FACTORS THAT HINDER AND HELP THE SEXUAL LIVES AND SEXUAL WELLNESS OF INDIVIDUALS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

By

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Abstract

This major paper aims to critically analyze current research regarding the sexual lives and sexual wellness of individuals with intellectual and developmental disabilities (IDD), with a particular focus on the factors that hinder and help the sexual lives and wellness of individuals with IDD. While many themes arose regarding factors that hinder the sexual lives of those with IDD, the scope of this paper is limited and, therefore, the following four themes are the focus: myths of asexuality and/or hypersexuality; controlled and restricted sexual lives; lack of accessible sex education, knowledge, and resources; and an absence of policies that acknowledge and protect the sexual lives of individuals with IDD. Conversely, recommendations for fostering and helping the sexual lives and sexual wellness for IDD include: acknowledgement and empowerment of sexual lives; sexual voice: autonomy and self-determination; knowledge and sex education; and supportive policies. These findings are important to the social work profession, as being equipped with increased knowledge and subsequent training within this area of practice will benefit the sexual lives and wellness of individuals with IDD. Finally, this literature review highlights the dearth of literature regarding the sexual lives of individuals with IDD, particularly a lack of research with lesbian, gay, bisexual, transgender, queer, intersex, and asexual (LGBTQIA+) people with IDD, socioeconomic factors, and a lack of studies that evaluate policy, education, and quality of life.

List of Acronyms

AAIDD – American Association on Intellectual and Developmental Disabilities

DSM – Diagnostic Statistical Manual

IDD – Intellectual and Developmental Disabilities

LGBTQIA+ – Lesbian, gay, bisexual, transgender, queer, intersex, and asexual

PWD – Person with Disabilities

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Dedication

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Introduction

Human sexuality is complex and multifaceted. It is surrounded by an army of social 'norms,' hegemonic assumptions, religious restrictions, moral prohibitions, shame, and discourses of being 'dangerous' (Shakespeare, 2014). For many of us though, sexuality is an important part of our identities and lives; above all, it is a fundamental human right (Black & Kammes, 2019; Pariseau-Legault & Holmes, 2017; Rushbrooke et al., 2014). The World Health Organization (WHO) recognizes sexuality as "…a central aspect to being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy, and reproduction" (2022, p. 4). As a vital part of human rights, sexual rights include the right to be guaranteed access to sexual health services, education, and, if desired, to have safe and pleasurable sexual experiences that are free from discrimination, violence, and coercion (WHO, 2022). Despite these, and additional protections put in place by the United Nations that defend sexuality as a human right (UN, 2018), evidence suggests that individuals with intellectual and developmental disabilities (IDD) have had their sexual rights consistently denied throughout history and still routinely face a lack of acknowledgment that sexuality is an important part of their lives (Shah, 2017).

People with disabilities are the world's largest minority group (Robertson & Larson, 2016). Approximately 15 percent of the global population, or more than one billion people, are reported to live with a disability (WHO, 2021). As many as 200 million people, which is 1-3 percent of the global population, have an intellectual disability (WHO, 2021). According to a study done by Fieldman (2019), more than half of people with IDD have sexual relationships. Thus, a lack of acknowledgment of the sexual lives of people with IDD is a significant issue as it affects people's lives and can impact their wellness.

Defining disability, especially IDD, is difficult though because the term attempts to encompass a range of heterogeneous and fluid identities, impairments, and embodied experiences (Campbell, 2017). Campbell goes on to argue that disability is also highly contextual – how it is viewed and experienced varies across time, place, and culture. In addition, they write that class, gender, race, age, and other marginalities all inform how disability is viewed and understood. Despite being a complex and multidimensional concept, inherent to the definition of disability is a sense of 'abnormality' or a deviation from the 'norm,'; more specific to IDD, this deviation is a deviation from the cognitive or neurotypical norm.

Conversations about sexuality or our sexual lives are often seen as being 'taboo' or off-limits, and this is even more so when it concerns individuals with IDD (O'Shea & Frawley, 2020). Anecdotally, sexuality and disability are not often heard together in the same sentence, and when they are, I have noticed that there tends to be a lot of silence, aversion, discomfort, sideways glancing, and nervousness. After all, as stereotypes dictate, persons with IDD are not sexual nor do they not participate in sexual activities or express their sexuality (Sitter et al., 2019). However, this is incorrect. In fact, much of the research indicates that IDD people are sexual.

This literature review is premised on the assertion that people with IDD are sexual beings who have sexual lives. They have romantic and intimate relationships, sex with others, sex with self, and participate in the same kinds of sexual media (e.g. pornography) that most people do (McConnell et al., 2021). IDD people have a wide variety of gender identities and sexual orientations, with many identifying as lesbian, gay, bisexual, transgender, transsexual, queer, and so on (Martino, 2017). These statements may be shocking to the majority of society because most people do not think of individuals with IDD as being interested in or capable of having sex,

or as sexual and experiencing sexuality at all (McConnell et al., 2021; Shah, 2017). This paper is firmly founded on the premise that individuals with IDD are capable of and have the right to sexual lives and sexual wellness. Thus, with the above in mind, I chose to research the following question:

"What factors hinder and help the sexual lives and sexual wellness of individuals with IDD?"

In seeking to answer this question, I will need to first explore the history of sexuality as it intersects with disability. Another important question that guides this literature review is "What are the current experiences of individuals with IDD with regards to sexuality/sexual lives?" I am also curious about how the attitudes and beliefs of others (e.g., parents, carers, professionals), as well as sexual learning and education for individuals with IDD, influence various aspects of their sexuality and sexual lives.

The intersection of sexuality and disability is a complex but important topic that requires more exploration and discussion in the field of social work. The research questions I am asking are significant to social work for a few reasons. First, as social workers, we often have the privilege of providing support, services, and care to individuals who have IDD, as well as their families (Robertson & Larsen, 2016). Social workers can work towards supporting the positive sexual wellness, rights, agency, and lives of people with IDD by understanding the factors that help and hinder the sexual lives of people with IDD. Additionally, the proposed research and findings could be beneficial for sexual expression and inclusion at both a micro-level and macro-level. For example, the findings of this major paper could be used at a macro level to improve interventions such as advocacy and activism, address policy concerns, fight for accessible spaces

and infrastructure, and create access to various needed sexual health, education, and wellness resources for individuals with IDD.

A Note Regarding Terminology

Robertson and Larson (2016) argue that language around disability is important; they state that "…the connection between language, ideology and social attitudes cannot be overstated as language and terminology have the power to influence and determine the meaning or value placed on power by the terms used to describe them" (p. 2). Thus, when engaging with various disability communities it is essential to understand and be curious about the 'values and meanings' attached to language (2016). Throughout disability research, there is the use of both 'identity-first' language (e.g. disabled people) and 'person-first' language (e.g. people with disabilities); however, there is much debate among scholars around what phrase is best (Campbell, 2019). Politics, group affiliation, culture, and other factors all impact what language is used to describe disability (2019).

Person-first terminology places the person first and the disability second and seeks to emphasize the 'personhood' of the individual, highlighting the "common humanity" among people with disabilities and non-disabled people (Shakespeare, 2014, p. 19). The theory behind person-first language is that it centers on the worth and value of the individual by recognizing them as a person instead of a condition (2014). Those who use person-first language argue that using terms such as 'disabled people' or 'the deaf' run the risk of dehumanizing and disempowering people with disabilities as these phrases underline the disability rather than the humanity of the individual (Snow, 2010). A large majority of individuals and people who work with/for individuals with IDD, as well as many disability advocacy groups in Canada, use person-first language (Robertson & Larson, 2016). It is often viewed as the more 'politically

correct' and appropriate way to address those with disabilities as it moves away from some of the derogatory terms that were used to describe disability in the past (Shakespeare, 2014). However, there are many critiques of person-first terminology and not all people with disabilities use the person-first language model.

