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Future Healthcare Professionals' Attitudes About the Sexuality of Women with Intellectual Disabilities

by

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ABSTRACT

Future Healthcare Professionals' Attitudes About the Sexuality of Women with Intellectual Disabilities

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Women with intellectual disabilities (WID) experience a number of systemic barriers to healthcare related to their sexuality and sexual expression. Additionally, they are vulnerable to sexual abuse which could lead to conditions that would adversely affect their health and wellbeing. There is a need for healthcare professionals to be able to provide comprehensive sexual healthcare to WID, and this service is currently lacking. To begin to address this gap in available care, content on the sexuality of WID in courses taken by undergraduate future healthcare providers (FHP) needs to be developed. To provide the foundation of such a curriculum, this study assessed the attitudes towards the sexuality of WID of 47 undergraduate FHP using the *Attitudes to Sexuality Questionnaire (Individuals with an Intellectual Disability)*, which includes 32 items having a 6-point Likert scale. With an overall mean score of 5.07, students showed overall agreement with statements affirming the rights and sexuality of WID. This finding suggests their likely acceptance of a curriculum that would include these topics. To build on these attitudes, educational recommendations are made to provide students with opportunities for: 1) clinical observations of healthcare professionals with expertise in caring for WID and 2) direct conversations with and exposure to WID in the classroom setting.

KEYWORDS: Intellectual disability, Women, Sexuality, Healthcare

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PREFACE

When I took a job as a respite care provider at the age of 16, I really had no clue where it would take me or the impact it would have on my future life. I had never before worked with an individual with a disability, but there I was, responsible for the well-being of a 19-year-old young woman with Down syndrome. I could go on forever about the light-hearted, funny stories I have from working with her (as she is still a part of my life and one of my very best friends to this day, 6 years later), but for the purpose of this thesis, I will keep it brief with a few important things I learned involving life, people with disabilities, and the supports for people with disabilities.

Like all human beings, people with intellectual disabilities are unique individuals. Despite their diagnosis of having a disability, they are still a person with wants, needs, hopes, and dreams for their lives and they face the same life-based issues as those experienced by other humans. There is no ‘golden rule of thumb’ that can be used to solve all issues relating to the sexuality of people with intellectual disabilities. One thing that can be ruled across the board, no matter the individual or the situation, is the fact they deserve utmost respect that does not differ from what would be afforded to anyone without a disability.

Learning these important life lessons early on in life also opened my eyes to some of the struggles people with intellectual disabilities faces, which in part motivated me to write this thesis. I have learned, in some cases, it may be true that people with disabilities will require extra support in some aspects of their life, but I would argue that everyone could benefit from extra support at some point in their lifetime. Including people with disabilities in vital parts of human life shows them that, just like their typically developing peers, they are worthy as individual beings with the undeniable rights to love, belonging, and appreciation. I chose to focus my thesis specifically on issues relating to women and their sexuality because I believe that this is an issue that is not talked about enough. It is often a topic that is swept under the rug because it makes people feel uncomfortable which has led to the rights and interests of women with intellectual disabilities to be ignored for far too long.

It is my hope that by educating future healthcare providers and bringing light to the importance of supporting women with disabilities, they will be supported to live full lives and be treated with dignity and respect in all regards. It is important for future and current healthcare professionals to recognize that there is no right or wrong way to go about life. It is very easy for society to assume that a person with a disability cannot do something merely because they are disabled. My challenge to future healthcare providers is to stop before you make these assumptions. Pause and then, ask yourself: Why do I think this way? Often the response to this question comes from misinformation, or lack of education and exposure. While this may have been an excuse in the past, it should be an excuse no longer. People with disabilities are a part of our everyday lives and are inevitably going to be a part of any future healthcare provider's practice. So let's be sure we are well trained and prepared to properly care for them.

CHAPTER ONE

Introduction

Nearly 16 million women in America have an intellectual disability (Disability Health and Data System, 2018). For comparison, this segment of the population is larger than that of all (women and men) with chronic obstructive pulmonary disease (12.7 million), epilepsy (3.4 million), and attention-deficit/hyperactivity disorder (6.1 million) (American Lung Association, 2013; National Center for Chronic Disease Prevention and Health Promotion, 2020; National Center on Birth Defects and Developmental Disabilities, 2020). While these data reveal the relative size of this population of women with an intellectual disability (WID) compared to other groups with identified health needs, concern that exists they may not be receiving healthcare that adequately addresses their unique needs, especially needs which relate to their sexuality.

Indeed, sexuality is a natural component of human life, but for WID it is often ignored, discouraged, or ridiculed (Ditchman et al., 2017). Nonetheless, WID are sexually active and at a high risk for sexual exploitation, abuse, and sexually transmitted infections (Cuskelly & Bryde 2004; Di Giulio, 2003; Grove et al., 2018; Martinello, 2014; Scotti & Morris, 1996). Further, many complex issues related to their intellectual capacity affect their reproductive behavior, use of contraception, pregnancy decisions, and preparation for parenthood. These multifaceted sexual health issues faced by WID emphasize their need for healthcare professionals who are prepared to provide them with comprehensive and de-stigmatized sexual healthcare that includes education that may prevent problematic outcomes specific to their vulnerabilities.

Unfortunately, there are relatively few healthcare professionals with specialized knowledge, training, or interest in working with WID (Corbin, 2005). When men and women with disabilities were asked who they believed was the most appropriate source of sexual health education, two-thirds believed their physician was the best person to provide this information. However, only a handful of respondents reported actually receiving such information from their physician (Di Giulio, 2003). Available evidence suggests healthcare service providers generally fail to acknowledge or may not even believe people with disabilities are sexual beings (Addlakha et al., 2017; Scotti & Morris, 1996).

Such findings revealing limited medical care responsive to the sexuality of WID are corroborated by data showing only a small number of Canadian and American medical schools formally include specific training regarding people with disabilities in their curricula (Holder et al., 2009; Minihan et al., 2004). Specifically, the *Curriculum Assessment of Needs Project* conducted by The American Academy of Developmental Medicine and Dentistry (2004) found 81% of medical students received less than three hours of formal education on people with intellectual or developmental disabilities and 38% reported no formal training (Jurczyk & Kelly, 2009; Waldman et al., 2005). More than half of all students and deans surveyed did not feel they were appropriately trained to competently treat people with intellectual disabilities. These studies reveal a paucity of basic content on disabilities in medical school curriculum and it is likely such deficits also exist in other health related professional educational programs. More specifically, these deficits likely include education related to the sexuality of WID.

To most effectively address this deficit in training, education can and should begin before future healthcare providers (FHP) enroll in a formal clinical training program. Courses in health sciences are often taken by students who plan to enter a broad array of clinically-oriented careers. Content in these courses may ideally include general topics related to disability and namely the sexuality of WID.

As research discussed later indicates, attitudes about the sexuality of those with disabilities are variable and can impede the effectiveness of clinical care (Murphy, 2005). An important first step in the development of an undergraduate curriculum addressing this educational deficit is an understanding of the attitudes of the students who would be exposed to it. This information can then be used to mold course content to address students' misunderstandings and potential challenges for their future abilities to sensitively and effectively care for WID. This research aims to provide such information with a survey of undergraduate FHP's attitudes about the sexuality of WID.

CHAPTER TWO

Review of Literature

Sexual Inclusion of Women with Intellectual Disabilities

According to the American Psychiatric Association (2013), an intellectual disability is defined as “a disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social, and practical domains” (p.1). Less formally, the American Association on Intellectual and Developmental Disabilities characterizes intellectual disability by deficits in intellectual functioning and limitations in adaptive behaviors (2013). Common stereotypical characterizations of people with intellectual disabilities include a childlike innocence, dependency, and an overall lack of intelligence (Ditchman et al., 2017).

Sexuality is an important aspect of quality of life, but this area of life comes with many challenges for WID. Historically, sexuality has served as one important aspect in the life of WID that has been heavily influenced by societal repression. In the past, sexual behavior was often misunderstood or punished due to generalizing interpretations of sexuality, and this issue was exacerbated by the widespread isolation and separation of WID from mainstream society in the 19th and 20th centuries. During this time, many WID were randomly sterilized and their basic human need for love and acceptance was neglected. In the late 1960’s and throughout the 1970’s, society became more open-minded in general about sexuality and also increasingly understanding of the need for the rights of people with intellectual disabilities to be recognized (Lofgren-Martenson, 2004).

Attitudes towards the sexuality of people with intellectual disabilities may make it difficult for them to find solutions to their problems, especially as they face increasingly complex issues over the course of their lives (Dagli et al., 2020). Human sexuality includes the sexual knowledge, beliefs, attitudes, values, and behaviors of an individual or population. The development of human sexuality is multidimensional and is closely intertwined with the basic human needs of being accepted, wanting to display and receive affection, feeling valued, and being able to share feelings with others (Murphy, 2005). Sexual function is also tied to anatomical and physiological processes, personality, emotions, and cultural beliefs. Put together, sexuality is a highly complex phenomena and WID may be limited in their sexual development by both intentional and unintentional societal barriers.

People with intellectual disabilities live in a defined and often isolated social environment, where the beliefs, attitudes, and support of those surrounding them play a paramount role in how they will live and make decisions for themselves throughout their lifetimes (Lofgren-Martenson, 2004). ‘Sexual ableism’ is a term used to describe the system of imbuing sexuality with determinations of qualification to be sexual based on criteria of ability, intellect, physicality, appearance, social acceptability, and gender conformity (Gill, 2015). Sexual ableism plays a large role in the development of sexual identity, confidence, function, and ability to find a partner for an individual with an intellectual disability. These societal determinations of qualification and lack of support impact the provision of sexual education, opportunities, and the natural human rights of a person with an intellectual disability.

