AUTISM AND SEXUALITY:
SELF ADVOCATES FOCUS GROUPS

A Thesis in
Special Education
by
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Abstract: Thirteen individuals who identified themselves as having ASD participated individually or in focus groups to ascertain their ideas about sexuality. Participants were asked to complete a questionnaire related to what types of socio-sexuality topics should be taught to students with ASD in schools. Themes from the focus groups/interviews were coded. Results showed that self-advocates spoke about significance of sex education as well as issues related to the content, delivery and instruction and the presenter. Themes included the need for communication and educational curriculum that emphasized dating and how to handle sexual harassment and intimidation. This study showed the importance of sexuality education for individuals with ASD to increase their knowledge and quality of life.

Key words: sexuality, advocacy, sexuality curriculum and sex education
# TABLE OF CONTENTS

List of Tables........................................................................................................pg. vi

Chapter 1. INTRODUCTION.................................................................................pg. 1
Chapter 2: LITERATURE REVIEW.................................................................pg. 6
  Individuals with ASD.......................................................................................pg. 6
  Sexuality and Disability................................................................................pg. 6
  Need for Sexuality Education for Individuals with ASD.........................pg. 10
  Sexuality Education Standards......................................................................pg. 11
  Self-Advocacy................................................................................................pg. 15
  Self-Advocacy and Sexuality.........................................................................pg. 16

Chapter 3: METHODS......................................................................................pg. 17
  Participants......................................................................................................pg. 17
  Instrumentation.............................................................................................pg. 17

Chapter 4. PROCEDURES..............................................................................pg. 18
  Recruitment....................................................................................................pg. 18
  Interview/Focus Groups................................................................................pg. 19
  Data Collection and Analysis.......................................................................pg. 20

Chapter 5. RESULTS.......................................................................................pg. 21
  Demographics...............................................................................................pg. 21
  Need for Sexuality Education for Individuals with ASD......................pg. 22
  Past Experiences with Sex Education.........................................................pg. 23
  Differences in Sexuality Education for Individuals who are high or low on the spectrum......................................................pg. 25
  Content of Sexuality Curriculum................................................................pg. 30
    The Dating World.........................................................................................pg. 30
    Sexual Harassment and Intimidation.........................................................pg. 31
  Delivery and Instruction of Sexuality Curriculum......................................pg. 33
    Communication..........................................................................................pg. 33
    From Whom to Learn about Sex Education............................................pg. 34

Chapter 6. DISCUSSION..................................................................................pg. 35
  Need For Sexuality Education.....................................................................pg. 35
  Past Sex Education Experience................................................................pg. 36
  Differences in sexuality education for individuals who are high or low on the spectrum......................................................pg. 37
  Content of Sexuality Curriculum................................................................pg. 38
  Delivery and Instruction of Sexuality Curriculum......................................pg. 39
  Recommendations........................................................................................pg. 41
  Implications..................................................................................................pg. 41
  Limitations.....................................................................................................pg. 42
  Future Research............................................................................................pg. 43
Chapter 7: Conclusion……………………………………………………........pg. 45

Appendix A: Sexuality Questionnaire………………………………………..pg. 47
Appendix B: Demographics Sheet…………………………………………..pg. 51
Appendix C: Informed Consent form………………………………………..pg. 52
Appendix D: Reimbursement form.......................................................pg. 54

References.........................................................................................pg. 55
LIST OF TABLES

Figure 1: Guidelines for Comprehensive Sexuality Education: Key Concepts and Topics

Figure 2. Demographics

Figure 3: Formal Sexuality Education

Figure 4: Educating Individuals who are higher or lower functioning

Figure 5: From whom would you most like to hear about sexuality?
Chapter 1: Introduction

Autism Spectrum Disorder (ASD) is one of the most commonly diagnosed developmental disabilities (Sullivan & Caterino, 2008). One in 68 children are estimated to be identified with ASD in the United States (Center for Disease Control, 2014). According to the Diagnostic and Statistical Manual of Mental Disorders (DSM) V (2015), “people with ASD tend to have communication deficits, such as responding inappropriately in conversations, misreading nonverbal interactions, or having difficulty building friendships appropriate to their age. People with ASD may be overly dependent on routines, highly sensitive to changes in their environment, or intensely focuses on inappropriate items…under DSM V individuals must who symptoms in early childhood even if those symptoms are not recognized until later” (p.1).

The Diagnostic and Statistical Manual of Mental Disorders is a manual used by clinicians and researchers to identify and categorize mental disorders (America Psychiatric Association, 2013). The Diagnostic and Statistical Manual for Mental Disorders or DSM has recently been updated to the 5th edition. In the 5th edition there has been changes to the diagnosis of Autism Spectrum Disorder. Under the DSM IV, individuals could be diagnosed with four separate disorders: autistic disorder, Asperger’s syndrome, childhood, disintegrative disorder or pervasive developmental disorder not otherwise specified. With the DSM –V, ASD is now an umbrella term for previous four categories. Researchers believe that this will improve the diagnosis of ASD (American Psychiatric Association, 2013).

Individuals with ASD have difficulty with communication; tend to respond inappropriately in conversation and misread nonverbal interaction (American Psychiatric Association, 2013). Sexuality is an area of social functioning where these deficits become more pronounced as the individual ages (Tullis & Zangrillo, 2013). According to National
Commission of Adolescent Sexual Health (1995), “Human sexuality is comprised of sexual knowledge, beliefs, attitudes, values and behaviors and deals with anatomy, physiology, biochemistry, gender roles, identity, personality, thoughts, feelings and relationships” (p.1). With this definition of human sexuality, increased knowledge of sexuality will not only assists in the development of relationships but also will help increase the quality of life for persons with ASD. Sex education is a priority for individuals with ASD because their lack of understanding of normal sexual behavior; e.g. public masturbation and lack of knowledge of what constituted sexual abuse (Tullis & Zanegrillo, 2013).

Sexuality is an important attribute of the human experience. It is a complex dimension of human functioning that involves behavior, emotions, and attitudes, which express the need for intimacy, love, and relationships with other people (Lease, Cohen, & Dahlbeck, 2007). Individuals with ASD need sexuality education particularly due to the characteristics described by the American Psychiatric Association in the DSM-V; communication deficits, misreading nonverbal interaction, and having difficult building relationships (American Psychiatric Association, 2013).

Myths about individuals with ASD and their sexuality have hindered the spread of information about social and sexuality issues. For example, Cornelius Chipouras, Makas and Daniels (1982) identified myths that may affect the negative perceptions of individuals with ASD and their sexuality including; people with disabilities are asexual, have uncontrollable urges, are dependent and child like, and if a person with ASD has a sexual problem it is because of their disabilities. These myths likely resulted in social isolation and lack of sexual information.
Cultural views of sexuality and individuals with disabilities are another barrier that self-advocates have found to hinder their sexuality education. Many teachers do not feel comfortable teaching individuals with disabilities sexuality education (Kalyva, 2013). Educators often are not taught proper procedures to create a safe space for individuals with ASD to explore their sexuality (Morgan, Manci, Kaffar & Ferrerira, 2011). This lack of information may hinder individuals’ ability to explore their sexual orientation. Many individuals assume that people with disabilities are asexual or heterosexual (Thompson, 2002; Cornelius et al, 1982). Creating a safe space for individuals to learn and explore their sexuality is an important job of the educational system. Professional development and teacher education can increase knowledge to educate all individuals specific to their needs (Cornelius et al, 1983).

There is often controversy related to the content of sexuality curriculum. There is no universal agreement on what should be taught. In 2011, with a collaboration of multiple health agencies, a National Standard for Sexuality Education was created. These standards outline the minimum and essential core standards that includes anatomy and physiology, puberty and adolescent development, sexual identity, pregnancy and reproduction, sexually transmitted disease and HIV, healthy relationships and personal safety (FOSE, 2011). Tullis & Zangrillo (2012), and Travers & Tincani (2010) investigated different sexuality curriculum. Their findings show that most sexuality curriculum have the same themes, preventing sexual abuse, facilitating relationships, promoting health and hygiene, social development and the “hidden curriculum”. The hidden curriculum are unspoken rules about typical behavior (Bieber, 1994). For example, most individuals intuitively know not to eat onions or other “smelly” foods on a date, do not ask the teacher a question when he or she is scolding another teacher or during a conversation face the speaker and position feet in their direction (Smith-Myles & Simpson, 2001). This unspoken
information causes tensions in relationships for many individuals with ASD. It is difficult to learn and generalize the hidden curriculum because of the vast differences based on culture, location, situations, people and age (Smith-Myles & Simpson, 2001). Smith-Myles & Simpson (2001) summarize how to teach the hidden curriculum through direct instruction, and other effective instruction teaching approaches.

An important part of most sexuality curriculum is the topic of sexual abuse. The U.S. Department of Health and Human Services (1996) defines sexual abuse as “…a type of maltreatment that refers to the involvement of individuals in sexual activity to provide sexual gratification or financial benefit to the perpetrator, including contacts for sexual purposes, molestation, statutory rape, prostitution, pornography, exposure, incest or other sexually exploitative activities” (p. 31). In 2012, approximately 1 in 6 boys and 1 in 4 girls experienced sexual abuse before the age of 18 (Center for Disease Control, 2012, p. 1). Sullivan and Knutson (2000) found that children with intellectual disabilities are 4 times more likely to be sexually abused. Studies have shown that individuals with disabilities are more vulnerable to sexual abuse because of their dependence of adults, social isolation and lack of sexuality education (Wassink, van Vugt, Moonen, & Stams, 2015). Further, language impairment is an issue when it comes to reporting sexual abuse. Many individuals with ASD have language impairments that can impede their ability to disclose on the abuse (Brownlie, Jabbar, Beitchman, Via & Aida, 2007).