Advocates of identity-first language have several criticisms of person-first terminology. First, disabled people and many academics have criticized the phrase 'people with disabilities' as it suggests that a disability is an individual deficit and that the experience of being disabled can be separated from a person's identity (Robertson & Larson, 2016). Or that 'disabilities' are "…unfortunate conditions attached to otherwise 'normal people'" (Withers, 2012, p. 7). Second, critics argue that the idea of separating the disability from the person "…stems from the idea that disability is something you should want to have separated from you, like a rotten tooth that needs to be pulled out" (Liebowitz, 2015, para. 4). These implications are offensive to some disabled people, especially for those who experience disability as an inseparable part of their identity and culture and as a source of pride and empowerment (Shakespeare, 2014). Those who prefer identity-first language generally embrace the term 'disabled' as a way to emphasize their membership to or involvement in 'minority group identity politics' (2014).

Liebowitz—a physically disabled woman advocate—further argues that: "I am disabled more accurately highlights the complex biosocial reality of disability. I am not merely a person existing with a label; I am constantly disabled and enabled by the interplay of my body and the environment" (2015, para. 7). Overall, advocates of identity-first language argue that society is disabling, and identity-first language is empowering and destigmatizing.

After careful reflection and thought on the above debates, and in an effort to include, consider, and respect the many different voices, perspectives, and interests of people with

disabilities, I will utilize both person-first ('person with a disability') and identity-first ('disabled person') language throughout this major paper.

Defining Intellectual and Developmental Disability (IDD)

To begin exploring and understanding what factors hinder and help the sexual lives and sexual wellness among people with IDD, I need to first define the meaning of 'intellectual and developmental disability.' Intellectual and developmental disability can be defined in numerous ways, having components specific to cognitive, emotional, physical, and social abilities (AAIDD, 2022). It is important to note that these terms are contested, and that no universally accepted definition exists (Ferrante & Oak, 2020). Throughout history and the literature, there have been a wide variety of terms that have been used to label people with intellectual and mental impairments. Some of these labels include, but are not limited to: "learning disability," "mental retardation," "mental disability," "cognitive disability," "developmental delay," "psychosocial disability," "mental handicap," "neuroatypical," "special need," and "intellectual impairment" (Bathje et al., 2021; Chrastina & Večeřová, 2020; English et al., 2018; Lam et al., 2019).

In my major paper, I will primarily use the term "intellectual and developmental disability" (IDD), which is the term most used across the literature and sourced to the American Association on Intellectual and Developmental Disabilities and the Diagnostic and Statistical Manual of Mental Disorders (AAIDD, 2022; APA, 2013). When referring to individuals without IDD, I will state 'individuals without IDD' and use the term "neurotypical," as this is the most common usage within the literature and among those in disability communities and advocacy groups (APA, 2013).

AAIDD defines intellectual and developmental disability as "…significant limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 22" (AAIDD, 2022, para. 1). Further, AAIDD states that "intellectual functioning" refers to overall mental capacity, which includes problem-solving, reasoning, and learning and that "adaptive behaviour" encompasses cognitive (e.g. language, money, time, literacy), practical (e.g. personal care, travel, safety, healthcare, occupational skills), and social (e.g. self-esteem, responsibility, interpersonal relations) skills.

In the past, the DSM recommended that the diagnosis of an IDD be based on an individual's IQ level; however, this is no longer the case (APA, 2013). Like the AAIDD, the DSM-5 now places more emphasis on adaptive functioning and the overall performance of basic life skills. In other words, instead of testing a person's IQ, there is a greater focus on what conceptual, social, and practical skills are learned and performed by people in their everyday lives (2013). For example, what various levels of understanding does an individual have of concepts of written or spoken language, what level of care and support is needed by caregivers for problems solving throughout life, and practically, what level of support is needed for activities of daily living such as meals, bathing, and dressing (2013)?

According to the DSM-5 (APA, 2013), three criteria must be met to diagnose an intellectual disability. The first of the criteria being deficits in intellectual functioning, such as "…reasoning, problem-solving, planning, abstract thinking, judgment, academic learning, and learning from experience" (p. 33). These must be "…confirmed both by clinical assessment and individualized, standardized intelligence testing" (p. 33). Second, there must be evidence of deficits in adaptive functioning "…that result in failure to meet developmental and sociocultural

standards for personal independence and social responsibility. Without ongoing support, the adaptive deficits limit functioning in one or more activities of daily life, such as communication, social participation, and independent living, across multiple environments, such as home, school, work, and community" (p. 33). The third criteria is that the "…onset of intellectual and adaptive deficits [occurs] during the developmental period" (p. 33).

The DSM-5 also states that intellectual and developmental disability varies in severity, and terms such as "mild, moderate, severe, or profound" are used to categorize an IDD (APA, 2013, p. 31). As seen in the literature, there are many different types of IDD, and along with that, a wide spectrum of impairment severity across individuals with IDD.

The social model of disability makes a distinction between impairment and disability (Shakespeare, 2013). This model defines disability in the following way "…the disadvantage or restriction of activity caused by a contemporary social organization which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities" (2013, p. 267). This model defines impairment as a personal limitation, whereas disability is understood as more closely related to social exclusion. According to this analysis then, it is recognized that people with IDD may have intellectual and developmental impairments, but it is primarily "…society and its social organizations that oppress and 'handicap' people with disabilities" (Robertson & Larsen, 2016, p. 69). This model poses that people with IDD are disabled by structural barriers to social inclusion.

Understanding and defining IDD within both the medical and social models is important, as it needs to be recognized that the very real impairment and lived experiences of a disability, along with social contextual elements – both impact the objective reality of people with IDD. By incorporating both the personal and political, a more holistic lens of critical disability analysis

and action emerges that acknowledges the day-to-day realities of people with IDD while also recognizing that socio-political and economic change is required to achieve full inclusion of people with IDD (Robertson & Larsen, 2016).

What is Sexual Wellness?

The WHO (2022) defines sexual health as incorporating dimensions of wellbeing: "sexual health is a state of physical, emotional, mental, and social wellbeing in relation to sexuality; it is not merely the absence of disease, dysfunction, or infirmity" (para. 8). Lee and Collins (2020) write that the term 'sexual wellbeing' is a broader concept that relates to how people experience their lives, rather than the word 'health' which suggests more clinical concerns (p. 305). Participants in this same study expressed sexual wellness as, "being close to another, knowing I am alive through sensual pleasure; sexual self-esteem; having sexual fun; being healthy, being desirable; physical and emotional connection to another and having a normal life; and being the powerful centre of sexual attention" (p. 312). Further to this, Mitchelle et al. (2021) developed a model of sexual wellness that has seven core domains: "sexual respect, sexual safety and security, sexual self-esteem, resilience in relation to past sexual experiences, forgiveness of past sexual events, self-determination in one's sex life, and comfort with one's sexuality" (p. 611).

Methodology

This methodology section will provide an overview of the methods and theoretical framework utilized when writing and researching this major paper. Additionally, I include a section about reflexivity, where I situate myself in relation to this literature review. The purpose of this section is to lay out the decisions I made while conducting this literature review.

Methods

The research method for this major paper is a thematic review of the literature. I utilized UFV's library research database and google scholar to conduct an extensive investigation of the literature. The key search terms used through these online databases included "developmental disability", "intellectual disability", "intellectual and developmental disabilities", "sexuality", "sexual lives", "sex", "sexual wellness", "intimate relationships", "experiences", "barriers", and "social work". Additionally, government websites, disability advocacy websites, and other relevant organizational websites were reviewed to obtain data and information as it relates to this topic.

