2015

The birds and the bees can have canes and wheels : the sexual identity formation of women with visible physical disabilities

Clara J. Miller
Smith College

Recommended Citation

Miller, Clara J., "The birds and the bees can have canes and wheels : the sexual identity formation of women with visible physical disabilities" (2015). Masters Thesis, Smith College, Northampton, MA.
https://scholarworks.smith.edu/theses/668

Clara J. Miller
The Birds and the Bees Can Have
Canes and Wheels: The Sexual
Identity Formation of Women with
Visible Physical Disabilities

ABSTRACT

The study descriptively examines the views women with visible physical disabilities have on their sexual identity formation. For the purposes of this study, the term sexual identity is defined as an awareness of one's self as a sexual being. 158 self-identified women with visible physical disabilities answered survey questions about their experiences during their adolescent years. Overall, this study found that women with disabilities face the same difficulties as their abled-bodied peers, but face additional struggles having to do with their disability when forming their sexual identity.

THE BIRDS AND THE BEES CAN HAVE CANES AND WHEELS: THE SEXUAL IDENTITY FORMATION OF WOMEN WITH VISIBLE PHYSICAL DISABILITIES

A project based upon an independent investigation,
submitted in partial fulfillment of the requirements
for the degree of Master of Social Work

Clara J. Miller

Smith College School for Social Work
Northampton, Massachusetts 01063

2015

ACKNOWLEDGEMENTS

There are so many people in my life who have supported me throughout this year, without whom this thesis would not have been possible. I wish to thank my thesis advisor, Elaine Kersten, for her time, support and encouragement. You made this thesis process possible and I am so grateful for all that you have done for me.

I also want to thank my mom. Thank you so much for helping me with all of the edits and support throughout the entire process. And thank you dad for all of your support through this thesis. Also, I would like to thank both of you for all of your love, encouragement and for being there for me throughout my life.

TABLE OF CONTENTS

CHAPTER

APPENDICES

LIST OF TABLES

Table

CHAPTER I

Introduction

The purpose of this study is to gain knowledge about the sexual identity formation of women with visible physical disabilities. For the purposes of this study, sexual identity formation can be defined as developing an awareness of one's self as a sexual being. Sexual identity develops from a multitude of interactions including the cultures view on sexuality, peer interactions, and the existence of role models to simulate (Juhasz & Sonnenshein-Schneider, 1987). Another important element of sexual identity formation is experimenting with ways to act in romantic relationships, which occurs when adolescences go on dates (Auslander et al, 2006). However, it is also true that sexual identity formation does not always evolve in this manner for people with physical disabilities. Adolescents with disabilities receive a significantly smaller proportion of sexual information from peers than non-disabled adolescents. The information they do receive is often a vague and distorted understanding of sexuality (Brown, 1988). The results of my study provide a deeper understanding about what women feel has both positively and negatively effected their sexual identity formation. Further, my study highlights areas of various forms of sexual education and other communications regarding sex for this population. Ultimately, the study can be used to inform clinical and school social workers about things to pay attention to and how to proceed while in discussions regarding sexual experience and formation with their clients who live with disabilities.

The over-arching research area of study is to find out what women with visible physical disabilities say has effected their sexual identity formation. For the purpose of this study, a visible physical disability is defined as a disability that effects physical tasks of daily living, such as walking, seeing, or hearing, that is also identifiable to someone else who sees them in the community. This focus was used to gather information about how having a visible physical disability may effect participant sexual identity formation, and thus, identify areas that social workers can be aware of when talking with their clients.

Historically, there has not been much research done in the field regarding sexuality and disability. Many of those studies that have been done have either addressed the education that professionals receive regarding it, or have only included male subjects. In one study done by Hasson-Ohayon et al. (2014), university students were instructed to read one of six randomly selected vignettes then fill out an attitude scale. The 6 vignettes were of a male with either a physical, psychiatric or no disability who was either involved or not involved in a sexual relationship. This study showed that reading about the man with a physical disability involved in a sexual relationship generates more positive attitudes towards the person than if they were not in a sexual relationship. The authors say that being in a sexual relationship conveys to others that the individual is not so absorbed by their disability that sex becomes irrelevant, that they have opportunities for sexual relations, and that they are not helpless, childlike or asexual. However, this study does bring up some important questions. One is what influences a person with a disability's sexual formation that enables them to get a partner in the beginning. Another is that the limited research to date has not included focus on women.

In her paper, Weeber (2005) explains that disability identity develops in a dual-dimensional process between integrating disability positively into one's sense of self and oneself into the disability community. She notes that having time with people of the disabled community may help to form that identity. But that integration is sometimes difficult to achieve. One of the major ways adolescents form their sexual identity is through having role models. But those with disabilities tend to lack peers, parents and professionals who have a disability and are in a sexual relationship. This lack of role models gives the teenager negative or confusing messages regarding his/her future possibilities of relationships (McKown, 1984). There is a need to have more direct research done in this field in order to expand upon the dialogue and examine more about the experiences of sexual identity of women with physical disabilities. This study attempts to fill that gap.

For the purposes of adding to this phenomenon, while preserving the privacy to participants, data collection utilized an internet based survey, ensuring participants' anonymity. I used SurveyMonkey to survey women with visible physical disabilities on their thoughts about their sexual identity formation. The survey based, quantitative study design included a set of survey items and also included several qualitative, open ended, questions in order to enable participants to share more detail if they choose. The study design was descriptive in nature, with the goal to gain general information regarding participants' perspectives and experience regarding their sexual identity formation.

CHAPTER II

Literature Review

In order to establish a basis for the importance and relevance of the study topic of sexual identity formation by women with visible physical disability, a review of the literature is presented reflecting several key content areas. Sexual identity formation in general will be presented in order to establish how researchers present this aspect of human development experience. Next, literature will be reviewed about the differences between men and women in their sexual identity formation specifically. The third section will examine general issues people with physical disabilities face when forming their identity as a whole; specifically what unique experiences they have that affect their experiences growing up. The forth section will then examine what literature is available on sexual identity formation for people with visible physical disabilities. Finally, the review will culminate in a look at the literature that establish the differences of sexual identity formation for men and women with visible physical disabilities. The content area is important as it suggests that study is indicated in the area of the woman experience.

General Sexual Identity Formation

Sexual identity formation is an important task of adolescent development. Adolescent sexual identity formation has been shown by Fingerson (2005) and Miller & Fox (1987) to be the result of many contributing factors such as peer relationships, family relationships and personality traits. As Connolly, Furman and Konarski (2000) notes, each of these factors combine in unique ways for each individual as they evolve their notion of their sexual identity. The important elements of general sexual identity formation will be discussed below and will reflect an understanding through contributions made by several key researchers in the area. First important theories behind sexual identity formation will be reviewed as examined by other important authors in the field (Eliason, 1995; Juhasz & Sonnenshein-Schneider, 1987; Miller & Fox, 1987). Then more specific factors throughout adolescence and the differences in the three stages of adolescences will be looked at through more recent studies from Connolly, Furman and Konarski (2000), Feldman, Holowaty, Harvey, Rannie, Shortt and Jamal (1997) and Crockett, Bingham, Chopak, and Vicary (1996) whose research has increased the knowledge in this topic area. Finally, a few specific considerations for homosexual development as understood by Auslander, Rosenthal and Blythe (2006) and Furman and Wehner (1997) will be stated.

Theories. Sexual identity formation has had a long history in the social sciences. Many theorists contributed to our understanding of how we humans form our sexual identity. Four of the major sexual identity formation theorists are Sigmund Freud, Erik Erikson, Lawrence Kohlberg and James Marcia. All four have theories of human development, each of which collectively help us understand the formation of sexual identity. Each built upon the others' ideas, and since they provide a broad view of sexual identity, each will be reviewed from the perspective of other sources who have done sexual identity formation research themselves, in order to gain an understanding of how we become sexual beings.

Beginning in Europe in the 19th century, Sigmund Freud formed some early understanding of sexual identity based on observations he made in his case study reviews. As a result of his case observations, Freud noted that sexual identity formation begins from shortly after an individual is born and continues to develop throughout all of the psychosexual stages

(Eliason, 1995; Miller & Fox, 1987). According to Freud, a contributing influence in sexual formation was based on early childhood experiences. It was important for a child to develop relationships with both the same and opposite sex parent (Miller & Fox, 1987). This continuous evolution of relating will have a significant impact on the child throughout development. Freud goes on to talk about the fact that during what he terms “the genital phase”, boys could develop castration anxiety and girls could develop penis envy. This development unfolds in the phallic stage with the Oedipal complex where the child learns to repress sexual desires for the opposite-sex parent and identify with the same-sex parent. Assuming this complex resolves successfully, then once the individual reaches maturity, they will select a partner of the other gender (Eliason, 1995).

Freud’s (2000) theory of infantile sexuality describes how an adolescent develops sexually. The theory offered by Freud suggests that as children grow into their adolescence, they experience a sexual appetite that is full of erotic meanings and it is completely pleasure seeking. When the individual is in the preadolescence latency stage, these feelings are repressed so that socialization can continue to be learned. But when it is awakened during puberty, the adolescent must learn how to subdue their early infantile urges in order to fit the socially developing self. They must also not completely suppress the urges, but learn to express them in ways that are socially acceptable (Juhasz & Sonnenshein-Schneider, 1987).

Erik Erikson had a different view of adolescence. Erikson noted that identity development represents a key function of the adolescent experience. Once identity development is achieved, it leads to individuality. The process to personal identity and individuality was not meant to be an easy journey. Erikson believed that in order to work through developmental tasks, the adolescent needed to experience some kind of personal turmoil or conflict. Erikson calls this experience ‘identity crisis’. Erikson suggested that it is in resolving this ‘identity crisis’ that the capacity for forming healthy intimate relationships is developed. (Eliason, 1995; Juhasz & Sonnenshein-Schneider, 1987).

Lawrence Kohlberg based his theory on the previous work of Freud and Erikson. As part of Kohlberg’s theory, he emphasized the importance of the level of cognitive development in decision-making, which is important when forming a sexual identity. In order to be able to make smart choices, the individual must have reached the capacity for formal operational thought, which is the ability to rationalize, justify and put the pieces together. Along with this emphasis, he agreed with Freud and Erikson on four points regarding adolescent sexual formation. Sexual expression is effected by many aspects of development, not just aspects that seem sexual, but from all kinds of experiences. Second, sexual actions vary tremendously across various sociocultural events. Next, puberty and sexual activity are not the same thing, and effect people in different ways depending on other factors. Lastly, the expectations of society influence how adolescents determine their level of sexual activity (Juhasz & Sonnenshein-Schneider, 1987).

James Marcia took a different approach from the previous theorists, describing identity in terms of existence in different states of statuses depending on whether exploration and commitment were present. In developing a sexual identity, a person goes through four stages. However, depending on the situation, the individual does not necessarily go from one stage to the next, they may step back a stage depending on where they are or who they are with. The first stage is diffusion, which is when the person has no active sense of identity and they have neither explored it nor committed to any identity. The second stage is foreclosure. In this stage the person has accepted an identity that may have been imposed on them by another or by society’s expectations without critique or exploring options. The third stage is moratorium, which is when the person is active in exploring options, but has not yet made a commitment to an identity. Finally, the last stage is achievement. This is when the process of moratorium has been completed and the person consciously commits to an identity (Eliason, 1995).

Factors effecting sexual identity formation during adolescence. The four major theorists developed a baseline from which other researchers based their studies on. These researchers identified a few specific factors that influence individuals' sexual identity formation. While there are many factors that have an influence over the entirety of adolescence, there are also some considerations that pose a greater impact on a specific stage of adolescence. In order to get a clear picture of sexual identity development, the literature on factors effecting the entirety of adolescence will first be considered followed by specific influences on the three stages of adolescence.

Peer relationships have been identified as being a major source of influence for developing sexual identity. Studies asking teenagers what they believe has influenced their sexual experience, consistently underscore the importance of friends, peers and media as key sources (Fingerson, 2005). However, the specifics of how peer relationships effect sexual behavior seems to be in debate. In Crockett, Bingham, Chopak, and Vicary's (1996) study they found that poorer peer relations were associated with later timing of the first intercourse experience and higher self-esteem was associated with earlier timing. Prior to this study, researchers found the opposite relation, that poor psychosocial adjustment was correlated with participating in intercourse early in life. This study opened the possibility that the combination of having positive peer relations and a positive sense of self contributes to having an easier time finding a sexual partner, and thus, leading to the possibility of engaging in sexual behavior earlier. Future study needs to be conducted to validate that hypothesis.

Connolly, Furman and Konarski (2000) conducted a longitudinal study to see how friend groups and peer networks could influence romantic relationships. In this study, the authors focus on influences for romantic love. Though not directly about sexual identity formation, this study does highlight peer influences. One of the study's major findings was that individuals who have small groups of close friends predicts the emergence of future romantic relationships. This finding supports Erikson's notion that learning socially acceptable behavior can lead to personal experimentation and discovery in a safe and friendly environment.

Another major factor in sexual identity development is the role of parents and family. Mothers' experiences and thoughts around sex have a major impact on the sexual discovery and experimentation of their adolescent children (Fingerson, 2005; Crockett, Bingham, Chopak & Vicary, 1996; Miller & Fox, 1987). In addition to the influence of mothers' values, the type of family structure may also influence sexual identity formation. For instance, in their study, Crockett et al. (1996) found that living in a non-intact family and having a teenage mother were associated with an earlier timing of sex. An explanation of this finding could be that the teenagers' model and norms are that of early or non-marital intercourse, thus giving off the perception that the family is accepting of such behavior.

Adolescents take their perceptions of parental supervision and what their parents believe into account when they make decisions regarding sex (Fingerson, 2005; Miller & Fox, 1987). Parental supervision is correlated to the postponement of sexual activity even though it is not the actual supervision, but the meaning adolescents may assign it. When investigating parents' knowledge regarding the sexual experiences of their adolescents, it was found that parents are not effective in controlling adolescents' activities or of even knowing about them. Most of the parents surveyed relied on voluntary reports and were unable to predict their child's level of intimacy involvement. However, if the adolescent perceived that the parent was supervising them, they were found to be more likely to postpone intimacy involvement. This may be due to the adolescent interpreting the supervision as caring and concern, and could be used as proof to them that they are important to their parents (Miller & Fox, 1987). However, as another study shows, if that supervision turns into having an open dialogue about sex between the parent and the adolescent, it can mean that there is a greater likelihood of the teenager having had sex. But the stronger the connection is between the mother and the adolescent, the less likely the adolescent is to have had sex (Fingerson, 2005). An adolescent reads what the atmosphere and view of sex is in their family and uses that information to help inform their own sexual behavior and choices.

Another contributing factor to an adolescent's sexual identity development is the presence of risky behavior. Engaging in various forms of risky behavior has been associated with the earlier initiation of sexual behaviors. Behaviors such as alcohol and illicit drug use, drinking and driving, and smoking are some of the activities found to be connected to early sexual behavior. When looking at specific sexual experiences, adolescents are less likely to be a virgin if they have previously engaged in other sexual behaviors such as masturbation or oral sex (Feldman, Holowaty, Harvey, Rannie, Shortt & Jamal, 1997). Engaging in some risky behaviors makes the adolescent more likely to engage in other risky behaviors. Part of this may have to do with having a certain personality type, specifically having a Type II personality, which is characterized by risk-taking and a desire for excitement, thrills and danger. A Type II adolescent is more likely to take risks and engage in this kind of behavior sooner than other personality types (Miller & Fox, 1987).

There are some other factors that the literature has identified as having an effect on sexual identity formation. In a study that looked at factors that influence virginity, one of the contributing factors was how much homework participants did each week. If the adolescent did 5 or less hours of homework per week they were less likely to be a virgin, versus if they did 14 or more hours of homework per week they were more likely to be a virgin (Feldman, Holowaty, Harvey, Rannie, Shortt & Jamal, 1997). Another main factor was guilt. Adolescents who have less guilt associated with having sex are more likely to engage in it. For adolescents, guilt often originates from negative attitudes about sex coming from their parents and other cultural sources (Fingerson, 2005).

Effects of the three stages of adolescence on sexual identity formation. Adolescence is a period of time where individuals are going through rapid growth and development. Due to the nature of adolescence, each year holds great importance and there are different milestones and experiences that are typically associated with the various stages. In order to study these differences, adolescence can be divided into three stages: early, middle and late. Each stage is associated with different factors in a person's formation of a sexual identity.

Early adolescence is defined as the range of ages 10 to 14 years. During this time, adolescents find the most important factors of a romantic relationship are physical attraction and companionship. They are less concerned with forming a romantic relationship that fulfills their attachment, caregiving and sexual needs (Auslander, Rosenthal & Blythe, 2006; Furman & Wehner, 1997). While many early adolescents express an interest in romance, their actual participation in such relationships is very infrequent and if it does occur it is usually done through brief, nonexclusive relationships with the majority of dating happening in a group setting (Auslander, Rosenthal & Blyth, 2006; Connolly, Furman & Konarski, 2000). Typically, during this time the adolescent will begin to understand how they should act and feel in romantic relationships, how to interact with someone they are attracted to, how to engage in sexual activity and what sexual activities to engage in by determining what actions are deemed acceptable by their peers (Auslander, Rosenthal & Blyth, 2006; Furman & Wehner, 1997). Some researchers have found that those who have sexual experiences during this time are more likely to also be participating in activities such as alcohol or other substance use (Feldman, Holowaty, Harvey, Rannie, Shortt & Jamal, 1997). While often society may attribute engaging in risky behavior to having low self-esteem, one study found an association of high self-esteem with an earlier timing of sexual intercourse. This could be due to an individual with high self-esteem having an easier time attracting a partner than if they had low self-esteem (Crockett, Bingham, Chopak & Vicary, 1996).

Middle adolescence ranges from age 15 to 17 years. This time is an important period of transition. Adolescents become more sexually experienced and the quality of the relationships becomes more layered. Importance transitions from being physically attractive and concerned with how the relationship will effect their status amongst peers to having a relationship that has reciprocity and commitment (Auslander, Rosenthal & Blyth, 2006; Furman & Wehner, 1997). In the US 40% to 50% of middle aged adolescents report being in a current romantic relationship that has lasted at least a few months (Connolly, Furman & Koarski, 2000; Furman & Wehner, 1997).

The period of late adolescence spans from ages 18 to 20 years. During this time, relationships become deeper and importance is placed greatly on reciprocity, commitment, and attachment especially as the role of parents change and there is a need to fill the spot of a new primary attachment figure (Auslander, Rosenthal & Blyth, 2006; Furman & Wehner, 1997). By this time of development, most people will have had experienced a romantic involvement of some degree of intensity (Connolly, Fourman & Konarski, 2000). However, in one fairly recent study, the results found were different than earlier findings from similar studies. Crockett et al.'s (1996) study found that poorer peer relations were associated with a later timing of first intercourse where as earlier findings contributed later timing with poor psychosocial adjustment. This difference in finding could be explained that by having poor peer relationships it may mean that the individual has not developed the social skills required in developing a romantic relationship, and thus, delaying the timing of it.

Considerations specific to homosexual adolescents. While many of the theories of the factors that influence sexual identity formation can be applied to heterosexual and homosexual adolescents, there are a few special considerations to be aware of when specifically considering homosexual adolescents. As adolescents become aware of their sexual orientation, their feelings of sexual attractions may vary and may manifest in the form of emotional feelings, physical feelings, or both and may change over time. It is therefore important not to place labels before the adolescents develop their identity and label it for themselves (Auslander, Rosenthal & Blyth, 2006). One aspect that may be of more importance to lesbian, gay, bisexual youth than in heterosexual youth is the importance of passionate friendships. These platonic yet intense friendships may lead to experimentation and learning about who they are attracted to (Furman & Wehner, 1997). Once the adolescent determines that they are homosexual, they will either "come out" or hide their true feelings from people. This choice will impact their lives in particular ways, which varies from person to person. In one study, self-identified heterosexual students were asked to write a paper on their sexual identity and the ways in which it effected their lives. Many of the students were unaware of what it means to be heterosexual in this society and what that meant for themselves (Eliason, 1995). This may be related to the view that heterosexuality is the societal norm, and those who are not must “come out” as such. The self-awareness component to sexual identity formation may differ in intensity between heterosexual and homosexual youths, but it is an important component for all adolescents to grapple with.

Section Summary. As adolescents grow older, it is important for them to have support from their parents, communities and clinicians in order to form close and connected relationships with peers and in order for them to develop appropriate and healthy ways to express their own sexuality (Auslander, Rosenthal & Blythe, 2006). It can be seen from the literature reviewed that influences such as peers, parent and family structure provide a major basis for how sexual identity is formed. Another important factor that contributes to sexual identity formation is the gender identity of the adolescent. In the next section gender differences will be discussed on how they contribute to sexual identity formation.

Role of Social Influences on Sexual Identity Formation: Differences Between Males and Females in Our Culture

Sexual identity formation of adolescents is effected by many factors. One of those factors is the person’s gender. Being a male or a female will include specific influences that are important to recognize. As noted by McElwain, Grimes & McVicker (2009), sexual identity formation is found to be influenced primarily by societal differences associated with being male or female. In this section, research reflected in the work of such authors as Morgan (2012), McElwain, Grimes & McVicker (2009) and Baumeister (2000, 2004) is examined in terms of their understandings regarding gender differences in sexual orientation. Then specific differences in the experiences of males and females is examined based on the literature from important authors in the field such as Fingerson (2005), Feiring (1996) and Blyth & Foster-Clark (1987).

Sexual orientation. Sexual orientation is one of the many elements that construct an adolescent's sexual identity. The process of identifying which sexual orientation fits an individual is different for everyone, however research has shown some distinct differences between males and females in navigating and exploring sexual orientation.

One of the key differences between males and females seems to be found in the sexual orientation process during childhood. In his 2012 study, Morgan concluded that men were less likely to explore their orientation than women. According to models of the sexual orientation of males, their orientation is determined from a sequential developmental path. This path begins with a sex act that then later develops into an emotionally committed relationship. Having the path begin with a sex act, which is a physical action, further supports the theory that male sexual identity is based on biology. Once a male has had sex, with either a male or female, it is very likely that will be his preferential gender for romantic relationships and it is likely to stay that way and manifest itself through his attitudes, behaviors and desires. These models of male sexual orientation suggest that the qualities of male sexuality are stable and are most likely based in evolutionary and biological factors (McElwain, Grimes & McVicker, 2009; Baumeister 2000, 2004).

According to some authors, women, appear to be more likely than men to experiment and consider different sexual orientations. Overall, female sexuality tends to be more flexible whereas males seem to stay committed to their sexual orientation as typically determined by their first sexual encounter (Eliason, 1995; McElwain, Grimes & McVicker, 2009; Morgan, 2012). It appears that women's flexibility with their attractions may make it difficult to define their sexual orientation into exclusive categories. Female sexual orientation tends not to fit into a set label, instead, according to the social constructionist model as offered by DeLamater and Hyde (1998), female sexuality is constructed by culture so it changes based on the context of the individuals experiences (McElwain, Grimes & McVicker, 2009). This concept is also supported by Baumeister (2000, 2004) whose idea of female erotic plasticity suggests that women are more likely to base their sexual attitudes, desires, decisions and behaviors on the contextual and societal meanings that are at play when they are expressing their sexuality. However, this view is not entirely agreed upon as some view sexual orientation as solely based on an inbred nature that they are born with, and not having anything to do with the environment.