Although there are sexual abuse prevention programs available, the research on their success is limited (McEachern, 2012). Some programs teach self-assertiveness and protection skills while others teach awareness of what constitutes sexual abuse and consent (Bruder & Kroese, 2005; Liou, 2014). Given the statistics about abuse and consent, information about sexual abuse, harassment and intimidation should be included in sexuality curriculums.
Information related to techniques to teach sexuality education is limited. Research has shown that most information taught to individuals with disabilities about sexuality is taught when a problem behavior is demonstrated; reactive education instead of proactive education is common (Tullis & Zangrillo, 2012). Shaafsma, Kok & Stoffelen (2015) conducted a systematic review of sexuality education teaching methods and found that the goals, what was exactly taught in the curriculum, and materials used were broad and not specific, nor were they able to be replicated. Their systematic review found the following techniques were effective in teaching sexuality education: social stories, corrective feedback, guided practice, modeling, rehearsal and reinforcement as effective to teach sexuality education (Shaafsma et al, 2015).

In this study, self-advocates who were diagnosed with ASD participated in focus groups or individual interviews to discuss their personal experiences with sexuality, their formal education related to sexuality, and what they though should be part of a sexuality education curriculum for individuals having ASD. By examining common themes, information can be provided to create a sexuality curriculum specific to the needs of individuals with ASD based on their unique perspectives and opinions. The research questions guided the study were:

1. What are the opinions of self advocates with ASD about common sexuality topics including:
   a. Their past experiences
   b. Their formal sexuality curriculum taught in school
   c. Topics they would include in a sexuality curriculum for individuals with ASD?
Chapter 2: Literature Review

Individuals with ASD

The number of individuals with autism spectrum disorder (ASD) is on the rise. ASD is one of the most commonly diagnosed developmental disabilities (Sullivan & Caterino, 2008). One in 68 children are estimated to be identified with ASD in the United States (Center for Disease Control, 2014); this number is thirty percent higher than the 1 in 88 statistics given in 2012. Under the new Diagnostic and Statistical Manual of Mental Disorders 5th edition (DSM-V), individuals with ASD have qualitative impairments in communication which is shown through the misreading of nonverbal interactions, responding inappropriately in conversations and having difficulty building age appropriate friendships. Individuals with ASD are highly sensitive to change, and are overly dependent on routines or intensely focused on inappropriate items (American Psychiatric Association, 2013).

Autism is a spectrum disorder. The word spectrum refers to the wide range of symptoms skills, and levels of impairment (NIM, 2014). Some individuals with ASD have mild characteristics while others have more severe symptoms. According to the American Psychiatric Association (2013), this spectrum will help when diagnosing individuals because it will account for the variations in symptoms from person to person.

Sexuality and Disability

Sexuality is an important attribute of the human experience. It is a complex dimension of human functioning that involves behavior, emotions, and attitudes that express the need for intimacy, love, and relationships with other people (Lease et al, 2007). Sexuality is multifaceted and has biological, sociocultural, psychological, and spiritual components (FOSE, 2011). Views on sexuality and individuals with disabilities are conflicted. Stereotypes about individuals with
disabilities may be a reason for these misconstrued views on persons with disabilities and sexuality. Negative perceptions of individuals with disabilities have been apparent since the early Egyptians to the present day (Brodwin & Frederick, 2010).

Historically, individuals with disabilities do not have the right to their own bodies and caretakers were allowed to force sterilization of individuals with disabilities. In 1927, thirty-four states had laws stating that sterilization was social therapeutic and seven thousand people were sterilized (Landman, 1929). Buck vs. Bell was a Supreme Court case where the Virginia sterilization law was found constitutional and did not violate the 14th Amendment. The decision may have been because of the widespread view of “negative eugenics”. Negative eugenics was a view that to improve the gene pool by eliminated the “defective” (Landman, 1929). Though there are less cases of forced sterilization, Buck vs. Bell has yet to be overturned and negative perceptions of individuals with disabilities continue to this day.

Cornelius et al (1982) identified the following myths that affect the negative perceptions of individuals with ASD and sexuality; Individuals with ASD are asexual or have uncontrollable urges, always child like, and if there is a sexual problem it is because of their disabilities. According these myths, individuals with disabilities are seen as dependent and childlike victims, which may lead to social isolation (Cornelius et al, 1982). We know now that these myths are untrue and that individuals with disabilities have the same sexual feelings as those without disabilities. According to Healey, McGuire, Evans and Carley (2009), individuals with intellectual disabilities, which includes ASD, express desires for intimate relationships but report limited opportunities (p. 912). Approximately 75% of individuals with ASD display some kind of sexual behavior (Sullivan & Caterino, 2008; VanBourgondein et al, 1997). These sexual behaviors may be different from the social perceptions of normal. For example public
masturbation or inability to identify what constitutes sexual abuse are common sexual behaviors (Tullis & Zangrillo).

The myth that individuals with disabilities are “eternal children” may skew the views towards individuals with disabilities and their sexuality (Parchomiuk, 2012). According to this stereotype, sexuality is not seen as important for individuals with disabilities because someone who is eternally a child would not even have the thoughts about sexuality. However, sexual self-acceptance is an important aspect of positive self-esteem (Cole, 1988). It is difficult for individuals to have sexual self-acceptance when they are viewed as children. These cultural views affect individuals’ ability to form relationships. Cultural beliefs influence the way people view their place in the world, which in turn affect the individual’s ability to form relationships with other people (Brodwin & Frederick, 2010).

Attitudes related to types of disabilities may affect perceptions of sexuality and disability. For example, Parchomiuk (2012) conducted a study on the views of specialists working with individuals with disabilities and their views on sexuality and people with disabilities. Over 98 people were interviewed. The author found that the respondent’s were more accepting of the sexuality of individuals with physical disabilities as compared to individuals with cognitive issues. Additionally, when asked to put their acceptance in a hierarchy, the participants were more accepting of the physical aspects of sexuality, contraception, physical attractiveness, the somatic sphere, realization of sexual needs, sexual drive and sexuality. There were a lower acceptance of partnership and parenthood. Both groups had the lowest acceptance for sterilization of individuals with disabilities (Parchomiuk, 2012).

There also may be a bias towards expression of sexuality. Adolescence is a time when individuals are experimenting with their identities and sexuality. This time of exploration can be
difficult for individuals with disabilities who need to understand their disability as well as their future goals (Morgan et al, 2011). Thompson (2002) cautions against assuming that individuals with disabilities are all heterosexual. A safe space for individuals with disabilities can be created with the assistance of teachers and staff. Unfortunately, many educators do not want individuals to explore their sexual identities, some viewing the exploration as dangerous (Aurnos & Feldman, 2002). Morgan et al (2011) summarize techniques that can assist in creating a safe environment for LGBT students with disabilities, with a focus on the collaboration between school administration, teachers, families and community. In the summarization of strategies, the authors emphasize on the creation of student organizations for LGBT individuals, professional development to educate teachers on LGBT issues and how to remove their own personal beliefs, intense anti-bullying procedures, and effective strategies of community implementation (Morgan et al, 2011). These strategies will help individuals with disabilities to explore their sexual orientation as well as dispel the myth that individuals with autism must be asexual.

Many teachers also may not feel confident teaching sexuality education to individuals with ASD. Kalyva (2013) conducted a survey with teachers on their perspectives of sexuality of children with ASD. Kalyva’s findings indicated that only seven teachers or 12% of the teachers felt confident that they could provide sexuality education to students with ASD. The teachers interviewed speak about a lack of education on how to teach individuals with disabilities sexuality education (Kalyva, 2013). This lack of confidence could also be because of the stigma associated with sexuality. Some educators have negative perceptions of individuals with disabilities and sexuality (Morgan et al, 2011).
Need for Sexuality Education for Individuals with ASD

Reports of sexual harassment, abuse and intimidation are on the rise in recent years. According to the Center for Disease Control (2012), approximately 1 in 6 boys and 1 in 4 girls have been sexually abused before the age of 18. Sullivan and Knutson (2000) conducted a study with over 55,000 children and found that children who showed any type of intellectual disability were four times more likely to be sexually abused than an individual without disabilities. According to the United States Department of Human and Health Services, (1996), “sexual abuse is a type of maltreatment that refers to the involvement of individuals in sexual activity to provide sexual gratification or financial benefit to the perpetrator, including contacts for sexual purposes, molestation, statutory rape, prostitution, pornography, exposure, incest or other sexually exploitative activities” (p.31). In 2007, persons with disabilities were victims of approximately 47,000 rapes and sexual assaults (McEachern, 2012).

Individuals with developmental disabilities are more vulnerable to sexual abuse due to a number of reasons. According to Wassink et al (2015), individuals with developmental disabilities are most susceptible to sexual abuse because of their dependence of other individuals for care, trained compliance, social isolation, lack of education about sexuality and sexual abuse, language barriers and a societal view that devalues individuals with disabilities. Brownlie et al (2007) studied a sample of children with speech impairments up to the age of twenty-five. The results showed that girls with language impairments were more likely to have experienced sexual abuse as children than their non-impaired peers. Language impairments can impede individuals’ ability to stop the abuse (Brownlie et al, 2007). Research shows that the victim most likely knows the perpetrators of sexual abuse and that perpetrators are most often male and from within the immediate or extended family (Akbas et al, 2009; Center for Disease Control, 2012).
There is limited research conducted on sexual abuse prevention programs or if these programs are effective (McEachern, 2012). One preventative approach to sex abuse education involves teaching individuals with disabilities assertiveness and self-protection skills. The research also specifically states that these skills should be taught early and maintained as an adult (Bruder & Kroese, 2005). Increasing awareness of sexual abuse is the first step towards prevention, detection and reporting. All interventions used to teach about sexual abuse should be adapted to the skills of the individual (McEachern, 2012). Prevention of sexual abuse starts with awareness of the information, what constitutes abuse, the legal definition of abuse, as well as identifying sexual abuse situations and coping mechanism (Liou, 2014). Individuals with disabilities need to learn about sexuality and sexual abuse.

