

SEXUALITY AND VISIBLE, PHYSICAL DISABILITIES: A SCOPING REVIEW

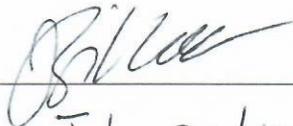
STEPHANIE BROOKS

Supervisor's Name: Rachel da Silveira Gorman

Advisor's Name: Jen Gilbert

Supervisor's Signature:   
\_\_\_\_\_

Date Approved: July 29/19

Advisor's Signature:   
\_\_\_\_\_

Date Approved: July 29/19

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**Abstract**

The historical and ongoing desexualization of people with disabilities (PWDs) along with the pervasive ableist narrative in Western societies have led to the equation of disability with asexuality. Although some members of the disability community may identify as asexual, labelling all PWDs as asexual serves to infantilize these individuals, deprive them of an appropriate sexuality education, and prevent them from accessing their sexual rights. In many Western countries, schools are required to provide their students with a sexuality education, which I believe could help dispel certain myths about the disability identity and promote a more unified society provided that it establishes disability awareness from a non-ableist perspective. Presently, this is not the case for Ontario's sexuality education, and the discrimination continues to go unrecognized. In order to determine whether a disability-positive program already exists, a scoping review was conducted, focusing on sexuality and physical, visible disabilities. Out of 4,432 articles, only 13 met the inclusion criteria. The most common type of teaching interventions were didactic sessions/presentations, group discussions, roleplaying exercises, films, and independent learning modules. Seven of the programs were primarily designed for healthcare professionals, whereas six were designed for PWDs. The findings highlight a lack of research on individuals living with congenital disabilities, a focus on the rehabilitation setting, and the need for a more holistic definition of sexuality. Additionally, the lack of inclusion of disability perspectives

illustrates the need for PWDs to be involved in the development, implementation and/or evaluation of a disability-positive sexuality curriculum.

*Keywords:* sexuality, disability, curriculum, education

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## **Land Acknowledgement**

As a white settler living in Ontario, I believe it is important to recognize the province's history of colonialism and perpetuation of colonial beliefs. With this in mind, I would like to acknowledge that the land on which I am studying is the traditional territory of many Indigenous Nations including the Mississaugas of the Credit, the Anishnabeg, the Chippewa, the Haudenosaunee, and the Wendat peoples. It is now also home to many diverse First Nations, Inuit, and Métis people. Finally, I would like to acknowledge the current treaty holders, the Mississaugas of the New Credit First Nation.

## **Preface**

In April 2018, while visiting a local bookstore in Halifax, Nova Scotia, I came across Jen Powley's memoir, titled *Just Jen: Thriving Through Multiple Sclerosis*. At this point in time, I had already accepted my offer of admission to York University's graduate program in Critical Disability Studies, and I was eager to learn more about what it is like to live with a disability in Canada. Little did I know that this memoir would end up serving as the inspiration behind my Major Research Paper (MRP).

One of the most eye-opening aspects of Jen Powley's work is her candor in regard to her sexuality. Throughout the memoir, Powley shares her desire for love and intimacy, but because of her disability (as she claims), she often struggled to find a suitable male partner. Longing for affection, Powley had contemplated changing her sexual orientation during her younger years. Because "women are traditionally socialized to be caregivers and nurtures [in Western society]," she wondered, "maybe the fact that I ha[ve] multiple

sclerosis wouldn't make me untouchable in the eyes of a woman" (Powley, 2017, p.23). This notion had left me astounded. As an able-bodied woman, I have never had to reconsider my sexual orientation in the hopes of finding a potential suitor. Discovering that some individuals, such as Jen Powley, question their sexual orientation in order to accommodate the partially innate desire for intimacy helped me acknowledge the many privileges I have been afforded as an able-bodied person.

My experience as a research assistant working with individuals living with lower limb amputations has also influenced the topic of my MRP. One of the most notable findings of my current project is how people with amputations view their sexual life. When asked to rate their sexual life on a scale from 1 to 6, where 1 denotes "very dissatisfying" and 6 corresponds to "very satisfying," the most common response has been "0." Due to the strict protocol I must follow, I am unable to ask the participants why they are so unsatisfied with their sexual life, leaving me with many unanswered questions. *Were these individuals satisfied with their sexual life prior to their amputation? Does their new physical appearance deter them from seeking out sexual partners? Are people uninterested in having intimate relations with people living with amputations?* Reflecting upon Jen Powley's narrative, I hypothesize that the dissatisfaction is related to how disability and sexuality are viewed in Western society, which I will discuss in the following.

## **Positionality**

For my MRP, I chose to research the topic of disability and sexuality primarily to become a better ally for people with disabilities (PWDs) but also to raise awareness on certain pertinent disability rights issues. However, as a white, presently able-bodied cis-woman, I am by no means an expert in the field. I acknowledge that my identities have afforded me many privileges in my life and will continuously impact the way I perceive the world around me. Throughout my research and the writing of my paper, it was thus imperative for me to be critical of my positionality in order to bring any biases I may have into consciousness and to ensure I am not speaking on the behalf of the disability community. Being the voice for PWDs would go against the “nothing about us without us” philosophy that is withheld by many community members, which is a motto I both support and respect. Furthermore, as someone who is unable to fully appreciate what it is like to live with a disability, this would be inappropriate.

## **A Note on Terminology**

In Canada, person-first language (i.e. PWDs) is more widely used and accepted than identity-first language (i.e. disabled people) when referring to people living with disabilities (Withers, 2012). As a result, I will be using person-first language throughout my paper except when referring to individuals who have explicitly requested for the use of identity-first language, such as the autistic community.

Because sexuality is a broad and complex topic, I must also clearly state what I mean when I use the term “sexuality.” According to the World Health Organization (WHO), sexuality is:

“a central aspect of being human [...] encompassing sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. [It] is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, legal, historical, religious and spiritual factors.” (WHO, 2006)

I have decided to use this definition for my MRP because it aligns with both my personal beliefs and understanding of what constitutes sexuality.

## **Introduction**

The concept of normality has become pervasive in Western society, especially in the medical field. Healthcare professionals are continuously labelling individuals as “normal” or “abnormal” according to socially constructed criteria (for the most part), which serves to reinforce the normality discourse and stigmatize those with more unique characteristics. As a result, the process of normalization has led to countless injustices, particularly for people living with disabilities.

During the Canadian eugenics movement, those who were denoted as “genetically inferior”—in other words, living with a disability—were subjected to coercive sterilization. The process of sterilization labelled certain groups of individuals as unfit parents, which assuredly negatively affected their ability to find a romantic partner.

Presently, many PWDs, notably women, are still considered to be unfit for parenthood because of this eugenic mentality (Reaume, 2018). Along with sterilization, many individuals promoted the institutionalization of PWDs. Actively segregating people living with disabilities from mainstream society was another measure used to control the reproduction of “undesirable” traits. Moreover, it served to further depict PWDs as the “others” who are undeserving of the same, ethical treatment as the rest of the population. Through eugenics, the government was able to shape how the general public should view non-normative bodies: as undesirable and problematic. Despite the societal changes that have taken place over the years, this belief is still widely accepted.

The historical—and ongoing—desexualization of PWDs along with the pervasive ableist narrative in Western societies have led to the equation of disability with asexuality (Addlakha & Naya, 2017; Shah, 2017; Baxter, 2008).<sup>1</sup> Although some members of the disability community may identify as asexual, associating all PWDs with asexuality serves to infantilize these individuals, deprive them of appropriate sexuality education, and prevent them from accessing their sexual rights. However, as stated by Jen Restle, an advocate in the disability community:

“Nobody makes a public announcement that they don’t find the woman in the wheelchair to be sexy. There aren’t any articles in Cosmo[opolitan] saying, ‘Men who use crutches have zero sex appeal.’ It is one of those unspoken and often unconscious things making it impossible to prove or disprove, yet disabled people are clear that it is part of their reality.” (Restle, 2011)

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<sup>1</sup> On the other side of the spectrum, PWDs who are not viewed as asexual are often considered to be hypersexual (i.e. perverse) beings. Although this stereotype also negatively affects PWDs, I will be focusing on the asexual label for my MRP.

Issues pertaining to individuals with disabilities are seldom at the forefront of people's minds. If they were, more buildings in Canada would be accessible, more public playgrounds would have attractions that everyone can enjoy, and most importantly, more members of the community would be respected and have all of their needs adequately met. The lack of public awareness on the desexualization of PWDs suggests that the majority of the Western World unanimously agrees, either consciously or subconsciously, that these individuals are undeserving of their right to sexuality. In order to change the status quo, a significant paradigm shift is needed, but how can this be achieved? As previously discussed, I am adamant that PWDs must be the lead decision makers in disability rights issues. However, as an able-bodied woman, I can provide a unique perspective that the disability community may choose to use to support their claims, recommendations, or resolutions. Reflecting upon my past, I believe that the incorporation of disability-related topics in Ontario's educational curriculum may help to initiate this paradigm shift.

Growing up, I had very little interactions with PWDs. I was raised in a relatively affluent neighborhood and attended a privileged private school. At times when I did cross paths with someone with a disability, I would feel tense and uncomfortable. Although it is shameful to admit, I was genuinely afraid of PWDs. They were "the others"—a group of people with whom I did not know how to interact. It was not until years later, when my dad suffered from an hemorrhagic stroke, that I began to question what it truly means to have a disability. Unfortunately, many of my peers continue to perceive PWDs as "the

others,” or alternatively, sub-human. Certainly, they have never admitted this to me, not because they are ashamed of their discriminatory attitudes, but because they are unaware that their mentality is problematic in the first place. This came to my attention when I accepted a position as a camp counsellor for children with disabilities in the summer of 2016. When sharing the news with my friends, I was constantly told:

“You are such an amazing person.”

“I could never do what you do.”

“That’s a really sad job.”

I knew my friends had no malicious intent, but these statements bothered me, though I did not know why at the time. Now that I have immersed myself into the field of critical disability studies, I know that my friends were reinforcing both the charity and medical models of disability, which view disability as a tragedy. According to these models, PWDs must adjust to the world as it is rather than holding society accountable for removing the multitude of barriers to participation (Reaume, 2018). This mentality is discriminatory and makes it clear that PWDs are the unwelcome others in an ableist community.

Throughout my MA degree, I have had the opportunity to reflect upon my past and ask myself how I would currently view PWDs if my dad had not had a stroke. In all likelihood, I would have shared many of the same beliefs that my friends currently hold. However, if disability-related topics were included throughout our educational careers, I believe we would have viewed disability in a more positive light. I presume that

teaching children at a young age that PWDs are not drastically different from able-bodied people, and that these differences should be embraced rather than neglected or rejected, would foster a more inclusive environment, because disability would no longer be seen as something to fear. Instead of being classified as “abnormal” or “the others,” individuals with disabilities would hopefully be viewed as valued members of society who are deserving of the same rights as those without disabilities, including but not limited to the right to sexuality.

In many Western countries, schools are required to provide their students with a sexuality education. This sexuality program could help prevent the continued desexualization of PWDs and promote a more unified society if it establishes disability awareness from a non-ableist perspective. Furthermore, it would allow PWDs who attend these classes to access pertinent knowledge regarding their sexuality. In the following, I will discuss and analyze the current state of sexuality education in Ontario to provide an example of what students are learning in these programs. I will then present the scoping review I have conducted, describing the established teaching interventions used to educate people living with or without a disability on the topic of sexuality and disability around the world.

### **Ontario and Sexuality Education**

In 2018, Lisa Thompson, Ontario’s newly appointed Minister of Education, announced the repeal of the 2015 Health and Physical Education (HPE) curriculum along with the reinstatement of a revised 2010 edition (Pilkey & Malloy, 2018). Although only

a small portion of the HPE curriculum is devoted to sexual education, the changes made to the program's learning objectives have generated significant controversy. Many students, parents, and teachers from all over the province have expressed their concerns with the modifications, notably with the removal of LGBTQ+ topics (Jones, 2019; McQuigge, 2018). The nongovernmental organization known as the Canadian Civil Liberties Association (CCLA) also joined the debate, claiming that the incumbent Conservative government's actions serve to discriminate against the LGBTQ+ community (2018).

A few months following Lisa Thompson's announcement, the CCLA collaborated with Becky McFarlane, a queer mother of a child enrolled in an Ontario public school, to take the Ministry of Education to court (Teotonio, 2018). The rationale for their lawsuit is that LGBTQ+ individuals are just as deserving of a relevant, factual sexual education as their non-LGBTQ+ classmates. Furthermore, including topics such as same-sex relationships would help students further understand LGBTQ+ issues, which could improve bullying rates and foster safer school climates. In court, the lawyers stated that the repeal infringes upon "Canada's Charter of Rights and Freedoms that guarantees equality and security; the Ontario Human Rights Code that outlaws discrimination; and the [province's] Education Act that requires schools [to] be an inclusive environment for students and families" (Teotonio, 2018). Although their lawsuit was unsuccessful (CCLA, 2019), Lisa Thompson has recently publicized that lessons on same-sex

relationships and gender identities are to be reintegrated within the 2019-2020 HPE curriculum (Jeffords, 2019).