Western society has shown gradual improvement in its recognition of the basic rights of people with intellectual disabilities, but there continues to be substantially less support for normalized life experiences for WID’s sexuality and sexual function (Scotti &

Morris, 1996). Research has shown, a society's attitudes towards the elderly and disabled populations are good indicators of the level of social progression of lack of stigma of that society. More specifically, attitudes concerning the expression of sexuality by elderly individuals or people with disabilities are good indicators of a society's ability to place all of its members on an equal footing (Esterele et al., 2008). It is important to note, society as a whole is increasingly accepting of the rights of those with disabilities and how they must be treated as equals in communities. As people with disabilities become more and more integrated into community settings, their right to sexual expression must be an important focus of society's efforts to work towards inclusion.

Sexual Rights of Women with Intellectual Disabilities

The Right to a Sexual Being

Historically, WID were thought to be 'asexual' or 'sexually deviant' (Di Giulio, 2003). This misconception is often associated with the belief that WID are not capable of exhibiting sexuality because of defects in their biology, one factor which leads them to be viewed as children (Milligan & Neufeldt, 2001). Many people believed WID lacked a biological sex drive, were unable to partake in sexual activities, and that WID lacked the necessary social judgement to be able to behave in a sexually responsible manner (Anderson & Kitchin, 2000). In the past, if sexual feelings were displayed by WID, society viewed this as problematic or maladaptive. Fear was consequently expressed about this perceived behavior and those who were assumed to exhibit it (Foley & Kelly, 2009; Jorissen & Burkholder, 2013). Moreover, the assumption that WID are asexual could prompt them to avoid or fear intimacy and sexuality, leading to a self-fulfilling prophecy and denying them of pleasurable sexual experiences.

There is a growing understanding that relationships and sexuality are important to the lives of those with disabilities (Brandlinger, 1985; Siebelink et al., 2006). It is now recognized by many that people with intellectual disabilities have the same sexual needs and desires as people without intellectual disabilities and their expressions of sexuality are similar to their typically developing peers (Mitchell et al., 1978; Oliver et al., 2002). Accordingly, like most, adolescents and teenagers with disabilities have the desire to marry, have children, and hope for satisfying adult sex lives (Murphy, 2005). But, without proper supports, expressions of sexuality by WID could be misunderstood or harmful to their personal and social health if they are not properly educated. Emerging research indicates that WID should be supported so their sexuality can be expressed (Dagli et al., 2020).

Despite it being important to their ability to develop fulfilling relationships with others, many studies have shown the importance of sexual expression is underestimated in WID (Medina-Rico et al., 2017). An analysis of data from the *US National Longitudinal Study of Adolescent Health* showed no significant difference in levels of sexual experience of teenagers with and without intellectual disabilities (Murphy, 2005). A number of studies have also indicated that WID are indeed sexually active. Reported sexual experiences included prolonged kissing, oral sex, and vaginal intercourse, among other activities. Also reported in these studies are experiences of sexual abuse in this population (Scotti & Morris, 1996). Because of the unique nature of relationships that would occur in this population, there are many ethical and legal implications for what is acceptable in a relationship, and what crosses over into being a questionable, or downright illegal, sexual practice. O’Callaghan and Murphy (2007) found that less than half of their sample of individuals with an intellectual disability knew about laws against sexual abuse and the minimum age for consent in a sexual relationship. Due to the serious nature of sexual abuse, and the increased prevalence and likelihood in this population, it is important for healthcare providers to fully understand the ethics of sexuality and be aware of what may or may not be appropriate expressions of sexuality for a WID.

Parents and healthcare providers may react to the fears of sexual abuse often encountered by this population by inadvertently denying youth with disabilities critical opportunities to develop social skills and appropriate personal boundaries (Murphy, 2005). Specifically, parents of children with intellectual disabilities are sometimes reluctant to acknowledge their children’s potential to live sexual lives. As a result, well-meaning parents may shelter their children from experiencing the developmentally typical expressions of sexuality experienced by their peers in their teen and early adult years (Di Giulio, 2003). Some individuals also worry that talking about sexuality may promote sexual behavior in WID and because of this, they are sheltered from understanding their own sexuality. Despite the well-meaning intentions, evidence suggests when sexual questions and behaviors are discussed, the likelihood of future abuse and issues related to sexuality can be reduced or eliminated completely (Murphy, 2005).

In summary, studies conducted over 30 years ago suggested the sexuality of those with disabilities was or should be considered highly inappropriate. Since then, the attitudes towards the sexuality of people with intellectual disabilities have evolved. In general, attitudes towards sexuality in recent years have become considerably more liberal (Bullough & Bullough, 1995), especially among young individuals (Le Gall et al., 2002; Wells & Twenge, 2005). With emerging research, society is beginning to recognize that WID do not deserve to be sheltered from a natural part of their human lives. The public at large has become more and more aware of the fact that people with disabilities have the right to live ordinary lives with the right to basic pleasure (Tepper, 2000). The progression of societal attitudes has been promising in confirming that WID do indeed have rights as sexual being.

The Right to Choose- Sterilization of Women with Intellectual Disabilities

Although there appears to be an increasing acceptance of sexual behavior in women with intellectual disability, there is evidence that at least some aspects of sexuality remain contentious. Sexual maturity and interest in sexual activity in young WID can be alarming for caregivers who may be concerned about menstrual hygiene, sexual exploitation or abuse, and unwanted pregnancy (Roy et al., 2012). Historically, the assumed inappropriateness of sexual expression by WID was reflected in the practice of involuntary sterilization as a means of inhibiting any possibility of unwanted pregnancies (Di Giulio, 2003; Hardie & Tilly, 2012). Historically, the sterilization of WID was often performed without regard for their decision-making capacities, ability to care for children, feelings, or interests (Murphy, 2005).

Despite the changed professional sentiment on involuntary sterilization, it appears many parents of WID still support it as a means of contraception, especially for women with severe intellectual disabilities (Aunos & Feldman, 2002). Today, reasons used to justify sterilization in addition to its use as a contraceptive measure include prevention of expressions of sexuality, decreased chance of sexual exploitation, ease of personal hygiene, and reduced likelihood of acquiring sexually transmitted diseases. In addition to the ethical issues raised by involuntary sterilization, sterilizing WID accomplishes none of these objectives (Di Giulio, 2003). Article 5 of the *United Nations Universal Declaration of Rights* states, “no one shall be subjected to torture or cruel or degrading treatment or punishment.” Article 16 describes the “right to marry and found a family” (UN, 2011, as cited in Roy et al., 2012). When a WID has the inability to provide consent for the procedure to be sterilized, her universal human rights are breached.

The American College of Obstetrics and Gynecology (ACOG) guidelines state the indications for sterilization procedures should be the same as what would be available for the general populations. Despite the pressure from families, healthcare workers need to be aware that the interests of families may not be the same as their patient’s (ACOG, 2011, as cited in Roy et al., 2012). Although many advocate for a ban on the involuntary sterilization of WID, there are many advocates who argue women should have the right to choose to be sterilized if they are able to make an informed and free decision (Bass, 1978). When the sexual autonomy of WID is seen as problematic, there is a tendency for WID to not be afforded equal opportunities for appropriate and adequate healthcare. Despite the assumption that disability is a medical condition requiring special intervention in sexual healthcare, women with disabilities should be afforded the right to choose what is done to their bodies within the boundaries of what is healthy and safe.

The Right to Preparation and Sexual Safety- Sexual Exploitation of Women with Intellectual Disabilities

While educating adolescents and young adults about sexuality is vital, this education needs to begin prior to the teen years to prevent exploitation. Children with intellectual disabilities are at an increased risk of sexual exploitation for many reasons, but often due to their inability to discern abuse from care, their lack of ability to defend themselves against abuse, inability to seek help or report abuse, and increased need for assistance in personal intimate care tasks (Martinello, 2014; Murphy, 2005). Specifically, research indicates, "between 39 and 68% of female children and 16 and 30% of male children with a disability will be sexually abused before they are 18 years old" (Mahoney & Poling, 2011, p.369). Children with intellectual disabilities are more likely to be abused by individuals they know, and care providers are frequently cited as the most likely perpetrator of sexual abuse (Martinello, 2014). Further, adolescents with intellectual disabilities are more than twice as likely to be sexually abused than their non-disabled peers (Conod & Servais, 2008; Grove et al., 2018; Martinello, 2014; Murphy, 2005; Wang et al., 2007). Each of these factors contributes to the likelihood that children with intellectual disabilities will be sexually exploited.

Even more significant is that nearly 80% of WID report being sexually assaulted over the course of their lives (Gigliotti, 1992; Murphy, 2005). There are many reasons for this, including WID's vulnerabilities, presumed inability to retaliate, and a lack of knowledge needed to determine if behavior is abusive (Martinello, 2014). Enow et al. (2015) and Calitz (2011) suggest a strong education is fundamental to teach young women about consent and psychological and legal supports for those who have been victims of sexual abuse are necessary. Healthcare providers often fail to promote or advocate for these supports and subsequently fail to provide appropriate sexual health education to their patients with intellectual disabilities. As a result, when WID are not given adequate information on sexuality they are made more susceptible to abuse because this opportunity for prevention of exploitation is missed (Owen et al., 2000).

To summarize, the expression of sexuality by WID is natural, but it is evident this population is more vulnerable to the risk of sexual abuse or exploitation, even prior to adulthood, due to cognitive ability and a lack of sexual health education. The opportunities to prevent these unfortunate experiences can be optimized in the healthcare setting with the assurance that education is provided in a developmentally appropriate manner and supports are in place to assure the discussion of sexual experiences for children, adolescents, and adults.

