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Sexual History Screening Tools For Individuals With Developmental Disabilities

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Walden University

College of Health Sciences

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Sarah Onyenwe

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Walden University
2018

Abstract

Sexual History Screening Tools for Individuals with Developmental Disabilities

by

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MSN, PACE University, 2013

AAS, College of Staten Island, 2008

Project Submitted in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Nursing Practice

Walden University

August 2018

Abstract

Individuals with developmental disabilities are at high risk for sexual abuse, exploitation, sexually transmitted diseases and unwanted pregnancies. Thorough screening by clinicians in outpatient settings recommending preventative measures to promote reproductive and sexual health, and developing caregiver trust are essential. The aim of this systematic review was to provide screening tools to assist clinicians in assessing the sexual histories of individuals with developmental or intellectual disabilities. The Iowa model and the cognitive behavioral theory were used as the theoretical frameworks that guided and informed this project. A total of 148 articles were sought and, of the 34 articles reviewed, 19 were pertinent to synthesize the literature. Articles were appraised using the John Hopkins evidence-based practice model. Results from the existing literature showed that no screening tools are available to assess the sexual histories of individuals with developmental and intellectual disabilities. Thorough screening the sexual histories of individuals with developmental and intellectual disabilities could empower safe sexual practices and the attainment of a life with personal fulfillment for members of this population. The results of this project can result in positive social change by protecting the population of individuals with developmental and intellectual disabilities from exploitation, unplanned pregnancy, and sexually-transmitted diseases. Future research is needed to fill the gap in the field and develop sexual history screening tools for this population.

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Dedication

This project is dedicated to almighty God for giving me the strength and inspiration to keep toiling the books.

To my husband, Kennedy; my son, Ogechi; my mother, Katie; and my father, Hassan, thank you for your love and support throughout this program and never giving up on me. You believed in me and my potential and always knew I would reach my childhood goal.

Acknowledgments

“The roots of education are bitter, but the fruit is sweet”

----Aristotle

To all of whom I benefited from and will not forget:

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The friends and relatives, who cheered me on, celebrated my successes, even though they often remarked they did not understand why I am still in school after all these years.

My committee members: Dr. Francisca Farrar and Dr. Janine Everett for their support, feedback, and persistence in getting my project through proposal and on to completion.

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Section 1: Overview of the Evidence-Based Project

Introduction

A developmental disability or intellectual disability refers to a group of disorders characterized by a limited mental capacity and difficulty with adaptive behaviors such as managing money, schedules and routines, or social interactions (National Institute of Health [NIH], 2013). Developmental or intellectual disabilities originate before the age of eighteen (NIH, 2013). The term developmental disability encompasses intellectual disability but also includes physical disabilities (NIH, 2013). Some developmental disabilities may be solely physical, such as blindness from birth, while others involve both physical and intellectual disabilities stemming from genetic or other causes, such as Down syndrome, fetal alcohol syndrome, and cerebral palsy (NIH, 2013). The first ever world report on disability, produced jointly by the World Health Organization [WHO] and the World Bank, suggested that over a billion people, about 15% of the world's population today have some form of disability (WHO, 2017).

It is estimated that approximately 3 million Americans have an intellectual disability (Larson, Lakin, Anderson, Kwak, Lee, & Anderson, 2001). In New York state, an estimated 1.5% to 2.5% of population has an intellectual or developmental disability (New York State Department of Health, 2015). Some of these individuals are at high risk for sexual abuse, exploitation, and eventually unplanned and unwanted pregnancies as well as sexually transmitted diseases (STDs) because they trust and depend on their caregivers for support (Servais, 2006). A systematic review on violence against adults with disabilities, published by (Hughes, Bellis, Jones, Wood, Bates, Eckley, 2012) found

that overall, they are 1.5 times more likely to be a victim of violence than those without a disability, while those with mental health conditions are at nearly four times the risk of experiencing violence. The review also indicated that children with disabilities are 3.7 times more likely than nondisabled children to be victims of any sort of violence, 3.6 times more likely to be victims of physical violence, and 2.9 times more likely to be victims of sexual violence (Hughes et al. 2012). Children with mental or intellectual impairments appear to be among the most vulnerable, with 4.6 times the risk of sexual violence than their nondisabled peers (Hughes et al. 2012). With this project, I sought to advance the need to improve the detection of individuals with developmental disabilities that are sexually active, abused, or exploited using revised screening tools by clinicians who provide them with care.

Problem Statement

Individuals born with developmental and intellectual disabilities are at increased risk for sexual abuse and exploitation and as a result, contract STDs, as well as spread them, and surprisingly there is little information on the frequency and nature of sexual experiences in this group (Greenspan, 2002; Spiecker & Steutel, 2002). Kim (2010) reported that people with mental retardation are at the highest risk for sexual abuse because of their total dependence and the trust they place in caregivers. Annually, the disabled are victims of approximately 47,000 sexual assaults (Rand & Harrell, 2009). Caregivers may be sex offenders while vulnerable victims remain silent about the abuse they suffer due to their concerns about retaliation, feelings that others will not believe their account, or they might be too emotionally and/or physically handicapped to report

the abuse (McCormack, Kavanagh, Caffrey, & Power, 2005). When experiencing the sexual assault as a child or an adult for years, they are forced to live with the trauma and guilt without treatment (McEachern, 2012).

One problem with providing appropriate free sexual healthcare for disabled people, including adults, is that they are more likely than others to live in institutions like group homes, adult homes, or assisted living facilities (Cheng & Udry, 2002). Although many clinicians engage proactively to support the sexual rights of disabled people, others do not have the knowledge or expertise. In a study with a nationally representative sample of middle and high school age youth (seventh to twelfth graders) with low cognitive ability, the findings indicated that 8% of adolescent male participants with low cognitive ability had been exposed to an STD as compared to only 3% of males with average intelligence; for adolescent females who were sexually active, 26% of the cognitively impaired reported having an STD, a sharp contrast to 10% of adolescent females with average cognitive ability (Cheng & Udry, 2002). The researchers also found that nearly 40% of cognitively-impaired teenage girls had become pregnant—more than double the 18% rate of teenage girls without a mental disability (Cheng & Udry, 2002).

When disabled adults live with their parents or other family members, these relatives may wish to prevent them from having sex, which may result in conflict with health professionals (Cuskelly & Bryde, 2004). Failing to address the problems presented by sexuality poses myriad dangers that will affect 10s of millions of people worldwide; however, directing attention and resources to issues of sexuality can be a powerful means to achieve gender equity, improved public health, and social justice.

The assessment of sexual history within this population is not routine during a medical office visit, and usually, the only time their sexual history is assessed is when there has been an incident of problematic sexualized behavior (Thompson, Stancliffe, Broom, & Wilson, 2016). The lack of identified screening tools to help clinicians assess the sexual history of individuals with developmental disabilities is a large concern and needs to be brought to light in a positive way.

Purpose

This project was geared towards gathering evidence from the literature on the screening tools available to better assess the sexual histories of the developmentally disabled. There are limited longitudinal studies about strategies to prevent sexual abuse in this population (McCormack et al. 2005). Several assessment tools have been developed to assess the sexual knowledge of people with an intellectual disability, but Thompson et al. (2016) stated that the clinicians using these screening tools reported that the tools have gaps and have not fully met their needs or the needs of the people with intellectual disabilities.

Nature of the Project

With this project, I conducted a systematic review of the literature to determine whether there are appropriate screening tools established to assist clinicians assess sexual histories in individuals with developmental disabilities. I carried out this comprehensive review of current research and synthesized, appraised, and analyzed the findings to examine the best evidence. Providing a proper screening tool to assist clinicians who

work with the developmentally disabled will allow clinicians to better assess these individuals who engage in high risk sexual activities whether consensual or nonconsensual.

Aim/Objectives

My aim with this systematic review was to identify evidenced-based screening tools for clinicians working with the developmentally disabled to better assess the sexual histories within this population to help lower the incidence of STDs, sexual abuse, sexual exploitation, and unwanted pregnancies. In this project, I had three objectives to achieve this aim:

Objective 1: To identify strengths and weaknesses in the available screening tools already established.

Objective 2: To identify gaps in research that assesses the sexual history of this population.

Objective 3: To recognize how proper screening improves sexual activity outcomes within this population.

Practice-Focused Question

I developed the following practice-focused question to guide this study: Are there any screening tools available to assist clinicians better assess the sexual histories of developmentally-disabled individuals in outpatient settings?

Evidence-Based Significance of the Project

The outcome of this type of evidence-based project is the ability to develop a tool for clinicians to promptly identify sexual histories of the study population. This tool will

help protect the high-risk members of this population against the incidence of STDs, sexual abuse, and exploitation. With a sexual history screening tool, clinicians will be in a better position to take the necessary action through education, mass media awareness if the sexual activity is nonconsensual and guide the individuals who engage in consensual sex to make sure it is safe sex. Nurse researchers can make positive contributions to knowledge and practice in sexuality education for these individuals by collaborating with stakeholders to develop a policy that would mandate sexual screening in all outpatient settings. They could also make positive contributions to knowledge and practice by evaluating outcomes to improve direct patient care.

Implications for Social Change in Practice

Promoting and developing better screening protocols for use by clinicians to determine the sexual practices of individuals with developmental disabilities has significant implications for practice, education, and research. Young people today, and, developmentally challenged individuals in past generations, are particularly vulnerable to the risks of unintended pregnancy, unsafe abortion, maternal mortality, violence, and sexual exploitation (Greespan, 2002). Failing to address the problems presented by sexuality poses myriad dangers that will affect 10s of millions of people worldwide; however, directing attention and resources to issues of sexuality can be a powerful means to achieve gender equity, improved public health, and social justice. A screening tool will help this population attain a life with as much personal fulfillment and protection as possible. Stakeholders for this project include the individuals themselves, their parents,

institutional staff, administration, and the Justice Department, as well as researchers and professionals in other disciplines like psychiatry; psychology; and physical, speech, and occupational therapies who will all eventually benefit from such an educational tool.

