

# White Paper

## **State of Affairs in Sex Education for People with Intellectual and Developmental Disabilities (IDD)**

Prepared for  
Planned Parenthood League of  
Massachusetts

By Nechama F. Sammet Moring, CPM, MA  
Rebel Girl Research Communications  
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## Executive Summary

Children and adults with intellectual and developmental disabilities (IDD) are increasingly integrated into community life<sup>1</sup>, but still face significant inequities in sexual health care and education<sup>2</sup>. People with IDD experience high rates of sexual violence victimization, are less likely to receive sexual health care, and lack access to comprehensive sex education<sup>3-12</sup>. Ensuring that people with IDD can receive accessible sex education is complicated by a host of practical, cultural, historical, and social justice-related barriers<sup>5,6,13-24</sup>. As a result, people with IDD often lack crucial sexual health information, as well as the skills needed for decision making, consensual sexual expression, navigating relationships, and preventing sexual violence victimization<sup>4,15,25-35</sup>. Access to comprehensive sex education is therefore an important component of achieving sexual health and social equity for the population of people with IDD<sup>5,15</sup>. Planned Parenthood League of Massachusetts (PPLM) is well-poised to facilitate collaborative efforts to fill the gaps in sex education access for people with IDD. Assets include PPLM's recognized expertise in sexual health and sex education, large networks of PPLM-trained sex educators, and strong partnerships with schools and other relevant institutions, particularly those working with people with disabilities.

To ensure that PPLM's ongoing work towards sex education equity is effective and meets the needs of the IDD community, PPLM hosted a convening, titled State of Affairs in Sex Education for People with IDD ("the Convening") on October 4, 2018. Planning for the Convening was informed by a thorough review of the academic and popular literature. PPLM engaged an outside consultant with expertise in disability and reproductive justice, sexual health of people with IDD, and anti-ableism approaches, who conducted community-based research, including key informant interviews, and an environmental scan. PPLM also engaged a pre-Convening Planning Committee, consisting of self-advocates with IDD, sex educators, parents, service providers, and clinicians, who provided guidance about the format and content of the Convening. Accessibility and inclusion were key considerations for the Convening; various accommodations were provided, including plain language summaries, visual schedules, a sensory break room, low lighting, and other efforts to make the Convening space and content physically and cognitively accessible. Self-advocates served as keynote speakers, workshop leaders, and panelists, and were supported and paid for their time and expertise.

The Convening brought together stakeholders with diverse interests and expertise from across Massachusetts and New England. Participants included direct care providers, counselors, general and adapted educators, skills coaches, program managers, public health officials, mental and physical health care providers, rape crisis counselors, researchers, sex educators, parents of people with IDD, parents with IDD, peer supporters, self-advocates with IDD, and others. These stakeholders participated in a full day of focused attention on the needs, resources, gaps, and opportunities related to sex education for people with IDD. The Convening included keynote addresses; topical break-out sessions in the morning and the afternoon; a lunchtime panel featuring innovative and integrative approaches to sexual health and education for people with IDD; and a closing session in which participants reflected on the day and generated key take away messages. The break-out sessions consisted of facilitated small

group conversations about the following topics as related to people with IDD: trauma-informed sex education; consent, autonomy and rights; educator best practices in sex education; parents as educators and advocates; and LGBTQIA+ inclusive sex education.

Findings spanned several important themes, beginning with many attendees' shared belief that while improving sexual health equity for people with IDD is a key priority, there is a lack of forums, such as the Convening, to enable progress in this area. Attendees also noted the siloed nature of many efforts and appreciated the opportunity to collaborate, learn about existing resources and programs, and share across fields. Attendees highlighted the need to shift from a reactive model of sex education – which often begins when sexual violence victimization comes to light – to a comprehensive, inclusive, affirming and rights-based model. Relatedly, another theme was protecting human rights, including the right to sexuality and consensual sexual expression, within the context of systemic social and institutional discrimination towards people with IDD. Intersectionality was a key concern, as many people with IDD are also subject to other systems of oppression (e.g. people of color with IDD who are disadvantaged by racism) that often intensify and interact with ableism. Finally, systemic gaps and structural problems were acknowledged, leading to a discussion of unmet needs. Action steps and priorities focused on increasing and sustaining collaboration, and on education, including professional development for sex educators about how to include learners with IDD.

## Background and Preparation

To prepare for the Convening, PPLM assembled a Convening Core Project Team and hired a consultant to conduct a literature review of academic and popular literature and community-based research, including key informant interviews and a gap analysis. PPLM also formed a Planning Committee consisting of self-advocates, sex educators, activists, policymakers, program managers, and other key stakeholders. This pre-work highlighted stark inequities in sexual violence victimization, sexual health knowledge, access to sexual health care and sex education, and troubling patterns related to lack of respect for the human rights of people with IDD<sup>3-5,8,12,15,16,27,28,31,34-44</sup>. To fully understand and address these inequities, PPLM's Convening Core Project Team began an extensive process of confronting internalized and organization-based ableism. *Ableism* is defined as bias or discrimination against people with disabilities, and, like other systems of oppression, is often unintentionally absorbed from our larger society<sup>45</sup>. Historically, people with IDD have often been excluded, and many organizations were therefore built without input from, or even awareness of, people with IDD<sup>1,18,45-50</sup>.

For the Convening Core Project Team, it was particularly important to examine the historic role and its ongoing legacies of the sexual and reproductive health field, including Planned Parenthood, in the systemic oppression of people with IDD. This included contending with the racist and ableist practices of eugenics and forced sterilization, which targeted Black, Indigenous and Latinx people of color, as well as people with IDD of all races<sup>20,36,37,51-53</sup>. Please note that the term *people of color* is used throughout this paper to include diverse peoples of many races who do not hold white privilege, and who are disadvantaged by systems of white supremacy.

Though this growth process was not always comfortable, it resulted in several meaningful changes to the team's operations. Notably, the team worked hard to center the voices of people with IDD, with specific attention to intersectionality and the experiences of people with IDD who also face additional systems of oppression, such as racism or cissexism, which interact with and often intensify ableism<sup>45,54</sup>. PPLM actively sought, and financially compensated, interviewees and Planning Committee members who have IDD. To enable their participation, PPLM adapted standard materials and email templates to be cognitively accessible and in plain language; PPLM also budgeted to compensate participants and allow support workers to attend meetings with participants with IDD. Additionally, PPLM helped with transportation costs, which is important given the high rates of poverty among people with IDD<sup>55</sup>. This focus on access increased inclusion, both in this project and in PPLM's future work.

Several key lessons emerged from PPLM's pre-work and internal growth process, contributing directly to the positive outcomes of the Convening. Examining organizational ableism helped PPLM better understand the barriers to sexual health equity that many people with IDD experience. These barriers include the lack of accessible sex education materials, gaps in universal design (educational practices that use multiple formats to reach all learners) in sex education<sup>15,25,27,38,56-58</sup>, lack of attention to disabled sexuality (i.e. the impacts of disability on

sexuality and the unique sexuality of people with disabilities<sup>59</sup>), and low representation of people with disabilities within the profession of sex education<sup>60</sup>.

