



The Sexual and Reproductive Health and Rights of Young People with Intellectual Disability: A Scoping Review

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Abstract

Introduction We examined the breadth of research on sex, sexuality, and sexual and reproductive health and rights with young people with intellectual disability in the past two decades.

Methods An inclusive scoping approach focused on agency and resilience was used to review studies in English-speaking, high-income countries (2000–2019).

Results In the 68 studies included, we found positive examples of sexual and reproductive agency across five key domains: 1) sexual development including sexual desire, identities, relationships, and menstruation, 2) sexual knowledge including sexuality education and sexual self-advocacy, 3) sexual activity and contraceptive use, 4) access to HPV immunization and cervical cancer screening, and 5) pregnancy, childbirth, and parenthood. The strongest factors in enabling agency were social support and sexuality education. However, several barriers including paternalist attitudes and infantilization of young people with intellectual disability affected all aspects of sexual expression, leading to the persistence of unfair and avoidable health inequities over the past two decades.

Conclusions Ensuring young people with intellectual disability have a voice on all matters affecting their bodies, even if they have high support needs, is essential to promoting sexual and reproductive health and rights for all.

Policy Implications Anti-ableist policies in sexual and reproduction health (e.g., education curriculum, service delivery) are key to moving forward.

Keywords Young people · Intellectual disability · Sexual and reproductive health and rights · Inclusive research

Sexual and reproductive health and rights are important to human happiness and wellbeing and remain a central concern for people of all abilities (Starrs et al., 2018). Because of intersectional stigma, social and economic marginalization, a lack of comprehensive sexuality education, and policies that regulate reproduction, people with disability are more vulnerable to human rights violations, such as reproductive

coercion (Horner-Johnson et al., 2019; Ngwena, 2018) and sexual violence (Fisher et al., 2016), leading to increased risk of both unintended pregnancies and sexually transmissible infections (STIs) (Servais, 2006). This is especially true for young people with intellectual disability (McCarthy, 2014). Studies have found that people with intellectual disability are not provided with the education and health services

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necessary to make informed decisions about their bodies, to learn about human relationships, and to feel prepared for sex and parenthood if desired (Brown & McCann, 2018; Dionne & Dupras, 2014; McCarthy, 2014; Medina-Rico et al., 2018; Whittle & Butler, 2018). Being excluded from these opportunities and resources can have significant consequences for their sexual and reproductive health and wellbeing.

Holistic Understanding of Sexual and Reproductive Health and Rights

This paper is theoretically aligned with the Gutmacher–Lancet Commission’s (2018) integrated definition, which recognizes that “good” sexual and reproductive health is not simply the state of being free from illness or injury. Rather, it is “...a state of physical, emotional, mental, and social wellbeing in relation to all aspects of sexuality and reproduction” (p. 2646). Importantly, this definition considers positive and respectful relationships and pleasurable and safe sexual experiences—in addition to freedom from discrimination, coercion, and violence—as integral to empowering all persons and increasing their self-esteem, self-confidence, and overall wellbeing. This definition also states that the achievement of health relies on the realization of human rights, including the right of all individuals to: “have their bodily integrity, privacy, and personal autonomy respected; freely define their own sexuality, including sexual orientation and gender identity and expression; decide whether and when to be sexually active; choose their sexual partners; have safe and pleasurable sexual experiences; decide whether, when, and whom to marry; decide whether, when, and by what means to have a child or children, and how many children to have; have access over their lifetimes to the information, resources, services, and support necessary to achieve all the above, free from discrimination, coercion, exploitation, and violence” (p. 2646). Of course, these rights apply to any person, including young people with intellectual disability.

Promoting the Health and Rights of Young People with Intellectual Disability

Young people with intellectual disability have been marginalized throughout history and this has affected their sexual and reproductive health and rights. In this paper, we use the term “young people with intellectual disability” in a social model context to describe individuals aged 10–29 who have a condition that affects learning or understanding things, as well as their adaptive skills (American Psychiatric Association, 2013), and who have been disabled by societal barriers rather than individual

impairments. Importantly, the sexual and reproductive health and rights of young people with intellectual disability must be understood in the context of varying access to support, and differences in age and the severity of the disability that individuals experience. Individuals with mild to moderate intellectual disability may be denied the right to parent or to access contraception due to perceptions or even laws that remove autonomy in reproductive decision making (Brown et al., 2018a), while the issues facing young people with severe intellectual disability may be very different. For example, Australia remains one of the few countries where sterilization through hysterectomy, to prevent menstruation as well as pregnancy, can still be granted by the courts for women with severe intellectual disability (Elliott, 2017). Depo-Provera has also been commonly used and abused in this group across the world (Wu et al., 2018a, b).

Another issue is growing up with the threat of pervasive violence. Children with intellectual disability face a ten times higher incidence of sexual abuse compared with children without disability (Wissink et al., 2015). This has substantial trauma associated with it, as sexually abused students and adults with intellectual disability tend to be passive in their future sexual relations and make poorer relational decisions (Byrne, 2018). Rather than conceiving of young people with intellectual disability as vulnerable to sexual abuse because of their impairment, or deserving of pity when they experience abuse, it is important to consider how social and cultural structures may hinder their sexual agency. Work by Gill (2015), for example, has drawn attention to the strong interplay between ableism, racism, classism, and sexism for individuals with intellectual disability, and its impact on the development of prejudicial social attitudes and, in turn, a range of discriminatory social policies and practices. From state-mandated eugenic practices, to risk-based sex education, to family-level decisions, these policies are designed to manage the private spheres of sexuality and reproduction in individuals’ lives, influencing how young people with intellectual disability construct and negotiate their sexual knowledge, identities, relationships, and behaviours.

Sexuality education building on strengths, in combination with social and material resources, offers a promising avenue for overcoming unequal power relations and carving out more supportive conditions and opportunities in the lives of young people with intellectual disability (Frawley & O’Shea, 2020; Gill, 2015). However, many teachers and parents withhold information from their children, motivated by a desire to shield them from knowledge of the harms and threats that exist in the world around them (McDaniels & Fleming, 2016; Wolfe et al., 2019). At schools, there are few sexuality education curricula specifically adapted for young people with intellectual disability, and there is little evidence regarding the effectiveness of these programs, with notable

exceptions using peer education (Frawley & O’Shea, 2020; Johnson et al., 2002). Teaching about sex, particularly in the context of intellectual disability, very much depends on what teachers feel comfortable with (McDaniels & Fleming, 2016; Wolfe et al., 2019). Other reasons for low sexuality education include the larger socio-cultural context, such as cultural taboos, the school environment (e.g., time, access to material and training), and the community trauma resulting from structural violence, interpersonal violence, and historical harms (Gill, 2015; Hanass-Hancock et al., 2018). Without access to trauma-informed education about sex and sexuality, the agency of young people with intellectual disability can be compromised, and this is a core issue in achieving sexual and reproductive health and rights (Starrs et al., 2018).

Rationale and Aim of Review

In the past two decades, there has been a growing interest in disability and sexuality research addressing the full scope of young people’s sexual and reproductive health and rights (Shuttleworth, 2007), whilst highlighting ambivalence and discrimination in legal and social policy (Shildrick, 2007). In 2000, Mitchel Tepper called for positive discourse about sexuality to be included in disability research. In 2006, the United Nations Convention on the Rights of Persons with Disabilities affirmed the rights of people with disability to enjoy all aspects of social and political life, including sexuality, on an equal basis with people without disability. It is worth noting that references to sexual rights in the Convention, particularly out of the context of marriage, were marked by considerable debate amongst member states although some affirmative wording was retained, including, for example, the right of people with disability to “retain their fertility” (Schaaf, 2011). In recent years, the concept of supported decision making in regard to reproductive autonomy has gained traction, as a way of supporting people with intellectual disability in choosing to use contraception, terminate a pregnancy, or continue a pregnancy (Kohn et al., 2012). As Conder et al. (2011) assert, “parents with a learning disability can care for their children well. To do this, they may need support from their family or friends and a range of services” (p. 105). This discourse on enabling choice has been accompanied by a global recognition that sexual pleasure and rights are central to health and wellbeing (Ford et al., 2019). In light of these developments, have the experiences and outcomes of sexual and reproductive health and rights for young people with intellectual disability changed? We sought to answer this question, examining the breadth of research on sex, sexuality, and sexual and reproductive health and rights conducted with young people aged 10–29 with intellectual disability in the past two decades.

Previous reviews of research involving people with intellectual disability have focused on adults or specific issues such as sexuality education (McDaniels & Fleming, 2016; Wolfe et al., 2019), sexual knowledge (Borawska-Charko et al., 2017; Kramers-Olen, 2017; Rowe & Wright, 2017), sexual assault (Fisher et al., 2016), and psychosocial factors impacting sex and relationships (Black & Kammes, 2019; Brown & McCann, 2018; Dionne & Dupras, 2014; McCarthy, 2014; Medina-Rico et al., 2018; Whittle & Butler, 2018). Given that sexual health and reproductive health have historically been studied as separate domains, both generally and for young people with intellectual disability, our aim was to contribute to a more complex and coupled understanding of these issues by integrating evidence from both areas and spanning both qualitative and quantitative research. We focused on studies from English-speaking, high-income countries, with the goal of identifying future research, policy and practice priorities relevant to the authors’ home countries of Australia and Canada, and similar contexts internationally. Specifically, we sought to understand the experiences and needs of young people with intellectual disability in the past 20 years, exploring the role of social policies and practices in impeding or facilitating progress on sexual and reproductive health and rights.

Theoretical Frameworks: Intersectionality, Agency, and Resilience Theory

As an interdisciplinary team, we integrated both biomedical and social perspectives to achieve a more holistic understanding of sexual and reproductive health and rights in the lives of young people with intellectual disability (Hankivsky et al., 2017). Our approach was also intersectional. Intersectionality is a critical, race-conscious, feminist theoretical framework created by US legal scholar Kimberlé Williams Crenshaw (1989) to describe how race, class, and gender overlap with one another to marginalize women of colour. Collins (1998), Hancock (2007), and many other theorists across diverse fields (e.g., Bowleg, 2008; Hankivsky & Christoffersen, 2008; McCall, 2005) have developed intersectionality further, emphasizing the interdependent and mutually constitutive relationships between social identities and social inequities that result from systems of privilege and oppression (e.g., racism, classism, sexism, homophobia, ableism). Drawing on this approach has ensured that our review is concerned with not only intellectual disability but also a variety of social factors that operate through structural, historical, and cultural pathways and how these factors intersect to create and maintain health disparities.

Of significance, we synthesized and interpreted results from studies within the context of Brady’s sociology of childhood perspective (2015) and concepts of sexual agency

and empowerment (Aggleton, 2018; Bay-Cheng, 2019; Spencer, 2013). While defined in various ways, the notion of sexual agency describes the process by which people exercise autonomy and choice about their sexual and reproductive health that goes beyond risk prevention to encompass healthy, positive sexual experiences, while navigating social worlds and power relationships at the macro and micro levels (Cense, 2019). This allowed us to see young people with intellectual disability as health actors and to examine which sorts of intersecting cultural and social-structural influences enable or constrain their decisions about sexual and reproductive health (Johnson et al., 2002). It also allowed us to shift attention away from deficit-based approaches to a framework focused on strengths and resilience, “an interactive concept that refers to a relative resistance to environmental risk experiences, or the overcoming of stress or adversity” (Rutter, 2006, p. 1). A key objective then was to ensure that we identified not only findings related to risk but also protective factors and processes, or the social, cultural, and personal resources that young people with intellectual disability access or draw on to build sexual and reproductive wellbeing.