Policymakers can use the results of this project to promote such a tool and pass it into law to becoming part of intake assessment protocols in outpatient settings. This clinical tool could enhance the educational experience of nurses to provide them with more opportunities to interact with this population across their lifespan, thereby increasing the level of comfort among those nurses and improving the standard of care. Nursing practice standards related to sexuality education, prevention of sexual abuse and exploitation, and promotion of sexual development and healthy sexual expression are needed (Ailey, Marks, Crisp, & Han, 2003)

Summary

A project of this nature was centered on determining the impact of clinicians' assessment of the sexual histories of the developmentally disabled using proper screening protocols and improving standard of care. I geared this systematic review towards the development of evidence-informed sexual screening tools through the synthesis of the current research literature. The method I selected for the project yielded a much needed research and quality improvement as well as opened doors for further research in this area of caring (see Ivankova & Kawamura, 2010). The results will maintain a safer screening protocol to assist clinicians in strengthening the resources of these individuals when it comes to preventing STDs, sexual abuse, exploitation, and unwanted pregnancies.

Section 2: Review of Scholarly Evidence

Introduction

Some individuals with developmental disabilities are at high risk for sexual abuse, exploitation, and eventually unplanned and unwanted pregnancies as well as STDs because they trust and depend on their caregivers for support (Servais, 2006). In a systematic review on violence against adults with disabilities, published by (Hughes et al. 2012), found that overall, they are 1.5 times more likely to be a victim of violence than those without a disability, while those with mental health conditions are at nearly four times the risk of experiencing violence. The researchers' review also indicated that children with disabilities are 3.7 times more likely than nondisabled children to be victims of any sort of violence, 3.6 times more likely to be victims of physical violence, and 2.9 times more likely to be victims of sexual violence. Children with mental or intellectual impairments appear to be among the most vulnerable, with 4.6 times the risk of sexual violence than their nondisabled peers (Hughes et al. 2012).

Problem

Individuals born with developmental and intellectual disabilities are at increased risk for sexual abuse and exploitation and as a result, contract STDs) as well as spread them, and surprisingly there is little information on the frequency and nature of sexual experiences in this group (Greenspan, 2002; Spiecker & Steutel, 2002). One problem with providing appropriate free sexual healthcare for disabled people, including adults, is that they are more likely than others to live in institutions like group homes, adult homes, or assisted living facilities (Cheng & Udry, 2002). Although many clinicians engage

proactively to support the sexual rights of disabled people, others have a long way to go, so it is necessary to reestablish screening tools that clinicians could use in primary care settings to better assess and determine the sexual health histories of these individuals.

Purpose

The purpose of this review was geared towards gathering evidence from the literature on screening tools to better assist clinicians assess the sexual histories of the developmentally disabled. There are limited longitudinal studies available about strategies to prevent sexual abuse in this population (McCormack et al. 2005). In addition, there is limited research about approaches to preventing sexual abuse among the disabled. Therefore, reestablishing screening tools to better assist clinicians assess the sexual histories of these individuals will meet the nation's overall goal of preventative care.

Theoretical Framework

A theoretical frame work guides and informs the DNP project (Moran, Burson, & Conrad, 2014). My recommendations on screening tools from this project will significantly improve the documentation on sexuality and sexual preferences, abuse, and exploitation of developmentally-challenged individuals. The cognitive behavioral theory (CBT) is a theory used in social psychology that focuses on the relationships of cognition and behavior to the affective state of the organism and the functioning of the organism in the larger social context (Kendall, 1993). CBT takes into consideration the external and internal environment of the individual and how well they integrate in the society in the context of social interaction (Kendall, 1993). The behavior is influenced between inner

process and environmental influences (Kendall, 1993). In the case of the study population, some developmentally-disabled individuals do not have a regular social life. They might want to engage in certain sexual practices just because of the fun of it or because they are told to do so, not realizing the consequences. The goal of using this theory to guide the framework is to control and change the poor behavior and feelings to a much better behavior, especially the high functioning individuals.

The Iowa model was originated in 1994 by Marita G. Titler, PhD, RN, Director of Nursing Services and Quality Care, University of Iowa Hospitals and Clinics (LoBiondoWood & Haber, 2006). This model allows the user to focus on knowledge- and problem-focused triggers, leading staff to question current nursing practices and whether care can be improved using current research findings (Titler, 2006). The Iowa model highlights the importance of considering the entire healthcare system, from the provider, to the patient, to the infrastructure using the following steps as a guide: identifying a problem-focused trigger that will initiate the need for change; review and critique relevant literature; identify research evidence that supports change; and implement a change and monitor the outcomes (Titler, 2006).

Role of the DNP Student

Nurses have long recognized that scholarly nursing practice is evident in discovering a new concept and applying new discoveries in increasingly complex practice. The DNP student's role is to apply clinical scholarship and analytical methods for evidence-based practice (American Association of Colleges of Nursing [AACN], 2006). DNP Essential 1, page 8 (Scientific Underpinnings for Practice) was completed

with the establishment of a practice problem and creating a research proposal, extensive management of the literature at doctoral level and providing a sample sexual history screening tool for the population under review. DNP Essential V11, page 15 (Clinical Prevention and Population Health for Improving the Nation's Health). The problem I detected in a clinical setting was vital for this project so that the implementation of a proper screening tool to help clinicians assess the sexual histories of the developmentally disabled, was translating research into practice and improving the nation's overall health. I have been privileged to diagnose some of these individuals with one STD or the other as well as provide care and ongoing monitoring to those who already live with some of those debilitating diseases.

Literature Review Related to Methods

Lack of sexual screening among developmentally-challenged individuals is an ongoing problem that needs to be tackled in many healthcare settings that provide care for them. The purpose of this doctoral project was to reestablish screening practice protocols or tools to use in healthcare settings that are beneficial to providers to detect sexual abuse and exploitation and manage chronic STDs and unwanted pregnancies.

Bambara & Brantlinger (2002); Hinsburger & Tough, (2002) stated that sexual health in this population is considered sensitive because it has been ignored for quite a long time or is controlled by caregivers or service agencies. The importance of sexual knowledge is underlined by other research showing that many young adults and children with intellectual disabilities are sexually active or have strong intentions to become so (McGillivray, 1999). Evidence has suggested that this population discussed sex-related

issues less frequently with their parents and their nondisability peers (Isler, Tas, Beytut & Konk, 2009; McCabe, 1999).

Caregivers are important to the developmentally-disabled individual's development of defined appropriate personal space and the recognition of appropriate and inappropriate behaviors that cross the personal space boundary of themselves and others (Swango-Wilson, 2011). The caregiver's role in the development of positive social behaviors is paramount. Education has been recognized as a mechanism to reduce vulnerability to sexual abuse/assault (Swango-Wilson, 2011). Education has the potential to encourage positive sexuality, promote the decision-making abilities about that sexuality, and empower the individual with developmental disability to act on their decision (Swango-Wilson, 2011).

McEachern (2012) found sexual abuse and victimization are experienced by the disabled at an alarming rate. Many of these individuals cannot speak for themselves or totally trust and depend on their caregivers for support (McEachern, 2012). Health care professionals are also complicit in denying disabled people their rights to sexual expression and sexual choices and in perpetrating myths about the disabled people (Milligan & Neufeldt, 2001). Often, disabled people have been viewed as asexual or as external children, while others have been viewed as sexually rampant and unable to control their sexual impulses (McEachern, 2012). Recently, sexual education programs tailored for the intellectual disabled to improve their sexual health have been developed, yet expansion of these programs and the improvement of their content remains a concern. For example, Schaafsma, Stoffelen, Kok, and Curfs (2013) reported that sex education

programs in the Netherlands are, in most cases, designed to be delivered by paid care staff; however, they found no evidence to support the efficacy of these programs to people with an intellectual disability. Many individuals with developmental and intellectual disabilities have insufficient or incorrect knowledge about subjects such as masturbation, pregnancy, safe sex, reproduction, and same-sex relationships (Healy et al. 2009; Kelly et al. 2009; Leutar & Mihokovic, 2007; McCarthy, 2009; Murphy & O'Callaghan, 2004).

However, new technologies, such as smart phones and Google, provide intellectually disabled (ID) people with increased access to sexual information. Limited education and ability to process such information puts people with ID at increasing risk of exploitation from exposure to these sources (Eastgate, Scheemeyer, Driel, & Lennox, 2012). Importantly, information about sex from these sources may involve sexualized imagery or connections to persons who can abuse (Eastgate et al. 2012). These technologies have been implicated in many cases of the sexual abuse of children and adolescents with ID, and therefore, more recent studies addressing these issues are warranted. Support for their sexual rights has grown through legal and legislative mandates supporting the development of specialized services for person with developmental disabilities (Walcott, 1997). Without early sexuality education, children and adults with developmental disabilities are precluded from reaching their sexual potential, and their continued ignorance makes them vulnerable to sexual exploitation (Keinin, Rodriguez, & Edwards 2001).

The 58th World Health Assembly (hosted by the WHO) increased awareness through their global forums when they formally recognized the importance of sexual health among the developmentally disabled. This act urged member states to include a disability component in sexual health policies and programs (WHO, 2005a). Sex education programs are designed to be delivered proactively, meaning that sex education should be provided before the person with intellectual disability is sexually active, so that the person has the knowledge, cognition, and skills needed to make decisions that have a positive effect on his or her sexual health (Schaafsma et al. 2013). Previous studies, however, showed that educational staff in general teach sex education reactively (Abbott & Burns, 2007; Abbott & Howarth, 2007) and respond idiosyncratically (Evans et al., 2009) to situations concerning sexuality issues, which is a cause for concern. Some direct staff members even worry about being prosecuted if they attempt to discuss sexuality with their client (Grieve, McLaren, & Lindsay, 2007). A lack of policy or ambiguities about the organization's policy may be a possible barrier to teaching sex education, even when staff members express a positive intention.