**Sexuality Education Standards**

In 2011, Advocates for Youth ad the Sexuality Information and Education Council of the United States (SIECUS) with the help of the American School Health Association, American Association for Health Education, National Education Association Health information Network and The Society of Heath leaders of Health and Physical Education came together to create the “Future of Sex Education Initiative”. The Future of Sex Initiative (FOSE, 2011) serves as the basics for the National Sexuality Education Standards: Core Content and Skills K-12. The goal of these standards is “to provide clear, concise, consistent and straightforward guidance on the essential minimum core content for sexuality education that is developmentally and age appropriate for students in grades K-12” (FOSE, 2011, p. 6). These standards were developed to address the inconsistency in sexuality education nationwide and were designed to outline what the minimum, essential content and skills for students in kindergarten to 12th grade (FOSE, 2011). The sexuality education standards are meant to develop a national curriculum and
“provide a framework for curriculum development instruction and student assessment that reflects the research based characters effective for sexuality education and be informed by relevant health behaviors and models” (FOSE, 2011, p. 8). There were seven topics chosen as minimum and essential for the National Sexuality Education standards by FOSE (2011). These topics included; anatomy and physiology, puberty and adolescent development, identity, pregnancy and reproduction, sexuality transmitted disease and HIV, healthy relationships and personal safety (FOSE, 2011). This national sexuality curriculum is not specific to individuals with disabilities.

A person with any disability has the right to sexuality education, health care and sexual expression. Health agencies need to guarantee that benefits and services will be provided without discrimination (SIECUS, 2002). In 2004, National Guidelines Task Force created Guidelines for comprehensive sexuality education 3rd edition to fit the needs of the current generation. These guidelines are adapted to the current generation, which includes individuals with ASD (National Guidelines Task Force, 2004). The guidelines have six key concepts that are divided up into topics. These key concepts included; human development, relationships, sexual behavior, sexual health and society & culture. The Guidelines for Comprehensive Sexuality Education states that “individuals with disabilities can have children and care for children” (National Task Force, 2004, p.41). The National Information Center for Youth and Disabilities was also a provider of information for these guidelines (National Guidelines Task Force, 2004). The figure below shows the different topics and concepts ((National Guidelines Task Force, 2004).

Figure 1. The Guidelines for Comprehensive Sexuality Education: Key Concepts and Topics

<table>
<thead>
<tr>
<th>Human Development</th>
<th>Sexual Behavior</th>
<th>Sexual Health</th>
<th>Society &amp; Culture</th>
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<td>Reproduction, Sexual</td>
<td>Sexuality Throughout</td>
<td>Reproductive Health</td>
<td>Sexuality &amp; Society</td>
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<td>Families</td>
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<th>Relationships</th>
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<td>Families</td>
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12
Currently there are materials related to sexuality educational curriculum and individuals with ASD, but scientific support for the curriculum is not present (Tullis & Zangrillo, 2012). For many individuals with ASD, sexuality education is only taught when a behavior is demonstrated that is problematic; reactive education is a common practice and there are limited proactive sexuality education techniques (Tullis & Zangrillo, 2012). There authors state that curriculum useful in teaching adolescents with ASD should focus on directly teaching sexuality skills presented through social stories, visual slides and programs models (Tullis & Zangrillo, 2012). Social stories are used to describe a situation, skill or concept using relevant social cues and common responses and may be effective to each sexuality education because they could be helpful for those who are sensitive to rule establishment (Gray, 2000). Research related to sexuality education shows a focus on preventing sexual abuse, facilitating relationships, promoting health and hygiene, and developing social skills (Tullis & Zangrillo, 2012; Travers &
Tincani, 2010). Individuals with ASD and other developmental disabilities have the right to learn about sexuality. Many of the deficits common to individuals with ASD make finding sexuality information from other means ineffective, leaving them vulnerable to sexual abuse, unable to acquire sexuality, relationships, and intimacy skills from their natural environment (Travers & Tincani, 2010).

Just as there is limited information about the content of sexuality information, there is limited information on how to teach the content. Schaadasma, Kok, & Stoffelen (2015) conducted a systematic review to identify effective methods for teaching sex education to individuals with intellectual disabilities. The authors compiled articles specific to sexuality education and found the following methods to improve sexuality knowledge; corrective feedback, guided practice, modeling, rehearsal, reinforcement and discussion (Schaadasma et al, 2015). The authors (Schaadasma et al, 2015) also found that procedures were not clear and goals of the curriculum were also broad and nonspecific. Specifically, the reported methods used and materials of programs were not always clearly defined, making it difficult for authors to identify what was useful and could be replicated in these curriculums.

According to the DSM-5, individuals with ASD have communication deficits, misread nonverbal language, and have difficulty forming relationships. These social deficits hinder an individual with ASD’s ability to understand the hidden curriculum. The hidden curriculum relates to societal rules that are not explicitly taught be needed for social acceptability (Bieber, 1994). These unspoken rules can cause tensions in forming relationships for many individuals with ASD. Temple Grandin (1999), a well-known author and scientists with ASD, wrote her own set of rules for the hidden curriculum. Grandin’s “rule system used to guide social interactions and behaviors” (1999) had four main themes, really bad things (ex: murder, arson et), courtesy
rules (ex: do not cut in line at the movie theater), illegal but not bad (ex: slightly speeding on the freeway), and sins of the system (ex: smoking pot, sexual misbehaviors).

Access to this hidden curriculum rules could help increase the social interaction of individuals with ASD (Shaafsma et al, 2015). Smith-Myles and Simpson (2001) developed instruction related to systematically teaching the hidden curriculum. Their approach included scope and sequence, direct instruction, social stories, self-esteem building and interpretation. Through use of these approaches, individuals with ASD will learn aspects of the hidden curriculum. Research shows that individuals with ASD have deficiencies with social interaction because of this, they inadvertently break the rules of the hidden curriculum and become isolated from their peers or ridiculed by adults (Smith-Myles & Simpson, 2001). Education of the hidden curriculum should be an important part of the sexuality curriculum for individuals with ASD using the techniques collected by Smith-Myles and Simpson (2001).

**Self-Advocacy**

Self-advocacy for people with disabilities is a civil rights movement can be traced back to the 1970s with de-institutionalization and the self-advocacy movement continues on today (Test, Fowler, Wood, Brewer & Eddy, 2005). Test et al (2005) created a conceptual framework for self-advocacy for individuals with disabilities. The authors found historically, there have been different definitions for self-advocacy; self-advocacy as an act or skill, and self-advocacy as a form of self-determination (Test et al, 2005). According to Test et al (2005), the most current definition of self-advocacy is “a social change movement. It is a civil rights movement of individuals and organizations to empower people with disabilities to speak for themselves make their own decisions, and stand up for their rights both individually and collectively” (Advocating Change Together, 2002, p. 7).
Individuals with disabilities need to acquire certain skills that will lead to self-determination and self-advocacy. These skills are goal setting, problem solving, and decision-making (Wehmeyer, 2002). According to Wehmeyer (2002), there is an educational planning and decision-making process to help teach self-determination. In this process the individual sets a goal, solves problems that act as barriers to achieving this goal, makes choices based on personal interest and participates in decisions that impact the quality of their lives. Throughout the process, the teacher needs to communicate high expectations to the individual and teach the student to be an advocate for their own learning through self-monitoring and self-evaluation (Wehmeyer, 2002).

**Self-Advocacy and Sexuality**

Self determined individuals are those who know how to choose, are aware of their own personal needs whether it is sexual or physical, chose goals and pursue them (Martin & Marshall, 1995). Self-determination is a form of self-advocacy (Test et al, 2005). In terms of sexuality, the Green Mountain Self Advocates in Vermont define sexual self-advocacy as “feeling good about yourself, knowing your rights and responsibilities when in a relationship and knowing about birth control and safe sex” (Planned Parenthood of Northern New England, Green Mountain Self Advocates, 2009). Teaching individuals with disabilities how to be independent will increase their self-advocacy (Wehmeyer, 2002). Individuals with ASD who have increased knowledge on different sexuality topics will be on their way to becoming self-advocates and to an increased quality of life. Research shows that when individuals with disabilities feel they have control over their lives and can make their own decisions, they have an increased self-esteem and self-worth (Ward, 1996).
There is limited research on self-advocates and their views on sexuality curriculum. The closest research topic would be in “Remember: Our Voices are Our Tools” (Friedman, Arnold, Owen & Sandman 2014). The authors (2014) researched self-advocates who have intellectual and developmental disabilities and how they defined sexuality. The research showed that specific central themes appeared; component for sexual self-advocacy, my choices, communication, respect and interdependence. The participants spoke about their right to share their opinion, the right to have an opinion, the right to be yourself and express yourself, the right to not be abused or harassed (Friedman et al, 2014). It is important to hear the views of self-advocates views on sexuality education for individuals with ASD. Involving self-advocates in the creation of a sexuality curriculum promotes self-determination, and self esteem as well as creates a curriculum that is socially valid and evidence based (Wehmeyer, 2002).

Chapter 3: Methods

Participants

The participants of this research were individuals who self identified as having ASD. The participants were individuals on the autism spectrum ages eighteen to forty-nine. Participants were selected based on their autism diagnosis and their ability to be self-advocates. The definition of self-advocates for this research is individuals with ASD are self sufficient in their daily lives, meaning the participants can live independently without the constant assistance of parent or other adult.

Instrumentation

To assess the sex education topics for inclusion in a curriculum for individuals with ASD, participants completed a demographic form (Appendix B) and the “Sex Education Topic Questionnaire (Appendix A). The demographic form asked for information about the participants
age, gender, venues they learned about sexuality, areas of sexuality that they would want to
know, their comfort level for sexuality conversation, whom would they like to hear sexuality
from, and difficulties due to lack of knowledge. The Sex Education Questionnaire had eight
sections. The sections included; sexual anatomy, reproductive health, sexual responses and
partnered sex, contraception and sexuality transmitted infections (STIs), the dating world, stages
of relationships and maintaining relationships, and sexual intimidation: harassment, aggression
and abuse. Participants were asked to place a checkmark in either “yes” or “no” column to
indicate that the topic should be included in a curriculum for “high functioning” or “low
functioning” individuals with ASD

Chapter 4: Procedures

Recruitment

Participants were recruited for the study through contact with agencies including: Autism
Services, Education, Resources and Training (ASERT) of Pa, Office of Disabilities at Penn
State, and Autistic Self Advocacy Network (ASAN). In addition, self-advocates were recruited
from the National Autism Conference held annually at Penn State. The conferences features
national speakers on issues related to ASD. The conference is co-funded by Penn State and The
PA Department of Special Education. The conference is held each year on the Penn State
University Park Campus.