Methods

Methodological Framework

We adopted Arksey and O’Malley’s (2005) scoping framework to review the literature, which included five stages: identifying the research question, identifying relevant studies, study selection, charting the data, and collating, summarizing, and reporting the results. We chose a scoping study in order to map the available evidence, identify the most prevalent themes and gaps in understanding, and inform policy and practice. Our review was based on the PRISMA-ScR (Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews) guidelines (Tricco et al., 2018). We also integrated the principles of inclusive research (Walmsley & Johnson, 2004), which is about involving and engaging people with intellectual disability in doing research. There is a wide spectrum of what inclusive research can look like. For this paper,

we engaged a person with intellectual disability (JL) as a co-author, having them help guide the content and outcomes of the research with contributions at every stage, from conception and design, through analysis and interpretation of the data, to revising the manuscript’s major themes and recommendations based on their lived experience. This process of engagement was facilitated through discussion of an easy-read version of the protocol and manuscript with JL and the first and second authors (Chinn & Homeyard, 2017; Sutherland & Isherwood, 2016). These conversations were audio-recorded and supplemented by hand-written comments given by JL, with the data used to inform and strengthen the research from a lived experience perspective.

Search Strategy

With these frameworks in mind, we searched PubMed, CINAHL, Medline, Psych Info, and Sociological Abstracts. Search terms (Fig. 1) captured the commonly recognized components of sexual and reproductive health and rights such as pregnancy, contraceptive services, sexuality education, prevention of STIs, and reproductive cancers (Starrs et al., 2018), as well as the neglected areas of agency, parenthood, and pleasurable sexual experiences. We also reviewed the reference lists of articles.

Inclusion Criteria

A paper was eligible for inclusion (Table 1) if it was focused on sexual and reproductive health and rights in young people aged 10–29 with intellectual disability in the USA, Canada, Australia, New Zealand, the UK, and Ireland. Studies where young people with intellectual disability made up all or part of the sample were included, and findings specific to youth were emphasized where possible. A paper was excluded if it did not contain primary data; was focused on the perspectives of parents or caregivers rather than young people; and was published in a language other than English. Publication dates were from 1 January 2000 to 31 December 2019, mapping the period following a 2000 paper by Tepper, which called for positive discourses about sexuality to be included in disability research.



Fig. 1 Search terms used to identify studies on sexual and reproductive health and rights among young people with intellectual disability

Table 1 Inclusion criteria

Study population	Young people with intellectual disability ages 10–29
Study focus	Sexual and reproductive health and rights
Country	USA, Canada, Australia, New Zealand, UK, Ireland
Method	Qualitative and quantitative studies
Publication type	Peer-reviewed reports of primary research
Publication language	English
Publication dates	1 January 2000 to 31 December 2019

Study Selection and Data Extraction

Two independent reviewers (AC and CW) led study selection, screening titles and abstracts, and reviewing full-text articles to determine whether they met the inclusion criteria (Cohen's Kappa (k) = 0.82, indicating almost perfect agreement). Consensus with co-authors was used to resolve discrepancies. A flowchart summarizing the search strategy and selection of studies is shown in Fig. 2, illustrating how we progress from 2097 to 68 records for analysis. The main findings from each study were extracted according to the primary focus of the research (Supplementary Tables 1 and 2) and summarized below.

Results

Characteristics of Included Studies

The 68 included studies were conducted in Canada ($n = 12$), the USA ($n = 23$), the UK ($n = 21$), Australia ($n = 11$), and New Zealand ($n = 1$). Thirty-two studies focused solely on adolescents and/or young adults (of which, most participants' ages ranged from 14 to 29, with younger age groups engaged in studies of HPV immunization and menstruation), whilst 36 studies included both young people and older adults, particularly in the area of reproductive health. Eight studies examined sexual and reproductive health and rights among those with differing disabilities (Haynes et al., 2018; Malouf et al., 2017a, b; Mosher et al., 2018; Pownall et al., 2017; Redshaw et al., 2013; Shandra & Chowdhury, 2011; Shandra et al., 2016).

Most studies focused solely on women ($n = 39$), with just three studies involving men only ($n = 3$) (Shandra et al., 2016; Wheeler, 2007; Yacoub & Hall, 2009). Among the remaining gender-mixed studies ($n = 26$), only eight disaggregated their data by gender and/or conceptualized gender differences in health (Baines et al., 2018; Cheng & Udry, 2005; Cheng & Udry, 2002; Frawley & Wilson, 2016; Mandell et al., 2008; O'Neill et al., 2019a, b; Savasi

et al., 2014). The inclusion of sexual minority and gender non-conforming participants was limited. McClelland et al. (2012) specifically focused on the experiences of lesbian, gay, bisexual, trans, and queer (LGBTQ) youth with intellectual disability.

The intersection of intellectual disability with other social determinants of sexual and reproductive health and rights was primarily addressed through the lens of gender. For example, the construction of femininity and masculinity for young people with intellectual disability was examined in a handful of studies (Frawley & Wilson, 2016; O'Shea & Frawley, 2019; Wheeler, 2007). However, few articles explicitly examined the role of other social positions and structures in the sexual and reproductive health and rights of young people with intellectual disability, such as sexual orientation and homophobia (McClelland et al., 2012), or poverty and income inequality. Although some samples were diverse in terms of race and ethnicity, particularly in the USA (Barnard-Brak et al., 2014; Cheng & Udry, 2005; Shandra & Chowdhury, 2011), the literature avoided discussions of racism as an overlapping determinant of sexual and reproductive health inequities. Across 33 studies with comparative data to peers without disability, young people with intellectual disability were disproportionately affected by violence, socioeconomic disadvantage, and concurrent physical and mental health problems. In only a small number of studies were these factors analysed intersectionally (e.g., Brown et al., 2016a, b, c, d). That is to say, a within-group analysis (that identified variance within groups of young people with intellectual disability without comparing them to people who do not have a disability) was rare, highlighting a need for more complex intersectional approaches to research on this topic with this population.

Included studies were predominantly quantitative ($n = 48$) rather than qualitative ($n = 20$). Within the quantitative studies, the number of study participants with intellectual disability ranged from four (Dukes & McGuire, 2009) to 21,181 (Brown et al., 2016c) and data were collected from medical records ($n = 24$) or surveys ($n = 24$). Most of these articles did not report a specific theory, though a "social determinants of health" framework was apparent in some research, particularly the work of Hilary Brown and colleagues (Brown et al., 2016a, b, c, d, 2017a, 2019, 2017b, 2018a, 2018b). Within the qualitative studies, the number of study participants with intellectual disability ranged from four to 101. The most prevalent data collection and analysis methods were in-depth interviews and interpretative phenomenological analysis. Theoretical perspectives included social constructionist theories of identity development, systems theory, and grounded theory.

The majority of studies did not report the use of inclusive research methods; however, there were some notable exceptions. A service user group was involved in the formative stages of research by McCarthy (2009b), whilst McClelland et al.

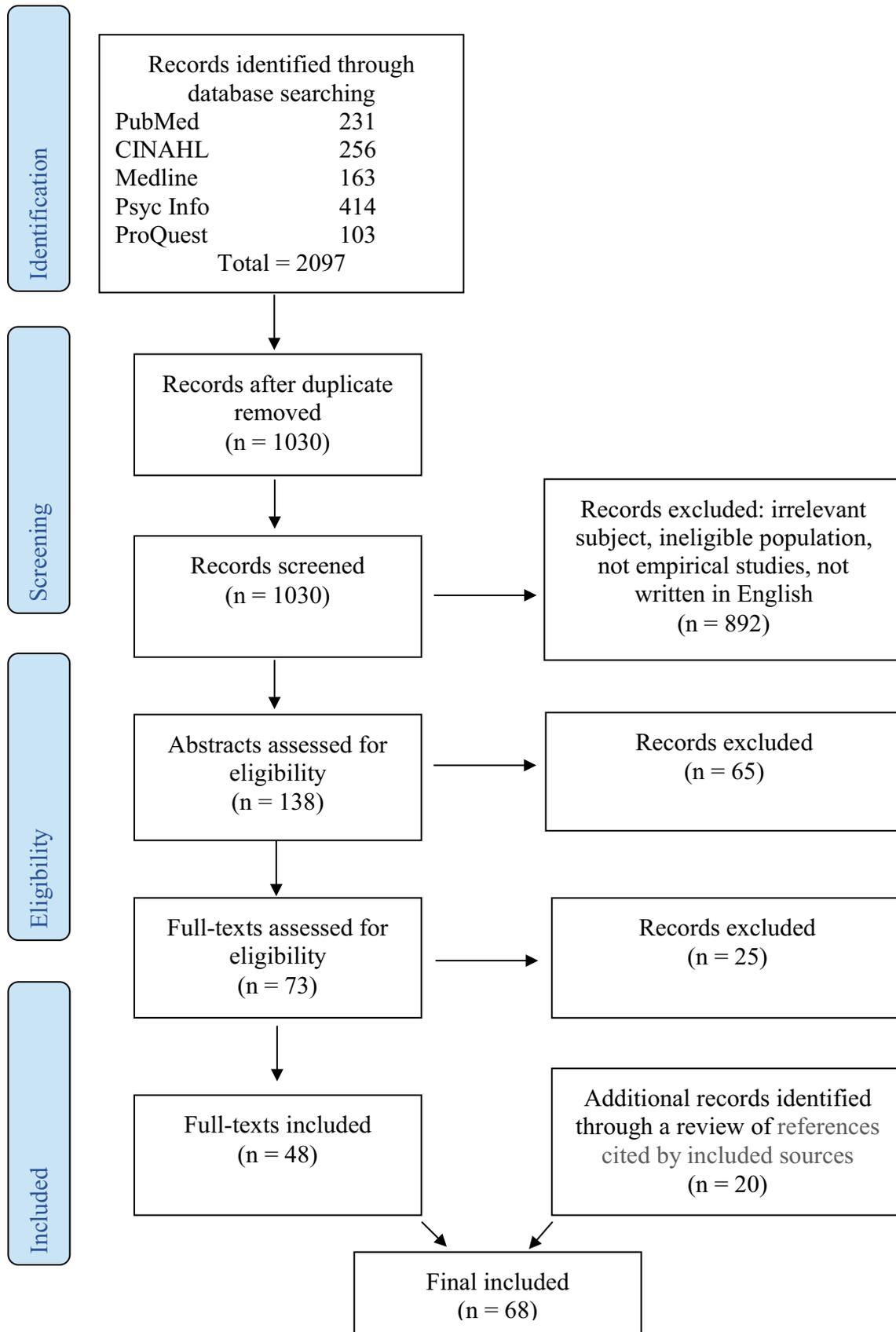


Fig. 2 PRISMA flow diagram showing records identified, screened, and included

(2012) used a community-based research approach to ensure action-oriented outcomes with the input of a youth advisory team. In addition, O’Shea and Frawley (2019) described using elements of narrative, ethnographic, and Photovoice methods to collaboratively produce stories from participants’ lives; however, this was the only study to report the use of any arts-based methods.

Key Themes

Key themes across the literature were sexual development including: 1) sexual desire, identities, relationships, and menstruation; 2) sexual knowledge including sexuality education and sexual self-advocacy; 3) sexual activity including safer sex practices and access to contraception; 4) access to human papillomavirus (HPV) immunization and cervical cancer screening; and 5) pregnancy, childbirth, and parenthood including reproductive decision-making. These themes and the sources that fit into each theme are presented in Table 2.

Sexual Development: Sexual Desire, Identities, Relationships, and Menstruation

Nine qualitative studies addressed issues related to the emerging sexuality of young people with intellectual disability (see Table 2 for list of articles). In all of these studies, participants expressed themselves as sexual beings, with sexual desires similar to people without disability. As

in the general population, young people with intellectual disability had explored, or hoped to explore, their sexual identity, including sexual relationships with people from the same sex (McClelland et al., 2012; Yacoub & Hall, 2009). Frequently, sexuality and sexual identity were conceived of as much more than simply sex. For example, a 2016 study including young adults and older adults explored the multifaceted meanings of sexual pleasure for the participants, who had different ways of “being sexual” that encompassed physical and emotional enjoyment, from the tension release of an orgasm to feelings of love and connection that come with romantic relationships (Turner & Crane, 2016a).