Regarding self-efficacy, several studies have showed that clinicians reported a lack of experience in dealing with sexuality (Abbott & Howarth, 2007) and also a lack of training in this area (Abbott & Burns, 2007; Evans et al., 2009; Grieve et al., 2007). When it comes to perceived social norms, some staff members expressed concerns about the reactions of other staff members or parents if they were to talk to clients about sexuality (Abbott & Howarth, 2007). While not abundant, materials helpful for those with mental retardation about sexuality have been developed and are available from

organizations such as Planned Parenthood, and professionals dealing with the developmentally disabled should have such materials readily available in their offices or waiting areas (Abbott & Howarth, 2007). Consciousness raising about the sexuality of those with developmental disabilities and promoting appropriate, family-based sexuality education are everybody's business (Fritz, 2003).

Individuals with ID may be at increased risk of sexually transmitted diseases including HIV/AIDS (McCabe & Cummins, 1996). In the same study, McCabe & Cummins (1996) also found that individuals with mild intellectual disabilities had a higher percentage of experience with STDs than did a group of college students, indicating the need for education on prevention. Person-centered planning is a philosophy and a set of strategies aimed at promoting self-determination on the part of persons with intellectual and developmental disabilities (McCabe & Cummins, 1996). This planning involves understanding each person's specific context, dreams, and aspirations and responding by creating the conditions that will promote and support the person's own view of a positive future (Holburn & Cea, 2007).

Hillier, Johnson, and Harrison (2002) reported the reflections of 25 Australian adults with an intellectual disability about autonomy, sex, secrets and desire in their lives. Their report revealed that most adults in their study were sexually active but understood that this was not approved of by others. Many participants reported that formal education about sex was lacking, and those who had received such education had not found it helpful. A problem with providing appropriate emancipatory sexual healthcare for disabled people, including adults, is that they are more likely than others to live in

institutions. Although many institutions engage proactively to support the sexual rights of disabled people, others have a long way to go. Clinicians may experience conflict between their own views about sexuality and those of the institution and may not wish their patients to come into conflict with staff who have considerable influence over their lives. Even where disabled adults live with their parents or other family members, these relatives may wish to prevent them from having sex, and this may result in conflict with health professionals (Cuskelly & Bryde, 2004).

The literature reveals that sexuality is an area of risk for developmentally disabled individuals that there is a trend toward normalization of this population in the United States (Delores & Walcott, 1997). At the same time, support for the sexual rights of the developmentally disabled has grown and legal and legislative mandates support the developments of specialized services for persons with developmental disabilities (Hamilton, 1997). Conod & Servais (2008) revealed that the expectancies of persons with intellectual disabilities towards sexuality vary considerably according to their level of disability. This was the case for only 32 and 9% of women with moderate and severe disability respectively. Program planners must accept that there is bound to be limitations or challenges in assessing a problem such as this, therefore existing data must be used creatively to bring out positive targets (Kettner, Moroney, & Martin, 2017, p. 64).

Summary

The project was centered on the impact the clinician assessment of sexual histories of the developmentally disabled using proper screening tools and improving

standard of care. It is a systematic review which includes the development of evidence informed sexual screening tools through the synthesis of the current research literature. The method selected for the project will yield a much-needed research and quality improvement as well as open doors for further research in this area of caring (Ivankova & Kawamura, 2010). A safer screening tool to assist clinicians strengthens the resources of these individuals when it comes to preventing STD's, sexual abuse, exploitation, and unwanted pregnancies. It will provide the tools needed to integrate into general communities successfully (Swango-Wilson, 2011).

Section 3: Approach

Introduction

Some individuals with developmental disabilities are at high risk for sexual abuse, exploitation, and eventually unplanned and unwanted pregnancies as well as STDs because they trust and depend on their caregivers for support (Servais, 2006). In a systematic review on violence against adults with disabilities, published by Hughes et al. (2012), found that overall, they are 1.5 times more likely to be a victim of violence than those without a disability, while those with mental health conditions are at nearly four times the risk of experiencing violence. The researchers also indicated that children with disabilities are 3.7 times more likely than nondisabled children to be victims of any sort of violence, 3.6 times more likely to be victims of physical violence, and 2.9 times more likely to be victims of sexual violence. Children with mental or intellectual impairments appear to be among the most vulnerable, with 4.6 times the risk of sexual violence than their nondisabled peers (Hughes et al. 2012).

Purpose

The purpose of the project was to gather evidence from the literature on screening tools to better assess the sexual histories of the developmentally disabled. There are limited longitudinal studies available about strategies to prevent sexual abuse in this population (McCormack et al. 2005). In addition, there is limited research about approaches to preventing sexual abuse among the disabled. Therefore, reestablishing screening tools to better assist clinicians assess the sexual histories of these individuals will meet the nation's overall goal of preventative care.

Practice-Focused Question

I developed the following practice-focused question to guide this study: Are there screening tools available to assist clinicians better assess the sexual histories of developmentally-disabled individuals in outpatient settings?

Project Approach

I chose a systematic review of the literature to assess screening tools for this project. These types of reviews are based on research evidence and can be used to provide information on a myriad of topics, including quality, safety, and the value of healthcare (Bettany-Saltikov, 2012). A systematic literature review allows for the compilation of research information into an easy to read format (Adams, 2016). A review of literature research studies was conducted for findings on screening tools and the recommendations made. I used the John Hopkins Nursing Evidence-Based Model Research Evidence Appraisal Tool to evaluate the various studies. This tool is used to identify studies based on their levels of evidence to determine which ones are relevant to answering the research question, first by rating the type of evidence, then the quality of the evidence (Dearholt & Dang, 2012).

Sources of Evidences

To answer the practice-focused question, I conducted a literature search to gather research articles to review from the following databases to attain a condensed but broad description of the problem: the Cochrane Library, Evidence-Based Practice Research Guide from the Walden University Library, Joanna Briggs Institute's Evidence-based Project Database, and Database National Guideline Clearinghouse database of clinical

practice guidelines summaries). The relevant studies were identified by using the following variety of keywords separately and in various combinations: *developmental disabled, sexual screening, screening tools, sexual history of individuals with developmental disability, sex and the intellectually disabled, sexual health questionnaires for developmentally disabled, sexual orientation, and guidelines for sexual history for the disabled, autism*. The articles I reviewed were peer reviewed and were published in the past five years. My search was intensive and exhaustive. I also took exclusion and inclusion criteria into consideration to minimize bias.

Project Evaluation Plan

Evaluation of a project starts right from its initiation through developing its outcomes. Evaluation answers crucial questions regarding a research problem. For a project of this nature to be considered evidence-based, it needed to be supported by extensive research ascertaining its effectiveness (Adams, 2016). I developed three questions to evaluate this project with:

- Will clinicians agree to use the tool?
- Will the tool be incorporated into the daily assessment during office visits?
- Will the tool increase detection of sexual abuse, exploitation, and unwanted pregnancies?

Impact evaluation checks the extent to which the objectives of the program have been attained and is a portrayal of changes in knowledge levels, viewpoints, behaviors, or any other related outcomes (McNabney, Willging, Fried, & Durso, 2009). This type of evaluation generally assesses the changes in the well-being of individuals that can be

attributed to a particular project, program, or policy (Gerard, Martinez, Premand, Rawlings, & Vermeersch, 2016).

Summary

This project is centered on the impact the clinician assessment of sexual histories of the developmentally disabled using proper screening tools and improving standard of care. It is systematic review which includes the development of evidence informed sexual screening tools through the synthesis of the current research literature. The research presented, implemented, and evaluated added to the growing body of nursing literature, and its usefulness to look for ways to improve sexuality in individuals with ID. A safer screening tool to assist clinicians strengthen the resources of these individuals when it comes to assessing their sexual histories will provide the tools needed to integrate into general communities successfully (Swango-Wilson, 2011).

Section 4: Findings, Discussion, and Implications

Introduction

Individuals born with developmental and intellectual disabilities are at increased risk for sexual abuse and exploitation and as a result, contract STDs as well as spread them (CITE). Surprisingly, there is little information on the frequency and nature of sexual experiences in this group (Greenspan, 2002; Spiecker & Steutel, 2002). One problem with providing appropriate free sexual healthcare for disabled people, including adults, is that they are more likely than others to live in institutions like group homes, adult homes, or assisted living facilities (Cheng & Udry, 2002). Although many clinicians engage proactively to support the sexual rights of disabled people, others have very little experience and training according to the literature in caring for these individuals (Cheng & Udry, 2002). Consequently, it is necessary to reestablish or recommend screening tools that clinicians could use in primary care office settings to better assess and determine the sexual health histories of these individuals.

Purpose

I geared this project towards gathering evidence from the literature on screening tools that are available to better assist clinicians assess the sexual histories of the developmentally disabled. If these screening tools are available, they should be used by clinicians in their daily day to day assessment of these individuals. If there are none available, provision should be made for a screening tool that is currently being used for another population be recommended to be used for this population in the outpatient settings.

Goal Statement and Project Question

My aim with this systematic review was to identify evidenced-based screening tools for clinicians working with developmentally-disabled individuals to better assess the sexual histories within this population to help lower the incidence of STDs, sexual abuse, sexual exploitation, and unwanted pregnancies. The evidence-based question for this doctoral project was: Are there screening tools available to assist clinicians better assess the sexual history of developmentally-disabled individuals in outpatient settings? To better answer this question, I conducted an extensive review of the literature to collect articles, categorize those articles that answer the evidence-based project question, assess them, and then extract the relevant data and summarize the evidence.

