

Comprehensive Sex Education for Youth with Disabilities

A Call to Action



Images courtesy of Alireza Attari, Cliff Booth, Cottonbro, Disabled and Here, Mikhail Nilov, Polina Tankilevitch, and Tima Miroshnichenko.

About the authors

Laura Graham Holmes, Ph.D.

Laura Graham Holmes, Ph.D., is an Assistant Professor at the Silberman School of Social Work at CUNY Hunter College. She has a Ph.D. in clinical psychology from the University of Utah and completed her internship and fellowship at the Children's Hospital of Philadelphia (CHOP) as a fellow of the interdisciplinary Leadership in Education for Neurodevelopmental Disabilities (LEND) training program and the CHOP Center for Autism Research, followed by postdoctoral fellowships at A. J. Drexel Autism Institute and the Boston University School of Public Health. For a decade, she has worked to bring awareness of the importance of sexuality and relationships to quality of life for people with disabilities. She conducts stakeholder-engaged research that connects processes at individual, family, community, and societal levels to life course outcomes with the goal of scalable sexual health interventions that improve people's lives.

SIECUS: Sex Ed for Social Change

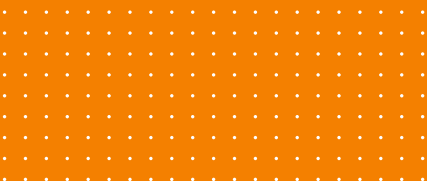
SIECUS: Sex Ed for Social Change has served as one of the national voices for sex education for 55 years, asserting that sexuality is a fundamental part of being human, one worthy of dignity and respect. SIECUS works to create a world that ensures social justice is inclusive of sexual and reproductive rights. Through policy, advocacy, education, and strategic communications efforts, SIECUS advances sex education as a vehicle for social change—working toward a world where all people can access and enjoy their own sexual and reproductive freedom.

Special thanks to Gabrielle Doyle, M.A, lead author for SIECUS. We also extend our deep appreciation to Leigh Ann Davis, M.S.S.W., M.P.A, Nora Gelperin, M.Ed., Peter Gerhardt, Ed.D., Mary Greenfield, Melissa Keyes-DiGioia, CSE, Katherine McLaughlin, M.Ed., Perryn Reis, Daniel Rice, M.Ed., John Santelli, M.D, M.P.H, and Katie Thune, M.Ed., for providing their support in the development and finalization of this publication.

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I.

Public Support for Disability Inclusive Sex Education



PHOTO BY
POLINA TANKILEVITCH



These organizations have voiced public support for disability inclusive comprehensive sex education.

Advocates for Youth

Advocates for Youth works to ensure the reproductive and sexual health and rights of young people. Many young people, especially those with disabilities, receive little or no formal sexual health education, either in school or at home. Yet all young people need access to and can benefit from sexual health information. Young people with disabilities have the same right to this education as their peers, with programs designed to share information in a way that is meaningful to them. Further, young people understand the need for inclusion of their peers with disabilities in advocacy for reproductive and sexual health and the need for justice for people with disabilities. That's why this toolkit is a huge achievement and a boon to our field. I'm grateful to Dr. Laura Graham Holmes & SIECUS for this publication and believe it will be of great use to many working on these issues.

Nora Gelperin, M.Ed.

*Director of Sex Education & Training
Advocates for Youth*

Answer

Answer commends SIECUS: Sex Ed for Social Change for their work on this report and for elevating this important conversation. With nearly 40 years of experience providing training for teachers and sexual health resources for young people, Answer knows the power of education and the impact that it can have on the lives of individuals. People with disabilities often face disparities in the services and resources they are offered. Perhaps the greatest challenge that exists in this area is that too many people do not acknowledge that people with disabilities are sexual beings. As a field, sex educators must do

more to ensure that access to high-quality instruction and resources are not treated as discretionary for those with disabilities, but rather as a human right. As with all sex education programs, we must begin by bringing people with disabilities to the table to engage in these conversations, and advocate for their right to this life saving information.

Daniel Rice, M.Ed.

*Executive Director
Answer*

Bryan Payne

With the passing of the California Healthy Youth Act in 2016, school systems across the state embarked on a search for a curriculum adoption that would meet the needs of all their learners. As a member of a school system evaluation team, I was looking for materials that were created with people with disabilities in mind from the outset. Instead, I found watered down versions of general education programs that gave little more than tips for adaptation, leaving individual teachers responsible for creating their own pacing, scope, sequence, and materials for a subject that most had barely taught. Our learners with the most challenges deserve curriculum with the most focus on their needs—instructional needs to improve their learning and content needs that recognize their lived experience of sexuality. Unpublished Justice Department data documented that women and men with intellectual disability experience sexual assault at a rate more than seven times that of those of people without disabilities in the United States¹. How are teachers supposed to prepare their students for life without educational programs that recognize their realities?

Bryan Payne, M.S.Ed.

*Curriculum and Instruction Specialist
Spectrum Center Schools and Programs*

Health Connected

As a comprehensive sexual health organization in California that has reached close to 250,000 youth, we know first hand the importance of inclusive education for all youth, including youth with disabilities. Our work led us to adapt our general education materials to better meet the needs of these youth whether mainstreamed or in special classes. We salute the work of SIECUS to bring to national attention to the disparities that these youth face and offer concrete recommendations to create a healthier world for all.

Perryn Reis

Associate Director

DeAnna Quan

Special Education Coordinator

Health Connected

Publishers of Teen Talk, Adapted for All Abilities

Katherine McLaughlin

Sexuality education must be inclusive of people with disabilities, and must also incorporate the disability movement's perspective of "nothing about us without us." Rather than tweaking an existing curriculum, we need to start at the beginning with people with disabilities at the table, telling us what they need and want, being self advocates, and being part of the design of materials, or being part of selecting an existing curriculum and becoming the instructors for other people with disabilities about sexuality and relationships. We as educators need to shift our thinking to go beyond adaptations to inclusive creation or selection of materials and implementation of programs and see people with disabilities as part of the solution.

Katherine McLaughlin, M.Ed.

AASECT Certified Sex Educator

Founder, www.elevatustraining.com

Mad Hatter Wellness & Sexuality for All Abilities

We at Mad Hatter Wellness and Sexuality for All Abilities fully support comprehensive sexuality education for people of all abilities. All people have the right to healthy and safe relationships. Unfortunately, there is a lack of appropriate education to support those relationships for people with disabilities. Sexuality for all Abilities is working to lower the high rate of sexual assault for people with intellectual disabilities by supporting sexual health for this population through conversations, education, and awareness.

Mad Hatter Wellness envisions a world that provides and promotes equitable health and wellness education for all people. Mad Hatter Wellness creates comprehensive sexual health education programming that educates, trains and empowers people with intellectual disabilities and their support systems. We appreciate and support the work SEICUS is doing to promote inclusive sexuality education for people with disabilities.