The fact that Ontarians are taking the time to protest against the 2010 HPE curriculum illustrates their desire for an inclusive, comprehensive sexuality education program. This is unsurprising given the effect sexuality has on our physical and mental health. When compared to more traditional or abstinence-only sex education curricula, the newer models take on a more holistic approach and focus on empowering students to realize their health, wellbeing, and dignity (United Nations Educational, Scientific and Cultural Organization [UNESCO], 2018). Furthermore, they often utilize a more fluid definition of sexuality and thus provide a wider variety of topics such as relationships, interpersonal skills, and sexual expression. (Advocates for Youth, 2009). According to UNESCO (2018), children and youth are in need of comprehensive sexuality education because of the inconsistent, and potentially damaging, information they receive on the topic as they develop into adulthood. The current evidence-based research on the matter (Baams, Dubas & van Aken, 2017; Kohler, Manhart & Lafferty, 2018) also supports the need for a more holistic approach to sex education, as it has shown to lead to better health outcomes and foster more inclusive environments. Evidently, sexuality education that provides students with accurate information and the ability to develop a sex-positive attitude can have a favourable impact on the welfare of a population. However, in order for society to truly benefit from these programs, they would have to stand in opposition to the prevailing heteronormative, ableist discourse.

Ensuring that LGBTQ+ topics are incorporated into a sexuality program is needed to create a more inclusive society. Therefore, I applaud those who have voiced their concerns against the repeal of the 2015 curriculum. In a similar vein, the exclusion of disability-related sexual health concerns from the curriculum continues to go unrecognized, which I find terribly problematic. Michael Briant, the head of the CCLA, once said the following during an interview regarding the 2010 HPE program:

“What the government did is it took out any reference to a group of Canadians who are real and who have lives and who deserve to be included in this curriculum and the only reason that they’re being excluded is because the government thinks that that content is age inappropriate **and that’s just homophobic**” (Jones, 2019).

Briant’s claim is powerful and can be extended to recognize ableism as well, yet very few have been advocating for the community. I believe that topics related to disability and sexuality are excluded not because the content is age inappropriate, but rather because the policy-makers consider such knowledge to be irrelevant, **and that’s just ableist**. Even if the exclusion of disability topics was unintentional, it is nonetheless an act of discrimination. LGBTQ+ rights and the rights of PWDs should be treated equally in the context of the Ontario sexuality curriculum dispute, as both of these marginalized groups deserve to be represented in the program. Many, if not all, of the claims made in the CCLA lawsuit also pertain to PWDs, but it appears as though many have not made this connection. This unfortunate, but unsurprising, reality reflects how the Western World continues to infantilize and desexualize the disability community. However, it does

illustrate the need to educate the public on disability-related issues and dismantle the normalization of ableism.

When implementing any new school curriculum, I believe students should be involved in the decision-making progress, as they will be the ones who will be the most impacted by the change. In the case of Ontario's sex education reversion, this did not occur. On August 22, 2018, the Office of the Premier released a statement informing the public that the Government of Ontario will be engaging in consultations with parents across the province in the fall. Through the use of online surveys, telephone calls, and a "submission platform," parents were supposedly able to have their voices heard on topics such as the sex education reversion. However, elementary and secondary school students were not given the same opportunity. The 519, a local charity devoted "to the health, happiness and full participation of the LGBTQ2S communities" remarked how the consultation process described by the Office of the Premier did not provide "any opportunity for meaningful, interactive, and critical discussions, and raises questions about the reliability of the consultation's findings" (2018). A parent-centred consultation may work to ensure that the rights of parents are maintained, but what about those of the students? Another question arises in regard to individuals who are unable to partake in the consultation process due to accessibility reasons. How do these individuals get their voices heard? In order for the Government of Ontario to gather the opinions of a representative provincial sample, these questions must be addressed.

### The 2010 HPE Curriculum

While reading the interim 2010 HPE program, it is evident that PWDs were not consulted during the revision process. Out of all the 60+ core sexuality education learning objectives for students in Grades 1-8, only three explicitly incorporate the topic of disability:

1. “explain how the portrayal of fictional violence in various media (e.g., television dramas, video games, Internet, movies) can create an unrealistic view of the consequences of real violence (e.g., physical trauma, **chronic disability**, family stress, death).” (Grade 3 learning objective C3.2; Ministry of Education, 2018, p.111)
2. “explain how a person’s actions (e.g., negative actions such as name calling, making homophobic or racist remarks, **mocking appearance or ability**, excluding, bullying, sexual harassment; positive actions such as praising, supporting, including) can affect the feelings, self-concept, emotional well-being, and reputation of themselves and others.” (Grade 5 learning objective C3.2; Ministry of Education, 2018, p.146)
3. “recognize the responsibilities and risks associated with caring for themselves and others (e.g., while babysitting, staying home alone, caring for pets, volunteering in the community, **assisting someone with a disability**, preparing meals, travelling to and from school and other locations), and demonstrate an understanding of related safety practices and appropriate procedures for responding to dangerous situations (e.g., safe practices for preparing food; responses to allergic reactions, fire, sports injuries, dental emergencies, hypothermia, bullying)” (Grade 6 learning objective C3.2; Ministry of Education, 2018, p.162)

Although children need to understand the consequences of bullying and the importance of helping those who ask for assistance, neither of these learning objectives serve to abolish the misconception that disability equates to asexuality. To make matters worse, the curriculum actually perpetuates both the charity and the medical models of disability. The Grade 3 learning objective written above, for example, implies that living

with a chronic disability is a personal tragedy. Furthermore, the wording of the Grade 6 learning objective suggests that PWDs are always in need of assistance and that it is the students' responsibility to take care of them. Not only are these statements false, but they are also damaging in that they reinforce the idea that PWDs are inherently different than people without disabilities, illustrating how governmental policies continue to oppress the disability community. This ableist discourse is prevalent throughout the guide, leading me to suspect that the authors of the 2010 HPE curriculum were able-bodied individuals. Thus, to change the status quo, PWDs should be involved in the creation of an inclusive sexuality education.

If the exclusion of LGBTQ+ topics from the curriculum is viewed as a human rights issue, so too should the exclusion of disability topics, as students with disabilities are being denied the same opportunity as their able-bodied peers to learn about their sexual health. Examples of disability-related sexual health concerns include worrying whether a partner will find them attractive, as Jen Powley expressed in her memoir, the physical possibility of having children, or issues surrounding consent. Many PWDs are more reliant on other people for assistance in their day-to-day activities than the general public, resulting in them being more susceptible to abuse (Reid, 2018). Although the Toronto District School Board (2018) claims that consent is incorporated in the 2010 curriculum—despite the term “consent” not being written anywhere in the guide—it is unlikely that it is discussed in the context of caregiving. If a student is unable to connect the knowledge they have learned about consent in romantic relationships to consent in

caregiving relationships on their own, they are likely to be at greater risk of sexual exploitation. In a 2015 study on abuse of college students with disabilities at a large northeastern public university, 40% of students who were abused in the past year stated that they had “little or no knowledge of abuse-related resources” (Findley, Plummer & McMahon). As such, only 27% of these students reported the abuse. There are many other barriers to disclosure that would prevent PWDs from reporting abuse, such as the fear of a caregiver withdrawing lifesaving services or the inability to find a replacement due to financial reasons (Reid, 2018), illustrating the importance of educating PWDs about their sexual rights.

Evidently, students with disabilities are unable to adequately learn about their sexual health from a sexuality education program that does not incorporate disability-related topics. Because many PWDs are sexually active and continue to receive inadequate sex education, they are at greater risk of unwanted pregnancies, sexually transmitted infections, harmful sexual behaviours, and sexual exploitation (Abells, Kirkham, & Omstein, 2016). As Dr. Lunksy explains (2018), PWDs are kept vulnerable through their exclusion in sexual health discussions. Along with these risks, it is important to note that like their peers, individuals living with a disability are also deserving of intimacy and sexual pleasure. Having a disability of any form does not equate to someone’s sexuality, their desire to express it, or the emotions that accompany it (Better Health Channel, 2017). However, the current state of Ontario’s sex education

curriculum suggests otherwise, and if students with disabilities internalize this belief, their self-esteem may decline.

Without extensive sexuality education, students may be limited in their ability to form their true identities and fully grow as individuals, which would hinder their socio-sexual development. Although many of the sexuality learning objectives of the 2010 curriculum apply to PWDs, I would assume that the dominant ableist narrative makes these students feel as though the information is irrelevant to them, preventing them from acquiring valuable knowledge. What is interesting to note is that at the beginning of the curriculum, the authors provide a few guidelines for teachers working with students with disabilities (Ministry of Education, 2018, p.48-51). For students who are unable to participate in the regular curriculum, the Individual Education Plan (IEP) committee will create modified sexuality learning objectives that represent “specific, realistic, observable, and measurable achievements” (Ministry of Education, 2018, p.50). At first glance, this may appear to be a fair solution. No two PWDs are alike, making it highly unlikely that an accessible, disability-friendly curriculum will be able to meet the needs of every student. In this respect, modifying the curriculum seems acceptable. However, if the members of the committee believe, either consciously or subconsciously, that PWDs are asexual, they may choose to forgo the majority of the sex education learning objectives in the student’s plan to make room for “more important” goals. To render matters worse, students under the age of 16 are legally not entitled to be present at their IEP development meeting (O. Reg. 181/98 under the Education Act, 2005; Ministry of

Education, 2004), which prevents those who want sex education to advocate for themselves and their right to sexual health knowledge.

According to the Government of Canada (2014), 88.7% of Canadian youths with disabilities who attend school are not isolated in separate classrooms, meaning, the majority are able to participate in the regular curriculum with or without accommodations. The 2010 curriculum has few if any guidelines for teachers to follow when it comes to providing this population with an adequate sex education, and as a result, the students are expected to meet the same learning objectives as their peers. This would be appropriate if the curriculum incorporated a non-normative discourse, but as previously discussed, this is not the case. The authors of the HPE program do acknowledge that “some additional considerations may be relevant” when teaching certain students with disabilities, such as their “greater risk of exploitation and abuse” (Ministry of Education, 2018, p.51); however, these considerations are up to the teacher’s discretion and would really only apply to students requiring a modified curriculum. In short, if the developers of the 2010 HPE program were truly invested in creating “an atmosphere in which students of all body shapes and sizes, abilities, gender identities and sexual orientations, and ethnocultural, racial, and religious backgrounds can feel accepted, comfortable, and free from harassment” (Ministry of Education, 2018, p.11), the topic of disability would have been included in a positive manner, but this did not occur.

### **The Need for a Formal Sexuality Curriculum**

While in the preliminary stages of my MRP, I began to consider the importance of a mandatory sex education program. Growing up, I attended the same private school from Pre-Kindergarten to Grade 12, and I can only recall attending one sexuality education class. In Ontario, private schools are not required to follow the same educational curricula as public schools (Ministry of Education, 2013), and because my school prized itself on its “academic rigour,” it is very likely that we were only offered that one class. As a result, my sexuality education was far from ideal, but I still managed to become relatively sexually competent. The majority of my sexual knowledge came from my friends and family who share many of the same identities as me, my own online research, and the media. As a white, heterosexual, able-bodied cis-woman, the heteronormative discourse did not yield any cognitive dissonance within me, and therefore, becoming sexually competent was not a challenge. However, I am aware that this is an exception rather than the norm. I was fortunate that my family and my friends’ families were, more often than not, highly educated individuals, which allowed me to have access to factual sexual health knowledge. Although the media very rarely conveys accurate sexual information, I was still able to identify with the heterosexual characters, which most definitely played a role in my sexual development. Lastly, identifying as a heterosexual cis-woman allowed me to ask questions regarding my sexuality because I never feared being judged, shamed, or discriminated against. Acknowledging my privileges, I arrived at the conclusion that formal sexuality education programs should be mandatory in

schools to ensure everyone has the ability to become sexuality competent. Certain individuals, particularly PWDs, struggle to acquire sex education beyond the classroom, making it especially important for these students to have access to appropriate sexuality information at school.

