

## **A Call to Action for Sexual and Reproductive Health, Wellbeing, and Bodily Autonomy for Youth with Intellectual and Developmental Disabilities**

By Natalie M. Chin

April 25, 2024 (last revision)

When Janice Bartley shared her story of first love at the [Moth “New York Stories”](#) storytelling showcase, the audience engaged with her laughter, going on the storytelling adventure with Janice about her first time having sex with her now long-time fiancé. Janice, who has cerebral palsy and is a wheelchair user, ended her Moth story, which she affectionately titled “the Italian Stallion,” by saying, “I want people to know that even though I have a disability, I can still move. And I also realized someone could see me for the real woman that I am and not just my disability.”

Janice represents one voice in a community of people with intellectual and developmental disabilities (I/DD) who are speaking up to challenge the stigma, misinformation, and desexualization of disabled people. As a society, the topic of sex and sexuality for young people with I/DD is often avoided, ignored, or dismissed as not relevant. As a result, there are stark inequities in access to comprehensive sexual education (CSE) for young people with I/DD. [CSE “encompasses a spectrum of topics such as sexual and reproductive anatomy, puberty and adolescent development, consent, relationships, contraception and pregnancy, among others; and should support learners to build content knowledge and apply related.”](#)

The World Health Organization defines sexuality as [“a central aspect of being human throughout life.”](#) Despite this essential role of sexuality, people with I/DD have long been excluded from conversations about sexuality and sex education. As was recognized in a joint position

statement by American Association on Intellectual and Developmental Disabilities and the Arc of the United States in 2008 and remains current today, "[Individual rights to sexuality](#), which is essential to human health and well-being, have been denied . . . [negatively affect\[ing\] people with intellectual disabilities in gender identity, friendships, self-esteem, body image and awareness, emotional growth, and social behavior.](#)"

## **Project SHINE**

---

In 2020, the Sexual Health Innovation Network for Equitable Education with Youth with Intellectual Disabilities project - referred to as [Project SHINE](#) - was formed as seven New York State organizations joined together to take steps to address some of the sexual and reproductive health inequities that young people with I/DD ages 16-24 experience. A central tenet of Project SHINE is to center the voices of the individuals most impacted by sexual and reproductive healthcare disparities. In doing so, leadership and input from youth and adults with intellectual and developmental disabilities directed the efforts of Project SHINE. A 16-member Advisory Board comprised of youth with I/DD, self-advocates, parents, and other family caregivers of persons with I/DD, and professionals and educators who support youth with I/DD helped guide the work of Project SHINE.

The lack of resources created and designed by people with I/DD to strengthen the dialogue and educational information around sexuality motivated Project SHINE to develop a "Design Collective." The Design Collective comprised of organizational partners and Advisory Board members who worked collaboratively with young people with I/DD to build components of a web-based sexual health toolkit. After extensive focus groups with young people with I/DD and the people who support them, the topics were chosen for the toolkit and an extensive and interactive sexuality resource about anatomy and bodily autonomy created.

The [“Your Sexual Health Toolkit”](#) includes an illustrated [“Sexual Health Glossary,”](#) reflection questions and conversation starters to discuss sexuality and sexual and reproductive health, a resource hub, and a “choose your own adventure” style educational game. In one recent study, professionals who serve this community, which included [“licensed/credentialed direct service professionals \(social workers, nurses, teachers\), non-licensed direct service providers \(case managers, supportive care specialists, residential care line staff\), and program administrators,”](#) confirmed the [importance of medically accurate](#) sexual and reproductive health information, however, there are very few available and accessible tools that provide this resource. As expressed by Tina, a self-advocate and member of Project SHINE, “we need more disability centric information on intimacy and sexuality. I still think that the opinion is around today that people with disabilities don't need to know ...about sex and sexuality.”

The toolkit design prioritizes equitable and accessible design and is available in English and Spanish. [“How to”](#) pages help orient users to the website. Users can read, listen, watch, and view detailed visuals about sexuality information on their own or with trusted people in their lives.