While attempts were made to gather literature specific to Canada on this topic, there was a significant dearth of literature and the scope of the review had to be broadened to other countries. Upon expanding the geographical range of the search, it is worth noting that research on the sexual lives of people with IDD is mostly carried out in 'high-income' Western countries (e.g. USA, UK, Iceland, and Australia) with data from "low- and middle-income countries and comparative cross-cultural research remaining sparse" (McConnell et al., 2021, p. 384). While most of the articles are from Western countries, it is important to acknowledge that this does not necessarily equate to the transferability of the research to Canadian contexts. Because of this, an attempt was made to select a variety of articles to include many perspectives and different voices to broaden the scope of the paper.

The articles reviewed were dated from the past 10 years (2011-2021), and the articles selected for this paper are mostly from the past five years (2016-2021) to make sure the most recent and relevant literature is highlighted. Utilizing recent literature ensures that significant changes in legislation, political, and social context are captured and highlighted in the research

and findings. This helps guarantee that the most up-to-date knowledge and information are provided on the topic.

The research articles explored can be relied upon, as they are all peer-reviewed articles found in peer-reviewed journals. Many of these articles were found in journals such as *British Journal of Learning Disabilities*, *Disability & Society*, *Journal of Research in Nursing*, *Journal of Applied Research in Intellectual Disabilities*, and *Sexuality & Disability*. While I attempted to find literature within social work specific journals, there was ~~a~~n absence of social work specific literature on this topic and thus I utilized journals of related 'helping' professions. Similarly, the authors of the literature chosen represent a wide variety of academic disciplines, and I was able to find and include five research articles that were published by social workers (see Linton et al., 2016; Turner & Crane, 2016a, 2016b; Sitter et al., 2019; Lee & Collins, 2020).

Around 60 articles were searched and selected for potential inclusion in this paper. Every article selected for inclusion was based on the search terms above. I read each of the article abstracts and if the information in the article was relevant, I continued to carefully read the rest of the article. The articles chosen for this major paper all contain rigorous explanations and justifications of the research design, data collection and analysis, and ethical considerations utilized – these are all important to be aware of when considering the reliability of the research. I also attempted to find literature that focuses on the lived experience of disability by prioritizing the voices and experiences of IDD people. The majority of IDD participants found in the qualitative studies were mostly identified as having mild to moderate IDD, apart from one study by Björnsdóttir and Stefánsdóttir (2020) in which the participants were those with IDD who require intensive support and communicate with non-verbal language.

40 or so articles were selected to be included in this paper, and each of them was critically analyzed to ensure the content and themes of the article would provide useful information. The literature reviewed and included in this major paper are primarily qualitative studies, including thematic analyses, scoping reviews, interpretive phenomenological analysis, critical phenomenological analysis, ethnography, and critical discourse analysis. At first, none of the articles chosen included caregivers reporting on behalf of individuals with IDD, though in some of the studies caregivers were gatekeepers to facilitating or receiving consent for participation of the individuals with IDD. However, I decided that because the voices of others so heavily influence factors like organizational policy, care of those with IDD, values, education, access to sexual lives, and on, I have chosen to include several articles that include the perspectives of care providers, families, and advocates of IDD people.

Through this initial review of the literature several themes emerged. Themes that emerged regarding gactors that hinder the sexuality of those with IDD include myths of asexuality and/or hypersexuality; controlled and restricted sexual lives; lack of accessible sex education, knowledge, and resources; and absence of policies that acknowledge and protect sexual rights. Themes that emerged regarding factors that help include acknowledgement and empowerment of sexual lives; sexual voice: autonomy and self-determination; knowledge and sex education; and supportive policy.

Theoretical Framework

The theoretical frameworks that guide my understanding of the research are, feminist, anti-oppressive, and critical disability theory. This section provides a brief overview of how I understand these theories and highlights the ways that these theories informed my reading and analysis of the literature.

Feminist Theory

One theory of particular value to disability-sexuality research is the feminist theory of intersectionality because it presents a means to further examine disability and sexuality in relation to social identities and experiences such as age, race, gender, ethnicity, age, socioeconomic status, and sexual orientation (Crenshaw, 1989). By utilizing an intersectional approach in examining the research, I began to understand the multiple and intersecting forms of discrimination experienced by IDD people. This lens also helps to demonstrate how ableism and other structures of oppression, such as ageism, homophobia, racism, and sexism are interconnected (Campbell, 2019).

Feminist theory also helped informed my selection of the literature, as this theory aims to center the voices and the experiences of those at the margins. As Foucault (2003) explains, subjugated knowledge refers to a "…whole series of knowledges that have been disqualified as non-conceptual knowledges, as insufficiently elaborated knowledges: naïve knowledges, hierarchically inferior knowledges, knowledges that are below the required level of erudition or scientificity" (p. 7). In this way, I hope that in utilizing feminist theory, my major paper creates space for individuals with IDD – and their often 'subjugated knowledge' – and allows for their voices and experiences with sexuality to be highlighted. In doing so, the goal is to challenge the invisibility of their voices and sexualities by contributing to a growing body of literature that is finally listening to people with IDD (Rushbrooke et al., 2014).

Anti-Oppressive and Critical Disability Theory

Anti-oppressive theory involves fighting for social justice and challenging existing structural and social power imbalances that perpetuate inequality and oppression (Robertson & Larsen, 2016). Throughout my review of the literature and the collection of data, an anti-

oppressive theoretical framework was utilized to identify how external power structures operate and impact the sexual lives of individuals with IDD (2016). An anti-oppressive framework was critical to understanding how discrimination, ableism, and oppression operate and affect the sexual wellness of IDD people. Anti-oppressive theory also contributed to an acute awareness of the power imbalances noticed throughout the research, particularly as the IDD participants represent the marginalized, and the researcher the oppressor. When selecting research to include in this major paper, I sought to find studies where research was conducted collaboratively, and that understood the participants with IDD as the experts of their own lived experiences.

Similar to anti-oppressive theory, I also applied a critical disability studies approach to my examination of the literature. Within this theory, disability is understood to reside within relationships of power through which one group, those within the constructed 'norm', are legitimized by possessing "…culturally valued cognitive characteristics (e.g. 'able-mindedness')" (Sandberg et al., 2021, p. 1422). The construction of the 'norm' and who falls within or outside of its definition is an essential tool for how those in positions of power work to maintain that power. Applying this theory helps me understand how falling outside of the 'norm' throughout history has created many devastating consequences for people with IDD, such as dehumanization, poverty, institutionalization, forced sterilization, loss of autonomy, desexualization, and abuse (Campbell, 2019). Applying a critical disability framework also challenges approaches that pathologize mental and physical differences as needing correction, and instead advocates for both accommodation and equality for people with disability in all areas of life.

Reflexivity

Since reflexivity is core to feminist and critical disability research (Liddiard, 2011), it is also a practice that is an important part of writing this major paper. For this paper, reflexivity means that I am critically examining and acknowledging my role as the researcher, asking questions like, "how does who I am, who I have been, who I think I am, and how I feel affect the processes of research and analysis?" (Campbell, 2019). Practicing reflexivity is especially important for non-disabled researchers, such as myself, who review and interpret research that involves disabled persons because there is an inherent power relationship between the researcher and researched. This dynamic is emphasized even more so by the broader societal imbalance of unequal power relations that already exist between disabled and non-disabled people; therefore, it is essential to be aware of (2019).

Despite working in the field of disability for many years, as a non-disabled person, it is important to acknowledge that I am researching and writing about a topic of which I do not have lived experience. I am a young, white, educated, healthy, able-bodied, neurotypical, middle-upper-class, married, heterosexual, cisgender woman – the overlapping intersections of my social location and identity carry immense privileges. I am aware that my story and social location is very different than those of the IDD people I have read about in the research. My sexual life and wellness have always been accepted, celebrated, protected, and respected. I have not had to face the oppression and marginalization that individuals with IDD do regarding accessing and engaging in a sexual life.