Evaluations/Findings Discussion

Literature Search

I conducted a search strategy to produce relevant literature relating to my investigation of available screening tools. An extensive cumulative search of only peer-reviewed articles and grey literature published between 2013 and 2018 was conducted in May through June 2018 in the following electronic databases: EBSCO, ProQuest Nursing & Allied Health, ProQuest Health & Medical Complete, and CINAHL plus Medline websites. I used the following keywords and phrases from combinations of keywords: *developmental disability or intellectual disability, sexual history, sexuality, screening tools, questionnaires, and interviews*. I focused on literature published in the past five years in order to determine whether the expert opinion has changed since the older

sources were written. The articles I found for this project were narrowed down intentionally to identify any existing sexual history screening tool.

Search Outcome

The keywords and phrases I used in the literature search in each database were as follows: In CINAHL plus Medline plus, the keyword *autism* quickly yielded thirteen thousand and eleven results, *sexual health* yielded two hundred and five results, and finally, *assessment tools* yielded twenty-two pertinent articles. In EBSCOhost, the keyword *developmentally disabled* yielded a thousand and ninety-one results, *sex* yielded forty-seven, or *questionnaire* yielded eighteen articles. In ProQuest Nursing and Allied Health, *intellectual disability* yielded thirteen thousand four hundred and seventeen articles, *sexual history* yielded a hundred and fifty-seven, and screening tools yielded only 5 articles. In ProQuest Health and Medical Collection, the keyword *developmentally challenged* yielded one thousand three hundred and sixty-five results, *sexual** yielded two hundred and eighty-eight results, and interviews yielded one hundred and three results. My searches for grey literature yielded 8 articles, and only 1 was applicable. Although there were numerous published reports of sexual knowledge assessment tools, I reviewed a total of one hundred and fifty-six reports and only nineteen were applicable to the evidence-based study question.

I interchanged some of the keywords words; for instance, instead of typing intellectual or developmental disability, I began with screening tools for assessment, then sexual health, then developmental disability or intellectual disability. Articles presenting research on the sexuality of those with an intellectual disability and mental health

screening tools were eliminated. Some of the titles of the articles on mental health screening were written in English, but the entire articles were in a different language. Some of the articles I also excluded were narratives and commentaries, not suitable or sufficient for research purposes. I also reviewed articles on developmentally-disabled individuals that are sex offenders, which was not the emphasis of the project, so these articles were excluded. The articles included in my review did not present as sexual history screening tools for clinicians; rather focused on the sexual knowledge of developmentally-disabled individuals and clinicians, parents, educators, or staff views on the sexual knowledge of intellectual/developmentally-disabled individuals. Figure 1 is a flow diagram of how I collected and eventually chose articles for inclusion in the project.

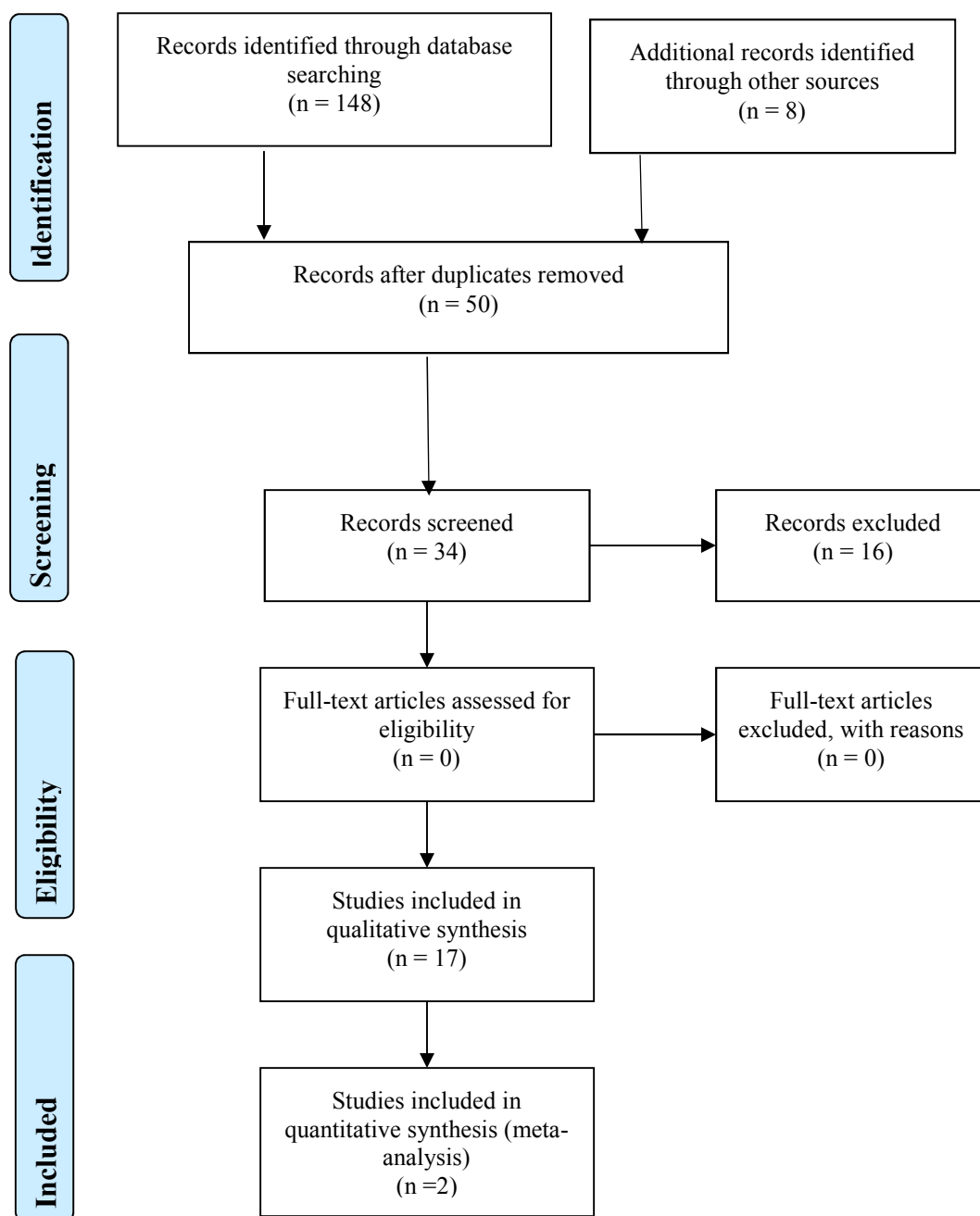


Figure 1. Demonstration of identifying including and excluding articles for the systematic review. Adapted from “Preferred Reporting Items for Systematic Reviews and Meta-Analysis: The Prisma Statement,” by D. Moher, A. Liberati, J. Tetzlaff, D. G. Altman, & The Prisma Group, *PLoS Med*, 6(7), e100097. Copyright 2009 PRISMA

Data Abstraction and Synthesis

I critically appraised each of the articles chosen using the John Hopkins Nursing Evidence-Based Practice Model and Guidelines Tool (see Newhouse, Dearholt, Poe, Pugh, & White, 2007). None of the articles could provide a sexual history screening tool or answered the evidence-based project question. I plotted the articles on an individual, evidence-based, summary tool with the following headings: title of table, article number, author(s), research type, sample size, setting, results of study, limitations, level, and quality (see Appendices A, B, and C). Out of the thirty-four articles I summarized, only nineteen were thoroughly synthesized: seventeen nonexperimental/qualitative and 2 quasi-experimental.

Sexuality in Developmental Disabled Individuals

I found four studies conducted to determine the importance of sexuality education of individuals with developmental disabilities. (Ballan & Freyer, 2017; Dewinter, Vermeiren, Lobbesrael, & Nieuwenhuizen, 2015; Krantz, Tolan, Pontarelli, & Cahill, 2016; Martinello, 2014). Dewinter et al. (2015) conducted a study with native Dutch and Belgian boys aged 15–18 with at least average intelligence, who were high functioning, and diagnosed with autism spectrum disorder (ASD) and Asperger's disorder. Control participants were from the Netherlands. Both Ballan et al. (2017) and Martinello (2014) did not use any subjects in their studies. Krantz et al. (2016) conducted a study in Chicago among high school educators. All these researchers presented the fact that sexuality among individuals with developmental disabilities is a normative part of their existence and must be supported.

Dewinter et al. (2015) conducted a quasi-experiment using 146 adolescents, native Dutch and Belgian speaking participants diagnosed with ASD and Asperger's disorder. The control data were taken from 90 boys aged 12–25 in the Netherlands. Participants with ASD and controls reacted equally permissively to statements about sexual contacts in different male-female relationships; however, the questions the researchers included in the survey did not contain questions on specific sexual behaviors.

In their study, Ballan & Freyer (2017) reviewed an article to support three techniques for application in social skills components of sexuality education programs. They revealed that sexuality education with regards to individuals with intellectual disabilities should not be limited to one environment and the skills learned must be transferable to multiple contexts. Martinello (2014) also supported the notion that staff training can result in a more sexually supportive environment for individuals with intellectual disabilities. Martinello stated that by acknowledging the role of pleasure in sexuality, children with intellectual disabilities may be able to discern abuse from care. Since this study was narrative in nature, it only provided one view of the story.

Krantz et al. (2016) conducted semi structured interviews among 10 high school educators in Chicago, Illinois to compare how adolescents with intellectual disabilities were taught about sexuality and dating. The results revealed that sexuality is unique to each student. Krantz et al.'s study was limited by its generalizability and the fact that there was variability in obtaining a broad range of perspectives from the participants.