Romantic relationships—including but not limited to marriage—were an important feature of young peoples’ sexual identities across the literature. Many participants had experienced fulfilling relationships already or hoped to in the future. Healy et al. (2009) noted that for many of their participants, romantic relationships were formed while attending disability services—one of few contexts for meeting potential partners. However, young people were uncertain about the permissibility of relationships within the service setting, and sexual relationships were often either implicitly or explicitly restricted (Healy et al., 2009). For young women in one study, the continuation or development of relationships was identified as a core part of their goals for self-determination; however, none of their transition plans took romantic or sexual relationships into account (Trainor, 2007).

Table 2 Summary of key themes

Theme	Subthemes	References
Sexual development	Sexual desire Identities Relationships Menstruation	Healy et al. (2009), McClelland et al. (2012), O’Shea and Frawley (2019) Trainor (2007), Turner and Crane (2016a, b), Wheeler (2007), Wilkinson et al. (2015), and Yacoub and Hall (2009) Chuah et al. (2017), Dizon et al. (2005), Hillard (2012), Pillai et al. (2010), and Savasi et al. (2014)
Sexual knowledge	Sexuality education Sexual self-advocacy	Barnard-Brak et al. (2014), Cheng and Udry (2002), Dukes and McGuire (2009), Frawley and Bigby (2014), Frawley and Wilson (2016), Friedman et al. (2014), Graff et al. (2018), Healy et al. (2009), Jahoda and Pownall (2014), Murphy and O’Callaghan (2004), Murray (2019), O’Callaghan and Murphy (2007), Pownall et al. (2017), Sheppard (2006), Turner and Crane (2016b), and Williams et al. (2014)
Sexual activity	Safer sex practices Contraceptive use	Baines et al. (2018); Cheng and Udry (2002, 2005); Haynes et al. (2018); Mandell et al. (2008); McCarthy (2009a, b); McCarthy (2010); Mosher et al. (2018); Shandra and Chowdhury (2011); Shandra et al. (2016); Shearer et al. (2002); and Wu et al. (2018a, b)
HPV immunisation and cervical cancer screening	HPV immunisation Cervical cancer screening	O’Neill et al. (2019a, b) Brown et al. (2016a, b, c, d), Cobigo et al. (2013), Osborn et al. (2012), Parish and Saville (2006), Parish et al. (2012), Reynolds et al. (2008), and Swaine et al. (2014)
Reproductive health	Pregnancy, childbirth, and parenthood, including reproductive decision-making	Akobirshoev et al. (2017), Brown et al. (2016a, b, c, d, 2017a, 2017b, 2018a, 2018b), Conder et al. (2011), Goldacre et al. (2015), Malouf et al. (2017a, b); Mayes et al. (2006), McConnell et al. (2008a, 2008b), Mitra et al. (2015), Parish et al. (2015), Redshaw et al. (2013), Shearer et al. (2002), and Zhang et al. (2019)

Across the literature, participants acknowledged the barriers placed on their sexual development, as they negotiated the intersection between different identities. For young women in an Australian study, the socially valorized role of “wife” or “girlfriend” was an important way of expressing their gender and sexuality, in contrast to discourses of intellectual disability that still tend to emphasize incapacity (O’Shea & Frawley, 2019). In another study in England, young people sought to develop a positive adult sexual identity that was “as normal as possible” and to resist their intellectual disability identity, which tends to be socially constructed as “child-like,” “not normal,” and “not sexual” (Wilkinson et al., 2015). People with intellectual disability recognized that despite having the same sexual desires as other people, they were often not able to live them out in the same way (Wheeler, 2007).

Overall, studies consistently identified a range of barriers faced by young people with intellectual disability as they explored and developed a positive sexual identity (McClelland et al., 2012; O’Shea & Frawley, 2019; Wheeler, 2007). These included stigma (around both disability and LGBTQ sexuality), others’ perceptions of their difference, assumptions about being non-sexual, lack of accessible sex education, lack of support to engage in romantic or sexual relationships, embarrassment by young people and their parents about discussing sex, and a lack of control over their lives, often due to the nature of their support systems. As a result, many young people with intellectual disability felt infantilized and treated in a way that denied their sexual independence (McClelland et al., 2012; O’Shea & Frawley, 2019; Wheeler, 2007). Many of these issues seem to persist well into adulthood. For example, the restrictions placed on people with intellectual disability by the need for parental permission and cultural norms were found in a study in the USA of both young people and adults, ranging from 21 to 54 years of age (Turner & Crane, 2016b).

Whilst no studies described themselves as focusing on the onset of puberty for people with intellectual disability as a facet of their sexual development, a small literature examined menstruation—a visible marker of puberty—and control of menstruation more specifically. Five studies focused on this topic, all of which were retrospective audits of the medical records of young women referred to clinics regarding their menstruation (Chuah et al., 2017; Dizon et al., 2005; Hillard, 2012; Pillai et al., 2010; Savasi et al., 2014). Anxiety of parents and carers was a key reason for presentation to clinics—often before menarche—due to concerns regarding hygiene, problems coping, and, in some cases, protecting young people from unwanted pregnancy due to coercion or abuse. A Canadian study published in 2005 reported that Depo-Provera was the most widely used method of menstrual suppression in women with intellectual disability (Dizon et al., 2005), a hormonal contraceptive

frequently associated with reports of misuse without consent across the globe (Wu et al., 2018a, b).

The time-span of publications indicates that the combined hormonal estrogen and progestogen pill (Chuah et al., 2017) or the hormonal intrauterine device (IUD, known as Mirena), often inserted under general anaesthetic, are now commonly used for menstrual control in this context (Hillard, 2012; Pillai et al., 2010; Savasi et al., 2014). There was just one instance of a young woman 16 years of age with intellectual disability (of 243 adolescents whose experiences were reported in this literature) who described making an empowered choice to remove the IUD to become pregnant, independently of her parents/carers and against the advice of her doctor (Pillai et al., 2010). The issue of agency for young people with intellectual disability regarding menstrual control overlaps with the literature on contraceptive use, which is reported later in this article.

Sexual Knowledge: Sexuality Education, and Sexual Self-Advocacy

Sixteen studies (six qualitative, ten quantitative) addressed the issue of sexual knowledge, including sexuality education and the development of a “sexual voice,” or sexual self-advocacy (see Table 2). A key question raised by the studies in this theme was how to empower young people with intellectual disability to make informed, health-promoting choices (Frawley & Wilson, 2016; Friedman et al., 2014; Turner & Crane, 2016b). For self-advocates in one study, communication and respect were vital issues that affected their ability to make decisions about their sexuality (Friedman et al., 2014); they also said that families and professionals could increase their voice by improving opportunities for inclusion through accessible information and non-judgmental attitudes. Another study highlighted the importance of recognizing the capacity of young people with intellectual disability to lead teaching and learning about sex and relationships with their peers (Frawley & Bigby, 2014). Many of the young adult peer educators in this study felt they were more approachable and relatable to participants because of their own disability and personal experiences.

Overall, young people with intellectual disability seemed to access sexual knowledge in different ways to young people without disability; for example, relying more on family (parents and siblings), whilst their peers without disability tended to tap into knowledge from friends embedded in broader social networks (Jahoda & Pownall, 2014). Across studies, young people with intellectual disability reported less social opportunities where they could develop knowledge and explore relationships, as well as fewer formal and informal sources of education (Frawley & Wilson, 2016; Jahoda & Pownall, 2014; Turner & Crane, 2016b). For example, Cheng and Udry (2002) found that

young people with intellectual disability had lower exposure to information about sex, contraception, and pregnancy both in school and at home, and, thus, scored worse on knowledge tests compared with their non-disabled peers.

Similar findings about access to sexual information and support were reported in later years, suggesting little improvement over time, especially for those with severe disability. For example, in a large US study, students with moderate to profound intellectual disability were significantly less likely to receive sexuality education in public schools (16.2%) than students without intellectual disability (47.5%) and those with mild intellectual disability (44.1%) (Barnard-Brak et al., 2014); in fact, only 25% of teachers believed that youth with moderate to profound intellectual disability would benefit from sexuality education. Furthermore, a small UK study found that less than 15% of young people with intellectual disability had used sexual health services, and very few would go to their support staff about sexual issues (Williams et al., 2014).

Such disparities in access to comprehensive sexuality education and counselling may help explain the recurrent findings that young people with intellectual disability have lower levels of knowledge about key aspects of sexual health than their peers without intellectual disability (Cheng & Udry, 2002; Frawley & Wilson, 2016; Jahoda & Pownall, 2014; Murphy & O’Callaghan, 2004; Murray, 2019; O’Callaghan & Murphy, 2007; Pownall et al., 2017; Turner & Crane, 2016b). In particular, they tended to be less informed about sexual anatomy, pregnancy, contraception, and STIs (Cheng & Udry, 2002; Jahoda & Pownall, 2014; Murphy & O’Callaghan, 2004). They also had a lower understanding of their sexual rights, expressing uncertainty about the “permissibility” of masturbation, sexual intercourse, same-sex relationships, and marriage, and the difference between abusive and consenting relationships (Healy et al., 2009; Murphy & O’Callaghan, 2004; O’Callaghan & Murphy, 2007). Jahoda and Pownall (2014) found that gaps in knowledge were more pronounced for women with intellectual disability, underlining how multiple marginalized identities can intensify the silence surrounding sex. They also suggested that social exclusion may be a stronger barrier to attaining knowledge than intellectual impairment, noting that young people with physical disability were also less sexually literate (Pownall et al., 2017).

Irrespective of the time period, concerns about the content and quality of sexuality education in schools were common in the included studies. In the Australian context, young people with intellectual disability felt that their sexuality education was inadequate, focused on “rules” and presenting sex as something to be concerned about, rather than taking a more holistic approach as seen in mainstream sexuality education curriculums (Frawley & Wilson, 2016). In response, four studies developed and evaluated sexuality

education programs for young people with intellectual disability, often in collaboration with students, parents, and teachers (Dukes & McGuire, 2009; Graff et al., 2018; Murray, 2019; Sheppard, 2006). These were generally well-received by adolescents as well as caregivers as meaningful educational experiences and useful for their overall well-being and development. Young people liked the program topics (e.g., hygiene, body parts, boundaries, sexual health, protective behaviours) and interactive learning activities (e.g., games, videos, storytelling) (Graff et al., 2018; Murray, 2019; Sheppard, 2006), and pre- and post-assessments indicated they acquired greater knowledge and understanding through these interventions (Dukes & McGuire, 2009; Graff et al., 2018).

Despite tremendous obstacles, young people with intellectual disability identified many ways that parents, educators, and service providers could better support them in their efforts to learn about sexuality. It was suggested that mainstream services should be adapted to special needs (Williams et al., 2014) and that educational resources should be tailored to different levels of functioning (Murray, 2019). They wanted to get information from multiple sources (e.g., parents, friends, schools, doctors, and the Internet) and called for more holistic sexuality education including more social skills activities to help them develop positive relationships (Frawley & Wilson, 2016; Murray, 2019), emphasizing the importance of practice and repetition (Frawley & Wilson, 2016; Murray, 2019; Turner & Crane, 2016b; Williams et al., 2014). Young people were also interested in more information about how to date and help with meeting people, having privacy at home, and talking to parents (Frawley & Wilson, 2016; Friedman et al., 2014; Turner & Crane, 2016b). Young people perceived these supports as essential for their ability to develop sexual knowledge and express their own sexual voice, as a tool of self-determination (Turner & Crane, 2016b).