While sexuality and sexual orientation have some bases in biology, they have a greater effect on males who feel the pressure to express their sexuality during adolescence (McElwain, Grimes & McVicker, 2009; Crockett, Bingham, Chopak & Vicary, 1996; Miller & Fox, 1987). When it comes to starting a relationship, boys put the focus on their partners' physical attraction and sexual relations experienced with the partner. In studies, such as one by Feiring (1996), boys did not show high levels of intimacy to their romantic partners or their friends. They instead base their connections on joint activities and companionship. However, research on adult males indicates that males often use their romantic partners as primary confidants. This suggests that as the male ages, intimacy as self-disclosure becomes more important. The findings could also be a product of the research design as 15-year-old adolescents were asked their thoughts about themselves, so the males may have felt reluctant to state intimacy and support as being important aspects of a relationship due to traditional masculinity stereotypes (Feiring, 1996). Another aspect that is typical of male relationships is that adolescent boys are more likely to date people who are younger than them than adolescent girls are likely to do (Blyth & Foster-Clark, 1987). This developing theme of surface level connections found by the above researchers also applies to connections adolescent males have with their family members. For boys, having a direct verbal connection with their family members is more impactful than an indirect and nuanced connection when learning about the sexual norms of the family, which then influences their sexual identity (Fingerson, 2005).

Social influences. With females, sexuality is mainly based on emotional intimacy and less on biological influences (McElwain, Grimes & McVicker, 2009; Feiring, 1996; Blyth & Foster-Clark, 1987). Growing up, girls are socialized to be more expressive of their feelings. They are expected to be relationship and caregiving oriented (McElwain, Grimes & McVicker, 2009; Crockett, Bingham, Chopak & Vicary, 1996; Feiring, 1996). This socialization and approach to relationships first takes shape in family connections, then in their friendships growing up, subsequently translating into approaches for romantic relationships once adolescence is reached. As girls grow up, it is important in identity transmission, and specifically for sexual norm transmission, to have and maintain a good emotionally intimate connection with their mother (Fingerson, 2005). With every mother daughter relationship the level of connection is different, but the level does effect the adolescent's sexual identity. For example, in a study done by Miller and Fox (1987) sexually inexperienced daughters rated their relationship in more positive terms with their mother than sexually experienced daughters do.

Another aspect that can effect sexual identity formation is the types of relationships adolescents have with their friends. Girls are more likely than boys to have higher levels of intimacy with their friends. They are more likely to share their feelings and they value having intimate knowledge of and having intimate conversations with their friends. When females begin to have romantic relationships, they mention that they value the intimacy and support they get from them. This suggests that there is some degree of continuity in girls' perceptions of the importance of intimacy in all types of relationships in their lives (Feiring, 1996; Blyth & Foster-

Clark, 1987). Girls base their relationships on mutual support and the practice of self-disclosure. These actions form the basis for the emotional intimacy in relationships they will typically have in various aspects of their life. In addition to emotional intimacy, girls mention that another benefit of dating is gaining social status (McElwain, Grimes & McVicker, 2009; Feiring, 1996). This supports another finding that girls are more likely to want to date in a group. The need to feel loved and connected, coupled with an anxiety of being rejected and not sex driven supports these female characteristics (Feiring, 1996).

Two other elements that effect the sexual identity formation of females are social influences inherent in education and power. Due to the historical nature of power in this society, men hold greater power physically, socially and politically. Because of this, women, who have less power, have had to learn how to adapt in order to fit into the society (McElwain, Grimes & McVicker, 2009). This concept is seen in the study by Short, Succop, Mills, Stanberry, Biro and Rosenthal (2003) where adolescent girls were asked about the exclusivity in their relationships. One of their findings was that girls who felt that their boyfriends had seen someone else when they were together were more likely to report that they have also seen someone else. Their boyfriend changed the power dynamic of the couple by cheating, so the girl adjusted to the new norms of the relationship and adapted for the loss of power. Education also effects female sexual formation more than males and it is tied into the idea of power. Along with adapting to power dynamics, education is a way that females increase their amount of power. Education allows for economic stability. This allows her more options for sexual expression because she can support herself financially. She is able to be more independent and does not have to tie herself down with a partner in order to be supported. Having more education also leads to greater self-confidence which means that females feel more free to express themselves the way they want to as opposed to what society dictates for them (McElwain, Grimes & McVicker, 2009).

Section Summary. Sexual identity formation is a complex topic that is effected by many factors including being a male or a female. Overall, for males, sexual identity is greatly influenced by biology and for females, sexual identity is greatly influenced by social connections, though ultimately, social norms have a huge influencing force. These main influences are seen throughout development and all types of relationship connections, not just romantic ones. While there are vast amounts of literature surrounding sexual identity formation, the group of physically disabled is not as represented. Before specifically exploring the literature on sexual identity in the physically disabled it is important to understand specific issues people with physical disabilities must face that have to do with their overall identity development.

Issues Effecting Identity Formation of People with Physical Disabilities

As noted by key theorists such as Erik Erikson (1968) and James Marcia (1966) in their examinations about how an individual's identity develops, many factors combine to form a person's personal identity. Identity formation for those who live with visible physical disabilities is influenced in similar ways as the general population, but also includes a set of additional influencing factors. Cultural attitudes, values and assumptions regarding the meaning of disability influence the individual. Equally critical are the individual's own personality traits, their level of education, the age of disability onset and the influence of role models (Weeber, 2005). For the purposes of this literature review, three general areas will be discussed that are specific to issues and factors that people with disabilities encounter in the process of their identity development. Fundamental factors that add to identity formation to persons who live with physical disabilities appear to be linked to their experience of struggle with the ongoing cultural perceptions and reactions to their disabling condition (Schultz, 2009; Lawrence, 1991). Nested in the issue of incorporating cultural perceptions is the notion of how persons who live with physical disabilities engage with and develop a sense of independence (Ozhek, 2008 and Mauer, 1979). Finally, Gill (1997) and Fitzgerald and Stride (2012) note a third major area that effects disability identity development in disabled persons as a dichotomy between feelings of exclusion and inclusion. These three areas will be discussed here because they are fundamental in understanding the unique factors that lead to personal identity formation in persons who live with physical disabilities.

Erikson (1968) and Marcia (1966) described the identity formation process as being effected by two main processes: exploration or testing different identities and commitment or adhering to a set of norms and expectations associated with the identity. Identity exploration and then commitment is formed by a number of factors. One of these factors is physical ability, which is an awareness individuals first discover when they are young children. It is a way children first develop a separate identity from their caretakers by facilitating receiving, processing and responding to stimuli. As the child grows older, physical ability then assists in building self-esteem and working toward goals by allowing the individual to move around easily and not have to worry about how to maintain basic bodily functions (Lawrence, 1991). Identity is also developed by the expectations and perceptions society has on the individual (Allport, 1954). This includes a high importance society places on a person's physical fitness level and a beautiful body image. Movies, television, magazines, and other media sources are constantly reinforcing this body beautiful attitude. The relentless pressure has been known to pressure individuals to be outstanding in everything including having material success, marital success, and achieving both sporting and intellectual accolades (Lawrence, 1991). Identity development for individuals with physical disabilities are effected by these factors and additional factors specifically related to their disability.

For individuals with physical disabilities, their identity formation is effected by the society's perception and expectations of what a disability is and what having a disability means. These social perceptions may take on many forms including people's beliefs around disability, social barriers, and physical barriers. Thus, people who live with physical disabilities experience some struggle in the process that establishes our personal identity.

People with physical disabilities from an early age have additional issues to address and incorporate into their emerging 'self'. Indeed, people with physical disabilities do need to worry about maintaining basic bodily functions ranging the gamut of severity. This struggle of worrying about maintaining basic mobility continues on throughout life. When individuals with physical disabilities reach adolescence they often do not find support in developing autonomy and individuality since the focus of their lives is on activities of daily living, such as walking, eating and toileting. It makes it difficult for people to relate to normalcy by claiming independence (Stolz, 2010). Due to the specific requirements of having to put lots of energy into taking care of basic living activities, people with physical disabilities also have even greater challenges achieving the outsized expectations of society and therefore are negatively impacted and struggle even more with the universal questions of self-esteem and self-identity (Lawrence, 1991).

Cultural perceptions. Cultural perceptions held about persons who live with disabilities have a strong influence on adolescents' self-perceptions (Stolz, 2010). These views about people with disabilities are learned and ingrained early in life. In a study by Mauer (1979), children with and without disabilities were read a story, which had two male heroes, one had a physical disability and one did not, then they were interviewed on their thoughts. As part of their findings it was suggested that the children had already internalized the society's gender roles. The nondisabled male participants perceived the disabled hero as nonthreatening, reassuring, and less of a competition to them and therefore responded more positively towards the disabled character than the nondisabled character. However, the female nondisabled participants responded more negatively towards the disabled hero. This may mean that the female participants conceived him as not having the "typical" male traits such as being physically able and aggressive. These types of views and assumptions from other people have effects on the self-perceptions of individuals with disabilities and may cause anxiety and unclear and negative aspects of self-identity to develop (Lawrence, 1991).

Often times, negative conceptions of people develop into low expectations of individuals. Less than thirty percent of parents of adolescents with physical disabilities expect their children to earn a degree from a four-year college or university, compared to 88% of parents with adolescents in general (Stolz, 2010; Wagner, Newman, Cameto, Garza & Levine, 2005). Living with others having low expectations then leads to the individuals either embracing those low expectations for themselves, or overcoming them and proving people wrong by achieving the unexpected. Overcoming expectations is far more difficult because they may not receive support from others. This idea is supported by the fact that 28% of adolescents with disabilities drop out of high school, which far exceeds the general population's percentage. Less than one-third of people with disabilities who graduate high school go to some form of postsecondary education, which is half the number of their nondisabled peers. These lower achievement rates are reflected in other aspects of life also. Individuals with disabilities also have a substantially lower rate of employment and are likely to live with their parents for a longer amount of time than individuals without disabilities, thus limiting the experience of learning from others (Stolz, 2010**;** Wagner, Newman, Cameto, Levine, & Garza, 2006).

As part of forming a self-identity, it is important to have experience in groups. One way to do this is by developing friendships. For those with physical disabilities, it can be difficult forming relationships due to limited access to public services. These barriers require adolescents with physical disabilities to be flexible and to be resourceful in working to develop and maintain friendships (Fentin-Thompson, 2012; Stolz, 2010). One of the important aspects of finding friendship is having someone understand you. When there are physical differences between the people, this understanding is never completely there. For an adolescent with a physical disability, it is common to believe that no one understands what he or she is dealing with (Fentin-Thompson, 2012). Mauer's (1979) study suggested that nondisabled females prefer nondisabled males as friends over disabled males, but males prefer disabled males as friends over nondisabled males. This could be due to masculine stereotypes effecting males in that they perceive the disabled male as nonthreatening to them, but females see disabled males as like to them in that they do not have as much power. This study is, however, not inclusive in that it only studied the effects of male characters, not female characters which may or may not change the findings. Keeping these findings and limitations in mind, it does suggest that having a physical disability does effect the way the person is viewed by others, which makes it difficult in forming relationships, and thus negatively impacting the development of an identity.

Developing a sense of independence. Becoming an independent person is often difficult for adolescents with disabilities. As children, they may not have had the opportunity to develop mastery in certain areas and develop a sense of self apart from others due to physical limitations and having to depend on others for help (Lawrence, 1991). Due to this need of having to depend on others for some activities of daily living, parents grow used to caring for their children to a higher degree than that of a nondisabled child. This often leads to overprotection during adolescence. Overprotection is if the parent protects the child against unreal sources of danger. The overprotective parent treats the adolescent like a child. This does not allow for an opportunity to rebel or experiment with new experiences and only hinders the adolescent's ability to learn their true capabilities. They may find themselves feeling incapable and isolated which can result in feelings of hopelessness and frustration (Fentin-Thompson, 2012; Ozhek, 2008).

Another common issue people with physical disabilities must face is overcoming a psychological barrier that has been put up by family members, professionals and other significant social figures effecting the individuals' lives. Often times, people with physical disabilities are taught to ignore the parts of their body their disability has effected. Instead they are encouraged to value and put forth the parts that have not been impaired. This puts forth the message that the individual must try their best to overcome their disability and that they will never truly be fully accepted (Gill, 1997**)**.

In adolescence, people become more independent and start to separate from their families and form their own identity. However, due to the increased physical and financial support youths with disabilities often need, they often feel that they cannot set up their own personal goals for their future (Ozhek, 2008; Fentin-Thompson, 2012; Zeltzer, 1985). If they do set up those goals, they feel that they cannot challenge their parents' authority and struggle to recognize when the parent is being overprotective. This leads to strains in the relationship between the adolescent and the parent, and it causes difficulties for the adolescent to form his or her own identity (Fentin-Thompson, 2012; Zeltzer, 1985).

Although the negative views and low expectations from the important adults in the adolescents' lives are barriers for success, they can often persevere and succeed beyond those low expectations (Stolz, 2010). Due to the restraints adolescents with disabilities often feel when they are trying to form their own identity, it is very important that they are given opportunities to grow into themselves and discover who they are. Adolescents with disabilities are frequently treated differently than their abled body peers. This can have the effect of limiting their identity development. Adolescents with disabilities need to be held to the same standard and be given the same opportunities as their able bodied peers in order to have a strong individual identity. Meaning, in areas such as education, leisure, and physical and intellectual activities, adolescents with disabilities must be given the opportunity to explore to their full potential. In these areas, they need the opportunity to lead so they can view themselves as capable leaders, not just followers. Adolescents with disabilities also need the opportunity to self-advocate and try new things. People often learn the most about themselves when they take a risk and fail; adolescents with disabilities need to be given the opportunity to fail, allowing them the same opportunity to learn and grow from their mistakes. Focus must also be changed from what the adolescent can't do, to what the adolescent can do (Stolz, 2010). All of these opportunities will help to encourage the adolescent to form a strong self-identity, however, these opportunities must also be coupled with positive encouragement from the adults in the adolescent's life. If the important adults are positive it will help the adolescent build positive self-esteem and be better able to overcome the views and messages the adolescent receives from the general society (Lawrence, 1991).

Integrating in a social context. Another major struggle many adolescents with disabilities face with forming their identity is being excluded. This feeling comes from both internal and external forces. External forces such as having inadequate mobility assistance and transportation problems effect some adolescents (Gill, 1997). At school, adolescents with disabilities can feel excluded by classes and activities having to do with physical ability such as team sports and physical education (PE). In the majority of mainstream schools, PE is the one class that is not adapted to fit the needs of students with disabilities (Fitzgerald & Stride, 2012). This usually results in the student either being pulled out of the class or sitting on the sidelines while the rest of the class gains the benefits of participating. Feeling excluded from PE often results in feelings of anxiety that impact the student during school and at home. These feelings bring out internal thoughts of exclusion such as being ostracized by other students leading to feelings of rejection and loneliness. From the teacher, the student with a disability may feel singled out for not being able to participate like other classmates can (Taub & Greer, 2000; Fitzgerald & Stride, 2012). The idea of separating and excluding the student with a disability does not benefit the student; it only benefits the teacher by not having to make the effort to adapt the class. Through exclusion, the teacher has denied the student the chance to gain the skills learned and emotional benefits gained by participation (Fitzgerald & Stride, 2012).

Being integrated into activities and experiences positively impacts the formation of identity. Participating in physical activity is a normalizing experience, creating a place to interact with peers, gain social ties and therefore facilitate the formation of a social identity. Participation in a shared activity emphasizes commonalities and shared interests instead of drawing negative attention to the student's disability (Taub & Greer, 2000). Having a sense of belonging reaches beyond the setting of school. As part of developing an identity, people with physical disabilities must also come to terms with their disability and how the general society may perceive them. The desire to integrate into general society is usually expressed by children having the desire to attend mainstream schools "just like everyone else" and adults wanting to have equal opportunities for employment (Gill, 1997). Feeling the sense of belonging can be achieved through a variety of avenues including participating in athletics, being a member of a team, feeling supported throughout life, and having some connection to their disability and the disability community (Fentin-Thompson, 2012; Weeber, 2005). In developing a strong sense of identity, it is important to not forget or ignore any part of the individual. Bonding time with the disabled community has been found to be an essential part of positive identity development and the feeling of wholeness for people with disabilities (Weeber, 2005).

For some people with disabilities, connecting with other people in the disability community can bring up some negative feelings, while others feel extremely comfortable integrating into the disabled community. Those who feel that they don’t want to connect with the disability community may feel if they affiliate with others like them, they will be viewed by others not as an individual but as part of a group stereotype. For some, it may bring back depressing memories of having experienced segregation. For others, gathering in groups of people with disabilities may be seen as a statement of giving into the messages of segregation and acceptance of the inaccessibility of public activities and events (Gill, 1997). There are many reasons why a person with a disability may not want to associate with the disability community, but those who are able to come out and accept their disability and what that means to them are strengthened by it. Identity is strengthened when the individual both integrates himself or herself into the general society and is given the opportunity to participate alongside their abled body peers, as well as form a connection with role models and peers with disabilities. Working on both allows the adolescent with a disability to feel accepted and learn to understand and appreciate their differences (Fentin-Thompson, 2012; Taub & Greer, 2000).

Section Summary. Adolescents with disabilities face a unique set of struggles in developing their sense of identity. They must overcome the society's views on disability and learn their own sense of what disability means for them as individuals. Another related struggle is the messages adolescents often receive from society and adults in their lives about what they can and cannot do. Part of identity development is finding ways to be an individual, which can be particularly difficult for people with disabilities. An offshoot of identity development is sexual identity development, which for individuals with physical disabilities has some particular and unique factors and aspects, which will be explored.

Sexual Identity Formation of People with Physical Disabilities

Sexual identity is one part of a person's identity that is a process formed throughout life, and begins at or before we reach adolescence (Freud, 2000). Adolescents with visible physical disabilities also experience this part of identity formation. There are some additional issues that people with physical disabilities need to attend to in their unique experience with sexual identity formation. Several of these additional 'tasks' or 'factors' are reviewed here. For instance, one major added factor identified suggests that how they are viewed in terms of their disability by the larger society has a significant influence on development of a persons sexual identity is formed (Hasson-Ohayon, Hertz, Vilchinsky & Kravetz, 2014; Whitney, 2006; Schulz, 2009). An additional factor that influence sexual identity formation for these people is the fact that many adolescents with disabilities appear to lack of knowledge about sex (McKown, 1984; Brown, 1988; McCabe and Cummins, 2000). This lack of knowledge does not allow them to make informed decisions on what they will experience and often stems from a lack of knowledge from their caretakers. Finally, a discussion is included about the effects of cultural assumptions, the lack of communication and education and knowledge has on adolescents with disabilities. Such authors as Jones and Lollar (2008), Robinson (1979) and East and Orchard (2014) have noted the effects of cultural assumptions and the lack of communication and knowledge has on adolescents with disabilities.

Influences of society's perceptions of disability and sex. One of the major areas that effect the sexual identity formation of people with physical disabilities is the society's perception of disability and sex. Even though about 15% of the world's population lives with a disability (United Nations), their gender and sexuality is often rendered invisible (Higgins, 2010). Until relatively recently, the sexuality of individuals with physical disabilities has been ignored and believed to be nonexistent as people with disabilities were viewed by society as being asexual (Whitney, 2006; Shakespeare, 1999). It is interesting to note that while society appears to hold a common belief that people with physical disabilities are asexual, when it is known that an individual with a disability is in a romantic relationship, the individual is thought of in a more positive way. In Hasson-Ohayon, Hertz, Vilchinsky & Kravetz (2014) study, nondisabled participants were read scenarios in which a male had a relationship with a female. In one of the scenarios the male had a physical disability. From the results of that scenario, the study found that by being in a sexually active relationship the individual with a disability is conveying to society that they are not absorbed by their impairments. Further, the study noted that they have opportunities for sexual relations, and they are not helpless, childlike and asexual. However, a limitation of this study was that the individual with a disability in the scenario was male, so the finding may not be applicable to females with disabilities.

While there are models that are used to describe the sexuality of people with disabilities, they are not all encompassing and tend to focus on the dysfunction of the individual. Most are based on the medical model which addresses disability as an illness that can be treated which places the onus on the individual, as opposed to the system in which the individual resides. The sexuality models also focus more upon acquired disabilities than congenital disabilities and often fail to recognize intersectionality (Whitney, 2006; Schulz, 2009). Due to this lack of knowledge, as evidenced by a lack of a useable model and societal disapproval, individuals who identify as having a disability and being gay report that they often split themselves and are rejected by both communities. This leads them to feel that they have a lack of community and support (Whitney, 2006).

Lack of knowledge about sex. There is a strong reluctance by parents and educators to talk about sexual development and health education to adolescents with physical disabilities (McKown, 1984; Valvano, West, Wilson, Macapagal, Penwell-Waines, Waller & Stepleman, 2014). Typically, children access sexual education from family, siblings, friends, media, and formal classes in school (Higgins, 2010). However, adolescents with disabilities report receiving significantly less sexual information than their peers (Brown, 1988; McCabe, Cummins & Deeks, 2000). It is unclear in the literature where the majority of sexual education adolescents with physical disabilities is derived from. A study by Brown (1988), concluded that peers appeared to be one of the greatest sources of sexual information. The study by McCabe, Cummins and Deeks (2000) on the other hand concluded that adolescents with physical disabilities receive the majority of their sexual education from media and formal sexual education programs, not friends and family. This disparity requires further study to gain more specific information, however, the common and agreed upon finding that youth with disabilities do not receive adequate information about sex is seen in many avenues including conversations with doctors and parents and in sexual education classes.

Healthcare and mental health providers often do not bring up sexual matters with their clients who have physical disabilities even though if they were to bring it up, the clients would likely want to talk about it more (Valvano et al., 2014). When it is the adolescent who brings up a question or concern regarding sex to their healthcare provider, oftentimes the provider ignores and dismisses it. This only reinforces the messages adolescents with disabilities get that they should be asexual and silent about their feelings (Dune, 2012). This lack of communication from healthcare providers may have to do with internalizing societal views, but it likely also has to do with receiving a lack of education on the topic. In one study where students studying to be healthcare professionals were surveyed on how much sexual health education they received in order to pass on to their patients, it was found that there was a severe lack of education, with psychology students lacking the most. 94% of psychology students surveyed reported having 0 hours of direct patient contact relating to sexual health problems (Valvano et al., 2014). Many healthcare providers believe that speaking about sexuality issues with their clients with physical disabilities is not pertinent or too intimate a topic for the situation because they feel their main focus should be on the person's physical problem. While sexuality is not very important for the physical state, it is extremely important for a person's mental and emotional state. It is very important to have conversations around the topic for the adolescent to form their sexual identity. Healthcare providers who do engage in sexual health conversations with their adolescent patients prove that they respect and listen to the patient, which works to build positive relationships. Engagement in these conversations also signifies an acknowledgement of the patients' understanding of their own body and desires (Dune, 2012).