In my ten plus years of working with and for individuals with IDD, sexuality is rarely considered or discussed. It was only in the last couple of years that issues regarding inclusion and access to sexual lives and sexual wellness for individuals with IDD were brought to my

attention. As I have explored this issue further, the lack of discussion surrounding sexual experience and sexual wellness for this population has persisted. The more I research, the clearer it becomes that the sexual lives of individuals with IDD is not a topic commonly addressed in academic literature or everyday discussions, which makes me question the potential implications of such silence.

One of the core values guiding this major paper is my belief that people with IDD, just like people without IDD, if they so choose, deserve opportunities to experience sexual lives, love, intimacy, consensual sex, meaningful relationships, heartbreak, companionship, and sexual wellness. I want to help foster a more inclusive sexual society, one in which disabled sexualities can thrive. As an emerging social worker, my hope for this major paper is to amplify and highlight the voices of the participants with IDD in the literature, embodying the disability rights movement saying, 'nothing about us, without us.'

Literature Review: Thematic Findings

The goal of this literature review is to critically analyze current research regarding the sexual lives and sexual wellness of individuals with intellectual and developmental disabilities (IDD), with a particular focus on the factors that hinder and help the sexual lives and wellness of individuals with IDD. First, a brief history of sexuality and disability is explored and then the themes that emerged in the literature are discussed. While many themes arose regarding factors that hinder the sexual lives of those with IDD, the scope of this paper is limited and therefore, the following four themes are the focus: myths of asexuality and/or hypersexuality; controlled and restricted sexual lives; lack of accessible sex education, knowledge, and resources; and an absence of policies that acknowledge and protect the sexual lives of individuals with IDD. Conversely, recommendations for fostering and helping the sexual lives and sexual wellness for

IDD people include: acknowledgement and empowerment of sexual lives; sexual voice: autonomy and self-determination; knowledge and sex education; and supportive policies. Despite there being a dearth of literature on this topic, this literature review seeks to point to and highlight specific literature that does discuss this topic and it identifies specific evidence regarding the sexual lives of individuals with IDD. It concludes with an examination of some of the gaps in the current research, implications for social work, and an identification of potential areas of future research.

Outlining Contexts: A History of Ableist Oppression and Discrimination

Issues around sexuality and disability are necessary to understand against a historical background. Disability advocate, Anne Finger (1992), writes "…sexuality is often the source of our deepest oppression; it is also often the source of our deepest pain. It's easier for us to talk about – and formulate strategies for changing – discrimination in employment, education, and housing than to talk about our exclusion from sexuality and reproduction" (p. 9). Throughout history, the sexual lives of people with IDD have been controlled and oppressed in multiple ways such as through eugenics and sterilization, and through the medical model-tragedy (Liddiard, 2011). It is evident though that most of the barriers to sexual lives and sexual wellness that IDD experience are in some way related to or rooted in binary ableist ideas of who is 'fit' or 'unfit,' 'normal' or 'abnormal' (2011). Ableism refers to the "…ideas, practices, institutions, and social relations that presume ablebodiedness, and by doing so, construct persons with disabilities as marginalized… and largely invisible" (Chouinard, 1997, p. 380). These ableist attitudes have been engrained into public spaces, law, and social policy, thus further inhibiting people with IDD chances for sexual expression, exploration, and satisfaction (Liddiard, 2018).

Eugenics and Sterilization

One of the most overt and inhumane historical examples of how these negative attitudes permeated western society and acted as institutional oppression is the violent state-sanctioned sterilizations of IDD in Canada during the eugenics movements of the early 1900s (McConnell et al., 2021). During this period, eugenicists sought to eliminate people who they believed were 'inferior' and 'undesirable' from the gene pool in an attempt to create a society that was genetically 'superior' (Robertson & Larsen, 2016). Throughout the world, not only were people with IDD institutionalized in huge numbers, but many were also sterilized by force to "…[eliminate] the risk of multiplication of the evil by transmission of the disability to progeny" (The Sexual Sterilization Act, Sec. 5; Province of Alberta, 1928, as cited in McConnell, 2021, p. 388).

The enforcement of involuntary sterilization laws, such as Canada's Sexual Sterilization Act of 1928, continued into the late 1900s and violated the human and sexual rights of thousands of people with IDD (Campbell, 2019). Alberta was the first province to introduce these laws and the last to repeal them in 1972 (Grekul et al., 2004). During this period, over 4,739 residents of that province were recommended for sterilization, which resulted in approximately 3,000 people being sterilized (2004). One of the most well-known cases of eugenic sterilization in Canada is that of Leilani Muir. In 1955, just before her eleventh birthday, she was institutionalized, and, at the age of fourteen, she was sterilized without her consent (Whiting, 1996). Muir did not know she was sterilized until she left the institution and attempted to start a family (1996). She went on to successfully sue the government of Alberta for wrongful confinement and sterilization in 1996. Many lawsuits followed her legal case, given that Muir's experiences of dehumanization, institutionalization, sterilization, and abuse were not atypical (Malacrida, 2015).

In 1986, a Canadian Supreme Court ruling made it illegal to involuntarily sterilize people anywhere in Canada (*E. (Mrs.) v. Eve,* 1986). Yet, while Canada has abolished the laws that allowed such apparent and aggressive systemic oppression, it can be argued that the eugenic and ableist ideas that informed these laws have not disappeared and still exist in many post-institutional and medical settings today (Altermark, 2017). New forms of eugenics, or 'neo-eugenics' move "…beyond biological and medical interventions, to encompass systematic barriers to education, services, policy, and supports for disabled people in terms of sexuality and reproduction" (Eugenics to Newgenics, 2017, para. 3).

Medical and Tragedy Model of Disability

The controlling, dehumanizing, and sexually restrictive practices faced by persons with disabilities (PWD) are still ongoing today. While these practices are less obvious now, they remain rampant and continue to undermine the equal rights of people with IDD, their need for access to sexual health information and services, and their desires for sexual expression and reproduction. For example, the 'preventative' use of long-term birth control; a lack of information about sexuality; or the automatic removal of children from disabled parents who are believed to be incompetent simply because of their disabilities, are all practices that reflect the idea that people with IDD sexuality is 'dangerous' and needs management (Aunos & Feldman, 2002).

Other commonly held, present-day ideas about disability are medicalized understandings that view disability as an unfortunate, individual, biological problem that requires 'fixing.' Disabled individuals' bodies and minds are constructed as broken, malfunctioning, and undesirable. Which in turn, creates a perception that disabled persons are "…medical anomalies, helpless victims, and lifelong burdens on family and society" (Yau, 2019, p. 101). These views

result in disabled persons being seen as unsuitable to be sexual partners, spouses, or parents, and creates many challenges in accessing their sexual rights (Campbell, 2019).

For many disabled people, living in a society that consistently denies their sexuality can also lead to internalized oppression and feelings of failure and shame, resulting in low self-esteem (Liddiard, 2011; Shah, 2017). Many persons with disabilities report staying in abusive or unfulfilling relationships because they believed that they do not deserve any better (2011). As has been demonstrated, for decades, the sexual rights of persons with IDD have been collectively neglected and they have a sexual history marked by oppression, prejudice, discrimination, and violence (Liddiard, 2011, 2018).

Factors that Hinder the Sexual Lives and Sexual Wellness of Individuals with IDD

Myths of Asexuality and/or Hypersexuality

As part of being 'othered' by an ableist society that constructs disabled bodies and minds as non-normative, there are many myths cast about disabled persons by dominant sexual stereotypes (Alexander & Gomez, 2017; Lam et al., 2019; Shah, 2017). Within the research, these myths were clear in the voices of many research participants. Many expressed that they were: perceived as not needing loving or intimate relationships; portrayed as not sexually attractive to non-disabled people; infantilized or fetishized; seen as unable to have or consent to have sex; as having more important needs than sex; or as requiring protection (Björnsdóttir & Stefánsdóttir, 2020; Campbell, 2017; Lee & Collins, 2020; McDaniels & Fleming, 2016; Sitter et al., 2019, Turner & Crane, 2016a). Often, disabled people are faced with a 'double bind' as they are subject to stereotypes that position them as either promiscuous and predatory 'deviants,' or, conversely, as asexual and sterile 'innocents' (Björnsdóttir & Stefánsdóttir, 2020; Esmail et al., 2010; Kulick and Rydström, 2015; McConnell et al., 2021). Disability activist, Stella Palikarova,

expresses the dichotomy faced by disabled persons when she states "…sometimes I feel invisible, and sometimes I feel like a freakshow" (as cited in Osborne, 2017, 14:48).