According to a 2008 study, 1171 Canadian youths aged 14 to 17 years old considered their school (51%), parents (43%), friends (29%), and doctors (17%) as the most useful/valuable sources for learning about sex (Frappier et al). As previously discussed, school sexuality curricula are seldom a sufficient resource for PWDs, owing to the prominent able-bodied discourse. Thus, it is likely that students with disabilities rely more on the other sources to fully develop their sexuality. However, are these sources any better? For youths who have a close relationship with their family, parents and siblings can be a valuable sexual health resource. Ashcraft and Murray (2018, p.1) believe that “parents are the single largest influence on their adolescents’ decisions about sex,” and therefore can have a significant impact on their children’s sexuality. Unfortunately, able-bodied family members are unlikely to have adequate knowledge on disability and sexuality due to its limited exposure in sexuality education, social conversations, and the media (Esmail, Darry, Walter & Knupp, 2010). As a result, they would most likely be unable to provide their children with appropriate information.

Even if someone with a disability has a positive relationship with their family, their parents may still be reluctant to speak to them about their sexuality. Murphy and Elias note in their 2006 study that the fear of becoming a victim of sexual abuse has led

parents to protect their children from unsupervised social contacts and knowledge about sex, despite this actually heightening their risk for sexual exploitation. Another reason why parents may not discuss sexuality topics with their children is because of infantilization, which is a particular problem for individuals who require assistance with many basic activities of daily living. Although infantilization often occurs subconsciously, it acts to deprive PWDs of their right to healthy sexual expression and is a subtler form of social control. Friends can be a better resource because they are less likely to treat the person as a child. But again, the limited exposure of sexuality and disability in Western society suggests that they too do not possess sufficient knowledge to be able to effectively teach sexuality, assuming that they are able-bodied individuals. Other PWDs can be useful, as they are more likely to have a better understanding of the challenges associated with sexual expression. However, not everyone with a disability is friends with other PWDs who have similar needs and desires.

Well-informed family physicians or other knowledgeable healthcare professionals can also be a valuable sex education resource for PWDs if they can help their patients “learn and adapt to changes in [their] life, and can advocate for [them] when needed” (Eastgate, 2005, p.163). Because individuals with disabilities are often devalued and dehumanized, having an advocate can confer certain benefits. However, unlike the other sources discussed, individuals may have to pay a fee to obtain sexuality education from a doctor or a nurse. Healthcare is expensive, and thus those living in a country without universal healthcare may not possess the financial means to visit a family physician.

Additionally, since sexuality is not considered to be a pressing health issue, particularly for PWDs, it is unlikely that insurance companies will cover the expenses associated with this type of appointment. Another problem stems from the physical barriers some must overcome to actually meet with a physician. Contrary to popular belief, medical offices are not very accessible. The common examination table used for female pelvic exams illustrates this point well. Female patients are expected use a small step ladder to step up onto the table without handrails available for support. They are then required to place their legs into the stirrups at a precise angle to allow the healthcare professional to complete the examination. Although more accessible medical equipment exists (Welner & Hammond, 2009), only 8.4% of primary care clinics in America reported having height-adjustable examination tables (Mudrick, Breslin, Liang & Yee, 2012). This is an example of systemic ableism in the healthcare field, which reinforces the false assumption that the sexuality of PWDs is non-existent and prevents PWDs from attaining their basic right to health. Those who are fortunate enough to meet with a physician are not guaranteed to leave their appointment with a better understanding of sexuality. Peter Baxter, a practicing physician, admitted in his 2008 paper that discussions of sexual matters are not frequent with his patients living with a disability and presumes this is the case for the majority of his colleagues. In the 2019 UofTMed Magazine Sex Issue, Andrew Gurza, who identifies as a queer, disabled man, confirmed that healthcare practitioners are not comfortable talking about sex with their patients with disabilities, as illustrated in the following:

“[The doctor] looked me up and down, motioning with his eyes that my disability made him uneasy, and said that he couldn’t help me and I would have to go elsewhere. He didn’t offer a reason, and I had to slog back in the slush and snow. I ended up going to the hospital two days later to try and get tested [for sexuality transmitted infections]. When I approached the desk to ask for help, after explaining myself, the nurse looked at me and exclaimed: “Well, what do you need that for?” It was as if the whole idea of a disabled person trying to access sexual health services was completely unheard of and foreign to her. When I finally saw a doctor, he looked annoyed with me. He told me that I should go back to my [general practitioner’s] office. After pleading with him about access, the doctor begrudgingly gave me the tests.” (Gurza, 2019, p.16)

Evidently, those who want to discuss sexuality-related issues with their practitioners will most likely have to initiate the conversation on their own, and in some cases, continuously advocate for their right to sexual health.

According to McCabe, Cummins and Deeks (2000), PWDs receive most of their sexuality education from the media. Although some outlets may be beneficial, relying on TV shows, music, and pornographic magazines for information is a cause for concern. The Council on Communications and Media (2010) report a significant disconnect between what the mainstream media portrays (i.e. casual sex with no consequences, limited use of protections and contraceptives, a lack of sexual consent, etc.) and what children and youth should be learning in regard to sexuality (i.e. autonomy, different forms of intimacy, respect, etc.). Media content rarely reflects reality and this may not be fully understood by children and youth. As a result, the knowledge gained from these sources could have damaging effects on the individual’s health and wellbeing. People with disabilities are also underrepresented in popular culture, which not only serves to marginalize and stigmatize members of the community but also deprives them of positive

role models. In Western society, only “conventionally” beautiful people are represented in mainstream media (i.e. white, well dressed, physically fit, young, and able-bodied people). Because beauty is highly valued in our society, this underrepresentation insinuates that PWDs are unattractive or visually unappealing, which could lower a person’s confidence and self-worth. Additionally, when individuals with disabilities are featured in the media, they are often negatively portrayed and inappropriately represented (United Nations, n.d.), illustrating how relying on the media for sex education can lead to poor practices and limited sexual development for PWDs.

Evidently, there are many different avenues to gain sexual health knowledge. Unfortunately, many of them may not be useful or accessible to PWDs. In most if not all of the Western World, children and youth of a certain age are required to attend school. Therefore, many individuals with disabilities are forced to rely on their school’s sex education program. From my perspective, having a mandatory sexuality curriculum that incorporates disability perspectives and challenges ableist attitudes would benefit PWDs, but again, this is not for me to decide. However, as an able-bodied woman, I do believe that such a program would allow other able-bodied students to gain a better understanding of disabilities. In return, this could foster better school climates, promote a more inclusive society, and ideally abolish the binary categorization of “normal” versus “abnormal” or “abled” versus “disabled.”

Formal sexuality programs have the potential to improve the lives of many, but they do have their limits. A school that incorporates disability perspectives in their

sexuality education will see little-to-no changes in their students' attitudes towards PWDs provided that the overall curriculum is not modified as well. If the school's biology curriculum focuses on the medical model of disability, the English curriculum only incorporates novels with able-bodied, heterosexual main characters, and the history curriculum does not include a discussion of normality, the sexuality curriculum would lose its credibility. In order for a program to be effective, a transdisciplinary approach is needed to allow students to consolidate their newfound knowledge and apply it to the real world. An example of a transdisciplinary approach is the SOGI 123, a **Sexual Orientation and Gender Identity** resource implemented in certain schools across Alberta and British Columbia. SOGI 123 is unique in that it is not a curriculum but "a resource to assist in helping school districts and educators to build inclusive environments for students of all sexual orientations and gender identities" (Campbell River School District, n.d.). In order to provide a SOGI-inclusive education, the school must follow the resource's three components (hence the name **SOGI 123**): (1) policies and procedures, (2) inclusive environments, and (3) teaching resources. In short, these SOGI-inclusive education "essentials" are the changes that need to be made to a school's existing curriculum in order "to reduce discrimination, suicidal ideation, and suicide attempts for all students," create positive learning environments, and appropriately teach diversity and respect (The ARC Foundation, n.d.). From my understanding, these goals would be accomplished by creating a positive shift in the school's hidden curriculum, which consists of the implicit values, behaviours, and attitudes that students learn through socialization and interactions

with their peers and educators (Alsubaie, 2015). All schools have a formal and informal curriculum that can shape the minds of young learners. At times, a school's hidden curriculum can be more influential than the formal one and thus needs to be addressed by the education system. If the informal education replicates some of the dominant Western social and cultural norms, this would create a hostile learning environment for marginalized students (Walton, 2005). Additionally, it would compromise the effects of a well-designed disability awareness program. Although SOGI 123 most definitely has some flaws, it may be a useful framework for program-developers to familiarize themselves with in order to combat the current disability-related injustices in schools.

## **The Scoping Review**

### **Methodology**

After reviewing Ontario's discouraging 2010 sexuality curriculum, I wanted to know whether an adequate, disability-positive sexuality education exists. To answer my question, I decided to conduct a scoping review, studying already-established teaching interventions used to educate people, either with or without disabilities, on the topic of sexuality and disability. The purpose of the scoping review will be to: (1) determine whether there are existing programs for able-bodied individuals and PWDs to learn about disability and sexuality, (2) discover what is being taught in these programs, and (3) identify any current gaps in knowledge. However, prior to commencing the review, I had to examine the existing literature on Google and Google Scholar.

Using Google Scholar, I searched “sex education for disabled people,” “sex education for people with disabilities,” and “sexuality and disability.”<sup>2</sup> There were no significant differences in the types of articles retrieved from the searches except for their publication date. For the first two searches, more than half of the papers were published prior to the year 2000, whereas the “sexuality and disability” search generated relatively more current articles; however, many of them were still published in the late 20th century. With sexuality becoming less of a taboo subject, I anticipated all of the papers to be fairly current, hence why I decided to investigate the matter further. Through my research, I learned that the sexual revolution began around the 1960’s (Escoffier, 2004; Smith, 1999). Owing to the fact that research often mimics the current socio-political climate of the time, the publication dates were more understandable. However, the fact that the most relevant articles were so old led me to question whether there have been any significant changes to the sex education programs over the years.

The literature review also brought my attention to the types of disabilities academics were studying: (i) individuals with intellectual and/or developmental disabilities and (ii) individuals with physical disabilities. Although this dichotomization of disability is fairly common, it is problematic. Firstly, the categorization suggests that people with intellectual disabilities are distinct from people with physical disabilities, when in reality, many PWDs live with both. Secondly, it implies that other types of disabilities do not exist, which is not the case. There are numerous types of disabilities

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<sup>2</sup> Because I am interested in interventions used around the world, I needed to incorporate both identity and people-first language in my search.

(i.e. sensory, emotional, chronic illnesses, etc.) and they are all equally deserving of the same recognition. Without their recognition, identifying all of the possible barriers to participation within a community would not be possible.

Along with the dichotomization, I noticed a lack of research on sexuality teaching modalities for people with physical disabilities compared to those for people with intellectual disabilities. According to Swango-Wilson (2011, p.113), “individuals with [intellectual or developmental disabilities] may lack experience with skills needed for relationship building and healthy sexuality,” yet the same can be said about people with physical disabilities, so why the discrepancy? Again, the dichotomization may be at play. If academics falsely assume that all students with physical disabilities have the ability to learn about sexuality—or any other topic for that matter—in the same manner as their able-bodied peers, then in their minds, these students would not require a modified sex education, and as a result, there would be little-to-no need for research in the field.

Acknowledging that many important and useful information goes unpublished, I decided to explore the grey literature on Google as well, using the same search words as before. Again, I found a greater number of articles discussing sexuality topics for individuals living with intellectual, rather than physical, disabilities. However, the individuals with disabilities were rarely the target audience. Many of the articles and websites were designed to reshape society’s views on disability and sexuality, and advocate for proper sex education programs for people with intellectual disabilities. In addition, there were some created to provide parents or caregivers resources for learning

about the subject matter (Advocates for Youth, 2018; Antigonish Women's Resource Centre & Sexual Assault Services Association, 2018) and how to speak to their child or the recipient of care about sexuality (State Government of Victoria, 2018; Clatos & Asare, 2016).

After reviewing the literature and reflecting upon my interests, I decided to limit my scoping review to teaching interventions used to educate people on the topic of sexuality and visible, physical disabilities, around the world. Although a disability-positive sexuality program will have to include all types of disabilities, I chose to study visible, physical disabilities for a variety of reasons. First and foremost, I have a greater connection with the community given my current field of work, and I hope the knowledge I gain from this review will allow me to better assist my study participants and the individuals I will work with moving forward in my career. Secondly, I want to learn how a sexuality program can be adapted to challenge Western society's definition of a "normal" body. Individuals with visible disabilities are more likely to be labelled as asexual than other PWDs solely because of their physical appearance (Esmail et al., 2010). Therefore, programs discussing visible, physical disabilities may be the most useful in deconstructing the norm. Lastly, due to time constraints, I am limited in the number of articles I can review independently and consequently had to narrow down my research question.