## **Sexuality is a Central Aspect of Being Human**

---

It is critical to reframe sexuality as [“as an essential aspect of community integration and sexual and psychosocial health”](#) rather than an issue that is responded to reactively and punitively. As one provider said, “I think a lot of conversations are incident-driven, like maybe there will be some sexual interaction that happens that you become aware of and then it’s like, ‘Oh, this conversation needs to happen,’ rather than being more proactive.” Addressing sexuality proactively is not difficult. Several participants in a Project SHINE youth focus group offered suggestions for how to approach sexual education. [One focus group participant said,](#) “I suggest we need to establish [learn about] all the types of sexual

relationships; like one night stand, decent dating relationships and relationships that can go even further.”

[Another youth member of the group chimed in](#) by saying that he wants to learn how to ask questions such as, “If you could go out with me, or do you want to date me, you know, those type of questions.” Another participant expressed that he wanted to know [“how to interpret the verbal and non-verbal cues.”](#) Several youth members discussed wanting to learn [“how to identify abuse, sexual abuse and relationships, and who to call,”](#) [“the risks and like the side effects of taking birth control,”](#) and about [“\[a\]bortion...and having more education about those things to help you make practical decisions in the future, if you were to run into that situation.”](#)

The erasure of sexuality as an essential aspect of community integration leaves a gap for young people with I/DD who seek access to information and knowledge around healthy intimate relationships, bodily autonomy, issues of sexual and reproductive health, and healthy boundary-setting in relationships. This erasure further fuels the suppression of sexual awareness and expression and healthy sexual exploration. Sexuality is not just about sex. It is [deeply connected to other aspects of one’s life](#) that include the emotional, physical, cultural, and psychological. The breadth of one’s sexuality includes [“sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction.”](#)

Access to [comprehensive sexual education](#) is an essential component for young people with I/DD to develop their sexuality in a healthy way and bridge inequities in sexual health and education access. Sexuality education encompasses a huge variance of topics including but not limited to sex, sexual orientation, gender identity, dating, healthy relationships, living together, consent, capacity, marriage, and having and raising children. Research shows that the development of decision-making skills through comprehensive sexual education contributes to increased self-esteem, sexual self-awareness, the ability to make knowledge-based

choices, which [“reinforce\[s\] the decision to act for the good of one’s health and well-being.”](#) Sexual education also [“reduc\[es\] vulnerability”](#) and [“inappropriate sexual expression.”](#)

Sexuality education does not just start and stop in a classroom, it occurs throughout a person’s life and is guided by the resources, staff, family, and support systems around the individual. Family members, care givers, educators, and support staff who are most often the facilitators of the developmental needs of young people with I/DD play an equally critical role in fostering healthy sexual development.

## **The Cascading Consequences of Sexual Health and Education Inequities**

---

Many young people with I/DD expressed that they were not taught about sex and sexuality until they requested the education well into their adult lives. The few self-advocates who received sexual education in their teens recalled the experience as being “brief,” not informative, and “excluding key information.” One young person commented in a conversation with a Project SHINE member, [“I feel like in sex ed they will teach you certain things, but not everything. It’s class and they are really restricted about certain things, but I still felt they could have taught us more about it.”](#)

Studies confirm that tailored sex education has [“positive effects . . . on knowledge, skills, attitudes, and behaviors of adults with \[intellectual disabilities\]”](#) and has proven successful to [“improve capacity to make sexuality-related decisions.”](#) Further, [“\[s\]exual education is a ‘mechanism to promote the ability to make good choices and empower’” people with intellectual disabilities. In that, “the development of decision-making skills through sex education contributes to the ability to make knowledge-](#)

Sexual health inequities have cascading consequences. A lack of information on healthy sexual behavior, for example, is shown to increase

the likelihood of abuse and sexual exploitation of persons with I/DD. One estimate determined that people with intellectual disabilities are sexually assaulted at rates more than [seven times than adults without disabilities](#). Further, "[when people are not provided with accurate and accessible information about social-sexual behavioral norms](#), they are at risk for demonstrating unexpected social-sexual behavior" which may include "[public masturbation](#)" and "[touching people's private body parts without permission](#)."