Sexual Activity: Safer Sex Practices and Contraceptive Use

Thirteen studies (10 quantitative, three qualitative) addressed sexual activity, including safer sex practices, and contraceptive use (see Table 2). Evidence from nationally representative surveys in the USA and the UK suggests that about 72–75% of young people with intellectual disability have had sexual intercourse (versus 86% of people without intellectual disability), of whom boys (41–48%) were more likely than girls (15%) to have done so before age 16/17 (Baines et al., 2018; Shandra et al., 2016). However, compared with those without disability, young people with intellectual disability reported lower rates of contraceptive use (Baines et al., 2018; Cheng & Udry, 2005; Shandra et al., 2016) and higher rates of STIs (Cheng & Udry, 2005; Mandell et al., 2008), and pregnancy (Baines et al., 2018;

Cheng & Udry, 2005). Relationship status and pregnancy intentions were not reported. While further research is needed to understand why, studies suggested that accessible sexual knowledge and tools may help young people with intellectual disability who are having sex to make informed choices about safer sex practices.

Six additional studies, also from the USA and the UK, examined young women's experience of contraception (Haynes et al., 2018; Mayes et al., 2006; McCarthy, 2009b, 2010; Mosher et al., 2018; Wu et al., 2018a, b). Participants in several studies described pressures from family and health professionals to have abortions (Mayes et al., 2006; McCarthy, 2009b, 2010), and young people's resistance against such pressures as well as a lack of access to abortion when desired (Mayes et al., 2006). In general, women with intellectual disability were less likely than women without disability to be prescribed long acting reversible contraceptives (such as implants and IUDs) or moderately effective methods (including the pill, patch, ring, shot, or diaphragm) (Wu et al., 2018a, b). They were also more likely to report no method at last intercourse as well as sterilization (Haynes et al., 2018; Mosher et al., 2018). Among those with intellectual disability, sterilization was less common in males than females (2.6% vs. 22.8%) (Mosher et al., 2018).

In terms of choice and control over contraception, some women, e.g., 5 of 23 in the study by McCarthy (2010), reported autonomy about their contraceptive use, whereas the majority said that starting or stopping contraception, and which methods to use, required approval from an authority figure. Cultural or religious prohibitions, negative attitudes of parents and the medical community about women getting pregnant, and a lack of easy-read information about contraception methods, and how well each method works, were apparent in women's stories (McCarthy, 2009a, b, 2010). Despite these challenges, many women with intellectual disability said there were people they could go to for advice about contraception (e.g., mothers, partners, disability service staff) and recommended that third-parties be present during medical consultations regarding their reproductive health and rights (McCarthy, 2009a, b, 2010).

HPV Immunisation and Cervical Cancer Screening

Nine quantitative studies reported on HPV immunisation and cervical cancer screening rates among people with intellectual disability (see Table 2). According to two Australian studies, young people with intellectual disability were half as likely to receive the HPV vaccine than their typically developing peers, both through the school immunisation program and within tertiary care (O'Neill et al., 2019; O'Neill et al., 2019a, b). Reasons for non-immunisation in schools were

absenteeism, lack of parental consent, behavioural concerns, and preference to receive the vaccine from their GPs (O'Neill et al., 2019a, b), though authors noted a need for qualitative inquiry to explore determinants of under-vaccination more thoroughly.

Similar disparities were observed in cervical cancer screening rates across the study period in multiple countries, including the UK (Osborn et al., 2012; Reynolds et al., 2008), the USA (Parish & Saville, 2006), and Canada (Brown et al., 2016a, b, c, d; Cobigo et al., 2013), which provided the strongest population-based evidence. Where recorded, the main reasons for not screening were patient refusal (Osborn et al., 2012; Reynolds et al., 2008), with two studies suggesting a difference in knowledge of preventive health screenings (Parish et al., 2012; Swaine et al., 2014), as well as provider beliefs that this was "inappropriate" medical care (Osborn et al., 2012; Reynolds et al., 2008). Surprisingly, the inequity in access to screening was found even among women who have had a pregnancy (an indicator of sexual activity) (Brown et al., 2016a, b, c, d).

Reproductive Health: Pregnancy, Childbirth, and Parenthood

Although we are discussing this in the final section of our review, the most common theme in the literature was pregnancy, childbirth, and parenthood including reproductive decision-making (three qualitative and 17 quantitative studies, including several large retrospective population-based cohorts; see Table 2). Women with intellectual disability across the study period mostly desired to have children, despite continued stigma (Mayes et al., 2006; McCarthy, 2009b, 2010), and some were supported to do so. For example, several studies found that parents with intellectual disability had active decision-making roles in choosing to continue their pregnancy, and then who would care for their child (Conder et al., 2011; Malouf et al., 2017a, b; Mayes et al., 2006). They also described receiving easy-read information that enabled them to understand health professionals at their appointments and participate in shared decision-making regarding their pregnancy care (Malouf et al., 2017a, b). All parents with intellectual disability relied on support networks such as families, social workers, health visitors, and children's centres, with some people more supportive than others of the pregnancy (Malouf et al., 2017a, b). The nature of these support networks had a significant impact on the parenting experiences of the participants (Conder et al., 2011; Malouf et al., 2017a, b; Mayes et al., 2006).

In contrast, others experienced significant barriers to good pregnancy care and parental supports. For example, in the UK, women with intellectual disability reported many instances of infantilization and exclusion, for example, not "being spoken to by health professionals in a way that

they could understand,” not “being involved in decisions,” “feeling left alone and worried,” not having “concerns taken seriously,” and not receiving the help they needed postnatally (Malouf et al., 2017a, b; Redshaw et al., 2013). Some differences were evident by disability type, and authors suggested a “flexible and responsive” approach to pregnancy care was essential (Malouf et al. 2017a, b). Negative experiences were also reflected in qualitative interviews with mothers with intellectual disability in the UK (Malouf et al., 2017a, b). Barriers to accessing information and support that met their needs included exclusion from decisions, lack of clarity over what constitutes “normal” care leading to feelings of abnormality, inadequacies in communication of oral and written information including matters relating to consent, and having to prove themselves as adequate mothers (Malouf et al., 2017a, b).

While overall fertility rates were lower for women with intellectual disability compared with women without disability (Brown et al., 2016c; Zhang et al., 2019), age-specific fertility rates were similar in 18- to 24-year-olds Brown et al., 2016c). In addition, data from two studies in the USA and Canada shows that women with intellectual disability were more likely to experience “early childbearing” (which was defined in the literature as before age 18) (Shearer et al., 2002) and “rapid repeat pregnancy” (which was defined as another pregnancy within 12 months of giving birth) (7.6% vs. 3.9%; adjusted RR 1.34, 95% CI 1.18–1.54) (Brown et al., 2018b). However, these findings were attenuated upon adjustment for social and health inequities (Brown et al., 2018b), suggesting that other factors such as low income or poorer access to effective family planning services may help explain the differences between women with and without intellectual disability. In these studies, pregnancy intention was not reported. These experiences may reflect women’s choice to have children (despite societal attitudes that childbearing at an early age is universally negative), or be due to coerced sex, lack of contraceptive information, or lack of service access to family planning.

Most studies also identified that women with intellectual disability had elevated risks for a range of adverse pregnancy outcomes versus women without disability, including pre-eclampsia, stillbirth, preterm birth, and small for gestational age (Brown et al., 2017b) (Akobirshoev et al., 2017; Brown et al., 2017b; Malouf et al. 2017a, b; McConnell et al., 2008b; Mitra et al., 2015; Parish et al., 2015). They were also more likely to have longer hospital stays (Malouf et al. 2017a, b; Parish et al., 2015), induced births and caesarian sections (Brown et al., 2016b; Malouf et al., 2017a, b; Parish et al., 2015). Elevated risks of these outcomes were not fully explained by differences in socioeconomic status and pre-pregnancy health conditions, although smoking in pregnancy was higher than in women without disability (Goldacre et al., 2015; Mitra et al.,

2015). Conversely, induced abortion appeared to be less likely in participants with intellectual disability than those without intellectual disability (Baines et al., 2018). Further, some reproductive outcomes, including preterm birth and neonatal mortality, were worse in women with co-occurring mental health disorders than women with intellectual disability only, highlighting the compounding effects of living with both mental health disorders and disability (Brown et al., 2016a, b, c, d). Post-pregnancy, women with intellectual disability had increased risk for postpartum hospital admissions and emergency department visits (Brown et al., 2017a), and were less likely to breastfeed (Goldacre et al., 2015; Mitra et al., 2015).

Providing adequate social and mental health support before, during, and after pregnancy is critical, as pregnancy-related distress was extremely common in women with intellectual disability (McConnell et al., 2008a). Authors postulated that this may be due to opposition to childbearing and fear of children being taken away. All too often, mothers faced the stark reality of discrimination, with 32 times higher risk of custody loss immediately postdelivery (5.7% vs 0.2%; aRR 8.10, 95% CI 6.51–10.09) (Brown et al., 2018a). This risk was greatest in groups with high support needs, such as those with mental health disorders, social assistance needs, and low prenatal care utilization.

Discussion

This is the first review to provide a synthesis of two decades’ worth of quantitative and qualitative research on topics related to sex, sexuality, and sexual and reproductive health and rights for young people with intellectual disability in English-speaking, high-income countries. We have responded to the call to integrate sexual health and reproductive health (Starrs et al., 2018), while shaping an affirmative discourse that acknowledges the many strengths of young people with intellectual disability as they navigate the complex terrain shaping their sexual and reproductive health and rights (Tepper, 2000). Here, we return to our guiding question: across 20 years of published empirical research, have the experiences and outcomes of sexual and reproductive health and rights for young people with intellectual disability changed?

To start with an obvious, but important constant, we uncovered a rich literature that stands witness to the fact that young people with intellectual disability are sexual beings, each with their own unique desires and health needs. This has not changed. However, they have also faced persistent inequities, from limited access to information and resources to poorer sexual and reproductive health outcomes. Over the following paragraphs, we unpack the re-occurring barriers and facilitators identified in the literature and,

using a strength-based approach, focus on the capacities and resources that young people with intellectual disability draw on to experience good sexual and reproductive health.

Of significance, the findings highlight several positive examples of sexual and reproductive agency across the five key themes, despite numerous reports of systemic barriers and social injustice. Overall, the strongest enabling factors to young people's self-determination were social support and sexuality education. In particular, families were a main source of sexual health information and multiple studies—involving both quantitative (Barnard-Brak et al., 2014; Cheng & Udry, 2002; Jahoda & Pownall, 2014) and qualitative data (Conder et al., 2011; Mayes et al., 2006; McCarthy, 2009a, 2010)—showed that stronger support networks, higher household incomes, receipt of easy-read information, and other supports resulted in a range of better outcomes such as sexual knowledge, receipt of good healthcare, and confidence in parenting. However, several barriers including paternalist attitudes and infantilization of young people with intellectual disability affected all aspects of sexual expression, leading to the persistence of unfair and avoidable health inequities over the past 20 years. Although there was a lack of explicit attention to intersectionality in most published research, due to a tendency to focus exclusively on intellectual disability, it was nevertheless evident that sexual and reproductive health possibilities were strongly linked to gender and larger narratives of violence, mental health, income inequality, and other larger social injustices that intersect with intellectual disability.