Sexual Knowledge Assessment in Individuals with Developmental/Intellectual Disabilities

Individuals with intellectual or developmental disabilities generally have lower levels of sexual knowledge than those without an intellectual disability (Kramers-Olsen, 2017). Multiple researchers provided evidence to show that a good level of sexual knowledge among these individuals is necessary to determine a wide and varying degrees of health literacy level; (Liou, 2014; Kramers-Olsen, 2017; Tanabe, Nagujjah, Rimal, Bukania, & Krause, 2015; Williams, Scott, & McKechanie, 2014). Liou (2014) conducted a study in Taiwan, while Kramer-Olsen did not use any human subjects. Tanabe et al. (2015) conducted their research study in refugee settings in Kenya, Nepal, and Uganda, while Williams et al. (2014) conducted their study in Lothian, Scotland. These studies demonstrated the varying degrees of awareness of sexual knowledge among individuals with developmental or intellectual disabilities.

Liou (2014) used a scale to measure the sexual-abuse prevention knowledge of 196 high school female students with intellectual disabilities who studied at special education schools in Taiwan. A convenience sample was used. Results indicated a relatively good knowledge among the participants on puberty, physiology, body boundaries, and identification of improper sexual relationship. The scale used on the other hand included only thirty items which may not be broad enough to include a wide range of content areas. Kramers-Olsen (2014), briefly reviewed the more commonly used sexual knowledge and consent assessments for people with mild to moderate intellectual disability. The author assessed the Bender Sexual Knowledge Questionnaire, the General

Sexual Knowledge Questionnaire, the Socio-Sexual Knowledge and Attitudes Assessment Tool-Revised, and the Sexual Knowledge, Experience, Feelings and Needs Scale. It was revealed that the assessment of sexual knowledge and consent capacity is essential to elucidate the nature of supports required by people with intellectual disability in order to determine individualized teaching and sexual literacy interventions.

Tanabe et al. (2013) used a qualitative participatory method to recruit two hundred and eighty-seven refugee women with intellectual, mental, physical, and sensory disabilities in Kenya, Nepal, and Uganda. In addition, their caregivers were consulted. The results revealed that these women demonstrated varying degrees of awareness around sexual and reproductive health, especially regarding the reproductive anatomy. The pitfall of this study did not represent all impairment and ages adequately. Williams, Scott, & McKechnie (2014) administered structured questionnaires during face to face interviews of thirty-four younger adults with intellectual disability about whom they could go to for advice and information about sex and relationships. It was revealed that the participants expressed a wide variety of experiences and preferences regarding sexual health services. The downside of the study was that the sample size was quite opportunistic and therefore less represented.

Evaluation of Sexuality Educational Programs

Sexuality education goes beyond traditional sex education in that it focuses on all aspects of human sexuality, including relationships (Travers, Whitby, Tincani, & Boutout, 2014). Individuals with developmental disabilities lack sexuality education, training as well as sexual knowledge, and the lack thereof places them at heightened risk

for sexually transmitted diseases, and unwanted pregnancies (Travers et al. 2014). Ballan, & Freyers, 2017; Travers, et al. 2014; McDaniels, & Fleming, 2016; Lofgren-Martenson, Sorbring, & Molin, 2015; and Yildiz, & Cavkaytar, 2017 established five studies that presented the fact that sexuality is limited with these individuals and providers and caretakers can help address these changes.

Ballan & Freyers (2017); Travers et al (2014); & McDaniels & Fleming (2016) conducted systematic reviews of the literature, Lofgren-Martenson et al. (2015) conducted focused interviews. They conducted their study in Sweden, while authors Tildiz & Cavkaytar (2017) conducted a quasi-experimental study in Turkey. Ballan & Freyers (2017) reviewed articles and came up with the conclusion that most sexuality education trainings and programs developed for children and adults with ASD are not evaluated to determine their effectiveness. Also, that most research on ASD and sexuality excludes adolescents with ASD and fails to examine the issues faced by individuals with ASD as they enter adolescence and adulthood.

McDaniels & Flemings (2016) reviewed ninety-two articles to examine the status and effectiveness of sexual education curricula for individual with intellectual disability. The results concluded that because of inadequate sexual education, individuals with ID are at greatest risk for sexual abuse, STDs and misinformation. The researchers only used published literature; therefore, there is a high chance of unreliability of research findings. Travers et al. (2014) conducted a systematic review of sexuality education intervention for individuals with ID. Only peer-reviewed journal articles were included in the search. They came up with the conclusion that given that sexual knowledge, skill, and

experiences are critical to individuals' ability to make informed choices about relationships, intimacy, and sex (i.e. to be self-determined), it is apparent that more research with this population is urgently needed. Out of the twelve studies done in the review, only one included adolescents under eighteen years old. Again, lack of sexual knowledge among younger persons with significant disability increases their chances of abuse.

Lofgren-Martenson et al. (2015) conducted five semi structured focus groups interviews with professionals (n = 8) and parents (n = 13) working DD individuals to prove the use of the internet to express their sexuality. A strategic sampling method was used to deepen the research. They came up with a conclusion that both professionals and parents agreed that the internet is a commonly used social arena for these young people, however the Internet use is tied to their identity as having complex challenges like higher levels of loneliness and negative effect compared to young people without ID. The data is limited and consists only of females.

Yildiz & Cavkaytar (2016) came up with a quasi-experiment with a pre/posttest design to scrutinize the effect of a sexuality education program for mothers of young adults with intellectual disability (SEPID). The participants were mothers living in Eskisehir, Turkey. The experimental group consisted of 22 mothers (n = 22), while the control group also consisted of 22 mothers (n = 22). This study concluded that the SEPID changed the participating mothers' attitudes toward sexuality education for their children, increased participating mothers' social support perceptions, and social validity findings were positive. This goes to show that sexuality education programs provided to parents

and children with ID improved knowledge levels on sexual development and education.

The only downside of this research was that the research was limited to only 44 mothers.

Evaluation of Clinicians and Caretakers Perceptions About Sexual Assessment

Tools and Providing Sex Education

Providers working with ID individuals have a special role to empower themselves to support this population by making their sexual health a priority. Some lack the training and are often uncomfortable and ambivalent expressing sexual education and training. A couple of studies reviewed, presented the perspectives of clinicians, social workers, and educators, and caretakers. Saxe & Flanagan, 2016; Holmes & Himle, 2014; Linton, Rueda, Williams, Sandoval, & Bolin, 2016; Van der Stege, Hilberink, Bakker, & Van Staa, 2016; Lee, Devine, Marco, Zayas, Atkinson, & Vaughan, 2015; Murphy, Lincoln, Meredith, Cross, & Rintell, 2016) acknowledged the fact that these individuals have the right to express sexual desires and be given comprehensive sex education which is paramount to be their physical and mental health. Saxe & Flanagan (2016); Holmes & Himle (2014); van der Stege et al. (2016), & Murphy et al. (2016) conducted surveys, while Lee et al. (2015) & Linton et al. (2016) conducted interviews.

Saxe & Flanagan (2016) conducted a survey on a sample of a total of 25 individuals; 18 with support worker experience (n = 18) and seven without support worker experience (n = 7). The participants were recruited from a Canadian University to give their opinions concerning training and knowledge regarding sexuality of adults with DD. It was concluded that they are either not being aware of any sexuality-related policies at their places of employment, or there being a lack of such policies in general.

The study reflected a lack of experience and confidence on the part of the support workers in dealing with sexuality with their clients. The study revealed limited sample size. Holmes & Himle (2014) also conducted an anonymous survey online on parents of adolescents with ASD about ASD and sex education (n = 198). It was reported in this study that parents reported covering some sexuality-related topics with their children but no others leaving the youths to learn about other sexual health topics from other sources less credible. Selection bias was noted in this study.

Van der Stege et al. (2016) conducted a cross-sectional mixed-methods evaluation study among 151 professionals working with adolescents with DD to evaluate the use of a new board game SeCZ TaLK (a game used to facilitate discussing sexual health). Results showed the actual use of SeCZ TaLK was associated with positive attitude towards discussing sexuality if it corresponds with work routines. Professionals appreciated the board game but still think management should prioritize discussing sexuality and support professionals in developing skills. Murphy et al. (2016) conducted a pilot study to survey genetic counselors (n = 38) to explore their experiences with being asked to provide sex education counseling and their comfort in doing so for patients with ID ages 9-17. The study revealed that genetic counselors were most comfortable when they could provide sex education counseling within the context of a condition and least comfortable when they lacked familiarity with the patient, caregiver, or family's culture. It was however noted that the structure of the survey was unclear, and the sample size was small.

The authors who conducted interviews came up with the conclusion that providers have very little training and expertise to provide sexual and reproductive health to individuals with ID/DD. Lee et al. (2015) conducted face –to- face in-depth interviews and focus group discussions with 32 (n = 32) sexual and reproductive health service providers across two research sites in the Philippines. The aim of the study was to get the providers perceptions of providing sexual and reproductive health services to women with ID. The result concluded that some providers have limited awareness of sexual and reproductive health needs of women with ID and inadequate understanding of their rights. Linton et al. (2016) on the other hand conducted a purposive sampling technique to recruit social workers and other related professionals serving adults with ID to assess their reproductive and sexual health needs and to offer their perspectives. Eleven social workers, (n = 11) were recruited and interviewed. It was concluded that social workers demonstrated the need to support clients, but there are challenges in performing these roles, which included gaps in sexual education and struggles with ethical dilemmas regarding autonomy and client well-being. Limitations of this study included small sample size as well data from the perspective of social workers.

Summary of Synthesis of Literature

Given the lack of available data to validate sexual history screening tools used by clinicians to better screen individuals with developmental disabilities, it is wise to state that more research is needed in this area to fill the gap. This population will be in a better position to build on the existing knowledge about sexuality as well as make informed decisions regarding their reproductive and sexual health needs. Providers should be

supported in managing the ambivalent feelings that it evokes to provide sex education to these individuals if such screening tools are made available.