When participants replied to the email given which included information about the focus
group, the informed consent (Appendix C) and the sexuality questionnaire, an interview was set
up based on the schedule of participants and researcher. The agencies listed above forwarded the
researcher’s information to the individuals with ASD in their group. If the participant was
interested, they emailed the researcher to set up a common time to meet. At Penn State, flyers
about the research were sent through the Office of Disabilities to all participants who qualified for the study. Those interested individuals emailed the researcher who set up a time for a focus group. All recruitment materials stated that participants would receive $40 for their time and effort. The reimbursement monies were provided to a Research Initiation Grant for the College of Education (under the supervision of Dr. Wolfe, the researcher’s advisor).

Interview/Focus Groups

Once a time had been agreed on, the interviews were conducted via phone or videoconference (Skype). Videoconferencing was used when participants were outside of a two and half hours radius of Penn State University Park campus. Participants in the two and half hour vicinity had interviews face to face. Depending on the size of the group, the participants took part in either an individual interview or a focus group (ranging in size from 2-10 individuals). The session lasted a maximum of two hours and a minimum of thirty minutes. At the session, the researcher (the author) conducted the interview (some interviews done under the supervision of author’s advisor and co-author.) Once the session date was determined, the participant was either sent materials to review or given materials at the beginning of the session. There were four forms that were distributed. One form was the Informed Consent Form. The second form was the Reimbursement form (Appendix D), asking for the participants name, address, social security number and signature in order to send the $40 reimbursement. The third form was the demographic sheet. The final form was the Sex Education Topic Questionnaire. All forms are located in Appendix. Once the forms had been distributed, the researcher verbally asked participants if there were any questions about the study, and their willingness to participate. If there were no questions, participants were asked to sign the Informed Consent Form and the Reimbursement Form and return them to researcher. If the session was conducted on Skype, the
participants were asked to email the informed consent and reimbursement forms to the researcher before the session. After the first two forms were completed, each participant was asked if he/she was willing to permit the session to be audio recorded. All participants had to agree to permit audio recording if it was a group session. Once the recording method was agreed upon, the participants were asked to complete the Sex Education Topic Questionnaire. After the questionnaire was completed, an open ended discussion occurred. The participants were asked a series of questions about the topics including; Was it difficult to differentiate between “high and low” functioning individuals? How did you make this determination? Were there topics you believe should not be covered? What are the most important topics and why? What was missing/what should be included that wasn’t? What are some “hot button” or controversial topics (abortion, STIs, etc)? Additionally, the researchers asked participants to describe their own sexuality education and if/how it could have been better.

Data Collection and Analysis

Data were either recorded via Apple Voice Memo or recorded via written notes, depending on the participant’s wishes. Accuracy of the quotes was determined through listening of audio transcripts of interview multiple times. The demographic sheets, and sexuality curriculums were then organized into two piles. The demographic sheets were put into different sections based on self-advocates’ satisfaction with the formal sexuality curriculum, divided into a very satisfied and somewhat/no satisfied/ no curriculum. Finally, the sexuality questionnaires were looked through and compared using the low functioning compared to high functioning and yes/no. Specifically, the information was organized if the participants said yes to all or had specific questions that they answered no.
The researcher coded the interview results into thematic categories, which were put onto cards. The initial themes that emerged were a) the dating world b) sexual intimidation and harassment c) communication and d) educational curricula. The coding of information was discussed between the two researchers, Dr. Wolfe and Allison Fleming. The two researchers found similar themes in the interviews. Both researchers were also present for all interviews that included more than one participant.

Chapter 5: Results

Demographics

Participants were found online with the assistance of ASERT of PA, ASAN, other self-advocacy groups and the Office of Disabilities at Penn State University. Figure 1 contains information about the initials assigned to each self-advocate (unrelated to their true identity), their age, and gender.

Figure 2. Demographic information of Self Advocates.

<table>
<thead>
<tr>
<th>Initials</th>
<th>Age</th>
<th>Gender</th>
</tr>
</thead>
<tbody>
<tr>
<td>T.F</td>
<td>20-25</td>
<td>Male</td>
</tr>
<tr>
<td>S.D.</td>
<td>25-29</td>
<td>Male</td>
</tr>
<tr>
<td>K.T.</td>
<td>18-19</td>
<td>Male</td>
</tr>
<tr>
<td>A.C.</td>
<td>45-49</td>
<td>Female</td>
</tr>
<tr>
<td>T.S.</td>
<td>25-29</td>
<td>Male</td>
</tr>
<tr>
<td>B.B.</td>
<td>20-24</td>
<td>Female</td>
</tr>
<tr>
<td>S.R.</td>
<td>35-39</td>
<td>Male</td>
</tr>
<tr>
<td>S.F.</td>
<td>25-29</td>
<td>Male</td>
</tr>
<tr>
<td>N.R.</td>
<td>20-24</td>
<td>Female</td>
</tr>
<tr>
<td>C.C.</td>
<td>20-24</td>
<td>Female</td>
</tr>
<tr>
<td>P.K.</td>
<td>18-19</td>
<td>Female</td>
</tr>
<tr>
<td>M.S.</td>
<td>20-24</td>
<td>Male</td>
</tr>
<tr>
<td>R.H.</td>
<td>20-24</td>
<td>Female</td>
</tr>
</tbody>
</table>

Per the qualitative methodology, interview/focus group sessions were coded into themes. Broad themes that emerged centered on the following: a) the need for sex education; b) past experiences with sexuality c) differences in content for individuals termed “higher” or “lower”
functioning on the spectrum; and d) the content and delivery of sex education instruction. The content and delivery themes were further coded into subthemes including: the importance of teaching about the dating and sexual harassment and intimidation as well as the delivery of sexuality information using opening communication and whom participants preferred to learn sexuality from.

**Need for Sex Education for Individuals with ASD**

The overarching theme of the interviews was the need for sexuality education for individuals with ASD. Educating individuals with ASD on sexuality will not only increase their knowledge of sexuality but also protect them from abuse and humiliation. “The best way to protect people is by giving them the information, not picking out what you think is important for them to know...look at an individual with autism who has a developmental delay and compare to a typical child, (sexually) a lot of will overlap though the timing may be different. (A.C.)” Individuals with ASD have the same sexual needs and desires as their typically developing peers, though some may be, not all individuals with ASD are asexual. “It is a lot easier to think that your child is asexual…if your child is typical you don’t want that, if you have a child with special needs there is a lot of stress (A.C.)” Individuals with ASD have communication and social deficits that hinder their ability to acquire sexual knowledge. “People on the spectrum have trouble with social cues, social behaviors that needs to be covered. (K.T.)” Sexuality education for individuals with ASD will help bridge the gap of information because of their social and communication deficit. “A child is going to sexually mature whether you like it or not…people assume that everyone should know not to play with yourself in public. (A.C.)” Sexuality education is important to keep individuals with ASD informed about the hidden
curriculum, what everyone is assumed to already no, and other sexuality topics. “Everyone who is living needs to know this (sexuality) information…it should be taught in all schools” (A.C.).

Past Experiences with Sex Education

The self-advocates spoke of need for balanced curriculum and how for many of their formal sexuality curriculum at school did not have information that was adapted towards their needs. The figure to right shows that number of participants and their view on their formal sexuality curriculum in school. In the figure, Curriculum were labeled as inadequate if participants answered that they were not satisfied, somewhat satisfied or had no curriculum. Curriculum was labeled adequate if participants said that they were satisfied with their formal sexuality curriculum.

The self-advocates wanted to be taught everything that they could, the bad and the good but with a neutral tone. S.R. believed that the current curriculum was “all negatives with no benefits…showing what not to do instead of what to do right.” The curriculum should be balanced and not bias towards the negative, completely neutral. Sexuality curriculum that were worthwhile and memorable were completely neutral and showed no bias. C.C. was very satisfied with the curriculum in her school district because it “wasn’t preachy, did give options, risks but was very neutral…here are your options (C.C.).” The curriculum did not just focus on puberty and hygiene, the participant was taught about other topics like sexting, abortion and how to use a condom. The only way to be educated on a topic is to be well informed. “All we can do is inform
(M.S.).” M.S. continues to say, “You can’t control what they do with the information.” It is important that current and appropriate sexual information is available for individuals to be able to attain so that individuals can make informed sexual decisions.

When teaching sexuality, symbolism should not be used. It is common for individuals with ASD to be more literal thinkers. S.R. spoke of the symbolism constantly used when teaching sexuality. The birds and the bees are too vague, as a child S.R. assumed that the teacher was really talking about flying birds and buzzing bees and did not understand the connection to sexuality. Slang was another idea that was not straightforward enough to be understood by many of the self-advocates. “When my one friend said she was called a female dog, I had no idea what she was saying (C.C).” Slang terms was one of the only parts of this sexuality questionnaire that some self advocates believed either should not be taught at all or that the actual names needed to be taught first.

Right now, talking about sexuality is seen as inappropriate for younger individuals. R.H. talks about how “talking about these things (sexuality information) is seen as inherently kid unfriendly.” There is information that should be taught earlier than middle and high school, but it must be age appropriate, like hygiene and personal space. Sexuality education should start young because “talking about sexuality later in life may be harder to grasp (R.H.)” if there is not a good educational base. K.T. talks about the importance of learning certain aspects of sexuality young because he “had problems with personal space as a kid so it would have been helpful to learn sexuality young (K.T.).” This education should continue on to high school and so on. S.R. stated that there should be “support for romance that start in high school and help with other transition periods like going to college.” A balanced curriculum would start from youth to adulthood.
specifically during transition periods and educate individuals based on their needs, whether it is about romance or hygiene.

The curriculum should show all human diversity, including all types of families. “I definitely talk about the range of human diversity a lot, just the curriculum tend to be focused on the monogamous heterosexual nuclear family…there should be more information on different types of people, there are inner sex people, polygamous people sometimes kids with two moms and community parenting (B.B).” Individuals should be educated on all different family models as well as orientations so that they understand that they have different options. Self-advocates want a balanced diverse curriculum where individuals on the autism spectrum learn developmentally appropriate sexual topics during transition periods on their life.