The findings across the main themes suggest that young people with intellectual disability have the same desires with regard to sexuality and reproduction as young people without disability, but continue to face restrictions in making choices about their bodies and developing romantic relationships (e.g., Healy et al., 2009; McClelland et al., 2012; O'Shea & Frawley, 2019; Trainor, 2007; Turner & Crane, 2016a, b; Wheeler, 2007; Wilkinson et al., 2015; Yacoub & Hall, 2009). Infantilization and an associated assumption of non-sexuality were common barriers (McClelland et al., 2012; O'Shea & Frawley, 2019; Wheeler, 2007; Wilkinson et al., 2015), along with a lack of sexual and reproductive autonomy (Healy et al., 2009; O'Shea & Frawley, 2019; Trainor, 2007; Turner & Crane, 2016b). This was particularly evident in the literature on menstrual suppression (Chuah et al., 2017; Dizon et al., 2005; Hillard, 2012; Pillai et al., 2010; Savasi et al., 2014), where it appears decisions are often made by parents or carers, and go against the wishes of—or without the understanding of—women with intellectual disability (e.g., Chuah et al., 2017; Dizon et al., 2005; Hillard, 2012; Pillai et al., 2010; Savasi et al., 2014). Despite contraception often being used as technologies of coercion, there were examples of women making the choice to start using contraception in the literature, with social networks playing a

crucial role in supporting self-determination and, thus, sexual agency (McCarthy, 2009a, b, 2010).

A common thread through most of the articles was the processes of empowerment for individuals with intellectual disability to make informed decisions regarding their sexual rights (Frawley & Bigby, 2014; Frawley & Wilson, 2016; Friedman et al., 2014; Turner & Crane, 2016a). Providing more knowledge, not less, through comprehensive sexuality and relationships education tailored to meet the needs of students with intellectual disability holds real promise for the quality of their sexual and reproductive health, now and into adulthood (Dukes & McGuire, 2009; Graff et al., 2018; Murray, 2019; Sheppard, 2006). Still, evidence across the 20-year study period showed that young people with intellectual disability continue to be less likely to receive sex education (Cheng & Udry, 2002; Frawley & Wilson, 2016), especially those with profound intellectual and multiple disabilities. While the non-provision of sex education is often rationalized in the name of protecting vulnerable children, as young people with intellectual disability face a much greater likelihood of sexual violence (Wissink et al., 2015), our review of the literature suggests that not talking about sex may, in fact, exacerbate vulnerability. Young people also identified a broader array of sexual health topics for which they would like more information and support from parents, schools, and disability services—in particular, relationships (Frawley & Wilson, 2016; Friedman et al., 2014; Turner & Crane, 2016b). Put simply, sex education has usually taken a reductionist approach focused on the prevention of disease and other unwanted outcomes in the body. Having parents, carers, teachers, and support workers that listen and respond to young people's needs for accessible, more expansive information is crucial to their wellbeing.

Without access to information and support about sex, sexuality, and sexual and reproductive health and rights, negative reported outcomes were more common in individuals with intellectual disability than those without disability, such as unsafe sex (Baines et al., 2018; Cheng & Udry, 2005; Shandra et al., 2016), limited access to preferred contraceptive methods (Mayes et al., 2006; McCarthy, 2009b, 2010), and gaps in HPV vaccination (O'Neill et al., 2019a, b) and cervical cancer screening (Brown et al., 2016a, b, c, d; Cobigo et al., 2013; Osborn et al., 2012; Parish & Saville, 2006; Reynolds et al., 2008). The lack of autonomy within reproductive healthcare environments was particularly striking. It is important to note that healthcare professionals and parents of individuals with intellectual disability can participate in stigma without realizing the harm they cause, making women feel unsupported and isolated through pregnancy and related decision making. At the same time, the challenges families face reflect the failure of health and social care systems to provide individuals with intellectual disability with adequate resources and information to support

parenting. Notably, while some participants reported positive pregnancy and parenting experiences, owing to support received from families, care workers, and self-advocacy groups (Conder et al., 2011; Malouf et al., 2017a, b; Mayes et al., 2006), what was distressingly clear from one study was that many parents with intellectual disability do not get that chance—children are just taken (Brown et al., 2018a). Despite tremendous barriers affecting women’s freedom to have children when desired (Malouf et al., 2017a, b; McConnell et al., 2008a), a re-occurring theme across time was that mothering was important to their identity, wellbeing, and health (Conder et al., 2011; Malouf et al., 2017a, b; Mayes et al., 2006; McCarthy, 2009b, 2010).

Ultimately, this scoping review identified significant and persisting tensions between the view of young people with intellectual disability as vulnerable and in need of protection versus acknowledging their sexual development and supporting their autonomy within a sex-positive, rights-based framework (e.g. McClelland et al., 2012; O’Shea & Frawley, 2019; Wheeler, 2007). It was obvious when reviewing the articles that the infantilization of young people with intellectual disability is still much alive, even though the myth of the person with intellectual disability as an eternal child was debunked a long time ago. Compounding this issue is the continuous over-medicalization of sexuality and reproductive health issues for this population, evident for example in the literature on menstrual suppression and apparent forced contraception of girls and women with intellectual disability—human rights issues that were shrouded in a medico-legal discourse of “best interests.” These issues, together with numerous barriers to sexual and reproductive health information and services (e.g., intersectional stigma, lack of inclusive sex education, overly protective attitudes by parents and authority figures, societal anxieties around emerging sexuality), restrict young people’s freedom and contribute to a lack of control over their sexual and reproductive lives. While often intended to be protective, these social conditions have a clear and consistent negative impact on their health.

Despite these struggles, young people with intellectual disability have demonstrated considerable strength and have highlighted the ways change can take place. These findings are relevant across the lifespan, but are particularly important to acknowledge as young people navigate major transitions in their sexual health and identity. The literature offered many examples of young people exercising their agency around their sexual and reproductive health and rights. Peer educators and self-advocates empowered themselves, and others, as they shared their experiences (Frawley & Bibgy, 2014; Friedman et al., 2014; Turner & Crane, 2016a, 2016b). Young people countered deficit discourses and infantilizing attitudes by highlighting the complexity of their sexual and gender identities (McClelland et al., 2012; O’Shea & Frawley, 2019; Trainor, 2007; Wheeler, 2007; Wilkinson

et al., 2015). They drew on networks of support and a wide range of information sources to explore their life choices—from making decisions about contraception and parenthood to forming meaningful romantic relationships (Conder et al., 2011; Jahoda & Pownall, 2014; McCarthy, 2009a, b). Thus, in reflecting on our original research question—have the experiences and outcomes of sexual and reproductive health and rights for young people with intellectual disability changed?—we can conclude that positive change has indeed happened, and is possible, despite the constraints and harms of ongoing disadvantage and disempowerment.

Future Research

Until about 20 years ago, sexual and reproductive health constituted the periphery of disability studies. Centring this topic in other fields such as health inequalities still remains necessary. This review revealed several key gaps in the literature that could be prioritized in future research. Firstly, there is a lack of literature surrounding young people with profound and multiple learning disabilities. Research is urgently needed to explore how the sexual and reproductive health and rights of young people with this level of intellectual disability can be promoted, for example through accessible sexuality education. There are numerous ways in which the voice of this population can be heard, including, but not limited to, arts-based methods and research approaches that draw on new technologies (Nind, 2020).

Secondly, while there is a strong body of literature focusing on issues relevant to the sexual and reproductive health of women with intellectual disability, their voices on matters such as menstruation, contraception, HPV immunization, and cervical cancer screening were understudied. Future research priorities should explore how they would like to be enabled to exercise choice and control when it comes to these areas of their lives. In addition, the voices of young men with intellectual disability were missing. Topics such as male contraception, forced vasectomy, or experiences of fathers with intellectual disability deserve researchers’ attention.

Thirdly, the omission of positive aspects of sexuality, such as what happy, mutually fulfilling relationships entail, and their benefits for health and rights, including the prevention of STIs and violence, is starkly evident. A focus on ethical approaches to the participation of young people with intellectual disability in sexual and reproductive health research may be one way of addressing this omission. This could be complemented by investigations of resilience in sexual and reproductive health. Amid the multiple and complex barriers young people with intellectual disability face such as trauma and social stigma, how do some individuals realize reproductive self-determination and experience healthy sexuality?

Finally, there is need for longitudinal research to address the question of changes in health more adequately over time. Given the findings of persistent health inequities, an increase in implementation science would be timely and relevant to ensure the uptake of evidence-based knowledge into regular use by young people in addition to parents, practitioners, and policymakers. Interventions are urgently needed to improve HPV vaccine uptake in unvaccinated students. Training is also needed for health professionals, teachers, social workers, and others in supporting young people's autonomy to be able to give consent and manage their health. Above all else, the 32-fold increased risk of experiencing custody loss of a newborn immediately after birth for women with intellectual disability (Brown et al., 2018) highlights the urgent necessity of research to determine how best to put supports in place for those who need it instead of approaching parenthood with disability punitively.

Limitations

There are several limitations to this scoping review. Firstly, the inclusion criteria and search strategy, while carefully considered, likely resulted in overlooking relevant studies. Thus, the results might not be generalized to all populations of young people with intellectual disability nor cover all issues that affect their lives. Secondly, the definition of intellectual disability varied widely across studies, with many qualitative studies recruiting participants who self-identified as users of intellectual disability services, and quantitative studies relying on self-reported disability status, medical diagnostic codes, or tests of cognitive ability. Moreover, few of the papers reviewed here included young people with severe or profound intellectual disability, who likely experience greater barriers to comprehensive services, supports, and programs. Therefore, an underestimation of sexual and reproductive health inequities is plausible. In addition, while we sought to be inclusive of all studies involving young people, the paucity of age disaggregated data remains a critical element to address in future research to strengthen youth-friendly services. Furthermore, due to the large variety of study designs and methods, we did not assess the quality of included research. However, this is not part of the role or purpose of a scoping study (Arksey & O'Malley, 2005). Finally, it is important to note that as this review covers twenty years of published research, the trends and patterns we have charted may not reflect the needs and strengths of young people with intellectual disability today. Nevertheless, the many constants within the findings—from persistent inequities to complex lived experiences of sexuality and reproduction—suggest that the literature still has relevance.

The strengths of this review include its resilience framework and use of inclusive research principles.

Previous research on young people with intellectual disability and sexual and reproductive health has almost exclusively focused on problems. This paper provides an alternative narrative, building on strengths. It also offers an alternative approach by involving a person with experience of intellectual disability (JL) as a co-author. Their insights and perspectives were integrated throughout our analysis of findings and have added unique and important contributions to this paper. Such methods are key to increasing the relevance and impact potential of research, in addition to helping build capacity for people with intellectual disability to contribute to knowledge about their own community. As JL pointed out during our discussions, people with intellectual disability should be consulted to look at what they want to do, even if they have high support needs.

Recommendations

Through synthesis and analysis of the works included in this paper, we make seven recommendations for supporting anti-ableist action and policy in sexual and reproductive health (e.g., education curriculum, service delivery) for young people with intellectual disability. These recommendations are applicable to diverse groups of stakeholders, including teachers, health professionals, government agencies, and researchers:

1. Assume that young people with intellectual disability are sexual beings with sexual interest and a sexual voice. As such, they may require the space and opportunity to have sexual relationships, contraception (with choice), HPV vaccines, cervical screening, and pregnancy care and support.

2. Assume competency and assist young people with intellectual disability to develop autonomy and make their own decisions about their sexual and reproductive health. This includes ensuring that menstrual suppression is not occurring without proper patient consultation, providing young people with accessible information to make contraception decisions for themselves, and supporting young women with intellectual disability who are pregnant and protecting their parenting rights post-birth.

3. In cases where a young person does not have the ability to decide, even after extensive support, ensure that the decision is made in the best interests of the young person, not the caregiver. *Supporting Decision Making* is a free tool to assist clinicians in effective communication (fpnsw.org.au/sites/default/files/assets/Supporting_Decision_Making_Tool_20180327.pdf). This should be supplemented with clear ethical and clinical practice guidelines to meet the unique care and support needs of young people with intellectual disability.