Across the literature, the most prominent myth that is cast about people with IDD is that they are asexual, even though research shows that many people with IDD have rich and meaningful sexual lives (Fitzgerald & Withers, 2013; O'Shea & Frawley, 2020; McDaniels & Flemming, 2016). As discussed earlier, there is an assumption that the sexual desires and lives of people with IDD are non-existent, and thus their sexuality is rendered invisible. In an article written by Stevens (2010), they write that "…being deemed asexual is the most egregious sexual harm that disabled people contend with because it is a direct assault on our personhood" (p. 62). It is a failure to recognize people's full humanity and negatively affects disabled persons' sense of their sexual allure and sexual well-being (2010). Similarly, Shah (2017) writes that it is this invisibility that most significantly contributes to restricting chances for sexual exploration, expression, and satisfaction for people with IDD, which then contributes to IDD people's low levels of sexual knowledge compared to their non-disabled peers. Consequently, individuals with IDD are more vulnerable to sexual violence, unplanned pregnancies, sexually transmitted diseases, and prostitution (2017). While these are distinctive areas, they all involve relationships that are exploitative and disempowering in different ways (2017).

Interconnected to the myth that IDD people are asexual is the myth that they are hypersexual (Campbell, 2019; McDaniels & Fleming, 2016). Throughout the literature, rather than being opposite, these two myths seem to interplay with one other. For example, because it is viewed that persons with IDD are not supposed to be sexual, any sexual desires they do express are seen as 'too much' or perverted (Campbell, 2019). Two studies included in this literature review also found that men with IDD are often stereotyped as predatory and licentious (Barrett,

2014; Ćwirynkało et al., 2017). In this regard, the sexuality of individuals with IDD becomes perceived as either dangerous or as needing oversight.

Whether individuals with IDD are perceived to be asexual, hypersexual, infantilized, or fetishized, the myths surrounding disability and sexuality dehumanize and marginalize disabled persons and maintain unequal power dynamics between IDD people and non-disabled people. The invisibility and oppression of individuals with IDD sexuality contributes to their low levels of sexual knowledge, inadequate sex education, increased vulnerability to sexual violence, and lack of access to sexual rights compared to persons without disabilities (Shah, 2017).

Controlled and Restricted Sexual Lives

It became evident throughout the literature that people with IDD experience oppression related to their sexual lives because of barriers at family, organization, and societal levels. A major theme concerning the sexual lives of persons with IDD as generated from the review of the literature, is control and 'regulation by others' (Bathje et al., 2021; Lee & Collins, 2020; Turner & Crane, 2016a; Winges-Yanez, 2014). Sitter et al.'s (2019) 12-month participatory action research study, which included nine adults with developmental disabilities and three allies, found that people with IDD lack support from family members, carers, and guardians when it comes to cultivating and nurturing positive sexual lives. This lack of support is noticed in terms of practical needs, such as accessible sexual education, maintaining sexual health, intimate personal care, and inclusive and private spaces to explore sexuality (2019). It is also noticeable in the negative attitudes that family members, carers, and guardians have regarding the sexuality of individuals with IDD that can make it hard for them to informally have open discussions, learn about, be exposed to, and experience healthy sexual relationships (2019). Many of the participants in this study expressed frustration at the power of others over their sexual lives, with

one individual stating that "…even though I was born a sexual being, my parents still don't think I have the right to love and make my own decisions about who I love" (Sitter et al., 2019, p. 260).

Similarly, in a qualitative study done by Rushbrooke et al. (2014) with nine participants with IDD, the same experiences of having their sexual lives and choices constrained or restricted by family or carers was evident, this included limits on individuals' access to privacy. One participant stated that "…people think they can rule you because you've got a disability… you can't choose the colour that you like… as well as your boyfriend you can't pick" (p. 537). This participant continued by stating that family and support staff should not choose ''…who I love and who I like and pick the man for me'' (p. 537). English et al.'s (2018) study also found that families and caregivers imposed rules and restrictions on people with IDD. Individuals discussed how they would be scolded for holding hands or kissing, and that they would be punished if caught having sex (2018).

Across the literature, participants discussed restrictions put on their sexual lives and experiences. Many individuals mentioned restrictions that came in the form of interfering and overprotective parents, other family members, caregivers, or service providers (Azzopardi-Lane & Callus, 2015; Björnsdóttir et al., 2017; Black & Kammes, 2019; Rojas et al., 2016; Rushbrooke et al., 2014; Sullivan et al., 2013; Winges-Yanez, 2014). One individual stated, "…they would scold me if they found out I was dating a young man" (Azzopardi-Lane & Callus, 2015, p. 35). And another, when responding to their parent's control, stated that "…parents need to trust us, we are old enough to be in a relationship" (p. 36). These parents and family members were often both the caregivers and legal guardians of individuals and would limit with whom their family member could have a relationship (Azzopardi-Lane & Callus, 2015; Stoffelen et al.,

2019). In part, families and caregivers may put these restrictions in place due to concerns about "…vulnerability to exploitation, sexually transmitted diseases, and pregnancy", but may also reflect "societal stigma and residual infantilizing attitudes" towards people with IDD (Baines et al., 2018, p. 1). Likewise, a qualitative study by Linton et al. (2016) in which eleven social workers were interviewed found that social workers have also reported that the individuals with IDD that they serve have experienced challenges in sexual wellness due to protective families and caregivers who "…limit the IDD person's autonomy in accessing health care," see the person as "childlike or asexual," and/or "promoted sterilization" (p. 150).

Restrictions were also highlighted in the form of restrictive programs and policy in the disability-centered environments in which the participants lived (Azzopardi-Lane & Callus, 2015; Bernert & Ogletree, 2013; Black & Kammes, 2019; Fitzgerald & Withers, 2011; McConnell et al, 2021; Rojas et al., 2016; Rushbrooke et al., 2014; Stoffelen et al., 2019). This is discussed in further detail later in the paper under the subsection 'Absence of policies that acknowledge and protect sexual lives.'

There was a sense of powerlessness in individuals' voices and stories in much of the literature examined. When discussing environments and outside circumstances, feeling controlled by a lack of privacy, reliance on others, and limited finances were huge concerns (Azzopardi-Lane & Callus, 2015; English et al., 2018; Feely, 2016; Rojas et al., 2016; Sitter et al., 2019; Stoffelen et al., 2019). In Rojas et al.'s (2016) study, one woman discussed how her partner was not allowed to come to her house, a group home, and that she was never allowed to be alone with him. If she broke this 'rule' it would mean that she would no longer be able to live there (2016).

Finally, another way in which individuals felt controlled was the "…air of secrecy surrounding sex" (Black & Kammes, 2019, p. 221). In over a third of the studies, individuals stated that sex was to be kept a secret. Several of the participants in Turner and Crane's study (2016a) shared how they feel that sex is embarrassing and unsafe to talk about, and therefore they avoid and do not know how to have conversations about it. Additionally, several other studies found that this silence and secrecy prevented some individuals from reporting or talking about incidents where they had been abused, forced, or pressured to have sex (Bathje et al., 2021; Bernert & Ogletree, 2013; Fitzgerald & Withers, 2011; Sullivan et al., 2013). In general, the individuals in many of the reviewed studies wanted choice and control over their sexual lives and experiences, however, they faced many barriers.