Katie Thune

Author of "[Sexuality for All Abilities: Teaching and Discussing Sexual Health in Special Education](#),"

CEO and Founder of Mad Hatter Wellness and Sexuality for All Abilities

Anna Hayek

Educator and Heart of Operations

Leah Bauman-Smith

Educator and Outreach Specialist

Organization for Autism Research

As noted by Waxman (1994), “No group in this country faces the sort of sexual and reproductive restrictions disabled people do; we are frequently [prevented from] learning about sexuality, having sexual relationships and having access to sexual literature”.² In practice, this means that sex education is usually provided only after an individual displays sexual behavior that is situationally inappropriate, problematic or potentially criminal in nature. A more appropriate and effective approach would be to address sexuality as just another instructional area, the teaching of which would allow youth and adults with autism and other disabilities to be safer, more independent and more integrated into their own communities. Not only are many youth left out of sex education, but there is little published data documenting empirically validated sex education content and processes for learners

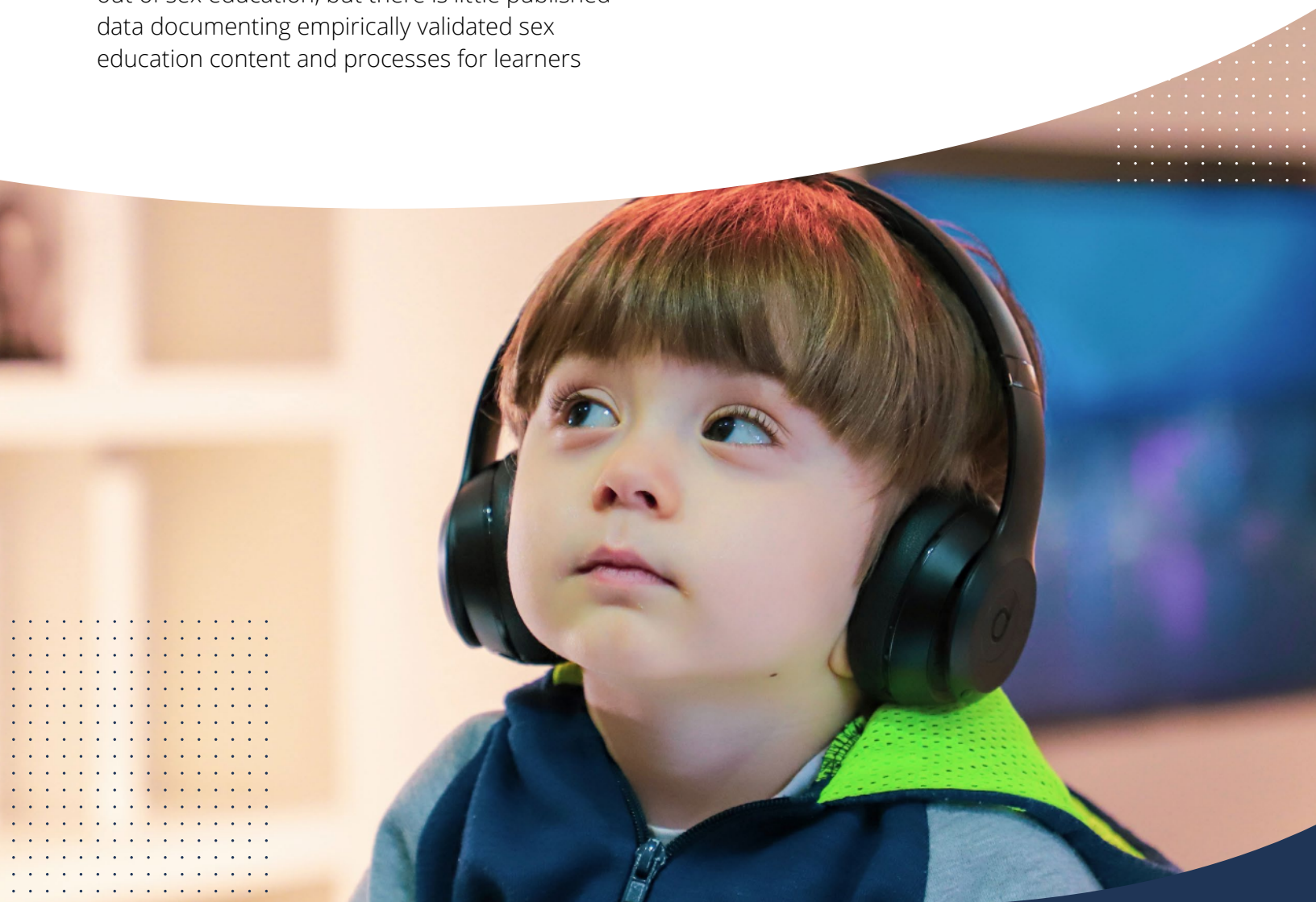
with intellectual disabilities.³ As such, the question can no longer be if sexuality education should be provided, but rather how it will be offered. OAR strongly supports the provision and research on the effectiveness of school-based sexuality education for learners with autism across the spectrum.

Peter Gerhardt, Ed.D.

Executive Director, The EPIC School

Co-Chair, Organization for Autism Research

Scientific Council

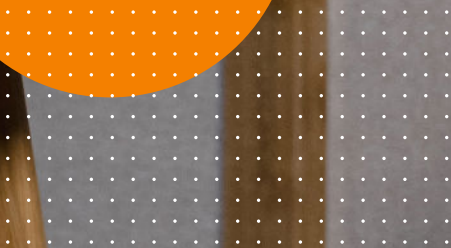


II.

Executive Summary

Youth with disabilities (YWD) need developmentally appropriate sex education to stay safe and healthy and to achieve self-determination.⁷ The United Nations Convention on the Rights of Persons with Disabilities, an international human rights treaty of the United Nations, states that YWD should be afforded the same range and quality of sexual and reproductive health services—including sex education—enjoyed by youth without disabilities. To date, school-based efforts toward inclusion and integration of YWD in classrooms and social activities has not extended to sex education. Further federal and state regulations are needed to ensure that YWD have access to free and appropriate public education on sexual health and can achieve health equity with their peers.

PHOTO BY
TIMA MIROSHNICHENKO



School-based sex education is one of the few sources of reliable sexual health information for young people.

This is especially true for YWD, who are less likely to learn about sexuality from their parents⁸ or healthcare providers⁹ and are often excluded from informal learning that occurs in peer social networks. Instead of receiving sex education from these social sources, YWD report learning about topics like sexually transmitted infections (STIs) and contraceptives from television/radio, the Internet, or even pornography.¹⁰ While the Internet can be an important source of sexual health information for young people, it requires direction to successfully navigate misinformation online. Lack of accurate information leaves YWD more vulnerable to sexual victimization or to being viewed as a sex offender and leads to difficulty achieving the healthy relationships that many desire.

The failure to explicitly mandate effective sex education for YWD may be partly due to myths that these young people lack the desire or maturity for sexual or romantic connection, will not attract sexual or romantic partners, are not subject to sexual abuse, and do not require sex education.^{11 12 13} Many YWD have their first relationship and sexual experiences during adolescence and early adulthood, similar to their peers.^{14 15 16} Data from the National Longitudinal Study of Adolescent to Adult Health (Add Health) shows that while YWD who have the most significant support needs are less likely to report sexual activity than youth with no disability, teens with mild to moderate physical disabilities report similar rates of sexual activity.¹⁷ Furthermore, YWD are at far greater risk for sexual abuse and exploitation.¹⁸ Compared to youth with no disability, YWD were more likely to report coercive sex (18.6% vs. 12.1%),

forced sex (13.2% vs. 7.9%), and sexual abuse (8.4% vs. 4.8%).¹¹ In a national study of youth Internet behavior, YWD reported more sexualized behaviors online than youth with no disability (20% vs. 13%) and more sexual solicitations from others (14%), including distressing solicitations (7%).¹⁹ In today's increasingly connected world, YWD (and all youth) must learn the principles of "yes means yes" enthusiastic consent, bodily autonomy, and self-advocacy. Being left out of sex education only makes YWD more vulnerable.

