of sexual
knowledge after controlling for the consumers’ gender. No significant interactions
between gender and living arrangement were found (not shown in the table). As shown in
Table 2, only one gender difference was found. Specifically, male consumers had
significantly higher knowledge about individual sexual expression than females.
Controlling for gender did not seem to significantly impact the differences between living
arrangements on level of sexual knowledge.
CHAPTER V
DISCUSSION

Summary of Findings

The purpose of this study was to examine the relation between the support persons’ overall knowledge of sexuality and developmental disabilities in relation to the sexual knowledge of the individual with developmental disabilities (i.e., consumer). The findings suggest that support persons’ knowledge is significantly related to consumer’s overall sexual knowledge. The age of the consumer was significantly and negatively correlated to the consumers’ overall sexual knowledge and many of the subscales. Consumer’s IQ was significantly and positively correlated to the consumers’ total knowledge and each of the subscales. There were consumer gender differences with two sexual knowledge subscales: individual sexual expression and illegal sexual acts with males surpassing females. The differences found between the three living arrangements of consumers indicated that consumers living in independent living situations in comparison with those who lived in supported living and with family members, had higher overall sexual knowledge. When IQ was included in the models, the differences between the three living arrangements on the consumers’ sexual knowledge was diminished. Age and gender did not seem to greatly impact the differences between living arrangement and consumers’ sexual knowledge.

Discussion of the Findings

The significant relation found between the support persons’ knowledge and consumers’ sexual knowledge suggests how influential the support person can be in the sexual knowledge of the consumer. As Walker-Hirsch (2007) states, support persons are
known to be the direct source of knowledge for individuals with developmental
disabilities. Since information can be construed and misinterpreted for individuals with
developmental disabilities by social media and individuals in their lives, the support
person should be the one providing accurate information. According to Stinson et al.
(2002), support persons’ attitudes and beliefs can also influence the amount of knowledge
provided to the consumer.

The results also indicate that consumers who resided in independent living
situations had higher sexual knowledge than those living in other settings (supported
living, family home). Similar to past research, those that live in independent living
arrangements would be more likely to have more sexual knowledge than family settings
(Timmers, Du Charme, & Jacob, 1981). Given the opportunity to explore one’s sexuality,
individuals with developmental disabilities living independently have more freedom to
make independent decisions and experience sexuality compared to those in controlled
residential facilities (e.g., supported living) or with family members.

Hingsburger and Tough (2002) recognize individuals with developmental
disabilities living in residential facilities or group settings had lack of privacy and the
inability to engage in healthy appropriate sexual behaviors. Similarly, individuals with
developmental disabilities express lack of privacy in residential facilities since staff
members were always present and consumers were reprimanded for any appropriate
sexual expression (Bernert, 2011; Lesseliers & Van Hove, 2002). Residential facilities set
contradictory policies such as sexual acts are acceptable in private domains (i.e.,
bedroom), however when consumers have a roommate, the bedroom is defined as a
public domain (Hingsburger & Tough, 2002). This sheds light on agencies that set
policies that support appropriate sexual expression yet circumstances make it impossible for consumers to engage in sexual acts in private.

Evans and colleagues (2009) examined the differences in attitude among staff and family caregivers related to sexuality and individuals with intellectual disabilities. Staff members in supported living or residential facilities were more likely to have positive attitudes and agreed that individuals with intellectual disabilities should have intimate relationships compared to the opinions of family caregivers. Further, studies demonstrate that those staff with more training in sexuality are more likely to hold positive attitudes compared to support staff with minimal or no training (Grieve et al., 2008; McGuire & Bayley, 2011). Cuskelly and Bryde (2004) found parents to have conservative opinions when it came to sexuality and intellectual disabilities, thus limiting the knowledge and opportunity for consumers.

Also, parents’ level of comfort with the topic of sexuality can be different than their children’s due to generational gaps (Lesseliers & Hove, 2002). Walker-Hirsch (2007) sheds light on the hesitation parents have on sex education for their children and the added pressure of having a child with a disability. Parents might not realize how sexuality is an essential part of human development and individuals with developmental disabilities have the same needs as others.

