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Sexual Health Education Among the Intellectually and Developmentally Delayed Populations: An Examination of Medical Providers Perspective

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Abstract

Sexuality is a recognized human right as it influences mental, social and emotional wellbeing. Despite this, individuals with intellectual or developmentally delays (ID/DD) rarely receive the necessary sexual education. ID/DD persons are also at an increased risk for sexual abuse, further demonstrating the strong need for education. A natural setting in which to receive unbiased and informative sexual health information is through their medical provider. The purpose of this research was to examine current clinic standards, education, and perceptions of medical providers in regards to sexual education for ID/DD adolescents. Medical providers and students within West Michigan were surveyed with follow up intensive ethnographic interviews conducted. Themes developed from interviews and additional quantitative data demonstrated that medical providers view sexual education for ID/DD persons. However, doctors and advanced practice practitioners note barriers to teaching in time, comfort level, and knowledge. Further research on medical providers teaching sexual education to ID/DD persons is necessary. Recommended next steps for providing this teaching to ID/DD persons involve the development of resources for medical providers along with consistent formal training in medical institutions.

Table of Contents

List of tables

List of Figures

Abbreviations

APP Advanced Practice Practitioners

DNP Doctor of Nursing Practice

ID/DD Intellectually Delayed/Developmentally Delayed Population

IRB Institutional Review Board

PA Physician Assistant

Chapter I: Introduction

Sexuality is an important human right as it impacts the social, mental and physical health of individuals (Lunsky & Konstantares, 1998). Sexual recognition and the important impacts it has on health have been dismissed, currently and historically, for persons with intellectual and developmental delays (ID/DD) (Center for Reproductive Rights, 2016). ID/DD persons were not viewed as sexual beings or capable of sexual actions until the 1970's and nearly fifty years later, it is apparent that acknowledgment of sexuality and sexual education for this group is still lacking (Dionne & Dupras, 2014). This continued lack of instruction on sexual health stems from viewing ID/DD persons as asexual and lacking ability to understand sex education (Sinclair, Unruh, Lindstrom, & Scanlon, 2015). Avoidance of recognizing ID/DD person's sexuality creates restrictions in access to education and the available resources to educate with (Lafferty, McConkey & Simpson, 2012). This has contributed to many ID/DD persons that never receive any form of sexual education (Sinclair, Unruh, Lindstrom, & Scanlon, 2015). Minimal sexual education for ID/DD adolescents can have a much more negative impact than just lacking understanding of their own sexual development however.

Sexual education, including discussion of safety and sexual boundaries are important concepts for ID/DD persons. These topics are so important because this population experiences an alarming rate of sexual abuse. Adolescents with cognitive impairments are at an estimated four-time greater risk of sexual assault when compared to children without a disability (Sullivan & Knutson, 2000). This abuse can negatively impact the health of rape survivors, resulting in feelings and behaviors of aggression, depression and self-harm cope (Perilloux, Duntley, & Buss, 2012; Rape, Abuse and Incest National Network [RAINN],

2016). Without knowledge of the true violation of sexual assault or feelings of helpless to stop it can influence future behavior. Passive actions during sexual abuse can influence and allows for passive behaviors to continue, making individuals more susceptible to future violence (Swango-Wilson, 2009). This is evident in the increased rates of abuse in the lifetime of the ID/DD community, as 49% of ID/DD person's experience 10 or more sexually abusive events (Valenti-Hein, & Schwartz, 1995). Further victimization continues for this population with lack of reporting, as only a total of 3% of sexual violence cases are reported to authorities, (Valenti-Hein & Schwartz, 1995). ID/DD individuals are more vulnerable to this sexual violence for several reasons including being unable to articulate their abuse due to disability or lack of vocabulary to explain the assault (Sullivan, 2003; Sullivan & Knutson, 2000). To reduce vulnerability to sexual assault, it is important that ID/DD persons receive education on sexual health and how to understand their sexual safety.

Education, including discussion of consent and empowerment, can provide evidence for ID/DD persons to understand their sexuality and sexual boundaries (National Sexual Violence Resource Center, 2011). With a growing need for this dialogue to occur, medical providers have been identified as a potential source for teaching. According to Merrick, Greydanus, and Patel (2014), health providers are integral in providing developmental and age appropriate sexual education. Medical organizations also recognize that providers can play a critical role in education, but the literature is sparse in illustrating medical professional's understanding of sexual education. Medical school curriculums show little instruction on sexual health and little consensus on the type of material students should learn (Coleman et al., 2013). With inconsistency in formal education and sparse literature, it is

important to evaluate current knowledge and standards in the medical field for sexual health. Obtaining perspectives from health providers will allow for reflection on their attitudes and values, which can increase their ability to feel comfortable to discuss sexuality (Committee on Psychosocial Aspects of Child and Family Health and Committee on Adolescence, 2001). This study evaluates the perceptions and training of medical providers including physicians, nurse practitioners (NPs), and physician assistants (PAs) through survey and intensive ethnographic interview. The analysis will provide perspective on the potential for furthering the intersection of the medical community and sexual education for the ID/DD population.

1.1 Purpose

As a whole, the ID/DD community experiences sexual abuse at a higher incidence than other populations. To mitigate this, it is necessary to implement developmentally appropriate sexual education to help reduce sexual abuse and allow for full sexual expression by ID/DD persons (Planned Parenthood, 2016). Often, though, parents, teachers and physicians place responsibility on someone else to teach ID/DD adolescents about sexual health, rather than themselves (East & Orchard, 2014). Examining potential resources for education is necessary to allow for evaluation of the most appropriate source of education for ID/DD persons. One profession to examine is the medical field and the ability for medical providers to normalize sexual education for ID/DD patients.

Medical practitioners are recognized as experts in physical maturation and provide the potential for assuring education on the sexual development of ID/DD adolescents. Determining when and how health professionals provide this training is imperative. Current literature provides minimal research on the views from medical providers themselves and

their role in sexual education among ID/DD individuals. This study explores medical providers approach and desire to educate through evaluating provider's knowledge, perspectives on need and ability to educate, and current practice. Analysis from this study will create for more discussion and awareness of the need for sexual education amongst ID/DD person and allow for an further examination by health professionals.

1.2 Scope

This study attempts to clarify current perceptions, knowledge, and practice of medical providers and PA students and doctor of NP students in the arena of sexual education for the ID/DD population. Sexual health curriculum involves a significant amount of physical maturation content, of which medical professionals are experts. Gaining a perspective on health care provider's ability to discuss sexual health topics with ID/DD persons will demonstrate what aspects the medical profession is most comfortable and able to provide. To determine knowledge and practice of professionals, three research questions were created.

Research Aims

1) Identify sexual education topics medical providers are discussing with ID/DD patients and parents within the last year at a medical system located in West Michigan. The present practice methods will demonstrate what standards are being implemented in clinical practices in West Michigan and allow for critique.
2) Examine current perspectives of DNP and PA students on sexual education for adolescents within the ID/DD population. The current curriculum and student perspectives will demonstrate if practitioners in practice and present students received different formal education and if this field is advancing in recognizing

ID/DD person's sexual education.

3) Allow for response from practicing physicians on perspectives of sexual education provided to ID/DD individuals in a medical setting. Variability in comfort level and perceived ability can provide information on best practices and how the medical field can positively impact ID/DD persons furthered sexual health education.

1.3 Assumptions

In a review of the literature, limited research was generated on physician and advanced practice providers [APP], understanding for the need for sexual education and ability to provide such to the ID/DD population. Evaluation of these measures will help determine the medical field's potential to impact and provide this teaching. This study assumes that no system-wide standards exist for providing and asking questions related to sexual health for ID/DD patients in the study institutions evaluated. Assumptions include that ID/DD persons and guardians will acknowledge provider's expertise in this area and guardians will wish to discuss sexual health development in a medical setting.

1.4 Hypothesis

Health care professionals vary widely in training and experience, which impacts their knowledge of sexual education for the ID/DD population. Evaluation through survey and interview will demonstrate perceptions and knowledge among medical providers in this content area. No hypothesis was developed as this study is exploratory in scope and will work to provide thematic development for further discussion.

1.5 Significance of the Study

Prater and Zylstra (2006) note that a commonly overlooked health issue for ID/DD persons is sexuality. The American Association of Family Practitioners echoes this

perspective and calls upon medical providers to address this need. The purpose of this study is to examine health professional's education, knowledge, and practice of sexual education amongst ID/DD persons. Examining these will allow for reflection on the demands of health professionals and discuss the ability of this profession to provide sexual education. Obtaining perspectives from medical professionals will allow for reflection on their attitudes and values, which can increase their capacity to feel comfortable to discuss sexuality. With the alarming rates of sexual assault amongst the ID/DD population, it is necessary that they be provided with the proper education to recognize and report these violations. The significance of this work is that it provides a much-needed addition to the literature and increases discussion and reflection on sexual education for the ID/DD population, increasing attention to potential for developing necessary sexual education methods and resources.

Definitions

Intellectual and Developmental Delay: A mental impairment or delay is a defined as a condition developed before age 18, an IQ below 70-75, and significant limitation in adaptive areas. Persons within this population comprise about one to three percent of the global population equating to 200 million individuals (American Association of Intellectual and Developmental Disabilities, 2013).