Disability is the intersection between an impairment that limits a person's movement, senses, or activities, and features of that person's society, including whether needed supports are provided and the extent to which disability is stigmatized.⁴ In 2016, over six million youths ages 6 – 21 were served by the U.S. special education system. These include students with learning disabilities, speech or language impairment, autism and Down syndrome, intellectual disability, attention deficit/hyperactivity disorder, mental health conditions, mobility limitations, cerebral palsy, spina bifida, and genetic syndromes (e.g., Fragile X). Youth with these disabilities have a broad range of support and learning needs that must be addressed. Intellectual and developmental disabilities (I/DD) are present at birth and affect the trajectory of a person's intellectual, physical, or emotional development. Many affect multiple body parts or systems.

Enthusiastic consent encourages people to make sure the person they are with is enthusiastic about the sexual interaction and wants to be there.

Bodily autonomy is the right to decide what happens to your own body without pressure from others.

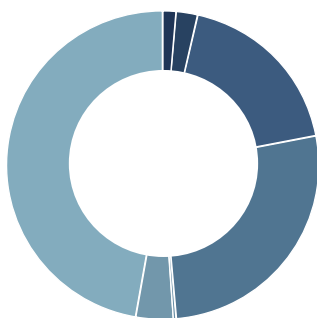
According to Individuals with Disabilities Education Act (IDEA) data from 2017, the U.S. special education system serves 6,130,637 students ages 6–21 years. Of these students:

4,018,474 (66%) are boys.

2,051,438 (34%) are girls.

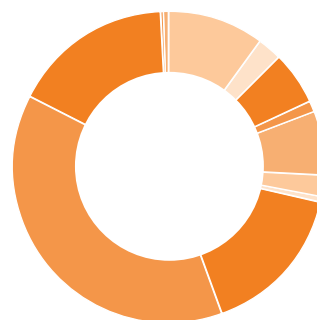
Transgender and gender non-conforming youth are not counted in IDEA data.

Students with disabilities by race and ethnicity were:



- American Indian or Alaska Native: 1.4%
- Asian: 2.4%
- Black or African American: 18.2%
- Hispanic/Latinx: 26.8%
- Native Hawaiian or Other Pacific Islander: 0.4%
- Two or more races: 3.8%
- White: 47.1%

Primary disability classifications for youth ages 6–21 years were:



- Autism: 10.1%
- Deaf-blindness: 0.02%
- Developmental delay: 2.6%
- Emotional disturbance: 5.5%
- Hearing impairment: 1.1%
- Intellectual disability: 6.8%
- Multiple disabilities: 2.0%
- Orthopedic impairment: 0.6%
- Other health impairment (includes attention deficit hyperactivity disorder (ADHD)): 15.8%
- Specific learning disability: 38.2%
- Speech or language impairment: 16.6%
- Traumatic brain injury: 0.4%
- Visual impairment: 0.4%

Components of effective sex education for YWD are inclusion in general education classes, accommodations similar to those supporting other learning, and specially designed curricula. For parents and educators, the implementation of age and developmentally appropriate sexuality content that YWD can understand and apply to their lives can be a challenge. Fortunately, effective curricula exist for all students with disabilities, including those with intellectual disability who have significant support needs. However, without guiding policies that support the rights of YWD to access sex education services and funding for schools to hire trained sex educators or purchase curricula, little can be done to ensure that a student's right to appropriate education and services will be realized. In a 2012 national survey of special education students who could answer survey questions on their own behalf, only 53.1% of YWD participated in sex education.²⁰

As renowned disability scholar Tom Shakespeare has said, "... Talking about sex and love relates to acceptance on a very basic level—both acceptance of oneself and acceptance by significant others ..."²² Sex education can create an atmosphere of openness and reveal the truth that YWD are sexual beings with the same desires as others, which can promote acceptance of differences.

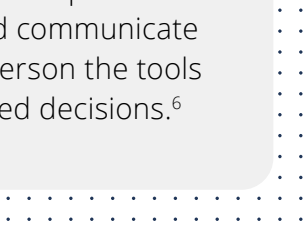
Through this publication, educators, policy makers, parents, and community members will be able to better advocate for the inclusion of YWD in sex education instruction. This will be accomplished through the implementation of advanced regulations and guidelines established at the local, state, and federal level to ensure YWD are afforded the same sex education experience as their peers without disabilities. Youth with physical disabilities and youth with cognitive and intellectual disabilities have unique barriers to receiving affirming sex education. While this publication includes youth with physical disabilities, it primarily discusses youth with cognitive and intellectual disabilities.

Comprehensive Sex Education

are programs that build a foundation of knowledge and skills relating to human development, relationships, decision-making, abstinence, contraception, and disease prevention. Ideally, school-based comprehensive sex education should at least start in kindergarten and continue through 12th grade. At each developmental stage, these programs teach age-appropriate, medically accurate, and culturally responsive information that builds on the knowledge and skills that were taught in the previous stage.⁵

Self-determination means having the freedom and support to make choices about one's own life and requires the knowledge and skills to advocate for oneself.

Supported decision-making means a person with disabilities chooses trusted advisors who help the person understand, consider, and communicate their choices, giving the person the tools to make their own informed decisions.⁶



What YWD or adults with disabilities have said about sex education experiences:

In qualitative research, YWD have talked about having limited sex education that rarely or never includes any mention of disability.