This process also enhanced PPLM's understanding of current societal realities, such as the ways in which people of color with IDD of all ages are often demonized as sexual "monsters" or "deviants"<sup>47,52,61,62</sup>, while white adults with IDD are often assumed to be "innocent," "child-like," and categorically nonsexual and/or without a sexual identity<sup>63-67</sup>. Both perceptions are incorrect, dehumanizing, and result in lack of opportunities for comprehensive sex education for people with IDD. As a result of this process, PPLM's efforts were grounded in the strengths of people with IDD and their allies and communities, represented by the growing leadership, expertise, voice, and activism of people with IDD and disability-led organizations.

## Findings

This section summarizes the conversations of the Convening, and highlights the priorities identified by attendees. Findings have been grouped into several key themes and represent conversations that took place throughout the day. To emphasize the voices of Convening participants, illustrative quotes from attendees are included.

### Comprehensive Sex Education

Interest in sex education and people with IDD is growing rapidly<sup>4,20,33,58,68-70</sup>. Advocacy by people with IDD<sup>1,71</sup> and their supporters has raised general awareness of the inequities in sexual health care and sex education, and there is a growing demand for equity across many sectors.

PPLM's pre-Convening research and Convening attendees highlighted the historical context for sex education inequities. In the past, people with IDD were often institutionalized, and therefore excluded from many aspects of society and community life, including sex education and sexual health care services<sup>1,5,79</sup>. Today, largely due to the advocacy work of people with disabilities and their supporters<sup>71</sup>, the vast majority of people with IDD live in houses and communities with people without disabilities; attend neighborhood schools; receive health care in mainstream, non-IDD specific settings; and are employed in non-segregated work places. While this progress towards inclusion in society at large is positive, many of our systems were not designed with people with IDD in mind. As a result, service providers, including sexual health clinicians and sex educators, often lack awareness of people with IDD and their needs<sup>1,14,18,21,80</sup>. This lack of awareness can lead to inadvertent exclusion and missed opportunities to serve people with IDD effectively. Per federal law, education, including sex education, must be inclusive of all learners, with and without IDD<sup>56</sup>. However, many stakeholders expressed a high degree of uncertainty about how to translate awareness to action in terms of creating resources and policies for equity and inclusion.

While all Convening participants agreed that the topic of sex education for and regarding people with IDD is crucial, there was some variation among stakeholder groups in terms of

specific needs and expectations. For example, self-advocates, including the keynote speaker, spoke about access to sexual health information as a human right, while some parents spoke about access to this information as a means of managing “inappropriate” behaviors. There were also many shared needs across groups. The most consistent piece of feedback was that the Convening was a necessary and important first step towards addressing an issue that demands sustained attention and work.

Many educators, parents, and service providers noted that issues of sex education and sexuality frequently arise in the context of serving people with IDD<sup>36,68,75-77</sup>, and reported that they are sometimes unsure of how to respond to issues related to sexuality<sup>5,40,75,78</sup>. One example discussed include parents who feel unsure how to teach consent and decision-making skills to their adolescent child with IDD who is beginning to date; another includes an employment services agency that wants to proactively train the adults with IDD they support about recognizing and responding to workplace sexual harassment.

### Sexual Violence Prevention and Consensual Sexuality

The increased awareness of sexual health inequity among people with IDD is in part fueled by the epidemic of sexual violence against people with IDD<sup>35,41</sup> even as society at large makes strides in addressing sexual assault<sup>74</sup>. Due to many factors, including factors associated with ableism and the disability experience, people with IDD have extremely high rates of experiencing sexual violence<sup>2,5,28,29,30,35,36,42,46,70,72-74,76,81,82</sup>. Individuals with IDD are vulnerable due to potentially increased dependency on caregivers who may abuse their power, exposure to compliance training and other “therapies” that may inadvertently decrease agency, and systems for reporting sexual violence that may be cumbersome or inaccessible for survivors with IDD<sup>ibid</sup>.

People of color with IDD, and particularly men, have historically been racially stereotyped as sexual predators, and therefore may be perceived as the aggressor, rather than the victim in need of support, when they experience sexual violence<sup>46,47,54,61</sup>. Sexual violence victimization is traumatic, and people with IDD have less access to trauma support services than their non-disabled peers<sup>25,27,79,83-88</sup>. As many as 90% of women with IDD are estimated to have survived sexual violence, with high rates also seen among men and people of other genders<sup>35,41</sup>.

Comprehensive sex education has been shown<sup>15,89-91</sup> to increase reporting rates and prevent sexual violence victimization, but many people with IDD do not receive any sex education at all<sup>5,25,76,79</sup>. The sex education that is provided to people with IDD is often focused exclusively on sexual violence prevention. In contrast, comprehensive sex education includes information about consensual sexuality, relationships and communication, decision-making, consent, gender and sexual identity, and safer sex practices<sup>4,15,16,27,82,92</sup>.

While sex education focusing exclusively on violence prevention may be more comfortable for parents, service providers, and other people who have power over people with IDD, it represents a missed opportunity to decrease inequities in sexual health knowledge<sup>31,36,40,44,93,94</sup>. Many people with IDD can and do engage in consensual sexual expression, but are more likely

than their non-disabled peers to report that they want more information about sexual health than they currently have<sup>30,38,68</sup>. Many self-advocates describe these inequities as a human rights issue because people with IDD have the same right to sexual knowledge, agency, and consensual expression as everyone else<sup>4,30,33,38,57</sup>. Comprehensive sex education is an important strategy for sexual violence prevention and ensuring that people with IDD can access their right to sexual agency<sup>15,32,72,81</sup>.

In line with this evidence, Convening attendees discussed the importance of shifting from reactive sex education, focused solely on sexual violence prevention/response, to inclusive, human rights-focused, comprehensive sex education. This proactive, affirming approach may be particularly important for LGBTQIA+ people with IDD, who are often infantilized and ignored<sup>43,58,95,96</sup>; people of color with IDD who often face additional racialized inequities in access to sexual health information<sup>46,47,61</sup>; and other marginalized sub-populations of people with IDD.

Access to comprehensive sex education that gives people language for sexuality may also prevent future difficulties or misperceptions, as in a case described by an attendee, in which an adult with IDD who was searching the internet for “boys without clothes.” After receiving comprehensive sex education, this individual was able to clarify that he wanted pictures of naked adult men, not children. This education helped him avoid potential legal and other challenges. As one attendee advised, “[we must] consider a broad definition of sex and presume that everyone will have the capacity to consent [on their own terms]. And [that means we need to] build a foundation [of training, education, and materials to support] that presumption [that people with IDD have the capacity and right to consent to sexual expression/activity].”

#### Non-Compliance is a Social Skill: Ensuring People with IDD Can Say ‘No’ and ‘Yes’

Adolescents and adults with IDD are often infantilized (and often demonized as inherently sexually dangerous if they are of color), they have the right to unbiased sexual health information and to consensual sexual expression if desired<sup>15,20,27,38,45,47,63,65,67</sup>. However, service providers, parents, and other people in positions of power over people with IDD may not be aware of these rights<sup>ibid</sup>. Providers and parents may also lack education about sexuality, deny the sexuality of people with IDD, or approach the subject with their own personal values and biases<sup>ibid</sup>. Further, direct support providers who are personally supportive of sex education and consensual sexual expression may feel unsure of how they are “supposed” to respond when sexuality-related questions or concerns arise. They also may lack training and education related to comprehensive sexual health information, and may experience pressure from parents, employers or others to disregard the sexual rights of people with IDD<sup>27,31,40,75,77</sup>.