Results

The systematic literature review evidence focuses on mostly sexual knowledge, a few on the knowledge and attitudes of clinicians, parents, and caretakers were also found. It was a very challenging few weeks of identifying evidence-based articles that could answer the evidence-based question- the consequences of no assessment tool. The evidence shows that there are no existing evidence-based screening tools that clinicians could use to better assess the sexual histories of developmentally disabled patients. Evidence from the literature also indicates that there are inconsistencies when it comes to discerning the sexual knowledge of these individuals. Some of the studies indicated that by acknowledging the role of pleasure in sexuality, children with intellectual disability may be able to detect abuse from care. Other reports suggested positive effects of sexuality education programs on knowledge, skills, attitudes, and behaviors of adults with IDs. Still this validated a need for an evidence-based tool to be implemented to screen sexual histories in the daily assessment of this population in the outpatient settings.

The first objective of this project was to identify strengths and weakness in the available screening tools already established. There is no currently available sexual history screening tool, and thus one cannot correctly identify any strength or weakness in one or more tool. This objective was just not met. Most of these individuals live their sexual lives without a sense of history. They understand what the sexual organs are and what they are used for; which sexual knowledge is, but do not know what the

consequences are for engaging in inappropriate or nonconsensual sexual intercourse. The focus is more on the knowledge of sex from all the peer-reviewed articles explored. There is nothing found in the literature that addresses sexual history taking in these individuals. Therefore, the essence of what is to be captured in this project is not focused on. It is the in the best interest of clinicians who work with this population to explore sexual history taking training.

The second objective of the project mentioned identify gaps in research that assesses sexual history of this population. There is scant literature and no assessment tool found. There are a lot of gaps in this area of research. Researchers have paid relatively little attention to the sexual functioning of individuals with developmental disabilities simply because they rely too much on reports from caregivers and focus only on problematic behaviors (Thompson et al. 2016). Scarce findings of tools indicate the need for research in this area to develop tools. Therefore, the second objective was also not met.

The third objective was to recognize how proper screening improves sexual activity outcomes within this population. The public is very much aware about the problematic sexual encounters of these individuals face, yet they remain to be underdiagnosed and undertreated by healthcare professionals. Extensive research yielded no available sexual history screening tools. Proper sexual history screening puts the clinician in a better position to assess readiness for change, provide support, and a sense of hopefulness to these individuals. They will also feel that the clinician is interested in that aspect of his or her life.

Implications

Sexual history screening is the beginning of a process that may result in treatment recommendations being offered, treatment being initiated, or just the best course of action for the developmentally disabled population (Althof, Rosen, Perleman, & Rubio-Aurioles, 2012). The literature did not yield any screening tools. The lack of sexual history screening tools result in undiagnosed and undetected STDs sexual abuse and exploitation ultimately leading to unwanted pregnancies. Some of the implications to consider are as follows; Individuals with developmental disabilities go through their normal day today lives at home with their parents, in institutions or group homes without discussing their sexual health issues with health care professionals. These individuals avoid discussing their sexual problems because they are not given the opportunity to, and the clinicians probably might insinuate the lack of time, inadequate training in dealing with the sexual health of this population, and the growing knowledge gap between developments in sexual medicine and the clinical skills of the clinician (Althof et al. 2012).

Pros of a screening tool to be used in daily assessments, no matter how long it takes will eventually be acceptable and used by most clinicians caring for developmental disabled individuals; it might also alert the clinician to the need for a confidential conversation about sexual health needs in situations in which such conversations might not typically occur otherwise. Example if there are four or five quick sexual history questions asked, and the individual responds to all in the affirmative, the clinician is

prompted to follow him or her more closely over time or provide other intervention and prevention needs.

Recommendations

Holistic and patient-centered care requires a sexual history and screening tool for this vulnerable population. High risk for inappropriate sexual behavior and unwanted pregnancies can be prevented. Buildup of this tool is needed, education to the population and caregivers. The following recommendations need be taken into consideration; sexual history taking, or screening should be maintained in a culturally sensitive manner-patient-centered approach.

All new patient encounters and follow-up visits must entail one to two broad and simple questions like; Are you sexually active? Are there any sexual concerns or problems you would want to discuss with me today? Parents should also be provided an opportunity for frank and open discussions of sexual issues with respect and dignity so that these individuals can become knowledgeable and make informed decisions regarding their own sexuality and ultimately enhancing their overall quality of life (Sinclair, Unruh, Lindstrom, & Scalon, 2015).

Questions regarding sexual assault can be difficult for providers to ask and patients to answer. In fact, healthcare providers most often cite their discomfort in obtaining the information as a reason for not screening patients (Moore, 2015). There are screening tools developed to assess sexual assault in the outpatient setting, and intimate partner violence by the U.S Preventive Services Task Force for individuals without developmental disabilities. While reviewing these tools, the one that stood out the most

from the American Congress of Obstetrician and Gynecology (ACOG; 2013) website, captures the sexual history to help physicians with this difficult process of assessment.

Sexual Assault Screening Tool

Five verbal questions screening tool that providers can use to screen for sexual assault in outpatient setting was developed. The questions are short, simple and easy to understand, and clinicians could easily incorporate them in their daily assessments without wandering about the time it will take. Therefore, it is recommended that these questions be used as a sexual history screening tool for the developmentally disabled individuals. American Congress of Obstetrics and Gynecology (ACOG) recommends that physicians screen all patients at every visit for sexual assault. To help physicians with this difficult process, ACOG has developed tools to screen for sexual assault: Screening teens for rape and sexual assault can be conducted by making a statement and asking the following questions:

- Do you have someone special in your life? Someone you're going out with?
- Are you now – or have you been – sexually active?
- Think about your earliest sexual experience. Did you want this experience?
- Has a friend, a date, or an acquaintance ever pressured or forced you into sexual activities when you did not want them? Touched you in a way that made you uncomfortable? Anyone at home? Anyone at school? Any other adult?

- Although women are never responsible for rape, there are things they can do that may reduce their risk of sexual assault. Do you know how to reduce your risk of sexual assault? (ACOG, 2013).

Limitation(s) of the Project

The strength of this evidence-based project is the recognition of the fact that individuals with developmental or intellectual disabilities are overlooked as far as screening for sexual histories by clinicians who work for them is concerned. Research within other population have come out stronger as evidenced in the literature. These individuals are at increased risk for sexual abuse and exploitation as a result contract STDs as well as spread them. A significant review evidenced by the fact that, there are gaps in the literature with no sexual history screening tool found, which can pose a challenge in outpatient settings as it sheds light on the need for more research to identify and minimize this bias in caring for these individuals. There is an identified the need for the development of a tool.

Providers cannot perform a patient-centered holistic assessment from an evidence-based tool for consistency. Sexual history is mostly reliant on the caregiver since they are always involved in their care obviously, they would provide answers that providers would want to hear and just move on. This is not evidence-based practice; there is need for education. A major limitation of this project is the fact that out of all the articles reviewed, no screening tool was found to critique and to answer purpose questions, and the research question.

Section 5: Dissemination Plan

Problem

Individuals born with developmental and intellectual disabilities are at increased risk for sexual abuse and exploitation and as a result, contract STDs as well as spread them. There is little information on the frequency and nature of sexual experiences in this group (Greenspan, 2002; Spiecker & Steutel, 2002). One problem with providing appropriate free sexual healthcare for disabled people, including adults, is that they are more likely than others to live in institutions like group homes, adult homes, or assisted living facilities (Cheng & Udry, 2002). Although many clinicians engage proactively to support the sexual rights of disabled people, according to the literature, others have very little experience and training in caring for these individuals, so it is necessary to reestablish or recommend screening tools that clinicians could use in primary care office settings to better assess and determine sexual health histories of these individuals.

Purpose

I geared this project towards gathering evidence from the literature on available screening tools to better assist clinicians assess the sexual histories of the developmentally disabled. If screening tools are available, they should be used by clinicians in their daily day to day assessment of these individuals. If there are none available, provision should be made for a screening tool that is currently being used for other population be recommended to be used in the outpatient settings.

Goal Statement and Project Question

My aim with this systematic review was to identify evidenced-based screening tools for clinicians working with the developmentally disabled so they can better assess the sexual histories within this population to help lower the incidence of STDs, sexual abuse, sexual exploitation, and unwanted pregnancies. The evidence-based question for this DNP project was: Are there existing screening tools available to assist clinicians better assess the sexual history of developmentally-disabled individuals in outpatient settings?

Project Dissemination

According to Leape (2015), implementing evidence-based safety practices is difficult and requires strategies that address the complexity of systems of care and individual practitioners. The results of this project can bring about a change in the health care culture of caring for developmentally-disabled individuals. One of the most important strategies of disseminating this work is based on the building of strong relationships through integrating the appraised evidence in the clinic with clinical experts and change champions who are themselves clinicians committed to improving quality care by teaching and encouraging them to use the tool. The patient care units will include the staff of group homes and assisted living facilities as well as other healthcare professionals who have positive working relationships with the individuals. The senior leaders of these organizations should be aware of the change and would further carry out mass media interpersonal communication.

Finally, a research study is not complete until the study findings have been disseminated via presentations at professional forums and published in a peer-reviewed journal where appropriate recommendations regarding how the research findings could be translated into clinical practice are made (Curtis, Fry, Shaban, & Considine, 2016). This is exactly what I intend to accomplish after implementing the change in my own work with the population. In other words, I intend to (a) promote my skills to work collaboratively with members of my interdisciplinary team, (b) foster my ability to follow a holistic approach to patient care, and (c) foster my skills to assess each patient's social determinants of health and to provide tailored/suitable care based on the patients' needs.

I am planning to apply at the Practicing Clinician Exchange and the National Conference for Nurse Practitioners to present my research findings through a poster board or oral presentation. These conferences are held annually in different locations in the United States. It might take weeks to months, but with constant audits and feedback, walls would be broken, and the patient population will feel the need for a better and healthier existence. As a member of the American Nurses Association, I plan to advertise my project and findings through the association to create awareness to nurses and administrators alike.