Sexuality and Preventative Healthcare

The Need for Sexual Health Education and its Current Provision

As previously noted, WID have the same sexual needs as the general population, yet this is often neglected or poorly understood by healthcare professionals. Women with disabilities, especially those living with an intellectual disability, experience multiple systemic barriers when accessing appropriate healthcare. These include the lack of providers with adequate knowledge about disabilities and the widespread fear of stigmatization surrounding this patient population. In addition to often not having access to sexual health information, WID may be deliberately misinformed in some cases about sexuality in order to discourage their interest (Hinsburger & Trough, 2002). Limiting a

WID access to proper information on sexual health can further perpetuate the misconceptions among WID who themselves may potentially internalize such stigmatizing beliefs.

WID tend to have a higher prevalence of health problems compared to the general public (Cooper et al., 2004; Krahn et al., 2006), yet their sexual health needs often go unrecognized and unmet (Cooper et al., 2004). For people with disabilities and non-disabled people alike, access to comprehensive and relevant sexual health information is an indispensable component of an individual’s ability to avoid sexual health problems and enhance sexual health (Di Giulio, 2003). Barnard-Brak et al. (2014) identified that 53-56% of people with intellectual disabilities receive sexual education and many other studies (Dagli et al., 2020; Ditchman et al., 2017; Grove et al., 2018; Medina-Rico et al., 2017) have concluded that students with moderate to profound intellectual disabilities are significantly less likely to receive relevant sexual education when compared to their peers. This deficit is notable, especially when compared to the finding that 96% of teenagers, not specifically labeled with an intellectual disability, report receiving formal sexual education before the age of 18 (Martinez et al., 2010).

Commonly cited reasons for the low prevalence or improper level of care for WID include providers not feeling prepared to clinically respond to or care for sexual health issues with these patients. Some medical practitioners may have a fear of perceiving WID as sexual beings, which leads to their difficulty in talking about sexuality with these patients (Medina-Rico et al., 2017). This is true as well for married couples with disabilities. Research has shown in one sample of couples, only 48.7% had received information about pregnancy and reproductive health, and only 10.6% had received information about sexual matters from a health professional. Nonetheless 35.5% of them expected health professionals to provide such information (Othelia & Oh, 2005).

Additional barriers in the attainment of proper sexual health education include stigma around disability and sexuality and the assumption that the developmental status of the individual will prevent them from comprehending sexual education (Groce, 2003). Not only do WID require the same basic sexual health information as the non-disabled population, but people with disabilities also require information and skills related to sexuality that are appropriate for their disability (Di Giulio, 2003). This can be difficult when considering WID because often though having a ‘normal’ appearance, their capabilities may be misjudged. Healthcare providers may assume that the physical development of a WID is comparable to their mental/emotional development, which is not always the case (Carter, 1999). These perceptions held by healthcare providers about their patients with disabilities impact the care they provide, especially when education on sexual matters is needed.

Lack of knowledge among WID regarding the mechanism of sexual intercourse and contraceptive methods leaves them with a greater risk and vulnerability to unwanted pregnancies and sexually transmitted infections (Medina-Rico et al., 2017). Studies have found specific deficiencies in knowledge about body function during sexual intercourse, the use of contraceptives, and sexually transmitted diseases (STD). In a study by Leutar & Mihokovic (2007), 20% of adult WID were not able to identify the meaning of the word ‘penis’, and 12%: ‘vulva’. Overall, WID seem to be participating in sexual relationships without the knowledge needed to keep them healthy, safe, and happy (Murphy, 2005). Although their development may be hindered by both functional limitations and societal barriers, opportunities for people with intellectual disabilities to be sexual beings do exist.

Contraception and Sexually Transmitted Diseases

Not surprisingly, most adolescents with a disability report that they have not received adequate education on topics such as birth control, sexually transmitted infections, and parenthood (Murphy, 2005). Because of the assumption that WID are not likely to be sexually active, healthcare providers may not encourage or suggest access to Human Immunodeficiency Virus (HIV)/STD/Sexually Transmitted Infections (STI) testing, pregnancy testing, or contraceptive counseling (Di Giulio, 2003). The use of contraception by WID is a major concern for many caregivers. Despite this, the prevalence of contraception and its frequency of use, and different methods prescribed, remain generally unknown for this population. Furthermore, the indications for use of contraception specific to WID are controversial (Servais et al., 2002). Van Schrojenstein Lantman-De Valk et al. (2011) reported less use of contraceptive methods in WID than the noted in general population. It is not clear if this is because of compliance or lack of provision of contraception for WID. Regardless of the cause of inadequate prevention of pregnancy, there is a need for health professionals' attention to this important concern for WID.

Current research has shown that those with intellectual disabilities also often have known risk factors for HIV infection (Scotti & Morris, 1996). In addition, sexually active youth with intellectual disabilities are at a higher risk for contracting sexually transmitted infections (Groce 2003; Grove et al., 2018). Overall, people with disabilities tend to be educationally, economically, and socially disadvantaged, making them a high-risk group for the transmission of sexually related diseases (Di Giulio, 2003). WID are rarely a targeted population for measures the prevent sexually transmitted diseases, despite the number of risk factors that they are known to possess (Groce, 2003; Scotti & Morris, 1996). Support from healthcare providers will become increasingly important for this aspect of their lives with the ever-increasing risk of acquiring sexually transmitted infections.

Synthesis of Literature as Foundation for Research

Healthcare Providers' Education on the Sexuality of WID

WID's increased risk for exploitation and sexually transmitted diseases underscores the urgent need for healthcare professionals to provide them with high-quality developmentally appropriate sexual health education and care. As noted in the data previously reported, those with disabilities look to the healthcare system for education and care, but not infrequently fail to receive it (Di Giulio, 2003). Reasons for this failure vary. Research has suggested that barriers to providing health services to people with disabilities include providers' lack of time, self-confidence, and knowledge about cultural values and communication with this population (Bal, 2014; Tugut et al., 2016; Jaarsma et al., 2020). Some healthcare providers claim because of their lack of training and their inexperience in dealing with this population, they are uncomfortable interacting clinically with patients who have an intellectual disability (Chew et al., 2009). While most all health professionals receive training in clinical communication skills, there appears to be variation in the inclusion of this curriculum content that fosters students' ability to effectively provide care to a person with intellectual disabilities (Minihan et al., 2004).

Healthcare professionals, in general, vary in their skills and knowledge related to caring for the sexuality of their patients. In a study done among practicing nurses, only 19% reported they had experience in giving sexual care and only 27.5% reported comfort in talking to their patients about sexual issues (Askoy, 2020). Specifically, Earle (2001) claimed that nurses and healthcare professionals are negligent in their approach to sexual issues regarding people with disabilities and stated some have a negative attitude toward the sexual expression of WID.

Alternatively, data from a sample of midwifery students showed more than half of the students surveyed reported they would feel comfortable talking to people with disabilities about their sexual health needs. Despite this, relatively few actually had experience providing care or counselling to people with disabilities (Askoy, 2020). The majority of this sample (74%) believed health professionals should provide sexual health education for people with disabilities, and 66.9% suggested this education should start when people with disabilities begin to express their sexuality. These findings are similar to those in a study which suggested that a large portion of nursing students (80–87.8%) agreed that health professionals should discuss sexual health matters with people with disabilities (Tugut et al., 2016). While these data describe attitudes held by various healthcare professionals about sexual care for those with disabilities, it is unknown if those professionals actually received training to effectively provide sexual healthcare or education.

There is no question that healthcare professionals should be capable of providing WID with healthcare that addresses their need for holistic sensitive education and care related to their sexuality. This is clearly documented by the *International Association for the Scientific Study of Intellectual and Developmental Disabilities and Inclusion International* (2000) that recommended all educational programs ensure health professionals be trained to be able to care for individuals with disabilities. The presence of an intellectual disability should not override the right of women to develop and express their sexuality or to have access to health information that would permit them to make safe and healthy life choices. Put differently, the experiences and desires of WID ought to be given the respect afforded to all other individuals without the label of 'intellectual disability.' By increasing the knowledge and awareness of healthcare professionals on this subject, future populations of people with intellectual disabilities will be provided the necessary individualized support with decision making that affects their sexual behavior and their lives as sexual beings.

Attitudes of Future Healthcare Providers Regarding Sexual Care for WID

Throughout this review, there are threads of evidence of previous and past attitudes possessed by society and healthcare providers regarding the sexuality of WID. These threads show a history of dismissal, denial, and opposition to the reality that WID are sexual and need care for the management of this aspect of their lives. Currently, the sexuality of WID is recognized and awareness exists that this population is sexually active, but they are frequently underserved by those who provide relevant healthcare.

WID are at high risk for exploitation, abuse, serious and even fatal sexually transmitted diseases, unwanted pregnancies, and challenging parenting.

Healthcare providers vary in their professional ability to adequately serve this population by addressing these complex health needs. This is not surprising as their training programs typically provide inadequate education essential to address this need. Nonetheless, WID indicate that they seek education and care regarding sexual issues from those who provide healthcare services (Murphy, 2005). Underlying this gap in care for a vulnerable population are the attitudes of emerging health professionals that they will bring to educational offerings provided for them. Curriculum can be most effective when it is built with an understanding of the existing attitudes and biases of students that will impact their responsiveness to it. This is especially true when its focus is on topics having complex social implications such a caring for the sexuality of WID.

Little is known about the current attitudes of undergraduates who are in the early stages of their education to become healthcare professionals. The literature has scant evidence that this topic of sexuality, fundamental to future care for WID, has been explored. Thus, this study will begin to fill this void in an effort to provide information on these attitudes that will serve as a foundation for how curriculum can be developed so that it will effectively address this current unmet need.

CHAPTER THREE

Methods

This descriptive study was approved by the Institutional Review Board at the University of South Dakota (see Appendix A).