A good sexuality curriculum in middle and high school encouraged participants to be more open about the topic of sexuality. It made them feel that they were more prepared for other sexual discussions. The main aspect of a good sexuality curriculum was that it was non-bias. Participants spoke about how the curriculum did not put sexuality in a positive or negative light; it was completely neutral. Having a well-written and neutral curriculum made talking about sexuality easier. When a participant was asked, do you think that your curriculum made it easier to talk about sexuality? C.C. replied, “Yes, it was clearly stated, it is what it is”. Having an informed curriculum about sexuality made talking about sexuality outside the formal setting easier.

**Differences in sexuality education for individuals who are high or low on the spectrum**

Participants were asked to fill out the Sexuality Education Topic Questionnaire. Before beginning to fill out the Sexuality Education Topic Questionnaire, a frequent question was the division between high and low functioning. Participants were concerned and confused about the
separation between high and low functioning. Even though some participants did show the need for an adapted curriculum based on the functioning of the individual, many did not agree with the low functioning, high functioning labeling. “Two categories can’t encompass what’s going on, the term low functioning could be insulting (R.H.).” B.B explained that as a self-advocate, she did not believe in labels, such as low and high functioning, everyone should be taught about sexuality. “As a self advocate I reject functioning with labels and I think that everyone should learn everything…. (And) I think the thing I am most adamant about is that it is important no matter perceptions about so called low functioning people that they get this curriculum. Disabled people’s sexuality and genders tend to be se erased (B.B).” A.C. told the researcher that asking if there is a difference between low and high functioning was “not even worthy of asking the question” and “Anyone who is alive needs to know the sexual reality that they are able not because they need to go out and have sex but they need to understand the reality of the situation good or bad.” These self-advocates defied the idea of labeling individuals, justifying that there are individuals who are higher or lower functioning but that is was hard to distinguish the line between them. Individuals on the autism spectrum are “not a straight line (S.R.).” Participants had difficulty determining the line between low and high functioning. “No two autistics people are the same, it’s a spectrum, where is the line (between high and low functioning)? (C.C.).” Autism is a spectrum disorder, some individuals may be lower functioning than others and may need an adapted curriculum, but many self-advocates did not agree with the label of low functioning.
The self-advocates had different views on what should be taught in the sexuality curriculum based on the Sexuality Education Topic Questionnaire. Figure 4 shows the number of participants who completed the questionnaire comparing the different views on the curriculum. Individuals who checked Yes for all were labeled “Learn all”, while the number of participants who believed a sexuality curriculum may need to be adapted for individuals who are lower functioning was labeled “adapted curriculum”.

As shown in the figure, more individuals indicated the need for an adapted curriculum than “wanting everyone to know everything”. All participants talk about the need to educate all individuals on sexuality, but some did not see a need for those who are higher functioning to learn specific information or vice versa.

Four of the thirteen participants filled out yes for the entire questionnaire, while nine of the thirteen showed some differences on the questionnaire between lower and higher functioning individuals on the autism spectrum. The most common difference found in the sexuality questionnaire between higher and lower functioning individuals on the autism spectrum was the “understanding the meaning of slang words and the correct terminology for anatomical details (Wolfe, 2015).” Many participants believed that it was not necessary for lower functioning individuals to learn about the slang words. One participant explained to the researcher that if the individual didn’t understand the non-slang word what was the point of teaching the slang word, “if you are going to teach the slang words, make sure the individual knows the actual word first
Another common adaptation was educating lower functioning individuals on the opposite gender’s sexual organs. Four of the thirteen participants checked off no on the sexuality questionnaire for learning about the opposite sex internal organs. Males do not need to learn about internal female reproduction organs, and females do not need to learn about male reproduction organs. Self-advocates explained that if not taught in detail and in order, these topics could be confusing to lower functioning individuals and that other topics may be more important.

For the higher functioning section, many checked “no” for certain sections because they believed it was “common sense”. When asked why she didn’t check yes for private vs. public, private body parts and talking about sex with appropriate audiences, R.H. explained, “More things are intuitive for individuals with Asperger’s Syndrome (compared to those with autism)”. One participant when talking about the questionnaire viewed himself as the “higher functioning” individual and answered the questions based on his knowledge. For example, the participant explained that he understood what dating was and how it related to other relationships, so he checked off “no” in the higher functioning section. Nine of the thirteen understood the need for sexuality education, but did not feel that all the topics on the sexuality questionnaire needed to be addressed. All participants talked about the importance of sexuality education for individuals on the autism spectrum and how it would have helped them when they were growing up.

The self advocates expanded on the sexuality questionnaire and added topics based on their personal experiences. T.S. talked about long distance relationships and how when he was in a long distance relationship, how hard it was and how he wishes he had been taught how to maintain a long distance relationship. A.C., R.H. and S.R. showed an interest in the expansion of the sexual orientation topic and teaching about LGBT issues and adding more information about
resources for individuals who are LGBT. Participants focused on the importance of dating, no matter your sexual orientation, and how individuals on the autism spectrum may need assistance with social cues and how this could affect their ability to date. “Personally from experience, the dating and relationship building is a real important area to discuss, people on spectrum have trouble with social cues, and social behavior (K.T.).”

When asked what the most important topics were, the self-advocates found it hard to distinguish what was the most important when teaching sexuality to individuals on the autism spectrum. A.C. “found these very hard to isolate and put in an order of importance because they are all important because once you get started, (she wasn’t sure) where one lesson starts and the other ends.” The overlying themes of the interviews show that self-advocates believe that there is a need for individuals on the autism spectrum to be educated about common sexuality topics. One self advocate, A.C. was in support of sexuality education for all individuals across all parts of the spectrum in all aspects of sexuality. Here are some quotes from the interview with A.C. “Anyone who is alive needs to know the sexual reality…not that they need to go out and have sex but they need to understand the reality of the situation good or bad…there are no topics (in the sexuality questionnaire) that shouldn’t be covered” and “The only thing that I thought when I read (the sexuality questionnaire) was that everyone who is living needs to know this information…it should be in all schools, it is all important in a way that should be included like healthy eating is important.” (A.C.). Though the self-advocates had different views on how much individuals should be educated and what topics, the need for individuals on the autism spectrum to be educated in sexuality was a common theme among the self-advocates. The broad themes of content and delivery and instruction revealed additional subthemes. The subthemes within content included the importance in teaching about dating world and sexual harassment and
intimidation. The subthemes within instruction and deliver included: the need for open communication and education and description of whom participants believed should delivered the sexuality information.

**Content of Sexuality Curriculum**

Content of the curriculum was a main focus of these participants, specifically that the “usual” content of a sexuality curriculum, e.g. puberty, reproduction, etc, needed to be more in-depth and specific to the needs of individuals on the autism spectrum, who need have a “limited understanding of non-verbal language (S.R.)” All participants understood the need to understand more about relationships. The younger participants had more of a prevalent interest in dating, and in turn wanted to learn more about the dating world. For all participants sexual harassment and intimidation was an important topic of conversation. Lack of awareness of social cues, and social awareness may affect the knowledge of the dating world, which was emphasized during these focus groups. All participants talked about the value that a sexuality curriculum could have to individuals on the autism spectrum specifically with content that expands past the normal school curriculum.

**The Dating World.** Dating is a vital part of sexuality for both individuals on the autism spectrum and those who are not. Those not on the autism spectrum may understand the hidden curriculum that comes with dating, while individuals on the spectrum need to be explicitly taught how to date. This lack of understanding puts individuals on the autism spectrum at a disadvantage when it comes to dating. Through not all the self-advocates had an interest in dating, all understood how dating is a ritual that others may see as fundamental for a human being’s social interaction and sexuality. From a younger self-advocates point of view, dating was seen as the most important topic to teach on the questionnaire. Both T.S. and K.T. talked about
how having information about dating could have been really helpful to them now and as an adolescent growing up. T.S. put an emphasis on long distance dating and how to keep a long distance relationship. “From personal experience, it would have been nice to know more about long distance relationships (T.S.).” K.T. talked about why dating is difficult for those on the autism spectrum “Personally from experience, the dating and relationship building is a real important area to discuss, people on the spectrum have trouble with social cue, social behaviors that needs to be covered…the formation of a relationship before sex… important to teach how to make conversation, make eye contact.” K.T. continued to talk about the dating world, “The dating world is SUPER important, picking activities and places, communication skills, what to do afterwards…don’t learn the nitty gritty in health class…have to learn on their own when they go on dates…It is important to teach how to make conversation and eye contact…the formation of relationships before sex. (K.T.)” When asked some areas of sexuality that you want to know more or wish you had known more about, participants focused on sexual orientation and dating, either by wanting information about how to form romantic relationships or about LGBT groups in general. R.H. specifically wanted to learn about “LGBT sexualities, mechanics of LGBT sex and where sexual pleasure comes from.” While, S.R. wanted to know more about “dating and how to build romance as supposed to friendship…I didn’t know how to date…wanted to know how to build relationships romantically.” He also spoke about a fear of sexuality and how “there was fear instead of knowledge (S.R.).” The overlying theme with many of the interviews is the need to learn the hidden curriculum, what to do on a date, and how education would decrease the fear of the unknown in terms of sexuality.

**Sexual Harassment and Intimidation.** When asked what the important topics were in the sexuality questionnaire, all the self advocates, “zeroed in” on sexual harassment and
intimidation. The self-advocates showed a need to identify and define harassment and intimidation from both point of views. A pervasive fear specifically more prominent in male candidates was the fear of being labeled a sexual deviant. T.S. spoke about the importance of knowing what harassment is; friendly touch compared to unfriendly in order to avoid it, and to not say it is harassment when it isn’t. S.R. had a similar outlook on harassment to be taught how to “approach appropriately so it wasn’t seen as harassment.” Understanding the legal definitions of what harassment is, and what the parameters are legally may be helpful for individuals on the spectrum especially to avoid being labeled as a harasser. “Teach the legal definitions of sexual harassment, this is against the law, this definitions of rape, and you could go to prison, be very clear (N.R.).” Teaching individuals on the autism spectrum the legal definitions and assisting them in distinguishing between what is friendly compared to non-friendly and different body language may help decrease the anxiety of individuals being labeled a sexual deviant as well as decrease the amount of individual sexually assaulted. If you know the signs, it will be easier to avoid. “Just telling them the consequences would be very beneficial…(sexual intimidation) is very prevalent in our culture (M.S.).” Unfortunately, sexual intimidation does occur, the statistics are 1 in 6 boys and 1 in 4 girls will be sexually abused before the age of eighteen (CDC, 2012). All individuals need to know where they could go to get the information and assistance they need.