To conduct the scoping review, I used specific search words that included the following three core concepts and their associated keywords: teaching interventions,

sexuality, and disability (Table 1). Because many of the published articles relating to disability and sexuality were published in the 20<sup>th</sup> century, I also had to incorporate outdated and insulting terminology in my search, otherwise potentially relevant articles may have been omitted. Originally, my search strategy had more than 30 keywords for the sexuality core concept. The intention was to incorporate as many sexuality components as possible to ensure I have access to the greatest number of sexuality-related articles. Furthermore, I wanted my search strategy to reflect the WHO's broad definition of sexuality (2006). However, when this strategy was inputted into the databases, over 9,000 articles were retrieved. With the limited time available to conduct the scoping review, it would not have been possible for me to scan all of these articles alone. Therefore, important words such as "relationships," "dating," "self-esteem," and "queer" had to be removed.

In order to retrieve the articles, I inputted my search strategy (Table 2) into the five databases: MEDLINE (Ovid interface), PsycINFO (Ovid interface), CINAHL (EBSCO interface), Web of Science, and SCOPUS (Elsevier interface). Unlike the others, Web of Science and SCOPUS search through published and grey literature, which allowed me to obtain articles from a wider range of literature. Unfortunately, the grey literature these databases have access to is unrepresentative of the articles that laypeople find when searching phrases such as "disability-positive sexuality education programs" on Google, for example. Owing to its abundance, I was unable to adequately search through the grey literature myself, which is a significant limitation of my scoping review.

Because most academic journals are very unaccommodating, individuals who are unable to navigate the system or meet the required standards—despite it being no fault of their own—are more likely to publish their work or share their stories on websites that can be readily accessed using Google. It is possible that PWDs have posted their desired disability-positive sexuality education online, but because I am relying on academic journals, these postings will not be found in my scoping review. However, I would like to note that policy makers often solely rely on studies published in academic journals when developing new programs because of their supposed reliability and validity. Therefore, omitting this type of grey literature will allow me to have a better understanding of the resources to which policy makers have access to and whether or not they are appropriate. Another limitation is that the majority of these databases search through medical journals exclusively. Because the medical model of disability is widely utilized in the healthcare system, the studies published in these journals will most likely depict disability in a negative light, which stands in direct opposition to the goal of my scoping review. Nonetheless, I was required to use these databases, as they were the only ones to which York University students have access (Maimets, 2019).

With my final search strategy, 4,942 articles were retrieved, which were then imported into the program Mendeley. Using Mendeley's deduplication feature, 510 articles were removed, yielding a total of 4,432 articles for screening (Figure 1). The screening process was divided into two phases: (1) title and abstract screen and (2) full text screen. In order to be eligible for inclusion, the articles must have been written in

English and thoroughly defined a teaching intervention that discusses sexuality in relation to visible, physical disabilities. Studies not available in English or in which a sexuality program (i) was not accurately described, (ii) did not include both sexuality and visible, physical disability topics, or (iii) did not differentiate between types of disabilities were excluded. To access the full text of the articles meeting the inclusion criteria for phase 1, York University's online library was used. If unsuccessful, the articles were searched using Google. The full texts that met the criteria for phase 2 were then analyzed using a critical disability theory (Rocco, 2005) and a queer theory (Callis, 2010) lens.

## **Results and Discussion**

The title and abstract screen yielded 64 articles for inclusion; however, only 13 were eligible for data analysis (Figure 1). The reasons for exclusion were as follows: unable to access full text (n=20); no discussion of sexuality (n=14); visible, physical disabilities were not included (n=10); no description of a teaching intervention (n=5); full text not available in English (n=1); and unrelated to disabilities (n=1). Having to eliminate articles solely because I was unable to access their full text negatively impacts my review, as many of these articles may have met the inclusion criteria for phase 2. Although I could have tried to contact the authors of these articles or paid various journals to access their full texts, I did not have the appropriate time or resources to do so, which I acknowledge as another significant limitation of my work. However, even with these resources, acquiring the full texts would most likely still have been a challenge since all 20 of them were published between 1964 and 1988. Consequently, the majority

of the articles eligible for data extraction were fairly current, which does not accurately reflect the state of the literature, as illustrated in my literature review. Excluding these older articles also limits my ability to determine whether disability-positive teaching interventions have changed over the years, which would have been an interesting finding.

One challenge I had encountered during phase 2 of screening was determining whether visible, physical disabilities were incorporated in a program. I erroneously assumed this would be obvious, as I did not take into consideration that certain conditions may lead to visible, physical disabilities for some and invisible disabilities for others. Examples include multiple sclerosis, strokes, and traumatic brain injuries. In addition, while scanning through the articles, I began to question where blindness and deafness fall on the disability spectrum. These challenges highlighted the importance of a disability-positive sexuality education that incorporates all types of disabilities and helped further my understanding of just how limiting labels can be. To overcome these obstacles, I had to adjust my inclusion criteria. If the authors did not describe what they believe constitutes a disability, or if they only mentioned disabilities that are not typically visible and physical, the studies were excluded. I also chose to exclude studies focusing on deaf, hard of hearing, or blind individuals, as I believe they represent their own categories of disability.

In regard to the 13 articles eligible for data extraction (Table 3), the majority are North American studies (n=7) and were published after the year 2000 (n=8). The most common type of teaching interventions employed were didactic sessions/presentations

(n=8), group discussions (n=9), roleplaying exercises (n=4), films (n=4), and independent learning modules (n=3). However, the majority employed a multi-modal approach (n=10). One of the more notable findings from the data analysis is that the programs designed for individuals living without a disability either worked, or were training to work, in a rehabilitation healthcare centre (n=7). Because rehabilitation is the only medical field devoted to helping PWDs, staff members working in such a facility must be able to appropriately assist members of the disability community, which explains the participant demographics. The overall goal of these studies was to prepare the healthcare professionals to speak about sexuality-related concerns with their clients, as “sexuality is part of the overall healthcare agenda” (Higgins et al, 2012). Although I applaud the authors for acknowledging the importance of sexuality and their attempt at recalibrating how people view disability and sexuality, I question the impact of their teaching modalities.

Five out of the seven studies (Gianotten, Bender, Post & Mechtild, 2006; Higgins et al, 2012; Kim, Murphy, Kim, Moberg-Wolff, & Trovato, 2010; Neistadt, 1986; Simpson, Anwar, Wilson & Bertapelle, 2006) focused heavily on medical sexology, which is concerned with “sexuality, sexual dysfunctions and sexual problems in patients with physical impairments due to congenital defects, disease, accidents or medical interventions” (Gianotten et al, 2006, p. 303). This is problematic, as the medicalization of sexuality serves to further define PWDs as deviant and in need of constant medical intervention. Neistadt’s study (1986) made this abundantly clear with their three-hour

education session that was devoted to “normal” sexuality. Another detail I noticed during the data extraction is that none of the authors defined what they meant by “sexuality” in their work. However, since they primarily focused on the medical aspects of sexuality, it is reasonable to assume that a more medical definition of the term was employed when creating the teaching interventions.

According to Merriam-Webster’s Medical Dictionary (n.d.), sexual intercourse is defined as “heterosexual intercourse involving penetration of the vagina by the penis.” This dominant, heteronormative discourse on human sexuality not only delegitimizes relationships that involve other forms of sex, but it also negatively impacts the self-esteem of individuals who are unable or unwilling to engage in this type of activity. Therefore, instead of trying to “fix” PWDs through the use of medical interventions to allow them to have penetrative sex, which appears to be the goal of these studies, healthcare professionals in the rehabilitation setting should be informed regarding how to deconstruct the prevalent definition of sex with their patients in order to improve their quality of life. Unfortunately, the goal of rehabilitation is often to better equip PWDs to live in a disabling world rather than attempt to remove the barriers that societies impose on these individuals. As stated by the WHO (2011), rehabilitation is “a set of measures that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environments.” Although omitting the social aspect of sexuality is troublesome, viewing the patient as problematic appears to be the basis of rehabilitation services. Thus, a pressing question arises. Can a

disability-positive sexuality program be incorporated in the training of rehabilitation staff? In short, it can, as illustrated by the other two articles (Cole & Stevens, 1975; Halstead et al, 1976) that did not focus heavily on medical sexology.

The remaining two articles are unique in that the teaching interventions were designed for the healthcare professionals and the patients of the designated rehabilitation facilities. They were also the only studies to incorporate PWDs in the program itself. Along with group discussions and viewings of relevant films, the participants of both studies attended a panel session run by PWDs who shared their personal sexual adjustments after acquiring their disability. I believe it is imperative that all teaching interventions relating to disability and sexuality give PWDs a platform to be heard, as they are the ones who will be the most affected by the programs. Doing so will also help to establish appropriate clinical practices that accurately meet the needs of the disability community. Ideally, PWDs would have been involved in the program's developmental stage as well to ensure the teaching modality did not perpetuate the dominant ableist and heteronormative definition of sexuality that is present in Western societies. However, since the studies were published in 1975 and 1976, and because emancipatory research was most likely not as well-known at the time as it is now, I do not believe it is reasonable to expect that level of work from the authors.

As previously mentioned, these two articles did not heavily focus on medical sexology like the others, which I hypothesize is due to the inclusion of PWDs as part of the studies' targeted audiences. Because most laypeople are unfamiliar with medical

jargon, a program that solely discusses the medical aspects of sexuality would be futile for these participants. Furthermore, the majority of patients are usually more interested in learning what can be done to improve their quality of life rather than knowing the intricate scientific details of their condition. Assuming the program developers were aware of this, they were then forced to expand their horizons and examine sexuality from a more holistic perspective in order to create a teaching intervention that is useful for all its audience members. The following are examples of the goals Halstead and colleagues wanted to accomplish through the use of their teaching intervention, which illustrate their use of a more disability-positive sexuality framework:

“(4) to increase tolerance of the wide variety of human sexual behaviors and responses; [...] (6) to foster the recognition that we are all sexual people whether professional or nonprofessional, disabled or able-bodied, and to initiate discussion, as equals, of this aspect of our lives” (1976, p.1352).

Although these articles were published in the 20<sup>th</sup> century, they provide a more well-rounded definition of sexuality when compared to the previous five articles. Furthermore, the authors appear to be truly invested in changing the asexuality stereotype, unlike the others, who focus on “rehabilitating” people to meet the heteronormative and able-bodied definition of sex. This finding suggests that disability-positive sexuality teaching interventions can be created for rehabilitation staff provided that the program developers are willing and able to acknowledge that sexuality is not solely a medical issue. In addition, it highlights the need for program creators to analyze all of the existing literature on a certain topic instead of limiting their search to more recently published

studies—a common practice in the scientific community—as important knowledge may be missed.

In all of the seven articles, the healthcare professionals were working with individuals with acquired disabilities. In other words, there was not a single study that analyzed a teaching modality used to educate people without disabilities on the topic of sexuality and congenital disabilities. There are many reasons why this may be the case. According to Bogart, Rosa, and Slepian (2018), individuals with congenital disabilities are more stigmatized than people with acquired disabilities even when the same disability is present (i.e. a person born without their left lower limb faces more discrimination than a person who lost their left lower limb while serving their country), suggesting that members of each group are viewed as inherently different from one another in the Western World. If society perceives individuals born with a disability as asexual and those who acquire a disability as sexual beings, then this essentialist way of thinking may be the culprit for the lack of research on the matter. Suppose academics subconsciously believe that asexuality is an intrinsic characteristic of the congenital disability identity. They would accordingly not devote their resources to creating a program that suggests otherwise. Another reason underlying this difference could be that individuals with acquired disabilities are more vocal about their sexuality health needs. Unlike people who are born with physical disabilities, these individuals once benefitted from able-bodied privileges and were able to access their sexual rights more easily. However, once they acquired their disability, these rights were most likely taken away from them. Knowing

what they are missing, these patients may be more adamant about accessing sexual health resources from their physicians. In addition, these individuals have not been fighting their whole life for disability justice as some people with congenital disabilities have been, meaning they may have more energy to engage in the fight for equal sexual rights. Lastly, it appears that disability and sexuality programs are currently only being designed for healthcare professionals working in a rehabilitation setting. The majority of patients in these facilities were not born with a disability but rather acquired one. Thus, if staff members are rarely working with patients who have a congenital disability, then the program developers would likely omit a teaching intervention on the subject matter.