4. Educate yourself about intellectual ableism and the many forms of prejudice and discrimination that emerge in relation to sexual and reproductive health, from the assumption that young people with intellectual disability are asexual or

incapable of making a decision to their limited access to preventative health interventions, inadequate support of healthy sexual development, or the removal of children from the care of parents with disability. Reflect upon how these issues lay bare society's discomfort with sexuality among people with intellectual disability. Incorporate strategies to sensitize service providers to young people's rights and take steps to develop non-stigmatizing individual practices and agency-wide policies.

5. Listen to and include the voices of young people with intellectual disability and ensure access to quality support services that promote self-care. Inclusive and accessible sexuality education is essential in this regard. Teachers, carers, parents, professionals, and trusted adults all have an important role to play in assisting young people through learning and decision-making processes about this area of their lives. *Sexuality, Relationships, and Your Rights* (secca.org.au/resources/sexuality-relationships-and-your-rights-resource) is a free resource for people of all abilities that addresses critical information about bodies and identities, relationships and sexuality, reproductive choices and sexual health, and navigating health care and rights.

6. Ensure inclusive sexual and reproductive health research and practice by including individuals with intellectual disability in the design and implementation of projects and programs (Walmsley & Johnson, 2004). This may include a range of participatory approaches such as hiring and training peer researchers and peer educators, forming and implementing Community Advisory Boards, developing ethical practices that are explicitly anti-ableist/oppressive, and cultivating a mutual responsibility among all relevant stakeholders to create a safe environment, one that is diverse (including sexual and gender minorities and racialized persons), respectful, supportive, non-judgmental, and fun.

7. Incorporate an intersectional framework into research and practice to understand in greater complexity how sexual and reproductive health experiences and outcomes are affected by conditions of social inequality based not only on intellectual disability, but also race, ethnicity, sex, gender, sexual identity, and class—as a whole, rather than siloed parts of the self (Collins, 1991; Crenshaw, 1989; Hancock, 2007). Recognize that trauma and social stigma may be intensified for young people with intellectual disability who face multiple forms of marginalisation in society. Develop solutions informed by the entirety of young people's lives. Improving healthy equity must include a commitment to stigma reduction, economic empowerment, and safety and human rights protection.

Conclusions

Advancing sexual and reproductive health and rights centres around helping young people with intellectual disability become active agents with individual power and

autonomy. This is only possible within structural contexts that enable a young person's capacity to exercise choice and to develop physically, socially, emotionally, and intellectually. The findings from this review demonstrate that sexual and reproductive health inequities, at their root, could be reduced with the right mix of anti-ableist social policies, tailored supports, and access to information unfettered by the stigma of intellectual disability. Sexuality and reproduction are human rights, not rights to be given based on ability status. Young people with intellectual disability deserve the best possible support in this area of their lives—support that respects their human dignity and worth.

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References

- Aggleton, P. (2018). Youth. *Sexuality and sexual citizenship*. <https://doi.org/10.4324/9781351214742>
- Akobirshoev, I., Parish, S. L., Mitra, M., & Rosenthal, E. (2017). Birth outcomes among US women with intellectual and developmental disabilities. *Disability and Health Journal*, 10(3), 406–412. <https://doi.org/10.1016/j.dhjo.2017.02.010>
- American Psychiatric Association. (2013). *Diagnostic and Statistical Manual for Mental Disorders. 5th Edition*. American Psychiatric Press.
- Arksey, H., & O'Malley, L. (2005). Scoping studies: Towards a methodological framework. *International Journal of Social Research Methodology*, 8(1), 19–32. <https://doi.org/10.1080/1364557032000119616>
- Baines, S., Emerson, E., Robertson, J., & Hatton, C. (2018). Sexual activity and sexual health among young adults with and without mild/moderate intellectual disability. *BMC Public Health*, 18(1), 667. <https://doi.org/10.1186/s12889-018-5572-9>
- Barnard-Brak, L., Schmidt, M., Chesnut, S., Wei, T., & Richman, D. (2014). Predictors of access to sex education for children with intellectual disabilities in public schools. *Intellectual & Developmental Disabilities*, 52(2), 85–97. <https://doi.org/10.1352/1934-9556-52.2.851934>
- Bay-Cheng, L. Y. (2019). Agency is everywhere, but agency is not enough: A conceptual analysis of young women's sexual agency. *Journal of Sex Research*, 56(4–5), 462–474. <https://doi.org/10.1080/00224499.2019.1578330>
- Black, R. S., & Kammes, R. R. (2019). Restrictions, power, companionship, and intimacy: A metasynthesis of people with intellectual disability speaking about sex and relationships. *Intellect Dev Disabil*, 57(3), 212–233. <https://doi.org/10.1352/1934-9556-57.3.212>

- Borawska-Charko, M., Rohleder, P., & Finlay, W. M. L. (2017). The sexual health knowledge of people with intellectual disabilities: A review. *Sexuality Research and Social Policy*, 14(4), 393–409. <https://doi.org/10.1007/s13178-016-0267-4>
- Bowleg, L. (2008). When Black + lesbian + woman ≠ Black lesbian woman: The methodological challenges of qualitative and quantitative intersectionality research. *Sex roles*, 59(5–6), 312–325. <https://doi.org/10.1007/s11199-008-9400-z>
- Brady, G., Lowe, P., & Olin Lauritzen, S. (2015). Connecting a sociology of childhood perspective with the study of child health, illness and wellbeing: introduction. *Sociology of Health & Illness*, 37(2), 173–183. <https://doi.org/10.1111/1467-9566.12260>
- Brown, H. K., Cobigo, V., Lunsy, Y., Dennis, C. L., & Vigod, S. (2016a). Perinatal health of women with intellectual and developmental disabilities and comorbid mental illness. *Canadian Journal of Psychiatry*, 61(11), 714–723. <https://doi.org/10.1177/0706743716649188>
- Brown, H. K., Cobigo, V., Lunsy, Y., & Vigod, S. (2017a). Postpartum acute care utilization among women with intellectual and developmental disabilities. *J Womens Health (Larchmt)*, 26(4), 329–337. <https://doi.org/10.1089/jwh.2016.5979> ([Comment in: *J Womens Health (Larchmt)*. 2017 Apr;26(4):303–304; PMID: 28355095 [<https://www.ncbi.nlm.nih.gov/pubmed/28355095>]])
- Brown, H. K., Cobigo, V., Lunsy, Y., & Vigod, S. (2019). Reproductive health in women with intellectual and developmental disabilities in Ontario: Implications for policy and practice. *Healthc Q*, 21(4), 6–9. <https://doi.org/10.12927/hcq.2019.25748>
- Brown, H. K., Cobigo, V., Lunsy, Y., & Vigod, S. N. (2017b). Maternal and offspring outcomes in women with intellectual and developmental disabilities: A population-based cohort study. *Bjog*, 124(5), 757–765. <https://doi.org/10.1111/1471-0528.14120>
- Brown, H. K., Kirkham, Y. A., Cobigo, V., Lunsy, Y., & Vigod, S. N. (2016b). Labour and delivery interventions in women with intellectual and developmental disabilities: A population-based cohort study. *J Epidemiol Community Health*, 70(3), 238–244. <https://doi.org/10.1136/jech-2015-206426>
- Brown, H. K., Lunsy, Y., Wilton, A. S., Cobigo, V., & Vigod, S. N. (2016c). Pregnancy in women with intellectual and developmental disabilities. *J Obstet Gynaecol Can*, 38(1), 9–16. <https://doi.org/10.1016/j.jogc.2015.10.00420152015.10.0042015>
- Brown, H. K., Plourde, N., Ouellette-Kuntz, H., Vigod, S., & Cobigo, V. (2016d). Brief report: Cervical cancer screening in women with intellectual and developmental disabilities who have had a pregnancy. *Journal of Intellectual Disability Research*, 60(1), 22–27. <https://doi.org/10.1111/jir.12225>
- Brown, H. K., Potvin, L. A., Lunsy, Y., & Vigod, S. N. (2018a). Maternal intellectual or developmental disability and newborn discharge to protective services. *Pediatrics*, 142(6). <https://doi.org/10.1542/peds.2018-1416>
- Brown, H. K., Ray, J. G., Liu, N., Lunsy, Y., & Vigod, S. N. (2018b). Rapid repeat pregnancy among women with intellectual and developmental disabilities: A population-based cohort study. *Cmaj*, 190(32), E949–e956. <https://doi.org/10.1503/cmaj.170932>
- Brown, M., & McCann, E. (2018). Sexuality issues and the voices of adults with intellectual disabilities: A systematic review of the literature. *Research in Developmental Disabilities*, 74, 124–138. <https://doi.org/10.1016/j.ridd.2018.01.009>
- Byrne, G. (2018). Prevalence and psychological sequelae of sexual abuse among individuals with an intellectual disability: A review of the recent literature. *J Intellect Disabil*, 22(3), 294–310. <https://doi.org/10.1177/1744629517698844>
- Cense, M. (2019). Rethinking sexual agency: proposing a multicomponent model based on young people's life stories. *Sex Education*, 19(3), 247–262. <https://doi.org/10.1080/14681811.2018.1535968>
- Cheng, M., & Udry, J. (2005). Sexual experiences of adolescents with low cognitive abilities in the U.S. *Journal of Developmental and Physical Disabilities*, 17(2), 155–172. <https://doi.org/10.1007/s10882-005-3686-3>
- Cheng, M. M., & Udry, J. R. (2002). How much do mentally disabled adolescents know about sex and birth control? [Mental Retardation 3256]. *Adolescent & Family Health*, 3(1), 28–38. <http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=psyc4&NEWS=N&AN=2003-03731-007>
- Chinn, D., & Homeyard, C. (2017). Easy read and accessible information for people with intellectual disabilities: Is it worth it? A meta-narrative literature review. *Health Expectations*, 20(6), 1189–1200.
- Chuah, I., McRae, A., Matthews, K., Maguire, A. M., & Steinbeck, K. (2017). Menstrual management in developmentally delayed adolescent females. *Aust N Z J Obstet Gynaecol*, 57(3), 346–350. <https://doi.org/10.1111/ajo.12595>
- Cobigo, V., Ouellette-Kuntz, H., Balogh, R., Leung, F., Lin, E., & Lunsy, Y. (2013). Are cervical and breast cancer screening programmes equitable? The case of women with intellectual and developmental disabilities. *Journal of Intellectual Disability Research*, 57(5), 478–488. <https://doi.org/10.1111/jir.12035>
- Collins, P. H. (1991). *Black feminist thought: Knowledge, consciousness, and the politics of empowerment*. Routledge.
- Collins, P. H. (1998). It's all in the family: Intersections of gender, race, and nation. *Hypatia*, 13(3), 62–82.
- Conder, J., Mirfin-Veitch, B., Sanders, J., & Munford, R. (2011). Planned pregnancy, planned parenting: Enabling choice for adults with a learning disability [Developmental Disorders & Autism 3250]. *British Journal of Learning Disabilities*, 39(2), 105–112. <https://doi.org/10.1111/j.1468-3156.2010.00625.x> (MentalHandicap)
- Crenshaw, K. (1989). Demarginalizing the intersection of race and sex: A black feminist critique of antidiscrimination doctrine, feminist theory and antiracist politics. *The University of Chicago Legal Forum*, 1989(1), 139–167.
- Dionne, H., & Dupras, A. (2014). Sexual health of people with an intellectual disability: An ecosystem approach. *J Sexologies*, 23(4), e85–e89.
- Dizon, C. D., Allen, L. M., & Ornstein, M. P. (2005). Menstrual and contraceptive issues among young women with developmental delay: A retrospective review of cases at the Hospital for Sick Children, Toronto. *J Pediatr Adolesc Gynecol*, 18(3), 157–162. <https://doi.org/10.1016/j.jpap.2005.03.002>
- Dukes, E., & McGuire, B. E. (2009). Enhancing capacity to make sexuality-related decisions in people with an intellectual disability. *Journal of Intellectual Disability Research*, 53(8), 727–734. <https://doi.org/10.1111/j.1365-2788.2009.01186.x>
- Elliott, L. (2017). Victims of violence: The forced sterilisation of women and girls with disabilities in Australia. *Laws*, 6(3), 8.
- Fisher, M. H., Baird, J. V., Currey, A. D., & Hodapp, R. M. (2016). *Victimisation and social vulnerability of adults with intellectual disability: A review of research extending beyond Wilson and Brewer*, 51(2), 114–127. <https://doi.org/10.1111/ap.12180>
- Ford, J. V., Corona Vargas, E., Finotelli Jr, I., Fortenberry, J. D., Kismödi, E., Philpott, A., Rubio-Aurioles, E., & Coleman, E. (2019). Why pleasure matters: Its global relevance for sexual health, sexual rights and wellbeing. *International Journal of Sexual Health*, 31(3), 217–230. <https://doi.org/10.1080/19317611.2019.1654587>
- Frawley, P., & Bigby, C. (2014). “I’m in their shoes”: Experiences of peer educators in sexuality and relationship education. *Journal of Intellectual Developmental Disability*, 39(2), 167.
- Frawley, P., & O’Shea, A. (2020). ‘Nothing about us without us’: Sex education by and for people with intellectual disability in Australia. *Sex Education*, 20(4), 413–424. <https://doi.org/10.1080/14681811.2019.1668759>
- Frawley, P., & Wilson, N. (2016). Young people with intellectual disability talking about sexuality education and information. *Sexuality & Disability*, 34(4), 469–484. <https://doi.org/10.1007/s11195-016-9460-x>