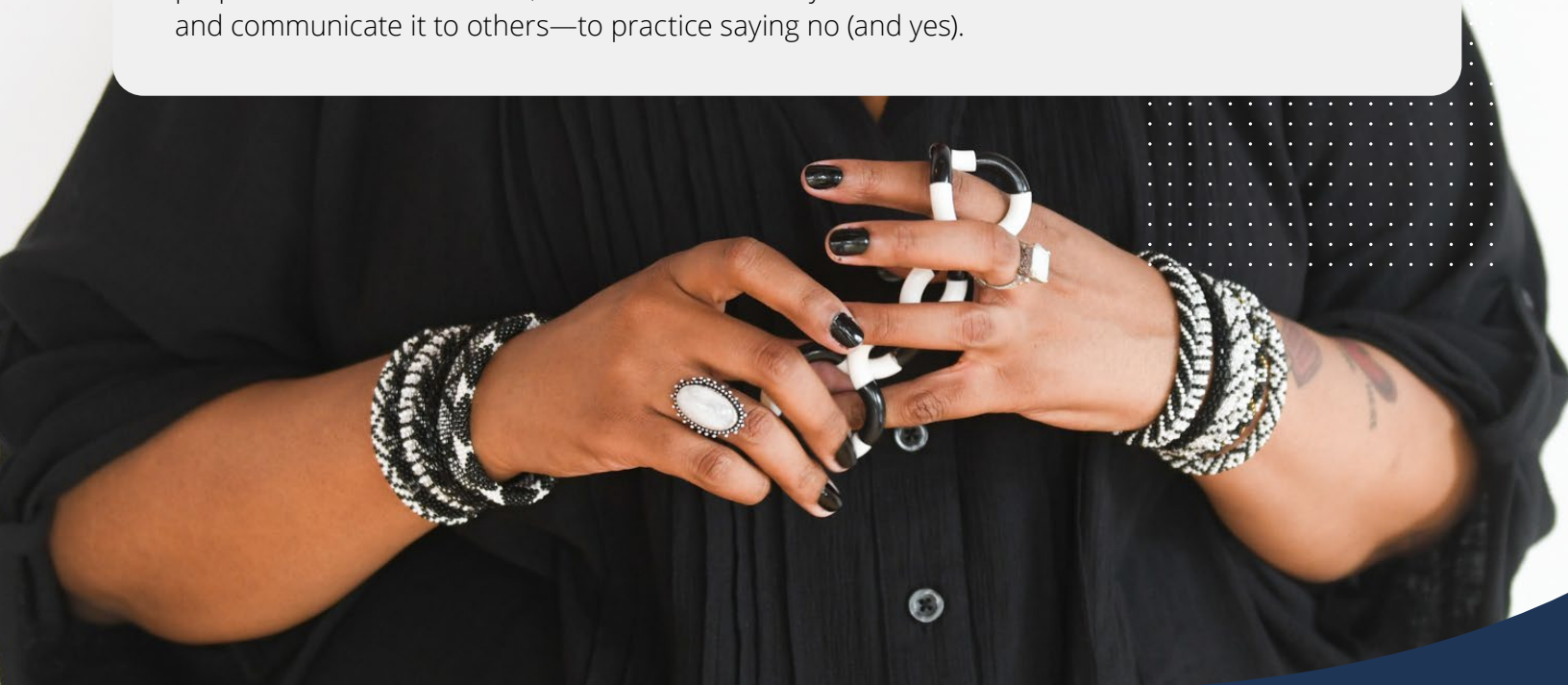
When it comes to sex education, individuals with disabilities are often left out of the conversation. Disability is messy, confusing, and sometimes painful, but so is sex, and we need the knowledge and tools to make the same choices as our non-disabled peers. To deny people with disabilities the opportunity to embrace our sexuality is to deny us part of the human experience. This is why it is so important to make sex education inclusive for all."

Amy Gravino

Autism sexuality advocate, international speaker

Major public health, medical, parent, and advocacy organizations are in favor of sex education for YWD, including the American Academy of Pediatrics, the Society for Adolescent Health and Medicine, The Arc, and the Organization for Autism Research.

Consent—asking permission—is for everyone. Safety is a basic need. YWD must learn their rights and responsibilities for communicating and respecting physical, emotional, and sexual boundaries. Some YWD are taught to accept that adults will touch their bodies to care for them, often without asking. Some adults with disabilities report long histories of invalidation of their physical or emotional needs or requests for accommodation. Others describe learning that the only way to get desired objects or privileges is to follow directions and please adults and authority figures. These experiences make YWD targets for sexual victimization, especially when combined with communication or other challenges that make it difficult for them to report perpetrators. In this context, educators can teach youth to listen to their own discomfort and communicate it to others—to practice saying no (and yes).



For YWD to experience comparable health benefits to peers, they need access to sex education, evidence-based teaching strategies, and social inclusivity. The inclusion of YWD in all parts of the educational curriculum—with appropriate accommodations so that students can understand the content—teaches other children that YWD are no different from themselves in terms of their basic humanity, need for social relationships, and rights to sexual health and safety. Educators can counter stereotypes about disability and emphasize the need for education, safety, and protection for all people regardless of disability status.

Disability inclusion benefits all students: Sex education that is disability-inclusive is important for everyone. Although 5.6% of 5–17-year-olds have disabilities, rates increase with age. According to the Center for Disease Control and Prevention (CDC), one in four U.S. adults—61 million Americans—have disabilities.²¹

Disability inclusion is a racial justice issue: Disability justice is a racial justice issue. Young people of color with disabilities need culturally responsive curriculum that is both affirming of their disability and taught in a manner that is informed by an understanding of racism and other structural barriers young people of color experience. Considering the impacts of white supremacy and ableism is crucial for ensuring that youth of color with disabilities receive adequate instruction.



III.

The Problem

Historically, oppression of people with disabilities has partly been due to eugenicists-induced fears about the effects of their reproduction on society. Their lives and humanity have been devalued, meaning they are not seen as people with the same relational and sexual needs as others. There is a long history of segregation and sexual suppression of people with disabilities. This has resulted in lingering myths and attitudes toward the sexuality of people with disabilities that still affect their access to appropriate services and social inclusion.²³

Research is needed on effective instructional practices for sex education for YWD.



PHOTO BY
DISABLED AND HERE

A. History of Sexuality and Disability in the United States

The United States has a dark and disturbing legacy in our treatment of people with disabilities. For most of our history, people with disabilities were isolated into institutions, neglected, abused, and denied the opportunity to contribute to their communities. This treatment was explicitly related to sexuality and reproduction. From the founding of our country in **1770** to the **1940s**, people with disabilities saw their humanity and sexual needs denied, their sexual behavior punished, and their ability to form relationships and reproduce curtailed through forced sterilization and isolation in homes or sex-segregated institutions.²⁴

As urbanization occurred in **1880–1940**, people with disabilities were more visible and became a target for eugenicists. Certain people believed that those with intellectual and developmental disabilities (IDD) were sexually promiscuous and able to have more children than others. Laws permitting involuntary sterilization spread to 32 states. Between **1907** and **1957**, around 60,000 people with disabilities were forcibly sterilized, some without their knowledge. After Americans learned about Nazi eugenics in the 1940s, support for forced sterilization declined, yet many such laws remained active into the 1970s.

Until the 1960s, many people with IDD resided in institutions that severely restricted romantic and sexual expression. Many institutions punished people who attempted to have heterosexual relationships or masturbate in private, while paradoxically accepting same-sex contact and inappropriate or public behavior as being part of disability or mental illness.¹⁶ Many people with physical and sensory disabilities lived

in communities, but discrimination often made it difficult for them to gain employment or even access to many buildings.

During the **1960s**, a civil rights advocacy movement on behalf of people with disabilities was bolstered by support from President Kennedy. Although the **1964** Civil Rights Act did not include people with disabilities, another movement—normalization—was spreading through institutions and other programs. People with IDD began to have opportunities to participate in the normal developmental tasks of childhood, adolescence, and adulthood. There was more recognition that each person had desires and could make autonomous decisions, and less restriction to interacting only with people of one's own sex. Healthcare providers and caregivers began to recognize “the dignity of risk”²⁵, setting the stage for acknowledgement of the right to sexual expression.

Beginning in **1967**, around 228,500 people with IDD and severe mental illness were moved from institutions into community placements.²⁶ Former residents were not taught about social norms and laws that govern sexual behavior and knew little about the basic facts of reproduction.¹⁶ It was clear that a national effort to train health-care and service professionals and to educate people with disabilities about their sexual health was needed.

Professionals' work to develop the first formal sex education curricula for people with disabilities was boosted by the **1975** passage of the Handicapped Children Act (now the Individuals with Disabilities Education Act), which mandated that all YWD have access to free and appropriate public education.¹⁶ The 1980s brought highly publicized cases of sexual abuse of people with disabilities, the advent of AIDS, and a focus on sexual offenses committed by people with IDD. Supporters of sex education for YWD focused on preventing the dangers of sexuality rather than promoting sexual well-being.