The lack of research on congenital disabilities and sexuality teaching interventions for healthcare professionals represents a significant gap in the literature that necessitates further investigation. The same can be said about the absence of programs available for healthcare workers practicing in other fields, such as pediatrics or critical care. Currently, many PWDs are not receiving adequate quality of care from their healthcare system, as depicted in Andrew Gurza's piece in the 2019 Sex Issue of UofTMed Magazine. In order to change the status quo, these professionals are in need of an education that appropriately discusses disability perspectives. Instead of providing one workshop on the matter, such as the studies included in this review, I believe it would be more efficient and effective to incorporate a critical disability framework into the curriculum of various schools of health (i.e. medical school, nursing school, occupational therapy school, etc.). This way, all students would have access to the important

knowledge, which would help to overcome the discrimination their patients with disabilities face while under their care. I also believe that implementing a well-designed sexuality curriculum that utilizes a non-normative approach in elementary and high schools across the world would yield a decrease in the amount of research on acquired disabilities specifically and sexuality. Teaching students that the disability identity does not automatically classify someone as asexual and providing them with a more holistic definition of sex would help make the transition from able-bodied to non-able-bodied easier, as they will probably still view themselves as sexual beings. Although a sexuality program would still be needed in the rehabilitation setting to ensure the staff members are properly equipped to assist their patients, it would not be designed to teach participants the “ground-breaking” concept that PWDs have sex. However, more research on the subject is needed to determine if this is the case.

In regard to the six remaining articles included for data analysis, two used a teaching modality designed for PWDs and their able-bodied partners (Madorsky & Dixon, 1983; Songa, Ohb, Kimb & Seo, 2011). The programs were offered when the participants were inpatients in a rehabilitation facility because of an acquired disability. Again, congenital disabilities were not studied for reasons I associate with ableism. Mainstream society often struggles to accept that interabled couples<sup>3</sup> both exist and can thrive. When seeing an interabled couple, it is common for onlookers to falsely label the able-bodied partner as a devotee—someone with a sexual fetish for PWDs—or as the

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<sup>3</sup> Interabled relationships are intimate relationships between an able-bodied and a non-able-bodied person.

caregiver of the person with a disability, which can significantly impact the wellbeing of these individuals. Shane Burcaw, a 26-year-old disability advocate living with spinal muscular atrophy, made this evident in his online article discussing his relationship with an able-bodied fiancée named Hannah:

“This one feels quite obvious, but you’d be shocked by how often strangers assume that Hannah is my nurse, my mom, my sister or my babysitter. Because of the widespread and deeply-ingrained misconceptions about disability, people tend to see me as a child, or as someone who could not possibly be involved in a romantic relationship. Hannah and I were once checking out at a liquor store when the cashier said to Hannah: ‘Does this big guy want a lollipop?’” (2019)

Shane’s story is presumably one of many that highlights the importance of deconstructing society’s skewed perception of disability and the need to abolish ableism. I first heard of Shane from his and Hannah’s YouTube channel entitled *Squirmy and Grubs*, which is a channel I recommend for those interested in disability and sexuality. Through their videos, they hope to normalize interabled relationships and “show people that [their] love is just as exciting, fulfilling and real as any other” (Burcaw, 2019). Presently, their channel has been viewed over 40 million times (Squirmy and Grubs, 2019). Although the cognitive impact of their channel on the public remains unknown, it is certain that their work is helping to raise awareness on the issue. Hopefully, with this increase in knowledge, individuals will begin to advocate for the inclusion of interabled relationships in sexuality education programs.

The final four studies that have yet to be discussed were designed exclusively for individuals living with a mobility impairment (Bahner, 2018; Pendergrass, Nosek & Holcomb, 2001; Weiss, 1992; Xenakis & Goldberg, 2010), but they all utilized a unique

teaching intervention: a high school sexuality curriculum, an internet website, a pamphlet, and a multimodal program, respectively. Out of the 13 articles, Bahner, as well as Pendergrass and colleagues, were the only authors to include their participants' opinions on the teaching intervention to determine its effectiveness, rather than relying on the results of a questionnaire. Validated questionnaires can be a useful methodology, particularly for researchers wanting results in a timely manner. Unfortunately, a problem arises if the researchers and the participants have a different understanding of what constitutes an effective program. For example, assume a group of academics were interested in learning whether their newly developed video game helps children better understand the importance of recycling. To answer their question, they may ask the participants whether they have increased their recycling behavior since playing the game. If the majority answered "yes," then the researchers would conclude that the program is effective. That being said, the children may have found the graphics unappealing and, consequently, would not have enjoyed the game. Assuming that the participants would have stopped playing if they were not required to complete it for the study, then they would not receive the benefits associated with the program, and most likely would have rated it as ineffective. This is pertinent knowledge, as the video game would not be widely utilized if it was made readily available to the public, putting the researchers' work to waste. Understandably, not all researchers will have the time or financial means to develop an appropriate survey, which may have been the case for the articles included in this scoping review. However, this presents a significant limitation in their work. I

believe that conducting one-on-one interviews or focus groups with participants who have completed a teaching intervention can yield a tremendous amount of knowledge if done correctly (i.e. the research environment is positive and supportive, confidentiality is maintained, etc.) by learning what the target audience truly wants and identifying room for improvement. Additionally, it can be a more accessible means of collecting data when compared to the rigid structure of conventional questionnaires.

The interviews conducted in both Bahner's and Pendergrass's works highlighted the participants' desire for a sexuality program that provides pertinent information on LGBTQ+ topics. As one student stated, "it should be less of straight-teaching and more LGBT-teaching [...] 'cause you already know about the usual things anyways!" (Bahner, 2018, p.646). Out of all the 13 studies included in this scoping review, only Bahner's incorporated some form of discussion on LGBTQ+ related issues, although the participants found the level of coverage insufficient. Providing students with disabilities a sexuality program that addresses disability-specific needs is important, but an effective teaching intervention would also explore the intersectional experiences of other important variables such as gender, sexual orientation, and race. Focusing on one aspect of sexuality will not properly equip these students to access their right to sexuality and may hinder their ability to develop a healthy self-concept. Furthermore, it suggests that the disability and LGBTQ+ identities are mutually exclusive when in reality, many PWDs live with other oppressed identities. A sexuality education that explores intersectionality and the effects of interlocking identities would presumably help students of all abilities to

discover who they truly are as well as provide them with a deeper understanding of the current social inequalities.

Bahner's work is also unique in that it is the only study to explore a high school sex education curriculum. In Sweden, it is compulsory for students to acquire a sexuality and relationship education (SRE) that includes topics such as pregnancies, sexually transmitted infections, relationships, gender equality, sexual harassment, love, discrimination, and normality. The program is not taught as an independent subject, such as Math or History, but is integrated into these subject areas. Bahner describes this Swedish curriculum as "part of a[n] ongoing move towards a 'norm-critical' approach in SRE, rooted in queer theory and the grassroots activism of non-governmental organizations" (2018, p.641). Norm criticism is a fairly recent tool used to shed light on systemic oppressions and social inequalities through the critical evaluation of social norms, power imbalances, and privileges (Jónsdóttir, Kovacs & Joksimović; 2015). Its use in the mandatory SRE would presumably be beneficial for both able-bodied and non-able-bodied students; however, Bahner only sought out the opinions of youths who attended a segregated school for students with mobility impairments.

Along with wanting more LGBTQ+ content, some of the participants wished the program incorporated more disability perspectives, such as "what it's like to have a relationship when you have assistance or with someone who is not disabled [...] or like, this position you can't do because..." (Bahner, 2018, p.648). Although these are important topics of discussion, I wonder if the participants would have wanted these

personal issues to be addressed in their SRE curriculum if they did not attend a segregate school. As Bahner mentioned, many of the youths involved in their study left the mainstream education system because of the multitude of disabling barriers they faced, including high rates of bullying. Whilst it is true that Sweden's SRE is supposed to utilize a norm-critical approach, this does not mean that the teachers have the necessary knowledge to do so. Bahner remarks themselves in their work that many of the Swedish high school teachers are inadequately equipped to address sexuality issues that may arise. If these personal disability perspectives are poorly addressed in a mainstream program, they may serve to further depict PWDs as "abnormal," rendering the school environment even more hostile for certain students. A solution may be to provide students with disabilities a customized sexuality program in adjunct to the disability-positive education they receive in school with their peers; however, this is not for me to decide. For future research endeavors on the subject matter, I recommend interviewing students with disabilities who are attending mainstream schools to give these individuals the opportunity to have their voices heard. I also believe it is important to hear the opinions of the able-bodied students who partake in the program to understand its effect on how they perceive disabilities. Overall, I believe Sweden's SRE curriculum has a lot of potential, and once it is finalized, it could be used as a model for high school sexuality programs around the world, including Ontario.

Pendergrass's and colleagues work is also interesting because it is the only study designed for PWDs that focuses on medical sexology. Notable topics include the well

woman exam, autonomic hyperreflexia, the breast self-exam, contraception, sexually transmitted infections, and finding a clinician. However, I do not find their work as troublesome given that their teaching modality serves to empower PWDs by enabling them to have more control over their bodies. Research has shown that women with disabilities have worse gynecological healthcare outcomes and are less likely to receive preventative screening when compared to able-bodied women of the same age due to the discriminatory attitudes, assumptions, beliefs, and practices in the healthcare system (Abells et al, 2016; Gibson & Mykitiuk, 2012). Therefore, teaching women with disabilities how to conduct a breast self-exam, for example, will also help to reduce their dependency on a system that was not designed to care for them effectively. Although reproductive health is a subcategory of sexuality that is more medical in nature, there are many social aspects that need to be addressed as well, such as the right to *not* have an abortion. Throughout history, pregnant PWDs have been medically coerced into having abortions, and sadly, this practice continues to this day, highlighting the need to educate these individuals on the role that society plays on people's reproductive health and to inform them of their basic human rights.

When comparing the studies that had PWDs as part of their target audience, Xenakis and Goldberg's (2010) made the most concerned effort in ensuring their teaching intervention was as accessible as possible for the participants. Their comprehensive health and wellness program took place in "an ample and accessible space" and was adapted to ensure all women could participate. A care assistant was also hired on staff "to

assist the young women with activities of daily living or program activities as needed.”

Another aspect of this study that I appreciate is that the staff members were required to have prior experience working with PWDs or to identify as having a disability themselves in order to be accepted for the position. Additionally, mandatory training sessions were also created to ensure that all of the instructors were all properly equipped for their role. Having a team of staff who can personally relate to the challenges the participants may be facing and have the skills needed to provide them with the appropriate support will help to foster a safe environment for the participants. As a result, the youths will most likely be more comfortable asking sexuality-related questions and will probably benefit more from the program. Having knowledgeable staff and an appropriate learning environment are only some of the details that must be carefully considered during the developmental phase of any new curriculum in order to achieve accessibility for all individuals with disabilities, which is why I was surprised to find only one study addressing these issues. Consequently, out of the 13 studies included in this scoping review, I believe those who are interested in creating a program for PWDs should review Xenakis and Goldberg’s methodology.

Owing to the wide range of teaching interventions employed, it is futile to try and compare all 13 studies with each other. However, I did notice an overarching theme when conducting the data extraction: six of the sexuality programs were designed using the PLISSIT model, a hierarchical sexual counselling framework that is an acronym for Permission, Limited Information, Specific Suggestions, and Intensive Therapy (Gianotten

et al, 2006; Higgins et al, 2012; Madorsky & Dixon, 1983; Neistadt, 1986; Simpson et al, 2006; Weiss 1992). Permission is the first and most basic level of the model that involves healthcare professionals giving permission to, or asking permission from, their patients to discuss feelings and concerns related to sexual health issues. The goal is to validate the patient's concerns and to build a trusting relationship (University of Wisconsin-Madison School of Medicine and Public Health, n.d). For the second level, limited information, the practitioners provide their patients with basic information when answering their questions and attempt to dispel any withheld misconceptions. Level three, specific suggestions, will be needed for fewer patients than levels one and two. As the name implies, clinicians are expected to give specific suggestions regarding their patients' unique situations, discuss concerns more thoroughly, and collaboratively create a plan to resolve the issues (University of Wisconsin-Madison School of Medicine and Public Health, n.d). Evidently, adequate knowledge in human sexuality is critical at this stage. Lastly, intensive therapy, the most complex level of the hierarchy, involves referring the patient to a specialist, but only a few patients will require this level of care (University of Wisconsin-Madison School of Medicine and Public Health, n.d).

From what I have gathered about the PLISSIT model, I believe it is an appropriate framework to incorporate when developing a sexuality program. Firstly, it reminds healthcare professionals that sexual health is an important aspect of someone's overall wellbeing, and it is thus their duty to address individual sexuality concerns. Consequently, it should force these professionals to take the time to properly educate

themselves on the subject matter. Secondly, the model does not appear to be specifically designed for medical sexology, but rather for sexuality as whole. If the program developers base the PLISSIT model off of a holistic definition of sexuality, then hopefully the participants of the interventions will realize that relying on the biomedical approach to health will not lead to the best outcomes for their patients.

Typically, scoping reviews do not reference the excluded articles since they do not pertain to the study's research question. Although this is also true for this review, I do want to make note of one overarching theme. Out of the 51 articles that were excluded at phase 2 of screening, 11 of them focused on changing able-bodied, elementary, high school, and/or university students' attitudes towards individuals with disabilities. These studies were excluded because they did not provide a sexuality education. However, since their research goals were to abolish some of the myths surrounding disabilities, I believe they are important to discuss.