Analysis of Self

As a nurse practitioner, I am appreciative of how I identified a problem in my clinic setting and focused my energy on to how to improve that problem. This evidence-based project provided me with the opportunity to work on this issue. Even though there was no evidence to substantiate the problem in the literature, I was able to come up with

sexual history questions that could be used to gather this information. This systematic review was more than just reading a lot of articles, but rather a structured methodology of evaluating the materials at hand in the field. The process of gathering all the articles and critically appraising them, even though they were unrelated to my project question, gave me inner satisfaction and opened my eyes to the fact that there is more to be done as far as this area of practice is concerned. We are all aware of sexual knowledge but the process of taking a sexual history and determining the next outcome is far from perfect. As a clinician who chooses to provide exceptional care to developmentally-disabled individuals, I will use my acquired knowledge from writing this manuscript to perform exceptionally in a community-oriented organization and contribute to the improvement of the overall care of these patients, their families, and their communities.

Project Summary

Advanced knowledge demonstrated in an area can be demonstrated through the writing of a scholarly project (Moran et al., 2014). Although the results from this project were not what I anticipated, they still brought me closer to be a critical thinker and an expert in the field. My goal with this systematic literature review was to identify a screening tool that is used by clinicians working with developmentally-disabled individuals to better assess or screen their sexual history. The articles that I collected and reviewed did not provide that information, yet I developed five simple questions that can be incorporated into the daily assessment of these individuals. One positive result of this review was that I was able to successfully identify selected articles related to the assessment of sexual knowledge; the views of clinicians, educators, and parents on the

sexuality of these individuals; and the need for sexuality education programs which helped me identify the gap.

The opportunities for future research on this topic are extensive and would lead to various decision-making strategies. A small review of this magnitude can lead to additional research to elaborate on the screening tools clinicians could use in an outpatient setting that would ultimately better assess the sexual histories of members of this population.

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Appendix A: Evidence Summary Tool Sample

Article #	Author & Date	Sample, Sample size & Setting	Study that helps answer evidence-based question	Limitations	Evidence level & Quality
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Appendix B: Summary of Sexual Knowledge Assessment of the Developmentally

Disabled: Evidence Table

Article #	Author & Date	Evidence Type	Sample, Sample Size, Setting	Study findings that help answer the EBP question	Limitations	Evidence Level & Quality
1	Ballan, M. S., & Freyer, M.B. (2017)	Non-Experimental	Article reviewed three techniques for application in social skills components of sexuality education programs.	Most sexuality education programs and curricula developed for children and adults with Autism Spectrum Disorder have not been evaluated to determine effectiveness.	No human subject involved	Level 111; Grade C
2	Dewinter, J., Vermeiren, I. V., Lobbestaal, C.V., & Nieuwenhuizen, V. (2015)	Quasi-Experimental	Convenience sampling. Participants were native Dutch and Belgian boys aged 15-18 (n=50). Control data selected from a large survey study aged between 12-25 in the Netherlands. Surveys were completed at home.	Sexuality is a normative part of adolescent development in high functioning boys with ASD.	Different parents refused to let their sons participate in studies. Survey did not contain questions on specific sexual behaviors.	Level 111; grade B
3	Liou, W. (2014)	Non-Experimental	Convenience sampling. A total of 196	Results indicated a relatively good level of	Scale developed by this study may	Level 111;

			female high school students participate in the study in Taiwan (n=196)	knowledge among the participants for puberty physiology, body boundaries, and identification of improper sexual relationship.	not be broad enough to include a wide range of content areas. Scale includes only 30 items	Grade B
4	Travers, J., Tincani, M., Whitby, P.S., Boutot, E.A. (2014)	Non-Experimental	Peer-reviewed journal articles included in searches which yielded articles published between 1057 and 2011. A systematic review of sexuality education for individuals with developmental disability. Group and single-subject designs; (n=8) with 3 conducted RCTs, others used quasi-experimental, pre-test, post-test comparisons,	All studies reported positive effects of sexuality education programs on knowledge, skills, attitudes, and behaviors of adults with IDs.	Only 1 of 8 studies in the review included adolescent under 18-years-old. Lack of research on curricula or published programs to teach sexuality.	Level 11; Grade B
5	Kramers-Olen, A. (2017)	Non - experimental	Article reviews the more commonly used instruments	The assessment of sexual knowledge and consent capacity is essential to elucidate the	Broader qualitative assessment may be more beneficial to identify	Level 111; grade B

			designed for the measurement of sexual knowledge and sexual consent capacity in people with mild to moderate intellectual disability.	nature of supports required by people with intellectual disability in order to determine individualized teaching and sexual literacy interventions.	strengths and gaps.	
6	Ballan, M.S., & Freyer, M.B. (2017)	Non-experimental	Exploratory; Article explores sexuality education and sexual healthcare for female adolescents in foster care with ID/DD and recommends practice guidelines to support and prepare their emergent sexual development	Sexual health must not be a secondary consideration in the well-being of foster youth with disabilities, but rather a hallmark of their healthy development.	No interviews were conducted; this is only a narrative	Level 111; Grade C
7	Dionne, H., & Dupras, A. (2014)	Non-experimental	A literature review (ecosystem approach) to propose the state of knowledge on the situation of PWID regarding their sexual	Ecosystem approach shows that the different environments may impact the sexual life of people with an intellectual disability.	Ecosystem approach was a general approach	Level 111; Grade C

			health from factors that facilitate or obstruct it			
8	Hannah, L.A., & Stagg, S.D. (2016).	Non-experimental	A between-subjects design and a mixed method approach. A parallel concurrent design with a linear process for the study. The sexual awareness questionnaire and semi-structured interviews were used; 40 participants (n= 40) between ages 18-25.	There was no statistically significant difference between groups on measure of sex education feelings or on the measure of sex education needs.	No quantifiable amount of formal education that participants received nor the category of school that participants attended	Level 111; Grade B
9	Tanabe m., Nagujjah, Y., Rimal, N., Bukania, F., & Krause, S. (2015)	Qualitative	Qualitative participatory method. 287 refugees with disabilities (n=287).	Refugees in Kenyan and Uganda with disabilities demonstrated varying degrees of awareness around sexual and reproductive health, especially regarding the reproductive anatomy.	Not all impairment and ages were adequately represented; identification of persons with ID was challenging; no strict screening process employed; social desirability present	Level 111; Grade B
10	Wells, D.K., Clark, K.D., & Sarno, K. (2012)	Quasi-experimental	Quasi-experimental; within-subjects design to evaluate the	Women with ID showed statistically significant increase from pre-test to post-	Failure to assess knowledge and skill maintenance	Level 11; Grade B

			effects of a computer-based interactive multimedia (CBIM) program to teach HIV/AIDS knowledge, skills, and decision making. Sample six 25 (n=25	test in all knowledge and skill domains.		
11	Alvarelhao, J., & Lopes, Daniela (2016)	Non-experimental	A semi-structured interview with structured questionnaires to address sexuality knowledge using the Guttman scale. Forty-two participants (n=42) were interviewed in Portugal	Study showed that it is possible to combine questions that represent diverse aspects of STDs knowledge in an ordered scale and be used in an assessment of adults with Cerebral Palsy.	Small sample size, the localized recruitment in a single region and the wide ranges of participants could cause an informative bias.	Level 111; Grade B
12	Thompson, V.R., Stancliffe, R.j., Broom, A., & Wilson, N.J. (2016)	Qualitative	A semistructured qualitative interviews With clinicians who use sexual knowledge assessment tools.	Clinicians concluded that they need the tools to support work they do, but there are gaps in the tools.	Few clinicians with experience and expertise in sexual health of PWID, small potential participants in research, research was limited to NSW in Australia only.	Level 111; Grade B

13	Williams, F., Scott, G., & McKechnie, A. (2014)	Qualitative	Structured questionnaire during face to face interview of younger adults with ID about whom they could go to for advice and information about sex and relationships. Interview took place in Lothian, Scotland with 34 participants (n=34)	Participants expressed a wide variety of preferences regarding sexual health services.	Opportunistic sample size, less representative sample, broader age range than common definition of young people.	Level 111; Grade B
14	Gallagher, A., & Jennings, C. (2015)	Non-experimental	Qualitative (13), and quantitative (3) adopted in 16 research studies (n=16)	Analysis of 16 studies revealed three predominant themes; sexual knowledge, experiences of sexuality and relationship, and barriers to sexuality and relationships.	Lack of privacy consistently evident in literature	Level 111; Grade B

15	Corona, L.L., Fox, S.A., Christodulu, K, V., & Worlock, J.A. (2016)	Non-experimental	Purposive sampling of 8 adolescents with ASD living in NY State completed questionnaire in a six-session program designed to provide education on sexuality and relationships	It is unclear whether receiving this type of sensitive information in a group format negatively impacted the adolescent in the current study in any way.	Dearth of standardized assessment for measuring knowledge of sexuality and relationships among adolescents with ASD	Level 111; Grade C
16	Byers, S., & Nichols, S. (2014)	Non-experimental	Online survey with a background questionnaire ; the IEMSS questionnaire and a measure of autism symptoms. A total of 205 (n=205) participants recruited for an internet study of sexual well-being of high-functioning adults with ASD	Study suggests that for individuals in a relationship, the same factors are associated with the sexual satisfaction of individuals with HF-ASD as with the sexual satisfaction of neuro-typical individuals.	A community sample including participants not formally diagnosed with ASD. Extent to which the results are representative of all adults with ASD living in the community is unknown	Level 111; Grade B
17	Doughty, M., Race, L., Emery, P., & Salt, K. (2017)	Non-experimental	A six-week program delivered by representatives from community nursing and	Study showed that the environment is molded to shape the needs of the group members; the group	Due to staff change the two groups were dissolved, meaning referrals were	Level 111; Grade B

			occupational therapy in the UK, to enhance members' knowledge and understanding of sex, sexuality and relationships. A mixed-gender group	members are not molded to fit a group structure as this may induce feelings of disempowerment and create a power balance.	dealt with on an individual basis. Clinicians involved in the work were becoming overwhelmed	
18	Martinello, E. (2014)	Narrative	No sample size noted, no randomization	Study showed that by acknowledging the role of pleasure in sexuality, children with IDs may be able to discern abuse from care.	Reader limited to the interpretation of narrator, narrative texts provide only one view of story	Level 111; Grade C
19	McDaniels, B., & Fleming, A. (2016)	Non-experimental	A systematic review of the literature using search engines and a final sample of 92 articles were selected to examine the current status and effectiveness of sexual education curricula for individuals with ID	Study showed that, as result of inadequate sexual education, individuals with ID are at greatest risk of sexual abuse, STD, and misinformation.	If the researchers only use published or readily available studies, the conclusions may be unreliable. Unpublished studies can be hard to find, but using published literature alone may lead to misrepresentation, because it does not include findings from all the existing research.	Level 111; grade B