Everyone whether you have autism or not, needs to be taught where they can go and who they can talk to if they were harassed sexually. “I think that disabled people in particular tend to be more vulnerable to sexual violence…there needs to be more on the idea of what sexual violence is and where to for go for help. I think it would be helpful to know how to report abuse. (B.B.).” Individuals on the autism spectrum may not know information about where to go when
you feel you have been sexually intimidated or assaulted. Sexual harassment and abuse has become very prominent in our culture today, and individuals on the autism spectrum are more vulnerable, which shows the need for education on sexual intimidation, how to avoid being intimidated or the one intimidating.

**Delivery and Instruction of Sexuality Curriculum**

After specific content was explained, participants talked about how they wanted the content delivered or instructed. Open communication where sexuality was not a topic talked about in hushed voices and balanced curriculum that was unbiased and neutral were the two ways to deliver and instruct sexual information. When participants were satisfied with the formal sexuality curricula they received, there were similarities in the way the instruction was delivered. These similarities are talked about in this delivery and instruction section.

**Communication.** Sexuality needs to be a topic that is open for discussion not a taboo where individuals feel uncomfortable with certain aspects of the topic. All individuals including those on the autism spectrum should be taught to ask questions about sexuality if they are confused or need information. A.C. summarizes the need for communication sexuality, “The best way to protect people is getting them the information and not trying to pick out what you think is important for them to know” and that “talking about sexuality makes it a safe reality.”

Self-advocates interviewed saw sexuality as a topic that should be conversed. Open communication will make resources for sexuality education and different sexual needs (condoms, information about STIs and pregnancy, tampons, etc) more readily available not only for individuals on the autism spectrum, but also for all individuals. “Not understanding (sexuality) turns it into something that you can’t talk about openly (R.H.).” Everyone needs to know where to go to get information about sexuality as well as the help they may need, there
needs to be a safe network of information and assistance. “I did a lot of research for my friends, I found out where to go when you have STI symptoms and you can’t go to your parents, I ended up networking my friends together to get medicine (B.B).” There could be a network of information for individuals to learn more about sexuality and become more educated on their own needs. The first step is open communication about sexuality and all related needs; an informed sexuality curriculum could be the key to opening this communication.

**From Whom to Learn about Sex Education.** Participants talked about whom they wanted to learn sexuality from based on their own experiences. When asked by the researcher the specific question “Whom would you most want to learn sexuality from?” most said no one, they would teach themselves. To the left is a bar graph showing whom the participants would most like to hear sexuality from, parent, classroom teacher, health teacher, school nurse, and no one (I’d just like resources). It shows that most individuals wanted to research sexuality topics on their own. Before answering the question with no one, most participants went on to explain how the sexuality curriculum at their school did not have enough information and they had to continue research through blogs and books.

Some advocates had limited motivation to be apart of the school curriculum on sexuality. When asked about the formal sexuality education curriculum at her school, B.B replied, “I think my school had them but I never bothered to get the paper signed.” Advocates want schools to do...
more to motivate and talked about sexuality that is adapted to all individual’s needs. “School should do more (S.R.)” to educate individuals on the autism spectrum.

Instead of learning from their school curricula, media and other social interactions, most participants educated themselves and sought other means of sexuality education based on their experiences. When B.B started becoming interested in sex and heard in casual conversation a statement or phrase she did know, instead of asking peers, teachers or family, B.B. would research the information herself. “I wasn’t sexually active but a lot of my friends were, everyone was talking about the pull out methods…we need to talk about how it doesn’t work (B.B).” Many self-advocates interviewed would research the topics on their own in order to be educated on sexuality. Having an available sexuality curriculum for individuals on the autism spectrum would make sure that the research is accurate.

It was not an aspect of who delivered the curriculum but how effective the curriculum and information itself was, many researched for themselves because the participants were not receiving enough information from school or other venues. Those who had a sexuality curriculum that they believed they learned a lot from, continued to research for themselves, but knew they had the base that many individuals on the autism spectrum lack. The individuals who had well informed sexuality curriculum had a starting point to continue research on their own.

Chapter 6: Discussion

Need for Sexuality Education

According to the results found in this study, individuals with ASD are not receiving the sexuality education structured to their needs. Of the self-advocates interviewed, only three were satisfied with their formal sexuality curriculum. Sexuality education is important to the quality of life of all individuals, especially those with ASD. Individuals with ASD have a qualitative
impairment in social and communication skills, limiting their ability to form relationships (American Psychiatric Association, 2013). As individuals with ASD age, their social deficits may become more pronounced and appear in new areas of their life (Tullis & Zangrillo, 2013). A well-informed cumulative sexuality education for individuals with ASD will help bridge this gap and is beneficial for teaching sexuality skills (Tullis & Zangrillo, 2013). With the Center for Disease Control (2012) showing an increase in sexual harassment, education about sexual intimidation and consent is a priority. Individuals with disabilities are four times more likely to be sexually abused (Sullivan & Knutson, 2000). The results above show that individuals with ASD see the need for sexuality education in order to increase their own quality of life.

**Past Sex Education Experience**

This research opened discussion on sexuality to this limited group of thirteen self-advocates. The self-advocates had varying ideas about the adaptations of the curriculum, which was discussed in the results of the paper. Similar to Schaadasma et al (2015) whom in their systematic review of sexuality curriculum found that the content of the curriculum was not explained in detail and goals of the curriculum were broad and nonspecific.

Most self-advocates found that they were not satisfied or only slightly satisfied with their formal sexuality education. An interesting topic discussed that was not a part of the main theme was the influence of the media. All participants spoke of different aspects of media that had seen which may have effected their sexuality. One participant turned the question around on the researcher, who talked about peers and how television had a big impact. S.R. responded how it was interesting the researcher answered how television was a form of sexual education. The researcher and participant compared shows and found out that while the researcher was watching romantic comedies, the participant was watching the history and nature channel. When this
question was asked to other participants, the answers varied from Bay Watch to wildlife documentaries to murder mysteries. It was an interesting side note to see the different television shows the individuals watched and how it could have affected their views on sexuality. This access to media brings to light the importance of safe Internet use. Bethany Good & Lin Fang (2015) talk about how individuals with disabilities are more susceptible to risk and harm with media, specifically on the Internet. Self-advocates spoke about their different media outlets now and as children. There is a proposed model that aims to strengthen parent’s familiarity with techniques as well as educated individuals on traditional problem solving and social skills development, which could decrease harm on the Internet (Good & Yang, 2015). These interviews prove that individuals with ASD do access different media outlets and need to be educated.

**Differences in sexuality education for individuals who are high or low on the spectrum**

Many of the self-advocates interviewed defied the stigma of low and high functioning. The self-advocates stated that autism is a spectrum disorder, and using the labels “high” and “low” is demeaning. Recently, the American Psychiatric Association (2013) re-established the definition for Autism Spectrum Disorder (ASD) by eliminating the four different categorizes and using the umbrella term of ASD. ASD is a spectrum, meaning that there are those with more severe disabilities and those with less severe disabilities (NIMH, 2014). The self-advocates interviewed communicated that they understood that because ASD is a spectrum disorder that not all individuals can be taught the same. However, the self-advocates did not believe in the labeling of any individual into one category. Many individuals with more severe disabilities are perceived as unable to advocate for themselves because of their impairment, this research shows that self-advocates believe all individuals with ASD have the right to learn about self-advocacy.
and sexuality (Wehmeyer, 2002). There is limited research on self-advocates and their views on labeling individuals as high or low functioning but this research shows that individuals with ASD defy the idea of classifying individuals with ASD as high or low functioning.

**Content of Sexuality Curriculum**

A common theme among these focus groups was the lack of education of sexual harassment and how sexual abuse is on the rise. The research proves that these self-advocates are correct. According to the Center for Disease Control (2012), approximately 1 in 6 boys and 1 in 4 girls have been sexually abused before the age of 18. Sullivan and Knutson (2000) did a study with over 55,000 children in Nebraska and found that children who showed any type of intellectual disability were four times more likely to be sexually abused then an individual without disabilities. Individuals with disabilities are more vulnerable to this harassment. In 2007, persons with disabilities were victims of approximately 47,000 rapes and sexual assaults (McEachern, 2012). Though the research shows that men are more likely to be abusers then females (Center for Disease Control, 2012), what was not present in the research literature was the individuals who are labeled sexual deviants because of a lack of sexual knowledge. A misunderstanding of what constitutes abuse and accidentally being seen as an abuser was a pervasive fear among the male participants in this research. This idea of individuals with ASD accidentally becoming sexual deviant was not pictured in the research literature this research compiled.

The participants for these interviews had diverse sexual orientations, two individuals were gay, most were heterosexual while one participant said she was “heterosexual but not interested in dating at the moment (C.C.).” The participants spoke about how they worked past the stereotype of asexuality to find their own sexual orientation. The myths researched by
Cornelius et al (1982) support how participants spoke about asexuality. The authors (1982) identified the following myths that affect the negative perceptions of individuals on the autism spectrum and sexuality; individuals with disabilities are asexual, have uncontrollable urges, dependent and child like. Asexuality, a common topic among the participants, is one of the common myths found by Cornelius et al (1982).

Specific participants who were homosexual wanted an increase in knowledge about LGBT rights. The exploration of sexual identity is difficult for individuals with disabilities who need to understand their disability as well as their future goals (Morgan et al, 2011). A safe space for individuals with disabilities can be created with the assistance of teachers and staff. Unfortunately, many educators do not want individuals to explore their sexual identities, some portraying the explorations as bad (Aurnos & Feldman, 2002). Teachers need to be educated on how to work with individuals with disabilities and their sexual exploration (Morgan et al, 2011). All participants wanted to be educated on sexuality and be informed of groups where they could work with others as well as where they could get information about sexuality that is accurate, a safe space (Morgan et al, 2011).