A significant part of the identity of adolescents is shaped by how their parents raise them. Due to the overprotective nature most parents of children with disabilities have for their children, once they grow up to be an adolescent, sometimes the disabled youngster finds it difficult to separate from their parents. This separation difficulty may lead them to feel more like children and be treated like children. Not being treated their age, the adolescent may not be able to gain accurate or sufficient knowledge about sex and sexuality from their parents (Fentin-Thompson, 2012).

When it comes to sexual education classes, adolescents with disabilities often do not get the same level as their abled bodied peers. One topic in particular is sexual abuse (Brown, 1988). This topic is overlooked because of misconstructions people have relating to sexuality and disability. But, overlooking this topic is one reason why people with disabilities are sexually abused at a greater rate than the general population (Washington State Coalition Against Domestic Violence, 2013). McKown (1984) identified nine myths about people with physical disabilities that influence the feeling of reluctance to provide adolescents with disabilities a detailed sexual education. Four of these myths are that all disabled people are asexual, they cannot have orgasms, people with disabilities are childlike and need protection from interactions with others, and parents of children with disabilities do not want them to have sexual education. These four myths are denying people with disabilities the right to grow up and experience the same opportunities as their peers. The remaining myths take an opposite stance on the subject. These are that people with disabilities are oversexed, sexual problems must be due to the disability itself, disabled people should be segregated and only be with and marry each other, all people with disabilities give birth to children with disabilities, and that there must be something wrong with a nondisabled person who has a relationship with a person with a disability. These are nine stereotypes and myths that people with disabilities must navigate because they are the beliefs of some people in society. Sexual identity is formed in part from the messages gained from the larger society, and if these myths are internalized they may effect the sexual identity formation of an adolescent with a disability.

Effects of assumptions and lack of knowledge on adolescents with disabilities. Societal assumptions and stereotypes about adolescents who live with physical disability are often based on limited and exaggerated knowledge and are usually wrong; therefore basing decisions off of them typically leads to problems. Adolescents with disabilities have been found consistently to be either as likely or more likely than their nondisabled peers to engage in risky health behaviors (Jones & Lollar, 2008). Students with disabilities in Jones and Lollar's (2008) study reported, more than able-bodied students in the study, their health as fair or poor and that they feel sad or hopeless. They also engaged in a variety of types of risky behaviors including being in physical fights, being forced to have sexual intercourse or engaging in some type of sexual activity, and seriously considering and attempting suicide. They also reported engaging in more cigarette smoking, alcohol and marijuana usage, being on the computer for three or more hours a day, and being overweight more often than their able-bodied peers. These are consistent findings with other studies of adults with disabilities, which find that they are at particular risk of sexual assault and the rates of such instances are much higher than that of the general population (Higgins, 2010; Washington State Coalition Against Domestic Violence, 2013).

Self-esteem is an important concept that has to do with sexual identity formation. It is of particular importance for adolescents with disabilities who often struggle with their development of self-esteem. Having a low self-esteem can negatively effect individuals' sexual identity formation by shutting themselves down to potential experiences and not feeling worthy of romantic love. In a study by Brown (1988), adolescents with disabilities were found to have lower acceptance of their body, lower self-esteem, and lower awareness of their self-identity and acceptance of themselves as a unique and valid person than their abled body counter parts. These lower levels of self worth may also indicate lower levels of sexual esteem. This concept can be seen in McCabe, Taleporos and Dip’s (2003) study that indicated people with greater physical impairments experienced significantly lower levels of self and sexual esteem and sexual satisfaction and significantly higher levels of sexual depression than people who had mild impairments or no physical impairment. This low self-esteem may be due in part because many adolescents with disabilities lack peers, parents and professionals who have disabilities in their lives who are in a sexual relationship themselves. This lack of role models gives an adolescent with a disability a negative message and outlook about their future relationship possibilities (McKown, 1984). It does not help their sexual self-esteem to grow and develop in a healthy way. Although there are typically low levels of knowledge, experience, and self-esteem about sexuality in adolescents with disabilities, they also show a high desire to learn more about sexuality (McCabe, Cummins & Deeks (2000).

The experiences of adolescents with disabilities come with unique considerations compared to their nondisabled peers. Part of this has to do with health concerns that need to be addressed. Often times, issues of sexuality are ignored or overshadowed by the routine health needs of the individual. Parents, caretakers and health-care workers do not address sexuality concerns due to discomfort, lack of understanding, or a lack of knowledge (East & Orchard, 2014). Part of the experience of some adolescents with disabilities is that they live in a residential setting. While the numbers of adolescents with physical disabilities in residential settings are decreasing, there is still a significant population who are residentially placed. Children placed in residential schools often struggle more than children who grow up in a family home. Residential schools often have gender segregation of peers and children have multiple parent surrogates, typically all female. This makes it difficult for them to learn gender roles and gain a healthy attachment, which is an important part of sexual identity development (Robinson, 1979).

Section Summary. Youths' with physical disabilities face the same challenges forming their identity, their self-image and gaining social acceptance as their nondisabled peers. However, many of these issues are overlooked and ignored by adults in the lives of adolescents with disabilities (East & Orchard, 2014). Conducting studies aimed at gaining information about the sexuality of people with disabilities, works to fill in knowledge gaps and widespread societal misconceptions on the issue while also legitimizing and respecting the adolescents with disabilities needs as young people (East & Orchard, 2014). Sexual identity develops from a multitude of sources and interactions (Brown, 1988). One of these sources is the difference between being a male or a female with a physical disability.

Role of Social Influence on Sexual Identity Formation of People with Physical Disabilities: Differences Between Men and Women in Our Culture

Oftentimes people with disabilities are considered genderless (Shakespeare, 1999). Gender and disability is not often studied; even less so when paired with sexuality and sexual identity formation. Historically, researchers have ignored this intersection of identities (Ketz, 2002; Shakespeare, 1999). When forming a sexual identity, men and women are strongly impacted by the society's views of gender. Researchers such as Gerschick and Miller (1997) found how men with a disability are impacted by the societal views of masculinity and how the different ways of coping with societal influences effect their sexual identity. Societal views of femininity and disability often reinforce each other, which frequently result in the individual having a greater difficulty with overcoming those stereotypes (Shakespeare, 1999). Literature discussing these issues relating to sexual identity formation for females with physical disabilities from authors such as Hassouneh-Phillips and McNeff (2005) and Moin, Duvdevany and Mazor (2009) will be examined.

Societal perceptions and reactions of males with physical disabilities. Similar to abled body peers, individuals with disabilities are affected by the society's standards of beauty and gender roles. Societal perceptions and standards are internalized and effect sexual identity formation. For males, the societal expectation is that they be strong, courageous, aggressive, independent, self-reliant and career-oriented (Gerschick & Miller, 1997; Shuttleworth, Wedgwood & Wilson, 2012). The society's standards are held at an opposing stance for people with disabilities, who are expected to be weak, pitiful, passive and dependent. Men with disabilities are therefore constantly at odds with the expectations of the society (Gerschick & Miller, 1997). Up to very recently, in popular culture, disabled males are typically depicted as war veterans who work to come to terms with the loss of their masculinity. Sexuality of these male character depictions is often assumed to be lost. Popular notions of disabled masculinity and sexuality therefore focus on not being able to participate in sexual activity, assumed to be mainly due to erectile failure. This notion consequently has contributed to society's perception of disabled men as being less than men (Shakespeare, 1999). Facing these common perceptions from society has elicited a variety of reactions from men in how they respond in their daily lives.

Beliefs of sexuality only existing in the genital areas of a person are very sexually and psychologically damaging for people (Shakespeare, 1999). There are a variety of ways men are able to cope with this and other societal standards of masculinity in their lives. Gerschick and Miller (1997) found that these reactions and coping mechanisms of males can generally be categorized into three categories: reformulation, reliance and rejection. Reformation is when the male redefines the definition of masculinity to fit his own situation. For example, one man in the study discovered that when he had sex, concentrating on satisfying his partner satisfied him. This shows that he is confident in his own abilities and values. Men who use this form of coping are typically assertive and comfortable with confronting and changing the standards of masculinity to their terms. Reliance is seen as men typically not being as comfortable with their masculinity due to not being able to achieve society's standards because of their disability. They often do not see themselves as attractive and struggle to date. Men using this as a coping mechanism often believe that others perceive them as genderless and therefore compensate by never asking for help even when it is needed out of wanting to adhere to the society's standard and belief that males should always be self sufficient. Rejection is the complete renunciation of masculinity standards and either the creation of the males' own principles and practices or the denial that being considered masculine is important to them. Using this coping mechanism, the male is sometimes able to come to a realization that they are not the problem; it is the societal conceptions of masculinity that is problematic. Other ways males with disabilities cope with societal expectations is going to the two extremes of masculinity; either being hyper-masculine often involving themselves in sports or by completely rejecting the notion involving themselves in activities that are widely considered not masculine (Shakespeare, 1999). When it came to love, Shuttleworth, Wedgwood and Wilson (2012) found that some men attempt to find a partner to collude with them about the unimportance of their disability, which often resulted in them alienating women and being left feeling unfulfilled in their personal lives. They also found that many of the males were able to adapt their approach of negotiating sexual relations when they realized that acting within the strict social norms of masculinity was not working for them. Some men were able to expand what they considered to be masculine to include sensitivity and interdependence, which proved useful in certain romantic or sexual situations. Currently, some of this societal perception is beginning to change as a result of the return of soldiers from war who gained a physical disability. Many images of men with disabilities are being now being presented in popular media doing challenging physical tasks despite their disability. Adolescent boys with disabilities who see these images in the media may feel support and a sense of hope for their future. These media images provide adolescent boys with disabilities a valuable role model which will help them feel that they can do more in their life and strive to participate in activities like their abled bodied peers (Wheelchair basketball, 2013; Glee, 2009; Murderball, 2005).

Societal perceptions and reactions of females with physical disabilities. Women react differently to societal standards than men partly due to being held to different standards and expectations. While the societal image for males is beginning to change as seen through popular media beginning to include showing males with disabilities in a positive way, this is not the case for women. Therefore, adolescent females with disabilities are not receiving the same positive messages and role models as adolescent males with disabilities are receiving. For women in this society, there are strong messages about what the perfect body image is and what traditional gender roles to live by that women internalize when growing up and feel pressured to achieve. Adjectives used to describe women include innocent, vulnerable, sexually passive, dependent, and objectified. These are similar adjectives used by this society to describe people with disabilities. Women living with disabilities may find achieving independence and strong identities more difficult than men with disabilities due to the reinforcement of stereotypes from being both a woman and a person with a disability (Ketz, 2002; Shakespeare, 1999). Another aspect of societal expectations women with disabilities must live with is that women are expected to become caretakers and mothers. Due to having a physical disability, society may perceive a woman with a disability as being incapable of fulfilling the role of housewife and mother and thus will not consider her as a viable sexual partner (Shakespeare, 1999). People in the society who are potential romantic partners internalize these negative societal messages about the desirability of women with physical disabilities. Women with physical disabilities also internalize the messages. Hassouneh-Phillips and McNeff (2005) noted that having a higher degree of physical impairment is associated with having a lower sexual and body esteem.

Societal perceptions and expectations effect the sexual identity formation of women with disabilities due to their dual identity of being both a woman and a person with a disability. Women with and without disabilities experience unwanted attentions, intrusions, and stares. This is due to the similar societal stereotypes and adjectives that are used to describe women and people with disabilities (Shakespeare, 1999). Women with and without disabilities both have the same sexual needs and desires. However, women with physical disabilities are more likely than non-disabled women to have problems with sexual functioning, low sexual confidence, low sexual and life satisfaction, and greater body dissatisfaction. These feelings are even more pronounced for women with higher degrees of impairment or with acquired disabilities (Hassouneh-Phillips & McNeff, 2005; Moin, Duvdevany & Mazor, 2009).

Having low self-esteem makes it difficult for women with disabilities to find, develop and maintain safe and healthy romantic relationships (Moin, Duvdevany & Mazor, 2009). Women with higher degrees of physical impairment are less likely to marry than women with lower levels of impairment, partly due to a lower level of self-esteem, but also due to others internalizing societal messages of women with disabilities being unable to take on the role of housewife and caretaker (Hassouneh-Phillips & McNeff, 2005). There is a strong desire for women with disabilities to be in a relationship rather than being alone. While this is a feeling that women without disabilities also have, women with disabilities do find it more difficult to form a relationship with someone due to assumptions the other person has regarding disability. Due to this, women with disabilities often lower their standards in order to be in a relationship and not be alone. It also means that women with disabilities are at a greater risk of being in and staying in an abusive relationship (Hassouneh-Phillips & McNeff, 2005). By not being in safe and comfortable relationships, sexual satisfaction is often low for women with disabilities. In order to try to avoid being in substandard relationships it is important that throughout life, but especially when developing a sexual identity, women with physical disabilities receive sexual counseling, both alone and with their partner if they have one (Moin, Duvdevany & Mazor, 2009). Receiving this in adolescence will help the woman to develop a strong sexual identity so they are both confident in themselves, which will help them feel comfortable being alone, and to not lower their standards in a sexual partner, both which will make them less vulnerable for sexual abuse (Hassouneh-Phillips & McNeff, 2005; Moin, Duvdevany & Mazor, 2009).

In forming a sexual identity, women with physical disabilities will also have to learn to negotiate the societal bias that they cannot and should not bear children. While this bias is not as strong as it once was, it is still easily seen through the services and equipment surrounding childcare and family planning (Shaul, Dowling & Laden, 1985). Shaul, Dowling and Laden's (1985) study on mothers with physical disabilities found that they had to overcome many struggles in order to get to where they were at the time of the study. Their capacity to be a partner in an intimate, sexual relationship and to bear a child was doubted by many people in their life including, in some cases, their families. From a young age, the congenitally disabled women reported that their parents tried to program them to be super career women because they believed that others would never consider them as marriageable. Growing up with this message shapes the sexual identity of the women and contributes to an internalized belief that they are unworthy of other peoples' romantic love.

Section Summary. Societal perceptions of people with disabilities effect both males and females. Due to the different expectations, men and women are effected in different ways. Because of the presence of societal norms and expectations throughout life, the sexual identity formation of men and women with disabilities is impacted. On an individual basis, men feel pressured by societal norms to establish what masculinity means to them. Women with disabilities face additional struggles due to the similarities of societal norms directed towards women and people with disabilities. The majority of studies relating to sexuality and disability have involved male subjects (Ketz, 2002). There remains a gap in the literature regarding the sexual identity formation of women with physical disabilities as few researchers have yet to solicit their input.

Summary

Factors contributing to an individual's sexual identity formation are complex and are still being researched. Generally, sexual identity formation appears to be impacted by a multitude of external and internal factors. The literature review focused specifically on how relationships with peers and family members have a great impact on the adolescent (Crockett, Bingham, Chopak, & Vicary, 1996; Fingerson, 2005). An adolescent is more likely to participate in earlier sexual relations if they engage in risky behaviors such as alcohol use and smoking (Feldman, Holowaty, Harvey, Rannie, Shortt & Jamal, 1997; Miller & Fox, 1987). The formation of sexual identity also has to do with the internal biology of a person and the culture in which they are brought up by their caregivers, which is similar to nature vs. nurture. The ratio of internal biology to culture is impacted by the gender of the adolescent. Researchers such as McElwain, Grimes and McVicker (2009), Feiring (1996) and Crockett, Bingham, Chopak and Vicary (1996), suggest through their research that biology has a greater effect on males, whereas females may be more impacted by societal and cultural influences, and are more likely to be sexually fluid than males.

Being an adolescent with a disability means that there are certain factors that impact his or her sexual identity formation on top of the general factors. Societal perceptions and expectations of what it means to have a disability is something adolescents with disabilities must face when forming a sexual identity. Depending on how general societal misconceptions, such as being asexual, are internalized by the adolescent and how they are able to overcome expectations, the adolescent's sexual identity will be impacted (Whitney, 2006; Shakespeare, 1999; Dune, 2012; McKown, 1984). Other factors that could negatively impact the sexual identity of an adolescent with disabilities are the lack of sexual instruction they receive and how able they are to integrate with both society in general and the disabled community (McKown, 1984; Valvano, West, Wilson, Macapagal, Penwell-Waines, Waller & Stepleman, 2014). Similar to general sexual identity formation, gender roles effect the sexual identity formation of adolescents with disabilities. In popular media, images of people with physical disabilities participating in physical activities are becoming more common, but they are mostly males, which leaves females with disabilities a lack of role models to look up to. Femininity and disability assumptions often reinforce each other, while assumptions surrounding masculinity and disability conflict with each other (Shakespeare, 1999).

What is generally found to be a gap in the current literature is firsthand accounts from women with an array of visible physical disabilities about what they consider contributed to their sexual identity formation. My study seeks to fill this gap by gathering information on the sexual development experiences that women with visible physical disabilities had in their adolescence and how they felt that those experiences effected their sexual identity. The study hopes to benefit social work by identifying areas of sexual identity formation that are lacking for women with visible physical disabilities as well as areas of their sexual identity that may be less than fulfilling to them. This knowledge may open up conversations social workers have with clients and identify areas in which further education could be implemented in school sexual education programs. The next chapter outlines the study methods including, research design, sample criteria, ethics and safeguards, data collection strategies, and data analysis plan.

CHAPTER III

Methodology

Formulation

The current study descriptively gathered and assessed the perspectives held by women with visible physical disabilities about their sexual identity formation. The term sexual identity can be described as an awareness of one's self as a sexual being. This study relied on the self reports of women on their past experience during adolescence as well as their self identification as a woman with a visible physical disability.

Research Design

This descriptive study used an anonymous survey design to gather study data. The survey used both a set of quantitative, true/false and rating type questions as well as several open ended, qualitative questions in order to answer the over arching research question "What women with visible physical disabilities say has affected their sexual identity formation." The survey was developed using Survey Monkey software. This software is approved for use in survey research by Smith College School for Social Work, as its technology is such that it meets privacy and confidentiality requirements in the conduct of research.

Sample

158 self-identified women with visible physical disabilities over the age of 18 participated in taking the online survey.

Further, the study focused on participants who self identified as having a visible physical disability because not all forms of disability are the same for people. The experience of physical disability is different from other kinds of disabilities such as intellectual, emotional, and learning. By focusing on visible physical disabilities for this study, conclusions drawn were specific to the distinctive experiences of that population.

Only participants who are over the age of 18 were included and they shared their reflections on their experiences during their younger years. Participants also reported on what they thought were helpful and not helpful during their adolescence with respect to where they are now in life.

Recruitment Procedures

Identify participant pool. In order to identify a participant pool, a SurveyMonkey link was distributed through email and public Facebook messages. Because I am a person who lives with a visible physical disability, I have a wide network of contacts who have similar disabilities. I employed snowball sampling to reach others. Emails were strategically sent to individuals who fit the inclusion criteria of the study, and who also knew others who fit the criteria and forwarded the email to them. I also posted messages on my personal Facebook account, as well as relevant Facebook groups that I was already a part of and joined throughout data collection. See Appendix B to review specific recruitment email messages.

Screening procedures. Before being directed to the informed consent page and then the survey, the potential participants had to answer three questions in the affirmative to make sure that they met the inclusion criteria of the survey. The three questions they had to answer asked if they identified as a female, identified as having a visible physical disability and if they were 18 years or older. If they met these criteria, they were then directed to the informed consent page. If they were interested in proceeding with the survey, they clicked on ‘I agree to participate” at the end of the informed consent page, and were taken directly to the survey.

Ethics and Safeguards

Protection of human subjects. Through the use of the tools available within SurveyMonkey, anonymity of participants was assured. The data collected cannot be linked to the email addressed or other identity of individual participants.

Risk of participation. While taking the survey, participants had to reflect on their past experiences. This reflection might have brought up painful memories. In order to protect participants, it was not required that they complete the survey. The instructions stated that participants could exit the survey at anytime and there would be no way to link any of their information to their personal identity.

Benefits of participation. One potential benefit for the participant was to be given the chance to talk about and reflect on their sexual identity formation, which may be the first time that they were asked to. Participants may have felt relieved that they were asked about a topic that they may have never spoken about and this survey could have opened them up to speaking about it further in other areas of their life.

Data Collection

Overview. The participants completed a one time only survey over the Internet using the SurveyMonkey software. The survey consisted of a set of demographic questions used to develop groups for comparison, and to describe the sample. The survey items, consisting of both qualitative and quantitative questions, were developed to reflect key factors noted in the literature that underlie sexual identity formation, including education, communications with important adults in the participants' life including friends and family regarding sex and relationship experiences (See Appendices C, D and F for survey and instructions).

Informed consent procedures. Informed consent was obtained by utilizing SurveyMonkey's integrated services. The informed consent described the study purpose, procedures, risks and benefits and how privacy was assured. The consent was based on a standard template available for use to Smith students conducting their thesis projects. Before participants were able to take the survey, they had to read and agree to the informed consent page (See Appendix E for wording). Participants who read this consent and clicked on the "I Agree" button at the end of the informed consent, SurveyMonkey accepted it and redirected participants to the survey page.

Data Analysis

This study is descriptive in nature. As such, frequencies and percentages were done via univariate and bivariate statistical analyses in order to describe the participant pool and to identify patterns and trends in the responses across all completed surveys. Demographic information collected, such as the religion of a participant, was used to create comparative groups in order to determine any patterns and relationships in the sample sub groups. The statistician at Smith College School for Social Work assisted in running the quantitative statistics of the project. For the qualitative questions, units of measure of words and phrases were used to analyze the various responses participants offered. This information was then coded and led to patterns and trends across responses. Ultimately, the qualitative data was used to enhance the quantitative data by enriching the numbers with stories and quotes directly from the individual participants' experiences. The next chapter presents the findings of this study.

CHAPTER IV

Findings

This chapter presents the results from the quantitative and qualitative questions from the survey that I developed to gather my data. This was a descriptive study that used both quantitative and qualitative data collection methods. The purpose of the study was to assess the perspectives of women with visible physical disabilities on what factors influenced their sexual identity formation. Asking women with visible physical disabilities about their sexual identity formation produced results that expanded on previous information from studies that focused on the challenges this population faces. The quantitative section includes demographic information about the sample, and distribution and frequency information that formed the basis of the results of the survey questions. The qualitative section consists of patterns, trends and summaries reflective of the participants' responses to the two open ended questions. Surveys were responded to in the Survey Monkey software, accessed by participants by clicking on a link to the survey provided in the recruitment phase of the study.

Quantitative Results

Description of sample. A total of 158 participants agreed to take the survey. Not every question was required to be answered and as a result, individual questions were skipped for reasons unknown. The demographic questions led to a description of the sample of respondents. The majority of respondents were between the age of 18 and 55. About half of the respondents were single. Approximately 75% of participants had some college, bachelor's or master's degrees. Most of the respondents reported that they attended a mainstream type of school setting during their school years. Location of residence was evenly spread through urban and suburban setting, though 11% of respondents reported living in rural settings. Religion orientation seems to be mostly Catholic, Protestant Christian, Agnostic, Atheist or other. A key demographic category of interest to this study was the level of mobility of the respondents. The largest percentage of respondents (approximately 63%) reported that they either used a scooter or a manual or power wheelchair. A good percentage of respondents (16%) noted that they not use any mobility aids to get around. (See Table 1: Demographic Information.)

Analysis of survey responses.