Lack of Accessible Sex Education, Knowledge, and Resources

Another recurring theme that emerged during the review of the research is a lack of formal sex education, lack of sexual knowledge, relationship knowledge, and a lack of access to sexual resources, such as media and books on sexuality and IDD, assistive technology (e.g. accessible sex toys, augmented communication devices), funding for programs related to sexuality, or funding to access sex workers (Bathje et al., 2021; East & Orchard, 2014; Sitter et al., 2019; Shah, 2017; Turner & Crane, 2016b). A significant barrier that IDD people face when it comes to accessing sex education, knowledge, and resources, is an exclusion from certain social spaces in childhood which impacts exposure to sexual knowledge and opportunities (Shah, 2017). Compared to their non-disabled peers, IDD children are excluded from important social processes and childhood socialization by "…differential mechanisms of surveillance and segregation and are consequently prevented from developing their sexuality and exploring their sexual identity and body" at the same level (Shah, 2017, p. 3). For adults with IDD, one study

writes that this lack of sex education, knowledge, and resources is generally related to the view that IDD people are "…eternal children… innocent, naïve, and asexual" and that they are incapable in any form of "…sexual expression and exchange" (East & Orchard, 2014, p. 336).

McDaniels and Flemming (2016) found that even if formal sex education is provided to individuals with IDD, it is often vague, softened, indirect, and overly technical, which results in limited knowledge transfer and application. Their study also discovered that a significant barrier to sex education for IDD people is a lack of support and sexual health education training for families and caregivers. The effect of this is that family members, professionals (e.g. social workers), and support staff feel unequipped, in terms of training, to discuss sex and sexuality with individuals with IDD (2016).

Conversely, a couple of the studies noted how family members, professionals, and support staff would intentionally withhold or be selective about the information they provided about sex, often highlighting only the risks or negative outcomes to discourage sexual activity (Friedman et al., 2014; Sitter et al., 2019). Families justified the denial of comprehensive sex education as a form of protection (Sitter et al., 2019). An example of this is also in a study done by Pownall et al. (2012) that examined how sexuality and sex education are viewed by mothers of young people with IDD. They found that compared with mothers of non-disabled young people, mothers of those with IDD speak about fewer sex-related topics, introduce these topics at a later age, place greater emphasis on safety issues, and have more concerns about sexual vulnerability (2012).

In an Australian study that conducted focus groups with individuals with IDD, Frawley and Wilson (2016) discovered that the participants had not learned the 'how to' of sex and relationships, but rather only the facts and rules. A study done in Sweden in which individuals

with IDD were interviewed, also confirmed the same findings (Löfgren-Mårtenson, 2012). This same study found that individuals with IDD's sex education, both informal and formal, focused mostly on avoidance and safety, rather than on developing and exploring a positive view of sexuality. Echoing this, Stofellen et al. (2019) found that people with IDD have less knowledge about topics such as "…pregnancy, safe sex, reproduction, masturbation, and sexual diversity" than their non-disabled peers (p. 229). This lack of sex education and knowledge is problematic and oppressive as it marginalizes this population further and can create circumstances in which an IDD person might not recognize a high-risk situation, which can result in an increased risk of abuse (Stoffelen et al., 2019). Across the literature, participants strongly advocated for more comprehensive and inclusive sex education, including knowledge about relationships.

Absence of Policies that Acknowledge and Protect Sexual Lives

Noted as another significant theme under factors that hinder the sexual lives and wellness of individuals with IDD is the absence of policies that acknowledge and protect sexual lives. Throughout the literature, many participants and support workers discussed how both policies and programs were incredibly restrictive regarding sexuality in many disability-centered environments (Black & Kammes, 2019; Pariseau-Legault & Holmes, 2017; Sitter et al., 2019). Organizations that support people with IDD often avoid policy development on sexuality and disability out of fear due to the discourse of risks and vulnerabilities around this topic (Alexander & Gomez, 2017). In a 2016 study done by Turner and Crane, many participants were unsure if their organization had sexuality policy, and if their staff had any training in this area.

Failing to have policy that addresses the sexual lives of IDD translates into service issues as well (Sitter et al., 2019). Several support staff in Sitter et al.'s study communicated that they feel they do not have guidance on how to appropriately provide care for the sexual lives and

wellness of individuals with IDD because the organizations they work for do not address policy on sexuality (2019). A lack of policy also means a lack of resources and funding for services that support the sexual lives, wellness, and rights of those with IDD (2019). Alexander and Gomez (2017) had similar findings – without clear policy, support staff believe that they cannot support an individual with IDD's sexual life and become afraid of the consequences should they provide such support. Support staff may believe that they are 'on their own' if they openly support an individual's sexual life without a policy (2017).

When organizations do have policy regarding the sexual lives of IDD people, the policy is often focused on 'protection' and 'safety.' As a result of this, policy is incredibly restrictive and creates many barriers to sexual lives and expression for individuals with IDD. Examples that kept arising in the research regarded individuals with IDD who live in group residential facilities and homes (Pariseau-Legault & Holmes, 2017). While living conditions vary for those with IDD, many residential and housing facilities prohibit sexual or intimate contact between those living there, have 'no touch/no sex' policies, and will offer rooms with only single beds or have doors that cannot be locked (Black & Kammes, 2019; Fitzgerald & Withers, 2011; Hollomotz & Roulstone, 2014; McConnell et al., 2021). These policies impact the sexual lives of people with IDD, as they create a lack of private spaces. Pariseau-Legault & Holmes (2017) highlight that this lack of private space, and the silence surrounding this issue, is particularly harmful as in some circumstances it may drive people to express their sexuality outside of their home (e.g. in public). These same authors argue that when this happens, individuals may "…suffer abuse, sanctions, and criminalization" (p. 604)

Overall, the sexual lives and wellness of individuals with IDD are largely ignored or blatantly restricted in policies. It is also evident that discussions and decisions regarding policy

often exclude IDD people and focus more on the risks around people with IDD having sex versus the importance of relationships and sexual wellness (Friedman et al., 2014).

Factors that Help the Sexual Lives and Sexual Wellness of Individuals with IDD

Acknowledgement and Empowerment

Key to the expression of their sexual lives, IDD people want to know that they are being heard and that their wishes and needs are being acknowledged, respected, and empowered (Fitzgerald & Withers, 2013). Many participants in various studies (Campbell, 2019; Sitter et al., 2019) highlighted that, similar to people without IDD, those with IDD are also concerned about love, feeling special, doing the 'right thing' during sex and so on (Turner & Crane, 2016b). Echoing these findings is Azzopardi-Lane and Callus' (2015) research which also found that sexuality is a topic of interest to people with IDD, with many of the participants in their study putting forward ideas that are in line with people their age would talk about: "…going out with a boyfriend and girlfriend, how far they go or would go, getting married, having children, and their ideal mate" (p. 35).

In Fieldman's 2019 study, the majority of the 1,443 questionnaire respondents (57.4%) had sexual relationships. Similarly, in their interviews with six women with IDD, O'Shea and Frawley (2020) found that several of the women presented themselves as sexual, describing the pleasure they experienced. Another study found, too, that people with IDD are extremely resilient, often finding creative ways to escape sexual control within disability-centered environments (Feely, 2016). Participants in Turner and Crane's (2016a) study reported that they had a range of sexual experiences and hoped to engage in sexual activities in the future. Sexual pleasure was noted as is important to the participants, and they felt that their sexuality should not be viewed solely through the lens of 'safety.' While many of the individuals in this study

embraced their sexuality with pride, conversely, others denied it or felt ashamed of it due to a lack of recognition by family and support staff that they are sexual beings (Turner & Crane, 2016a, 2016b).