Materials

A two-part survey was used to collect data for this study. The first section was comprised of five multiple choice questions about the respondents' background. The responses to these questions were then used to determine if criteria for study participation were met by those who accepted the invitation to be a part of the study and became a part of the study's potential sample. The second part of the survey included the *Attitudes to Sexuality Questionnaire (Individuals with an Intellectual Disability: ASQ-ID)* (ASQ IID), which was developed by Australian researchers Cuskelly and Gilmore (2007). This questionnaire appears in Appendix B and permission to use it was granted by its publisher (See Appendix C). To conform with American English, several minor revisions in the spelling of words and terms used in the original survey were made for its use in this study.

The ASQ IID includes statements to which the respondents provided their level of agreement on a six-point (strongly disagree to strongly agree) Likert scale. This scale did not include a neutral option to avoid ambiguous responses nor did the ASQ IID provide a definition of the term "intellectual disability."

The ASQ IID was originally given to a community sample of 261 Australian adults. A factor analysis of the data from this sample yielded four clusters of items that were named "sexual rights," "parenting," "non-reproductive sexual behavior," and "self-control.” Several items on the questionnaire did not fit this four-factor model. Table 1 presents these four factors with the questionnaire items that comprise them and those items which did not fit with the four identified factors.

Due to the small sample size of this study, a factor analysis with the responses to the individual items of the ASQ IID was not able to be performed. It is, therefore, unknown if the data collected by this study would yield different factor loadings. The assumption is made that the factors would be the same for both of these samples and data from this study will be presented using the factors identified by Cuskelly and Gilmore (2007).

A few limitations of the questionnaire used in this study include the fact that the original samples, and subsequently the data that was used in performing the factor analysis, came from samples of Australian adults. Further, due to the geographical difference, there could possibly be differences in the societal norms of each geographic location. Additionally, this is the first time this questionnaire has been given to such a limited demographic of individuals, which may also sway the validity of the factor analysis groupings.

Table 1. The Individuals with An Intellectual Disability: ASD-ID: Items presented by Identified Factors

Item #	***Factor 1: Sexual Rights***
25	Advice on contraception should be fully available to women with intellectual disability whose level of development makes sexual activity possible
21	Women with an intellectual disability have the right to marry
15	Sex education for women with an intellectual disability has a valuable role in safeguarding them from sexual exploitation

2	Provided no unwanted children are born and no-one is harmed, consenting women with an intellectual disability should be allowed to live in a heterosexual relationship
14*	Women with an intellectual disability are unable to develop and maintain an emotionally intimate relationship with a partner
17	Sexual intercourse should be permitted between consenting adults with an intellectual disability
30*	Marriage should not be encouraged as a future option for women with an intellectual disability
27	Marriage between adults with an intellectual disability does not present society with too many problems
10*	Discussions on sexual intercourse promote promiscuity in women with an intellectual disability
5*	Women with an intellectual disability have less interest in sex than do other adults
13*	Women with intellectual disabilities typically have fewer sexual interests than other adults
18*	Group homes for adults with an intellectual disability should be either all male or all female, not mixed
16*	In general, sexual behavior is a major problem area in management and caring for women with an intellectual disability
	Factor 2: Parenting
11*	Women with an intellectual disability should only be permitted to marry if either they or their partners have been sterilized
6*	If women with an intellectual disability marry, they should be forbidden by law to have children
24*	Sexual intercourse should be discouraged for women with an intellectual disability
28*	Sterilization is a desirable practice for women with an intellectual disability
1	With the right support, women with an intellectual disability can rear well-adjusted children
31	Women with an intellectual disability should be permitted to have children within marriage
19*	Care staff and parents should discourage women with an intellectual disability from having children
	Factor 3: Non-Reproductive Sexual Behavior
12	Masturbation in private for women with an intellectual disability is an acceptable form of sexual expression
22	It is a good idea to ensure privacy at home for women with an intellectual disability who wish to masturbate
9*	Masturbation should be discouraged for women with an intellectual disability

3	Consenting women with an intellectual disability should be allowed to live in a homosexual relationship if they so desire
29	Masturbation should be taught to women with an intellectual disability as an acceptable form of sexual expression in sex education courses
	Factor 4: Self-Control
8*	Medication should be used as a means of inhibiting sexual desires in women with an intellectual disability
26*	Women with an intellectual disability are more easily stimulated sexually than people without intellectual disability
32*	Women with an intellectual disability have stronger sexual feelings than other individuals
	Not Included in Factors
23	Whenever possible, women with an intellectual disability should be involved in the decision about their being sterilized
7	Women with an intellectual disability should be allowed to engage in non-sexual romantic relationships
20*	It is best not to discuss issues of sexuality with women with an intellectual disability until they reach puberty
4*	It is best to wait for the woman with an intellectual disability to raise questions about sexuality before discussing the topic with her

**Denotes survey item that was reverse scored*

Procedure

This study was conducted at the University of South Dakota. Invitations to participate were sent to all students in the University Honors Program via their weekly newsletter and given to students by the faculty of two undergraduate Health Science courses. Included in these invitations was a short description of the purpose of the study, eligibility criteria for participation, contact information for the researcher, and a link to the survey (See Appendix D).

Prior to being able to begin responding to the survey questions, all those who desired to participate were required to read and agree to an informed consent document which appears in Appendix E. Respondents were informed that their participation was voluntary, there would be no compensation or consequence for agreeing or not agreeing to participate, no identifiable data would be collected about them, and their responses would be anonymous. Following their indication of agreement to these conditions, they then were able to complete the survey online using GoogleForms.

To be eligible for participation in the study, potential respondents needed to meet these criteria: age 18 or older, enrollment at the undergraduate level at the University of South Dakota and plans for a career in direct patient care. Responses to questions appearing in the first section of the survey provided the information needed to establish the eligibility of the respondent for study participation.

CHAPTER FOUR

Results

Sample Description

Fifty students completed the informed consent statement acknowledgement and submitted surveys. Of these, 47 met the criteria for participation in the study and comprised its sample. Table 2 presents data on this sample. Nearly all (98%) of respondents were between the ages of 18-22 with one student in the category of 30-49 years of age. Ninety-four percent were white with one each self-describing as either African American, Native American/Aleut or mixed race. As a group they ranged across the undergraduate years with 32% freshman, 23% sophomores, 17% juniors, and 28% seniors.

Table 2. Respondent Demographics

		Count (n=47)	Percentage
Gender			
	Male	7	14.90%
	Female	40	85.10%
Age (Years)			
	18-22	46	97.90%
	30-49	1	2.10%
Racial/Ethnic Identity			
	White	44	93.60%
	African American	1	2.10%
	Native American or Aleut	1	2.10%
	Mixed Race	1	2.10%
Current Academic Standing			
	Freshman	15	31.90%
	Sophomore	11	23.40%
	Junior	8	17.00%
	Senior	13	27.70%

Data from Questionnaire

The ASQ IID used in this study includes 32 statements, some of which are negatively phrased and others positively phrased. This required reversed scoring on some items as is noted in Table 3. Overall, a higher score on the six-point scale, the greater the respondents' agreement with the questionnaire item for which an accepting attitude regarding its content may be inferred.

Table 3. Mean Scores of Items Presented by Level of Subjects Agreement and by Factors

Item #	***Factor 1: Sexual Rights***	Mean	Mode	SD
		5.158		1.077
25	Advice on contraception should be fully available to women with intellectual disability whose level of development makes sexual activity possible	5.84	6	0.424
21	Women with an intellectual disability have the right to marry	5.8	6	0.505
15	Sex education for women with an intellectual disability has a valuable role in safeguarding them from sexual exploitation	5.61	6	0.745
2	Provided no unwanted children are born and no-one is harmed, consenting women with an intellectual disability should be allowed to live in a heterosexual relationship	5.55	6	0.802
14*	Women with an intellectual disability are unable to develop and maintain an emotionally intimate relationship with a partner	5.5	6	0.624
17	Sexual intercourse should be permitted between consenting adults with an intellectual disability	5.44	6	0.693
30*	Marriage should not be encouraged as a future option for women with an intellectual disability	5.36	6	1.069
27	Marriage between adults with an intellectual disability does not present society with too many problems	5.11	6	1.027
10*	Discussions on sexual intercourse promote promiscuity in women with an intellectual disability	5.11	6	0.875
5*	Women with an intellectual disability have less interest in sex than do other adults	4.77	5	1.108
13*	Women with intellectual disabilities typically have fewer sexual interests than other adults	4.68	5	1.175

18*	Group homes for adults with an intellectual disability should be either all male or all female, not mixed	4.42	5	1.422
16*	In general, sexual behavior is a major problem area in management and caring for women with an intellectual disability	3.86	4	1.133
	Factor 2: Parenting	5.05		1.761
11*	Women with an intellectual disability should only be permitted to marry if either they or their partners have been sterilized	5.53	6	0.937
6*	If women with an intellectual disability marry, they should be forbidden by law to have children	5.47	6	0.747
24*	Sexual intercourse should be discouraged for women with an intellectual disability	4.98	6	1.234
28*	Sterilization is a desirable practice for women with an intellectual disability	4.96	5	0.928
1	With the right support, women with an intellectual disability can rear well-adjusted children	4.85	6	1.197
31	Women with an intellectual disability should be permitted to have children within marriage	4.84	6	1.413
19*	Care staff and parents should discourage women with an intellectual disability from having children	4.73	6	1.176
	Factor 3: Non-Reproductive Sexual Behavior	5.41		1.867
12	Masturbation in private for women with an intellectual disability is an acceptable form of sexual expression	5.65	6	0.706
22	It is a good idea to ensure privacy at home for women with an intellectual disability who wish to masturbate	5.62	6	0.614
9*	Masturbation should be discouraged for women with an intellectual disability	5.5	6	1.111
3	Consenting women with an intellectual disability should be allowed to live in a homosexual relationship if they so desire	5.53	6	0.905
29	Masturbation should be taught to women with an intellectual disability as an acceptable form of sexual expression in sex education courses	4.73	6	1.355
	Factor 4: Self-Control	4.85		1.022
8*	Medication should be used as a means of inhibiting sexual desires in women with an intellectual disability	5.57	6	0.779
26*	Women with an intellectual disability are more easily stimulated sexually than people without intellectual disability	4.49	4	0.968
32*	Women with an intellectual disability have stronger sexual feelings than other individuals	4.49	4	0.920
	Not Included in Factors			

23	Whenever possible, women with an intellectual disability should be involved in the decision about their being sterilized	5.73	6	0.837
7	Women with an intellectual disability should be allowed to engage in non-sexual romantic relationships	5.61	6	0.922
20*	It is best not to discuss issues of sexuality with women with an intellectual disability until they reach puberty	3.56	3	1.324
4*	It is best to wait for the woman with an intellectual disability to raise questions about sexuality before discussing the topic with her	3.47	5	1.572
Overall		5.07	5.6	0.976

**Denotes a survey item that was reversed scored*

As noted in Table 3, responses to all items, except three (20, 4, and 16) showed mean scores above four, indicating agreement, thus reflecting a generally positive or accepting attitude towards topics related to the sexuality of WID. Another important trend in the data shows that, in general, items with higher mean scores also had a lower standard deviation. As means decreased, standard deviations generally increased. This trend in data would suggest that there was less agreement among respondents on items that were scored lower, revealing an opportunity for education to address these topics.