In **1990**, the Americans with Disability Act (ADA) was signed. The ADA is a civil rights law prohibiting discrimination against people with disabilities in public life: jobs, schools, transportation, and all public and private places open to the public. The ADA led many individuals with disabilities to realize greater opportunities and access public and private life domains previously closed to them. Many people with disabilities, including those with significant disabilities, are now integrated into meaningful work, education communities, and housing.

In **1998**, the Crime Victims with Disabilities Awareness Act was signed. A National Academy of Sciences report in **2001** showed that people with disabilities were at disproportionately higher risk of violent victimization and highlighted the limited evidence about crimes against people with disabilities who were being integrated into communities. The report eventually led to the addition of disability to the National Crime Victim Survey. In 2015, this data showed that the rate of

violent crime against people with disabilities was 2.5 times the rate of those without disabilities. Notably, people with disabilities were more likely to be victimized by people they knew, and they were as likely as people without disabilities to experience intimate partner violence. The highest rates of violence were found among people with cognitive or multiple disabilities and for youth ages 12–15.

In **2006** the United Nations Convention on the Rights of Persons with Disabilities endorsed that people with disabilities have the right to the same range and quality of sexual and reproductive health services enjoyed by non-disabled citizens.²⁷

In recent years, resources and curricula have been created to improve the sexual health of YWD.^{28 29} However, families and students with disabilities may not be aware of these resources and rarely have access to them.^{30 31} Furthermore, most states have no standard policy that ensures people have access to sex education in schools or community settings.²⁰ **Research is still needed on effective instructional practices for teaching YWD about sexuality.**³ There is much to be done before the United States has adequately met United Nations and World Health Organization standards.

B. Current State of Sex Education across the Country

For young people in the U.S., access to comprehensive sex education largely depends on their zip code. Only **60% of states** require schools teach any form of sex education, and the requirements vary wildly from state to state.³² Thirty-two states utilize abstinence-only-until-marriage (AOUM) programs when teaching about STIs/HIV, which do not allow teachers to provide information on contraception and condoms beyond their failure rates. **40% of states** don't require that sex education be based on evidence or be culturally appropriate for the intended audience.²⁶

Current policies exist at the state level to advance accessible educational curriculum for YWD. While advocates nationwide have worked to advance state policies and resources that further enhance access to sex education for YWD, many states continue to fall short in ensuring that their health curricula, including sex education, address the unique needs of YWD. Through the implementation of advanced curricula in Local Education Agencies (LEAs) that is culturally competent for YWD and aligns with the National Sex Education Standards, all students—regardless of ability—will have the knowledge to make informed decisions about their health and future.

Currently, **three** states explicitly include YWD within their sex education requirements. Further, **Illinois** mandates that individuals admitted to a developmental disability facility have access to sex education, and **Virginia** mandates that individualized education program (IEP) teams have access to guidelines established by the Department of Education that include age and developmentally appropriate instruction on sexual health and

personal boundaries. **Five** states have additional requirements that mandate health curriculum be accessible for YWD. **Six** states and the District of Columbia provide optional resources pertaining to accessible sex education curriculum for YWD. **36** states fail to include YWD in their sex education requirements or provide resources pertaining to accessible sex education curriculum for YWD. See Figure 1 in the appendix for a more detailed outline of state policies nationwide.

Federal Funding: Sexual Health Programs

At the federal level, there has been no funding allocated for comprehensive sex education. While the majority of control of sex education curricula exists at the state and local level, the federal government does control funding for many educational programs. Because of this, federal funding can impact sex education programs in local schools and communities. Over \$2.2 billion of federal funding has been wasted on failed AOUM programs over the past three decades. These programs have been found to be ineffective in delaying sexual intercourse or additional sexual risk behaviors³⁴ and utilize fear- and shame-based tactics that are often harmful to young people.³⁵

The CDC's Division of Adolescent and School Health (DASH) provides funding for HIV/STI and pregnancy prevention to local education agencies in 17 states (CDC, 2018).³⁶ DASH funds 28 LEAs to increase the ability of schools to provide students with advanced sex education, increased access to sexual healthcare providers, and safe and supportive environments.

Further, DASH funds 10 national organizations that aim to assist LEAs and build capacity for LEAs to provide HIV/STD and unintended pregnancy prevention efforts.

Two funding streams created in 2010 (the Personal Responsibility Education Program (PREP) and the Teen Pregnancy Prevention Program (TPPP) support evidence-based interventions that decrease teen pregnancy and STIs/HIV. PREP provides grants to implement complete, medically accurate, and age appropriate sex education programs based on evidence-based interventions (EBIs). There are currently 44 states in addition to the District of Columbia and six U.S. territories that receive PREP funding. TPPP has funded 84 five-year programs in 33 states to advance adolescent health and reduce unintended teen pregnancy. TPPP also requires programming to be based on EBIs.³⁷ In 2020, 49 new grantees were announced across 26 states to replicate teenage pregnancy prevention programs during the three-year project period through the TPPP Tier 1 grant.³⁸

While the above programs work to provide more comprehensive sex education to young people nationwide, gaps continue to exist in funding and programming to ensure YWD receive comprehensive sex education. The absence of a federal comprehensive sex education mandate, coupled with the current patchwork of state policies dedicated to ensuring young people receive comprehensive sex education, negatively impact young people nationwide. These policies are of particular concern for students with intellectual and developmental disabilities. YWD are frequently left out of sex education classrooms and conversations due to inaccurate stereotypes and assumptions³⁹ or due to the prioritization of other needed supports (e.g., occupational, physical,

or speech therapy). At times, YWDs are “included in the lesson,” but the content is not provided in a way that supports learning differences. All young people, including YWD, deserve access to sex education that is relevant to their learning, developmental, and socioemotional needs and affirms their identities.

Ensuring Highly Trained School Professionals

In 2019, the CDC released its [2018 School Health Profiles](#). These profiles measure school health policies and practices and highlight which health topics were taught in schools across the country through surveys. The report revealed that the median number of schools in which the lead health education teacher received professional development on teaching students with physical, medical, or cognitive disabilities increased from **40.6%** to **52.4%** over the past decade. This increase indicates a positive trend in ensuring educators receive the necessary professional development to educate YWD. Despite this increase, **less than half** of schools in 14 states provided this professional development between 2016 and 2018. Please reference [Table 2 on page 35](#) for a detailed list of the percentage of schools in each state who provided this professional development in 2018.

Disability Myths (adapted from Brodwin & Frederick, 2010)³³

Brodwin and Frederick are two rehabilitation counseling professionals who wrote about these disability and sexuality myths to help health professionals be aware of their own biases and provide holistic care.

MYTH: Disability is linked with sin, with sexual behavior that occurred outside of social norms deemed both a cause and an effect of disability.

MYTH: People with disabilities are asexual, lacking biological sex drive.

MYTH: People with disabilities are hypersexual and have uncontrollable urges.

MYTH: People with disabilities are sexually inadequate.

MYTH: People with disabilities are forever dependent and child-like, and therefore need to be protected.

MYTH: Sexual dysfunctions experienced by people with disabilities are always the result of the disability.

MYTH: People with disabilities cannot ovulate, menstruate, conceive, safely give birth, have orgasms, erections, ejaculations, or impregnate.