- Friedman, C., Arnold, C., Owen, A., & Sandman, L. (2014). "Remember our voices are our tools:" Sexual self-advocacy as defined by people with intellectual and developmental disabilities. *A Journal Devoted to the Psychological and Medical Aspects of Sexuality in Rehabilitation and Community Settings*, 32(4), 515–532. <https://doi.org/10.1007/s11195-014-9377-1>
- Gill, M. (2015). *Already doing it: Intellectual disability and sexual agency*. University of Minnesota Press. <https://doi.org/10.5749/j.ctt14jxvvh>
- Goldacre, A. D., Gray, R., & Goldacre, M. J. (2015). Childbirth in women with intellectual disability: Characteristics of their pregnancies and outcomes in an archived epidemiological dataset. *J Intellect Disabil Res*, 59(7), 653–663. <https://doi.org/10.1111/jir.12169>
- Graff, H. J., Moyher, R. E., Bair, J., Foster, C., Gorden, M. E., & Clem, J. (2018). Relationships and sexuality: How is a young adult with an intellectual disability supposed to navigate? *Sexuality & Disability*, 36(2), 175–183. <https://doi.org/10.1007/s11195-017-9499-3>
- Hanass-Hancock, J., Nene, S., Johns, R., & Chappell, P. (2018). The impact of contextual factors on comprehensive sexuality education for learners with intellectual disabilities in South Africa. *Sexuality and Disability*, 36(2), 123–140. <https://doi.org/10.1007/s11195-018-9526-z>
- Hancock, A.-M. (2007). Intersectionality as a normative and empirical paradigm. *Politics & Gender*, 3(02), 248–254. <https://doi.org/10.1017/S1743923X07000062>
- Hankivsky, O., & Christoffersen, A. (2008). Intersectionality and the determinants of health: A Canadian perspective. *Critical Public Health*, 18(3), 271–283.
- Hankivsky, O., Doyal, L., Einstein, G., Kelly, U., Shim, J., Weber, L., & Repta, R. (2017). The odd couple: using biomedical and intersectional approaches to address health inequities. *Glob Health Action*, 10(sup2), 1326686. <https://doi.org/10.1080/16549716.2017.1326686>
- Haynes, R. M., Boulet, S. L., Fox, M. H., Carroll, D. D., Courtney-Long, E., & Warner, L. (2018). Contraceptive use at last intercourse among reproductive-aged women with disabilities: An analysis of population-based data from seven states. *Contraception*, 97(6), 538–545. <https://doi.org/10.1016/j.contraception.2017.12.008>
- Healy, E., McGuire, B. E., Evans, D. S., & Carley, S. N. (2009). Sexuality and personal relationships for people with an intellectual disability. Part I: Service-user perspectives. *J Intellect Disabil Res*, 53(11), 905–912. <https://doi.org/10.1111/j.1365-2788.2009.01203.x>
- Hillard, P. J. A. (2012). Menstrual suppression with the levonorgestrel intrauterine system in girls with developmental delay. *Journal of Pediatric and Adolescent Gynecology*, 25(5), 308. <https://doi.org/10.1016/j.jpjg.2012.05.005>
- Horner-Johnson, W., Moe, E. L., Stoner, R. C., Klein, K. A., Edelman, A. B., Eden, K. B., et al. (2019). Contraceptive knowledge and use among women with intellectual, physical, or sensory disabilities: A systematic review. *Disability and health journal*, 12(2), 139–154.
- Jahoda, A., & Pownall, J. (2014). Sexual understanding, sources of information and social networks: The reports of young people with intellectual disabilities and their non-disabled peers. *J Intellect Disabil Res*, 58(5), 430–441. <https://doi.org/10.1111/jir.12040>
- Johnson, K., Frawley, P., Hillier, L., & Harrison, L. (2002). Living safer sexual lives: Research and action. *Tizard Learning Disability Review*, 7, 4–9. <https://doi.org/10.1108/13595474200200022>
- Kohn, N. A., Blumenthal, J. A., & Campbell, A. T. (2012). Supported decision-making: A viable alternative to guardianship. *Penn St. L. Rev.*, 117, 1111.
- Kramers-Olen, A. (2017). *Quantitative assessment of sexual knowledge and consent capacity in people with mild to moderate intellectual disability.*, 47(3), 367–378. <https://doi.org/10.1177/0081246317726457>
- Malouf, R., Henderson, J., & Redshaw, M. (2017a). Access and quality of maternity care for disabled women during pregnancy, birth and the postnatal period in England: Data from a national survey. *BMJ Open*, 7(7), e016757. <https://doi.org/10.1136/bmjopen-2017-016757>
- Malouf, R., McLeish, J., Ryan, S., Gray, R., & Redshaw, M. (2017b). 'We both just wanted to be normal parents': A qualitative study of the experience of maternity care for women with learning disability. *BMJ Open*, 7(3). <https://doi.org/10.1136/bmjopen-2016-015526>
- Mandell, D. S., Eleey, C. C., Cederbaum, J. A., Noll, E., Hutchinson, M. K., Jemmott, L. S., & Blank, M. B. (2008). Sexually transmitted infection among adolescents receiving special education services. *J Sch Health*, 78(7), 382–388. <https://doi.org/10.1111/j.1746-1561.2008.00318.x>
- Mayes, R., Llewellyn, G., & McConnell, D. (2006). Misconception: The experience of pregnancy for women with intellectual disabilities. *Scandinavian Journal of Disability Research*, 8(2–3), 120–131. <https://doi.org/10.1080/15017410600774178>
- McCall, L. (2005). The complexity of intersectionality. *Signs*, 30(3), 1771–1800.
- McCarthy, M. (2009a) Contraception and women with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities* 22 4 363 369 <https://doi.org/10.1111/j.1468-3148.2008.00464>
- McCarthy, M. (2009b). 'I have the jab so I can't be blamed for getting pregnant': Contraception and women with learning disabilities. *Women's Studies International Forum*, 32(3), 198. <https://doi.org/10.1016/j.wsif.2009.05.003>
- McCarthy, M. (2010). Exercising choice and control—Women with learning disabilities and contraception. *British Journal of Learning Disabilities*, 38(4), 293–302. <https://doi.org/10.1111/j.1468-3156.2009.00605.x>
- McCarthy, M. (2014). Women with intellectual disability: Their sexual lives in the 21st century. *Journal of Intellectual & Developmental Disability*, 39(2), 124–131. <https://doi.org/10.3109/13668250.2014.894963>
- McClelland, A., Flicker, S., Nepveux, D., Nixon, S., Vo, T., Wilson, C., et al. (2012). Seeking safer sexual spaces: queer and trans young people labeled with intellectual disabilities and the paradoxical risks of restriction. *Journal of Homosexuality*, 59(6), 808–819. <https://doi.org/10.1080/00918369.2012.694760>
- McConnell, D., Mayes, R., & Llewellyn, G. (2008a). Pre-partum distress in women with intellectual disabilities. *J Intellect Dev Disabil*, 33(2), 177–183. <https://doi.org/10.1080/13668250802007903>
- McConnell, D., Mayes, R., & Llewellyn, G. (2008b). Women with intellectual disability at risk of adverse pregnancy and birth outcomes. *J Intellect Disabil Res*, 52(Pt 6), 529–535. <https://doi.org/10.1111/j.1365-2788.2008.01061.x>
- McDaniels, B., & Fleming, A. (2016). Sexuality education and intellectual disability: Time to address the challenge. *Sexuality and Disability*, 34, 1–11. <https://doi.org/10.1007/s11195-016-9427-y>
- Medina-Rico, M., López-Ramos, H., Quiñonez, A. J. S., & Disability. (2018). *Sexuality in people with intellectual disability: Review of literature [journal article]*, 36(3), 231–248. <https://doi.org/10.1007/s11195-017-9508-6>
- Mitra, M., Parish, S. L., Clements, K. M., Cui, X., & Diop, H. (2015). Pregnancy outcomes among women with intellectual and developmental disabilities. *American journal of preventive medicine*, 48(3), 300. <https://doi.org/10.1016/j.amepre.2014.09.032>
- Mosher, W., Hughes, R. B., Bloom, T., Horton, L., Mojtabai, R., & Alhusen, J. L. (2018). Contraceptive use by disability status: New national estimates from the National Survey of Family Growth. *Contraception*, 97(6), 552–558. <https://doi.org/10.1016/j.contraception.2018.03.031>
- Murphy, G. H., & O'Callaghan, A. (2004). Capacity of adults with intellectual disabilities to consent to sexual relationships [Developmental Disorders & Autism 3250]. *Psychological Medicine*, 34(7), 1347–1357. <https://doi.org/10.1017/S0033291704001941>