Beliefs of effects of disability. The majority of participants reported that their disability effected them in negative ways. 127 (85.23%) participants said that they believed that their disability negatively impacted the way potential dates saw them as a prospective relationship partner. More than 70% of respondents said their disability negatively effected their confidence and their ability to date. 92 women (60.93%) said that their disability negatively impacted their likelihood of asking someone else out on a date. However, 14 (9.4%) participants said that their disability did not effect how others saw them as prospective relationship partners. A notable percentage of women (29.14%) said that their disability did not effect their likelihood to initiate asking someone out on a date. (See Table 2: Beliefs Participants had on the Effects of Their Disability).

Early education about sex. Participants varied regarding their level of comfort with talking or asking questions about sex with important people in their lives. About two thirds (66%) of respondents reported that they felt uncomfortable or very uncomfortable with talking to their parents about sex. Whereas 73% of participants stated that they felt comfortable talking to their friends about sex. While most of respondents indicated that they were very uncomfortable talking to their teacher about sex, respondents were fairly split on how comfortable they felt talking about sex with a counselor or therapist.

A high percentage of respondents (84%) said that they learned about sex from their friends. Other important places many respondents indicated played a role in them learning about sex was from media such as books, the Internet and television. Parents were the family members that taught participants the most about sex (57%) followed by siblings (25%) then other family members (16%).

The subjects of the survey were also asked about what they learned about sex in school. 11% of the subjects stated that they did not receive sex education in school. A significant percentage (44%) learned about abstinence. A high percentage (71%) of participants indicated that their sexual education in class included safe sex methods. Only about 2% of the respondents said that their curriculum included information about how disability may effect sex. About 40% of respondents felt like they received a decent level of sex education in school. Only one participant said she wanted less than she received. However, nearly 60% of participants said that they wish that their sex education was better or that there was more of it. (See Table 3: Comfort Level of Participants with Talking about Sex to Important People in Their Lives; Table 4: Places Respondents Learned about Sex, checked all that applied; Table 5: What Respondents Learned about Sex in School, checked all that applied; Table 6: Respondents' Feelings on the Amount of Sex Education Received in School).

Relationship history. Respondents indicated that their dating history in high school did not match what they wanted to experience in high school. The majority of participants wanted to be in a steady relationship (80%) and casually date (69%) in high school. But, the majority of participants did not have a steady relationship (72%) or casually date (75%) in high school. However, 60% of respondents said that they were content with their current relationship status. (See Table 7: Desire to have a Steady Relationship in High School; Table 8: Desire to Casually Date in High School; Table 9: Had a Steady Relationship in High School; Table 10: Casually Dated in High School; Table 11: Content with Current Relationship Status).

Connections. More than half of the respondents reported not having a connection with the disabled community growing up. Nearly 75% of participants said that they did not have anyone with a disability who they could look up to growing up. While the majority did not have someone to look up to with a disability, about 55% of participants had connections with peers who had disabilities. (See Table 12: Felt Connection to the Disabled Community Growing Up; Table 13: Someone to Look Up To When Growing Up with a Disability; Table 14: Connection to Peers with Disabilities Growing Up).

Opinions on sexual identity formation. Participants were asked to reflect on their own sexual identity formation. Nearly half of the participants said that they were encouraged to explore their sexual identity. Majority of respondents (62%) reported that their friends were an effective force in their sexual identity formation. Most participants had felt neutral on the effectiveness role models and school had on their sexual identity formation. Respondents also reported that they believe that their family and television and movies were more effective than ineffective force in their sexual identity formation. Another aspect of the participants' lives that was important in forming their sexual identity was their own self-esteem and self-image; about 56% said that it was effective or very effective. (See Table 15: Encouraged to Explore Sexual Identity; Table 16: Effect Factors had on Participants' Sexual Identity Formation in Their Opinion).

General factors effecting sexual identity formation. Women who participated in this survey were asked to comment on what degree they agreed or disagreed to ten statements related to various aspects of sexual identity formation. Overall, participants felt more comfortable talking to their friends than their parents about their romantic feelings and dating relationships. The majority of respondents (58%) said that when they first started feeling attracted to someone, it was based on an emotional attraction rather than a physical attraction. However, as for themselves as individuals, the majority of participants did not feel attractive during adolescence (66%).

About 56% of respondents indicated that their parents or caregivers did not talk to them about safe sex methods and 62% did not feel comfortable asking them about sex. A minority of respondents, about 26%, stated that their parents or caregivers encouraged them to date. Over 65% of respondents did not have a role model they could talk to about sex. The minority of participants (28%) reported that their religion helped shape the way they viewed intimate relationships. 58% of the women respondents believed that their disability got in their way of forming romantic relationships. In contrast, almost two thirds (65%) of the participants stated that most of their friends growing up were dating or in relationships. (See Table 17: Opinion Statements).

Qualitative Results

In order to gain a fuller picture of the thoughts and experiences women had regarding their sexual identity formation the survey included two open-ended questions. The first question asked participants what they believed would have made their sex education in school better and the second question asked participants if there was anything they wanted to add regarding their sexual identity formation process. Results are presented in terms of patterns and trend categories of responses across participants. Illustrative quotes are provided to illustrate the category in terms of participant specifics.

Aspects that would have made sexual education in school better. Participants were asked what they would have wanted to make their sexual education in school better. The majority wrote that they wanted more discussion about a variety of topics, “more detailed information not just girls have vaginas and boys have penis,” and an increase of time spent on the class, “There was no sex education save for one general school assembly if a hundred students where two people in wheelchairs talked about their relationship.” A couple of respondents shared that they were excluded from the health class due to the curriculum design of their school. They explained that in their school systems the health curriculum and the physical education program were tied together. As a consequence, because they did not take PE due to their disability, they were excluded from health class.

A large amount of participants wrote that they wanted health class to cover issues related to disability. Specifically, several women mentioned that they wanted to talk about how people with disabilities do have sex and that it is normal. One woman said, “I wish it had even been acknowledged that disabled people have sex,” another shared that she wished that sexual education conveyed the “understanding that an individual with a disability can have sex, and is not alien to the idea of it.” But, they also wanted the class to discuss that having sex with a disability may require some adaptions in regards to attitudes, techniques and an understanding of how sensations may be different for some people.

Several women reported that they wished sexual education in school had included the discussion of the importance of building healthy relationships, and the prevalence and prevention of sexual abuse and peer pressure. Specifically, respondents mentioned that they wanted to talk about “consent,” “safer sex practices and harm reduction” in romantic relationships.

Many of the participants mentioned that they wanted to talk about the LGBT experience. Mostly, they wanted the class to be more inclusive and talk about the variations of sex and not only talk about the heterosexual experience. As one participant explained, she wished that the curriculum included an “exploration of LGBT+ relationships and safe sex within that community.”

A few mentioned that they would like the class to be more normalizing and positive about sex. They did not want the class to talk about sex in a shameful way but instead to depict it in a more positive light than they experienced in the classes they took. Specifically, one woman wrote that she wanted her sexual education class to talk about “reducing shame of being sexual as a female.”

Only three participants mentioned that they would like less on certain topics. These were topics related to anatomy and STDs.

Other aspects effecting sexual identity formation. At the end of the survey respondents were asked if there was anything else they wanted to comment on regarding their sexual identity formation. The majority wrote about how their sexual identity formation was effected by their disability. Within this, subjects mentioned two main themes regarding disability. Most wrote about how their disability was an obstacle in their sexual identity formation. Others wrote how the problem with their sexual identity formation was other people’s view of their disability. In addition to those two themes, a few wrote how their lives were effected as a result of the exploration of their sexual identities as women with physical disabilities. A few people viewed their disability as a positive. One woman said that her disability worked in her favor “by weeding out shallow or otherwise terrible potential partners." One of the respondents who thought that their disability was a problem wrote that her mother "said it was illegal to have sex until [she] was 25 because [she] use[s] a wheelchair." A few women said that their sexual identity was formed in adulthood as opposed to in high school years.

Another main concept that participants said impacted their sexual identity formation was a lack of information and communication about sex. A respondent explained, "the closest thing I had to 'the talk' is when my parents were going out of town and my aunt and uncle were going to babysit and my dad told me and my sister to call him immediately if my uncle 'hugged too long' or otherwise did things that 'didn't feel right' to us." As part of this many mentioned that sex was never discussed in their family. They never discussed healthy self-esteem, healthy relationships, and sexual and emotional health with their family members. Others mentioned that while they talked to their friends about sex, they never truly felt a part of the conversation because of their personal lack of experience. One woman mentioned that she could not see herself in a romantic relationship because she never saw disabled women in media and movies in a relationship. Another woman mentioned that medical professionals rarely encouraged open dialogue on sex and disability and therefore acted as another deterrent to fostering a comfortable sexual identity.

A few mentioned that a LGBT experience effected their sexual identity formation. The process of realizing their sexual orientation shaped their sexual identity formation. A few did not realize their orientation until later in life. In one woman's description of her experience, she wrote, "when I first realized I was attracted to girls, I didn't even know such a thing existed."

Another topic some respondents wrote about that effected their sexual identity formation was religion. For one woman, it had a particularly positive effect. She mentioned "the Catholic views on marriage, sex and reproduction have given me the best hope I've ever had for a happy and healthy sexual/romantic relationship.” But for another participant, she wrote that she could not say that she had same-sex attractions because she grew up in a fundamentalist Christian environment where her grandmother once said that two girls having sex was “disgusting.”

A few respondents mentioned other life situations, which impacted their sexual identity formation. One person said that because she lived in Sweden, she experienced the sexual identity formation process differently. Another participant said that seeing her mother get divorced twice effected her sexual identity formation. An additional respondent said that she is a childhood sexual abuse survivor.

Summary

As reflected in the study findings, there are many issues that women with visible physical disabilities believe effected their sexual identity formation. These concerns include other peoples' beliefs about the meaning of disability, the internalization of disability, a lack of education about sex and healthy romantic relationships, and not having dating experiences they wanted when they were in high school. The next chapter consists of a discussion of how the study findings help explain the sexual identity formation experience of women with visible physical disabilities.

CHAPTER V

Discussion/Conclusions

Introduction

The purpose of my study is to gain information about the sexual identity formation of women with visible physical disabilities. It is a descriptive study designed to poll women who are over the age of 18 and self identified as having a visible physical disability on aspects of growing up that may have impacted their sexual identity formation. They were asked questions based on components identified in the literature that effect the sexual identity formation of people without disabilities as well as other components having to do with their disability. The survey questions were designed to determine if the participants were effected by the same components that effect sexual identity formation of women without disabilities as well as how having a disability impacted their sexual identity formation.

Overall, my study confirms and adds to the current literature on sexual identity formation, specifically the literature on women with visible physical disabilities. The study verifies that women with visible physical disabilities experience the same obstacles as able-bodied women, but they have additional barriers such as society's assumptions about disability and their internal struggles about their disability. Following is my interpretation of the results and how they compare to the existing literature. The results will be examined in four sections: force of disability and other factors on sexual identity formation, early education about sex, relationship history, connections and social influences, and religion.

Force of Disability and Other Factors on Sexual Identity Formation

In general, study participants appeared to feel that their disability had a negative impact on their sexual identity formation. Most reported that their disability negatively impacted the way potential dates saw them, their confidence, their ability to date and their ability to form intimate relationships. Many did not feel attractive during adolescence. While nearly half reported that they were encouraged to explore their sexual identity, more respondents were not encouraged. Participants reported that effective forces of their sexual identity formation were friends, family, media and their self-esteem. One concept that some women wrote about in the survey open response question was that they believed that their disability was a positive force in their sexual identity formation. As one woman stated, "I realized my disability could work in my favor by weeding out shallow or otherwise terrible potential partners." Others believed their disability was a negative force in their sexual identity formation. A woman wrote, "I feel like because I have a disability, others view will (sic) me as 'sterile' or not that interested in a sexual/romantic relationship."

There are many aspects that effect the sexual identity formation of women. Friends, family, media and self-esteem are a few that participants of my study identified. These are the same forces that have been noted in previous literature to contribute to the sexual identity formation of girls without disabilities. Specifically, many previous authors highlighted that beliefs about and experience of sex that mothers hold have a major impact on the sexual identity formation of their children (Fingerson, 2005; Crockett, Bingham, Chopak & Vicary, 1996; Miller & Fox, 1987). However, while the women living with physical disability who participated in my study did identify being impacted by these factors, unfortunately my study did not examine whether the participant pool believed that the forces effected them in a positive or negative way. Therefore, the forces may effect women with visible physical disabilities differently.

Another concept that emerged from my study is that the majority of participants reported that their disability had a negative effect upon their sexual identity formation. This finding validates what was noted in the Brown (1988) study, that adolescents with disabilities appear to have a lower self and body-esteem than their abled-bodied counterparts. Having this lower self-confidence appears to inhibit them in taking chances and pursuing relationships. Respondents in my study did not appear to believe they had the ability to date and believed that others did not view them as viable partners, which confirms the findings of Ketz (2002) and Shakespeare (1999). A respondent communicated, "…growing up I felt totally undesirable and believed that no guy would ever pick me." Holding beliefs that their disability impacted their dating ability seems to lead to the fact that their sexual identity formation was negatively effected. By not feeling that they were able to date, they did not have the same confidence level as abled-bodied peers, therefore signifying that having a visible physical disability can effect sexual identity formation.

As noted by Hassouneh-Phillips and McNeff (2005) and Moin, Duvdevany and Mazor (2009), being confident and feeling attractive contributes to a positive experience in a person's sexual identity formation. Most of the participants of this study reported having low confidence and not feeling attractive during adolescence. As some participants wrote, this had to do with societal perceptions of disability, specifically one woman noted that "…being disabled does have an impact, but it's because of discrimination rather than an innate trait." There are many myths that still exist in the society surrounding people who are disabled such as they are asexual and childlike so they need to be protected (McKown, 1984). Also there are strong messages of what the perfect body image is for women, and girls growing up internalize this image. Media then works to solidify that message and girls feel pressure to achieve it (Ketz, 2002; Shakespeare, 1999). Often women with disabilities are unable to see themselves in that perfect body image and can never achieve it, thus not feel attractive.

It was interesting to find that a significant number of participants revealed that they view their disability as a positive aspect of their sexual identity formation. Some people are able to overcome what the literature suggests in terms of self-concept and appreciate their disability as a positive. Many respondents seemed to feel that non-disabled peoples' perception of disability is the problem, as one woman put it, "I was aware that other people's attitudes toward me were the problem. So I did not think that my disability was the problem, but it was their problem that I had to deal with." This can suggest that women may be able to reach a place where they can ignore societal messages about disability. By being able to overcome societal messages and have confidence in themselves, some respondents felt that their disability did not have a strong effect on their sexual identity formation. For those who are able to see their disability as a positive in dating, these women may be more likely to have a similar experience with their sexual identity formation as their non-disabled peers. An example of this comes from a respondent who wrote the following:

> For me, while being disabled did hinder my ability to date when I was younger, as I got into late high school and college I almost began to appreciate it. I did not date as much as my able-bodied peers, which was at times very difficult, but the men who did express interest were typically very genuine, moral guys. In that way, I realized my disability could work in my favor by weeding out shallow or otherwise terrible potential partners.

Early Education About Sex

While most of the respondents felt comfortable talking with their friends, respondents did comment that they felt uncomfortable talking to their parents or teachers about sex. Most did not talk to their parents or caregivers about safe sex, nor did they feel comfortable asking them questions and were not encouraged by them to date. Sometimes the lack of communication appeared pretty extreme, such as this experience a participant articulated, “Mum said it was illegal to have sex until I was 25 because I use a wheelchair.” Instead, the main source of sex information appeared to come from friends. As for sex education in school, the majority of respondents reported that they wanted it to be better in various ways. The range of ways respondents wanted sex education in school to be different ranges included wanting to talk more in general about certain topics to specifically talking about the experience of people with disabilities and people who identify as Lesbian, Gay, Bisexual, Transgender (LGBT) when it comes to sex. Respondents also wrote about how the lack of communication about sex and LGBT issues impacted their sexual identity formation.

Overall, these results add to past literature by identifying where women with physical disabilities learn sex education. As Higgins (2010) found, children access sexual education from family, siblings, friends, media and formal classes in school. These sources are also named in my study as being a part of the sexual education of the women with physical disabilities, but to varying degrees. Respondents reported that they gained the majority of their sexual education from their friends. This contradicts the McCabe, Cummins and Deeks (2000) study in which the authors noted that adolescents with physical disabilities gain the majority of their sexual education from media and formal sexual education programs, not friends and family.

The results from my study validate the literature saying that women do not get enough sexual education. However, while women with physical disabilities may receive sexual education from typical sources they do not get enough of it, confirming that adolescents with disabilities receive significantly less sexual education than their peers (Brown, 1988; McCabe, Cummins & Deeks, 2000). But, the majority of respondents in my study reported that they wanted more sex education. Sexual abuse is a topic only 37% of respondents reported learning about during sex education in school. This topic is extremely important for everyone to learn about, but especially women with disabilities. The literature on this topic notes that women with disabilities are victimized at a greater rate than the general population (Washington State Coalition Against Domestic Violence, 2013). By not learning about the signs of sexual abuse, what to do if abuse is happening, and the specifics of sexual abuse as it effects people with disabilities, the cycle of abuse and victimization will only continue. There is a strong reluctance by parents and educators to talk about sexual health with adolescents with disabilities (McKown, 1984; Valvano, West, Wilson, Macapagal, Penwell-Waines, Waller & Stepleman, 2014), but ignoring the topics will only hinder the sexual identity formation of the girl by not setting her up to handle the positives and negatives that come with sex.

Participants in the study reported that they wanted to have their sexual education include more information specifically about disabilities and LGBT experiences. Often times, gender and sexuality are understood to be invisible for those with disabilities (Higgins, 2010). By bringing a voice to the disability population during sex education it will start to change the views society has on disability and sex. Teaching the considerations of disability and sex to students in school will begin to normalize disability for those with and without disabilities. This point is similar to talking about the LGBT experience. Many women in this study wrote about how they are a part of the LGBT community and how that was difficult for them as adolescents. Whitney (2006) reported that often times individuals who report being gay and having a disability feel split and rejected by both communities. These two minority groups often do not accept each other and it can make those who identify as both, feel rejected by both. By teaching about both the LGBT community and the disability community in school, it may help people to recognize that individuals can belong to both groups. This will help further the sexual identity formation of girls with disabilities, specifically those who feel that they identify as LGBT, because it may reduce the feeling of rejection and isolation that some participants in this study felt.

Some respondents wrote that they were not included in their schools health class because it was tied to Physical Education (PE). They were not included in PE due to having a disability. This is problematic in a few ways. Most likely, as noted in Fitzgerald and Stride's (2012) study, they did not have PE because they were deemed physically unable to participate and PE is often times the one class in mainstream schools that is not adapted to accommodate students with disabilities. But health class is not a physical activity, so they should have been included in the class. Another problem is that by being excluded from PE they are being excluded from the lessons students learn while in PE, like working as a team. By being excluded this can bring feelings of loneliness, isolation and rejection that can carry over to other areas of school and home life. This feeling of exclusion may have contributed to the lower levels of confidence and self-esteem the participants reported having felt as an adolescent.

Respondents shared that as adolescents, they did not feel comfortable talking or asking their parents about sex. They were also not encouraged to date. This may indicate that they did not feel supported enough to take risks or experiment. By not being encouraged to date, they may have felt nervous to go out and date due to the increased dependence on their parents. They may have felt they did not want to go against their parents. This further confirms literature that suggests that adolescents with disabilities are overprotected and do not feel that they can rebel or experiment because they feel they cannot go against their parents because they are so dependent on them (Fentin-Thompson, 2012; Ozhek, 2008).

Fingerson's (2005) study suggested that adolescents can sense what the atmosphere regarding the view of sex is in their family without talking to their parents about it. Fingerson further noted that when they do have a conversation about it, this usually means that the adolescent has already had sex. The results of my study demonstrate that adolescents with disabilities are like their peers without disabilities in that open dialogue with their parents does not seem to happen until the adolescent has had sex. The results also confirm past literature saying that parents do not offer adequate amounts of sexual information to their adolescent with a disability. By not opening the conversation, thus allowing the adolescent to know that the parents are available for conversations and questions, the adolescent may feel that they cannot start the conversation themselves.

Relationship History

Women participating in this survey were asked about various relationships in their lives. The majority of respondents noted that when they were growing up their friends were dating or in a relationship. Participants also noted that they could talk with their friends about dating relationships, experiences, wishes, questions, fears and concerns. When asked about early attractions, the majority of women reported that their feelings of first attraction were based on an emotional connection rather than a physical one. Even though they felt attracted to others and their friends were dating, the majority of respondents noted that they did not date or have a relationship in high school but they wanted to.

These results indicate that women with physical disabilities are raised to find the same aspects of relationships important as women without physical disabilities. Women are more attracted to emotional intimacy than physical intimacy (McElwain, Grimes & McVicker, 2009; Feiring, 1996; Blyth & Foster-Clark, 1987). The results indicate that is also true for women with physical disabilities because the majority of respondents reflected that when they were first attracted to someone, it was based on an emotional connection. However, this can become problematic in their sexual identity formation because while they were attracted to other people, they did not have the same dating experiences as their peers.

As established in studies such as Auslander, Rosenthal and Blyth (2006) and Furman and Wehner (1997), there is a trajectory that people appear to follow throughout adolescence that has certain benchmarks during the early, middle and late stages. As my study indicates, respondents seem to believe that their friends followed a similar trajectory in terms of dating and being in relationships. Respondents, however, did not have some of the same experiences as their peers did. Specifically, while their friends dated, they did not. Therefore, while their friends were gaining social status (McElwain, Grimes & McVicker, 2009; Feiring, 1996), they were not. Not having the dating experience means that their sexual identity formation suffered. Even though the majority of respondents did not participate in the actual dating experience, they did participate in conversations about dating topics with friends. Respondents' sexual identity formation benefited from the communication, but due to the lack of personal experience, they did not get the benefits of sharing them with their friends; they could only say what they wanted to happen, not what actually happened.

Crockett et al.'s (1996) study found that having poor peer relationships were associated with a later start timing of sex. However, findings from my study indicate that Crockett et al.'s study does not accurately describe the situation of women with visible physical disabilities. The results of my study indicate that participants had strong peer relations because they felt comfortable talking to friends, and being part of relationship conversations with them. But participants did not have dating or relationship experiences, which was not their choice because they wanted to date or be in a relationship. This difference may have to do with societal perceptions of disability and others not seeing them as a valuable partner, as well as the women not having the same confidence building experiences as their friends may have encountered.

Connections and Societal Influences

My study finds that the majority of respondents did not feel connections with the disabled community as adolescents. While most did not have a role model with a disability, or a role model they could talk to about sex, slightly more than half had connections to peers with disabilities.

For those with physical disabilities, their identity is strengthened when they have the opportunity to integrate into general society and form connections with people in the disability community (Fentin-Thompson, 2012; Taub & Greer, 2000). Having not had connections to the disability community and role models growing up may have negatively impacted their sexual identity formation. Part of the importance of being around others with disabilities, and being around abled bodied people, is that the adolescent learns to appreciate their differences and similarities to others. It helps them to develop into more of an individual. By not making those connections, these respondents missed out on a critical part of their identity development. By not learning to accept their differences, they did not fully develop their confidence, so they did not date. By not having a role model they could talk to about sex, they could not see themselves having the ability to date. Not seeing someone with a similar ability level as themselves dating most likely made it difficult for the participants to engage in dating relationships. This coupled with their parents not encouraging them to date makes it nearly impossible for them to make the leap. In order to leave themselves emotionally open to dating possibilities, they had to break the societal messages on disability and sex that have been taught to them from a young age.