Sexual Abuse: Sexual activity including touching and penetration that is unwanted perpetrated by force, threats or taking advantage of victims unable to consent (Encyclopedia of Psychology, 2015)

Chapter II: Review of Literature

The importance of providing comprehensive and medically accurate sexual education is a growing recognition for many populations. One of these groups is individuals within the Intellectually and Developmentally Delayed (ID/DD) population. As sexual health education involves a great deal of understanding physical maturation, medical providers who receive training on this topic have the opportunity to impact education of ID/DD persons. A literature review to determine what current sexual education practice is being implemented for ID/DD persons by medical providers was conducted. Medical provider's perspectives and other relevant issues regarding sexual education for ID/DD persons were also explored. Topics emphasized in the literature review influenced interpretation and development of the current study.

Databases included in the review were CINAHL Complete, PsychInfo, and PubMed. These databases were best suited for use as they all commonly identify articles about health education, sexual health and perceptions surrounding sexual health. Primary search terms utilized included: intellectual disability/delay or developmental disability/delay and were paired with terms of sexual education, health professional, physician, doctor, provider, physician assistant, nurse practitioner and medical. Searches utilizing these terms resulted in limited articles, with less than 100 provided. Restrictions of years from 1990 to current were chosen, as research in this area is relatively new. Restriction to peer-reviewed scholarly articles was also implemented to ensure the scientific integrity of the items chosen. Studies excluded were due to the focus on mental health issues rather than disability, articles not written in English, and articles focused on perceptions of individuals not related to sexual health.

2.1. Sexuality and abuse amongst the ID/DD population

The literature review demonstrates that recognition for ID/DD person's sexuality and the freedom to express their sexual desires is severely lacking. Historically and into present day, ID/DD person's education to understand their sexuality has been minimal and largely restricted from this population (Sinclair, Unruh, Lindstrom, & Scanlon, 2015; Lafferty, McConkey & Simpson, 2012; Dionne & Dupras, 2014). Resources and available teaching on sexuality are infrequent for ID/DD persons as they are viewed as child-like, despite their maturing physical bodies (Swango-Wilson, 2010; Sinclair et al., 2015). Viewing the ID/DD population as child-like influences perceptions of this population as being unable to desire sexual or emotional relationships. The effects of these views are demonstrated in the lack of understanding held by ID/DD adolescents when compared to non-ID/DD youth, as ID/DD persons have significantly lower levels of sexual knowledge (Jahoda, & Pownall, 2014). The limited sexual education and resources available for this population leaves them unable to comprehend their own sexuality. Views of ID/DD persons as child-like also work to increase their vulnerability to sexual abuse (Lund & Vaughn-Jensen, 2012; Smith & Harrell, 2013).

ID/DD adolescents and adults are at an increased risk of sexual abuse due to increased vulnerability from lack of education on consent and sexual topics as a whole. Sexual abuse occurs at a higher rate for this population as they often lack the understanding of what their sexual boundaries are and their ability to keep others from violating these limits (Wacker, Parish, & Macy, 2008; Martinello, 2014). This can be further complicated among individuals who also suffer physical impairments which require others to invade their personal space to assist them with toileting, bathing, and dressing (Foster & Sandel,

2010). Without an understanding of what forms of touch violate their being and the ability to discontinue inappropriate behavior, ID/DD persons can suffer through rape in silence. Recognizing the lack of education contributing to sexual violence is a major factor in influencing increased sexual education for this population. A growing recognition of the need for sexual education among those with ID/DD has brought to light the lack of research in teaching and the general lack of knowledge in this area (Taiwo, 2012; Rohleder, 2010). One profession increasingly called upon to teach sexual education is health professionals. To understand the lack of education that ID/DD persons receive regarding sexual teaching and development, it is important to examine current information that is being conveyed to ID/DD patients.

Sexual education on contraception, pregnancy, and intercourse for male and female ID/DD patients is infrequent (Greenwood, Ferrari, Bhakta, Ostrach, & Wilkinson, 2014; McGillivray, 1999). For young women within the ID/DD population, there is a lack of discussion on menstrual development and dealing with the physical and emotional changes of premenstrual syndrome (PMS) (Quint, 2008; Ibralic, Sinanovic & Memisevic, 2010). As beginning menses can be a difficult developmental stage for young women to go through, lacking knowledge and understanding of how to deal with the changes can put ID/DD women at a disadvantage. Research demonstrates that the provision of sexual development education by medical providers is very minimal as a whole (Prater and Zylstra, 2006; Murphy, Lincoln, Meredith, Cross, & Rintell, 2016

The literature attributes limited teaching on sexuality to the lack of knowledge and training medical providers receive (Greenwood, & Wilkinson, 2013; Fouquier & Camune, 2015; Sinclair, Unruh, Lindstrom, & Scanlon, 2015; Leutar & Mihokovic, 2007, Di Giulio,

2003; Lafferty, McConkey, & Simpson, 2012; Kijak, 2011; Rohleder, 2010; Taiwo, 2012). To understand what current curriculum in medical and health professional schooling lack, literature was examined to determine the current perspectives on these systems to educate medical providers on sexual education.

2.2 Health Care Professionals Education

Examination of current curriculum and practice methods for providing sexual education was analyzed in current research. Research evaluated shows education provided to health professionals contains little instruction on sexual health in medical schools and little consensus on the type of material students should learn (Coleman et al., 2013; Shindel, Baazeem, Eardley, & Coleman, 2016). This literature emphasizes that medical organizations and educational institutions recognize the lack of sexual health instruction included into the curriculum. Shortage of sexual health education within the medical field curriculum was so apparent that in 2011, a summit brought together leading medical schools and health organizations to discuss sexual education in medical schools. Those in attendance included top medical school educators, the Center for Disease Control, the Association of American Medical Colleges and sexual health organizations. Outcomes included increasing curriculum standards, training and ensuring evaluation mechanisms for education (Coleman et al. 2013). Medical residents also recognize a growing need for sexual education in the ID/DD population, stating they desire more sexual education resources to improve overall patient care (Waineo, Arfken, & Moreale, 2010). Representation of recognition for ID/DD people specifically was not mentioned in the noted lack of education in the curriculum and furthered training for medical students. For schools that do have a portion of their medical curriculum, education regarding sexual minorities is minimal (Shindel, & Parish, 2013.)

Changes to curriculums are necessary to enforce physicians and future medical practitioners to examine their views regarding sexual education for ID/DD persons before implementing sexual education. Without proper training and curriculum that force physicians and medical personnel to confront their perceptions of sexuality within the ID/DD community, a continued lack of acknowledgment will occur. Providing education to medical professionals to elevate their comfort level and ability to educate ID/DD persons on sexual health is imperative. Increasing medical provider education on the topic of sexual health and development for the ID/DD population can positively impact the health and safety of this community (Murphy et al., 2016; Murphy, & Young, 2005). Current improvements in education for health care professionals calls for the incorporation of sexual education and questions regarding patient's sexual health into general clinic exams (Oliver, Van der Meulen, June, Flicker, & Toronto Teen Survey Research Team, 2013; Merrick, Greydanus, & Patel, 2014). Current research notes that to improve educational practices physicians must confront and examine their attitudes towards sexual education of ID/DD individuals to become comfortable discussing the topic (Coleman, 2014; Committee on Psychosocial Aspects of Child and Family Health and Committee on Adolescence, 2001). To understand the attitudes of medical practitioners, the research was evaluated to determine physician opinion on sexual education and the ID/DD population as a whole.

2.3 Perceptions amongst Health Care Professionals

Articles were examined to elucidate the perceptions of students and medical providers in regards to ID/DD individuals. Evaluations of nursing students in the literature noted a variety of levels of comfort with patients with disability, with multiple factors such as experience with persons with a disability, education, and age as influencers (Uysal,

Albayrak, Koculu, Kan, Aydin, 2014; Sahin & Akyol, 2010). Research by Barnason, Steinke, Mosack & Wright (2013), notes that nurses feel they lack adequate education, resources and comfort level to address sexual education for patients. Nurses also pointed out that they are pressed for time with patients as well, with most of their focus on medical concerns versus social concerns patients will have once discharged. Though nurses in critical areas desire to educate on this topic, like this research stated, time constraints and education negatively impact their ability to do so. Medical providers state they are most uncomfortable discussing sexual topics with patients of the ID/DD community. This is in part attributable to the lack of understanding of the sexual needs of ID/DD persons due to the minimal training on sexual health discussions provided to physicians (Tervo & Palmer, 2004; Parchomiuk, 2013;Valvano et al., 2014). This lack of formal education and consistency in education has led to medical providers feeling uncomfortable and unprepared to discuss sexual topics with patients, creating barriers and negative perceptions of ID/DD patients sexuality (Solursh et al., 2003; Morreale, Arfken, Balon, 2010; Tracy & Iacono, 2008). Lack of comfort and familiarity with a topic can lead to practitioners avoiding inquiring on sexual topics with patients.

Research reviewed highly encourages the recognition of medical providers as key players to educate ID/DD patients on sexual health, despite medical personnel lack of comfort (Clark, Brey, & Banter, 2003; Merrick, Greydanus, and Patel, 2014). East and Orchard (2014) state that health professionals often place the responsibility for educating children on sexuality on others they may view as more qualified. Parents stated they believed health professionals were the best source to provide this education as they could provide physiological information as well as confirm their child's ability to be seen as a

sexual being (East and Orchard, 2014). However, medical providers may not echo this view due to the noted lack of education and comfort level on the topic.