The right to unbiased information delivered in a supportive setting is particularly important for LGBTQIA+ people with IDD, who are more likely to experience the erasure or dismissal of their sexual or gender identities by people who assume that they are confused or incapable of identifying as LGBTQIA+. Clinicians or caregivers may regard LGBTQIA+ identity as a “presenting problem” associated with disability, rather than as a valid identity<sup>27,43,58</sup>. This is also important

for people of color with IDD who are more likely to experience criminalization of their sexuality<sup>46,47</sup>.

Inherent to comprehensive sex education is an appreciation for every person's right to make informed decisions for themselves and to have their decisions considered and respected. However, people with IDD are often prevented from accessing the right to make decisions in many arenas, including decisions about their own bodies. For example, an autistic child may be forced to make eye contact or prevented from engaging in "stim" behaviors like hand flapping or fidgets. Many "therapies" and educational techniques used with people with IDD were developed with the intention of "managing" or controlling them and teaching compliance.

In contrast, self-advocates emphasize the importance of teaching bodily autonomy and non-compliance with authority figures as a social skill needed to navigate the world. Self-advocates also highlight that people with IDD need to experience "the dignity of risk" – the chance to make decisions of their own, including bad decisions, and experience their consequences. Though this can be a learning opportunity for many, people with IDD are often "protected" from their right to decision making. Truly accessible, equitable sex education, then, must take place in a context that both acknowledges ableism and other systems of oppression that hinder decision-making by people with IDD, and that empowers them to make and enforce autonomous decisions. As expressed by an attendee, "opportunities for decision-making is sometimes not offered (ever!) due to disability identity. How can we teach big decisions if they have not learned skills of decision making at a younger age?"

### Protecting Rights and Understanding Guardianship

A small minority of adults with IDD are under legal guardianships. Legal guardianship is the result of a process in which evidence is presented and a judge issues a ruling terminating a disabled individual's legal rights (i.e. privacy, decision-making etc.), with a specific person appointed as their legal guardian<sup>B</sup>. The designated legal guardian may or may not be the individual's parent and is assigned the responsibility of providing legal consent (e.g. for medical procedures) on behalf of the individual. In the absence of an established legal guardianship, with the parent assigned as their adult child's legal guardian, parental rights end when their child reaches the age of majority (age 18 in most states), regardless of the adult child's disability status<sup>C</sup>. However, many parents, service providers, self-advocates and others hold misconceptions about legal guardianship and the rights of parents of adults with IDD, and often wrongly assume that parental rights automatically continue into adulthood (e.g. that parental permission must be obtained before an individual can see a medical provider).

These common misunderstandings of legal guardianship and continued parental rights can lead to inadvertent and unfounded challenges to the human rights of adults with IDD, and often serve to limit agency and self-determination regarding sexuality, sexual health care, and sex education. For example, service agencies may require parental permission to provide sex education or safer sex supplies to adults with IDD; case managers may report private information about an individual's sexual health or expression to parents without their permission; self-advocates may believe they need their parents' permission to date or have

sexual relationships. While some young adults with IDD (as well as their non-disabled peers) may still desire support or guidance from their parents and other trusted people to make decisions, the legal relationship between parent and child is different after the child reaches the legal age of majority.

Work is needed to educate parents and other stakeholders about changes to parental rights and responsibilities after individuals with IDD legally become adults, as well as supports establishing new boundaries for parents transitioning to a new role in their adult child's life. To be effective advocates, service providers working with adults with IDD also need education about legal guardianship and the rights of adults with IDD – including their right to make sexual health and other decisions independent of their parents.

**Inclusion and Disability Justice: “Nothing About Us Without Us” and “Nothing Without Us”**  
“Nothing about us without us” has long been a rallying cry of the disability community as disabled people have fought for inclusion and self-determination in the face of ableism and oppression<sup>71,97,98</sup>. In recent years, self-advocates have also fought for “nothing without us” – i.e. people with disabilities having a voice in all areas of society, not just those that pertain specifically to disability<sup>97</sup>. This is particularly true for people with IDD, who, until relatively recently were segregated from society in institutions<sup>D</sup>, and still face significant barriers to full community inclusion<sup>1,71,98</sup>.

Considering this social context, PPLM sought to actively enable participation by self-advocates throughout the Convening and its planning process. This included paid participation in the Planning Committee and Convening, workshop development and presentation opportunities; subsidized transportation; accessible space and materials; and other methods previously described. Many participants expressed appreciation for the overall above-average accessibility level of the Convening.

However, despite this attention to inclusion, PPLM received critical feedback about the relatively low representation of people with IDD at the Convening, especially as compared with attendance by people who did not have IDD. Attendees also emphasized that while enabling attendance of people with IDD is important, achieving true inclusion demands continued efforts to address systemic ableism. This feedback may speak to the entrenched nature of ableism, historical mistrust of sexual and reproductive health providers and organizations, and other inequities in our society. PPLM is committed to actively continuing to build relationships and trust with self-advocates to keep inclusion and accessibility at the forefront of all efforts.

It is also crucial to apply the framework of “nothing about us without us,” and “nothing without us” to sex education programming. As several disability-focused organizations and organizations led by and for people with IDD engage with sexual health<sup>25</sup>, Planned Parenthood is well positioned to offer its collaboration and leverage its content-specific expertise for self-advocate led projects, such as the National Council on Independent Living's work to develop sex education resources for people with IDD or the Autistic Women and Nonbinary Network's work around sexual health care quality.

Engaging self-advocates in leadership opportunities is also advised. This might include training self-advocates to teach sex education, applying a peer leadership model, and using self-advocate-developed sex education curricula. As many of the current gaps in access to sex education relate to historic and present day ableism and other systems of oppression, organizations and individuals are advised to conduct a process of internal reviews and ongoing anti-ableism work, such as the process undertaken by PPLM. Adapting content to ensure access should involve, in the words of an attendee “breaking it down, not dumbing it down.”

Because many people with IDD are marginalized in multiple, complex ways, it is vital to utilize an intersectional, anti-oppression approach that recognizes all aspects of each individual’s identity. Incorporating a trauma-informed approach enabled more people to access programming and resources. As expressed by an attendee, “people with disabilities often learn that disability is their first, foremost, and only identity, [but] all pieces of our identity inform our decision making. If we only focus on one piece, we are neglecting the other pieces. Any education, outreach, services should be [focused on] anti-oppression on EVERY level. Services should be [designed] with the idea that we will empower people to make their own decisions. Not just top-down, but bottom-up, and side-to-side around the organization. Make sure that in the provision of services, we are not further traumatizing people or reinventing the wheel.”

#### Networking, Overcoming Siloes, and “Discovering” Existing Resources

Interest in the topic of sex education and people with IDD spans many different fields, as reflected by the diverse backgrounds and identities of participants at the Convening. However, one of the main barriers identified in PPLM’s prior research and by Convening attendees was the relative isolation of their various fields and roles from each other. Attendees further clarified that this silo effect was also sometimes felt within a given field, and sometimes even within the same agency. The silo effect is often compounded by different terms used for similar concepts, and the need to “translate” across fields.