In this thesis research, the IQ of the consumer also influenced the amount of information consumers’ can comprehend related to sexual knowledge. When IQ was included in the ANCOVAs, the differences in sexual knowledge of consumers living in three different living situations diminished. This may be because consumers with higher IQs would most likely reside in independent living situations. Thus, it is possible that part
of the difference between the three living situations is actually due to the IQ of the consumers. More research should examine whether this finding holds true in other studies.

Age was significantly and negatively related to sexual knowledge, but did not influence the overall ANOVA results when comparing the different residential settings. Specifically, younger individuals actually had more sexual knowledge than older individuals. This may be because younger individuals may have caregivers who are more liberal or knowledgeable about sexuality and disabilities. Also, older individuals may have lived in times when caregivers and society had much more narrow views of sexuality for individuals with developmental disabilities. Thus, their opportunities for sexual activities and education may have been constrained.

Consistent with previous research (Bernert, 2011; Lesseliers & Van Hove, 2002; Stinson et al., 2002), there were some significant differences in gender and sexual knowledge. Specifically, male consumers had significantly more knowledge about individual sexual expression and illegal sexual acts than female consumers. Cultural gender roles may lead women with disabilities to have decreased opportunities for sexual behaviors and to have fewer opportunities for discussions about sexual matters. Caregivers may ignore or suppress female consumers and not allow them to engage in sexual acts (Stinson et al., 2002). Societal misconceptions about women having fewer sexual needs may result in less attention to the sexuality education for women with a disability (Konstantareas & Lunsky, 1997; Siebelink, 2006). Thus, women may have less sexual knowledge.
Limitations

This thesis will add to the understanding of support persons’ sexual knowledge and the sexual knowledge of individuals with developmental disabilities, however, certain limitations to the study exist. Although the support persons and consumers in this study provided important information on their sexual knowledge, it is limited to the individuals that chose to participate in the Responsible Choices program. This study was based on voluntary participation that may have been limited to those support persons with more liberal views and positive attitudes on sexuality and disability. The sample was taken from the Oklahoma Health Care Authority and Developmental Disabilities Services Division, which can limit the generalizability to another state and/or to individuals who are not part of the agencies.

Also, the data were collected using self-report questionnaires for support persons and interviews for the consumers. It is assumed the consumers in this study understood the questions and answered to their best knowledge. Hingsburger and Tough (2002) suggest the inconsistency in assessment testing on sexual knowledge for individuals with a disability. One example is when the participant is given four picture choices (i.e. workplace, a park, a bedroom, and a bathroom) and asked to point to the picture that is the “appropriate place to have sex”, participants point to a picture of park, instead of bedroom. Participants are then marked incorrect, not taking to account the “real-world conditions” individuals with disabilities encounter (Hingsburger & Tough, 2002). Specifically, individuals with disabilities might be reprimanded if caught having sexual relations in the bedroom which leads them to resort to other areas (e.g., the park) to engage in sexual acts. It is important to make note of the assessment tools used when
studying sexuality and the circumstances individuals with developmental disabilities are faced with. In addition, the support person provided consumer IQ scores during the application process. There could be different ways in which consumer IQ was determined since support person reported this information and IQ was not measured. Further studies may want to assess IQ to ensure consistency in the variable.

Another limitation is that gender of the support person in relation to gender of the consumer was not compared. It is possible that same sex gendered relations (e.g., female primary caregiver and female primary consumer) may have more sexual knowledge transmission than cross-gendered relations (e.g., male primary caregiver and female primary consumer). Thus, future studies may want to consider this dynamic in relation to the transmission of sexual knowledge from support person to consumer.