The mean score on all 32 items of the ASQ IID was relatively high (5.07 on a 6-point scale). The data in Table 3 also show no item on the questionnaire had a mode of less than four, representing the sample's frequent agreement with the content of each item. Table 4 presents those items and their factors with the highest and the lowest mean scores. Items 25, 21, and 23 had the highest mean score and included the statements: "Advice on contraception should be fully available to women with intellectual disability whose level of development makes sexual activity possible" (M=5.84), "Women with an intellectual disability have the right to marry" (M=5.80), and "Whenever possible, women with an intellectual disability should be involved in the decision about their being sterilized” (M=5.73). Two out of three of these items (25, 21) came from the factor titled “Sexual Rights”, the third (23), arguably follows the same trend being that it is a statement on the rights of WID to consent to being sterilized.

Table 4 also includes the three items with the lowest mean scores. These included items 4, 20, and 16: “It is best to wait for the woman with an intellectual disability to raise questions about sexuality before discussing the topic with her” (M=3.47), “It is best not to discuss issues of sexuality with women with an intellectual disability until they reach puberty” (M=3.56) and, “In general, sexual behavior is a major problem area in management and caring for women with an intellectual disability” (M=3.86). Item 4 and 20 did not fit the Cuskelly and Gilmore (2007) factor analysis and item 16 fell into the factor of “Sexual Rights.”

Table 4. ASQ-ID Items with the Highest and Lowest Mean Scores.

Item Number	Factor	Items with the Highest Mean Scores in the Sample	Mean
25	Sexual Rights	Advice on contraception should be fully available to women with intellectual disability whose level of development makes sexual activity possible	5.84
21	Sexual Rights	Women with an intellectual disability have the right to marry	5.8
23	No Factor	Whenever possible, women with an intellectual disability should be involved in the decision about their being sterilized	5.73
Item Number	**Factor**	**Items with the Lowest Mean Scores in the Sample**	**Mean**
4	No factor	It is best to wait for the woman with an intellectual disability to raise questions about sexuality before discussing the topic with her.	3.47
20	No Factor	It is best not to discuss issues of sexuality with women with an intellectual disability until they reach puberty.	3.56
16	Sexual Rights	In general, sexual behavior is a major problem area in management and caring for women with an intellectual disability,	3.86

Table 5 presents the items with the highest and lowest standard deviations for the individual items of the ASQ IID. The lowest standard deviation would indicate the items with the highest level of consensus among the respondents. These included items 14, 21, and 25: “Women with an intellectual disability are unable to develop and maintain an emotionally intimate relationship with a partner” (SD=0.62), “Women with an intellectual disability have the right to marry” (SD=0.51), and “Advice on contraception should be fully available to women with intellectual disability whose level of development makes sexual activity possible” (SD=0.42). All three items came from the factor of “Sexual Rights” and it should be noted that items 21 and 25 were also previously noted for having the highest mean scores.

Items with the highest standard deviation reveal those with the least agreement among respondents. These items included items 4, 18, and 31: “It is best to wait for the woman with an intellectual disability to raise questions about sexuality before discussing the topic with her” (SD=1.57), “Group homes for adults with an intellectual disability should be either all male or all female, not mixed” (SD=1.42), and “Women with an intellectual disability should be permitted to have children within marriage” (SD=1.41). Item18 comes from the factor “Sexual Rights” whereas item 31 comes from the factor “Parenting.” Item 4 was among those that did not fit with the identified factors, but it should be noted that this question also stood out as having the lowest average score, representing lack of agreement with it.

Table 5. ASQ-ID Items with the Highest and Lowest Standard Deviations

Item Number	Factor	Items with the Lowest Standard Deviations	SD
22	Non-Reproductive Sexual Behavior	It is a good idea to ensure privacy at home for women with an intellectual disability who wish to masturbate	.61
21	Sexual Rights	Women with an intellectual disability have the right to marry.	.51
25	Sexual Rights	Advice on contraception should be fully available to women with intellectual disability whose level of development makes sexual activity possible”	.42
Item Number	**Factor**	**Items with the Highest Standard Deviations**	**SD**
4	No Factor	It is best to wait for the woman with an intellectual disability to raise questions about sexuality before discussing the topic with her	1.57
18	Sexual Rights	Group homes for adults with an intellectual disability should be either all male or all female, not mixed	1.42
31	Parenting	Women with an intellectual disability should be permitted to have children within marriage	1.41

CHAPTER FIVE

Discussion

The data gathered with this study revealed a distinct pattern reflecting a general awareness and acceptance of the sexuality of WID by study respondents. Further, the respondents' responses showed a predominate acceptance of WID's expression of their sexuality through masturbation and in relationships that could lead to parenthood. Additionally, these responses indicated an awareness of the need for these women to receive education regarding sexuality and contraception. In contrast, there was somewhat less agreement among the sample regarding the optimal age for sexual education to be provided and management of group residential life for those with disabilities.

What are the implications of these findings? To begin to address this question, caution in generalizing from this sample to other undergraduates or other populations needs to be addressed. The 47 subjects in this study were all aspiring healthcare professionals who may have already encountered course content regarding WID or the general rights of those with disabilities. It can also be assumed that many of the respondents have also taken courses in ethics or been exposed to other provocative content in seminars for students in the Honors Program. Such exposure could have minimized their responses revealing bias, stigma, or a propensity toward discrimination against those with disabilities, especially as it relates to the sexuality of WID.

Further, as young people on the brink of adulthood, it can be assumed this sample is in the midst of personal exploration of sexuality and may be experiencing resistance to infringement on the liberty of its expression. This developmental issue could enhance antipathy towards items on the questionnaire that indicated that sexual liberty should be thwarted for others, regardless of disability. Thus, prior to offering education on this subject, assessment of the specific attitudes of those for whom content on this topic is planned may be helpful to assuring its relevance for the needs of any specific group of students.

Limitations of the Study

Several limitations of this study need to be articulated. The questionnaire used to collect data did not specify the degree of disability for those described as "women with an intellectual disability." For some respondents, this identifier could have created images of a person with severe cognitive limitations and for others, very mild impairment. How this term was interpreted could have impacted the respondents' level of agreement with the questionnaire items. It would seem, from the study's findings, that the level of impairment assumed by the respondents was most likely trending toward minimal severity.

Further, there is, of course, a diverse population of people that is captured under this reference of WID, making it difficult to generalize the topic. Just as any other human condition, many different diagnoses could cause someone to be labeled with an intellectual disability and with this comes a wide range of function and ability. In additional to intellectual disability, WID may also experience physical disabilities which may contribute to greater the complexity of their needs and vulnerabilities. This means that references to women with an intellectual disability in this paper are made with the idea in mind that this is a broad reference and may not be applicable to or include all individuals falling under the category of having an intellectual disability.

As previously noted, attention was given to the possible developmental issues of the respondents in this study's sample. The geographical location of this study in the upper Midwest may also limit the ability of its findings to be generalized to other locales. All respondents were students at the University of South Dakota, an upper Midwestern university. Many students who attend this university likely have also been born and raised in the Midwest. Due to the very specific geographic location of this study, there are limitations in the assumptions that can be made for students at other institutions of higher education. As noted previously, caution should be taken when applying the findings of this study to the development of curriculum for students outside of this geographical region. Further, as with any population, it is best to assess each student groups' unique attitudes before proceeding with curriculum development.

Additionally, another issue necessary to consider when interpreting this study's findings is its lack of gender and racial diversity in its sample. The sample was predominately comprised of white females, and this too may have affected its results. Another bias apparent in the sample is its composition primarily of students in the University of South Dakota Honors program. These students may not be representative of the campus' overall student population.

A few limitations of the ASQ IID questionnaire used in this study include the fact that the original samples use to create this research tool, and subsequently the data that was used in performing the factor analysis, came from samples of Australian adults. Due to this geographical difference, there could possibly be differences in the societal norms of each geographic location. Additionally, due to the small sample size of this study, a factor analysis with the responses to the individual items of the ASQ IID for this data set was not able to be performed. Because of this, it is unknown if the data collected by this study would follow the same factor loadings as the factors identified by Cuskelly and Gilmore (2007). It is possible that this sample set could have yielded different sample loadings. Despite this limitation, it was assumed that the factors would be the same for both of these samples.