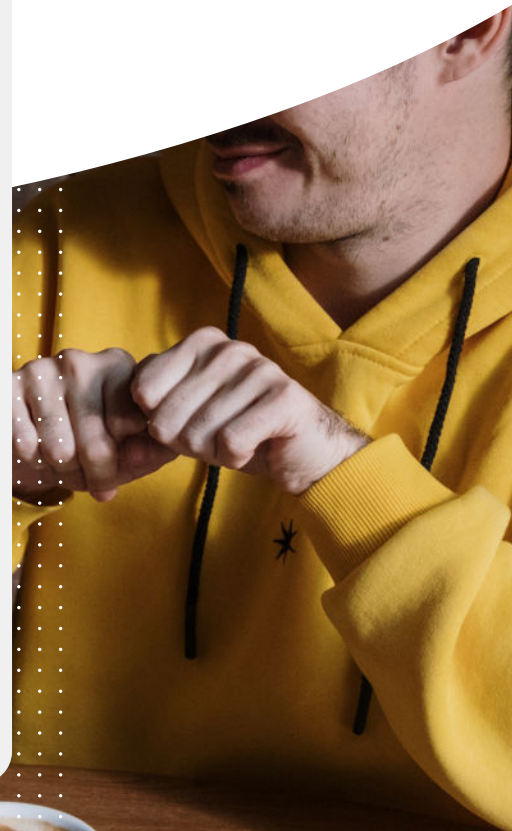
MYTH: People with disabilities inevitably have children with disabilities.

MYTH: People with disabilities should live with and marry other people with disabilities.

MYTH: People with disabilities are not capable of getting married or having children.

MYTH: If a person without a disability has a relationship with a person who has a disability, it is because something is wrong with them or they are settling for less.

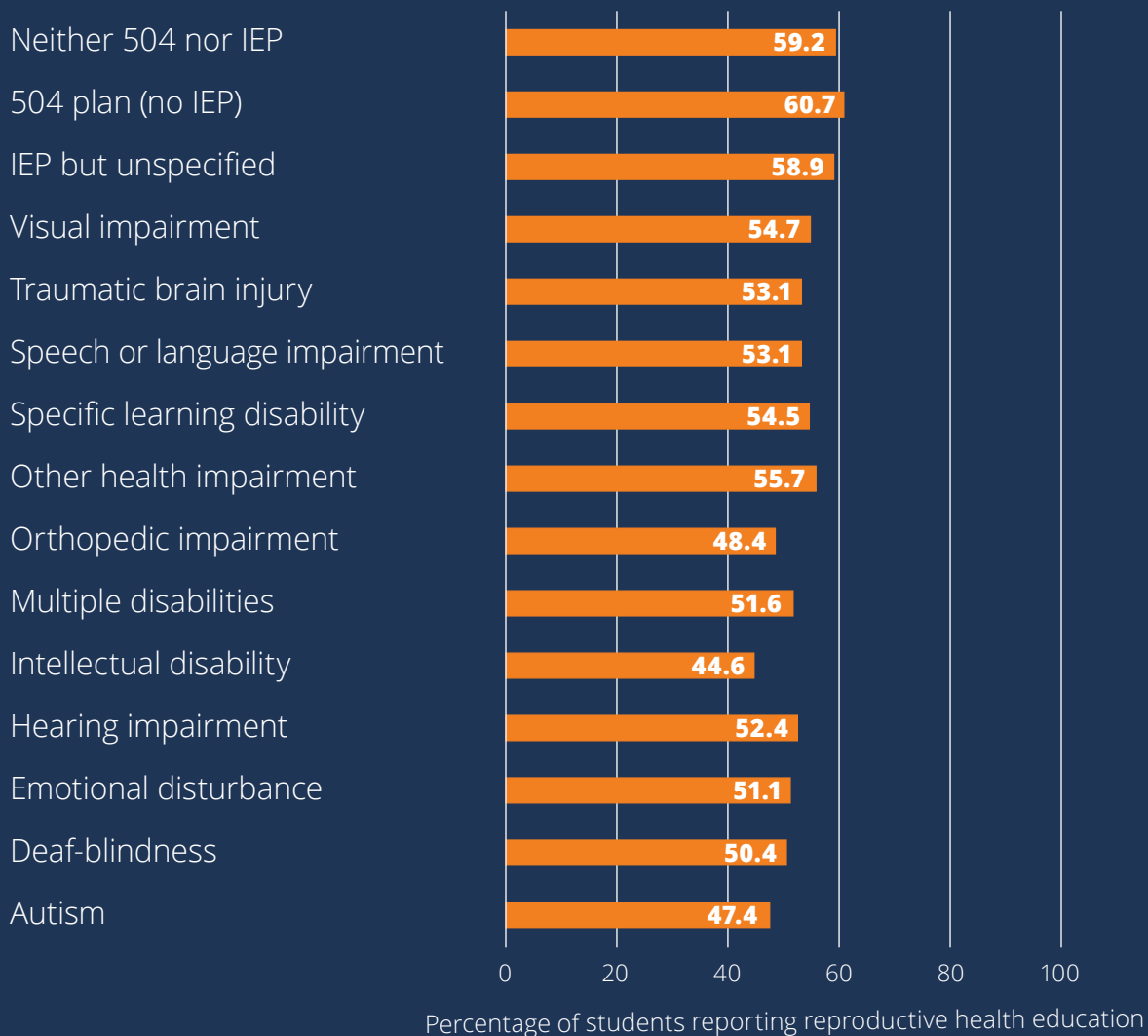
MYTH: If a person without a disability has a relationship with a person who has a disability, it is because they are exploiting the person with the disability.



IV.

Gaps in Sex Education

Figure 1. Receipt of reproductive health education among U.S. students able to self-report via interview



Source Figure 1: “National Longitudinal Transition Survey 2012” (NLTS-2012).
U.S. Department of Education, National Center for Education Statistics.

YWD are far less likely to receive sex education at school or at home compared to other youth.

Data from the National Longitudinal Study of Transition-2012 (NLTS-2012) show that even for YWD who can self-report (i.e., read, comprehend, and respond to questions), rates of reproductive health education are lower than for students who do not receive special education services. Those who do receive formal sex education at school may not receive appropriate accommodations.³¹ While some sex education curricula have been tailored to fit the needs of and be culturally responsive to YWD⁴⁰, this does not seem to be a common trend. Additionally, research into what kind of sex education YWD receive, how they feel about and engage with sex education, or even how many YWD receive sex education at all is sorely lacking. Researchers found that most curricula aimed at YWD are not evidence-based and that the few studies exploring sex education for YWD are incredibly vague when discussing the methods and topics covered by instructors.⁴¹