**Implications**

Support persons’ role in the development of consumers’ sexual knowledge is essential to the quality of life for individuals with developmental disabilities. Past research demonstrates individuals with developmental disabilities find sexuality to be of importance and engage in sexual activity with or without sexual knowledge (Siebelink, 2002; Walker-Hirsch, 2007). Support persons’ attitudes and accurate information can influence the amount of accurate sexual knowledge the individual with developmental disability obtains. To ensure support persons are a positive influence on the development of sexual knowledge for consumers, there are many ways to improve the relation between the support persons’ attitudes and knowledge of sexuality and disability. For example, increasing positive attitudes regarding sexuality can be possible with education for support persons (Swango-Wilson, 2008). Support persons with training in sexuality are
known to have more positive attitudes compared to those without training. This can be true for both family and supported staff caregivers. Grieve, McLaren, Lindsay, and Culling (2008) found that among support staff, there were differences in attitudes based on age, experience, and training. Some professional support persons might feel responsible ‘for’ the consumers they work with instead of feeling responsible ‘to’ the consumers (Rowe, 2007). Providing support persons across various services and living conditions (e.g., family members, staff, service provider agencies) with opportunities to have open discussions to guide the change of perception on sexuality and individuals with developmental disabilities is the beginning.

Sex education for individuals with developmental disabilities can enhance their knowledge of sexuality. Sex education can also reduce inappropriate sexual behaviors that can minimize the occurrences of abuse and being labeled as a perpetrator (Swango-Wilson, 2011). Evaluation of various sexuality education programs and combining the best approaches will allow for more effective sexuality education for individuals with developmental disabilities. Providing on-going sexuality education beyond high school is important for adults with disabilities with minimal sexuality education. According to Abbott, Howarth, and Glyde (2005), sexuality education is not provided to individuals with developmental disabilities unless it’s requested or as a prevention strategy after an inappropriate sexual act (cited in Hamilton, 2009). Most importantly, promoting self-advocacy can empower individuals with developmental disabilities to make positive sexuality decisions (Hingsburger & Tough, 2002; Swango-Wilson, 2011).

In addition, living arrangements can influence the development of sexual knowledge and experiences. Those consumers living independently were among the ones
with highest level of sexual knowledge. This can be due to IQ and age. Thus, programs should be tailored to consumers of different age groups and IQ. Given that male consumers had more knowledge in some areas; programs may need to specifically target female consumers.

Even so, the support persons’ liberal attitude on sexual knowledge can have influenced the development of independence. Past research demonstrates the need for more concise rules and policies regarding sexuality in residential facilities (Hingsburger & Tough, 2002; Rowe, 2007). Both individuals with developmental disabilities and staff have been found to be unclear of what behaviors are acceptable in residential facilities and sexuality (Grieve, McLaren, Lindsay, & Culling, 2008). Staff are uncertain whether to encourage sexual activity for the consumers they serve or abide to parental request to not provide sexual activity (Stinson et al., 2002). By setting sexuality policies, residential facilities and support persons can reduce inappropriate sexual acts by providing a safe place for individuals with developmental disabilities to engage in sex. Sexuality policies will set clear understanding for consumers, staff, parents, and family members as to what will be permitted in residential facilities.

**Conclusion**

The purpose of this study was to examine the relation between the support person’s sexual knowledge in comparison to the consumers for whom they support. Being the main source of information support (e.g., sexuality information), support persons are essential to all aspects of daily living and knowledge source for individuals with developmental disabilities. Victimization and being labeled as perpetrator can result in many challenges for individuals with developmental disabilities and sexual knowledge
can minimize the incidents of being abused.

Support persons’ sexual knowledge was significantly correlated with consumer’s overall sexual knowledge. Those living in independent living arrangements were more likely to have higher sexual knowledge in comparison with those consumers living in residential or with family. Sexuality education and support person’s attitudes can influence the amount of information provided to individuals with developmental disabilities and the ability to make healthy sexual choices.
REFERENCES


Leutar, Z., & Mihokovic, M. (2007). Level of knowledge about sexuality of people with


Available at http://www.ejhs.org/volume5/plunkett/titlepage.html


APPENDIX

MEASURES USED IN THE THESIS
SEXUALITY AND DISABILITY SUPPORT PERSON’S KNOWLEDGE SURVEY

Mark each of the following questions True (T) or False (F):

_____ 1. Heredity is the leading cause of mental retardation.

_____ 2. In general, the more seriously disabled a person is, the less he or she will seek intimate relations with others.