The Convening demonstrated one way this challenge can be addressed, by bringing people together within and across fields and providing networking opportunities. Attendees expressed strong support for continued exchanges, and for developing the infrastructure and relationships needed to collaborate across siloes in an ongoing manner. Highlighting the need for interagency collaboration, several attendees spoke of their desire for trauma-informed peer supports for people with IDD who experience sexual violence. During the lunchtime panel, a representative of the Disabled Persons Protection Commission, a state agency, spoke about their peer advocate program. This program offers peer counseling from a trained sexual violence survivor with IDD to adults with IDD who experience sexual assault. Learning about this existing program helped attendees see how collaboration across agencies can lead to expanding programmatic reach, tailoring content and materials for various communities of people with IDD, and developing best practices to be shared across fields. Attendees were unanimous in their appreciation for the opportunity to connect. As summarized by a participant, “there are resources that people don’t know about—the more we talk together, the more likely we can share resources and make change.”

## The System Wasn't Built for Us: Unmet Needs and Gaps

Despite the personal commitment of stakeholders to sexual equity, there are significant systemic barriers for people with IDD in accessing sexual health education and services. First, institutional infrastructures were built and are controlled by people with privileged identities and continue to lack representation of and leadership by people with IDD. Service systems are often complex and difficult to navigate, with a strong silo effect in place. Further, sex education and supports for sexuality are often in response to an incident or “inappropriate” behavior, or provided on the fly to address an urgent presenting need<sup>15,27,76</sup>.

Because of the reactive, rather than integrated, nature of sexual health and education services, responding to incidents or sexual health questions from people with IDD is often left to the people with the least systemic power, such as low-level direct support workers, rather than higher level agency managers or policymakers. Direct support workers are often underpaid, have minimal job security, and often lack training related to sexual health. They may or may not feel comfortable responding to questions or concerns about sexuality. They may also feel pressure from an individual's parents, or from their employers, to respond a certain way or to deny requests for information that they might otherwise feel comfortable providing. Training and supports for direct support workers should be attentive to these power dynamics and should center self-advocate voices. As described by an attendee, “we might have great tools – but can we use them? A lot of direct care providers are on the front lines but aren't always comfortable, informed, or ready, but they are still in that situation.”

Collaboration across fields, hierarchies, agencies, and systems would increase the quantity and quality of supports available to people with IDD, particularly those who are also marginalized by other systems of oppression. The current lack of standardization also hinders evaluation and reporting efforts. As stated by an attendee, “the idea that [the] job of change in this arena is on one group [is wrong]. State agencies, municipal groups, school systems, and disability service agencies should all be doing this work. Don't talk about it as though there can be only one source for the information or the work. [We] need support at the state level. Involve the whole system!”

## Priority Action Steps by Topic and Population

While there is genuine investment in improving sex education and sexual health care and services for people with IDD, there are also significant unmet needs<sup>5,15,18,27,30,36,76</sup>. These needs include infrastructure for collaborating, especially across fields; organization and coordination across systems; institutional and systems level support; up-to-date knowledge, information, and best practices targeting various stakeholders; training and education for self-advocates, parents, direct support providers, and professionals; trauma-informed, intersectional supports; and inclusion and leadership of people with IDD<sup>ibid</sup>. This section will discuss areas of unmet need with proposed action steps for remedying these important gaps. Gaps, needs and action steps are grouped by area, and action steps that are currently in progress by PPLM are highlighted.

### Inclusion

Inclusion of and leadership by self-advocates with IDD must be central to all efforts. Networking and collaborating with people with IDD are imperative to enable their access and participation in all aspects of this work. In practice, this means going beyond simply issuing an invitation, but also enabling participation by compensating people with IDD for their time and attendance, providing transportation and childcare, ensuring cognitively and physically accessible spaces, and other enabling resources. Accessibility audits and paid consultation by accessibility experts can assist with this goal, and anti-ableism training and internal review and growth should be part of the organizational process.

While people with IDD are often included in coalitions as “experts in their own lives,” successful efforts to increase sex education access must recognize the varied expertise, capacity, and talents of self-advocates, in addition to their disability identity. The field as a whole needs to increase leadership opportunities for people with IDD. People with IDD should be hired and compensated to develop curricula, mentor peers, lead efforts, and serve as sex educators. It is vital to pay attention to intersectionality and the additional barriers that may be present for people with IDD who are also members of other oppressed and marginalized groups (i.e. LGBTQIA+ people, people of color, etc.). People with IDD should be included in decision making capacities, as they were in the Planning Committee that guided preparation for the Convening.

#### **What Planned Parenthood League of Massachusetts is Doing**

PPLM is engaged in a process of self-reflection and growth related to addressing ableism wherever it appears within the work of PPLM. PPLM recognizes that this work is an ongoing process, and is committed to reflection, growth, and continuous learning to achieve true inclusivity. PPLM will continue to work with the IDD community to facilitate inclusion and share resources.

## Collaboration

The Convening was an important first step in PPLM’s work to collaborate with the IDD community and facilitate sharing across fields and siloes. Ideally, these collaborations will be developed proactively, to enable an integrated, coordinated approach that creates community supports – *before* they are needed. Efforts to translate across fields and develop a “shared language” will be vital in reducing the silo effect. PPLM is committed to the process of collaboration, including leveraging its resources and expertise to bring stakeholders together across divides. This is important for facilitating responsive, community engaged efforts.

### **What Planned Parenthood League of Massachusetts is Doing**

PPLM is listening to self-advocates with IDD and is committed to moving forward in partnership with the IDD community. PPLM is facilitating collaborative relationships and networking opportunities among self-advocates, educators, and service providers.

## Resource Development

Developing specialized resources, including identifying, articulating, publishing, and sharing best practices, will benefit several stakeholder groups as well as increase capacity for collaboration. Using “shared language” and clearly defining all terms will help stakeholders translate across fields, as terminology can vary widely. In all fields, it is important to build the evidence base, including collecting evaluation data from formal study of the programs and practices that are empirically believed to be effective. Advocacy tools, with options for customization for various stakeholders, will help individuals and groups drive systems change.

Resources that can accommodate multiple audiences are recommended. An example of this might include concurrent trainings in which people with IDD, parents, professionals, and other groups each receive unique, complementary content and then meet to share information and strategize collectively. Best practices and guidelines are needed in many areas, by different stakeholder types, including people with IDD, professionals, parents and educators; specific resources needed are listed below, by population.

### *People with IDD*

People with IDD need supports and resources for accessing sex education and consensual sexual expression, including education about their human rights and all other aspects of comprehensive sex education. The field should invest in the development of curricula and learning tools, ideally by or with self-advocates with IDD. These materials need to be intersectional and grounded in racial justice frameworks in order to combat the racism-related barriers to sexual health equity seen in the population of people with IDD. LGBTQIA+ people with IDD need inclusive, safe spaces to ask questions and get support without having their sexuality or gender questioned, made clinical, or dismissed. People with IDD need opportunities for leadership in the field of sex education and generally.