Recommendations based on Study Findings

With these above limitations of the study acknowledged, the data from this study are useful in guiding the development of curriculum for undergraduate FHP. Specifically, data from this study suggest class material addressing the need for an emphasis on the rights of those with a disability to be respected could be limited. Further, based on the overall awareness and acceptance of the sexuality of WID shown in the sample survey, anticipation of resistance to this topic is unlikely. With this apparent foundational understanding of rights and respect for the sexuality of WID, two recommendations are offered for curricular input for FHPs on WID. They are:

- student exposure to models of how sensitive clinicians provide education to WID.
- opportunities for students to directly interact with individuals with disabilities.

Allowing real-world, hands-on exposures would build upon foundations that this sample appears to bring to future education regarding WID.

The first recommendation requires the development of classroom experiences that would enable students to observe interactions between clinicians and WID. Interactions and classroom activities could be constructed to involve video-taped observations of how physicians or other care providers provide education to WID regarding sexual matters. If such materials are not currently available, their development could become a project worthy of efforts and perhaps funding from granting agencies. If health professionals trained in this area could be identified, shadowing-type experiences could also be offered to students in order to see how situations regarding the sexuality of WID are handled in everyday practice. Allowing students an opportunity to see models of effective care provided to WID could help them appreciate the complexity of care and allow them to make connections with what they have learned in the classroom to see how it is applied in patient care encounters.

The second recommendation would be to provide experiences for students in the classroom to directly interact with WID. *The Curriculum of Caring for People with Developmental Disabilities in Medical Education* (Boyd et al., 2019), is an example of a curriculum that provides experiential learning to improve the capacity of healthcare professionals to deliver person/family-centered care to people who live with intellectual and/or developmental disabilities. By bringing people with disabilities into the classrooms of FHP and allowing them to share their experiences, students may be better prepared to improve healthcare experiences for this population. Boyd et al. (2019) found when students were given early exposure to people with disabilities in their professional curriculum, they reported significantly higher levels of comfort, confidence, and competence when caring for this population. Allowing students to interact with those with disabilities provides a way for them to understand what it means to humanize medicine and see the importance of shifting to a person-oriented perspective of medicine.

In summary, the undergraduate FHP who participated in this study expressed a general agreement with statements on the ASQ IID questionnaire which suggested that WID are sexual and their rights for sexual expression should be honored. To advance the knowledge of these students during the formative and impressionable years of their education, experiential opportunities are recommended which would give students exposure to those with disabilities and to the expertise of clinicians who effectively serve this population. Allowing students to learn from professionals in the field in addition to interacting with individuals with disabilities in an educational setting would facilitate their ability to gain directly applicable knowledge that could be translated to their future professional work. By affording students these unique educational opportunities, FHP can build upon their formal education and be better trained to understand how best to care for the complex needs of WID.

CHAPTER SIX

Conclusion

Over the course of recent decades, there has been a growing sensitivity to the historic lack of social justice for those with disabilities. In the last 50 years, the passage of the Education of All Handicapped Children Act of 1975 (now IDEA), which assures a free public education for all children in the least restrictive environment, and the American with Disabilities Act of 1990, which prohibits discrimination based on disability, made monumental strides in opening society to those with disabilities. Nonetheless, negative attitudes and misinformation regarding the sexuality of those with disabilities have persisted.

Failure to recognize the sexuality of those with disabilities has led to a lack of appropriate education and medical care that is protective for those with disabilities, especially those with intellectual disabilities. Research has shown that those with disabilities perceive healthcare providers as the best source of this needed attention, but providers have been deficient in its provision (Askoy, 2020). Education enabling the development of this needed expertise can begin for FHP during their undergraduate years and prior to the beginning of their discipline-specific training. This study aimed to assess the attitudes of undergraduate FHP regarding the sexuality of WID and is a first step in filling this educational void. These findings, it is postulated, can subsequently be used in formulating a curriculum that would provide a foundation for developing professional skills in serving this population of patients.

Data gathered from the 47 FHP, who comprised the sample of this study, show that nearly all possess an accepting attitude toward the sexuality of WID and recognize their rights for its expression. These findings provide evidence that educational efforts need not anticipate student resistance to an integration of this topic into an undergraduate health sciences curriculum and can cautiously assume an openness to its inclusion in course material.

Final Remarks

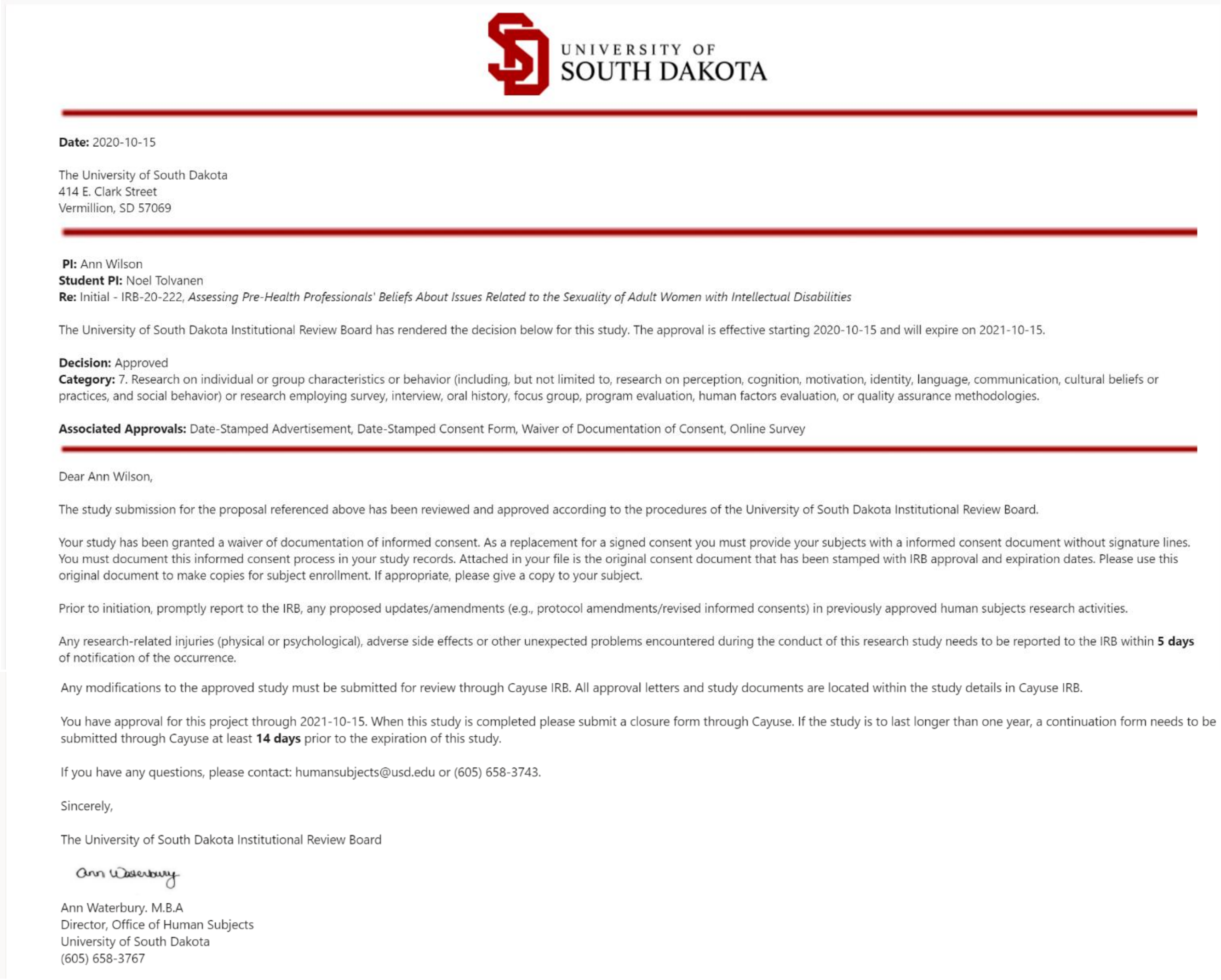
Despite limitations, this study's Review of the Literature and Results were able to bring light to issues that are impacting the sexuality and sexual healthcare of WID. As the data indicate, undergraduate FHP at the University of South Dakota appear to acknowledge the reality of the sexuality of WID. The generally accepting attitudes of students do show the potential for a strong foundation upon which a curriculum focusing on people with disabilities can be built. Recognizing this, the beneficial focus of educational efforts can then progress to expose students to skillful and sensitive interactions between experienced primary care providers and opportunities for direct interaction with this population of future patients.

The sexual health and wellbeing of WID are impacted by the care they receive from healthcare providers. When barriers to sexual education and healthcare for WID can be transcended, these women can experience safer and hopefully more fulfilling lives. Further, clinicians who provide this care can also experience a meaningful contribution to the lives of this population that is known to be underserved. Even though this study revealed students' understanding of concepts regarding the basic rights and capabilities of WID, fundamental education regarding these topics is essential at a basic educational level for all FHP. This does not currently exist in many educational programs for FHP, and such curriculum must be created.

Effective curriculum is built upon the current knowledge of its intended students. Further, an understanding of students' attitudes about a value laden topic provides an essential foundation for those who develop future curriculum. Taking these factors into account, ensures the development an effective, relevant and meaningful education with the long-term goal of creating competent, well-rounded FHPs who are equipped or well prepared to reach their goals of becoming clinicians with a future that will most likely include the care of patients with disabilities. This study provides a glimpse of this information that could be helpful to the faculty at the University of South Dakota who teach health science courses that include material on the sexuality of WID and those who hope to improve the current curricula of healthcare related professional programs.

Appendices

Appendix A
IRB Approval



UNIVERSITY OF
SOUTH DAKOTA

Date: 2020-10-15

The University of South Dakota
414 E. Clark Street
Vermillion, SD 57069

PI: Ann Wilson
Student PI: Noel Tolvanen
Re: Initial - IRB-20-222, *Assessing Pre-Health Professionals' Beliefs About Issues Related to the Sexuality of Adult Women with Intellectual Disabilities*

The University of South Dakota Institutional Review Board has rendered the decision below for this study. The approval is effective starting 2020-10-15 and will expire on 2021-10-15.