Kate Hoy, Director of Advocacy Services for AHRC New York City and education advocate for students with intellectual and developmental disabilities, [provided examples of the tangible harms experienced by students with I/DD when comprehensive sexual education is not prioritized](#) as an essential component to securing sexual and reproductive health and safety. She discussed the following: "[Students I work with have been](#) . . . denied basic information about their sexual and reproductive health; isolated from peers in overly restrictive settings; prevented from attending field trips, and rejected from after-school programs due to poor social skills." She continued, students have also been "denied use of their personal pronouns and gender affirming standards of care; they've been trafficked . . . catfished; sexually abused; suspended for bungled attempts to engage with crushes; harassed and threatened at school and home by intimate partners; bullied for their sexual orientation . . . and disciplined unknown times for 'sexually inappropriate behaviors.'"

These tangible harms are compounded by racism, heterosexism, homophobia, and transphobia that is experienced by LGBTQ+ people of color with disabilities and LGBTQ+ disabled people who encompass other marginalized identities. LGBTQ people with intellectual disabilities, for example, experience the "[erasure of their identity within their larger service environment](#)," rejection from family, and fear that they may lose services such as housing or put "[valued relationships with staff](#)" at risk by

expressing their authentic selves, or seeking out support related to questions about their sexuality and gender.

A lack of leadership, guidance, and proper sexuality education and supports for staff, family, and individuals with I/DD alike has led to severe harm in the community. This harm includes discrimination, sexual abuse and exploitation, the spreading of incorrect information concerning issues of sexuality, lack of bodily protection, disempowerment, and lack of life fulfillment.

## **A Call to Action: Looking Forward**

---

People with disabilities deserve access to the fullest range of sexual and reproductive health information and care they need and want. Project SHINE envisions a world where youth with intellectual and developmental disabilities have equitable access to high-quality information and affordable health care, with supportive laws and policies that ensure the greatest autonomy and informed sexual well-being possible across the lifespan.

The recommendations that follow are based on interviews, data, and information collected over the three years of the Project SHINE initiative. Input for these recommendations came from youth with intellectual and developmental disabilities, parents/guardians of people with intellectual and developmental disabilities, service providers, and others working in the disability field. This list of recommendations is in no way complete. The aim of these recommendations is to lay the foundation and framework necessary for substantive future action.

- 1. Stakeholder Input for Comprehensive Sexuality Education:** State agencies [and service providers](#) that provide supports and services to people with intellectual and developmental disabilities (hereinafter (“State Agencies for PWIDD”) must engage stakeholders across New

York State to learn about the needs of staff, family members, and people with I/DD on issues of sexuality supports and services.

Any effort by State Agencies for PWIDD to create and implement protocols, policies, and trainings related to sexuality supports and services must be carried out with multi-stakeholder input from across New York State. The needs and concerns of the I/DD community around issues of sexuality are vast. Issues of race, class, sexual orientation, gender identity, and others must be considered by State Agencies for PWIDD in any proposed policy changes and trainings around sexuality and people with I/DD.

**2. Mandated Funding for Inclusive Sexuality Education:** State Agencies for PWIDD must fund and mandate inclusive developmentally appropriate sexuality education. Agencies must lay a proper foundation for sexuality education and supports by funding and mandating these services. Self-advocates must be included in every step of this project to ensure the education and supports are relevant to their perspectives and lives. Without a foundation of mandated and funded sexuality services by State Agencies for PWIDD for agency staff, support workers, and people with I/DD, there is concern that any sexuality policy will fail to ensure that the sexuality rights of people with I/DD are supported and respected.

Any funded and mandated sexuality education must be inclusive of the lesbian, gay, bisexual, transgender, non-binary, queer, and asexual communities. Historically, sexuality education has focused on a heteronormative model that excludes critical information for young people who fall outside this model, which can lead to negative physical and sexual health outcomes.