20	Byrnes, L., & Hickey, M. (2016)	Non-experimental	Exploratory study on the perinatal experience of women who experience physical, sensory, and neurologic disabilities and how health care providers can deliver competent care to disabled women	Study showed that women with disabilities may need additional guidance and support and should expect knowledgeable and supportive health care to promote a healthy pregnancy and healthy baby, with minimal adverse impact on her own health.	Most of the recommendations made in this study have focused on women with physical disabilities. Few studies have been conducted on women with mental/ID during the perinatal period	Level 111; Grade C
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Appendix C: Summary of Clinicians, Caregivers, and Educators Assessment of Sexual

Health of Patients with Developmental Disabilities: Evidence Table

Article #	Author & Date	Evidence Type	Sample, Sample Size, Setting	Study findings that help answer EBP question	Limitations	Evidence Level & Quality
1	Krantz, G., Tolan, V., Pontarelli, K., & Cahill, S.M. (2016)	Qualitative	Semi-structured interviews with constant comparative method analysis to describe the perspectives of high school educators in Chicago regarding how adolescents with DD are taught about sexuality and dating. 10 participants were recruited.	Three major themes emerged in study; sexuality is unique to each student with DD; teachers and parents do not know what to do; a potential role for Occupational Therapists.	Generalizability of this study is limited by the study design. There was variability in obtaining a broad range of perspectives from participants.	Level 111; Grade B
2	Smeltzer, S.C., Mitra, M., Long-Bellil, L., Iezzoni, L.I., & Smith, L.D. (2018).	Qualitative	Semi-structured telephone interviews with 33 obstetric clinicians who care for women with DD to examine how the lack of education about disability in health professionals 'education is a pervasive barrier to quality care	Study showed that several clinicians provided obstetric care to women with DD because of requests from other clinicians and did not begin their career with the goal of providing obstetric care to those women.	Selection bias, small sample size.	Level 111; Grade B
3	Linton, K.F., & Rueda,	Non-experimental	Phenomenological study design to offer	Study showed that although social	Depth of understanding of the	Level 111;

	H.A. (2014)		perspectives concerning sexual and pregnancy experiences of youths with DD. 13 Social Workers from a metropolitan area of the southwestern United States were recruited using purposive sampling for the study.	workers value the use of strengths and empowering perspective in practice, their professional education often does not address how to evoke such a lens when working with adolescents with disabilities.	experiences with pregnancy of adolescents with disabilities is limited because adolescents themselves were not interviewed. A broad definition of disability was used to capture the experiences of a diverse population of adolescents across disability type and level of severity.	Grade B
4	Murphy, C., Lincoln, S., Meredith, S., Cross, E.M., & Rintell, D. (2016)	Non-experimental	A pilot study conducted on 38 genetic counselors to explore their experiences with being asked to provide sex education counseling and their comfort in doing so for patient's ID ages 9-17	Responses from the study showed that their comfort in providing sex education is dependent upon external factors such as the level of the patient's ID and counselor's knowledge of the patient's culture.	Small sample size, language or topic itself may have failed to attract respondents, structure of survey unclear.	Level 111; Grade C
5	Rohleder, P. (2013)	Non-experimental	Four individual interviews and one focus group with three teachers conducted to	Study revealed ambivalent feelings about providing sex education for	Small sample size	Level 111; Grade C

			explore the experiences of educators providing sex education for people with learning disabilities in South Africa.	people with disabilities.		
6	Lee, K., Devine, A., Marco, M., Zayas, J., Gill-Atkinson, L., & Vaughan, C. (2015).	Non-experimental	Fourteen in-depth interviews and two focus group discussions conducted with a total of thirty-two sexual and reproductive health service providers in Quezon City (QC), and Ligao (LC) in the Philippines.	Study showed service providers have very little training in relation to disability, limited awareness of the sexual and reproductive health needs of women with disability, some hold prejudiced attitudes towards them.	Perceptions and experience of service providers working in QC and LC may not reflect the views of service providers across such a diverse country.	Level 111; Grade B
7	Thompson, V.R., Stancliffe, R.J., Wilson, N.J., & Broom, A. (2016).	Qualitative	Constructionist grounded theory approach, semi-structured qualitative interviews were conducted with clinicians who use sexual knowledge assessment tools. Purposive and theoretical sampling resulted in recruiting 23 clinicians.	Study showed that clinicians want to use sexual knowledge assessment tools, want more guidance in relation to administering these tools to support their work, and have concerns about the usefulness and usability of sexual	Small sample size, limited development of sexual knowledge assessment tools identified means low priority of sexual health of people with ID.	Level 111; Grade B

				knowledge assessment tools.		
8	Gammino, G. R., Faccio, E., & Cipolletta, S. (2016).	Qualitative	A grounded theory approach using 22 semi-structured interviews conducted with 12 people with ID and 10 would-be assistants to explore views, needs, experiences, opinions, and concerns about sexual assistance (SA) in Italy.	Study showed that SA services might represent an opportunity for people with disabilities to discover new ways to satisfy their personal needs and to live more autonomously while at the same time, allowing would-be sexual assistants to fulfil their desire to be helpful.	Method of recruitment of would-be assistants on the basis of self-referral, high degree of interaction between the participants and the researcher was not possible because part of interviews with would-be assistants was conducted via the internet.	Level 111; Grade B
9	Holmes, L.G., & Himle, M.B. (2014)	Non-experimental	A survey was conducted with 190 parents with adolescents with Autism Spectrum Disorder (ASD) in order to better understand sexuality communication patterns between parents and adolescents with bot low and high functioning ASD.	Study showed that most parents reported covering some sexuality-related topics with their children but not others, leaving youth to learn about important sexual health topics from other sources that are potentially	Behavior of the parents and children cannot be independently verified. Parents were recruited through local and national autism support groups and the sample was relatively homogenous-selection bias.	Level 111; Grade B

				less credible than parents.		
10	Saxe, A., & Flanagan, T. (2016).	Qualitative	Three open-ended questions in the sexuality questionnaire was conducted on support workers concerning the training and knowledge of these support workers regarding the sexuality of adults with DD. 25 support workers participated in research.	Study reflects the lack of experience that support workers have as well as their lack of confidence in dealing with their clients when issues concerning sexuality arise.	Small sample size	Level 111; Grade B
11	Linton, K.F., Rueda, H.A., Williams, L.R., Sandoval, A., & Bolin, S. (2016)	Qualitative	Phenomenological study design and purposive sampling of 11 social workers to offer perspectives of the reproductive and sexual health needs of adults with various disabilities. 8-20 interviews were conducted.	Social workers demonstrated the need to support clients within a biopsychosocial framework since their biological, psychological, and social needs intersected to either restrain or empower their reproductive health.	Data is from the perspective of social workers, data does not provide information about how adults with disabilities perceive their own needs and experience. Small sample size.	Level 111; Grade C
12	Van der Stege, H.A., Hilberink, S.R., Bakker, E., & van	Non-experimental	A cross-sectional mixed-methods evaluation study among 336 professionals	Study showed that the actual use of SeCZ TaLK was associated with a positive	All professionals in the present study had actively requested the board game,	Level 111; Grade B

	Staa, A. (2016)		addressing a web-based questionnaire into use of a new board game to facilitate discussing sexual health with adolescents with chronic conditions in healthcare and special education.	attitude towards discussing sexuality, a high perceived feasibility of the game, own motivation and skills, and correspondence with work routines.	may not be representative of professionals working with adolescents with chronic conditions. Use of convenience sample of motivated professionals working in health care and education may limit the generalizability of the findings of the study.	
13	Yildiz, G., & Cavkaytar, A. (2017)	Experiment	Study employed an empirical pretest-posttest model with control group. 44 study participants (n=22; control=22) engaged in scrutinizing the effect of a Sexuality Education Program for Mothers of Young Adults with ID (SEPID) on the attitudes of mothers toward the sexuality education of their children and their perceptions of social support.	Study showed that SEPID changed the attitudes of mothers toward the sexuality education of their children in a positive direction and improved their perception of social support.	Research is limited to 44 mothers only. Presentations were only in the form of visual and narration; individuals with ID mostly learn by doing or by observing models.	Level 1; Grade A

			Randomization took place.			
14	Lofgren-Martensen, L., Sorbring, E., & Molin, M. (2015)	Qualitative	Five semi-structured focus group interviews were conducted with professionals (n=8) working with ID and with parents (n=5) to discuss the usage of internet for love and sexual purposes among young people with ID in Sweden.	Study showed that the internet is seen as a social arena with complex challenges; for love and sexuality, for sexual conduct, and for sexual risk and opportunities.	Data is limited and consists only of females, sample of professionals originate from a special teacher program-might reveal bias, parent informants recruited from the same upper-secondary special school-limit the variation of experiences	Level 111; Grade C