The majority of the 11 articles focused on disabilities and activities of daily living (i.e. going to work, playing games, etc.). Although the topic itself is not problematic, the ways in which the material was presented was, for the most part, troublesome. The programs heavily emphasized the physical differences between able-bodied and non-able-bodied individuals, which to me reinforces the binary categorization of abled versus disabled. Although most of the studies showed a positive change in the attitudes of the participants, which was frequently measured using the fairly ableist Attitudes Toward Disabled Persons survey (Yuker, Block & Youinng, 1970), I question if this truly is the

case. Disability history was not discussed in any of the programs, and I believe its exclusion makes it harder for students to understand some of the struggles certain PWDs face on a daily basis. Sarah Ismail, a woman who identifies as physically disabled and a community activist, wrote a piece for *The Guardian* stating her beliefs as to why disability history should be implemented in every school's curriculum. According to Ismail (2012), "teaching children how disabled people were treated in important periods of history, or that historical figures were disabled, might just reduce disability discrimination, or maybe even disability hate crimes in the future." The following quote from William Loren Katz, a well-known author, also highlights the need for a disability history education for all: "If you believe people have no history worth mentioning, it's easy to believe they have no humanity worth defending."<sup>4</sup> Although I agree with both Ismail and Katz, it is important to remember that these benefits would only be seen if the curriculum is taught appropriately. Using the medical model of disability and/or inappropriate disability language (i.e. referring to PWDs as "the handicapped") throughout the program would send conflicting messages to the students by completely undermining the disability rights movement, which is why I believe PWDs should be involved in the creation of any disability program.

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<sup>4</sup> I could not find the origins of this quote. However, it was recorded in numerous papers, such as Minarik and Lintner's "Disability History: Humanity Worth Defending."

## **Conclusion**

Out of the 4,432 articles retrieved from the databases, only 13 were included in this scoping review. Having found such few articles on sexuality and visible, physical disabilities suggests that it is not a research topic of interest in the academic world, which I attribute to Esmail and colleagues finding (2010) that individuals with visible disabilities are more likely to be labelled as asexual than other PWDs. As a result, program developers that rely on published literature have access to a limited amount of resources when developing a program on the subject matter. To make matters worse, a number of the teaching interventions did not make use of a disability-positive, non-normative approach. As discussed, the majority of the studies focused on the medicalization of sexuality in the rehabilitation setting, which in my opinion, depicts PWDs as deviant and in need of constant medical surveillance. Only one study provided some discussion of LGTBQ+ topics and none challenged Western society's definition of what classifies as a "normal" body. Additionally, the results highlight a significant lack of emancipatory research in the field, along with an over-emphasis of people living with an acquired disability. Unfortunately, the current teaching interventions on visible, physical disabilities and sexuality also provide very limited discussions on disability perspectives, which are needed to have a positive effect on the participants. In order to remediate this issue, PWDs must be involved in the development, implementation and/or evaluation of a disability-positive sexuality curriculum.

Moving forward, I would like to see more research on programs developed for elementary and/or high school students of all abilities. I believe that implementing a transdisciplinary, non-normative, and holistic sexuality program will help foster a friendlier learning environment for individuals of marginalized groups, which in turn may help create a more accepting society in the future. This knowledge would also make it easier for individuals to transition from an able-bodied to a non-able-bodied, since they ideally would have a greater understanding of the disability identity. Personally, I believe it is a shame that such disability awareness programs are needed in 2019. The Western World should already know that PWDs are simply people who too are deserving of love, dignity, and respect. However, until that day arrives, I will continue to advocate for the rights of PWDs.

### **Resources**

For those interested in learning more on the subject matter, there is a wide range of resources available to the public, including books, blogs, videos and more. To me, a good, reliable resource is one that is created by an individual, or individuals, with a disability rather than someone without a disability. Although there are plenty of able-bodied allies of the disability community who are highly knowledgeable in the field, it is not possible for them to truly understand what it is like to live in an ableist society as a non-able individual. Jen Powley's book *Just Jen: Thriving Through Multiple Sclerosis* as well as Shane and Hannah's YouTube channel *Squirmy and Grubs* are two sources

already discussed in my MRP that I highly recommend. However, the most informative and eye-opening source for me is the *Sins Invalid* Facebook group.

“*Sins Invalid* is a disability justice based performance project that incubates and celebrates artists with disabilities, centralizing artists of color and LGBTQ / gender-variant artists as communities who have been historically marginalized. Led by disabled people of color, *Sins Invalid*’s performance work explores the themes of sexuality, embodiment and the disabled body, developing provocative work where paradigms of “normal” and “sexy” are challenged, offering instead a vision of beauty and sexuality inclusive of all bodies and communities.” (Sins Invalid, n.d.)

Although *Sins Invalid* is a performance group, their Facebook page is a space for individuals all over the world to share pressing disability justice issues. It is a supportive online community moderated by PWDs, and new information is shared in the group daily. Patricia Berne, co-founder of *Sins Invalid*, also posts a monthly “Crip Bits” episode, discussing pertinent disability topics, including restrictive abortion laws, resisting white privilege, and fat liberation. The knowledge I gained from this group shaped the way I chose to explore my MRP topic and reminded me of the importance of reflecting upon privileges.

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Table 1: *Search Terminology Example: Medline Database*

	Teaching Interventions	Sexuality	Visible, Physical Disability
<b>MeSH Terms</b>	Teaching Methods; Education; Curriculum; Learning Methods; Teaching; Lecture; Electronic Books; Models, Education; Books; Education, Non-Traditional; Community; Programs; Government Programs; Adult Education	Health Education; Physical Education and Training; Physical Education, Adapted; Sexuality; Sex Education; Reproductive Health	Students, Disabled; Child, Disabled; Disabled; Parents, Disabled
<b>Keywords<sup>5</sup></b>	Educat*; Teach*; Program*; Workshop*; Resource*; Video*; Film*; Movie; Material*; Information; Model*; Special; Mainstream; Book*; Intervention*; Strateg*; Learning; Class*; Discussion*; Documentar*; Talk*; Course*; Presentation*; Resource Guide*; Curricul*; Lecture*; Seminar*; Teaching	Gender Identit*; Gender Role*; Sex*; Eroticism; Pleasure; Intimacy; Body Positivity; Body Image; Reproducti* Health; Reproducti* Education	Physical*; Visib*; Disab*; Impair*; Challenged; Deformed; Limitat*; Handicap*; Crip*; Special Needs; Invalid; Wheelchair Bound; Wheelchair User*; Lame; Debilitated; Incapacitated

<sup>5</sup> Asterisks (\*) represent any group of characters, including no character (ex. Educat\* includes education, educated, educate, educating, and so forth).

Table 2: Search Strategy Example: Medline Database

Line	Searches	Results
1	Education/ or Curriculum/ or Special Education/ or "Mainstreaming (Education)"/ or Teaching/ or Programs/ or Lecture/ or Books/ or Education, Distance/ or Models, Education/	152153
2	((educat* or teach*) adj3 (program* or workshop* or resource* or video* or film* or movie* or material* or information or model* or special or mainstream or book* or intervention* or strateg*)) or learning or class* or discussion* or documentar* or talk* or course* or presentation* or (resource adj3 guide*) or curriculum or lecture* or seminar* or teaching).mp. [mp=title, abstract, original title, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, unique identifier, synonyms]	3029796
3	1 or 2	3045463
4	Sex Education/ or Health Education/ or Sexuality/ or Reproductive Health/	75089
5	((gender adj1 (identitit* or role*)) or sex* or eroticism or pleasure or intimacy or (body adj1 (positivity or image)) or reproducti* or (health adj1 education)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, unique identifier, synonyms]	1206252
6	4 or 5	1206252
7	3 and 6	209276
8	Disabled Person/ or Disabled Children/	45407
9	((physical* or visib*) adj1 (disab* or impair* or challenged or deformed or limitat*)) or handicap* or crip* or (special adj1 needs) or invalid or (wheelchair adj1 (user* or bound)) or lame or debilitated or incapacitated).mp. [mp=title, abstract, original title, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, unique identifier, synonyms]	49765
10	8 or 9	84624
11	7 and 10	2015
12	limit 11 to (english language and humans)	1720

Table 3: *Characteristics of Included Studies*

Study	Study Design, Objective & Outcome(s)	Participant Characteristics	Intervention Description and Main Findings
<p><b>Bahner (2018)</b></p> <p><b>Location:</b> Sweden</p> <p><b>Title:</b> <i>Crippling sex education: Lessons learned from a programme aimed at young people with mobility impairments</i></p>	<p><b>Design:</b> Exploratory</p> <p><b>Objective:</b> To analyze the sexuality and relationship education (SRE) of a Swedish, impairment-specific college program</p> <p><b>Setting:</b> Program for pupils with mobility impairments held in a school</p> <p><b>Duration of Intervention:</b> Not reported</p> <p><b>Topics Discussed:</b> (1) gender norms; (2) LGBT+ issues; (3) online safety</p>	<p><b>Sample:</b> n=6</p> <p><b>Age/Grade:</b> 16-17 years old</p> <p><b>Gender:</b> n=1 female; n=5 males</p> <p><b>Target Audience:</b> Students with mobility impairments</p> <p><b>Type of Disability (if applicable):</b> Mobility impairments (not specified but do not require major assistance in their day-to-day lives)</p>	<p>SRE Program</p> <ul style="list-style-type: none"> <li>• A component of the college’s curriculum</li> <li>• Classes have 5-10 pupils and usually have more adults than students in the room</li> <li>• Taught by a specially trained team of school personnel (i.e. teacher led)</li> <li>• Consisted of lectures, group discussions, videos, and other activities</li> <li>• Co-ed classes offered occasionally (primarily single-sexed)</li> <li>• Took place in a mainstream school, but was only available to the students with mobility impairments</li> </ul> <p>Effectiveness</p> <ul style="list-style-type: none"> <li>• Overall, students found it a positive experience</li> </ul> <p>Students’ Opinions</p>

			<ul style="list-style-type: none"> <li>• Some wanted more LGBT examples (“should be less of straight-teaching and more LGBT-teaching”)</li> <li>• Over-emphasis on online dangers</li> <li>• Two students wanted the curriculum to include more of a disability perspective (ex. What it’s like to have a relationship with someone when you have an assistant? What is it like dating someone without a disability?)</li> <li>• One student believes he learned more in his spare time than in school</li> </ul>
<p><b>Cole &amp; Stevens (1975)</b></p> <p><b>Location:</b> United States</p> <p><b>Title:</b> <i>Rehabilitation professionals and sexual counseling for spinal cord injured adults</i></p>	<p><b>Design:</b> Prospective Study</p> <p><b>Objective:</b> To describe a method of sexual counseling for spinal cord-injured adults.</p> <p><b>Setting:</b> Rehabilitation organization</p>	<p><b>Sample:</b> n=213 (25% had a disability)</p> <p><b>Age/Grade:</b> Not reported</p> <p><b>Gender:</b> 126 men, 87 women</p>	<p>The Program</p> <ul style="list-style-type: none"> <li>• A conference presented by the faculty of the Program in Human Sexuality of the University of Minnesota Medical School</li> <li>• Consisted of talks, group discussions, a panel of three</li> </ul>