Decision: Approved
Category: 7. Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

Associated Approvals: Date-Stamped Advertisement, Date-Stamped Consent Form, Waiver of Documentation of Consent, Online Survey

Dear Ann Wilson,

The study submission for the proposal referenced above has been reviewed and approved according to the procedures of the University of South Dakota Institutional Review Board.

Your study has been granted a waiver of documentation of informed consent. As a replacement for a signed consent you must provide your subjects with a informed consent document without signature lines. You must document this informed consent process in your study records. Attached in your file is the original consent document that has been stamped with IRB approval and expiration dates. Please use this original document to make copies for subject enrollment. If appropriate, please give a copy to your subject.

Prior to initiation, promptly report to the IRB, any proposed updates/amendments (e.g., protocol amendments/revised informed consents) in previously approved human subjects research activities.

Any research-related injuries (physical or psychological), adverse side effects or other unexpected problems encountered during the conduct of this research study needs to be reported to the IRB within **5 days** of notification of the occurrence.

Any modifications to the approved study must be submitted for review through Cayuse IRB. All approval letters and study documents are located within the study details in Cayuse IRB.

You have approval for this project through 2021-10-15. When this study is completed please submit a closure form through Cayuse. If the study is to last longer than one year, a continuation form needs to be submitted through Cayuse at least **14 days** prior to the expiration of this study.

If you have any questions, please contact: humansubjects@usd.edu or (605) 658-3743.

Sincerely,

The University of South Dakota Institutional Review Board

Ann Waterbury

Ann Waterbury. M.B.A
Director, Office of Human Subjects
University of South Dakota
(605) 658-3767

Appendix B
Student Survey

Section 1: Attitudes to Sexuality Questionnaire, Informed Consent Statement
The purpose of this research is to explore attitudes about the sexuality of women with intellectual disabilities held by undergraduate students preparing for a career in a health related profession. The information gained from this study will be helpful in designing educational materials for those entering the field of healthcare. This survey contains 37 items and should take approximately 10-15 minutes to complete.

1.Have you read, and do you understand the above informed consent statement? (required)

A. Yes
B. No

Section 2: Demographic Questions
The following 5 questions are to gain information regarding your demographics. You will not be asked to provide any information that could identify you. All responses will be kept anonymous.

1. What is your gender?

A. Male
B. Female
C. Other (Please Specify)

2. What is your age?

A. 18-22 years old
B. 23-29 years old
C. 30-49 years old
D. 50-64 years old
E. 65 years and over

3. To which racial or ethnic group(s) do you most identify?

A. African-American
B. White
C. Latino or Hispanic
D. Native American or Aleut
E. Other (Please Specify)

4. What is your current academic standing?

A. Freshman
B. Sophomore
C. Junior
D. Senior
E. 5+ Years

F. Not an undergraduate student
5. What is your intended career path?
A. Direct Patient Care Provider (e.g. physician, physician assistant, nurse, therapist)
B. Indirect Patient Care Provider (e.g. healthcare administration, public policy, lab work)
C. Other (Please Explain)

Section 3: Attitudes to Sexuality Questionnaire (Women with an Intellectual Disability)

The following questions will ask you to describe your response to statements regarding the sexuality of women with intellectual disabilities.

This questionnaire was adapted from:

Cuskelly, M., & Gilmore, L. (2007). Attitudes to sexuality questionnaire (individuals with an intellectual disability): Scale development and community norms. Journal of Intellectual and Developmental Disability, 32(3), 214-221. doi:10.1080/13668250701549450

1. With the right support, adults with an intellectual disability can rear well adjusted children
2. Provided no unwanted children are born and no-one is harmed, consenting adults with an intellectual disability should be allowed to live in a heterosexual relationship
3. Consenting adults with an intellectual disability should be allowed to live in a homosexual relationship if they so desire
4. It is best to wait for the individual with an intellectual disability to raise questions about sexuality before discussing the topic with him/her
5. Adults with an intellectual disability have less interest in sex than do other adults
6. If an adult with an intellectual disability marry, they should be forbidden by law to have children
7. Adults with an intellectual disability should be allowed to engage in non-sexual romantic relationships
8. Medication should be used as a means of inhibiting sexual desires in individuals with an intellectual disability
9. Masturbation should be discouraged for adults with an intellectual disability
10. Discussions on sexual intercourse promote promiscuity in adults with an intellectual disability
11. Adults with an intellectual disability should only be permitted to marry if either they or their partners have been sterilized
12. Masturbation in private for adults with an intellectual disability is an acceptable form of sexual expression
13. Adults with intellectual disabilities typically have fewer sexual interests than other adults
14. Adults with an intellectual disability are unable to develop and maintain an emotionally intimate relationship with a partner
15. Sex education for adults with an intellectual disability has a valuable role in safeguarding them from sexual exploitation

16. In general, sexual behavior is a major problem area in management and caring for adults with an intellectual disability
17. Sexual intercourse should be permitted between consenting adults with an intellectual disability
18. Group homes for adults with an intellectual disability should be either all male or all female, not mixed
19. Care staff and parents should discourage adults with an intellectual disability from having children
20. It is best not to discuss issues of sexuality with individuals with an intellectual disability until they reach puberty
21. Individuals with an intellectual disability have the right to marry
22. It is a good idea to ensure privacy at home for individuals with an intellectual disability who wish to masturbate
23. Whenever possible, individuals with an intellectual disability should be involved in the decision about their being sterilized
24. Sexual intercourse should be discouraged for individuals with an intellectual disability
25. Advice on contraception should be fully available to individuals with intellectual disability whose level of development makes sexual activity possible
26. Individuals with an intellectual disability are more easily stimulated sexually than people without intellectual disability
27. Marriage between adults with an intellectual disability does not present society with too many problems
28. Sterilization is a desirable practice for individuals with an intellectual disability
29. Masturbation should be taught to individuals with an intellectual disability as an acceptable form of sexual expression in sex education courses
30. Marriage should not be encouraged as a future option for individuals with an intellectual disability
31. Individuals with an intellectual disability should be permitted to have children within marriage
32. Individuals with an intellectual disability have stronger sexual feelings than other individuals

Appendix C
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Thank you.

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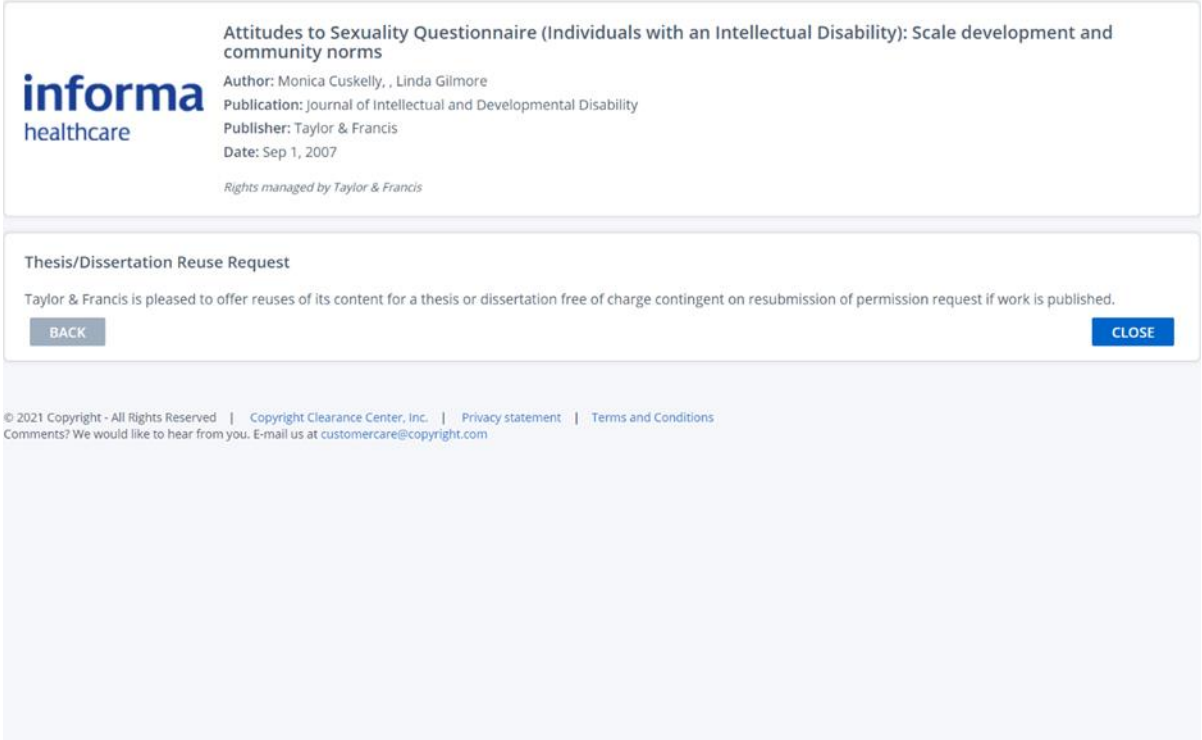

Attitudes to Sexuality Questionnaire (Individuals with an Intellectual Disability): Scale development and community norms

Author: Monica Cuskelly, , Linda Gilmore
Publication: Journal of Intellectual and Developmental Disability
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Appendix D
IRB Approved Advertisement Document

Honors Student Thesis
Ann Wilson, PhD
Noel Tolvanen

UNIVERSITY OF
SOUTH DAKOTA

Assessing Pre-Health Professionals' Attitudes About Issues Related to the Sexuality of Adult Women with Intellectual Disabilities

Hello, my name is Noel Tolvanen. I am a senior undergraduate student at USD and a member of the Honors Program. I am conducting a research project that is assessing attitudes of undergraduate pre-health professionals at the University of South Dakota regarding the sexual expression of women with intellectual disabilities. It is our hope that the findings of this research will be helpful in informing how educational programs on this topic should be designed for students entering health professions.