2.4 Conclusion

Ultimately, this literature review demonstrates the lack of sexual education provided to medical professionals in practice and schooling and the overall minimal literature available to demonstrate medical providers perceptions on providing sexual education. As ID/DD persons experience sexual assault at a significantly higher rate it is imperative to increase education for this population (Hickson, Khemka, Golden, & Chatzistyli, 2013; Valenti-Hein & Schwartz, 1995). The long-ignored needs of sexual education for this population can no longer be disregarded as these individuals suffer disproportionately from not being able to express their sexuality or establish sexual boundaries. It is essential that medical providers work to become educators who can provide medically accurate and developmentally appropriate information. This calls for further research on barriers, perceptions, and practices of medical providers in regards to ID/DD person's sexual education.

Chapter III: Methodology

3.1 Study Design

The prospective study design included electronic survey and in-depth interview methods. Institutional Review Boards (IRB) approved the study at both the health care institution and university to qualify for expedited review and exempt status, respectively.. Study participants include physicians, NPs, and PAs who were currently within practice within at a large medical system comprising hospitals and outpatient clinics located in West Michigan. Eligible medical providers included those who were employed within adolescent clinics within the health care system during April 2016 to August 2016. Eligible medical practitioners also required evidence of their division director's approval of the research by email to the IRB, of which the researcher requested. Participants also included PA and DNP program students at students at a public four-year university located in Michigan. To be eligible, current DNP and PA students had to enrolled at the school during between April and August 2016. Participants were recruited through convenience sampling by emails provided from the medical system and university. The survey was distributed three times over the span of May 1 - July 1, 2016 to different eligible medical clinics compromising a total of 63 health care professionals being provided with the study. The survey was disseminated twice to the student population over May 1, 2016, to July 1, 2016, with a total available group estimated at 60 students. University recruitment emails for the study were disseminated through the Office of Institutional Analysis, per university protocol. No respondents otherwise voluntarily withdrew from participation, however, practitioners or students lacking interaction with the ID/DD population were excluded from the study. This was evident in the 12 respondents removed including six nurse practitioners, three students,

one physician assistant and one physician, as they chose to only complete demographic identifiers. Of the 43 respondents only 31 were included in the final analysis of survey results. Three physicians provided consent to be interviewed for the research as well. This allowed for a total of 34 participants included in the qualitative and quantitative multiple method approaches for this study.

3.2 Survey

The electronic survey was developed and adapted from several sources. Questions regarding medical providers curriculum taught within the last year to ID/DD persons was adapted from a previous study on teachers providing sexual education, and the content was included (Dodge et al., 2008). Questions were provided based on age groups curriculum content responses were developed based on a previous study conducted among ID/DD persons in Poland (Kijak, 2011). Provider perceptions and level of comfort were collected with five-point Likert-scales response options. Likert scales are commonly used in studies of attitude and were most appropriate for examining perspectives of medical providers (Kurian, 2013).

Surveys were administered using Survey Monkey (SurveyMonkey, 2016). Surveys were conducted electronically to allow for anonymity and convenience for participants. Surveys [Appendix A] allowed for quantitative analysis for associations of gender, age, and profession with varying aspect of education for ID/DD person. Subjects were not provided with the option to withdrawal from the survey, as completion of the study was not linked to an individual. However, the ability for participants to skip questions was built into the system. The survey was distributed three times over the span of May 1, 2016- July 1, 2016.

Data was analyzed through gathering frequencies and counts to determine percentages of perspectives and topics instructed on in sexual education. Qualitative free-response within the survey was utilized in the discussion of interviews. Statistical analysis was completed in SASS 9.4 to determine association of gender (Male, Female, Transgender or prefer not to identify), age (grouped 20-29, 30-39, 40-49, 50-59, 60 plus), or profession (physician, nurse practitioner, physician assistant) to scaled questions examining level of comfort and agreeable. Gender response was coded for male (1), and female (2), as options of transgender and prefer not to respond were not provided by respondents. To allow for larger groupings age scales were combined to be 20-29, 30-39 and 40 and over.

Likert-type scale questions included comfort level ranging from very comfortable, comfortable, neutral, uncomfortable and very uncomfortable. This scale was coded with very comfortable as 1, neutral as 3 and very uncomfortable as 5. Agreeable scales ranged from strongly agree, agree, neutral, disagree and strongly disagree. This scale was coded with strongly agree as 1, neutral as 3, and strongly disagree as 5. With small sizes the Likert scales we regrouped from a five-level scale to three-level scale. Creating larger groups would allow for better comparison to test for differences or associations. Strongly agree and agree categories were grouped together, with neutral responses standing alone, and grouping of disagree and strongly disagreeing together.

Quantitative data was compiled from the electronic survey and analyzed for various associations with nonparametric testing utilizing SASS 9.4. Initial analysis of data in SASS 9.4 was completed with Chi-square. Fisher's exact test was determined to be the most appropriate form of analysis as sample sizes contained small values. Several comparisons were greater than two-by-two comparison, however, SASS software allows for the

generation of Fisher's exact test with larger groupings of data. Examination of demographic variables was deemed essential to determine if demographics were correlated to perceptions of sexual education to ID/DD persons. Reflections of the profession, gender, and age on Likert-scale questions can provide for a further discussion on potential influencers for this topic.

3.3 Interview

Semi-structured individual interviews were conducted to provide in-depth information on physician perspectives of sexual education of ID/DD persons. Open-ended questions developed allowed for physicians to provide personal feedback on experience and knowledge of sexual education within the ID/DD population. Questions discussed training on providing sexual education, the perceived preparedness to handle sex education questions and discussions, as well as positive and negative aspects of medical practitioners instructing on this topic. The interview was piloted before being conducted with physicians to ensure time and logical progression of questions.

To recruit subjects for the in-depth interviews, the electronic survey contained a separate optional link for interview respondents. The separate link allowed for participants to create an unassociated comment within their contact information for follow-up of scheduling an interview. Those who provided information for an interview were contacted via email and asked to confirm their interest in participating. In-person interviews were conducted one-on-one within closed and private office spaces. Before starting the interview, prior verbal consent was obtained to be audio-recorded and have comments transcribed. Physicians were first asked to provide minor demographic information on gender, their particular area of practice and years of experience in medical practice.

Interviews were carried out from May 1 to July 7, 2016. Each interview lasted between 30 to 45 minutes. Participants had the option not to answer any of the questions or provide as little or as much information as they preferred. Interviews were transcribed once and then listened to a second time by the researcher. Interviews were transcribed within 48 hours of being conducted. Once all transcriptions were verified to be accurate, audio files were destroyed to ensure the security of data and maintenance of anonymity of respondents. The interviews were transcribed verbatim and explored using thematic analysis (Grounded Hermeneutic approach). Grounded Hermeneutic approach is most appropriate for this research as the first researcher did not utilize codebooks, lacked experience in immersion techniques and had previous education in Grounded theory approach to coding. Nvivo software was used to develop thematic codes for analysis (Nvivo 11.2.2).

Chapter IV. Results

4.1 Survey Results

A total of 31 participants are included in the statistical analysis of survey results. Demographic characteristics of respondents are summarized in Table 1. Seventeen respondents identified as practicing medical providers with the remaining fifteen identifying themselves as students at GVSU. Seventy-seven percent (n=24) of respondents identify as female and 23% (n=7) as male. Thirty-seven percent (n=12) of respondents are age twenty to twenty-nine, 32% (n=10) age thirty to thirty-nine, 22% (n=7) age forty to forty-nine, 6 % (n=2) age fifty to fifty-nine and 3% (n=1) sixty or older. Physicians comprise 26% (n=8) of respondents, physician assistants at 32% (n=10) and nurse practitioners at 42% (n=13). Median years of medical practice was nine years for participants, of which 48% (n=15) of their health care settings averaged less than 25% ID/DD persons within their practice.

Table 1

Participant Characteristics

Sex	Age	Profession	n(%)
Female	20-29	NP	6(19.)
Female	30-39	NP	3 (10)
Female	40-49	NP	3 (10)
Female	20-29	PA	5 (16)
Female	30-39	PA	3 (10)
Female	30-39	Physician	1 (3)
Female	40-49	Physician	2 (7)
Female	50-59	Physician	1 (3%)
Male	30-39	NP	1 (3%)
Male	20-29	PA	1 (3%)
Male	30-39	PA	2 (7%)
Male	40-49	Physician	1 (3%)
Male	50-59	Physician	1 (3%)
Male	60 +	Physician	1 (3%)