_____ 3. Most developmentally disabled adults living in the U.S. suffer from loneliness and depression.

_____ 4. Masturbation to orgasm has been known to decrease behaviors such as head banging and physical aggression of low functioning individuals.

_____ 5. The more disabled a person is the lower his/her sex drive.

_____ 6. The onset of puberty is delayed for individuals with developmental disabilities.

_____ 7. Most developmentally disabled couples who are sexually active suffer from some form of sexual dysfunction.

_____ 8. Individuals with disabilities generally have higher sex drives than non-disabled individuals.

_____ 9. The divorce rate for disabled couples is higher than it is for non-disabled couples.

_____ 10. A female with Down’s Syndrome is almost certain to give birth to Down’s Syndrome children.

_____ 11. Most parents of children with developmental disabilities are in favor of schools offering sexuality information to their children.

_____ 12. People with developmental disabilities do not desire as much physical touch as does a non-disabled person.

_____ 13. Preventing pregnancy and sexually transmitted diseases should be the primary focus when providing sexuality education to individuals with developmental disabilities.

_____ 14. A person who receives sexuality education usually becomes more sexually active.

_____ 15. Individuals with developmental disabilities and individuals without disabilities are equally likely to be sexually violated.

_____ 16. Limiting a person’s opportunities for privacy will help reduce sexual behavior.

_____ 17. Individuals with developmental disabilities are able to love and care at the same emotional depth as non-disabled people.

_____ 18. Most individuals with developmental disabilities like themselves and believe that they have something to offer to others.

_____ 19. A male child has his first erection around age three.

_____ 20. Generally, victims of sexual abuse are abused by people that they know.
RESPONSIBLE CHOICES FOR SEXUALITY© – KNOWLEDGE BASE PRE-TEST (V-3)

Pre-Test Date: ____________ Score: ____________ Examiner: ____________________________

SESSION 1 – PERSONAL CARE

_____ 1. Identify location of “private” body parts of male
   □ penis   □ butt   □ IR________________________

_____ 2. Identify location of “private” body parts of female
   □ vagina  □ breast  □ butt  □ IR________________________

_____ 3. Identify proper name of “private” body parts of male
   □ penis   □ butt

_____ 4. Identify proper name of “private” body parts of female
   □ vagina  □ breast  □ butt

_____ 5. Identify appropriate tasks performed during daily hygiene
   □ brush teeth □ comb hair  □ shower  □ wash hair  □ wear deodorant □ shave  □ IR________________________

_____ 6. Identify the first and last body part to clean when bathing
   □ face/hair  □ butt

_____ Personal Care Total (18)

Female Participants Only:

_____ 7. Identify appropriate sanitary products used during menstrual cycle
   □ tampon □ pad  □ IR________________________

_____ 8. Identify how often to change sanitary products
   □ every time you go to the bathroom or when you see blood on the pad

_____ 9. Identify the appropriate direction for wiping
   □ front to back

_____ 10. Identify procedures of a routine gynecological exam
   □ internal vaginal □ breast

_____ 11. Identify two prerequisites of receiving a gynecological exam
   □ gloves □ nurse  □ IR________________________

_____ Female Care Total (8)

Male Participants Only:

_____ 7. Identify form of own penis
   □ circumcised or □ uncircumcised

_____ 8. Identify appropriate method of cleaning own penis
   □ Yes

_____ 9. Identify appropriate hygiene procedure for urinating
   □ lift lid □ flush  □ wash hands

_____ 10. Identify procedures of a routine male physical exam
   □ scrotum □ rectum

_____ 11. Identify the prerequisite of receiving a routine male physical exam
   □ gloves □ IR________________________
SESSION 2 – SOCIAL ETIQUETTE

12. Identify some things you can do to help you look good
   □ posture  □ clothing  □ manners  □ eating  □ IR_______________________

13. Identify some behaviors that would be rude to do in front of other people
   □ body fluids & germs  □ touching self  □ gas  □ IR_______________________

Etiquette Total (7)