### *Service Providers & Administrators*

Professionals and service agencies would benefit from “higher level” professional development workshops and educational content. Many professionals indicated that they already include a basic level training about supporting sexual health in their new staff orientation, but are in need of more advanced professional development opportunities and resources. Service agencies would also benefit from development of portable content and train-the-trainer models related to sex education, sexuality, and sexual health equity. Professionals would also like to see tailored supports and advocacy tools for systems change within agencies, such as tools for standardizing how sex education is approached agency-wide, uniform guidelines and best practices, and resources for direct support workers. Organizations may also consider establishing peer-led resources for LGBTQIA+ individuals with IDD, such as chapters of the Rainbow Support Group. Additionally, professionals need resources explaining legal guardianship, the rights of people with IDD, and the changed legal role of parents when a person with IDD reaches the age of majority.

### *Educators*

Educators would benefit from the development of best practices for including learners with IDD. It is also important to develop resources for educators, such as curricula, tools, and adaptations to enable them to “*break down, not dumb down*” sex education content. Educators also need professional development opportunities related to teaching sex education to their students with IDD.

### *Parents*

Parents and other trusted adults need materials and support to enhance their comfort in discussing sexuality and sexual health with their loved ones with IDD. Materials should support a diversity of family values and beliefs, and emphasize the importance of an individualized approach. Parents can be a powerful source of advocacy for their children and may need education about the importance of advocating for access to sex education. Parents would benefit from opportunities to attend concurrent education with their children, with parents in one room and their children in another, followed by the whole group meeting back for a larger group discussion and activities. Parents also need resources explaining legal guardianship, the rights of adults with IDD, and the changes to parental rights when their child reaches the age of majority.

#### **What Planned Parenthood League of Massachusetts is Doing**

PPLM is working with a co-creation team to develop a training for educators and service providers about sex education that is inclusive of learners with IDD. The training is set to take place in spring 2020.

## End Notes

- A. Historically, the eugenics movement primarily targeted Black Americans, though in some northern cities, European immigrants who would today be considered white (i.e. white Jews, Italians, etc.) were also targeted for sterilization. Indigenous people have also been targeted for sterilization throughout U.S. history, and coercive sterilization practices targeting Latinx people have been documented as well, particularly in the southwest and west coast. A comprehensive history of eugenics in the U.S. is beyond the scope of this white paper. However, it is important to note that ableism as a system of oppression has strong historical and current ties to white supremacy and white supremacist ideology. Therefore, efforts to address ableism must be grounded in racial justice. Throughout this report, the term “people of color” is used as a blanket term to describe people who are not advantaged by the system of racism and who do not have the unearned advantages of white privilege, including people who are Black, Latinx, Asian, Indigenous, and/or members of other historically oppressed racial groups.
- B. While a thorough discussion of guardianship is beyond the scope of this white paper, it should be noted that there is a fairly strong consensus within the disability community that legal guardianship is never benign. There may be positive results for some individuals under guardianship, such as increased access to needed health care services if an individual’s guardian is able to advocate for them. However, disability justice advocates argue that there are less restrictive ways to accomplish the same gains without sacrificing human rights. Some activists also point out that removing rights from people with disabilities is a slippery slope that has never ended well, regardless of intentions. Please see Lydia X. Z. Brown’s website, [www.autistichoya.com](http://www.autistichoya.com), for a thorough discussion.
- C. Many young adults with IDD receive youth-oriented services, like public school-based supports, through age 22. However, regardless of what services or supports they receive, people with IDD are legally considered adults when they reach the age of majority (usually but not always age 18). At this time, in the absence of an established guardianship, parental rights end, just as they do for non-disabled adults, at the age of majority, regardless of whether the person still receives youth-oriented services. As a comparison, the lack of relationship between services received and legal rights is similar to policies allowing young adults to remain covered by their parents’ health insurance policy until age 26. Continued coverage does not impact the young adult’s right to make decisions for themselves, and does not limit their privacy rights, regardless of whether they receive this benefit.
- D. Notably, people with IDD are still institutionalized, with people of color with IDD institutionalized at higher rates than their white counterparts. In Massachusetts, the Judge Rotenberg Center, an institution, practices electric shock-based behavior modification systems that several human rights agencies (i.e. Amnesty International) have described as abusive.

## Resource: Recommended Action Steps and Approaches

*This document can be used by organizations to focus workplace and workplan priorities, as well as advocate for funding. For more information on each section, please refer to the content of the PPLM White Paper.*

### Inclusion

- Continue networking and collaborating with self-advocates and the IDD community
- Work to enable access and participation by people with IDD (i.e. invite people but also compensate them, provide transportation and childcare, and make the space accessible)
- Pay attention to intersectionality, multiple marginalized identities
- Include people with IDD in decision making capacities (i.e. the Planning Committee is an example of this)
- Develop training for people with IDD to be sex educators, peer mentors, etc.
- Conduct anti-ableism trainings and internal reviews within organizations

### Collaboration

- Create spaces that facilitate more opportunities for networking, sharing resources, and working together (i.e. yearly Convenings, working groups etc.)
- Share information
- Work to break down specialized terms across fields and come up with “shared language” that everyone can understand, because the same term can mean different things to different people
- Build coalitions – and make sure that the voices and leadership of people with IDD are centralized
- Elevate existing and impactful resources and share them widely

## Develop Resources for the Following Stakeholder Groups

### *People with IDD*

- Develop sex education curricula and learning tools (ideally by/with people with IDD)
- Create safe, LGBTQIA+-inclusive spaces for people with IDD to ask questions and get support around sexuality, without having their sexuality or gender identity questioned, made into a clinical problem, or dismissed
- Train people with IDD to be sex educators, peer mentors etc.
- Provide leadership opportunities to people with IDD
- Include people with IDD in decision-making capacities across all efforts

### *Service Providers & Administrators*

- Conduct concurrent trainings for professionals and self-advocates
- Develop content about sexuality/sexual health that could be included in staff orientation
- Develop intermediate and advanced professional development opportunities for professionals

- Develop portable content or a train-the-trainer model to be used by agencies serving people with IDD
- Create tools and resources for direct support workers, and policies for supporting them
- Create advocacy tools for systems change within agencies
- Provide education about legal guardianship and the legal rights of adults with IDD

#### *Educators*

- Develop best practices for providing sexual health education to learners with IDD
- Develop resources, curricula, tools, adaptations for students with IDD that “break down, not dumb down” content etc.
- Build the evidence base and gather evaluation data of implemented programming
- Create professional development opportunities for educators about sex education that includes learners with IDD

#### *Parents*

- Create resources and materials to support parents in discussing sexual health and sexuality with their children and adolescents with IDD, including enhancing parental comfort in approaching these topics
- Ensure that materials for parents are accessible to families with diverse values and emphasize the importance of an individualized approach
- Conduct concurrent trainings for people with IDD and their parents
- Provide parents with information and guidance to advocate for their child to receive sexual health education
- Provide information about legal guardianship and the legal rights of adults with IDD