Religion

Another influence that effected participants differently was the concept of religion. While the majority of participants felt that religion did not shape how they viewed intimate relationships, a few participants wrote how they believed religion effected their sexual identity formation in some capacity. This idea was not discussed in the literature. This may be due to the fact that religion seems to be polarizing in the way people feel about it, at least in relation to this study's participants. The majority indicates that religion did not effect their sexual identity formation, but a few participants write how they were effected by it. This can indicate that unless religion was a big part of the participants' lives, or they had a fomenting and lasting experience with religion in forming their sexual identity, then religion did not have a great impact in the sexual identity formation of women with physical disabilities.

Strengths of the Study

My study had several strengths. The precision and focus of the over arching research question was one of the strengths of the study. The question aimed at gathering a variety of information relating to the sexual identity formation of women with visible physical disabilities directly from women with visible physical disabilities. The clarity of the over arching question helped my study succeed in doing what it set out to do and gathered the information.

The data collection method was a strength in my study. Collecting both quantitative and qualitative data allowed the survey to get a range of responses. Having the survey online allowed for a greater pool of participants to privately share, and encouraged the opinions of women living in different places to be considered. Because the survey was anonymous, it allowed participants to feel more comfortable about sharing. Also, the survey's quantitative questions led to clear descriptive analysis. The quantitative questions also allowed for quick answers and allowed for a wide range of information from a greater amount of people in the least amount of time.

My study's sample was diverse in some ways. There was a wide representation of ages, location, religion and levels of mobility. Through the study design, women with physical disabilities were my 'experts' in terms of their own experiences. Thus, I was able to collect their own thoughts regarding their upbringing surrounding the various elements of sexual identity formation.

Limitations of the Study

Limitations of my study were mostly due to a relatively small sample size; to the fact that it was purely descriptive, and did not allow for multiple groups for comparison purposes; and was not highly diverse in terms of cultural and regional differences.

Implications of this Study for Practice and Policy

My study has some implications for practice and policy. Women with disabilities need more sex education. They must be included in existing curriculums at school, and those sex education curriculums should be updated to include more diversity including disability and LGBT information. Due to the major hurdle of the formation of sexual identity for women with disabilities being the perception of disability by society, disability needs to be more integrated. This means that people with disabilities need to have more of a presence in social settings, such as in schools, television, movies, books, jobs; essentially being more present in order to be more normalizing. Also, people who work with girls with disabilities in various ways including counselors, medical personnel, teachers and parents, need to talk about the same things as they would to girls without disabilities. This means subjects including romantic relationships and sex.

Recommendations for Future Study

The sexual identity formation of women with visible physical disabilities is an incredibly important, but understudied topic. More research needs to be done in order to further learn about the impact of physical disability on sexual identity formation. Specifically, future research can be done by looking at the impact of ableism, the impact of teasing and being ignored by peers, the presence of social supports and the effects of intersectionality with traits such as sexual orientations, socioeconomic status and race. Another distinguishing aspect to also be looked at is the difference of sexual identity formation between people with congenital disabilities, acquired disabilities and the presence of co-occurring disabilities and mental health issues. Studies in the future might examine cultural and location differences and might attempt to do more with comparative groups within the disability status. Finally, more similar study of this nature is also indicated, as this is an area where more study is definitely indicated.

References

Allport, G. W. (1954). *The nature of prejudice* Cambridge, Mass. : Addison-Wesley Pub. Co., 1954.

Auslander, B. A., Rosenthal, S. L., & Blythe, M. J. (2006). Sexual development and behaviors of adolescents. *Psychiatric Annals, 36*(10), 694-702.

Baumeister, R. F. (2000). Gender differences in erotic plasticity: The female sex drive as socially flexible and responsive. *Psychological Bulletin, 126*(3), 347-374. doi:10.1037/0033-2909.126.3.347

Baumeister, R. F. (2004). Gender and erotic plasticity: Sociocultural influences on the sex drive. *Sexual & Relationship Therapy, 19*(2), 133-139. doi:10.1080/14681990410001691343

Blyth, D. A., & Foster-Clark, F. (1987). Gender differences in perceived intimacy with different members of adolescents' social networks. *Sex Roles, 17*(11), 689.

Brown, D. E. (1988). Factors affecting psychosexual development of adults with congenital physical disabilities. *Physical & Occupational Therapy in Pediatrics, 8*(2-3), 43-58.

Connolly, J., Furman, W., & Konarski, R. (2000). *The role of peers in the emergence of heterosexual romantic relationships in adolescence* Blackwell Publishers.

Crockett, L. J., Bingham, C. R., Chopak, J. S., & Vicary, J. R. (1996). Timing of first sexual intercourse: The role of social control, social learning, and problem behavior. *Journal of Youth and Adolescence, 25*(1), 89.

DeLamater, J. D., & Hyde, J. S. (1998). *Essentialism vs. social constructionism in the study of human sexuality* Society for the Scientific Study of Sex.

Dune, T. (2012). *Sexuality and physical disability: Exploring the barriers and solutions in healthcare.* (No. 30). Springer Science & Business Media B.V. doi:10.1007/s11195-012-9262-8

East, L. J., & Orchard, T. R. (2014). 'Why can't I?': An exploration of sexuality and identity among canadian youth living with physical disabilities. *Journal of Youth Studies,17*(5-6), 559-576.

Eliason, M. J. (1995). Accounts of sexual identity formation in heterosexual students. *Sex Roles: A Journal of Research, 32*(11-12), 821-34.

Erikson, E. H. (1968). *Identity, youth, and crisis* New York : W. W. Norton, 1968; 1st ed.

Feiring, C. (1996). Concepts of romance in 15-year-old adolescents. *Journal of Research on Adolescence (Lawrence Erlbaum), 6*(2), 181-200.

Feldman, L., Holowaty, P., Harvey, B., Rannie, K., Shortt, L., & Jamal, A. (1997). A comparison of the demographic, lifestyle, and sexual behavior characteristics of virgin and non-virgin adolescents. *Canadian Journal of Human Sexuality, 6*(3), 197-209.

Fentin-Thompson, N. (2012). *Identity development and athletic participation among female adolescents with physical disabilities* . (2012-99080-585).

Fingerson, L. (2005). Do mothers' opinions matter in teens' sexual activity? *Journal of Family Issues, 26*(7), 947-974.

Fitzgerald, H., & Stride, A. (2012). Stories about physical education from young people with disabilities. *International Journal of Disability, Development & Education, 59*(3), 283-293. doi:10.1080/1034912X.2012.697743

Freud, S. (2000). *Three essays on the theory of sexuality* (J. Strachey Trans.). (Revised ed.) Basic Books.

Furman, W., & Wehner, E. A. (1997). Adolescent romantic relationships: A developmental perspective. *New Directions for Child Development,* (78), 21-36.

Gill, C. J. (1997). Four types of integration in disability identity development. *Journal of Vocational Rehabilitation, 9*(1), 39-46.

Glee. (2009). [Television series] Fox.

Hasson-Ohayon, I., Hertz, I., Vilchinsky, N., & Kravetz, S. (2014). Attitudes toward the sexuality of persons with physical versus psychiatric disabilities. *Rehabilitation Psychology, 59*(2), 236-241. doi:10.1037/a0035916

Higgins, D. (2010). Sexuality, human rights and safety for people with disabilities: The challenge of intersecting identities. *Sexual and Relationship Therapy, 25*(3), 245-257.

Jones, S. E., & Lollar, D. J. (2008). Relationship between physical disabilities or long-term health problems and health risk behaviors or conditions among US high school students. *Journal of School Health, 78*(5), 252-257.

Juhasz, A. M., & Sonnenshein-Schneider, M. (1987). Adolescent sexuality: Values, morality and decision making. *Adolescence, 22*(87), 579-590.

Lawrence, B. (1991). *Self-concept formation and physical handicap: Some educational implications for integration.* (No. 6). Carfax Publishing Company.

Marcia, J. E. (1966). Development and validation of ego-identity status. *Journal of Personality and Social Psychology, 3*(5), 551-558. doi:10.1037/h0023281

Mauer, R. A. (1979). Young children's responses to a physically disabled storybook hero. *Exceptional Children, 45*(5), 326-330.

McCabe, M. P., Cummins, R. A., & Deeks, A. A. (2000). Sexuality and quality of life among people with physical disability. *Sexuality & Disability, 18*(2), 115-123.

McCabe, M. P., Taleporos, G., & Dip, G. (2003). Sexual esteem, sexual satisfaction, and sexual behavior among people with physical disability. *Archives of Sexual Behavior,32*(4), 359-369.

McElwain, A., Grimes, M., & McVicker, M. (2009). The implications of erotic plasticity and social constructivism in the formation of female sexual identity. *Journal of Feminist Family Therapy, 21*(2), 125-139. doi:10.1080/08952830902911347

McKown, J. M. (1984). Disabled teenagers: Sexual identification & sexuality counseling. *Sexuality and Disability, 7*(1-2), 17-27.

Miller, B. C., & Fox, G. L. (1987). Theories of adolescent heterosexual behavior. *Journal of Adolescent Research, 2*(3), 269.

Morgan, E. M. (2012). Not always a straight path: College students' narratives of heterosexual identity development. *Sex Roles, 66*(1-2), 79-93.

Murderball. Rubin, H. A. and Shapiro, D. A. (Directors). (2005).[Motion Picture] Paramount Pictures.

Ozhek, S. R. (2008). Overprotection and adolescents with physical disabilities. *Journal of Special Education & Rehabilitation,* (1), 100.

Robinson, L. D. (1979). Sexuality and the deaf culture. *Sexuality and Disability, 2*(3), 161-168.

Schulz, S. L. (2009). Psychological theories of disability and sexuality: A literature review. *Journal of Human Behavior in the Social Environment, 19*(1), 58-69.

Shakespeare, T. (1999). The sexual politics of disabled masculinity. *Sexuality & Disability, 17*(1), 53.

Short, M. B., Succop, P. A., Mills, L., Stanberry, L. R., Biro, F. M., & Rosenthal, S. L. (2003) Non-exclusivity in adolescent girls' romantic relationships. *Sexually Transmitted Diseases, 30*(10), 752-755.

Stolz, S. M. (2010). *Disability trajectories: Disabled youths' identity development, negotiation of experience and expectation, and sense of agency during transition*

Taub, D., & Greer, K. (2000). Physical activity as a normalizing experience for school-age children with physical disabilities. *Journal of Sport & Social Issues, 24*(4), 395-414.

United Nations. Factsheet on persons with disabilities. Retrieved from http://www.un.org/disabilities/default.asp?id=18

Valvano, A. K., West, L. M., Wilson, C. K., Macapagal, K. R., Penwell-Waines, L., Waller, J. L., & Stepleman, L. M. (2014). Health professions students' perceptions of sexuality in patients with physical disability. *Sexuality and Disability.*

Wagner, M., Newman, L., Cameto, R., Garza, N., & Levine, P.(2005). *After high school: A first look at the postschool experiences of youth with disabilities. A report from the national longitudinal transition study-2 (NLTS2).* ().Online Submission.

Wagner, M., Newman, L., Cameto, R., Levine, P., & Garza, N. (2006). *An overview of findings from wave 2 of the national longitudinal transition study-2 (NLTS2). NCSER 2006-3004.* ().National Center for Special Education Research.

Washington State Coalition Against Domestic Violence. (2013). Disability community. Retrieved from http://www.wcsap.org/disability-community

Weeber, J. E. (2005). *Disability community leaders' disability identity development: A journey of integration and expansion*. (2005-99010-236).

Wheelchair basketball. Guinness (Director). (2013).[Video/DVD]

Whitney, C. (2006). Intersections in identity-identity development among queer women with disabilities. *Sexuality and Disability, 24*(1), 39-52.

Zeltzer, L. (1985). Chronic illness and disability in adolescents. *International Journal of Adolescent Medicine and Health, 1*(3-4), 239-248.

Appendix A

SMITH COLLEGE

School for Social Work
Smith College
Northampton, Massachusetts 01063
T (413) 585-7950   F (413) 585-7994

November 13, 2014

Clara Miller

Dear Clara,

You did a very nice job on your revisions. Your project is now approved by the Human Subjects Review Committee.

Please note the following requirements:

Consent Forms: All subjects should be given a copy of the consent form.

Maintaining Data: You must retain all data and other documents for at least three (3) years past completion of the research activity.

In addition, these requirements may also be applicable:

Amendments: If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

Renewal: You are required to apply for renewal of approval every year for as long as the study is active.

Completion: You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Congratulations and our best wishes on your interesting study.

Sincerely,

Marsha Kline Pruett

Marsha Pruett, PhD
Co-Chair, Human Subjects Review Committee

CC: Elaine Kersten, Research Advisor

Appendix B

Recruitment Message

Hello! I am working to complete my Masters degree in Social Work and this survey is part of my thesis project. I am interested in gaining information on how women with visible physical disabilities experience their sexual identity formation. By “visible physical disability” I mean disability that affects physical tasks of daily living, such as walking, seeing or hearing, that is also identifiable to someone else who may see you in the community. In this study, sexual identity formation is defined as developing an awareness of one’s self as a sexual being. If you self-identify as a woman with a visible physical disability who is 18 years or older, please take this survey and share your experiences, in order to increase knowledge of sexuality and disability. Please also consider forwarding this message to anyone you think may have interest in this survey.

Link to survey: (link)

Thank you so much!

Appendix C

Welcome to My Survey

Hello and welcome to the Sexuality and Disability Study. This study will fulfill part of my Masters in Social Work degree. The goal of this study is to further the understanding about how having a visible physical disability may affect the sexual identity formation of women. Sexual identity is defined as an awareness of one's self as a sexual being. Sexual identity formation is the process everyone goes through, typically during adolescents where you develop sexual feelings towards others, learn what you find attractive in a partner, and may learn to develop romantic relationships.

By choosing to participate in this survey, your answers will help identify different aspects of your past experiences that went into your sexual identity formation. The information gathered from the study will offer an opportunity of insight to social workers and educators on how to better serve adolescents with visible physical disabilities in supporting them in developing their sexual identity.

Thank you,
Clara Miller
MSW Candidate

Please continue to the screening page.

NEXT

Appendix D

Screening

***1. Do you self identify as female?**

Yes
No

Prev Next

***2. Do you self identify as having a visible physical disability?**

Yes
No

Prev Next

***3. Are you 18 years or older?**

Yes
No

Prev Next

NEXT

Appendix E

Informed Consent Agreement

Dear Participant,

This study is being conducted by Clara Miller, an MSW candidate at Smith College School for Social Work, as part of my thesis. You are being asked to be in a research study of the factors involved in the sexual identity formation of women with visible physical disabilities. You were selected as a possible participant because in the previous page you self identified as being a woman with a visible physical disability who is over the age of 18.

The purpose of the study is to gain knowledge about how having a visible physical disability has shaped how you see yourself as a sexual being. This study is being conducted as a research requirement for my master's in social work degree. Ultimately, this research may be published or presented at professional conferences.

If you agree to be in this study, you will be asked to do the following things: answer questions about your experiences growing up specifically about influences you may have had that effected your sexual formation. It is a survey that will only be done once but the length of time required will differ from person to person.

This study may bring up some painful memories as it asks you to reflect on your past experiences. The potential benefit of being in this study is that you will have the opportunity to share your experiences about this important topic that you may have not spoken of before. The potential benefits to social work is to identify areas that may be lacking around the formation of sexual identity and areas that women are unhappy about, which may then lead to greater supports to be put in place to better support adolescents with visible physical disabilities form their sexual identity.

This study is anonymous. I will not be collecting or retaining any information about your identity.

You will not receive any financial payment for your participation.

The decision to participate in this study is entirely up to you. You may refuse to take part in the study at any time during the survey without affecting your relationship with the researchers of this study or Smith College. You have the right not to answer any single question, as well as to withdraw completely at any time. If you choose to withdraw, you may exit the survey at anytime by clicking on the ‘Escape’ button and none of your answers will be saved.

If you have any further questions about the study, at any time feel free to contact me, Clara Miller at cjmiller@smith.edu. If you have any other concerns about your rights as a research participant, or if you have any problems as a result of your participation, you may contact the Chair of the Smith College School for Social Work Human Subjects Committee at (413) 585-7974.

By checking “I Agree” and clicking “Next” you are indicating that you have read and understood the above information, that you have had the opportunity to ask questions about the study, your participation, and your rights and that you agree to participate in the study.

Thank you in advance for your participation!

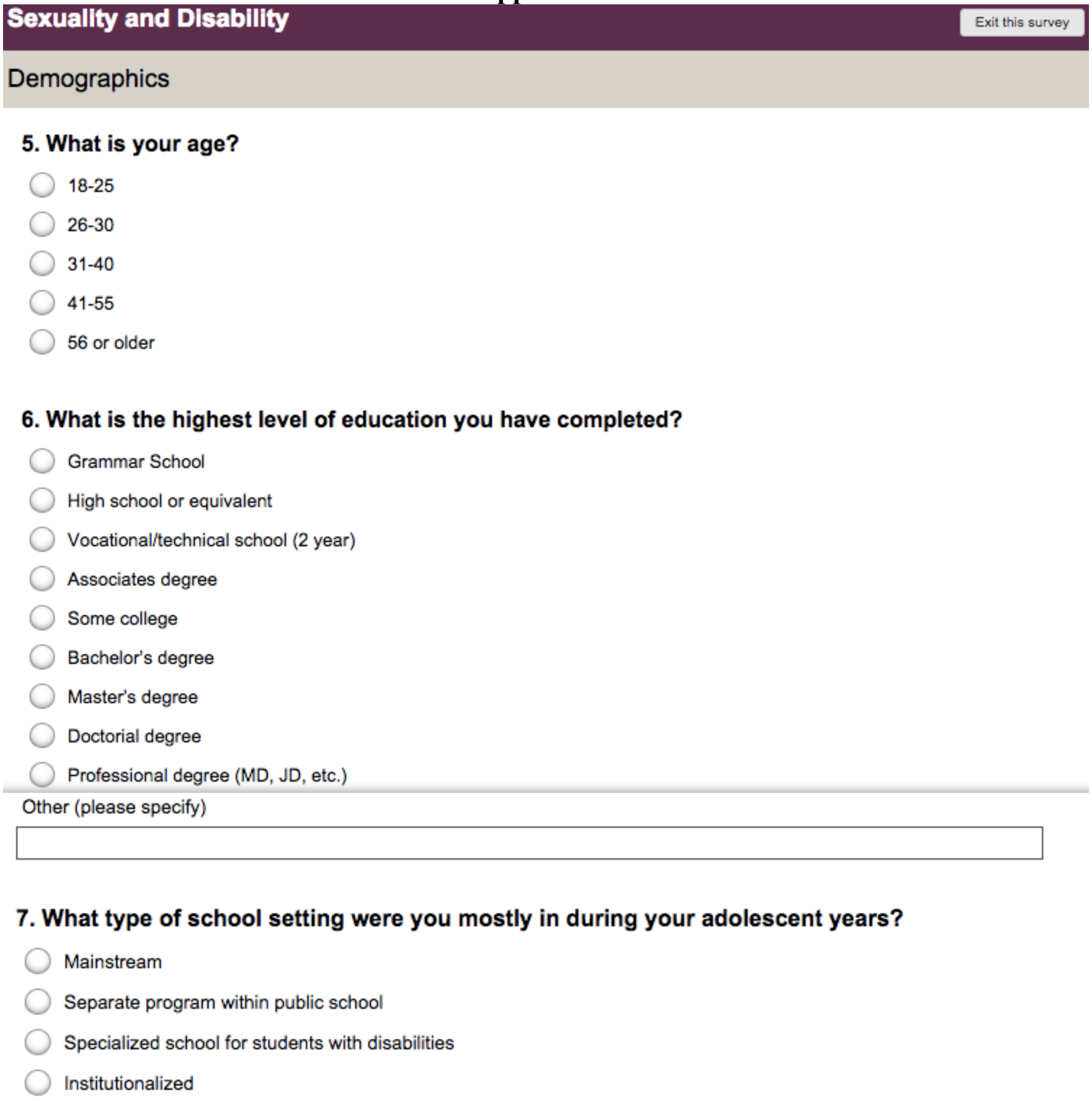
***4. Do you agree to participate?**

○ I Agree

○ I Do Not Agree

NEXT

Appendix F



Sexuality and Disability

Demographics

5. What is your age?

○ 18-25
○ 26-30
○ 31-40
○ 41-55
○ 56 or older

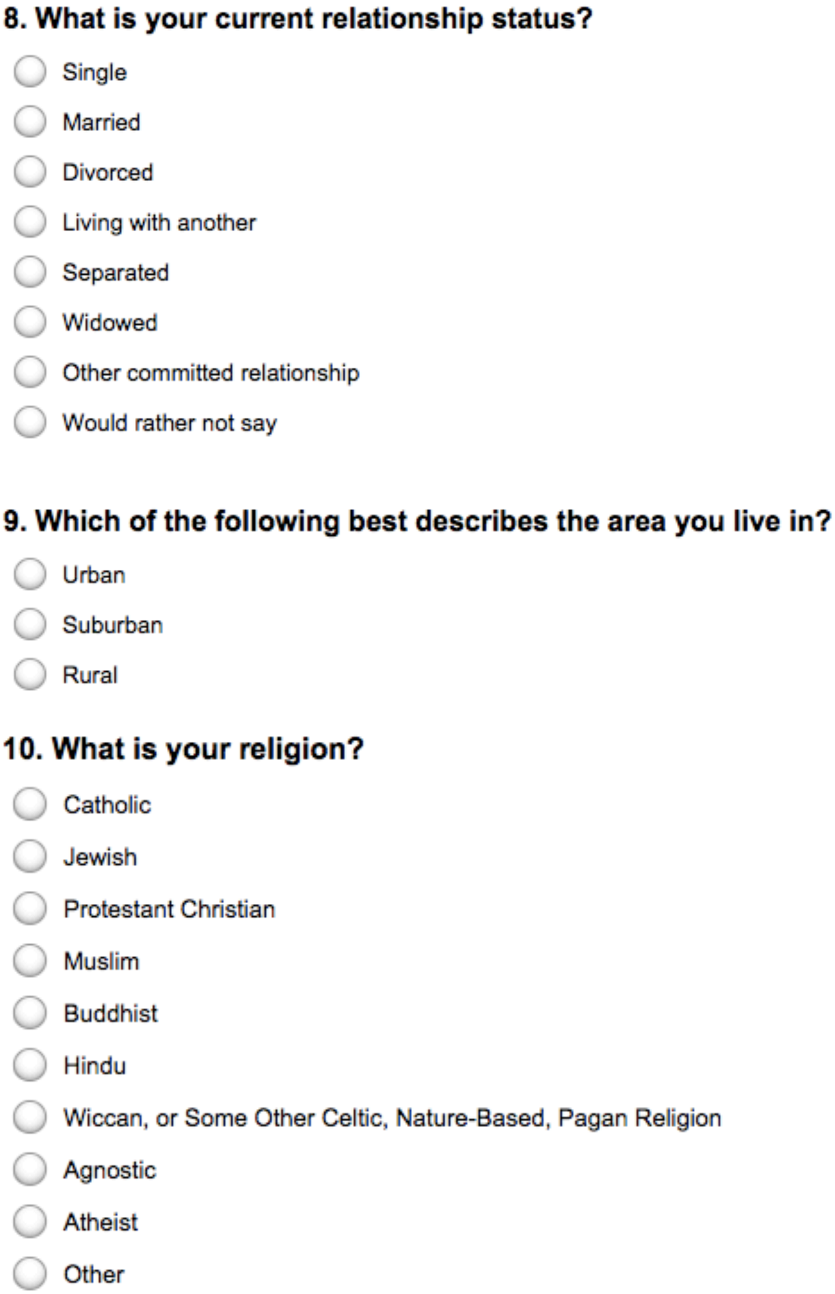
6. What is the highest level of education you have completed?