SESSIONS 3 & 4 – EXPRESSING FEELINGS IN RELATIONSHIPS

14. Identify feelings of others
   □ happy  □ sad  □ scared  □ mad

15. Identify things that show self-respect
   □ appearance  □ behavior  □ activities  □ IR_______________________

16. Identify different types of families
   □ birth  □ adopt  □ foster  □ step-family

17. Identify appropriate behaviors to express feelings for family
   □ hug  □ kiss  □ shake hands  □ acts of kindness  □ tell them  □ IR_______________________

18. Identify things that describe a friend
   □ do things  □ known for long time  □ talk/ trust  □ help  □ IR_______________________

19. Identify appropriate behaviors to express feelings for friends
   □ hug  □ kiss  □ tell them  □ acts of kindness  □ IR_______________________

20. Identify professional helpers
    □ case manager  □ professional service  □ staff  □ IR_______________________

21. Identify appropriate behavior to express feelings for professional helpers
    □ shake hands  □ side hug  □ tell them  □ IR_______________________

22. Identify acquaintances
    □ neighbor  □ coworker  □ boss  □ community helpers  □ IR_______________________

23. Identify appropriate behavior to express feelings for acquaintances
    □ shake hands  □ IR_______________________

Expressing Feelings in Relationships Total (35)

SESSION 5 – SAFETY AWARENESS

24. Identify who is a stranger
    □ someone you don’t know

25. Identify appropriate behavior toward unfamiliar children
    □ wave  □ hello  □ IR_______________________

26. Identify appropriate behavior toward unfamiliar adults
    □ wave  □ hello  □ IR_______________________

27. Identify response to abusive situations
SESSION 6 – INDIVIDUAL SEXUAL EXPRESSION

28. Identify responses to romantic feelings
   □ psychological  □ physiological

29. Identify appropriate response to romantic feelings in public
   □ make them go away  □ IR________________________

30. Identify individual sexual expression choices
   □ abstinence  □ masturbation

31. Identify responsibilities of masturbators
   □ private  □ safe  □ hygiene

Individual Sexual Expression Total (8)

SESSION 7 & 8 – Dating

32. Identify positive attributes in a potential partner

   □ □ □

   □ IR________________________

33. Identify safe place to meet someone
   □ friend  □ party  □ work  □ church  □ IR________________________

34. Identify details involved in planning dates
   □ day  □ where  □ money  □ transportation  □ time

Dating Total (12)

SESSION 9 – SEXUAL expression in a RELATIONSHIP

35. Identify ways to build a positive relationship
   □ activities  □ acts of kindness  □ time apart  □
   □ communication  □ IR________________________

36. Identify public progressive intimacy levels
   □ yes

37. Identify private progressive intimacy levels
   □ yes

38. Identify who in a relationship decides how sexual feelings are expressed
   □ both individuals

39. Identify response to one person saying “no” to a level of intimacy
   □ stop

Sexual Expression in a Relationship Total (8)

SESSION 10 – Illegal Sexual Acts

40. Identify illegal sexual acts
Illegal Sexual Acts Total (8)

SEXUATIONS 11 & 12 – PREGNANCY AND SEXUAL DISEASES

41. Identify conception process
   - penis in vagina

42. Identify proper name of penis-vagina penetration
   - intercourse

43. Identify methods of birth control
   - condom
   - oral contraceptive

44. Identify how each birth control method is used
   - penis
   - female oral

45. Identify how often a condom should be used
   - every act of intercourse

46. Identify how many times the same condom should be used
   - one time

47. Identify potential consequences of having sexual intercourse
   - pregnancy
   - HIV/std

48. Identify HIV modes of transmission
   - blood
   - sex

49. Identify proper HIV/std prevention
   - condom

Pregnancy & STD Total (13)

PRE-TEST TOTAL (125)

DEMOGRAPHICS

Age

IQ

Gender
0. Male 1. Female

Race

Current Living Situation
0. Independent 1. Companion 2. Supported 3. Family Home

Past Residential Institution
0. Yes 1. No

Program Schedule
0. Biweekly 1. Weekly

Session 10 & Post-test Time