- Murray, L. B. (2019). Sexual health education for adolescents with developmental disabilities. *The Health Education Journal*, 78(8), 1000–1011. <https://doi.org/10.1177/0017896919859605>
- Ngwena, C. G. (2018). Reproductive autonomy of women and girls under the Convention on the Rights of Persons with Disabilities. *International Journal of Gynecology & Obstetrics*, 140(1), 128–133.
- Nind, M. A., & Strnadová, I. (2020). *Belonging for people with profound intellectual and multiple disabilities: Pushing the boundaries of inclusion in education, research and community*. Routledge.
- O'Callaghan, A. C., & Murphy, G. H. (2007). Sexual relationships in adults with intellectual disabilities: understanding the law. *J Intellect Disabil Res*, 51(Pt 3), 197–206. <http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=med5&NEWS=N&AN=17300415https://onlinelibrary.wiley.com/doi/full/10.1111/j.1365-2788.2006.00857.x>
- O'Neill, J., Elia, S., & Perrett, K. P. (2019a). Human papillomavirus vaccine uptake in adolescents with developmental disabilities. *J Intellect Dev Disabil*, 44(1), 98–102. <https://doi.org/10.3109/13668250.2017.1310827>
- O'Neill, J., Newall, F., Antolovich, G., Lima, S., & Danchin, M. (2019b). The uptake of adolescent vaccinations through the School Immunisation Program in specialist schools in Victoria Australia. *Vaccine*, 37(2), 272. <https://doi.org/10.1016/j.vaccine.2018.11.034>
- O'Shea, A., & Frawley, P. (2019). Gender, sexuality and relationships for young Australian women with intellectual disability. *Disability & Society* 1–22. <https://doi.org/10.1080/09687599.2019.1647148>
- Osborn, D. P. J., Horsfall, L., Hassiotis, A., Petersen, I., Walters, K., & Nazareth, I. (2012). Access to cancer screening in people with learning disabilities in the UK: Cohort study in the health improvement network, a primary care research database. *PLoS One*, 7(8), e43841. <https://doi.org/10.1371/journal.pone.0043841>
- Parish, S. L., Mitra, M., Son, E., Bonardi, A., Swoboda, P. T., & Igdalsky, L. (2015). Pregnancy Outcomes Among U.S. Women With Intellectual and Developmental Disabilities. *Am J Intellect Dev Disabil*, 120(5), 433–443. <https://doi.org/10.1352/1944-7558-120.5.433>
- Parish, S. L., & Saville, A. W. (2006). Women with cognitive limitations living in the community: evidence of disability-based disparities in health care. *Ment Retard*, 44(4), 249–259. [https://doi.org/10.1352/0047-6765\(2006\)44\[249:Wwclli\]2.0.Co;2](https://doi.org/10.1352/0047-6765(2006)44[249:Wwclli]2.0.Co;2)
- Parish, S. L., Swaine, J. G., Luken, K., Rose, R. A., & Dababnah, S. (2012). Cervical and breast cancer-screening knowledge of women with developmental disabilities. *Intellectual and Developmental Disabilities*, 50(2), 79. <https://doi.org/10.1352/1934-9556-50.2.79>
- Pillai, M., O'Brien, K., & Hill, E. (2010). The levonorgestrel intrauterine system (Mirena) for the treatment of menstrual problems in adolescents with medical disorders, or physical or learning disabilities. *Bjog*, 117(2), 216–221. <https://doi.org/10.1111/j.1471-0528.2009.02372.x>
- Pownall, J., Wilson, S., & Jahoda, A. (2017). Health knowledge and the impact of social exclusion on young people with intellectual disabilities. *J Appl Res Intellect Disabil*. <https://doi.org/10.1111/jar.12331>
- Redshaw, M., Malouf, R., Gao, H., & Gray, R. (2013). Women with disability: The experience of maternity care during pregnancy, labour and birth and the postnatal period. *BMC pregnancy and childbirth*, 13(1). <https://doi.org/10.1186/1471-2393-13-174>
- Reynolds, F., Stanistreet, D., & Elton, P. (2008). Women with learning disabilities and access to cervical screening: Retrospective cohort study using case control methods. *BMC Public Health*, 8(1), 30–30. <https://doi.org/10.1186/1471-2458-8-30>
- Rowe, B., & Wright, C. (2017). Sexual knowledge in adolescents with intellectual disabilities: A timely reflection. *Journal of Social Inclusion*, 8(2), 42–53.
- Rutter, M. (2006). Implications of resilience concepts for scientific understanding. *Ann NY Acad Sci*, 1094(1), 1–12. <https://doi.org/10.1196/annals.1376.002>
- Savasi, I., Jayasinghe, K., Moore, P., Jayasinghe, Y., & Grover, S. R. (2014). Complication rates associated with levonorgestrel intrauterine system use in adolescents with developmental disabilities. *Journal of Pediatric and Adolescent Gynecology*, 27(1), 25. <https://doi.org/10.1016/j.jpaa.2013.08.010>
- Schaaf, M. (2011). Negotiating sexuality in the convention on the rights of persons with disabilities. *SUR-Int'l J. on Hum Rts.*, 14, 113.
- Servais, L. (2006). Sexual health care in persons with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews*, 12(1), 48–56. <https://doi.org/10.1002/mrdd.20093>
- Shandra, C., & Chowdhury, A. (2011). The first sexual experience among adolescent girls with and without disabilities. *A Multidisciplinary Research Publication*, 41(4), 515–532. <https://doi.org/10.1007/s10964-011-9668-0>
- Shandra, C. L., Shameem, M., & Ghori, S. J. (2016). Disability and the context of boys' first sexual intercourse. *Journal of Adolescent Health*, 58(3), 302–309. <https://doi.org/10.1016/j.jadohealth.2015.10.013>
- Shearer, D. L., Mulvihill, B. A., Klerman, L. V., Wallander, J. L., & et al. (2002). Association of early childbearing and low cognitive ability. *Perspectives on sexual and reproductive health*, 34(5), 236–243. https://search.proquest.com/docview/224559519?accountid=12763http://primoa.library.unsw.edu.au/openurl/61UNSW_INST/UNSW_SERVICES_PAGE?url_ver=Z39.88-2004&rft_val_fmt=info:ofi/fmt:kev:mtx:journal&genre=article&sid=ProQ%3A sociology&atitle=Association+of+early+childbearing+and+low+cognitive+ability&title=Perspectives+on+Sexual+and+Reproductive+Health&issn=15386341&date=2002-09-01&volume=34&issue=5&spage=236&au=Shearer%2C+Darlene+L%3BMulvihill%2C+Beverly+A%3BKlerman%2C+Lorraine+V%3BWallander%2C+Jan+L%3Bet+al&isbn=&jtitle=Perspectives+on+Sexual+and+Reproductive+Health&btile=&rft_id=info:eric/12392216&rft_id=info:doi/
- Sheppard, L. (2006). Growing pains: a personal development program for students with intellectual and developmental disabilities in a specialist school. *Journal of Intellectual Disabilities*, 10(2), 121–142. <https://login.wwwproxy1.library.unsw.edu.au/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=cin20&AN=106330410&site=ehost-live&scope=sitehttps://doi.org/10.1177/1744629506064009>
- Shildrick, M. (2007). Contested pleasures: The sociopolitical economy of disability and sexuality. *Sexuality Research & Social Policy*, 4(1), 53–66. <https://doi.org/10.1525/srsp.2007.4.1.53>
- Shuttleworth, R. (2007). Critical research and policy debates in disability and sexuality studies. *Sexuality Research & Social Policy*, 4(1), 1–14. <https://doi.org/10.1525/srsp.2007.4.1.01>
- Spencer, G. (2013). Empowerment, health promotion and young people: A critical approach. *Empowerment, Health Promotion and Young People: A Critical Approach*, 1–183. <https://doi.org/10.4324/9780203071038>
- Starrs, A. M., Ezeh, A. C., Barker, G., Basu, A., Bertrand, J. T., Blum, R., et al. (2018). Accelerate progress: Sexual and reproductive health and rights for all: report of the Guttmacher-Lancet Commission. *The Lancet*, 391(10140), 2642–2692. [https://doi.org/10.1016/S0140-6736\(18\)30293-9](https://doi.org/10.1016/S0140-6736(18)30293-9)
- Sutherland, R. J., & Isherwood, T. (2016). The evidence for easy-read for people with intellectual disabilities: A systematic literature review. *Journal of Policy and Practice in Intellectual Disabilities*, 13(4), 297–310.
- Swaine, J. G., Parish, S. L., Luken, K., Son, E., & Dickens, P. (2014). Test of an intervention to improve knowledge of women with intellectual disabilities about cervical and breast cancer screening. *Journal of Intellectual Disability Research*, 58(7), 651–663. <https://doi.org/10.1111/jir.12062>

- Tepper, M. S. (2000). Sexuality and disability: The missing discourse of pleasure. *Sexuality and disability*, 18(4), 283–290.
- Trainor, A. A. (2007). Perceptions of adolescent girls with Id regarding self-determination and postsecondary transition planning [Special & Remedial Education 3570]. *Learning Disability Quarterly*, 30(1), 31–45. <https://doi.org/10.2307/30035514>
- Tricco, A., Lillie, E., Zarin, W., O'Brien, K., Colquhoun, H., Levac, D., Moher, D., Peters, M., Horsley, T., Weeks, L., Hempel, S., Akl, E., Chang, C., McGowan, J., Stewart, L., Hartling, L., Aldcroft, A., Wilson, M., Garrity, C., & Straus, S. (2018). PRISMA extension for scoping reviews (PRISMA-ScR): Checklist and explanation. *Annals of Internal Medicine*, 169. <https://doi.org/10.7326/M18-0850>
- Turner, G. W., & Crane, B. (2016a). Pleasure is paramount: Adults with intellectual disabilities discuss sensuality and intimacy. *Sexualities*, 19(5–6), 677–697. <https://doi.org/10.1177/1363460715620573>
- Turner, G. W., & Crane, B. (2016b). Sexually silenced no more, adults with learning disabilities speak up: A call to action for social work to frame sexual voice as a social justice issue. *British Journal of Social Work*, 46(8), 2300–2317. <https://doi.org/10.1093/bjsw/bcw133>
- United Nations. (2006). *Convention on the rights of persons with disabilities*. <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>
- Walmsley, J., & Johnson, K. (2004). *Inclusive research with people with learning disabilities: Past, present and futures*. Jessica Kingsley Publishers.
- Wheeler, P. (2007). 'I count myself as normal, well, not normal, but normal enough' men with learning disabilities tell their stories about sexuality and sexual identity. *Learning Disability Review*, 12(1), 16–27. <https://login.wwwproxy1.library.unsw.edu.au/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=cin20&AN=105927659&site=ehost-live&scope=site>
- Whittle, C., & Butler, C. (2018). Sexuality in the lives of people with intellectual disabilities: A meta-ethnographic synthesis of qualitative studies. *Research in Developmental Disabilities*, 75, 68–81. <https://doi.org/10.1016/j.ridd.2018.02.008>
- Wilkinson, V. J., Theodore, K., & Raczka, R. (2015). "As normal as possible": Sexual identity development in people with intellectual disabilities transitioning to adulthood [Mental Retardation 3256]. *Sexuality and Disability*, 33(1), 93–105. <https://doi.org/10.1007/s11195-014-9356-6>
- Williams, F., Scott, G., & McKechnie, A. (2014). Sexual health services and support: The views of younger adults with intellectual disability. *Journal of Intellectual Developmental Disability*, 39(2), 147–156. <https://doi.org/10.3109/13668250.2014.899326>
- Wissink, I. B., Van Vugt, E., Moonen, X., Stams, G.-J.J., & Hendriks, J. (2015). Sexual abuse involving children with an intellectual disability (ID): A narrative review. *Research in Developmental Disabilities*, 36, 20–35.
- Wolfe, P. S., Wertalik, J. L., Domire Monaco, S., Gardner, S., & Ruiz, S. (2019). *Review of sociosexuality curricular content for individuals with developmental disabilities.*, 34(3), 153–162. <https://doi.org/10.1177/1088357618800040>
- Wu, J., Jianying, Z., Mitra, M., Parish, S. L., Minama Reddy, G. K., & Zhang, J. (2018a). Provision of moderately and highly effective reversible contraception to insured women with intellectual and developmental disabilities. *Obstetrics & Gynecology*, 132(3), 565–574. <https://doi.org/10.1097/AOG.0000000000002777>
- Wu, J., Zhang, J., Mitra, M., Parish, S. L., & Minama Reddy, G. K. (2018b). Provision of moderately and highly effective reversible contraception to insured women with intellectual and developmental disabilities. *Obstet Gynecol*, 132(3), 565–574. <https://doi.org/10.1097/aog.0000000000002777>
- Yacoub, E., & Hall, I. (2009). The sexual lives of men with mild learning disability: A qualitative study. *British Journal of Learning Disabilities*, 37(1), 5–11. <https://doi.org/10.1111/j.1468-3156.2008.00491.x>
- Zhang, Y., McLain, A. C., Davis, B., & McDermott, S. (2019). Fecundity and infertility among women with disabilities in the United States. *Journal of Women's Health (15409996)*, 28(7), 934–940. <https://doi.org/10.1089/jwh.2018.7267>

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