What was clear in the research is that people with IDD want to be recognized as people who desire relationships. Many of the participants in the research also acknowledge the reality that they may need help with developing and maintaining more intimate and sexual relationships (Friedman et al., 2014). This information changes the perspective that people with IDD are 'asexual' and instead raises awareness that those with IDD have sexual lives. People with IDD want to be empowered to have more social experiences to meet new people, in the hopes of establishing friendships or intimate relationships (Brown & Mccann, 2018). To explore and express their sexuality, IDD people want to see the development of person-centered approaches from their families, professionals, and support staff that enables and empowers them to have fulfilling sexual lives (2018). As part of participating in their sexual lives, people with IDD also expressed the need for access to support services such as counselling, advocacy, and talking therapies (Brown & Mccann, 2018; Friedman et al., 2014).

Sexual Voice: Autonomy and Self-determination

Several tensions arose in the literature between self-determination and perceived risks of exploitation and harm (Shah, 2017). While individuals with IDD are at a higher risk of abuse, many self-advocates argue that this is due to the oppressive discourses of asexuality and infantilization which creates barriers to education, empowerment, and autonomy (2017). An important concept that arose in much of the literature was sexual voice, which embodies autonomy and self-determination (Turner & Crane, 2016a, 2016b). Turner and Crane (2016b) define sexual voice as "…how a person reveals their social-sexual self through communication"

(p. 2301). They found that helping people with IDD have a sexual voice can support them in being the subject of their own lives, it is about power and is a tool of self-determination (2016b). When one has a sexual voice, they affirm their right to be sexual (2016b).

For many of the participants in the literature, their IDD means that they may require support staff in their everyday lives; earlier it was seen how this often means that participants were denied privacy, and in some cases, autonomy, in order to access opportunities to their sexual lives (Campbell, 2019). It is important for organizations, support staff, and families to acknowledge the day-to-day care and assistance people with IDD may need, and when it is requested, to provide equal assistance to access opportunities for sexual lives (2019). In their 2014 study, Friedman et al. interviewed 35 self-advocates with IDD. Friedman et al. (2014) found that self-advocates' "choices" arose as a central component of engaging in a sexual life (p. 520). The self-advocates stated that being able to make their own choices about what they want or how they engage in sexuality is central to sexual self-determination (2014). While self-advocates recognized the key role that others can play in their lives, they strongly voiced that others should never assume they "…know the choice an [individual with IDD] might make about sexuality" (2014, p. 520). Rather, self-advocates strongly desire that the support they receive work together with a recognition of their choices, such as the ability to choose how and with whom they express their sexuality (2014). Self-advocates also said that families, organizations, and support staff could increase voice of people with IDD by improving opportunities for inclusion through accessible information and non-judgmental attitudes (2014).

Knowledge and Sex Education

Another reoccurring theme that arose in the literature was the need for comprehensive and accessible sexual knowledge, education, and resources. As seen above in the factors that

hinder the sexual lives of IDD people, Alexander and Gomez (2017), highlight in their article that without access to sex education and the accompanying sex literacy, people with IDD are denied essential conversations about sex, sexual expression, and pleasure thus creating barriers to their sexual lives and sexual wellness. When accessing support around sexuality, Lee and Collins (2020) study reported that participants identified how important it is for professionals to have knowledge about disability issues, including the "…impact of impairment on sexual identity and wellbeing" (p. 317). In other words, it is essential that professionals understand what impairment is and how it affects the lived experiences of individuals with IDD particularly in terms of their access and inclusion in sexual lives. One participant gave the example of professionals needing to have "…information about different sexual activities suitable for someone with his impairment" (2020, p. 317). It was found that professionals can positively influence the confidence and self-esteem of people with IDD through having the knowledge to discuss issues that are important to the individual, which includes "…recognizing and acknowledging IDD people as sexual beings" (2020, p. 318).

Likewise, participants in Rushbrooke et al.'s (2014) study indicated that individuals with IDD did not know how to ask someone to date or if they wanted to have sex and that they would benefit from having that information. In Black and Kammes (2019) research, people with IDD expressed that they desired a sexual relationship, but felt they needed support in sustaining it and that education was a means of developing the skills necessary to be successful, such as: interpersonal communication, reading social cues, body language, learning how to ask questions, understanding pleasure, different methods of touching, and how to be safe. This review of the research shows is that professionals, and in particular social workers, can positively influence sexual confidence, esteem, and autonomy through having the knowledge to discuss issues that

individuals identify as important, which includes acknowledging people with IDD as sexual beings (Parchomiuk, 2021).

Traditionally, when sex education has been offered, it is typically 'for' people with IDD provided 'by' professionals, families, or teachers. One study reviewed a peer-led relationship and sexuality program called *Sexual Lives and Respectful Relationships* and found that when people with IDD were shifted from being "subjects to owners, developers, and facilitators" of sex education and knowledge, that the power dynamics and privileging of cognition was challenged (O'Shea & Frawley, 2020, p. 3). This model of sex education ensures that the experiences and voices of IDD people are heard. It was successful in empowering people with IDD and creating more knowledge through the "sharing of stories, listening to each other's experiences, and linking these to real life issues" (2020, p. 6). Sex education that builds on strengths, combined with social resources, seems to offer a very promising possibility for overcoming unequal power relations and creating more supportive sexual opportunities in the lives of IDD people. The success of this approach to sex education for individuals with IDD warrants more research and application in practice.

Despite many barriers, throughout the literature, individuals with IDD identified ways that families, professionals, organizations, and support staff could better support them to learn about sexuality. Some of these suggestions included adapting mainstream sex education, and tailoring resources to different levels of functioning; offering more holistic sex education including pictures and social skill activities; practice and repetition; information on how to date and on how to talk to their families about their sexuality (Frawley & Wilson, 2016; Friedman et al., 2014; Turner & Crane, 2016b).

Supportive Policy

People with IDD and their allies, throughout the literature, call for clear policy that acknowledges and supports their sexual lives and wellness. Bathje et al. (2021) and Bernert and Ogletree (2013) both agree that policy and overall systems changes should be used to create, protect, and advance individuals with IDD sexual lives and opportunities. Likewise, Turner & Crane (2016a) write that "…implications for policy include acknowledgement of physical pleasure in the scope of essential services. Tying outcome evaluation and funding to pleasure institutionalizes this concept as an important measurement of quality of life" (2016a, p. 686). Results from another study suggest an obvious need for policy that favours positive approaches to sexuality and that facilitate effective sexual expression (Pariseau-Legault & Holmes, 2017, p. 609).

The focus of policy change throughout the literature was mostly general and at a mezzo, or organizational level, though some research included targeted and specific policy changes needed. Bernet and Ogletree (2013) suggested developing organizational policy statements that are supportive of IDD people's sexual lives and expression. More specific calls for policy change included the following: allowing individuals with IDD who live in residential settings to "have guests in their bedrooms" and overnight (Rushbrooke et al., 2014, p. 540); adding a requirement that yearly individual support plan meetings include sexuality as a component (Turner & Crane, 2016b); removing policies that ban flirting and dating (Turner & Crane, 2016a); and having a policy that ensures that sex education and sexual health information is available from a number of sources and accessible to individuals with IDD at their interest and discretion (Frawley & Wilson, 2016).

Several of the articles also mentioned having supportive policy that allocates and makes available resources and funding to provide more social opportunities within services for individuals with IDD, creating spaces for people to meet one another and form relationships (Bates et al., 2017). Bates et al. (2017) encouraged policymakers to "…ensure that policies are designed to facilitate the provision of support surrounding relationships" (p. 71).

Discussion and Implications

Gaps in the Literature

Numerous gaps and limitations became apparent throughout the development of this literature review. Despite many valuable contributions to this body of research over the last several years, the lived experience of IDD people and sexuality remains under-researched at all levels. One of the most common limitations listed in each of the studies included in this major paper was that the sample was not representative of the larger population of people with IDD. Many of the articles (Björnsdóttir & Stefánsdóttir, 2020; O'Shea & Frawley, 2020; Sitter et al., 2019; Turner & Crane, 2016a, 2016b) noted that their studies were limited by little diversity among participants in terms of age, race, and severity of impairment, and by small sample sizes. Larger samples would speak to the generalizability of findings across populations and would allow for more stable research.