A report from the National Longitudinal Transition Study-2 (NLTS-2) showed that only 53.1% of youth age 14 and older served by the special education system had received reproductive health education. School staff who knew students well reported that an additional 29.6% could have benefitted from sex education yet did not participate. Unmet need for sex education was especially pronounced for African American and Hispanic youth, young people from low-income households, and those attending schools where greater than 25% of students were eligible for a free or reduced lunch.² Notably, this analysis represents a cohort from two decades ago, and there has been no further analysis of YWD inclusion in sex education using representative data. While there are dozens of studies on the effectiveness of comprehensive sex education

and student engagement in sex education, YWDs are left behind by current sex education research and curriculum. Some states have recognized these gaps and the resulting harm and have taken action. [Virginia](#) recently enacted legislation that requires the Department of Education to establish guidelines for IEP teams to use while developing IEPs for YWD to ensure that instruction on sexual health, self-restraint and protection, and respect for personal privacy and boundaries is age- and developmentally appropriate. [Illinois](#) enacted legislation requiring that individuals with developmental disabilities have access to sex education and resources through their institutional facilities that support their right to have healthy sexual practices free from sexual violence. [Colorado](#) requires sex education to be culturally sensitive to people with intellectual and physical disabilities, stating that the resources, references, and information included in sex education curriculum must be meaningful to YWD. [California](#) has a similar policy that requires instruction to be appropriate and accessible for YWD. While these states begin the work of filling in the gaps, more must be done across the country to ensure inclusive sex education for YWD. This may include the passage of local and state mandates that require curricula to be accessible to YWD and establish accountability measures, or the passage of federal legislation such as the Real Education for Healthy Youth Act (REHYA) that mandates comprehensive sex education for all young people. Additional states have gradually began introducing legislation that mandates inclusive sex education for YWD. Such policies include language that curriculum must be “appropriate for students regardless of gender, race, disability status, or sexual orientation.”⁴² While these progressive policies demonstrate much-needed action to further include the needs of YWD in sex education, further accountability procedures are needed to ensure such regulatory measures are enforced.

A. Exclusionary and Hostile School Environments for YWD

The inclusion movement and IDEA Act have ensured that many YWD are educated in classrooms with their peers without disabilities rather than in segregated settings. However, physical integration does not guarantee that YWD are accepted and socially included.²⁰

From preschool through graduation, YWD are at greater risk for bullying, have fewer friends, and are lonelier than their peers.^{43 44 45} Bullying and social exclusion are increasingly recognized as serious public health issues with potential for lasting effects on young people's psychosocial and academic development. Students who are bullied are at risk for school avoidance and absences; poor academic performance; loneliness and social withdrawal; low self-esteem; physical health problems; drug and alcohol use; and increased risk for depression, self-harm, psychotic symptoms, and suicidal ideation.^{35 46}

Although peer victimization receives more attention, social exclusion can be equally harmful. Youth need sustained participation in diverse social activities to develop relationships, skills, and competencies and to support physical and psychological health.⁴⁷

Social inclusion means meaningful involvement in society, the foundation for "overall well-being and becoming a valued and contributing member of the community."⁴⁸ For YWD, this means making friends, participating in school activities, engaging in leisure and play, and accessing high-quality inclusive instruction in the classroom. Including YWD in sex education and showing that people with disabilities have the same needs, desires, and hopes as any other person is an important part of changing school cultures that give rise to hostile and exclusionary environments.



Key milestones of adolescent development include attaining an adult body capable of reproducing, having and maintaining intimate relationships, managing a range of complex emotions, and independently thinking and problem solving. The successful attainment of these developmental goals by individuals with disabilities may be hindered directly by functional limitations or indirectly by intentional or unintentional social isolation."²⁶

McCabe, M.P. (1993). Sex education programs for people with mental retardation. *Mental Retardation*, 31, 377-387.



What does social inclusion mean for sex education?

YWD are included in general education classes to learn about sexuality and provided accommodations as needed so that the learning process is accessible and effective.

This gives all students the best chance to learn and teaches all students that people with disabilities are fully human and have the same needs, desires, and hopes as everyone else. YWD are included in all mainstream societal efforts to educate about sexual health.

YWD are represented in materials and activities. Pictures, vignettes, curricula, role plays—all can include YWD as people who are interested in and who have sex and romantic relationships. Just as materials should optimally not depict only white, cisgender, heterosexual individuals, they should not depict only individuals who do not have disabilities. Including YWD in materials and activities means that a broad range of cultures and a diversity of voices are included.

YWD (and all youth) learn self-advocacy, bodily autonomy, and consent. Many YWD are taught to comply with authority figures or that adults have the right to touch and examine them in intimate ways regardless of their own comfort.

Educators can prevent abuse and victimization by teaching about enthusiastic consent, and how people identify and communicate their own needs while negotiating the needs of partners. All youth must be taught how to report any sexual contact that makes them feel uncomfortable and to seek help. Furthermore, healthcare providers and other mandated reporters must follow through and report. See www.talkaboutsexualviolence.org for resources.

YWD (and all youth) benefit from role plays, interactive exercises, and concrete examples.

Using visual supports like pictures or videos is critical, and discussion of sexuality or relationships in popular media can be especially motivating. Use a show about a person with a disability—but make sure that YWD are never the butt of jokes or a punchline. Share news stories about real-life examples of people with disabilities in loving and healthy relationships.

YWD with alternative or augmented communication (AAC) devices are included in sex education classes. In order for educators to support these youth in the classroom, AAC devices need to be programmed with vocabulary on gender identity, sexual orientation, sexuality, and relationships. This means communication between educators and speech pathology staff to make sure this programming occurs. Youth must also be directly taught how to use specific vocabulary, particularly for saying no, reporting abuse, and for requesting more information about a topic.

YWD have intersecting identities. Effective sex education is inclusive of LGBTQIA+ youth and youth with different cultural and religious backgrounds.

YWD have representation and role models. The peer-to-peer model of sex education means people with similar characteristics (age, race/ethnicity, disability status) teaching each other about sexuality.⁴⁹ Well-trained peer educators can provide high-quality instruction and unique insights, and they can serve as role models for YWD.

Information about physical maturation and sexuality for YWD is taught regardless of whether youth with visible disabilities are present. At least one in five Americans will have a disability in their lifetime, and almost all people will experience chronic pain, illness, or disability with age. Navigating sexuality with a disability is therefore a near-universal experience. Including information relevant to those with disabilities (e.g., barrier methods available for those with mobility limitations) tells YWD to expect that they may one day have a sexual relationship and establishes people with disabilities as potential partners for other youth. YWD may not feel comfortable speaking up and asking questions. Know the basics and include them in instruction for all youth.



B. Racial Justice and YWD

Sex education provides a vehicle to tackle not only myths around disability facing YWD, but also the white supremacy supported by and entwined with ablest structures of oppression that specifically affect youth of color with disabilities. Racial justice, defined by Race Forward as “the systematic fair treatment of people of all races, resulting in equitable opportunities and outcomes for all,” can be advanced through quality comprehensive sex education (CSE) curriculums. CSE can and should address the harmful stereotypes many youth of color, including youth of color with disabilities, learn in sex education courses that see people of color (POC) as “risk factors” and problems that need to be solved. Current sex education courses frequently use materials that only represent white bodies and experiences, erasing the identities of youth of color and YWD who sit in those classrooms. CSE should act as a vehicle to further racial justice through examining and challenging these inaccurate representations, as well as the frequent lack of representation of POC in sex education classrooms, curricula, and policies.

Considering the impacts of white supremacy and ableism is crucial for youth of color with disabilities. The Individuals with Disabilities in Education Act (IDEA) requires that YWD receive the same quality of education as their peers. IDEA also includes provisions to ensure that young people of color are not diagnosed with disabilities at higher rates in order to police them through special education

programs. However, students of color are far more likely to be diagnosed with disabilities than their white peers⁵¹, and Black and American Indian/Alaska Native students are more likely to be diagnosed with intellectual disabilities and emotional disturbances⁵², playing into harmful racial stereotypes. These findings suggest that diagnosis has become a “tool of segregation” according to the ACLU⁴², used to keep students of color out of mainstream classes. This means students of color are even more likely to miss out on receiving comprehensive sex education, since YWD are denied access to these classes, which increases their vulnerability to sexual violence as discussed in the next section. Sex education for youth of color with disabilities has the potential to be liberational. Through the use of a racial justice framework, youth of color with disabilities will be treated not solely as disabled or as a youth of color, but as the intersection of all the parts of their identities. Sex education that is inclusive of YWD but ignores the additional barriers and specific needs experienced by youth of color does not provide relevant information, skills, or services for youth of color with disabilities and is therefore not truly inclusive. Every student deserves to be seen as a whole, with all of their identities acknowledged, and applying a racial justice framework is the more effective way for youth of color with disabilities to receive sex education that is pertinent to their lives.