## References

1. Abbot S, McConkey R. The barriers to social inclusion as perceived by people with intellectual disabilities. *Journal of Intellectual Disabilities*. 2006;10(3):275-287.
2. McDaniels B, Fleming A. Sexuality education and intellectual disability: Time to address the challenge. *Sexuality & Disability*. 2016;34(2):215-225.
3. Eastgate G. Sexual health for people with intellectual disability. *Salud Pública de México*. 2008;50:s255-s259. doi:10.1590/S0036-36342008000800019
4. Gomez MT. The S words: Sexuality, sensuality, sexual expression and people with intellectual disability. *Sex Disabil*. 2012;30(2):237-245. doi:10.1007/s11195-011-9250-4
5. Greenwood N, Wilkinson J. Sexual and reproductive health care for women with intellectual disabilities: A primary care perspective. *International Journal of Family Medicine*. 2013;2013:e642472. doi:10.1155/2013/642472
6. Isler A, Tas F, Beytut D, Conk Z. Sexuality in adolescents with intellectual disabilities. *Sex Disabil*. 2009;27(1):27-34. doi:10.1007/s11195-009-9107-2
7. Krahn GL, Hammond L, Turner A. A cascade of disparities: Health and health care access for people with intellectual disabilities. *Ment Retard Dev Disabil Res Rev*. 2006;12(1):70-82. doi:10.1002/mrdd.20098
8. Mandell DS, Eleey CC, Cederbaum JA, et al. Sexually transmitted infection among adolescents receiving special education services. *Journal of School Health*. 2008;78(7):382-388. doi:10.1111/j.1746-1561.2008.00318.x
9. McCabe MP. Sexual knowledge, experience and feelings among people with disability. *Sexuality and Disability*. 1999;17(2):157-170. doi:10.1023/A:1021476418440
10. McConnell D, Mayes R, Llewellyn G. Women with intellectual disability at risk of adverse pregnancy and birth outcomes. *J Intell Disabil Res*. 2008;52:529-535. doi:10.1111/j.1365-2788.2008.01061.x
11. Parish SL, Saville AW. Women with cognitive limitations living in the community: Evidence of disability-based disparities in health care. *Mental Retardation*. 2006;44(4):249-259. doi:10.1352/0047-6765(2006)44[249:WWCLLI]2.0.CO;2
12. Whitehouse MA, McCabe MP. Sex education programs for people with intellectual disability: How effective are they? *Education and Training in Mental Retardation and Developmental Disabilities*. 1997;32(3):229-240.
13. Bernert DJ. Sexuality and disability in the lives of women with intellectual disabilities. *Sexuality & Disability*. 2011;29(2):129-141.

14. Ouellette-Kuntz H, Garcin N, Lewis MES, Minnes P, Martin C, Holden JJA. Addressing health disparities through promoting equity for individuals with intellectual disability. *Canadian Journal of Public Health / Revue Canadienne de Sante'e Publique*. 2005;96:S8-S22.
15. Swango-Wilson A. Meaningful sex education programs for individuals with intellectual/developmental disabilities. *Sex Disabil*. 2011;29(2):113-118. doi:10.1007/s11195-010-9168-2
16. Healy E, McGuire BE, Evans DS, Carley SN. Sexuality and personal relationships for people with an intellectual disability. Part I: Service-user perspectives. *Journal of Intellectual Disability Research*. 2009;53:905-912. doi:10.1111/j.1365-2788.2009.01203.x
17. Greenwood N, Dreyfus D, Wilkinson J. More than just a mammogram: Breast cancer screening perspectives of relatives of women with intellectual disability. *Intellect Dev Disabil*. 2014;52(6):444-455. doi:10.1352/1934-9556-52.6.444
18. Anderson P, Kitchin R. Disability, space and sexuality: Access to family planning services. *Social Science & Medicine*. 2000;51(8):1163-1173. doi:10.1016/S0277-9536(00)00019-8
19. Barroso C, Sippel S. Sexual and reproductive health and rights: Integration as a holistic and rights-based response to HIV/AIDS. *Women's Health Issues*. 2011;21(6, Supplement):S250-S254. doi:10.1016/j.whi.2011.07.002
20. Aunos M, Feldman MA. Attitudes towards sexuality, sterilization and parenting rights of persons with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*. 2002;15(4):285-296. doi:10.1046/j.1468-3148.2002.00135.x
21. Krahn GL, Fox MH. Health disparities of adults with intellectual disabilities: What do we know? What do we do? *J Appl Res Intellect Disabil*. 2014;27(5):431-446. doi:10.1111/jar.12067
22. McCarthy M. 'I have the jab so I can't be blamed for getting pregnant': Contraception and women with learning disabilities. *Women's Studies International Forum*. 2009;32(3):198-208. doi:10.1016/j.wsif.2009.05.003
23. Quint EH. Menstrual issues in adolescents with physical and developmental disabilities. *Annals of the New York Academy of Sciences*. 2008;1135(1):230-236. doi:10.1196/annals.1429.020
24. Wilkinson JE, Cerreto MC. Primary care for women with intellectual disabilities. *J Am Board Fam Med*. 2008;21(3):215-222. doi:10.3122/jabfm.2008.03.070197
25. Autistic Self Advocacy Network ASAN. Real Talk: Improving Quality of Sexual Health Care for Patients with Disabilities. Autistic Self Advocacy Network. <https://autisticadvocacy.org/projects/completed/realtalk/>. Accessed January 18, 2019.

26. Cambridge P, Beadle-Brown J, Milne A, Mansell J, Whelton B. Patterns of risk in adult protection referrals for sexual abuse and people with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*. 2011;24(2):118-132. doi:10.1111/j.1468-3148.2010.00574.x
27. Brown M, McCann E. Sexuality issues and the voices of adults with intellectual disabilities: A systematic review of the literature. *Research in Developmental Disabilities*. 2018;74:124-138. doi:10.1016/j.ridd.2018.01.009
28. Eastgate G. Sex, consent and intellectual disability. *Australian Family Physician*. 2005;34(3):163.
29. Dukes E, McGuire BE. Enhancing capacity to make sexuality-related decisions in people with an intellectual disability. *Journal of Intellectual Disability Research*. 2009;53(8):727-734. doi:10.1111/j.1365-2788.2009.01186.x
30. Friedman C, Arnold CK, Owen AL, Sandman L. "Remember our voices are our tools:" Sexual self-advocacy as defined by people with intellectual and developmental disabilities. *Sexuality and Disability*. 2014;32(4):515-532. doi:10.1007/s11195-014-9377-1
31. Galea J, Butler J, Iacono T, Leighton D. The assessment of sexual knowledge in people with intellectual disability. *Journal of Intellectual and Developmental Disability*. 2004;29(4):350-365.
32. Graff HJ, Moyher RE, Bair J, Foster C, Gorden ME, Clem J. Relationships and sexuality: How is a young adult with an intellectual disability supposed to navigate? *Sexuality and Disability*. 2017;2(36):175-183. doi:10.1007/s11195-017-9499-3
33. Jahoda A, Pownall J. 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*. 2014;58(5):430-441. doi:10.1111/jir.12040
34. McGuire B, Bailey A. Relationships, sexuality and decision-making capacity in people with intellectual disability. *Current Opinion in Psychiatry*. 2011;24(5):398-402. doi:10.1097/YCO.0b013e328349bbcb
35. Wacker J, Macy R, Barger E, Parish S. Sexual assault prevention for women with intellectual disabilities: A critical review of the evidence. *Intellect Dev Disabil*. 2009;47(4):249-262. doi:10.1352/1934-9556-47.4.249
36. Sinclair J, Unruh D, Lindstrom L, Scanlon D. Barriers to sexuality for individuals with intellectual and developmental disabilities: A literature review. *Education and Training in Autism and Developmental Disabilities*. 2015;50(1):3-16.
37. Tilley E, Earle S, Walmsley J, Atkinson D. 'The Silence is roaring': Sterilization, reproductive rights and women with intellectual disabilities. *Disability and Society*. 2012;27:413-426.