○ Grammar School
○ High school or equivalent
○ Vocational/technical school (2 year)
○ Associates degree
○ Some college
○ Bachelor's degree
○ Master's degree
○ Doctorial degree
○ Professional degree (MD, JD, etc.)

Other (please specify)

7. What type of school setting were you mostly in during your adolescent years?

○ Mainstream
○ Separate program within public school
○ Specialized school for students with disabilities
○ Institutionalized



8. What is your current relationship status?

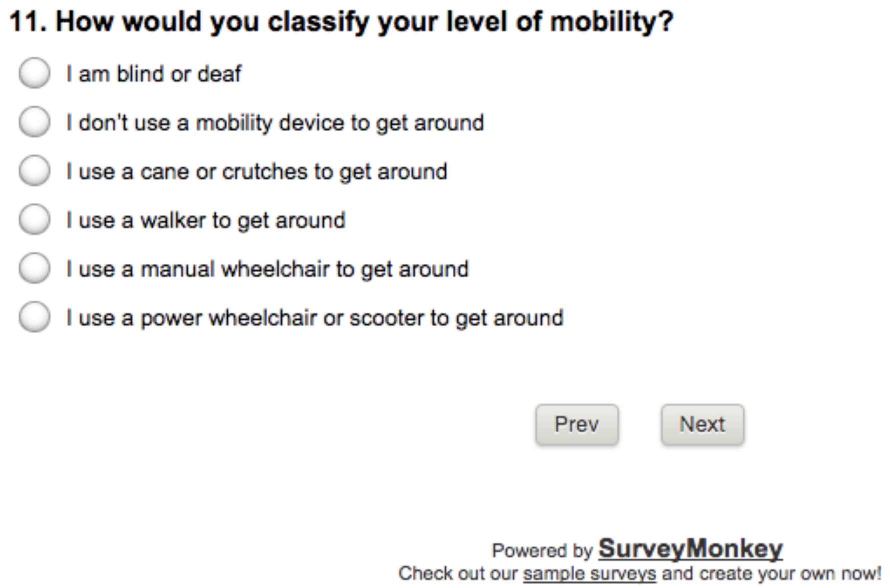
○ Single
○ Married
○ Divorced
○ Living with another
○ Separated
○ Widowed
○ Other committed relationship
○ Would rather not say

9. Which of the following best describes the area you live in?

○ Urban
○ Suburban
○ Rural

10. What is your religion?

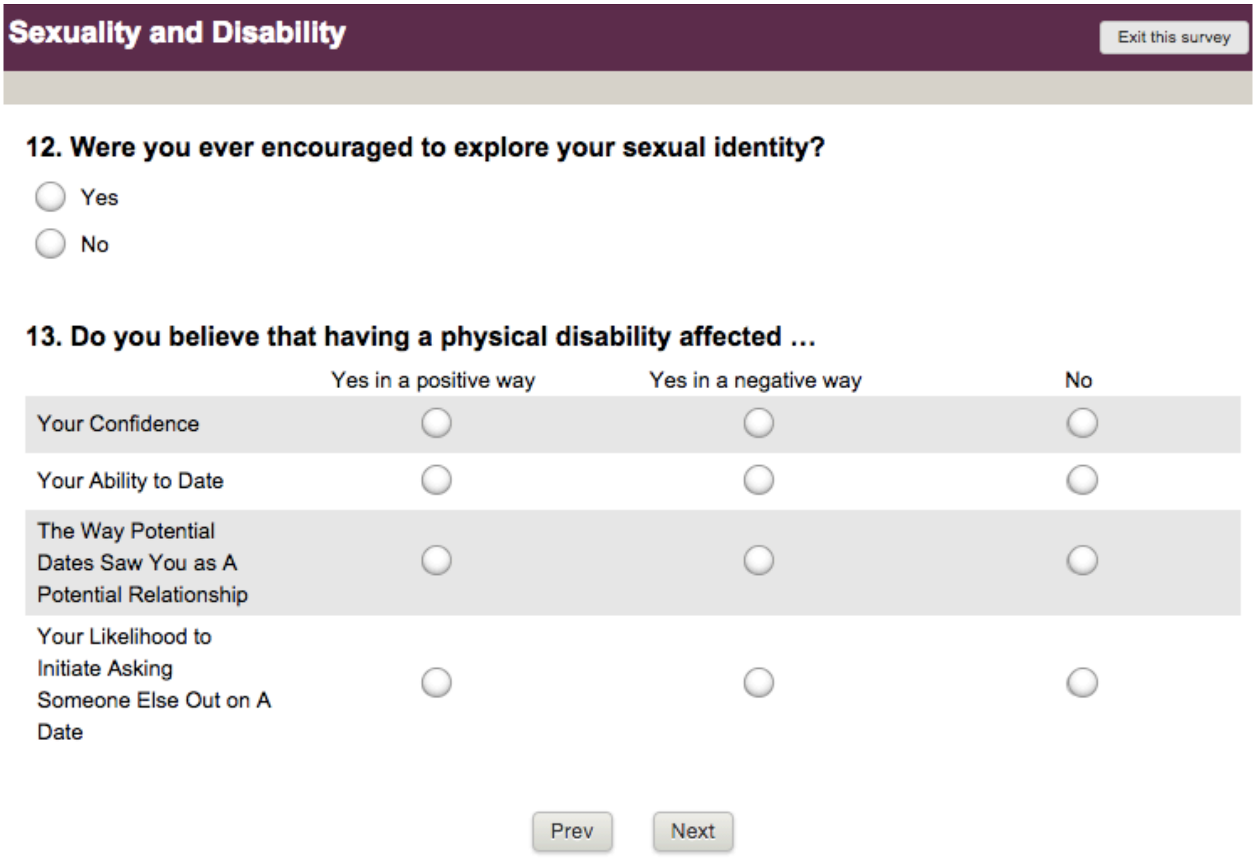
○ Catholic
○ Jewish
○ Protestant Christian
○ Muslim
○ Buddhist
○ Hindu
○ Wiccan, or Some Other Celtic, Nature-Based, Pagan Religion
○ Agnostic
○ Atheist
○ Other



11. How would you classify your level of mobility?

○ I am blind or deaf
○ I don't use a mobility device to get around
○ I use a cane or crutches to get around
○ I use a walker to get around
○ I use a manual wheelchair to get around
○ I use a power wheelchair or scooter to get around

Powered by SurveyMonkey
Check out our sample surveys and create your own now!

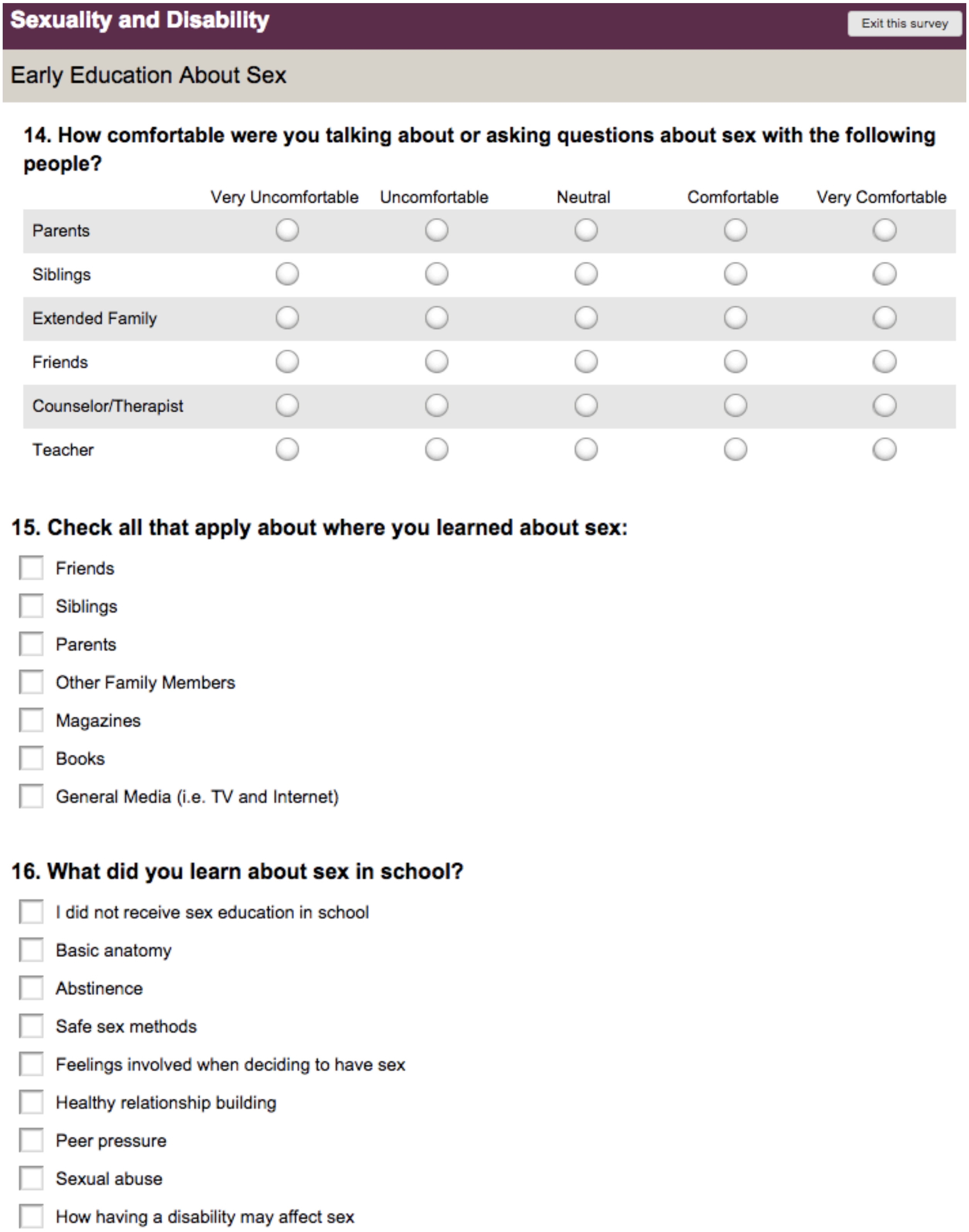


12. Were you ever encouraged to explore your sexual identity?

○ Yes
○ No

13. Do you believe that having a physical disability affected …

	Yes in a positive way	Yes in a negative way	No
Your Confidence	○	○	○
Your Ability to Date	○	○	○
The Way Potential Dates Saw You as A Potential Relationship	○	○	○
Your Likelihood to Initiate Asking Someone Else Out on A Date	○	○	○



Early Education About Sex

14. How comfortable were you talking about or asking questions about sex with the following people?

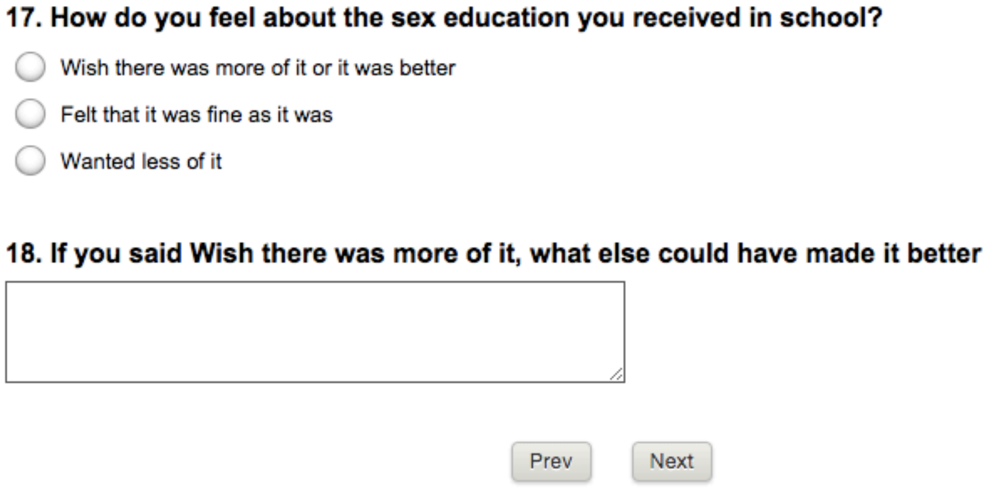
	Very Uncomfortable	Uncomfortable	Neutral	Comfortable	Very Comfortable
Parents	○	○	○	○	○
Siblings	○	○	○	○	○
Extended Family	○	○	○	○	○
Friends	○	○	○	○	○
Counselor/Therapist	○	○	○	○	○
Teacher	○	○	○	○	○

15. Check all that apply about where you learned about sex:

☐ Friends
☐ Siblings
☐ Parents
☐ Other Family Members
☐ Magazines
☐ Books
☐ General Media (i.e. TV and Internet)

16. What did you learn about sex in school?

☐ I did not receive sex education in school
☐ Basic anatomy
☐ Abstinence
☐ Safe sex methods
☐ Feelings involved when deciding to have sex
☐ Healthy relationship building
☐ Peer pressure
☐ Sexual abuse
☐ How having a disability may affect sex



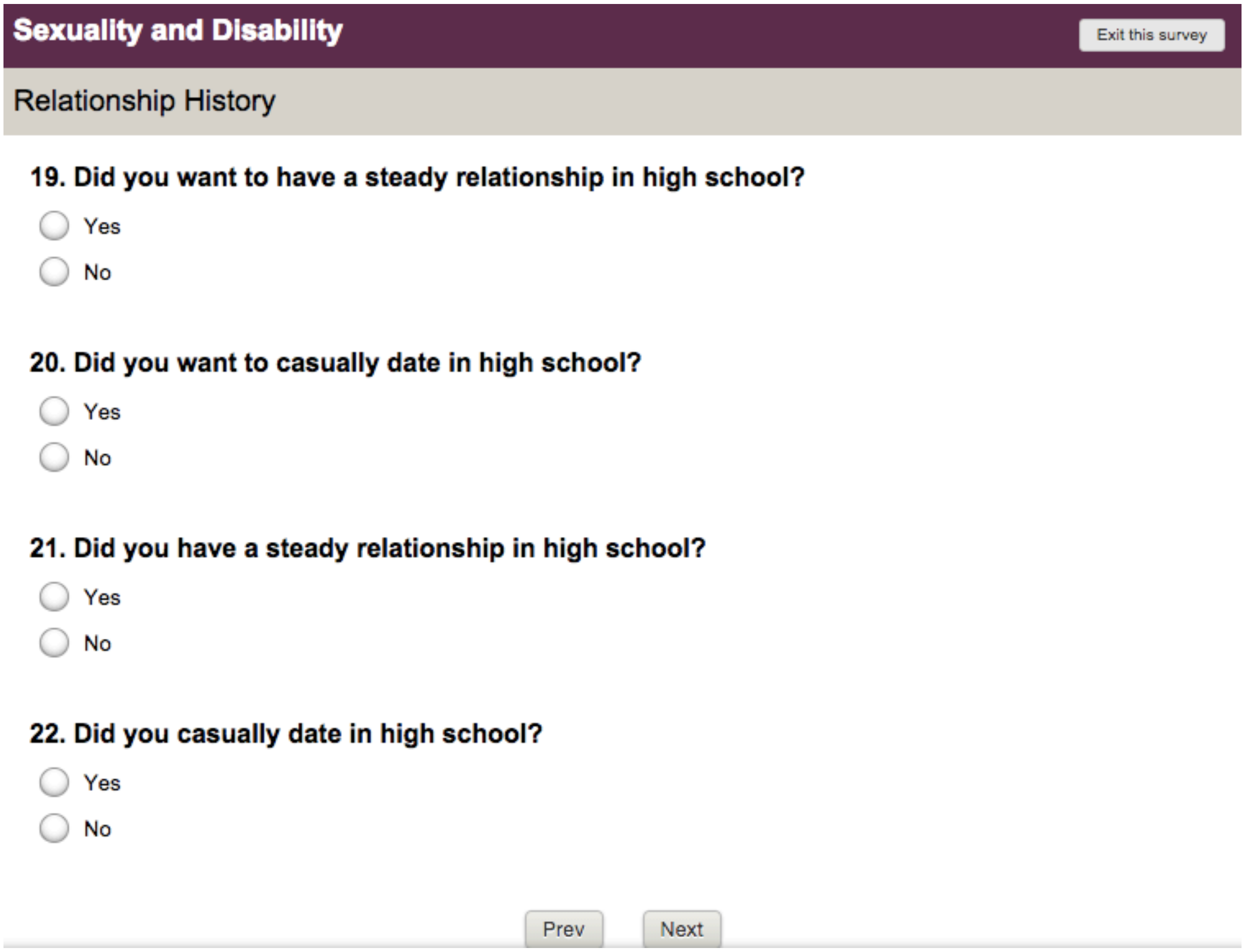
17. How do you feel about the sex education you received in school?

○ Wish there was more of it or it was better

○ Felt that it was fine as it was

○ Wanted less of it

18. If you said Wish there was more of it, what else could have made it better



Sexuality and Disability

Relationship History

19. Did you want to have a steady relationship in high school?

○ Yes

○ No

20. Did you want to casually date in high school?

○ Yes

○ No

21. Did you have a steady relationship in high school?

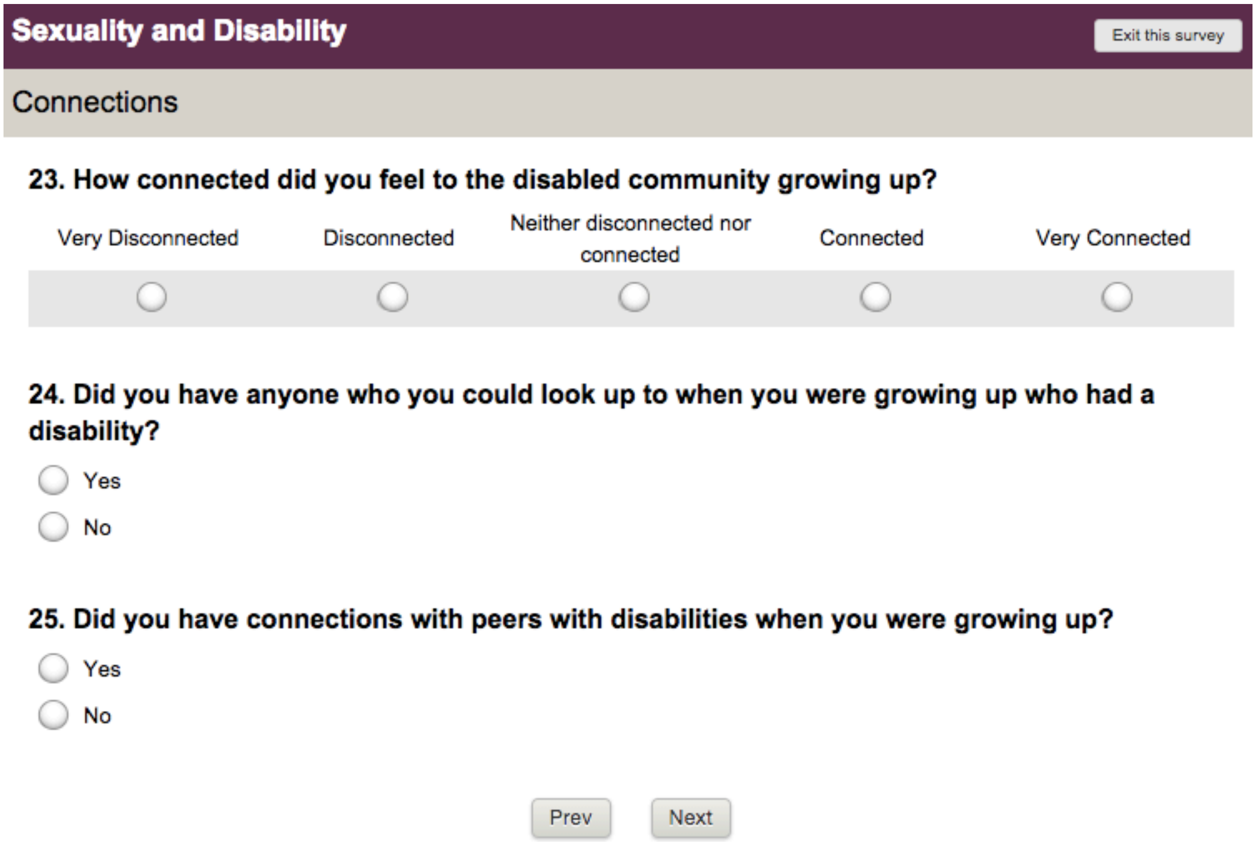
○ Yes

○ No

22. Did you casually date in high school?

○ Yes

○ No



Connections

23. How connected did you feel to the disabled community growing up?

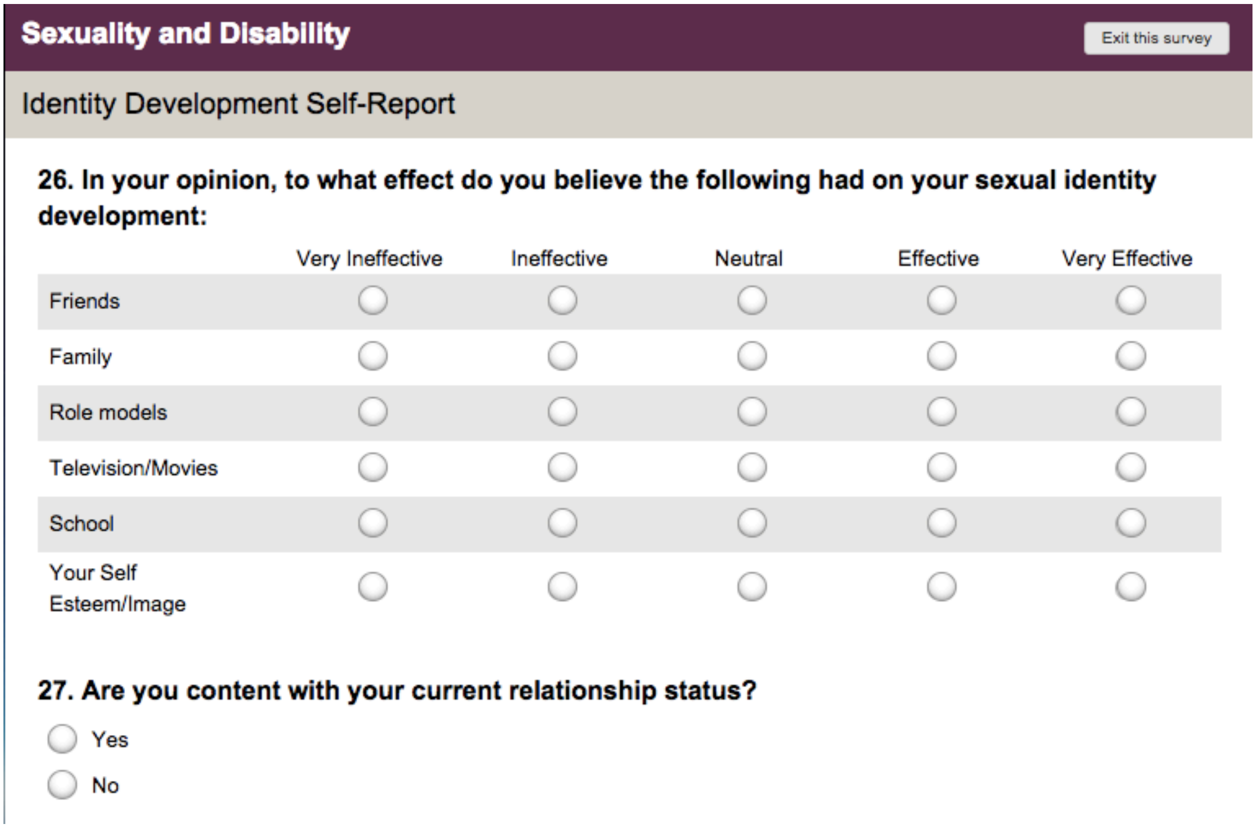
Very Disconnected	Disconnected	Neither disconnected nor connected	Connected	Very Connected
○	○	○	○	○