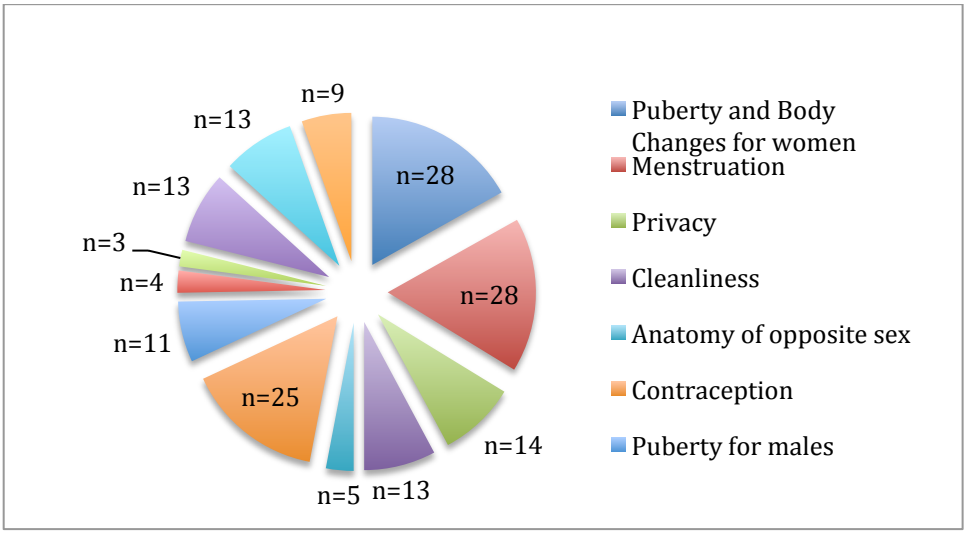
Participants were asked to choose which sexual education topics were provided for ID/DD patient's age 10 to 17 in the past year. Topics are shown in Figure 1 where numbers

represent the number of respondents who state they discussed the topic in the last year with ID/DD patients. For ages 10 to 13, topics most frequently taught include puberty and body changes for females (n=14), menstruation (n=14), privacy (n=14) and cleanliness (n=13). The least discussed topic is the anatomy of the opposite sex (n=5). For ages 14 to 16, the most discussed topics include puberty for females (n=14), menstruation (n=14), contraception (n=13) and puberty for males (n=11). The topics provided least to patients in this age group were male erections (n=4) and masturbation (n=3). For ages 17 and up, the most discussed topics were healthy relationships (n=13), pregnancy (n=13), and contraception (n=12). The least discussed topics for ID/DD patients 17 and up was sexual intercourse (n=9).

For age groups 10-13 and 14-16, physicians provide a majority of the education on various sexual education topics. For older age groups 17 and up, physician assistants are shown to give information on a majority of the subjects identified versus doctors and nurse practitioners.

Figure 1

Sexual Education Topics ages 10-17 and older



Frequencies of responses to Likert scale questions were collected. Table 2 details numbers of frequencies of responses. Scales were condensed to from a five point to three-point scale to allow for larger sample analysis. Respondents demonstrate that they have a higher level of comfort in providing sexual education to parent and guardians of ID/DD patients versus ID/DD patients themselves. Eighty-seven percent of respondents agree that sexual education for the ID/DD population is an important topic. Respondents also state that abstinence-only sexual education is not the preferred method of instruction for ID/DD persons (66%). Responses demonstrate a higher rate of disagreement with 80% disagreeing that adequate sexual education is provided for these individuals. In regards to responsibility for providing sexual education instruction, respondents note that they are more agreeable to medical professionals teaching this topic (74%) versus school systems (68%) other medical personnel (30%).

Table 2

Survey Attitude Questions

Statements	Comfortable/Agree n(%)	Neutral n(%)	Uncomfortable/Disagree n(%)
I am comfortable discussing sexual education with persons with ID/DD.	14(48.0)	5(17.0)	10(34.0)
I am comfortable discussing sexual education with guardians/parents of individuals with ID/DD.	19(61.0)	6(19.0)	6(19.0)
Adequate sexual education is provided to adolescents in the ID/DD population.	2(6.0)	4(13.0)	24(80.0)
Sexual education is important to persons within the ID/DD population.	27(87.0)	4(13.0)	0
It is medial practitioner's responsibility to discuss sexual education with ID/DD persons.	23(74.0)	5(16.0)	3(10.0)
It is the responsibility of other health care workers (social workers, MA, etc.) to	15(30.0)	10(33.0)	5(16.0)

provide sexual education to ID/DD persons.			
It is the responsibility of schooling systems to provide sexual education to ID/DD persons.	21(68.0)	7(22.0)	3(10.0)
Abstinence only sex education should be provided to individuals with ID/DD.	1(3.0)	9(31.0)	19(66.0)

Comparison of perspectives in the level of comfort and levels of agreeability to topics to aspects of sexual education can determine if certain demographic factors are influential. In Table 3, age was compared to Likert scale questions. The only question found to be statistically significant was the comparison of age to the scaled question of, "It is the responsibility of other health care workers (social workers, MA, etc.) to provide sexual education to ID/DD persons?" Differences exist between age groups, specifically 30-39, as respondents in this age bracket are less likely to agree that other health care workers should provide instruction to patients on sexual health. Individuals in age group 30-39, of which comprised all three professions and male and female respondents, tend to provide more neutral and disagree responses to this statement than the other age groups. However, with the very close p-value of .049 and the small sample size, findings are truly not representative as significant or generalizable. This analysis was shown to demonstrate that age is not an influential factor in this sample size on perspectives of sexual health in the ID/DD population.

Table 3

Age Group and Comparison of Likert Scale Questions

Questions	Agree Disagree	Age Groups 20-29 n(%)	 30-39 n(%)	 40 + n(%)	Fisher Exact Test
I am comfortable discussing sexual education with persons with ID/DD.		4(33.0) 5(2.0)	6(60.0) 2(20.0)	5(55.0) 3(33.0)	0.74
I am comfortable discussing sexual education with guardians/parents of individuals with ID/DD.		6(50.0) 3(25.0)	7(70.0) 2(20.0)	7(70.0) 1(10.0)	0.85
Adequate sexual education is provided to adolescents in the ID/DD population.		1(9.0) 8(73.0)	0 8(80.0)	1(10.0) 8(80.0)	1.0
Sexual education is important to persons within the ID/DD population.		9(75.0) 0	10(100.0) 0	9(90.0) 0	0.35
It is medial practitioner's responsibility to discuss sexual education with ID/DD persons.		8(66.0) 1(8.0)	7(70.0) 2(20.0)	8(80.0) 1(10.0)	0.83
It is the responsibility of other health care workers (social workers, MA, etc.) to provide sexual education to ID/DD persons.		8(66.0) 1(8.0)	3(30.0) 5(50.0)	4(44.0) 0	0.049*
It is the responsibility of schooling systems to provide sexual education to ID/DD persons.		9(75.0) 2(16.0)	6(60.0) 0	6(60.0) 1(10.0)	0.39
Abstinence only sex education should be provided to individuals with ID/DD.		1(8.0) 8(66.0)	1(10.0) 6(60.0)	1(10.0) 6(60.0)	1.0

Note. $p \leq .05$. N appears in parenthesis behind percentage.

Analysis to compare gender and Likert scale questions was completed demonstrate if gender plays a role in comfort and perspective of sexual education within the ID/DD population. All participants identify as either male or female, eliminating transgender and prefer not to respond from analysis. Male and Female students and medical providers show similar levels of comfort with parents and patients. No p-values are statistically significant in these comparisons. Ultimately, no results are found to be statistically significant in comparison of genders.

Table 4

Gender and Comparison of Likert Scale Questions

Questions	Agree Disagree	Gender Male n(%)	 Female n(%)	Fisher Exact Test
I am comfortable discussing sexual education with persons with ID/DD.		4(57.0) 3(43.0)	11(45.0) 7(29.0)	0.40
I am comfortable discussing sexual education with guardians/parents of individuals with ID/DD.		6(86.0) 2(25.0)	14(58.0) 4(16.0)	0.49
Adequate sexual education is provided to adolescents in the ID/DD population.		0 7(100.0)	2(8.0) 17(71.0)	0.42
Sexual education is important to persons within the ID/DD population.		7(100.0) 0	20(83.0) 0	0.54
It is medial practitioner's responsibility to discuss sexual education with ID/DD persons.		5(71.0) 2(25.0)	18(75.0) 2(8.0)	0.56
It is the responsibility of other health care workers (social workers, MA, etc.) to provide sexual education to ID/DD persons.		5(71.0) 1(14.0)	10(42.0) 5(21.0)	0.47
It is the responsibility of schooling systems to provide sexual education to ID/DD persons.		7(100.0) 1(14.0)	14(58.0) 2(8.0)	0.14
Abstinence only sex education should be provided to individuals with ID/DD.		2(25.0) 4(57.0)	1(4.0) 16(67.0)	0.42

*Note. $p \leq .05$.

The last demographic examined was professions of physician, physician assistant and nurse practitioners against Likert scale questions. Comparing different professionals on these scales can demonstrate if differing education or roles in patient interaction are influential in perspectives of sexual education of ID/DD patients. Within the small sample sizes, the differing medical professions provided similar levels of perspectives. One significant response at a p-value at .034 was found in comparison to professions and the question, "adequate sexual education is provided to the ID/DD?" NPs tended to provide more neutral responses to this question versus physicians and PAs who had a stronger disagree response. However, as sample response was low, results are not generalizable and

may not truly represent a statistically significant result. Statistical analysis did not provide any p-value significant results. However, further interpretation of frequencies can contribute to the discussion of this data. Along with qualitative interview data, quantitative results can confirm and add to themes developed from analysis.