38. Addlakha R, Price J, Heidari S. Disability and sexuality: Claiming sexual and reproductive rights. *Reprod Health Matters*. 2017;25(50):4-9. doi:10.1080/09688080.2017.1336375
39. Dionne H, Dupras A. Sexual health of people with an intellectual disability: An ecosystem approach. *Sexologies*. 2014;23(4):e85-e89.
40. Bazzo G, Nota L, Soresi S, Ferrari L, Minnes P. Attitudes of social service providers towards the sexuality of individuals with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*. 2007;20(2):110-115. doi:10.1111/j.1468-3148.2006.00308.x
41. Horner-Johnson W, Drum CE. Prevalence of maltreatment of people with intellectual disabilities: A review of recently published research. *Ment Retard Dev Disabil Res Rev*. 2006;12(1):57-69. doi:10.1002/mrdd.20097
42. Lewin B. Who cares about disabled victims of crime? Barriers and facilitators for redress. *Journal of Policy and Practice in Intellectual Disabilities*. 2007;4(3):170-176. doi:10.1111/j.1741-1130.2007.00115.x
43. McClelland A, Flicker S, Nepveux D, et al. Seeking safer sexual spaces: Queer and trans young people labeled with intellectual disabilities and the paradoxical risks of restriction. *J Homosex*. 2012;59(6):808-819. doi:10.1080/00918369.2012.694760
44. McGillivray JA. Level of knowledge and risk of contracting HIV/AIDS amongst young adults with mild/moderate intellectual disability. *Journal of Applied Research in Intellectual Disabilities*. 1999;12(2):113-126. doi:10.1111/j.1468-3148.1999.tb00070.x
45. Ben-Moshe L, Magaña S. An introduction to race, gender, and disability: Intersectionality, disability studies, and families of color. *Women, Gender, and Families of Color*. 2014;2(2):105-114.
46. Brown L. Disability in an Ableist World. *Autistic Hoya*. <https://www.autistichoya.com/2012/08/disability-in-ableist-world.html>.
47. Cevik K. #AutisticWhileBlack #SaveDarius Criminal Justice in Black and White. *Autism Wars*. October 2018. <http://theautismwars.blogspot.com/2018/10/autisticwhileblack-savedarius-criminal.html>. A
48. Lewis TA. Disability ain't for your dozes (or demons). <https://www.talilalewis.com/blog>.
49. van Ryn M, Fu SS. Paved with good intentions: Do public health and human service providers contribute to racial/ethnic disparities in health? *Am J Public Health*. 2003;93(2):248-255. doi:10.2105/AJPH.93.2.248
50. Hughes B, Paterson K. The social model of disability and the disappearing body: Towards a sociology of impairment. *Disability & Society*. 1997;12(3):325-340. doi:10.1080/09687599727209

51. Lombardo P. *Three Generations, No Imbeciles*. Johns Hopkins University Press Books. <https://jhupbooks.press.jhu.edu/title/three-generations-no-imbeciles>. 2019.
52. Mingus M. *Changing the framework: Disability justice*. *Leaving Evidence*. February 2011. <https://leavingevidence.wordpress.com/2011/02/12/changing-the-framework-disability-justice/>. Accessed January 19, 2019.
53. Carlson L. *Cognitive ableism and disability studies: Feminist reflections on the history of mental retardation*. *Hypatia*. 2001;16(4):124-146. doi:10.1111/j.1527-2001.tb00756.x
54. Cevik K. *Mustafa's Dilemma*. *Autism Wars*. August 2016. <http://theautismwars.blogspot.com/2016/08/mustafas-dilemma.html>.
55. Emerson E. *Poverty and people with intellectual disabilities*. *Ment Retard Dev Disabil Res Rev*. 2007;13(2):107-113. doi:10.1002/mrdd.20144
56. Chen E. *The importance of Universal Design for learning*. Harvard Graduate School of Education. <https://www.gse.harvard.edu/news/uk/08/12/importance-universal-design-learning>. Accessed January 18, 2019.
57. Alexander N, Taylor Gomez M. *Pleasure, sex, prohibition, intellectual disability, and dangerous ideas*. *Reproductive Health Matters*. 2017;25(50):114-120. doi:10.1080/09688080.2017.1331690
58. Noonan A, Taylor Gomez M. *Who's missing? Awareness of lesbian, gay, bisexual and transgender people with intellectual disability*. *Sexuality and Disability*. 2011;29(2):175-180. doi:10.1007/s11195-010-9175-3
59. Mingus M. *Video: Crip sex, crip lust and the lust of recognition*. *Leaving Evidence*. <https://leavingevidence.wordpress.com/2010/05/25/video-crip-sex-crip-lust-and-the-lust-of-recognition/>
60. Meijer C. *Music education should be inclusive. So where are the disabled teachers?* | *The Guardian*. <https://www.theguardian.com/teacher-network/2018/apr/13/music-education-should-be-inclusive-so-where-are-the-disabled-teachers..>
61. Abdelhadi A. *Addressing the criminalization of disability from a disability justice framework: Centering the experiences of disabled queer trans indigenous and people of colour*. *The Feminist Wire*. November 2013. <https://thefeministwire.com/2013/11/addressing-the-criminalization-of-disability-from-a-disability-justice-framework-centring-the-experiences-of-disabled-queer-trans-indigenous-and-people-of-colour/>.
62. Vallas R. *Disabled behind bars: The mass incarceration of people with disabilities in America's jails and prisons*. 2016. <https://cdn.americanprogress.org/wp-content/uploads/2016/07/18000151/2CriminalJusticeDisability-report.pdf>.