	<p><b>Duration of Intervention:</b> 1 day (7 hours)</p> <p><b>Topics Discussed:</b> (1) nudity; (2) fantasy; (3) masturbation; (4) physiology of sexual function in spinal cord injured adults; (5) sexual adjustment after injury</p>	<p><b>Target Audience:</b> personnel from the state rehabilitation agencies, regional offices, and private agencies, as well as people who use the services</p> <p><b>Type of Disability (if applicable):</b> Paraplegia, quadriplegia, polio, or multiple sclerosis</p>	<p>paraplegic or quadriplegic men and their able-bodied partners, a lecture, and movies</p> <p>Effectiveness</p> <ul style="list-style-type: none"> <li>• Determined by the results of a questionnaire</li> <li>• Majority found the program beneficial</li> <li>• 3% reported that they believe the program was harmful or somewhat so</li> <li>• 23% felt the program may have been harmful to others at the seminar</li> <li>• Most would either initiate discussions of sexuality with their clients or be more aware and open to sex-related aspects of the clients' rehabilitation</li> <li>• Majority believe the seminar should be part of the professional training of a rehabilitation professional</li> </ul>
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<p><b>Gianotten et al (2006)</b></p> <p><b>Location:</b> The Netherlands</p> <p><b>Title:</b> <i>Training in sexology for medical and paramedical professional: A model for the rehabilitation setting</i></p>	<p><b>Design:</b> Prospective</p> <p><b>Objective:</b> (1) Enable professional staff to feel at ease discussing sexual matters and apply their skills to the sexual concerns of patients</p> <p><b>Setting:</b> Rehabilitation facility</p> <p><b>Duration of Intervention:</b> 2-9 sessions (one 3hr meeting/week)</p> <p><b>Topics Discussed:</b> (1) understanding and treating different types of sexual dysfunction; (2) addressing sexuality with patients; (3) attitudes about sexuality and their impact on patient care</p>	<p><b>Sample:</b> n=302 (discipline-specific); n=16 (team-specific)</p> <p><b>Age/Grade:</b> Not reported</p> <p><b>Gender:</b> n=5 males, n=11 females (team-specific)</p> <p><b>Target Audience:</b> Rehabilitation staff (ex. social workers, physicians, occupational therapists, etc.)</p> <p><b>Type of Disability (if applicable):</b> Staff work with patients living with physical disabilities (ex. cerebral palsy, spinal cord injury, spina bifida, etc.)</p>	<p>Discipline-Specific Program</p> <ul style="list-style-type: none"> <li>• Consisted of a roleplaying exercise, group discussions, simulations with volunteer rehabilitation patients, and practical homework</li> <li>• Trainees were given a 170-paged textbook created by the authors</li> <li>• Trainees who were not interested in incorporating sexuality into their work were motivated to do so by appealing to their professional pride</li> <li>• Design was based on the PLISSIT model, previous research and input from one of the authors (a sex therapist)</li> </ul> <p>Team-Specific Program</p> <ul style="list-style-type: none"> <li>• Consisted of roleplaying exercises, lectures, group discussions, simulations with volunteer rehabilitation</li> </ul>
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			<p>patients, and practical homework</p> <ul style="list-style-type: none"> <li>• Trainees were given a 170-paged textbook created by the authors</li> <li>• The team created a working definition of sexuality, which is used throughout the program</li> <li>• Designed by one of the authors (an experienced rehabilitation sex therapist)</li> </ul> <p>Effectiveness of Discipline-Specific Program</p> <ul style="list-style-type: none"> <li>• Determined by the results of a questionnaire</li> <li>• Knowledge, recognising problems and communication skills improved significantly</li> <li>• General opinion of the training was between “moderately good” and “good”</li> <li>• Several physicians said their contact with patients had</li> </ul>
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			<p>become more personal and intimate</p> <ul style="list-style-type: none"> <li>• Majority found the textbook, the role-playing exercise and the program as a whole “very” instructive</li> <li>• Majority found the roleplaying exercise and the program as a whole “very” applicable to their daily work</li> </ul> <p>Effectiveness of Team-Specific Program</p> <ul style="list-style-type: none"> <li>• Determined by the results of a questionnaire</li> <li>• Participants were generally positive about the program and most of their goals were met</li> <li>• Significant improvement in knowledge, comfort, and approach skills and ability to identify sexual problems</li> <li>• Significant increase in the frequency of professionals introducing the sexuality as a</li> </ul>
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			<p>possible concern with their patients</p> <ul style="list-style-type: none"> <li>• Sexuality had become a part of the team's rehabilitation treatment</li> <li>• Attitudes towards patients' sexual issues improved somewhat, but were already positive prior to the program</li> </ul> <p>Team Opinions</p> <ul style="list-style-type: none"> <li>• General impression that the program was overfull and made the trainees feel pressurised</li> <li>• Many suggested using more examples from their own experiences</li> <li>• 3/16 doubted the relevancy of the program for their profession</li> </ul>
<p><b>Halstead et al (1976)</b></p> <p><b>Location:</b> United States</p> <p><b>Title:</b> <i>Human sexuality:</i></p>	<p><b>Design:</b> Prospective</p> <p><b>Objective:</b> To describe the objectives and content of the Sexual Attitude Reassessment</p>	<p><b>Sample:</b> n=508</p> <p><b>Age/Grade:</b> 53% over 27 years of age</p>	<p>The Program</p> <ul style="list-style-type: none"> <li>• Consisted of films, panels with patients and healthcare staff, tapes, slides, talks and small group discussions</li> </ul>

<p><i>An interdisciplinary program for health care professionals and the physically disabled</i></p>	<p>workshop and report preliminary data</p> <p><b>Setting:</b> A small hospital</p> <p><b>Duration of Intervention:</b> 2.5-day workshop</p> <p><b>Topics Discussed:</b> (1) personal attitudes, taboos and biases; (2) sexual attitudes and behaviours of people with physical disabilities; (3) anxieties regarding sexuality</p>	<p><b>Gender:</b> 55% female</p> <p><b>Target Audience:</b> Healthcare professionals (48%), students (23%) and people with physical disabilities (15%)</p> <p><b>Type of Disability (if applicable):</b> 73% had a spinal cord injury</p>	<ul style="list-style-type: none"> <li>• Design is based on previous developed programs</li> </ul> <p>Effectiveness</p> <ul style="list-style-type: none"> <li>• Determined by the results of questionnaires</li> <li>• Majority found the workshop beneficial, enjoyed it, and felt they could discuss sex more freely</li> <li>• Majority believe the program dispels myths about sex and that it should be a mandatory component of professional training</li> <li>• Participants felt more comfortable about different sexual activities (ex. mutual masturbation, polygamy, use of erotica)</li> </ul>
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<p><b>Higgins et al (2012)</b></p> <p><b>Location:</b> Ireland</p> <p><b>Title:</b> <i>Mixed methods evaluation of an interdisciplinary sexuality education programme for staff working with people who have an acquired physical disability</i></p>	<p><b>Design:</b> Prospective</p> <p><b>Objective:</b> To report a study evaluating the effectiveness a sexuality education program for staff working with people with physical disabilities</p> <p><b>Setting:</b> Hospital</p> <p><b>Duration of Intervention:</b> 1 day</p> <p><b>Topics Discussed:</b> (1) sexuality is part of the overall healthcare agenda; (2) impact on sexuality of acquired disability</p>	<p><b>Sample:</b> n=29</p> <p><b>Age/Grade:</b> 20-55 years old</p> <p><b>Gender:</b> 79.3% female</p> <p><b>Target Audience:</b> Staff members who had direct contact with patients with an acquired physical disability (ex. brain injury, stroke, spinal cord injury)</p> <p><b>Type of Disability (if applicable):</b> Not applicable</p>	<p>The Program</p> <ul style="list-style-type: none"> <li>• Developed and delivered by an interdisciplinary team of healthcare staff working within the hospital</li> <li>• Design is based on PLISSIT model</li> <li>• Consisted of didactic, reflective and roleplaying exercises, video clips, case studies, and group discussions</li> </ul> <p>Effectiveness</p> <ul style="list-style-type: none"> <li>• Determined by the results of a questionnaire and conducting interviews</li> <li>• Significant increase in knowledge (evident by questionnaire results and interviews)</li> <li>• Participants found the course was eye-opening to patients' needs</li> <li>• Participants considered themselves to be much more</li> </ul>
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			<p>conscious of the human being behind the label, disability, and diagnosis</p> <ul style="list-style-type: none"> <li>• Significant increase in average skills score</li> <li>• Significant increase in average comfort score</li> <li>• Participants described moving away from “you just ignore” patients’ comments or questions to being much more attentive to sexuality and patient’s lives</li> </ul>
<p><b>Kim et al (2010)</b></p> <p><b>Location:</b> United States</p> <p><b>Title:</b> <i>Pediatric rehabilitation: 5. Transitioning teens with disabilities into adulthood</i></p>	<p><b>Design:</b> Not applicable</p> <p><b>Objective:</b> To refine physicians’ knowledge of preparing adolescent patients with special health care needs for adulthood to improve their quality of life</p> <p><b>Setting:</b> Not applicable</p> <p><b>Duration of Intervention:</b> Not applicable</p>	<p><b>Sample:</b> Not applicable</p> <p><b>Age/Grade:</b> Not applicable</p> <p><b>Gender:</b> Not applicable</p> <p><b>Target Audience:</b> Medical rehabilitation residents</p>	<p>The Program</p> <ul style="list-style-type: none"> <li>• Self-directed learning module on women with spinal cord injuries</li> <li>• Notes the importance of prescribing sexual counseling and talking about sexuality with patients</li> <li>• States that “women with SCI can experience reproductive and sexual fulfillment when attention to their unique medical conditions are</li> </ul>

	<b>Topics Discussed:</b> (1) pregnancy; (2) contraception; (3) importance of talking about sexuality with patients	<b>Type of Disability (if applicable):</b> Not applicable	addressed”
<p><b>Madorsky &amp; Dixon (1983)</b></p> <p><b>Location:</b> United States</p> <p><b>Title:</b> <i>Rehabilitation Aspects of Human Sexuality</i></p>	<p><b>Design:</b> Case study</p> <p><b>Objective:</b> To advocate for sex therapy to be integrated into comprehensive rehabilitation programs</p> <p><b>Setting:</b> Rehabilitation hospital</p> <p><b>Duration of Intervention:</b> Not reported</p> <p><b>Topics Discussed:</b> (1) sexual capacities of spinal cord-injured men; (2) sexual concerns of dating a person with a spinal cord injury</p>	<p><b>Sample:</b> n=1</p> <p><b>Age/Grade:</b> 21 years old</p> <p><b>Gender:</b> Male</p> <p><b>Target Audience:</b> Patient with a recent spinal-cord injury and his partner</p> <p><b>Type of Disability (if applicable):</b> Quadriplegia</p>	<p>The Program</p> <ul style="list-style-type: none"> <li>• Consists of all staff applying the PLISSIT model of sex therapy</li> <li>• Participant met with his physiatrist alone and with the woman he intended to live with following discharge</li> <li>• Six weeks into the rehabilitation program, the couple stayed overnight in the Activities of Daily Living Apartment</li> </ul> <p>Effectiveness</p> <ul style="list-style-type: none"> <li>• Determined by interviewing the couple</li> <li>• Both had achieved sexual satisfaction after several sessions in the Activities of Daily Living Apartment</li> </ul>

			<ul style="list-style-type: none"> <li>• Both had questions regarding their prospects for having a child</li> <li>• A year after discharge, the couple continued to have a good sexual relationship</li> <li>• They felt that the opportunities they had for sexual exploration during his hospital stay strengthened their relationship and contributed to his overall positive attitude about himself and to his success in the total rehabilitation program</li> </ul>
<p><b>Neistadt (1986)</b></p> <p><b>Location:</b> United States</p> <p><b>Title:</b> <i>Sexuality counseling for adults with disabilities: A module for an occupational therapy curriculum</i></p>	<p><b>Design:</b> Retrospective</p> <p><b>Objective:</b> To prepare students to give limited sexuality counseling to their clients and teach them how to handle sexuality-related clinical situations appropriately</p> <p><b>Setting:</b> University class</p> <p><b>Duration of Intervention:</b> Two</p>	<p><b>Sample:</b> n=288</p> <p><b>Age/Grade:</b> Undergraduate and graduate students</p> <p><b>Gender:</b> Not reported</p> <p><b>Target Audience:</b> OT students</p>	<p>The Program</p> <ul style="list-style-type: none"> <li>• First module is devoted to “normal” sexuality and personal development</li> <li>• Second module is devoted to counseling areas and strategies</li> <li>• Both modules utilize didactic presentations and group discussions</li> </ul>

	<p>sessions (3hrs each)</p> <p><b>Topics Discussed:</b> (1) human physiology and sexuality; (2) sexual functioning and disability</p>	<p><b>Type of Disability (if applicable):</b> Not applicable</p>	<ul style="list-style-type: none"> <li>Interested students can contribute to a class collage “comprised of words and phrases that capture some of their positive and negative experiences”</li> <li>Design is based on PLISSIT model</li> </ul> <p>Effectiveness</p> <ul style="list-style-type: none"> <li>Determined by post-affiliation curriculum evaluations</li> <li>100% felt the program was a pertinent part of their academic program</li> <li>Many reported using the information and skills they gained during their fieldwork experiences.</li> </ul>
<p><b>Pendergrass et al (2001)</b></p> <p><b>Location:</b> United States and Canada</p>	<p><b>Design:</b> Prospective</p> <p><b>Objective:</b> (1) To determine if the Internet can effectively be used to educate women with disabilities about reproductive health.</p>	<p><b>Sample:</b> n=26</p> <p><b>Age/Grade:</b> Over the age of 18</p> <p><b>Gender:</b> 100%</p>	<p>The Program</p> <ul style="list-style-type: none"> <li>An internet website written in layman’s terms and with the assumption that the reader had an elementary understanding of</li> </ul>