Table *5*

Profession and Comparison of Likert Scale Questions

Questions	Agree Disagree	Professions Physician n(%)	Physician Assistant n(%)	Nurse Practitioner n(%)	Fisher Exact Test
I am comfortable discussing sexual education with persons with ID/DD.		4(50.0) 2(25.0)	4(40.0) 4(40.0)	7(54.0) 4(30.0)	0.95
I am comfortable discussing sexual education with guardians/parents of individuals with ID/DD.		7(88.0) 1(13.0)	6(60.0) 2(20.0)	7(54.0) 3(23.0)	0.90
Adequate sexual education is provided to adolescents in the ID/DD population.		1(13.0) 8(100)	1(10.0) 8(80.0)	0 8(62.0)	0.03*
Sexual education is important to persons within the ID/DD population.		8(100) 0	(80.0) 0	11(85.0) 0	0.52
It is medial practitioner's responsibility to discuss sexual education with ID/DD persons.		5(63.0) 2(25.0)	7(70.0) 1(10.0)	11(85.0) 0	0.26
It is the responsibility of other health care workers (social workers, MA, etc.) to provide sexual education to ID/DD persons.		3(38.0) 2(25.0)	4(40.0) 3(30.0)	8(62.0) 1(8.0)	0.66
It is the responsibility of schooling systems to provide sexual education to ID/DD persons.		5(63.0) 1(13.0)	8(80.0) 1(10.0)	8(62.0) 1(8.0)	0.79
Abstinence only sex education should be provided to individuals with ID/DD.		0 6(75.0)	2(20.0) 7(70.0)	1(8.0) 7(54.0)	0.43

*Note. $p \leq .05$.

4.2 Interview

Three physicians currently in practice consented to participate in in-depth interviews with characteristics summarized in Table 6. Analysis of transcribed interviews allow for thematic development. Three major themes are identified from interviews and include: 1)

Education vs. Experience, 2) Patient and Parent Knowledge, and 3) Medical Community Responsibility

Table 6

Interview Participant Demographics

Gender	Profession	Years in Practice
M	Neurologist	15
M	Neurodevelopmental	30
F	Adolescent Medicine	12

Education vs. Experience

Codes identified for education and skills are detailed in Table 7. Physicians recognize training regarding how to discuss and provide sexual health information as lacking. Inadequate training is noted as a major contributor to the lack of knowledge regarding sexual health. Further, unfamiliarity with available resources and literature is a noted barrier to physicians increasing their knowledge on the subject. For example Participant 1 stated, when asked where physicians receive information on this topic, they replied "*we don't*". All three participants state an overall lack of knowledge of resources available to educate physicians. Need for resources and educational sessions were expressed desires. Personal experiences were noted to have the greatest influences on provider knowledge of sexual education for the ID/DD population.

One provider considered parents and guardians to be a great source of knowledge, whereas two other physicians felt that parents were not knowledgeable in the sexual development of ID/DD persons. No participants note a regular occurrence of sharing experiences or developed tools for peer education amongst physicians.

Table 7

Education vs. Experience Coding

Final Theme	Initial Codes	Example Quotes
Experience vs. Education	Lack education, knowledge from experience	*"biggest bulk of education from experience"*
Lack of Education	No knowledge of educational resources, adequate education lacking	*"learning from mistakes"* *"We don't [get education]"* *"not sure what literature is out there"* *" would love to have it added to curriculum"*
Parent/guardian as Resource	Parent's knowledge, Story sharing by parents	*" I learned a lot from parents"* *"not knowledgeable"*

Varied Practice Standards

Respondent's clinic standards are varied across disciplines. Codes identified for this theme are highlighted in Table 8. Doctors encounter this topic daily, make efforts to incorporate into their standards, or fail to confront the subject. Parent and guardian questions influence practice standards, as two respondents receive fewer questions from guardians regarding the topic. Less questioning by guardians on sexual development is attributed to the "*embarrassing"* aspect of the sexual health issue, and the lack of perceived knowledge parents have regarding the sexual development of ID/DD persons. One participant viewed their clinic as well prepared to deal with discussing sexual education whereas others were noted to be "*ill-prepared*" and "*not prepared at all*."

Sexual health topics discussed were narrowed in scope to the particular concern guardians and ID/DD patients brought up. Concerns commonly addressed are regarding their child's puberty development or inappropriate sexual behavior in public such as

masturbation. All three physicians stated their practice provided minor instruction on sexual education. Topics on puberty development including menstruation and discussions are discussed with the input of parent desires on what their child should know in regards to sex. Topics discussed with patients varied by provider and specialty with the discussion of "*good and bad touch*" as well as "*avoidance of the subject of pregnancy*." All three participants state that sexual education provided is based on the safety needs of the patient and their cognitive abilities.

Table 8

Participant Practice Standards

Final Theme	Initial Codes	Example Quotes
Frequency of Sex Education	Parent questioning, patient questioning	*"never get asked questions by patient" "questions don't come up often"*
Clinic Preparedness	Practice standard, Experience in practice	*" our clinic is ill-prepared" " not prepared at all" "seasoned staff who are prepared"*
Discussions on Sex Education	Inappropriate behavior, puberty, safety	*"I don't get asked about this topic" " discuss puberty" " issues around inappropriate behavior"*

Medical Community Responsibility

Thematic development of medical community responsibility utilized codes developed in Table 9. All participants report there is a strong need for sexual education in

the ID/DD population and that the medical community should play a "*crucial role*" in providing that education. A stated positive aspect of medical providers instructing on sexual health include the provision of sexual education that is "*developmentally appropriate and medically accurate*." The developed relationship between provider and patient can allow for the provider to deal with problems over time with the patient. Negative aspects include "*barriers in time*" and that a "*physician might not educate or ask questions*" on sexual health due to their lack of comfort with the topic. Participants state that they "*only see the disease once the patient enters the medical system*." In regards to time restrictions, it was said that providers "*must spend a majority of a visit discussing the patient's disease*" and will not have a chance to ask sexual health questions. Doctors note that sexual health education is an uncomfortable topic, and that along with the lack of education would lower the probability that "*physicians bring up or ask about sexual health to ID/DD patients*."

With noted barriers, physicians state that there might be alternative resources for providing this education. Respondents mention schools as a place where patients should receive an education, but they associate negative views with this statement as providers said, "*they won't get the education there*." Parents are noted to be influential in the upbringing of their child regarding sexual health as well. However, all three participants view medical field personnel that receive training on the topic including nurses, advanced practitioners, and medical social workers, would also be suited to provide this form of education. These professions were noted to have "*more time within clinics*" to provide private instruction and education on sexual health.

Table 9

Medical Community Responsibilities

Final Theme	Initial Codes	Example Quotes
Important of Sexual Education	Need for ID/DD person, Training on topic Education, Schools,	*" need is very high" "huge need"*
Best Educators	Responsibility, Parent	*"health care providers and their parents" "perfect for medical social worker"*
Positive and Negatives	Barrier, Time restriction, Expertise, Comfort level	*"don't have time for that" "time" " uncomfortable topic" "difficult subject" "medically correct information"*

Chapter V. Discussion and Conclusion

5.1 Current instruction and sexual education topics

The goal of this research is to examine current practice standards and views of medical professionals in providing sexual education to the ID/DD population. Quantitative results from the survey portion of the study demonstrate that major sex education topics provided to ID/DD persons and their families include: puberty and body changes for females, puberty and body change for males, privacy in regards to space and their body, cleanliness, pregnancy, and contraception. The least discussed topics of sexual education include erections and masturbation; with generally male topics of sexual development, discussed to a lower degree than female sexual health. This is reflected in the literature that states male ID/DD adolescents hold less knowledge regarding sexuality than their female counterparts (Jahoda & Pownall, 2014). A total of 14 out of 31 participants (45%) provided education to patients on one or more of these topics for ages 10-17 and older over the past year. Close to half of the interviewees report providing some form of sexual education to the ID/DD population within the last year, and results for most respondents do not demonstrate consistency in providing topics to all age groups.

Overall, responses demonstrate that participants are somewhat comfortable with discussion of sexual education, exhibiting a higher level of comfort in discussing sexual education with parents versus the patients themselves. Practitioner's level of comfort can influence practice standards, as higher comfort level with a topic has been associated with increased practice in that area (Yip et al., 2015). Considering close to half of the respondent population had instructed on this topic and interview participants expressed some experience with sexual education, it correlated well with levels of comfort influencing

increased practice. Higher levels of comfort are not found in the research. However, sexual education may be viewed as a whole, and respondents could divide out this general idea to a specific topic they are comfortable with, such as puberty. This could have contributed to survey respondents demonstrating a higher comfort level, whereas two out of the three interview respondents stated practitioners in general felt uncomfortable, aligning more with current research (Solursh et al., 2003; Morreale, Arfken, Balon, 2010; Tracy & Iacono, 2008).

Despite the lack of uniformity in the topics, 27 respondents stated they agreed sexual education is important to persons in the ID/DD population. Furthermore, 11 participants strongly agree that this is essential to the ID/DD patients. The importance of this topic reflects in participants viewing medical professionals as responsible for providing sexual education to ID/DD persons. Provider perception that this form of education is necessary can impact provision as well. If sexual education is viewed as important, there is a higher potential that providers will have the desire to engage in this form of teaching. It is important to recognize the fact that a majority of providers in this sample believe that sexual education is important for ID/DD individuals, as historically this topic has been dismissed for this population (Dionne & Dupras, 2014). Viewing sexuality as an important discussion for this community demonstrates that for a small portion in the medical field the overall mindset is shifting towards more recognition of sexual rights and freedoms for intellectually and developmentally delayed persons (Coleman et al., 2013).

Corresponding with research and the absence of sexual education for ID/DD persons, a majority of respondents at 80% (24) do not believe that this population receives an adequate sexual education (Lafferty, McConkey & Simpson, 2012). Views on adequate

education vary between professional roles of physicians, PA and NPs. NPs responded with neutral feelings towards rather than disagreeing that there is adequate sexual education for ID/DD persons. Different views based on profession may be attributable to the role each of these professions plays in patient interaction and the Further research to determine who is providing sexual education in clinics would be of benefit for enhancing knowledge of individuals providing sexual education to ID/DD patients.