At present, there is also more research available on the sexual lives of people with physical disabilities versus people with IDD and most of the research in this field is carried out in "developed" Western countries (Campbell, 2017). The majority of the individuals who participated in many of these studies were primarily heterosexual, cisgender, white people with mild IDD. None of the articles found included Indigenous perspectives. Thus, the voices of people with IDD whose identities intersect in more than one area of marginalization, including

those marginalized by race, gender identity, gender expression, sexual orientation, and age are additionally silenced within the literature.

Failing to recognize various identities in the discussion of disability and sexuality erases the experiences of many, including those who are a part of the LGBTQIA+ community. The focus of this literature review was an exploratory overview of the literature 'landscape' about sexual wellness and people with IDD and, as such, it was outside the scope of this paper to do a deeper analysis here. However, it is important to note that evidence from one study suggests that LGBTQIA+ disabled people tend to face particular challenges due to disconnection, discrimination, and the 'double marginalization' experienced in both disability and queer communities (Martino, 2017). Overall, a large gap remains in knowing what the lived experiences of sexual lives and wellness for LGBTQIA+ people with IDD are, as it was difficult to find any research that included these groups.

Throughout the literature, there is also a significant gap in the research about levels of sexual health and activity amongst individuals with IDD, and gaps in the knowledge about what socioeconomic factors are associated with sexual health and experiences for this group. Similarly, there is also a lack of studies that evaluate policy, education, sexuality, and quality of life (Brown & Mccann, 2018).

Finally, while many of the participants included in the studies had IDD, there was not a single study found that included individuals with IDD as the researchers. Having the voices of individuals with IDD included from the development of the research questions, to choosing methods of collecting information and participants, to data interpretation and analysis could lead to distinctive perspectives and create research that more directly addresses the concerns of this population (Black & Kammes, 2019).

Implications for Social Work: Micro, Mezzo, Macro

The findings from this literature review provide many implications for social workers. As social workers, we are mandated to respect the unique worth and inherent dignity of all people, uphold human rights, including the right to self-determination, and to promote and advocate for social justice (CASW, 2005). For social workers cautious about confronting sexuality, it is helpful to frame this topic as a sexual justice issue and therefore part of social justice. Thus, it is essential to build an intersectional, anti-ableist, and anti-oppressive social work practice that works to recognize and protect the sexual lives and wellness of individuals with IDD. The findings of this literature review provide a more nuanced understanding of intersectional identities, particularly of sexuality intersecting with disability. Social workers are uniquely positioned to advocate for informed care and support, and to work on redefining current sexual narratives, not only for individuals with IDD, but to support all individuals in getting their sexual needs and desires met.

One of the first steps to this is that social workers need to feel comfortable and confident with their own sexuality if they are going to be helpful to others (Dodd & Katz, 2020). Social work education should include courses on the foundations of human sexuality. Having this knowledge would empower social workers to speak openly about sex and sexuality, including sexuality and disability. It is also important that social workers are aware of the diversity of experience that disability represents; and that each experience of disability and sexuality is going to be uniquely impacted by social and structural oppressions that require equally unique interventions.

Second, social workers need to avoid assumptions and challenge stereotypes. The truth is, ableism runs deep in every area of society, especially when it comes to the sexuality of

individuals with IDD (Lam et al., 2019; Lee and Collins, 2020). Not only does society have pervasive assumptions of cis-normative heterosexuality, but there is also a pervasive assumption of asexuality regarding individuals with IDD. These assumptions are harmful, and as some of the literature has shown, are not true (Campbell, 2019; Martino, 2017; Sitter et al., 2019). Social workers must correct the negative discourses and silence around the sexual lives of IDD people. The path forward towards empowering and recognizing the sexual lives and wellness of IDD people does not include just one strategy, but a multiplicity of strategies, interventions, and tactics at the micro, mezzo, and macro levels. Despite the many challenges and barriers outlined earlier, social justice work on these issues has already begun. Disability activists and self-advocates, allies, NGOs, and other various organizations have been recognizing the need to break down the barriers and myths of sexuality and disability through workshops, training sessions, courses, social media campaigns like #DisabledPeopleAreHot, documentaries, research projects, and on (Campbell, 2019). As social workers, we can and must seek to partner and collaborate with these communities. A vital strategy in all stages of the work towards sexual justice is to embody and uphold the principle of the disability rights movement, of: 'nothing about us, without us.'

Third, at the micro-level, clinical social workers should adopt a strengths-based view of individuals with IDD sexuality (Turner & Crane, 2016b). This perspective acknowledges that individuals bring their sexuality with them, as they do the other parts of their identities. It helps social workers understand the people they work with more holistically and recognizes them as the experts on their own lives, including their sexual lives. When working alongside clients who are disabled, we need to create safe non-judgmental spaces where individuals with IDD can freely discuss sexual concerns, know that their choices will be supported, and that available

resources and referrals will be offered to any sexual services that they may require (Turner & Crane, 2016b). Social workers need to remain competent in understanding local disability and sexuality resources. This includes knowing what resources are available for individuals and being able to identify the gaps in services. We have a duty to empower individuals with IDD understandings of and access to their sexual lives. By being well equipped to address sexuality with individuals, we can help eliminate sexual disparities and support the sexual wellness of individuals with IDD (2016b).

Social workers can also support policy development with organizations so that the human and sexual rights of individuals with IDD are recognized and that they are treated with equality, dignity, and respect. Another intervention at a mezzo level is to normalize sex through education, this includes inclusive and sex-positive sexual health education in schools, for individuals with IDD, for students, for families, for caregivers, for staff, for social workers, for all. Training should also be offered to various allied supporters such as doctors, nurses, and those in the legal system. Another finding from the literature is that it is crucial to create accessible spaces for the provision of self-advocate and peer-led sexual health education and knowledge sharing (O'Shea & Frawley, 2020). Promoting groups or programs run by self-advocates empowers individuals with IDD as the experts in their own experiences of disability and sexuality (2020).

Finally, at the macro level, social work interventions to this issue need to include advocacy and activism that uphold the sexual rights of IDD people, address policy concerns, fight for accessible spaces and infrastructure, and various needed sexual health and wellness resources. The findings of this literature review show that clear and comprehensive policy is needed, outlining person-centered, sexuality-focused service provision creating more sexually inclusive organizations. Additionally, at the macro level, social workers can promote media and

public discourse that deconstructs myths by celebrating and recognizing sex and disability in realistic, honest, and raw ways. Social media, podcasts, and other emerging forms of technology can be used as tools to readily and openly discuss this issue, directly dismantling the shame and stigma that typically surrounds it. These interventions can help challenge inaccurate media stereotypes and widespread misinformation about individuals with IDD.

Overall, this literature review highlights that the voices of individuals with IDD must be central to this conversation, they must be heard, and they must be acted on if there is to be any personal, institutional, or societal transformation. Building relationships, championing, and advocating for what individuals with IDD communicate and identify, in their own ways, as their unique sexual needs are the actions required to challenge the status quo and to begin dismantling the barriers society has created that hinder and harm the sexual lives and wellness of this population.

Conclusion

While sexuality and disability are often thought of as two disparate things that do not belong together, the findings of this literature review suggest that nothing could be further from the truth. Individuals with IDD need to feel empowered in their sexual lives and experiences and receive education about sex and sexuality as to increase sexual wellness. Sexuality is a right protected in international conventions (UN, 2018; WHO, 2022) and, as social workers, we must commit to supporting people with IDD to lead full lives, including sexually free lives. This literature review provides accurate, recent, and evidence-based information, to social workers, regarding the sexual lives of individuals with IDD. Being equipped with extensive knowledge and subsequent training within this area of practice will benefit not only benefit IDD people, but their entire support system. Social workers have an ethical obligation in preparing themselves to

best support people with IDD with knowledge, resources, and a safer space to ask questions and explore their sexual lives.

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