<p><b>Title:</b> <i>Design and evaluation of an Internet site to educate women with disabilities on reproductive health care</i></p>	<p><b>Setting:</b> Not applicable</p> <p><b>Duration of Intervention:</b> Not reported</p> <p><b>Topics Discussed:</b> (1) the well woman exam; (2) autonomic hyperreflexia; (3) the breast self-exam; (4) contraception; (5) sexually transmitted infections; (6) finding a clinician</p>	<p>female</p> <p><b>Target Audience:</b> Women with mobility impairments</p> <p><b>Type of Disability (if applicable):</b> Mobility impairments (ex. cerebral palsy; Parkinson's disease; brittle bones)</p>	<p>reproduction (link to Planned Parenthood guideline was provided for those without this knowledge)</p> <ul style="list-style-type: none"> <li>• Graphics were limited and no Java scripts were included to ensure the site can be accessed on all types of computers</li> </ul> <p>Effectiveness</p> <ul style="list-style-type: none"> <li>• Determined by the results of a questionnaire</li> <li>• Significant improvement in knowledge of reproductive health issues</li> <li>• Highest score on the sexually transmitted infection section and lowest on the well woman exam section</li> </ul> <p>Women's Opinions</p> <ul style="list-style-type: none"> <li>• Majority wanted the web site topics to be expanded (ex. pregnancy, LGBT issues, safe sex)</li> </ul>
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			<ul style="list-style-type: none"> <li>• One woman wanted to learn how to overcome obstacles with healthcare professionals (ex. getting them to listen)</li> <li>• Many wanted to eliminate technical language, include more graphics, include quotes and anecdotes from other women with disabilities, add self-tests and increase the spacing between text</li> <li>• Majority found the site effective and informative</li> <li>• Sections on autonomic hyperreflexia, contraception, breast cancer and sexually transmitted diseases were particularly useful</li> </ul>
<p><b>Simpson et al (2006)</b></p> <p><b>Location:</b> New Zealand</p> <p><b>Title:</b> <i>Improving the rehabilitative management of client sexual health concerns</i></p>	<p><b>Design:</b> Case control</p> <p><b>Objective:</b> To evaluate the effectiveness of a staff sexuality training programme as a means of improving the rehabilitative management of client sexual health concerns after neurological</p>	<p><b>Sample:</b> n=74</p> <p><b>Age/Grade:</b> Not reported</p> <p><b>Gender:</b> Not reported</p> <p><b>Target Audience:</b></p>	<p>The Program</p> <ul style="list-style-type: none"> <li>• Design is based on previous research and the PLISSIT model</li> <li>• Consisted of didactic and roleplaying exercises, and group discussions</li> <li>• Facilitators of the group</li> </ul>

<p><i>after neurological disability: evaluation of a staff sexuality training programme in New Zealand</i></p>	<p>disability</p> <p><b>Setting:</b> Rehabilitation centre</p> <p><b>Duration of Intervention:</b> Two-day workshops (3hrs each)</p> <p><b>Topics Discussed:</b> (1) sexual rights; (2) impact of disability on sexuality; (3) discussing sexuality topics with patients; (4) sexuality resources; (5) inappropriate sexual behaviours</p>	<p>Rehabilitation staff</p> <p><b>Type of Disability (if applicable):</b> Not applicable</p>	<p>discussion were provided with training</p> <ul style="list-style-type: none"> <li>• Created an environment that participants would feel safe in and empowered</li> </ul> <p>Effectiveness</p> <ul style="list-style-type: none"> <li>• Determined by the results of multiple questionnaires</li> <li>• Participants had significantly more liberal views towards sexuality than the controls, and this were maintained at 6 months follow-up</li> <li>• Participants had higher knowledge and comfort scores than the controls</li> <li>• Participants reported a significant increase in skills post-workshop than the control</li> <li>• Participants reported being active across a significantly broader spectrum of role areas in comparison to the controls</li> </ul>
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<p><b>Song et al (2011)</b></p> <p><b>Location:</b> South Korea</p> <p><b>Title:</b> <i>Effects of a sexual rehabilitation intervention program on stroke patients and their spouses</i></p>	<p><b>Design:</b> Case control</p> <p><b>Objective:</b> To examine whether a sexual rehabilitation intervention program designed for stroke patients and their spouses before hospital discharge is effective with respect to sexual knowledge and satisfaction, and frequency of sexual activity at 1 month post intervention.</p> <p><b>Setting:</b> Inpatient rehabilitation facility</p> <p><b>Duration of Intervention:</b> One 40-50 minutes session</p> <p><b>Topics Discussed:</b> (1) strategies to minimize post-stroke sexual dysfunction; (2) components of a healthy sexual life (ex. support, open communication); (3) diverse sexual behaviors; (4) common changes in sexual life after stroke</p>	<p><b>Sample:</b> n=46</p> <p><b>Age/Grade:</b> 40-46 years old</p> <p><b>Gender:</b> 19/23 stroke patients were male</p> <p><b>Target Audience:</b> Stroke patients and their spouses</p> <p><b>Type of Disability (if applicable):</b> Hemiplegia on left or right side</p>	<p>The Program</p> <ul style="list-style-type: none"> <li>• A component of the discharge teaching session provided 1 day before discharge for the couple</li> <li>• Couples left with a 35-page information booklet (readable text and illustrations)</li> <li>• Design was based on previous research and modified by the hospital's healthcare staff</li> </ul> <p>Effectiveness</p> <ul style="list-style-type: none"> <li>• Determined by the results of a questionnaire</li> <li>• Couples who completed the program did not have significantly higher levels of sexual knowledge than control group</li> <li>• Couples who completed the program had significantly higher levels of sexual satisfaction, higher frequency of sexual activity and higher</li> </ul>
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			frequency of sexual intercourse than control group
<p><b>Weiss (1992)</b></p> <p><b>Location:</b> Australia</p> <p><b>Title:</b> <i>Multiple sclerosis: Will it come between us? Sexual concerns of clients and their partners</i></p>	<p><b>Design:</b> Prospective</p> <p><b>Objective:</b> To describe the need, development and content of an educational pamphlet</p> <p><b>Setting:</b> Rehabilitation facility</p> <p><b>Duration of Intervention:</b> Not applicable</p> <p><b>Topics Discussed:</b> (1) sexual problems frequently encountered with MS; (2) steps in achieving maximum sexual satisfaction; (3) differences between sexuality and sexual behaviour; (4) safe sex</p>	<p><b>Sample:</b> Not applicable</p> <p><b>Age/Grade:</b> Not applicable</p> <p><b>Gender:</b> Not applicable</p> <p><b>Target Audience:</b> People with multiple sclerosis</p> <p><b>Type of Disability (if applicable):</b> Multiple sclerosis</p>	<p>The Program</p> <ul style="list-style-type: none"> <li>• A pamphlet written in nonthreatening, easily understood terms to facilitate discussion with partners and healthcare providers</li> <li>• Provides a guide for clients to read and refer back to</li> <li>• Design is based on previous research and the PLISSIT model</li> <li>• Was not implemented</li> </ul>

<p><b>Xenakis &amp; Goldberg (2010)</b></p> <p><b>Location:</b> United States</p> <p><b>Title:</b> <i>The Young Women's Program: A health and wellness model to empower adolescents with physical disabilities</i></p>	<p><b>Design:</b> Retrospective</p> <p><b>Objective:</b> To introduce a comprehensive health and wellness program that serves young women with physical disabilities</p> <p><b>Setting:</b> A hospital-based center serving women with physical disabilities/conditions</p> <p><b>Duration of Intervention:</b> 12 sessions (2.5 hour/week)</p> <p><b>Topics Discussed:</b> (1) expressing oneself; (2) emotional wellbeing; (3) taking care of one's body</p>	<p><b>Sample:</b> n=28</p> <p><b>Age/Grade:</b> 14-21 years old</p> <p><b>Gender:</b> 100% female</p> <p><b>Target Audience:</b> Women with disabilities</p> <p><b>Type of Disability (if applicable):</b> Not specified but 76% use a mobility device</p>	<p>The Program</p> <ul style="list-style-type: none"> <li>• Consisted of group classes, workshops, and individual health and wellness planning</li> <li>• Held at the hospital in an ample and accessible space</li> <li>• Special workshops are held on weekends and during school recess</li> <li>• Classes are adapted to ensure all women can participate</li> <li>• Staff comprises a program coordinator, instructors, tutors (to assist participants with homework and academic studies if needed), a care assistant (to assist the women with activities if needed), and two volunteers</li> <li>• Instructors are experts in their field, have prior experience working with adolescents and/or people with disabilities, and are trained prior to the first session</li> <li>• Program coordinator meets</li> </ul>
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			<p>regularly with staff and the center's director to review the needs of participants and to develop additional services, makes service referrals for participants, and meets with participants biannually to conduct personal health and wellness planning.</p> <ul style="list-style-type: none"> <li>• Participants must be able to follow instructions, function within a group structure, and give their consent, along with their guardians', to be eligible</li> <li>• Encourages participants to connect with each other by creating a contact list</li> </ul> <p>Effectiveness</p> <ul style="list-style-type: none"> <li>• Determined by the results of a questionnaire</li> <li>• Participants learned how to try new things, develop goals, and express themselves more effectively</li> </ul>
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			<ul style="list-style-type: none"><li>• Participants became more independent and their legal guardians exhibited less protective behaviors</li></ul>
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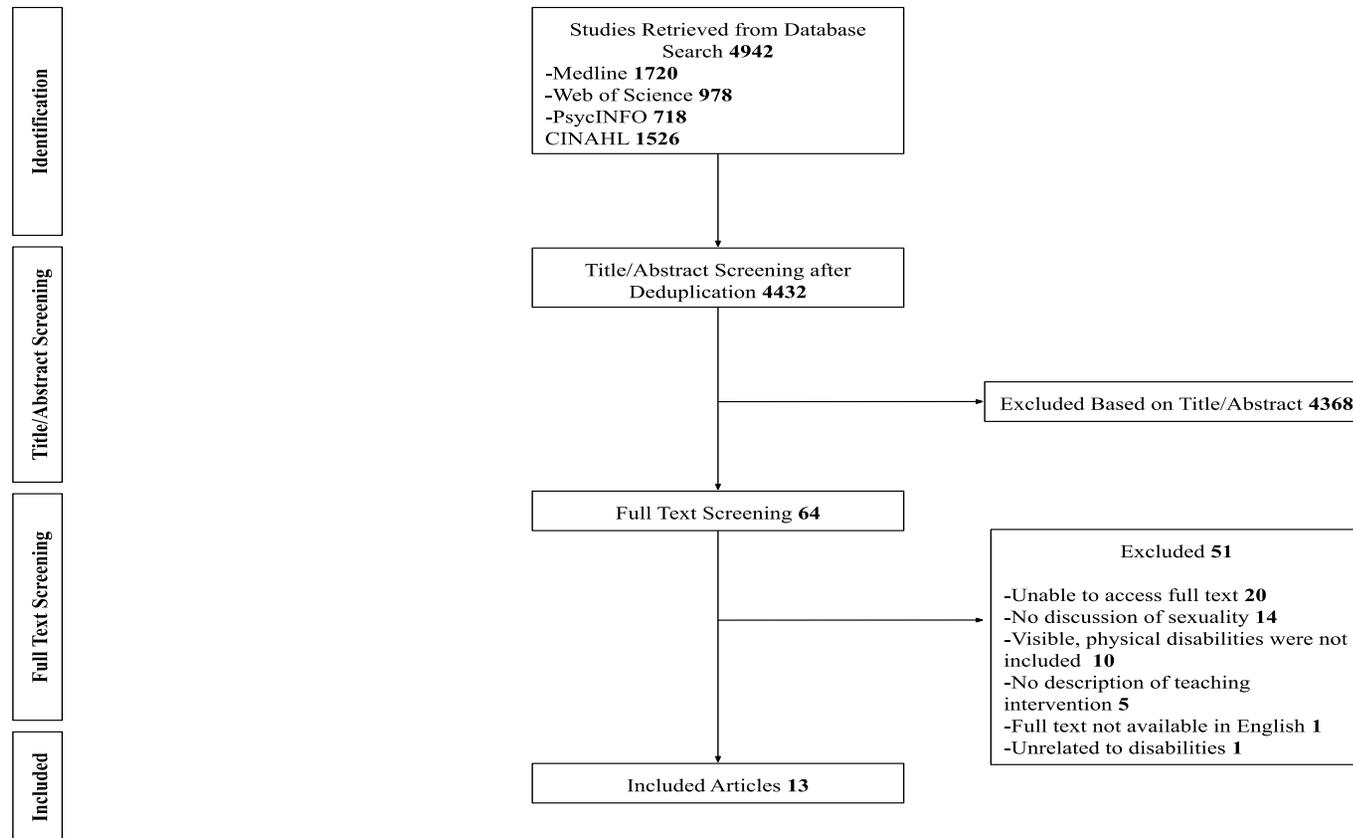


Figure 1 Scoping Review Flowchart