24. Did you have anyone who you could look up to when you were growing up who had a disability?

○ Yes
○ No

25. Did you have connections with peers with disabilities when you were growing up?

○ Yes
○ No



Sexuality and Disability

Identity Development Self-Report

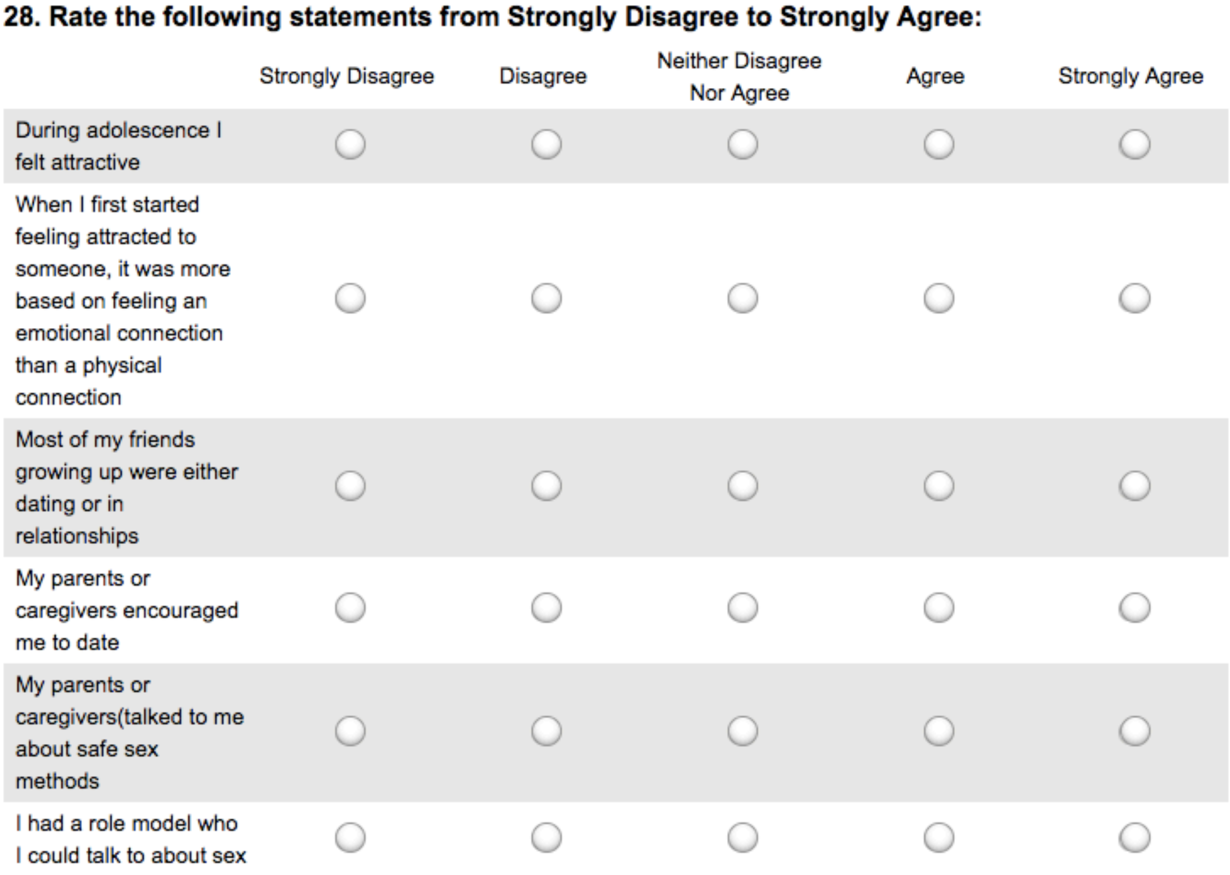
26. In your opinion, to what effect do you believe the following had on your sexual identity development:

	Very Ineffective	Ineffective	Neutral	Effective	Very Effective
Friends	○	○	○	○	○
Family	○	○	○	○	○
Role models	○	○	○	○	○
Television/Movies	○	○	○	○	○
School	○	○	○	○	○
Your Self Esteem/Image	○	○	○	○	○

27. Are you content with your current relationship status?

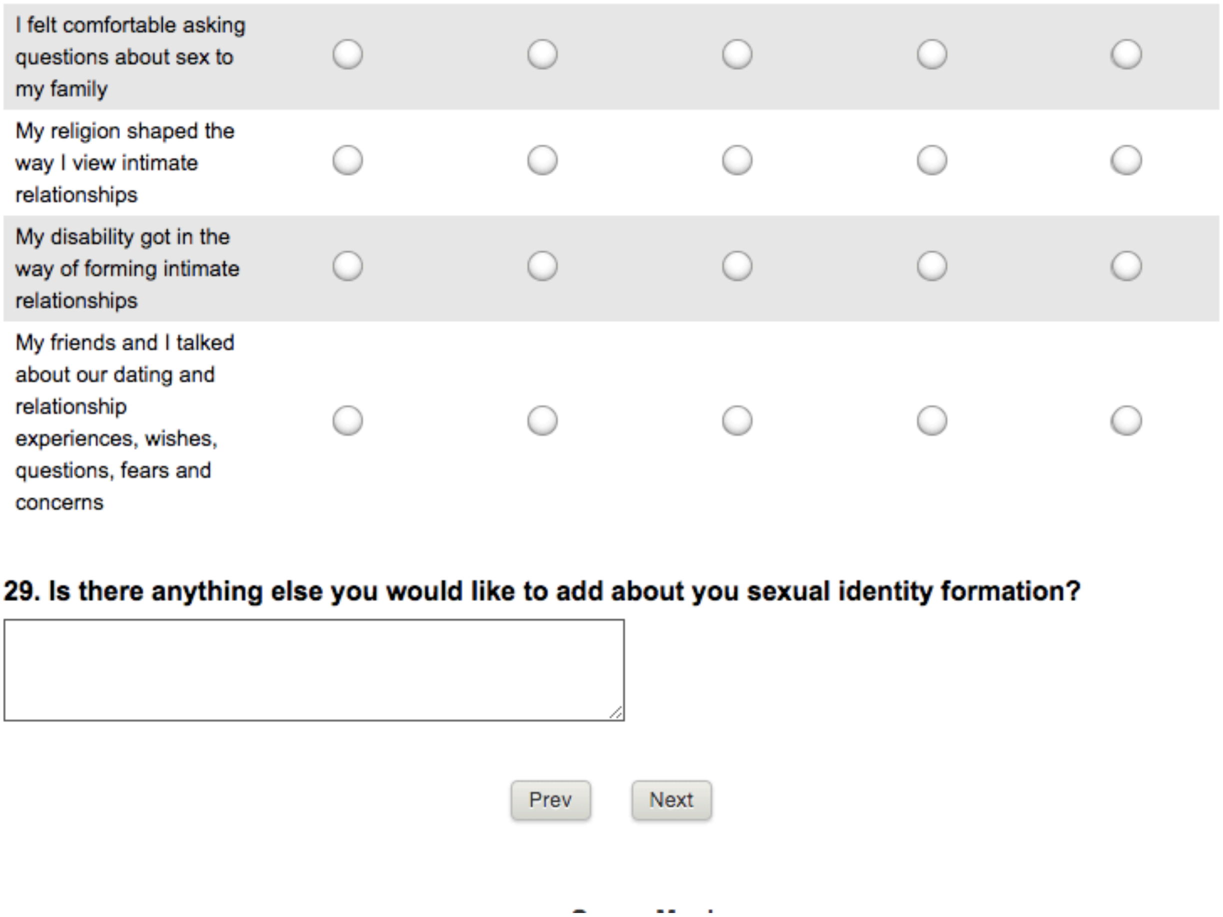
○ Yes

○ No



28. Rate the following statements from Strongly Disagree to Strongly Agree:

	Strongly Disagree	Disagree	Neither Disagree Nor Agree	Agree	Strongly Agree
During adolescence I felt attractive	○	○	○	○	○
When I first started feeling attracted to someone, it was more based on feeling an emotional connection than a physical connection	○	○	○	○	○
Most of my friends growing up were either dating or in relationships	○	○	○	○	○
My parents or caregivers encouraged me to date	○	○	○	○	○
My parents or caregivers(talked to me about safe sex methods	○	○	○	○	○
I had a role model who I could talk to about sex	○	○	○	○	○



I felt comfortable asking questions about sex to my family	○	○	○	○	○
My religion shaped the way I view intimate relationships	○	○	○	○	○
My disability got in the way of forming intimate relationships	○	○	○	○	○
My friends and I talked about our dating and relationship experiences, wishes, questions, fears and concerns	○	○	○	○	○

29. Is there anything else you would like to add about you sexual identity formation?

Table 1

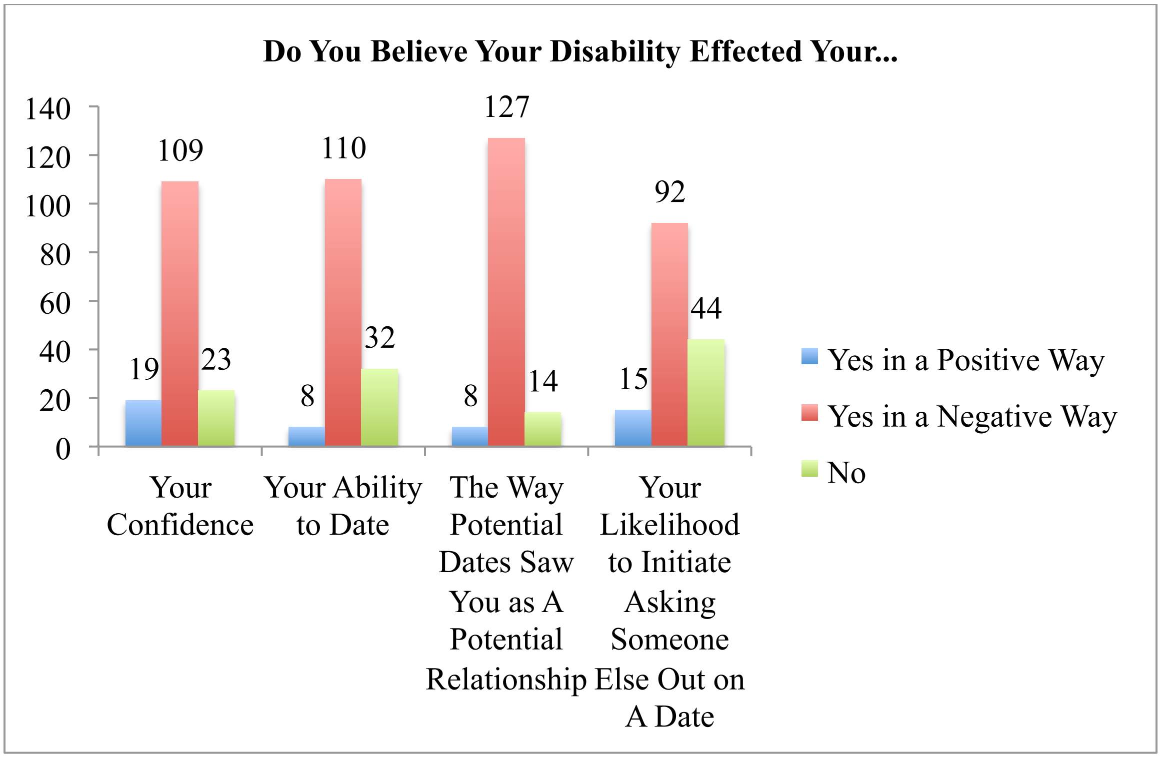
Demographic Information (N = 155)

	# of Participants	Percent
Age		
18-25	48	30.97
26-30	32	20.65
31-40	44	28.39
41-55	26	16.77
56 or older	5	3.23
Highest Level of Education Completed		
Grammar School	0	0
High School or Equivalent	17	10.97
Vocational/Technical School (2 Year)	3	1.94
Associates Degree	8	5.16
Some College	21	13.55
Bachelor's Degree	61	39.35
Master's Degree	38	24.52
Doctorial Degree	2	1.29
Professional Degree (MD, JD, etc.)	5	3.23
Type of School Setting During Adolescent Years		
Mainstream	140	90.32
Separate Program within Public School	7	4.52
Specialized School for Students with Disabilities	7	4.52
Institutionalized	1	0.65
Current Relationship Status		
Single	78	50.32
Married	31	20.00
Divorced	2	1.29
Living with Another	13	8.39
Separated	1	0.65
Widowed	1	0.65
Other Committed Relationship	28	18.06
Would Rather Not Say	1	0.65
Area of Residence		
Urban	64	41.29
Suburban	73	47.10
Rural	18	11.61

	# of Participants	Percent
Religion		
Catholic	33	21.29
Jewish	14	9.03
Protestant Christian	25	16.13
Muslim	0	0
Buddhist	1	0.65
Hindu	1	0.65
Wiccan, or Some Other Celtic, Nature-Based, Pagan Religion	7	4.52
Agnostic	22	14.19
Atheist	23	14.84
Other	29	18.71
Level of Mobility		
I am blind or deaf	3	1.94
I don't use a mobility device to get around	26	16.77
I use a cane or crutches to get around	17	10.97
I use a walker to get around	11	7.10
I use a manual wheelchair to get around	24	15.48
I use a power wheelchair or scooter to get around	74	47.74

Table 2

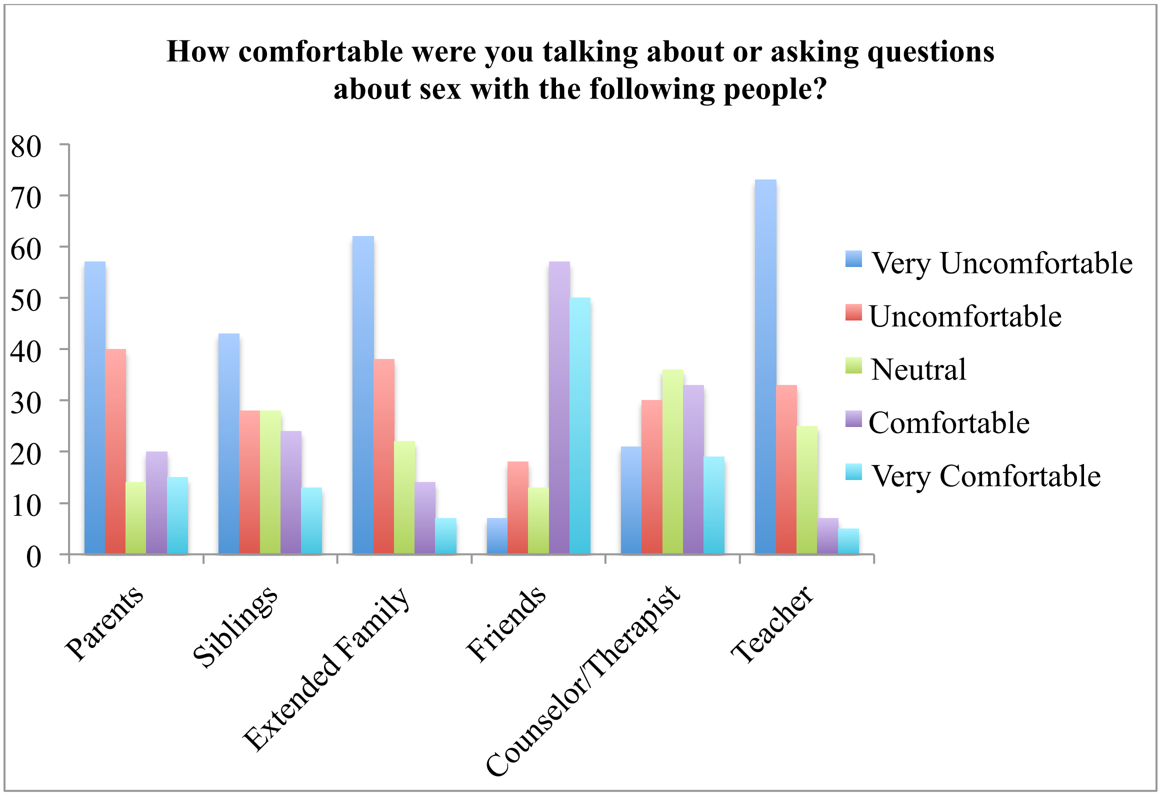
Beliefs participants had on the effects of their disability



	Yes in a Positive Way	Yes in a Negative Way	No
Your Confidence (N=151)	12.58%	72.19%	15.23%
Your Ability to Date (N=150)	5.33%	73.33%	21.33%
The Way Potential Dates Saw You as A Potential Relationship (N=149)	5.37%	85.23%	9.40%
Your Likelihood to Initiate Asking Someone Else Out on A Date (N=151)	9.93%	60.93%	29.14%

Table 3

Comfort level of participants with talking about sex to important people in their lives



	# of Participants	Percent
Parents (N = 146)		
Very Uncomfortable	57	39.04
Uncomfortable	40	27.4
Neutral	14	9.59
Comfortable	20	13.7
Very Comfortable	15	10.27
Siblings (N=136)		
Very Uncomfortable	43	31.62
Uncomfortable	28	20.59
Neutral	28	20.59
Comfortable	24	17.65
Very Comfortable	13	9.56
Extended Family (N=143)		
Very Uncomfortable	62	43.36
Uncomfortable	38	26.57
Neutral	22	15.38

	# of Participants	Percent
Comfortable	14	9.79
Very Comfortable	7	4.9
Friends (N=145)		
Very Uncomfortable	7	4.83
Uncomfortable	18	12.41
Neutral	13	8.97
Comfortable	57	39.31
Very Comfortable	50	34.48
Counselor/Therapist (N=139)		
Very Uncomfortable	21	15.11
Uncomfortable	30	21.58
Neutral	36	25.9
Comfortable	33	23.74
Very Comfortable	19	13.67
Teacher (N=143)		
Very Uncomfortable	73	51.05
Uncomfortable	33	23.08
Neutral	25	17.48
Comfortable	7	4.9
Very Comfortable	5	3.5

Table 4

Places respondents learned about sex, checked all that applied (N=145)

	# of Participants	Percent
Friends	123	84.83
Siblings	36	24.83
Parents	83	57.24
Other Family Members	24	16.55
Magazines	66	45.52
Books	105	72.41
General Media (i.e. TV and Internet)	110	75.86

Table 5

What respondents learned about sex in school, checked all that applied (N=145)

	# of Participants	Percent
I did not receive sex education in school	16	11.03
Basic anatomy	113	77.93
Abstinence	65	44.83
Safe sex methods	104	71.72
Feelings involved when deciding to have sex	42	28.97
Healthy relationship building	44	30.34
Peer pressure	63	43.45
Sexual abuse	53	36.55
How having a disability may effect sex	3	2.07

Table 6

Respondents' feelings on the amount of sex education received in school (N=144)

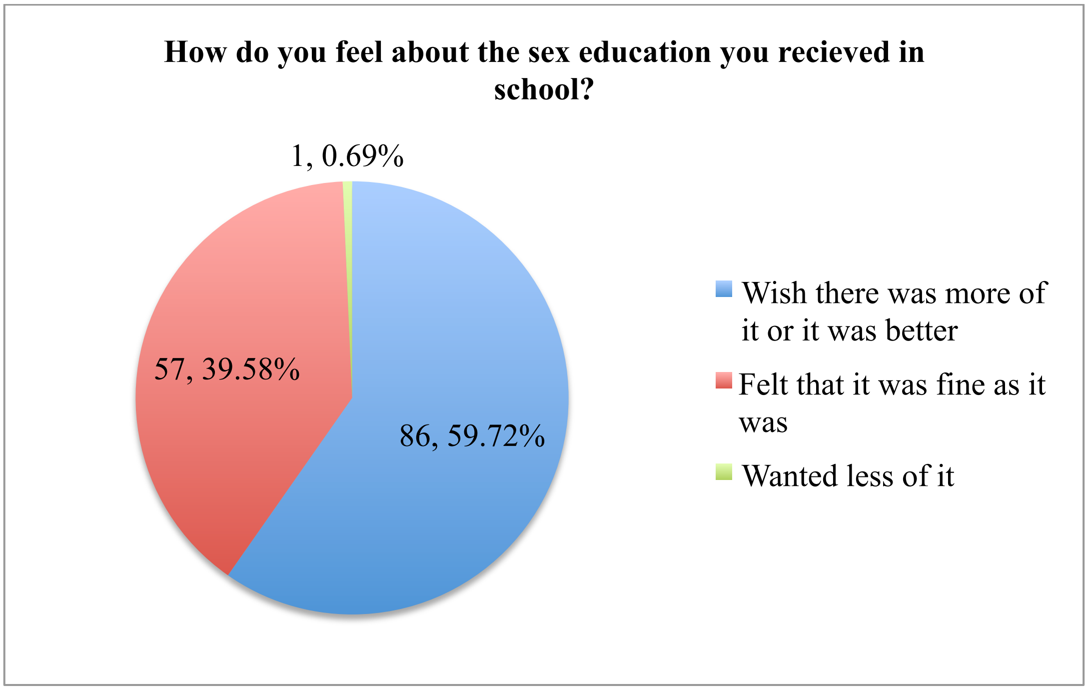


Table 7

Desire to have a steady relationship in high school (N=145)