**Delivery and Instruction of Sexuality Curriculum**

The self-advocates interviewed wanted a direct teaching approach that was neutral, non-bias and had accurate information. Curriculum that may be useful in teaching adolescents with ASD has a focus on directly teaching sexuality skills presented through social stories, visual slides and programs models, but there is little to no research to support (Tullis & Zangrillo, 2012). Tullis & Zangrillo focus on a direct teaching method similar to the themes of the focus groups from this research.
The Guidelines for Comprehensive Sexuality Education 3rd Edition (National Guidelines Task Force, 2004) has similar concepts and topics as the Sexuality Education Topic Questionnaire used in these interviews. Many of self-advocates interviewed viewed all the topics on the Sexuality Education Topics Questionnaire as important, showing that the Guidelines for Comprehensive Sexuality Education could be an effective tool for educating individuals with ASD about sexuality (National Guidelines Task Force, 2004).

All focus groups had at least one participant who did not know the meaning of “the hidden curriculum”. This lack of knowledge is in line with current research on individuals with ASD and the hidden curriculum. A qualitative impairment in communication and social skills includes an inability to understand the hidden curriculum (American Psychiatric Association, 2013). The hidden curriculum is everyday behavior that is not explicitly taught (Bieber, 1994). This unspoken information causes tensions in relationships for many individuals with ASD. When talking about the hidden curriculum, participants explained that a lack of understanding of different social rules like the hidden curriculum caused “a fear instead of knowledge” (S.R).

This research shows the view of self-advocates on sexuality and the different curriculum. The themes coded are comparable to those found in “Remember: Our Voices are Our Tools” by Friedman et al (2014). In both, self-advocates talked about the importance of communication and educating others on sexuality. The significance of the “Remember: Our Voices are Our Tools” was for “the expansion of research on sexual self-advocacy by bringing the sexuality and self-advocacy literatures together, reinforcing the value of people with IDD as legitimate sources of information about their own experiences, and providing a sustainable and accessible research method for working with people with IDD” (Friedman et al, 2014, p. 515). Similarly, the significance of the research conducted with these focus groups was to show that self-advocates...
have opinions about sexuality and the need for sexuality education. Specifically, the participants spoke about a sexuality education that encompasses the themes found in the results, open communication and a curriculum that has information on the dating world and sexual harassment and intimidation that is given in a neutral, non-bias tone.

**Recommendations**

The research above shows the need for sexuality education in all aspects. These interviews of self-advocates show the lack of sexuality education available in the school system, and how many found different outlets for the education, most specifically on their own. With the increase in different venues for dating and other sexuality, this researcher recommends access to a sexuality curriculum either online or in school that is specific to the results above. This researcher recommends an online curriculum where there should be sexuality curriculums used that emphasizes the needs and the learning of the autism community as well as open communication between the individuals with ASD using the website. This would be the most effective based on where these specific self-advocates accessed information; many used their own resources to find sexuality information. Self-advocates want a curriculum that is neutral, non-bias and “tells it like it is (C.C.).” Using open communication where they can be comfortable to ask questions, and have hands on demonstrations of certain sexuality topics.

**Implications**

The interviews conducted by this researcher show the views of self-advocates and their sexuality education. Many self-advocates stated that they were able to find information on sexuality themselves rather with the assistance of teachers and parents. Many participants stated that they did not receive information on the hidden curriculum from the health education their school provided. The health education that was provided to them was not adapted to their needs.
This implies there needs to be further research on how to teach individuals with ASD about their sexuality.

The research above shows that self-advocates feel that they do need sexuality education to help them become sexually knowledgeable. This also implies that the sexuality education they received in school was not sufficient in giving these self advocates the information they feel is needed to live a life that includes sexual experiences, not just sex but also dating, health and safety. According to Kalyva (2013), Teachers are not confident in their ability to teach sexuality. Kalyva’s findings indicated that only seven teachers or 12% of the teachers felt confident that they could provide sexuality education to students with ASD (2013). Though some were very satisfied with their formal sexuality curriculum, no self-advocate can state that their sexuality education was all inclusive of knowledge of dating and other hidden curriculum that would benefit individuals on the autism spectrum.

**Limitations**

There were a number of limitations in this study. It was difficult to get participants for the focus groups. Sexuality is a delicate subject and not many individuals want to have an open conversation about the topic. Self-advocacy groups are also “timid” groups, in a sense that they do not like “outsiders” coming into their groups without an “insider” inviting them. This made it very difficult to get responses from emails, until ASERT of PA assisted.

Some technical issues made it difficult to communicate via Skype, which made participants have to reschedule or have phone conversations. When video conferencing did occur, some participants were hesitant being on video and the recording of the interviews. Participant B.B. stated that she was “shy over video” and asked to “type some answers”. The sensitivity of the topic caused controversy in the recording of the interviews. Participants were
hesitant to have their conferences recorded for research purposes. One self-advocate refused to participate and believed that this was an invasion of their privacy and confidentiality, specifically using the Office of Disabilities at Penn State University to find participants. The summer season also made participants limited, especially on the Penn State campus. When Penn State University was back in session, more participants, specifically seven participants, became available to the researcher. These issues made finding participants difficult for the researcher.

Recording of interviews was limited because of the sensitivity of the topic, thereby affecting reliability and accuracy. However, interviews that were recorded were analyzed and discussed with an additional researcher (thesis advisor) in order to ensure reliability and accuracy of themes. Further the sample size was smaller than researcher anticipated; this could be because of the sensitivity of the content, or the lack of self-advocate groups that would allow research access to their group. Another limitation to this research was that the individuals interviewed chose to participate in the research, meaning that they had an interest in the topic, which may have skewed the data towards showing the need for sexuality.

The researcher based the participants’ diagnosis of autism on their word, no other details were needed. The researcher would have liked to extend the location of the self-advocates to the Midwest of America, participants were only found in California and the east coast. Finally, during large focus groups, the researchers were unable to get an accurate audio recording. With the lack of video recording it was difficult to distinguish the different voices of the different self-advocates with just audio recording. The researchers did however take notes while the focus group was occurring, specifically distinguishing, which self advocates was speaking. Both researchers took different notes and compared their information. With more researchers
available a video recording would have been more effective. Unfortunately, with limited resources and people this was not possible.

**Future Research**

In the future, researchers should create a curriculum that specifically fits the needs of individuals with ASD based on the research information given by the self-advocates in these focus groups. Since seven of the participants chose to research sexuality information on their own, an online curriculum may be the most effective way to give access to individuals on the autism spectrum. Access to conferences and other gathering of individuals on the autism spectrum may be helpful to spread information as well. Through these interviews, it is clear that these specific self-advocates are eager to learn about sexuality, want to date and want to be as educated about sexuality as possible. The self advocates showed that they see a need for sexuality education and that this knowledge of sexuality could increase their quality of life. The results show that an open conversation about sexuality could lead to the creation of a curriculum that fits the needs of all individuals, specifically those on the autism spectrum.

According to the self-advocates interviewed, this curriculum should assist with information on dating as well as making sure that everyone is knowledge about sexual harassment and intimidation. Self-advocates with ASD want a more in-depth sexuality curriculum. Future research should look into how to create this curriculum. This research is the first step in creating a well-informed balanced, neutral, chronological evidence based curriculum that spans across the lifespan of individuals with ASD, specifically during transition periods, and has open communication and content available that adapted to all individuals, whether lower or higher functioning on the autism spectrum.
Chapter 6: Conclusion

Through focus group interviews, self-advocates stated their opinions about common sexuality topics. The broad themes of content and delivery and instruction revealed additional subthemes. The subthemes within content included the importance in teaching about dating world and sexual harassment and intimidation. The subthemes within instruction and deliver included: the need for open communication and a description of whom participants believed should delivered the sexuality information. In this study, self-advocates identified the key components of a sexuality education that would be needed for individuals with ASD. These focus groups show the need for a sexuality curriculum that is adapted to individuals with ASD. Self-advocates believe that everyone should be educated on sexuality and that having this education would have been helpful for their own lives.

There was an emphasis on dating, and how the lack of knowledge of the hidden curriculum hindered their sexual growth. It is this researcher’s recommendation that there needs to be more access to sexuality education and health services for individuals with ASD. When asked about the different website she used, B.B. talked about Scarleteen, “there was one where you could ask questions...I know one that is really good today is scarleteen.” Though she could not identify any blogs in particular, R.H. talked about how the Internet and blogs were a useful resource for sexual information when she was growing up. Many individuals talked about how they researched the information about sexuality themselves, an accurate website where individuals on the autism spectrum could ask questions and educate themselves on sexuality would be a good recommendation to increase knowledge of all sexuality topics and have effective communication not only between individual on the autism spectrum but appropriate educators of sexuality.
Self-advocacy groups are an important resource for individuals on the autism spectrum to talk to one another and educate themselves on sexuality topics. Self-advocacy groups are where individuals can find people who may have had similar experiences. Self-advocates identified that education on dating, a need for communication about the topic, and identifying harassment and intimidation as important for individuals with autism. Through the words of the self-advocates, this information shows that individuals on the autism spectrum want to be educated on sexuality past what the average curriculum suggests. The individuals understood the need to teach the basic of sexuality including hygiene, reproductive organs and puberty but focused on dating and sexual harassment as well as open communication and a curriculum that uses diverse topics and is neutral.