As you are enrolled as an undergraduate student at the University of South Dakota, you are invited to take part in this research study. In order to participate, you must be 18 years of age or older and seeking a career in a health related profession (e.g. physician, nurse, physician assistant, pharmacy personnel, social worker, speech language pathologist, dental hygienist, direct support, physical therapist, occupational therapist, paramedic /EMT).

Your participation in this research study will involve completing a survey containing 37 items that should take approximately 10-15 minutes to complete. Participation in this research is voluntary. Even if you decide to be part of this research now, you may discontinue your participation at any time. You do not have to respond to any survey item in which you do not want to answer.

There will be no penalty from your health science classes if you choose to not accept this invitation to participate in this study. You will not be asked to provide any information that could potentially identify you. All responses will be kept anonymous.

If you have any questions about this project, please contact me at Noel.Tolvanen@coyotes.usd.edu.

Further, if you have questions regarding your rights as a research subject, you may contact The University of South Dakota- Office of Human Subjects Protection at (605) 658-3743. You may also call this number with problems, complaints, or concerns about the research. Please call this number if you cannot reach research staff, or you wish to talk with someone who is an informed individual who is independent of the research team.

If you agree to participate in this research, please follow the survey link copied below or as provided to you by your instructor.

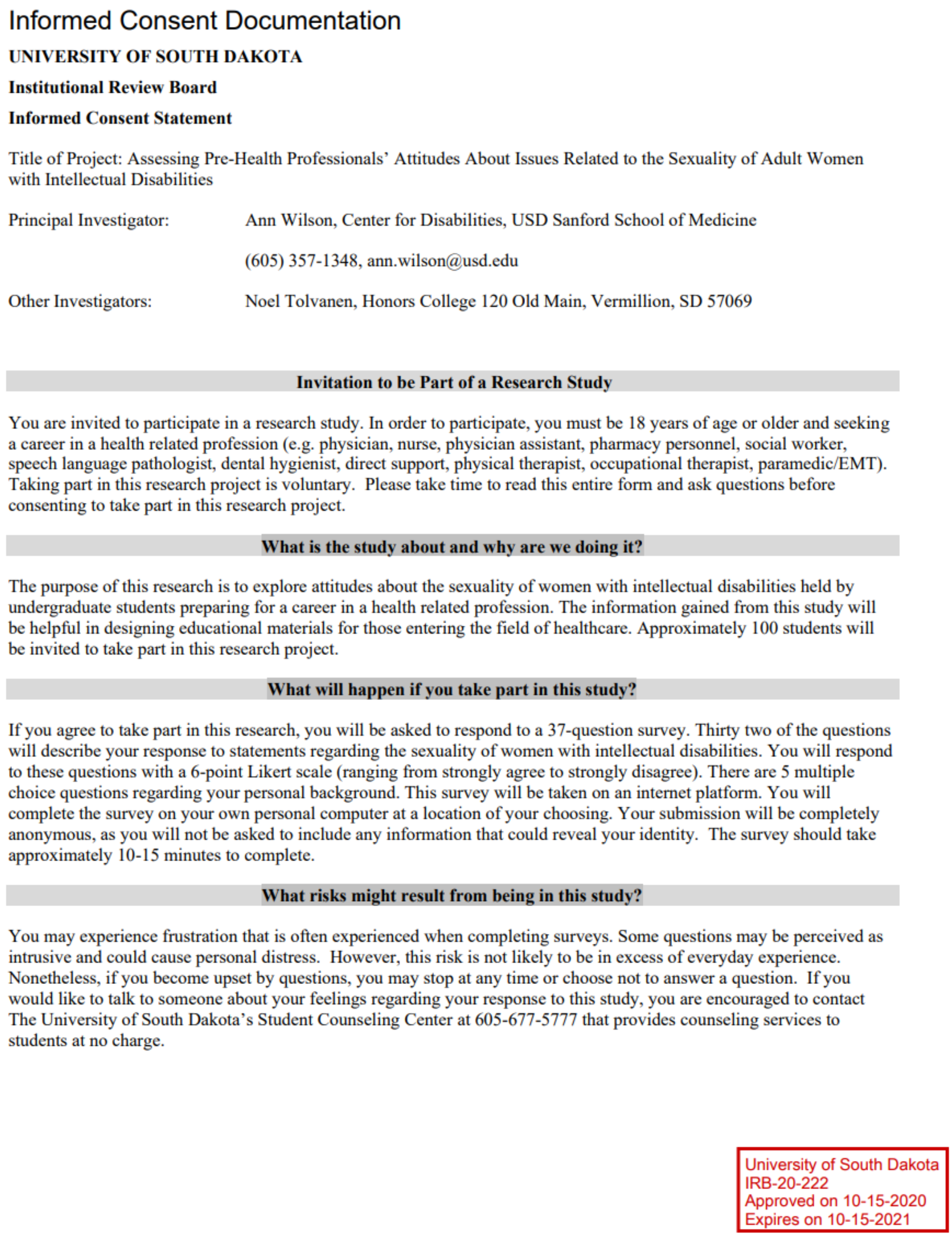
(survey link here)

Thank you for your consideration of taking part in this research.

Noel Tolvanen

University of South Dakota
IRB-20-222
Approved on 10-15-2020
Expires on 10-15-2021

Appendix E
Student Survey Informed Consent Statement



Informed Consent Documentation

UNIVERSITY OF SOUTH DAKOTA

Institutional Review Board

Informed Consent Statement

Title of Project: Assessing Pre-Health Professionals' Attitudes About Issues Related to the Sexuality of Adult Women with Intellectual Disabilities

Principal Investigator: Ann Wilson, Center for Disabilities, USD Sanford School of Medicine
(605) 357-1348, ann.wilson@usd.edu

Other Investigators: Noel Tolvanen, Honors College 120 Old Main, Vermillion, SD 57069

Invitation to be Part of a Research Study

You are invited to participate in a research study. In order to participate, you must be 18 years of age or older and seeking a career in a health related profession (e.g. physician, nurse, physician assistant, pharmacy personnel, social worker, speech language pathologist, dental hygienist, direct support, physical therapist, occupational therapist, paramedic/EMT). Taking part in this research project is voluntary. Please take time to read this entire form and ask questions before consenting to take part in this research project.

What is the study about and why are we doing it?

The purpose of this research is to explore attitudes about the sexuality of women with intellectual disabilities held by undergraduate students preparing for a career in a health related profession. The information gained from this study will be helpful in designing educational materials for those entering the field of healthcare. Approximately 100 students will be invited to take part in this research project.

What will happen if you take part in this study?

If you agree to take part in this research, you will be asked to respond to a 37-question survey. Thirty two of the questions will describe your response to statements regarding the sexuality of women with intellectual disabilities. You will respond to these questions with a 6-point Likert scale (ranging from strongly agree to strongly disagree). There are 5 multiple choice questions regarding your personal background. This survey will be taken on an internet platform. You will complete the survey on your own personal computer at a location of your choosing. Your submission will be completely anonymous, as you will not be asked to include any information that could reveal your identity. The survey should take approximately 10-15 minutes to complete.

What risks might result from being in this study?

You may experience frustration that is often experienced when completing surveys. Some questions may be perceived as intrusive and could cause personal distress. However, this risk is not likely to be in excess of everyday experience. Nonetheless, if you become upset by questions, you may stop at any time or choose not to answer a question. If you would like to talk to someone about your feelings regarding your response to this study, you are encouraged to contact The University of South Dakota's Student Counseling Center at 605-677-5777 that provides counseling services to students at no charge.

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How could you benefit from this study?

You may not directly benefit from being in this study, however:

- You may learn more about yourself by participating in this study.
- You may realize that others have had similar experiences as you.
- You may have a better understanding of how biases impact the lives of others.
- The information collected with this study may help with the development of educational materials regarding the sexuality of people with intellectual disabilities.

How will we protect your information?

This survey does not ask you to provide any information that would reveal the identity of those who respond, as your responses are recorded anonymously. You will not be asked to provide your name and there is no way for the researchers to link your name to your responses. If this research is published, no information that would identify you will be included.

All survey responses received will be treated confidentially and stored securely. However, given that the surveys can be completed from any computer (e.g., personal, work, school), we are unable to guarantee the security of the computer on which you choose to enter your responses. As a participant in our study, we want you to be aware that certain "key logging" software programs exist that can be used to track or capture data that you enter and/or websites that you visit.

Your Participation in this Study is Voluntary

Participating in this research is voluntary. Even if you decide to be part of this research now, you may change your mind and discontinue your participation at any time. You do not have to respond to any survey item in which you do not want to answer. There will be no penalty from your health science classes if you choose to not participate. Again, your responses are anonymous and your participation completely voluntary.

Contact Information for the Study Team and Questions about the Research

The researchers conducting this study are Ann Wilson, PhD, and Noel Tolvanen. You may ask any questions, or express concerns or complaints regarding this study by contacting Ann Wilson at 605-321-5500 or ann.wilson@usd.edu.

If you have questions regarding your rights as a research subject, you may contact The University of South Dakota- Office of Human Subjects Protection at (605) 658-3743. You may also call this number with problems, complaints, or concerns about the research. Please call this number if you cannot reach research staff, or you wish to talk with someone who is an informed individual who is independent of the research team.

Your Consent

Before agreeing to be part of the research, please be sure that you understand what the study is about. Keep this copy of this document for your records. If you have any questions about the study later, you can contact the study team using the information provided above.

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