**3. Confront Cultural Bias and Ignorance Around Disability and Sexuality:** State Agencies for PWIDD must provide a framework that



elevates the importance of sexuality education to combat [“the culture of ableism, bias and ignorance around sexuality and people with I/DD.”](#) State Agencies for PWIDD must work toward changing the culture at provider agencies to make sexuality a natural part of community integration. By incorporating sexuality education and resources into available and accessible community-based services, State Agencies for PWIDD will begin to remove the bias and ignorance that is pervasive in agencies around sexuality and people with I/DD.

State Agencies for PWIDD can take a leadership role to ensure that every agency incorporates sexuality education and resources into its programming. Through this effort, State Agencies for PWIDD would play a central role in changing the negative and, often harmful, culture around sexuality and people with I/DD and establish a framework that [“sexuality supports are a necessary and essential part of one’s life.”](#) Further, any sexuality education and resources must be available in more languages, including American Sign Language, for people with I/DD.

- 4. Mandate Sexuality Education for Agency Staff:** State Agencies for PWIDD must require sexuality education training for all staff. The inconsistency and lack of staff training in sexuality, coupled with challenges around family support, cause severe harm for people with I/DD. Participants in the Project SHINE initiative expressed the presence of substantial opposition to people with I/DD’s sexuality education by staff members, caretakers, and family. Staff who are improperly trained in how to handle questions regarding sexuality may inhibit an individual’s access to understanding their sexuality and exploring relationships. This lack of education may also prevent staff from recognizing signs of sexual assault and abuse.

- 5. Provide Culturally Appropriate Sexuality Education Supports for Families:** State Agencies for PWIDD must encourage family and caretaker education through providing accessible sexuality education and resources. This education must recognize the various language needs, including American Sign Language. Further, the approach of family education must prioritize the inclusion of families from different cultures and backgrounds.
- 6. Clarify Protocols and Policies Related to Sexual Consent Assessments:** To the extent that a sexual consent assessment is utilized by State Agencies for PWIDD or funded or certified provider agencies, State Agencies for PWIDD must develop a protocol to ensure that a consistent, impartial, and evidence-based tool is used for capacity to consent assessments. Further, any sexual consent assessment must reflect different relationship configurations to ensure that self-advocates from LGBTQIA+ communities are reflected.
- 7. Provide Safe Spaces for Youth to Have Facilitated Discussions Around Sexuality:** State Agencies for PWIDD must provide more safe spaces and facilitate discussions for topics around sexuality. Access to safe spaces to discuss sexuality topics is paramount to creating a trusted and open space for learning. Having access to more safe spaces, whether facilitated through a class, a counselor, or more agency staff members will provide a forum for people with I/DD to safely engage in conversations to explore sexuality and any related concerns or experiences.
- 8. Identify the Demographic Composition of Young People with I/DD Receiving Sexuality Education in Community-Based Settings:** State Agencies for PWIDD must prioritize identifying the demographic composition of people with intellectual and developmental disabilities across New York State between the ages of 16-24 who

are receiving community-based sexuality supports and services. An understanding of this demographic - and their geographic location - will allow State Agencies for PWIDD and service providers to understand their work, the demographic composition of the population, and what cultural approaches on issues of disability and sexuality should be considered. Identifying this demographic population will also clarify what gaps exist, and in what parts of New York State, for young people in providing sexuality supports and services.

- 9. Identify the Demographic Composition of Young People with I/DD Receiving Sexuality Education in Carceral Settings:** State Agencies for PWIDD must prioritize identifying the demographic composition of persons between the ages of 16-24 receiving sexuality supports and services within institutional, forensic, and other carceral settings.

*The project described is supported by grant number 1 TP2AH000068-01-00 from the HHS Office of Population Affairs. Contents are solely the responsibility of the authors and do not necessarily represent the official views of the Department of Health and Human Services or the Office of Population Affairs.*