

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.