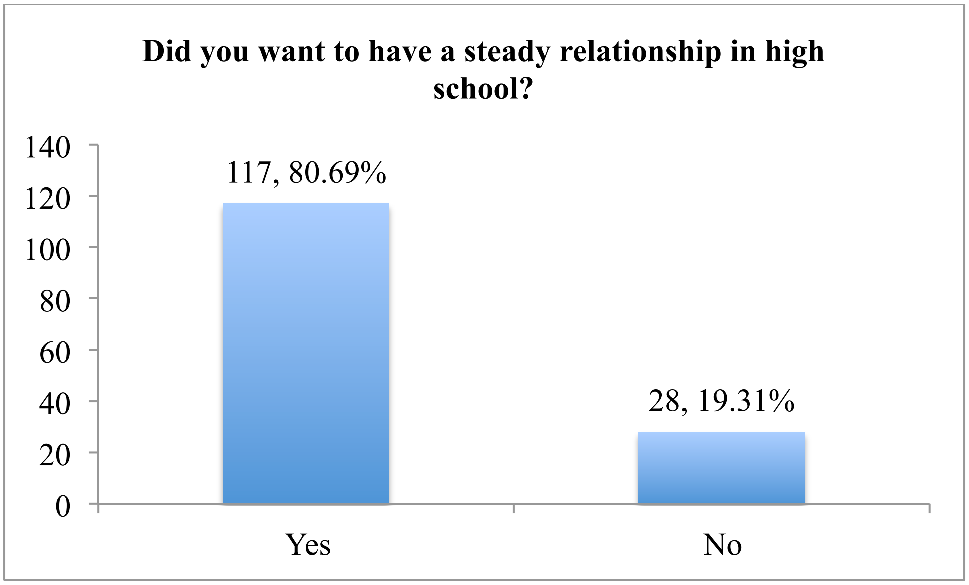


Table 8

Desire to casually date in high school (N=145)

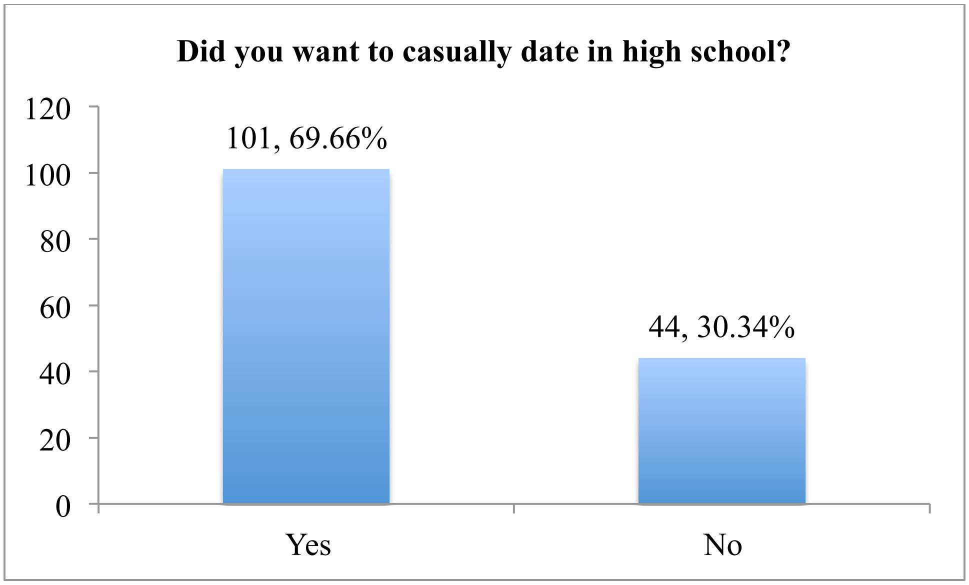


Table 9

Had a steady relationship in high school (N=145)

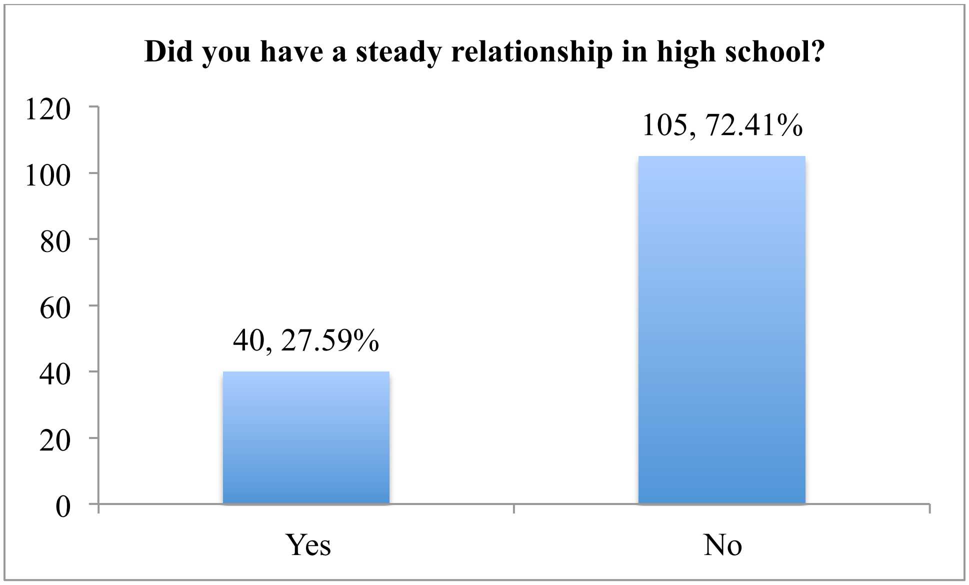


Table 10

Casually dated in high school (N=145)

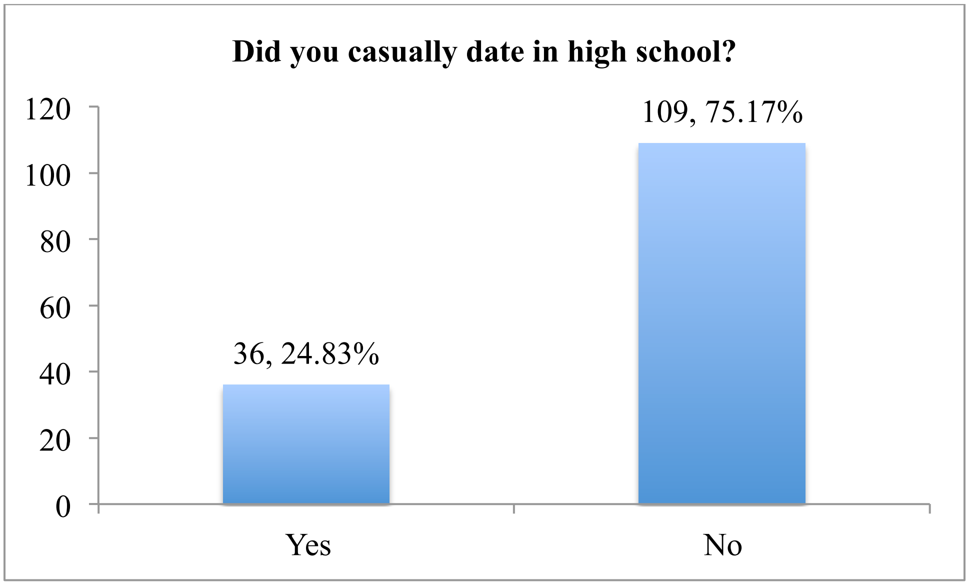


Table 11

Content with current relationship status (N=131)

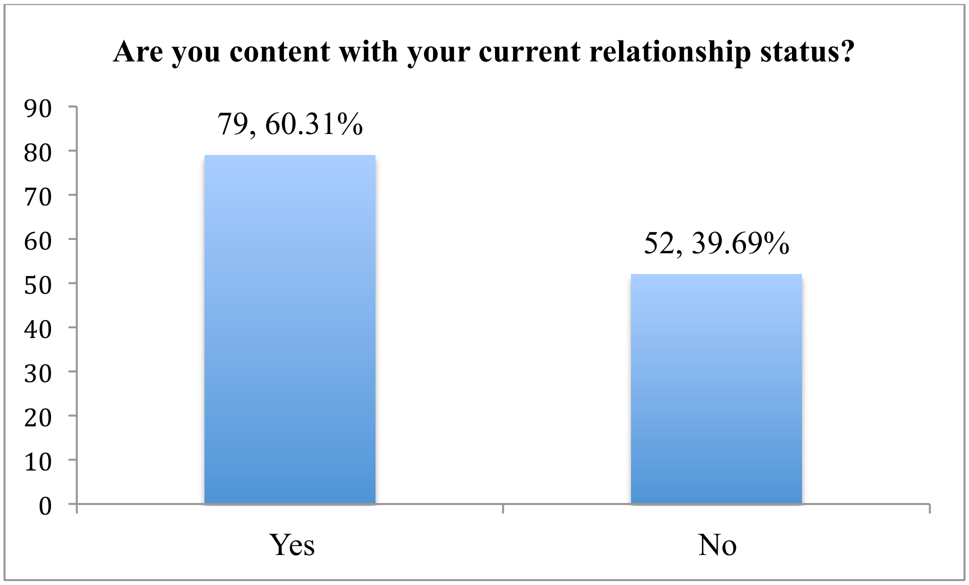


Table 12

Felt connection to the disabled community growing up (N=139)

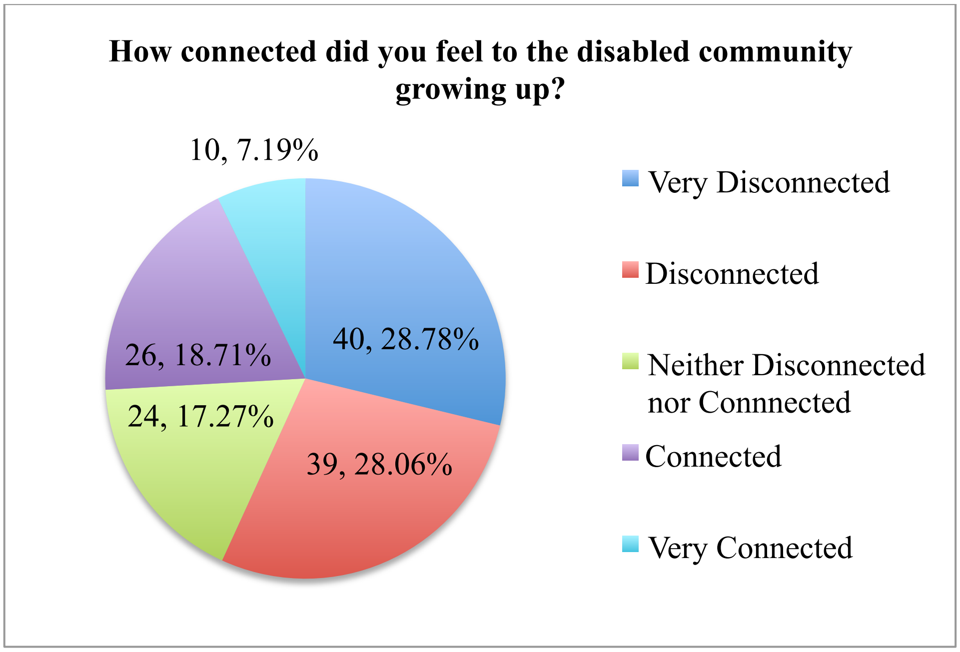


Table 13

Someone to look up to when growing up with a disability (N=142)

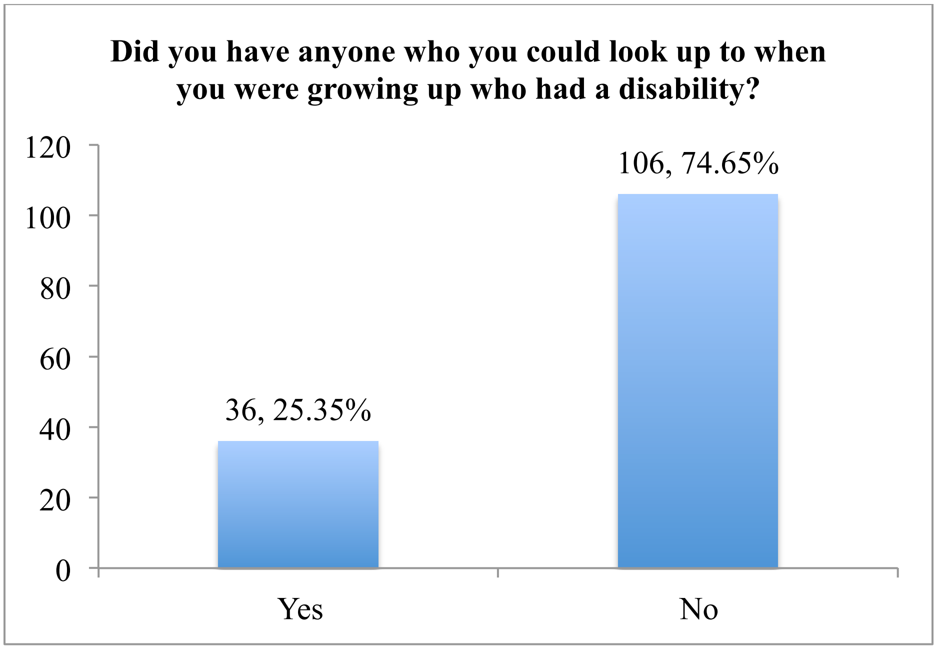


Table 14

Connection to peers with disabilities growing up (N=143)

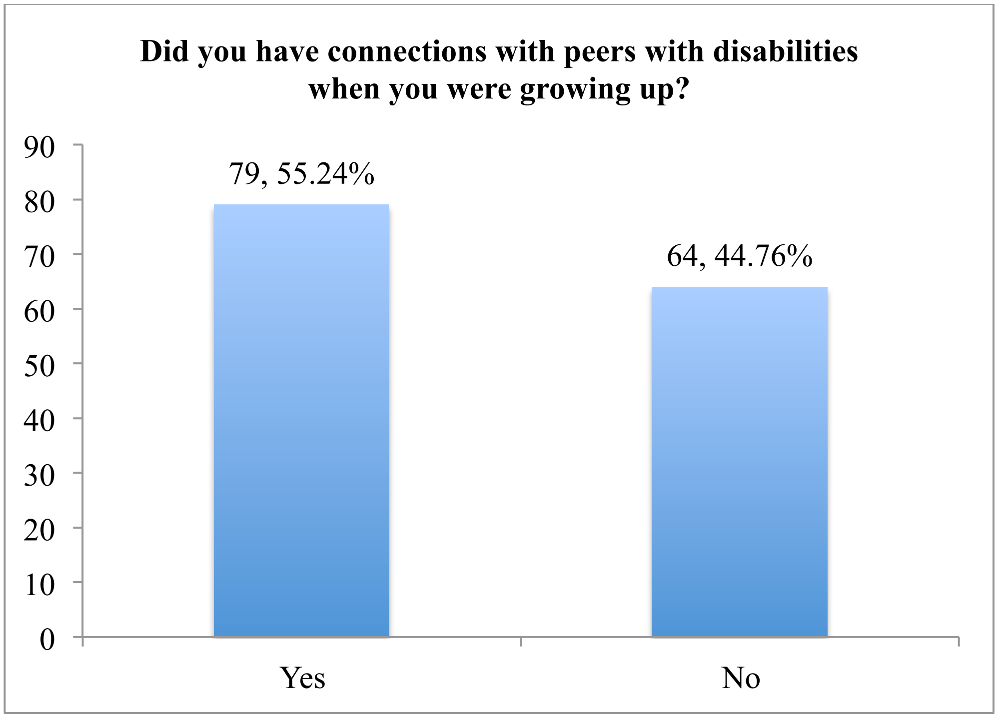


Table 15

Encouraged to explore sexual identity (N=149)

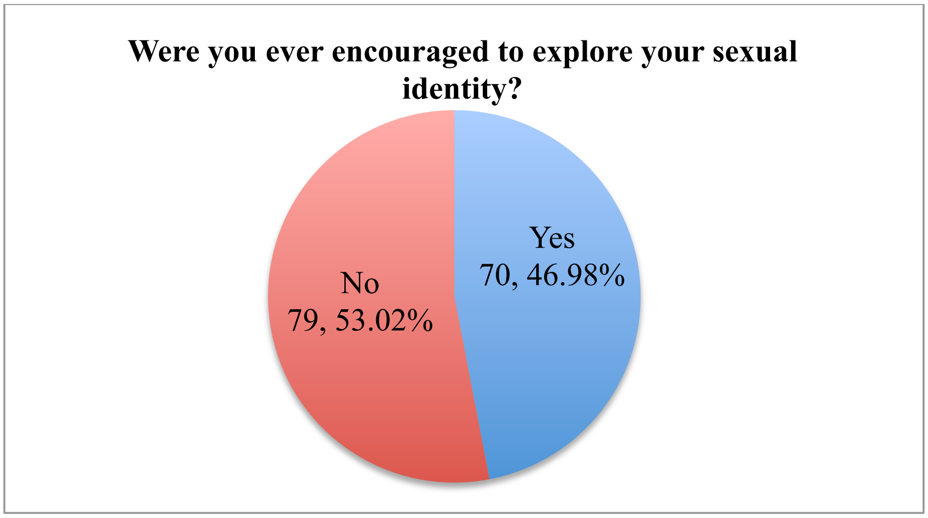
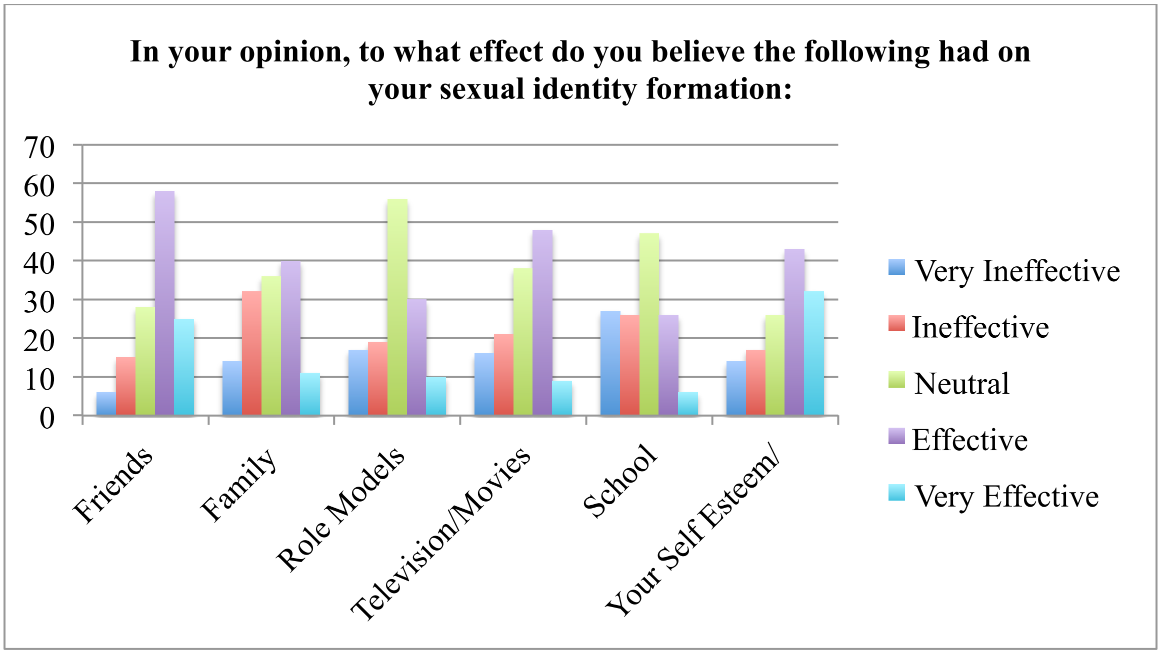


Table 16

Effect factors had on participants' sexual identity formation in their opinion



	# of Participants	Percent
Friends (N = 132)		
Very Ineffective	6	4.55
Ineffective	15	11.36
Neutral	28	21.21
Effective	58	43.94
Very Effective	25	18.94
Family (N=133)		
Very Ineffective	14	10.53
Ineffective	32	24.06
Neutral	36	27.07
Effective	40	30.08
Very Effective	11	8.27
Role Models (N=132)		
Very Ineffective	17	12.88
Ineffective	19	14.39
Neutral	56	42.42
Effective	30	22.73
Very Effective	10	7.58

	# of Participants	Percent
Television/Movies (N=132)		
Very Ineffective	16	12.12
Ineffective	21	15.91
Neutral	38	28.79
Effective	48	36.36
Very Effective	9	6.82
School (N=132)		
Very Ineffective	27	20.45
Ineffective	26	19.70
Neutral	47	35.61
Effective	26	19.70
Very Effective	6	4.55
Your Self-Esteem/Image (N=132)		
Very Ineffective	14	10.61
Ineffective	17	12.88
Neutral	26	19.70
Effective	43	32.58
Very Effective	32	24.24

Table 17

Opinion statements

	# of Participants	Percent
During adolescence I felt attractive (N=135)		
Strongly Disagree	44	32.59
Disagree	46	34.07
Neither Disagree Nor Agree	18	13.33
Agree	24	17.78
Strongly Agree	3	2.22
When I first started feeling attracted to someone, it was more based on feeling an emotional connection than a physical connection (N=134)		
Strongly Disagree	9	6.72
Disagree	31	23.13
Neither Disagree Nor Agree	16	11.94
Agree	51	38.06
Strongly Agree	27	20.15
Most of my friends growing up were either dating or in relationships (N=133)		
Strongly Disagree	4	3.01
Disagree	17	12.78

	# of Participants	Percent
Neither Disagree Nor Agree	25	18.80
Agree	64	48.12
Strongly Agree	23	17.29
My parents or caregivers encouraged me to date (N=134)		
Strongly Disagree	35	26.12
Disagree	32	23.88
Neither Disagree Nor Agree	32	23.88
Agree	27	20.15
Strongly Agree	8	5.97
My parents or caregivers talked to me about safe sex methods (N=132)		
Strongly Disagree	43	32.58
Disagree	31	23.48
Neither Disagree Nor Agree	21	15.91
Agree	27	20.45
Strongly Agree	10	7.58
I had a role model who I could talk to about sex (N=133)		
Strongly Disagree	49	36.84
Disagree	41	30.83
Neither Disagree Nor Agree	19	14.29
Agree	17	12.78
Strongly Agree	7	5.26
I felt comfortable asking questions about sex to my family (N=132)		
Strongly Disagree	51	38.64
Disagree	31	23.48
Neither Disagree Nor Agree	20	15.15
Agree	22	16.67
Strongly Agree	8	6.06
My religion shaped the way I view intimate relationships (N=132)		
Strongly Disagree	40	30.30
Disagree	26	19.70
Neither Disagree Nor Agree	29	21.97
Agree	23	17.42
Strongly Agree	14	10.61
My disability got in the way of forming intimate relationships (N=133)		
Strongly Disagree	12	9.02
Disagree	18	13.53
Neither Disagree Nor Agree	25	18.80
Agree	47	35.34

	# of Participants	Percent
Strongly Agree	31	23.31
My friends and I talked about our dating and relationship experiences, wishes, questions, fears and concerns (N=133)		
Strongly Disagree	6	4.51
Disagree	13	9.77
Neither Disagree Nor Agree	19	14.29
Agree	59	44.36
Strongly Agree	36	27.07