The results of these focus groups show that self advocates believe that there is a need to teach sexuality education, specifically to help increase knowledge of dating and sexual harassment and intimidation. These self advocates want to learn as much about sexuality as possible, whether it be through a formal well-written education system of through their own means of research. The self advocates interviewed in the study come from different age, different locations and even have different sexual orientation, yet they all understand that sexuality education is not only a way to increase knowledge but to help make sure that individuals on the autism spectrum are safe and secure in their sexuality.
Appendix A: Sex Education Topic Questionnaire

<table>
<thead>
<tr>
<th>Topic</th>
<th>High Functioning</th>
<th>Low Functioning</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td><strong>Sexual Anatomy</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Understanding the importance of learning about sex &amp; relationships</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Puberty</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Understanding the meaning of slang words &amp; the correct terminology for anatomical details</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Private vs. public places</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Private body parts</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Female sexual anatomy &amp; physiology</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Male sexual anatomy &amp; physiology</td>
<td></td>
<td></td>
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<tr>
<td>8. Body image</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Talking about sex with the appropriate audiences</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Reproductive Health</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Preventative health</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Understanding the internal female reproductive organs functions &amp; ovulation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Understanding menstruation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Understanding the internal male reproductive organs functions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Fertilization /reproduction/how pregnancy occurs</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Sexual Responses &amp; Partnered Sex</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Understanding the human sexual response cycle</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Masturbation of self</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Masturbation of others (mutual)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Understanding physical intimacy with a partner/intercourse</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
5. Understanding slang terms for self-intimacy & intimacy with a partner

6. Sexuality as positive aspect of self

7. Sexual orientation

8. Sexuality across the life span

9. Feelings and emotions related to relationships

10. Appropriate personal space

### Sex Education Topic Questionnaire

<table>
<thead>
<tr>
<th>Topic</th>
<th>High Functioning</th>
<th>Low Functioning</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Contraception &amp; Sexually Transmitted Infections (STIs)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Understanding why we need to learn about contraception options</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Knowing contraception options &amp; being able to use them</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Sexually transmitted infections</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Who makes the decision about how to prevent pregnancy or STIs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Abstinence</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Consequences of sex: abortion</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Consequences of sex: pregnancy</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Introduction to Dating</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Understanding what dating is &amp; how it relate to other relationships</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Becoming aware of own sensory sensitivities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Preparing to Date (i.e., physical appearance, independence, social skills, &amp; psychological state)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Hidden curriculum rules</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>The Dating World</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Finding someone to date</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
2. Picking successful places/activities for a date
3. Social communication skills needed on a date
4. What to do after a date
5. Developing a romantic relationship

<table>
<thead>
<tr>
<th>Stages of Relationships &amp; Maintaining relationships</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Understanding that relationships consist of stages</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sex Education Topic Questionnaire</th>
<th>High Functioning</th>
<th>Low Functioning</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Topic</strong></td>
<td><strong>Yes</strong></td>
<td><strong>No</strong></td>
</tr>
<tr>
<td>2. Having realistic expectations of how long it takes to develop a relationship</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Responsibilities in dating</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Responsibilities in marriage</td>
<td></td>
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</tr>
<tr>
<td>5. Responsibilities in parenthood</td>
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<tr>
<td>6. Understanding that maintaining a long-term relationship takes work</td>
<td></td>
<td></td>
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<tr>
<td>7. Family types and roles</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Sexual Intimidation:**

<table>
<thead>
<tr>
<th>Harassment, Aggression, &amp; Abuse</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Abusive behavior in a relationship</td>
</tr>
<tr>
<td>2. Understanding harassment &amp; why it is a problem</td>
</tr>
<tr>
<td>3. Understanding sexual aggression &amp; illegal sexual behaviors</td>
</tr>
<tr>
<td>4. Understanding use of technology &amp; cyber space</td>
</tr>
<tr>
<td>5. Avoiding coercion/saying “no”</td>
</tr>
<tr>
<td>6. Personal decision making</td>
</tr>
<tr>
<td>7. Identifying personal values</td>
</tr>
<tr>
<td>8. Alcohol and drug use</td>
</tr>
</tbody>
</table>
### Appendix B: Demographics Sheet

<table>
<thead>
<tr>
<th>Focus group/Self advocates</th>
<th>Date</th>
<th>Time</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>Your age</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• 18-19</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• 20-24</td>
<td></td>
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<td></td>
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<tr>
<td>• 25-29</td>
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<tr>
<td>• 30-34</td>
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<td>• 35-39</td>
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<tr>
<td>• 40-44</td>
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<tr>
<td>• 45-49</td>
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<tr>
<td>• 50-54</td>
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<td></td>
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<tr>
<td>• 55-59</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>• 60+</td>
<td></td>
<td></td>
<td></td>
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</tbody>
</table>

| Your gender                |      |      |          |
| Male                       |      |      |          |
| Female                     |      |      |          |

<table>
<thead>
<tr>
<th>List the venue you learned about sexuality</th>
<th>Did you receive FORMAL sex education in school</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>If yes, rate your satisfaction with the training</td>
</tr>
<tr>
<td></td>
<td>Very satisfied</td>
</tr>
<tr>
<td></td>
<td>Somewhat satisfied</td>
</tr>
<tr>
<td></td>
<td>Not satisfied</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>List some areas of sexuality that you want to know more about or wish you had know more about</th>
<th>Rate your comfort level</th>
<th>Who would you most like to hear sexuality from?</th>
</tr>
</thead>
<tbody>
<tr>
<td>High</td>
<td>High</td>
<td>Parent</td>
</tr>
<tr>
<td>Medium</td>
<td>Medium</td>
<td>Classroom teacher</td>
</tr>
<tr>
<td>Low</td>
<td>Low</td>
<td>Health teacher</td>
</tr>
<tr>
<td></td>
<td></td>
<td>School Nurse</td>
</tr>
<tr>
<td></td>
<td></td>
<td>No-one, I’d just like resources</td>
</tr>
</tbody>
</table>

| Did you have any difficulties you encountered due to lack of knowledge? If yes, please list. | |
|------------------------------------------------------------------------------------------------|
Appendix C: Informed Consent Form

Title of Project: Stakeholder’s Perceptions of Socio-sexuality Curriculum for Individuals with ASD

Principal Investigator: Pamela S. Wolfe, 212A CEDAR Building Penn State University, University Park, PA 16803 Ph 814-880-2575, email: psw7@psu.edu, Fax: 814-863-1002

Purpose of the Study: To identify components of a socio-sexuality curriculum for individuals with Autism Spectrum Disorders (ASD) from stakeholders.

1. Procedures to be followed: I’m Pamela Wolfe, an associate professor at Penn State University. As part of my research at Penn State, I am interested in finding out about curriculum for individuals with autism spectrum disorders (ASD) on issues related to social and/or sexual issues. I am asking you, as a stakeholder, to participate in a focus group. Because your participation is so critical, I will reimburse you $40 for your valuable time. As you may know, social/sexual issues can be very difficult for children having ASD. I hope that this research may help individuals with ASD have access to information that will inform them how to interact with others and make safe choices.

The focus group will be conducted in person or via Skype-whatever is most convenient for you. In the session, lasting about 2 hours or less, I will ask you to identify content that you believe is useful for individuals with ASD ages 13 or older to know. You will be asked to look at a list of categories that typically are included in socio-sexuality curriculum and then identify 3 concepts that you think are critical for the individual with ASD to know. I have attached a sample of possible topics for you to see as well as some example photos (all non explicit).

The sessions will be videotaped so that I can make sure that I have accurately recorded your ideas. You can decide not to participate at any time during the study. You can also feel free to ask questions or voice concerns at any time. My number is 814-880-2575 if you’d like to discuss any issues/concerns.

Social/sexuality information is difficult to teach. Social skill challenges for students having autism can make social/sexual education even more difficult. It is important that individuals having ASD learn to make decisions about socio-sexual issues that are safe and appropriate. This study has the potential to identify what to teach students with ASD about appropriate/inappropriate social and sexual behavior. Because there is very limited information about this topic, your participation can greatly affect what is taught in social/sexual education.

2. Discomforts and Risks: There are no risks in participating in this research beyond those experienced in everyday life. Some of the questions are personal and might cause discomfort.

3. Benefits: The benefits of the study may inform the field of special education by clearly identifying topics that should be included in socio-sexuality curriculum from a variety of perspectives.

4. Duration/Time: You will be asked to take part in a 2 hour focus group. For your time, you will receive $40.00.
5. **Statement of Confidentiality:** Your participation in this research is confidential. The data will be stored and secured in my locked office in a locked file cabinet. Only I or my transcriber will have access to any information from the study. All of the videotapes will be kept in my locked office in a locked filing cabinet. Your name will not be used individually after the information is coded from the videotapes. The videotapes will be destroyed 5 years after the study has finished. Penn State’s Office for Research Protections, the Social Science Institutional Review Board and the Office for Human Research Protections in the Department of Health and Human Services may review records related to this research study. In the event of a publication or presentation resulting from the research, no personally identifiable information will be shared.

6. **Right to Ask Questions:** Please contact Pamela Wolfe at (814) 880-2575 with questions, complaints or concerns about this research. You can also call this number if you feel this study has harmed you or your child. Questions about your rights as a research participant may be directed to Penn State University’s Office for Research Protections at (814) 865-1775. You may also reach me at 814-880-2575 24 hours per day during the study if you have any questions. My office address is 212A CEDAR; my e-mail address is psw7@psu.edu. At any time during the study, you are free to ask questions. You can withdraw from the study at any time.

7. **Voluntary Participation:** Your decision to be involved in this research is voluntary. You can stop at any time. You do not have to answer any questions you do not want to answer. Refusal to take part in or withdrawing from this study will involve no penalty or loss of benefits you would receive otherwise.

You must be 18 years of age or older to consent to be part in this research study. If you agree to take part in this research study as outlined in the information above, please sign your name and indicate the date below.

You will be given a copy of this consent form for your records.

_____________________________  ______________________
Participant Signature Date
Appendix D: Reimbursement Form

Name:______________________________ Date:____________________

SS#______________________________________________

Address:______________________________________________________________________

I agree that I have received $40 (cash) for my participation in the research study Stakeholder’s perception of socio-sexuality curriculum for individuals with ASD conducted by Dr. Pamela Wolfe and/or colleagues.

Signature_______________________________________________________

IRB# PRAMS000045681
References


Travers, J., & Tincani, M. (2010). Sexuality education for individuals with autism
spectrum disorders: Critical issues and decision making guidelines.


Wehmeyer, M. (2002). *Self-determination and the education of students with disabilities*. Reston, VA: ERIC Digest,