63. Cevik K. Autism Month Essays: Against the presumption of incompetence. Autism Wars. April 2018. <http://theautismwars.blogspot.com/2018/04/autism-month-essays-against-presumption.html>.
64. Cevik K. Against the autism parent feedback loop of woe. Autism Wars. June 2018. <http://theautismwars.blogspot.com/2018/06/against-autism-parent-feedback-loop-of.html>.
65. Gardiner F. Parents, do not infantilise your teenage and adult disabled children. <http://www.thinkingautismguide.com/2018/06/parents-do-not-infantilise-your-teenage.html>.
66. Peter NG, Forke CM, Ginsburg KR, Schwarz DF. Transition From Pediatric to Adult Care: Internists' Perspectives. *Pediatrics*. 2009;123(2):417-423. doi:10.1542/peds.2008-0740
67. Stout A. Presuming competence: What is it and why is it important? The Autism Site Blog. <https://blog.theautismsite.greatergood.com/presume-competence>.
68. Gill M. *Already Doing It: Intellectual Disability and Sexual Agency*. University of Minnesota Press, 2015.
69. Llewellyn G, Hindmarsh G. Parents with intellectual disability in a population context. *Curr Dev Disord Rep*. 2015;2(2):119-126. doi:10.1007/s40474-015-0042-x
70. Northway R, Jenkins R, Jones V, Howarth J, Hodges Z. Researching policy and practice to safeguard people with intellectual disabilities from abuse: some methodological challenges. *Journal of Policy and Practice in Intellectual Disabilities*. 2013;10(3):188-195. doi:10.1111/jppi.12037
71. Wehmeyer M, Bersani H, Gagne R. riding the third wave: Self-determination and self-advocacy in the 21st century. *Focus Autism Other Dev Disabl*. 2000;15(2):106-115. doi:10.1177/108835760001500206
72. Curry MA, Renker P, Robinson-Whelen S, et al. Facilitators and barriers to disclosing abuse among women with disabilities. *Violence Vict*. 2011;26(4):430-444.
73. Saxton M, Curry MA, Powers LE, Maley S, Eckels K, Gross J. "Bring my scooter so I can leave you": A study of disabled women handling abuse by personal assistance providers. *Violence Against Women*. 2001;7(4):393-417. doi:10.1177/10778010122182523
74. Smith SE. Disability should be integral to the #MeToo conversation. *Rewire News*. <https://rewire.news/article/2017/11/01/disability-integral-metoo-conversation/>
75. McConkey R, Ryan D. Experiences of staff in dealing with client sexuality in services for teenagers and adults with intellectual disability. *Journal of Intellectual Disability Research*. 2001;45(1):83-87. doi:10.1111/j.1365-2788.2001.00285.x

76. Pownall JD, Jahoda A, Hastings RP. Sexuality and sex education of adolescents with intellectual disability: Mothers' attitudes, experiences, and support needs. *Intellectual and Developmental Disabilities*. 2012;50(2):140-154. doi:10.1352/1934-9556-50.2.140
77. Swango-Wilson A. Caregiver perception of sexual behaviors of individuals with intellectual disabilities. *Sex Disabil*. 2008;26(2):75-81. doi:10.1007/s11195-008-9071-2
78. Servais L. Sexual health care in persons with intellectual disabilities. *Ment Retard Dev Disabil Res Rev*. 2006;12(1):48-56. doi:10.1002/mrdd.20093
79. Friedman C, Owen AL. Sexual health in the community: Services for people with intellectual and developmental disabilities. *Disabil Health J*. 2017;10(3):387-393. doi:10.1016/j.dhjo.2017.02.008
80. Wilkinson J, Dreyfus D, Cerreto M, Bokhour B. "Sometimes I feel overwhelmed": Educational needs of family physicians caring for people with intellectual disability. *Intellectual and Developmental Disabilities*. 2012;50(3):243-250. doi:10.1352/1934-9556-50.3.243
81. Schaafsma D, Kok G, Stoffelen JM, Curfs LM. People with intellectual disabilities talk about sexuality: implications for the development of sex education. *Sexuality & Disability*. 2017;35(1):21-38.
82. Sammet Moring N, Mitra M, Parish S, Alterio N. After disclosure: a protocol for responding to disclosures of sexual violence by research participants with IDD. *Journal of Policy and Practice in Intellectual Disabilities*. [in press].
83. Anderson LL, Humphries K, McDermott S, et al. The state of the science of health and wellness for adults with intellectual and developmental disabilities. *Intellect Dev Disabil*. 2013;51(5):385-398. doi:10.1352/1934-9556-51.5.385
84. Bryne G. Prevalence and psychological sequelae of sexual abuse among individuals with an intellectual disability: A review of the recent literature. *Journal of Intellectual Disabilities*. 2018;22(3):294-310.
85. Crocker AG, Prokić A, Morin D, Reyes A. Intellectual disability and co-occurring mental health and physical disorders in aggressive behaviour. *J Intellect Disabil Res*. 2014;58(11):1032-1044. doi:10.1111/jir.12080
86. Evans E, Howlett S, Kremser T, Simpson J, Kayess R, Trollor J. Service development for intellectual disability mental health: a human rights approach. *J Intellect Disabil Res*. 2012;56(11):1098-1109. doi:10.1111/j.1365-2788.2012.01636.x
87. Haverkamp SM, Scandlin D, Roth M. Health Disparities among adults with developmental disabilities, adults with other disabilities, and adults not reporting disability in North Carolina. *Public Health Reports*. 2004;119(4):418-426. doi:10.1016/j.phr.2004.05.006

88. Ouellette-Kuntz H, Burge P, Henry DB, Bradley EA, Leichner P. Attitudes of senior psychiatry residents toward persons with intellectual disabilities. *The Canadian Journal of Psychiatry*. 2003;48(8):538-545. doi:10.1177/070674370304800805
89. Santelli JS, Grilo SA, Choo T-H, Diaz G, Walsh K, Wall M, Hirsch JS, Wilson PA, Gilbert PA, Gilbert L, Khan S, Mellins CA. Does sex education before college protect students from sexual assault in college? *PLoS One*. 2018;13(11):published online. doi:10.1371/journal.pone.0205951
90. Schneider M, Hirsch JS. Comprehensive sexuality education as a primary prevention strategy for sexual violence perpetration. *Trauma, Violence & Abuse*. 2018; <https://doi.org/10.1177/1524838018772855>
91. Haberland N, Rogow D. Sexuality education: Emerging trends in evidence and practice. *Journal of Adolescent Health*. 2015;56(1s):S15-S21. doi.org/10.1016/j.jadohealth.2014.08.013
92. Whittle C, Butler C. Sexuality in the lives of people with intellectual disabilities: A meta ethnographic synthesis of qualitative studies. *Research in Developmental Disabilities*. 2018;75:68-81.
93. Gill M. Rethinking sexual abuse, questions of consent, and intellectual disability. *Sex Res Soc Policy*. 2010;7(3):201-213. doi:10.1007/s13178-010-0019-9
94. Pownall JD, Jahoda A, Hastings R, Kerr L. Sexual understanding and development of young people with intellectual disabilities: Mothers' perspective of within-family context.
95. Parkes GBJ, Biel N. Gender dysphoria and intellectual disability: presentation, diagnosis and course. *ResearchGate*. [https://www.researchgate.net/publication/303020278\\_Gender\\_Dysphoria\\_and\\_Intellectual\\_Disability\\_Presentation\\_diagnosis\\_and\\_Course](https://www.researchgate.net/publication/303020278_Gender_Dysphoria_and_Intellectual_Disability_Presentation_diagnosis_and_Course).
96. Wilson NJ, MacDonald J, Hayman B, Bright AM, Frawley P, Gallego G. A narrative review of the literature about people with intellectual disability who identify as lesbian, gay, bisexual, transgender, intersex or questioning. *J Intellect Disabil*. 2018;22(2):171-196. doi:10.1177/1744629516682681
97. Shapiro JP. *No Pity: People with Disabilities Forging a New Civil Rights Movement*. New York: Times Books; 1993.
98. Trent, James. *Inventing the Feeble Mind: A History of Intellectual Disability in the United States*.: Oxford, New York: Oxford University Press; 2016.