The fact that a majority of respondents do not believe the ID/DD community receives adequate sexual education corresponds highly with participants stating they do not think abstinence-only education is appropriate. A respondent specified that sexual education "*abstinence-only education is enticing, but it really needs to be individualized education based on the severity of ID/DD and patient/guardian preferences*." Changing perspectives on the sexuality of ID/DD persons can be influential to the view of providing sex education rather than abstinence-only ideals. Personalized sexual education was a highlighted component of intensive interviews as physicians stated this to be necessary for providing appropriate sexual education. Whether this includes abstinence-only or sexually positive methods ultimately come down to patient, parent and provider assessment and choice.

Experience, being the primary source of education for medical personnel, reveals that clinics consistently lack standards on which to ensure physicians provide sexual education. Respondents state that with less experience and encounters of sexual health education by patients and parents, they believe their clinics to be unprepared to address their patient's sexual education needs adequately. It is important to note that if clinics do not have standards to ask these questions across clinic specialties and primary care, this decreases the chance that patients and parents are surveyed on sexual health questions. Patients and

parents may also feel less unable to bring up sexual education topics if medical personnel do not address the issue, which was echoed in interview and literature (Murphy, et al., 2016). It is necessary that all physicians and clinics have at least a set of established issues and resources to ensure they provide the best standards of care for the community.

Knowledge based on professional experiences may be shared with peers within their clinic or between similar clinics but may not spread outside that space as an education tool. If physicians discuss their experiences amongst their peers, this may become an unofficial standard of the clinic on how to handle situations, but if they do not share experience as a whole for the medical community, it can leave certain patients receiving better care than others. As experiences will vary based on particular patient and provider encounters, there is a variety of education that physicians can be instructed to provide. Research has demonstrated that healthcare professional's desire interprofessional sharing of knowledge and that it can benefit practitioners to do so (Colclough & Gibbs, 2010). This study shows through interviews that physicians desire a shared experience as well but knew of few situations for interprofessional discussion on this topic. If one provider meets with patients and parents who consistently inquire about birth control, there is an increased likelihood that that provider will gain a better understanding in order to educate and further inquire on this topic for their other ID/DD patients. Interview respondents stated that topics discussed were very narrow in scope to the specific problem identified by the patient or guardians. Narrowed scope of issues can make for more precise education and scenarios for physician and medical providers to learn. Through interviewees noting that experience is the greatest learning tool it demonstrates that there is a difference between practices of sexual education to the ID/DD community.

Interview participants also note limited availability of resources for sex education methods amongst providers. An extensive search of the Internet by the student researcher for guidelines to instruct on sexual education in the ID/DD population produced a low volume of resources. Specific information for nursing practitioners and physician assistants was unavailable with limited physician resources as well. Healthcare websites, such as the Nursing Times, detailed how a group of nurses based in a schooling system developed an education packet but provided limited information on outcomes and effectiveness. Limited resources and knowledge of where to obtain educational tools for a physician creates inconsistency and can hinder practice standards from being established.

Overall, this sample of medical providers demonstrated that current practice standards for providing sexual education to ID/DD adolescents varied greatly. As individuals with impairments interact with the medical community at a higher rate than those without, medical offices provide an increased opportunity to educate on sexuality (World Health Organization, 2016). Variations in experience and specialized education can lead to disparities in the information that ID/DD adolescents and parents receive. Providers expressed positive views towards educating ID/DD persons on sexual topics, yet the ID/DD community will continue to be at a vulnerable disadvantage until standards are established in teaching for physicians. It is essential to have further studies on this topic across medical institutions to determine what other clinics are utilizing. The continued investigation will provide information on furthering the medical community's ability provide education to patients and parents of the ID/DD community in the most efficient manner.

5.2 Current student perspectives

DNP and PA students at a Midwest university were surveyed to determine their education regarding sexuality for the ID/DD population as well as their perceptions and comfort level with this topic. Mixed levels of comfort were not shown to be reflective of the number of years and program level of students within their field. This study did not identify these factors for respondents and thus cannot elucidate any further association. Students followed previously stated participant consensuses in not viewing abstinence-only sexual education as the best practice for this population. Students' consensus also identified sexual education as an important topic for the ID/DD population, which can impact their openness to discussing and providing education on this topic. The literature demonstrates that identified importance of sexuality to patients amongst medical student along with an identified lack of education on sexuality for students as well (Shindel & Parish, 2013).

Examination of curriculum for the study institution does not specifically identify sexual education for patients or specifically working with developmentally delayed adolescents within the DNP and PA programs. Despite recognized consistency in views of the importance of this topic, Coleman et al. (2013) demonstrate that national curriculum for sexual education varies widely within medical schools. As previously discussed, variation and lack of knowledge regarding available resources for providing sexual education can impact instruction to patients and families. Research calls upon medical education schools, with a focus on physician schooling, to provide adequate education on sexual education for the general population as well as for the ID/DD community (Shindel, Baazeem, Eardley, & Coleman, 2016). DNP and PA student education are not highlighted in this call upon the

medical community, but it is necessary to do so as PA and DNP utilization within the medical practice increases (Glied & Ma, 2015).

Overall, the current study demonstrates that students vary in the comfort level of providing sexual education to ID/DD patients and parents but recognize the importance of sexual education for this community. Student perceptions of the importance of this topic can lead to more open-mindedness for education on best practice for sexual education of ID/DD persons. Viewed importance may allow for easier incorporation by staff and teachers to include this into the curriculum. Increased education on this topic could also ultimately lead to changes in practice and improve consistency in clinic standards of providing sexual education. Further in-depth interviews with university students and educators nationwide would be of benefit to allow reflection on perception consistency on the need for sexual education and current practice.

5.3 Perspectives of medical professionals and students as educators

A majority consensus amongst health care professionals and students for the medical field to instruct on sexual education to ID/DD patients was found in this study. Though participants may state the importance of sexual education, if they do not view this as responsibility for medical professionals to instruct on, viewed importance of the topic is mute. Determining medical provider's desire to educate on this topic can be a large influence in their practice of asking questions about sexual health. To gain a better understanding, questions on the responsibility of educating on sexual health for the ID/DD community were requested in the study survey and through the intensive interview. Three areas of potential resources as educators include medical practitioners, other health professionals, and school systems.

Medical Practitioners

A majority of physicians view instruction of sexual education to be a responsibility of the medical field. Further questioning through interviews allowed physicians to reflect on barriers and positive and negative aspects of medical providers teaching sexual education. Doctors who were interviewed agree that the medical community is an important place for ID/DD adolescents to receive a sexual education. Positive aspects to receiving sexual education in clinics include that medical professional receive training in the physical development of persons and can provide this information to the ID/DD community. Medical professional's knowledge of sexual development can be beneficial to providing education to their patients throughout the years of the patient's physical development. As health care providers work with the development of adolescents over years, this allows for a trusting relationship to grow. The patient and provider relationship has the potential to provide a comfortable and safe setting for instruction on sexual health.

Medical professionals highlighted negative aspects associated with physicians providing this education as well. Physician knowledge of sexual education for the ID/DD population is inconsistent due to the lack of resources and training on educating. In interview analysis respondents state that they perceive that physicians lack comfort and knowledge to provide sexual education to ID/DD persons. Lack of comfort stated in interviews contracts with the survey results, however, respondents may have narrowed the scope of sexual education or state they feel comfortable education but have yet to interact with multiple ID/DD patients.

With changes in legislation through the Affordable Care Act, literature has shown that physicians experience increased demands on their time (Jones & Treiber, 2010; Lucier

et al., 2010; Nix & Szostek, 2016). This is reflected in the study, as limited time and the need to focus solely on health problems versus social and developmental issues of patients were stated amongst interviewees. Respondents note that doctors are less likely to have the time to ask patients and guardians about sexual topics as they spend a majority of their visit focused on specific medical problems for ID/DD patients. Within increasing time restrictions for physicians to see patients, health care systems are increasing reliance on nurse practitioners and physician assistants known collectively as advanced practice practitioners [APP] (Lucier et al., 2010).

Shifting responsibility due to time constraints to other practitioners can potentially overload their patient schedule and limit APP's time as well to discuss issues with patients. Limited time can play a factor in how patients feel their needs addressed if time limits the ability to discuss concerns in depth (Gross, Zyzanski, Borawski, Cebul, & Stange, 1998). Due to varied levels of comfort and education, time constraints and the overall medical focus of physicians and APPs, several respondents consider the job of the medical sector to teach sexual education to ID/DD persons might lie with other professionals in this field. Specifically, those professionals identified included medical social workers and nurses.

Health Professionals

With noted barriers, participants state that physicians might not be the best source for providing sexual education. All interview participants express that medical field persons including nurses, advanced practitioners, and medical social workers that receive training on the topic would also be suited to provide this form of education. Interview respondents stress the importance of training on the topic to ensure adequate knowledge and comfort. Current research has shown that social workers are in a unique position to provide social

justice viewpoints that can significantly benefit teaching of sexual education (Linton, & Adams Rueda, 2014; Adams Rueda, Linton, & Williams, 2014). These professions were noted to have more time within clinics to provide private instruction and education on sexual health. Results from the survey state medical professionals feel more neutral towards other health professionals providing sexual education responsibility, which differed from some of the interview responses. Heightened neutral responses for this group demonstrate medical professionals may not view other health professionals such as social workers as educated in the anatomical and physical aspects of sexual development for this population.

However, nurses were also highlighted as a potential health care resource for teaching sexual education and may be viewed with a higher level of physical development knowledge. Nurses interact with patients in a variety of settings including medical offices, schools, and even patient homes. The literature indicates that nurses in school settings in the literature stated they often provide information and education to students on sexual education but encounter many barriers to formally educating students in school. They noted the lack of support through the institutions in collaborating with health educators as well as external pressure from parents who are concerned with sexual education being taught to their child (Brewin, Koren, Morgan, Shipley, & Hardy, 2014). This study echoes that in practice, physicians generally allow parents to bring up sexual education topics and guide what patients should learn in regards to sexuality. NPs can also encounter this issue of parents directing care by restricting questions or asking without patients present to be educated.

Nurses certified as Sexual Assault Nurse Examiners (SANEs) may offer a unique perspective to provide sexual education. SANEs are educated to conduct medical-forensic

exams for sexual assault survivors and receive extensive education regarding the handling of medical and social interactions with survivors (Veidlinger, 2016). Nurses with this education will have a higher degree of knowledge in the arena of sexual health and a greater level of comfort discussing difficulty sexual topics. As ID/DD persons are at high risk for experiencing sexual abuse, SANEs offer the opportunity to be further educated on screening and providing education for this community. Ensuring that these nurses interact with ID/DD persons would require implementing this role in clinics or through community outreach, which may prove to be a difficult measure to ensure. Standardizing sexual health and education for home nurses and as a standard screening question in medical clinics may provide the best opportunity for nurses to educate.

Other health professionals highlighted offer a great opportunity for sexual education training for ID/DD persons and future education incorporated into medical settings. However, limited time and barriers encountered in administering sexual education can limit the responsibility the medical sector can shoulder in being the sole source of education for ID/DD persons.

Other Sources of Education

Schooling systems are a potential place for the sexual education of ID/DD adolescents. Physicians interviewed also agree that schools should provide sex education but do not believe they would receive developmentally appropriate education or any at all in schools. Survey respondents also agree that schools should provide this education. School curriculum for sexual education varies widely throughout the U.S with only 24 states and the District of Columbia requiring public schools teach this topic (National Conference of State Legislature, 2016). Literature also demonstrated that nurses face barriers to providing

sexual education for persons in schools. For states that do require sexual education, ID/DD adolescents may be separated from these classes that and may not have lessons adapted to their mental development level.

Providers view parents and guardians as an important piece in sex education for their ID/DD child. One respondent's states they " *assume parents are providing sexual education*" which can potentially be harmful to ID/DD persons who do not receive this training from parents. For parents who ware more open and willing to discuss sex, despite their perceived lack of knowledge for their child, their children are less open to discussing with them. The tendency for teenagers to be more private and avoid sexual discussion with parents is well noted. Mothers of ID/DD children were also seen to be more cautious in the discussion of sexual topics with their child in areas of contraception and intimate relationships (Pownall, Jahoda, & Hastings, 2012).

For parents to ensure their child is receiving adequate sexual education, they may serve as the best source for finding resources for their child. Ensuring questions are asked at medical visits, enrolling them in a healthy relationship curriculum or education group and validating their child as a sexual being are all potential areas for parents to tap into. As physicians in this study noted they often refer to guidance from parents on what should be taught to their child, based on family, religious or social standards, it is vital that parents educate themselves as well on the sexual development of their child. Knowing specific sexual aspects of a child's disease or developmental impairment will educate guardians on the reproductive capabilities of their child. Parents need to address sexuality for ID/DD adolescents to negate their child developing negative social perceptions of the topic for themselves (Pownall, Jahoda, & Hastings, 2012). Being a champion for the best form of

sexual education and expression for their ID/DD adolescents provides for parents to be a rallying source in bringing together community resources including schools and medical systems to educate on this much-needed topic.

Overall, the study shows that practicing physicians demonstrate recognition of the importance of sexual education for ID/DD persons but note restrictions in education and time to instruct upon this vital topic. As the literature and medical organizations continue to call on current and future physicians to implement sexual education in practice, the feasibility of physicians doing so needs to be evaluated. This study demonstrates some may not be fully prepared or unable to implement with time. While physicians note a desire to educate, ultimately there is a call upon the medical community as a whole, whether it be a nurse, physician or social worker to receive adequate training and provide sex education that is medically and developmentally appropriate in the clinical setting. Together, all three potential sources for sexual education, schools, parents and medical providers, should work to develop the most appropriate sexual education. Efforts of these systems combined can work to ensure that all ID/DD individuals have the opportunity to learn to express their sexuality and to recognize and prevent further sexual assault.

5.4 Recommendations

Several areas for comment on recommendations for improving the sexual education of ID/DD persons by medical professional arose from this research and literature review. Recommendations are discussed in areas of education for medical providers and the community as well as for methods to implement in practice.

As noted in the literature, teaching in medical schools on sexual health is lacking and varies widely across institutions (Shindel & Parish, 2013; Shindel, Baazeem, Earley &

Coleman, 2016; Coleman et al., 2013). The 2011 summit on sexual health education in medical schools recommended the creation of a sexual health course to be implemented over four years of medical schools with potential to integrate into residency (Coleman et al., 2013). A sexual health course should examine more than just gender identity and sexual preference, but also need to discuss the needs of adolescents with physical and developmental delays and when these groups integrate. Simulation patients who represent an ID/DD adolescent with sexual issues as a practice for medical students would be greatly beneficial in the curriculum to provide experience in discussing the topic. Education on the theme alone may not be enough to increase physician comfort truly with discussing the topic. It is essential for ID/DD patient's education that simulation includes patients who are in this population. Restricting LGBTQ education situations and simulation to non-ID/DD persons further restricts views on their sexuality to only being heteronormative (Sinclair, Unruh, Lindstrom, & Scanlon, 2015). As education is a great need the ID/DD community and deserves immediate attention, it is recommended by the author that while curriculum modifications are advised by professional organizations, such as the American Association of Medical Colleges, educational sessions, and resources for current use should be developed.

Health professionals currently in practice in adolescent clinics can significantly benefit from adopting shared resource and educational sharing. As Coleman et al., (2013) stated providing shared experience and knowledge on ID/DD persons through journal sessions or Grand Rounds can open up discussions across health care systems. Increased discussion and shared experience, which was demonstrated to be the greatest form of research for physicians in this study, can increase shared resources and knowledge of the

medical system as a whole. It will also allow for interprofessional feedback on this item with potential for multiple APPs and health care system individuals to provide their perspective and knowledge of sexual education. It may even be of benefit for a more formal multi-disciplinary and professional team to be developed to pioneer system-wide best practices. The American Medical Association promotes team-based care to improve patient outcomes, and this can readily be applied to the approach for providing sexual education as well (Coleman et al., 2013). Allowing for the attendance of educational sessions can be of benefit as well for improving teaching skills of health professionals (Curtiss & Ebata, 2016). Mandating this form of a training session for at least one clinic staff can allow for representation of their field and sharing of training with other clinic personnel.

The most appropriate staff to attend these training and champion changes for their clinic education standards can be a measure that specific clinics and institutions adopt as well. Examining workloads and available resources along with current knowledge of staff can help determine which personnel are more appropriate to attend trainings. Though there is a definite need for medical providers to gain greater education on this topic, each clinic may not feel that medical providers are the best fit for providing the training and asking these questions. While physicians can ultimately serve as the best resource and guidance for physical development issues and discussions, as highlighted in this study, other health professionals who have training and more time may provide a better experience for patients. This decision would ultimately come down to practice standards and may eventually be determined more by business practice than position but is an initial step medical systems should take to determine where to prioritize training and further discussions with their ID/DD patients.

A further recommendation regarding medical professionals impacting the sexual education of ID/DD adolescents comes through integrating medical professionals into community settings. As previously mentioned, nurses who provide home care visits for ID/DD persons can be integral in bringing to community settings a healthcare perspective. These nurses or appropriate health providers such as SANE professionals can also work to integrate discussion of sexual health in partnership with communities such as religious groups, ID/DD housing and organizations, parent and family support groups. Health care workers can engage with already established partnerships as well and provide information on sexual safety for ID/DD persons. Initial discussions of recognition of sexual assault, with a focus on the security of children, can work to open further discussions that focus on sexual expression and recognition for this population as well.

Future research on this topic is a much-needed area of literature and commonality across schools and professionals is lacking. Research can further evaluate perspectives from other health care professionals including social workers based on clinical rather than school settings. Gathering perspective on the type of questions medical social workers encounter can be beneficial to providing further feedback on the appropriateness and comfort of social workers for teaching sexual education to ID/DD persons. Gathering perspective from parents in clinic on if they would like to discuss sexual topics with providers, which providers they would prefer to discuss with and in which clinics they felt most appropriate to discuss in can provide feedback on best practice methods as well. Obtaining patient feedback from higher cognitive functioning ID/DD persons can help determine which topics they desire most to be educated on and discussed. These studies can work to modify much-

needed curriculum and education changes for medical professionals in universities and professional organizations as well.

Results from these furthered studies and current literature can also help to design a potential pilot program for implementing sexual education of ID/DD adolescents in medical settings. Several health professionals can be tasked with asking questions and providing forms of education to determine which health care providers patients and parents are most comfortable discussing with. It can also provide information on the best flow of practice for asking these questions and which care providers are most limited in providing the best responses for sexual education. Several avenues of future research are available to pursue and as demonstrated in this research, there are many areas of education and need for ID/DD persons to receive a sexual education.

5.5 Limitations

The goal of this study was to examine and learn from specific experiences and perspectives of medical providers and students within the West Michigan community. As this study was conducted within a profession with noted limits in time, it was not surprising that this study suffered from low response rate. However, each respondent provided a unique and valuable perspective and contributed to the amount of knowledge on this topic. Low variation of respondents in gender should be noted as well. However, more female respondents than males were expected with the higher rate of participants in nurse practitioners and physician assistant fields as historically these roles tend to be occupied more by women (Kaiser Family Foundation, 2016).

Response bias may also limit study results. Types of response bias could include social desirability, as providers may want to be seen as more inclusive and tend to respond

more positively to inclusive sexual education for ID/DD persons. Likert scale responses may also influence central tendency bias, where respondents are less likely to choose extreme response of strongly agree and strongly disagree. Bias may also be present as those medical professionals who chose to respond voluntarily to the survey may have felt strongly towards the topic of sexual education for the intellectually and developmentally delayed populations. Providers who had experience in this subject or viewed it as a medical field responsibility may have been more likely to participate. The study population was also from one health care system and one school in this area, which may limit the study by providing homogeneous perspectives gained through similar clinic practice, standards and education. Due to this, views and experiences may not apply to all providers within the state of Michigan or United States. Limitations of this study ultimately do not impact the intended effect of this research to bring to light perspectives of practicing medical professionals and students.

5.6. Conclusion

Sexual education among ID/DD persons is an essential to development and maturity through adolescence. This research extends the findings of current literature that health professionals are an untapped area of resource for providing sexual education. Lack of education, resources and barriers including time restrictions are reasons medical providers currently fail to ensure discussing this topic with ID/DD adolescents. Improvements to medical student curriculum can prepare future health provider to feel better ready to integrate sexual health questions into practice for patients across every spectrum of development and sexual orientation. While professional medical organizations and schools work to modify this education, it is important that health care systems take action now.

Modifying practice to include training and teaching of appropriate staff, shared experiences across specialties and systems and integration of education into the community are all ways that the current medical system can work to provide ID/DD persons better this vital education. It will take efforts from communities to include parents, school staff and medical professionals to ensure that ID/DD persons no longer suffer at the increased occurrence of sexual abuse and can be free to express their sexuality fully and live to the fullest degree.

Appendix A

Sexual Education Among Intellectually and Developmentally Delayed Adolescents Survey

Questions are based on the Sexuality Education in Florida: Content, Context, and Controversy survey (Dodge, B., Zachry, K., Reece, M., López, E. D. S., Herbenick, D., Gant, K., Martinez, O. (2008). Sexuality education in Florida: Content, context, and controversy. *American Journal of Sexuality Education, 3*(2), 183-209. doi:10.1080/15546120802104443) used for teachers in the state of Florida. Questions are adapted from article by Kijak, R. J. (2011). A desire for love: Considerations on sexuality and sexual education of people with intellectual disability in Poland. *Sexuality and Disability, 29*(1), 65-74. doi:10.1007/s11195-010-9184-2

You are receiving this email either because you are medical provider within the Spectrum Health System or a medical field student at GVSU. My IRB approved thesis is looking to examine the often ignore and highly important topic of sexual education among adolescents with Intellectual and Developmental Delays (ID/DD) and medical provider perspectives. It will take 5-10 minutes to complete this survey. No personal health identifiers (PHI) will be gathered in this survey, however there is a potential risk of disclosure of confidential information provided in this survey but all measures are being taken to prevent this. By clicking the link below and completing the survey you are providing consent to participate in this research.
Thank you for your participation and if you have any questions please contact Sarah Nota at notas@mail.gvsu.edu or 616-856-0711

The following section asks about your demographic characteristics, please select the response that best describe you:

Gender (Man, Woman, Transgender, Prefer not to identify)

Age (20-29, 30-39, 40-49, 50-59, 60 and up)

Please selected your current professional situation or schooling (Physician, Physician Assistant, Resident, Nurse practitioner)

Practice location (if applicable)

How many years have you been practicing medicine? _____ years

What percent of your practice's patients are Intellectually/Developmentally delayed (ID/DD) (less than 25%, 26-50%, 51-100%, don't know)

In each age group below, please choose what forms of sexual education information you have provided to patients with Intellectual and Developmental Delays and their guardians within the past year:

Age 10-13
Anatomy of their own sexual body parts
Anatomy of the opposite sex body parts
Puberty and body changes for women
Menstruation
Puberty and body changes for men
Privacy in regards to space and their own body
Cleanliness
Other (fill in)

Age 14-16
Puberty for women and body changes
Menstruation
Puberty for men and physical changes
Erections
Masturbation
Sexual Intercourse and safety measures (example: condoms)
Sexually transmitted infections including HIV

Contraception
Pregnancy
Healthy Relationships
Sexual boundaries and consent

Other (fill in)

Age 17 and up
Sexual intercourse and safety measures (example: condoms, birth control)
Contraception
Pregnancy
Sexually transmitted infections including HIV
Sexual boundaries and consent
Healthy Relationships
Other (fill in)

To what extent do you agree with the following statements?
You are comfortable discussing sexual education with persons with ID/DD? Very Comfortable, Somewhat Comfortable, Neutral, Uncomfortable, Very Uncomfortable

You are comfortable discussing sexual education with guardians/parents of individuals with ID/DD? Very Comfortable, Somewhat Comfortable, Neutral, Uncomfortable, Very Uncomfortable

Adequate sexual education is provided to adolescents in the ID/DD population? Strongly Disagree to Strongly Agree Scale

Sexual education is important to persons within the ID/DD population. Strongly Disagree to Strongly Agree Scale

It is medical practitioner's responsibility to discuss sexual education with ID/DD persons? Strongly Disagree to Strongly Agree Scale

It is the responsibility of other health care workers (social workers, MA, etc.) to provide sexual education to ID/DD persons. Strongly Disagree to Strongly Agree Scale

It is the responsibility of schooling systems to provide sexual education to ID/DD persons? Strongly disagree to Strongly Agree Scale

Abstinence only sex education should be provided to individuals with ID/DD? Strongly Disagree to Strongly Agree Scale

Please provide any additional comments you may have:

.

Appendix B

Sexual Education Among Intellectually and Developmentally Delayed Adolescents
Questions for interview

Interview information

Thank you for your willingness to participate in this interview. The interview will include additional and more in depth questions regarding the sexual education of individuals with an intellectual or developmental delay. The interview will take thirty to sixty minutes and will occur at your convenience. Please input your best contact information to reach you to arrange an interview. In doing so you are providing consent to be contacted to be interviewed. All information gathered from interviews along with date, and medical specialty will be collected and entered into a password-protected database. Results will be analyzed for themes along with other interviews gathered and will not be linked to individual responses. You can expect to be contacted by this method within two days. Thank you again for your participation.

Once an interview has been arranged, participants prior to the interview beginning will be read the following statement

Thank you for your participation in this interview. Interview questions will cover a range of topics surrounding sexual education amongst adolescents with an intellectual or developmental delay. Your personal information will be not collected, however date/time of the interview, your profession, gender and years of practice will be. All data and interview answers will be voice recorded. Once your interview has been transcribed it will be kept in a confidential password-protected file only accessible to the interviewer and the voice recording will be destroyed. You can stop this interview at any time. Results will not be published with any identifiers and will be available to you once the study is complete. Again, by answering these questions you are consenting to participate in this research and have your answers recorded. Do you have any questions or concerns before we begin?
1.1

Sexual Education Among Intellectually and Developmentally Delayed Adolescents
Questions for interview

DATE/TIME
GENDER
PROFESSION (SPECIALTY)
YEARS IN PRACTICE

1. What knowledge do you have regarding sexual education for persons with ID/DD?
2. How did you obtain this knowledge?
3. How do providers get adequate information on sexual education for this population?
4. How is your clinic prepared to address sexual education for this population?
5. Do you find you are often dealing with guardian/parent concerns regarding sexual education for their child?
6. What types of questions are asked by guardians/parents relating to sexual education for their child with ID/DD?
    -How knowledgeable are parents/guardians on this topic?

-What are they asking about relating to sex education or contraception?

7. What types of questions are patients within the ID/DD asking about relating to sexual education?

-How knowledgeable are your ID/DD patients on this topic?

-What are they asking about relating to sex education or contraception?

8. What aspects of sexual education do you feel comfortable providing to individuals with ID/DD?

-Anatomy, behavior, biological, STI, Privacy?

9. What do you think your ID/DD patients are interested in regards to sex education?

10. What do you believe should be best practice for sexual education for patients with ID/DD?

11. What is your opinion on the need for sexual education for persons with ID/DD?

12. Who should provide sexual education to the ID/DD population?

13. What barriers are there to providing sexual education to ID/DD individuals?

14. What are the positive aspects of medical providers teaching sexual education to ID/DD adolescents?

15. What are the negative aspects of medical providers teaching sexual education to the ID/DD adolescents?

16. Are there any other comments or recommendations you'd like to make regarding this topic?

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