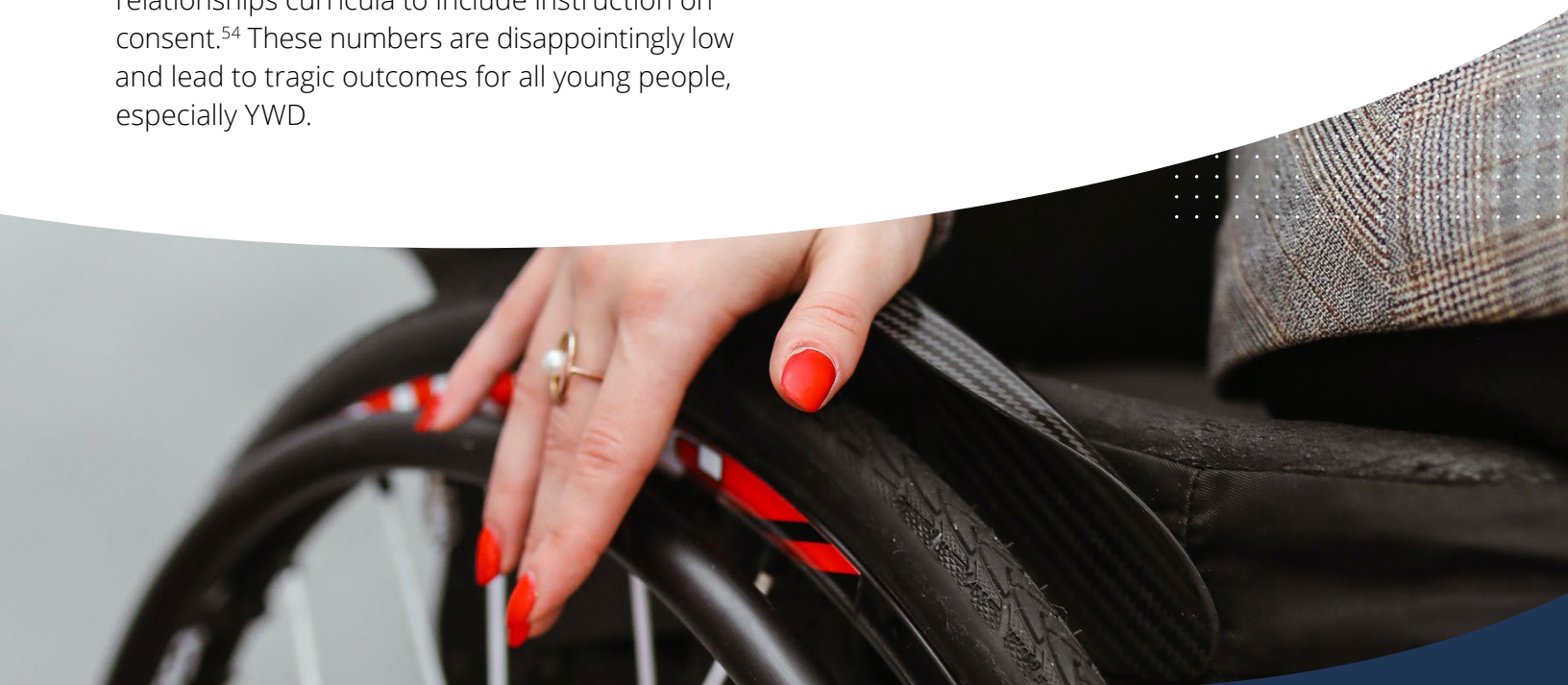
One of the most common forms of non-recognition in education is for a group to be generally left outside educational discourse by not being named or known. This form of non-recognition is often accompanied by an undercurrent of devaluation or condemnation (pg. 155).⁵⁰

C. Vulnerability to Sexual Violence

Sexual violence occurs on a continuum that includes sexual abuse, sexual assault, and other sexual crimes. “Sexual abuse” is mainly used to describe sexual behaviors toward children or vulnerable adults (e.g., the elderly, people with IDD). “Sexual assault” describes a range of unwanted sexual behaviors directed toward adults (e.g., unwanted kissing, touching, groping, or penetration). “Sexual violence” includes behaviors that are not criminal by law but are still harmful, such as false promises, insistent pressure, or reputational threats to coerce sexual behavior. The majority of people in the United States report never having learned about concepts like sexual assault and consent in middle school or high school.⁵³ While most sexual assault conversations focus on prevention in the workplace or on college campuses, we need to tackle this much earlier in a person’s life. Young people, including YWD, need to learn about the role of consent in preventing sexual violence, including respecting boundaries, asking before touching, and determining who to turn to if they feel uncomfortable. Thirty one states currently require sex education to include instruction on healthy relationships. Of these 31 states, only eight states require healthy relationships curricula to include instruction on consent.⁵⁴ These numbers are disappointingly low and lead to tragic outcomes for all young people, especially YWD.

Unfortunately, YWDs are at much higher risk of experiencing sexual abuse and violence than their peers without disabilities. Anywhere from 40% to 70% of girls with disabilities will experience sexual abuse before they turn 18, while up to 30% of boys with disabilities are at risk of sexual abuse during the same period.⁵⁵ Even more alarming is that girls with disabilities experience a higher risk of human trafficking than their peers, as they are more vulnerable overall to sexual exploitation and manipulation.⁵⁶

Researchers argue that this is likely because YWD do not know they have a right to bodily autonomy, may not recognize abuse, and may not know how to make a report or tell someone when they have been abused.⁵⁷ Unsurprisingly then, receiving ineffective sex education, or no sex education at all, is a correlating factor in the sexual abuse of YWD.⁴⁶ Organizations including The Arc’s National Center on Criminal Justice and Disability (NCCJD) and The Arc’s 600+ chapters provide resources on supporting child sexual abuse victims with disabilities and community-based sexual health and education services.⁵⁸



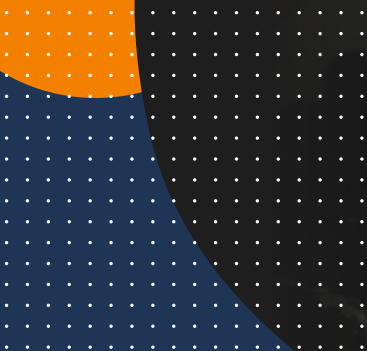
V.

Recommendations

By Dr. Laura Graham Holmes and SIECUS: Sex Ed for Social Change

Dozens of general recommendations could be made that would lead to better outcomes for all youth, such as requiring CSE for all students starting in kindergarten and eliminating funding for AOUM programs. These recommendations and more can be found within the [National Sex Education Standards](#), [Future of Sex Education collaborative](#), and the [Sex Education Collaborative](#). However, the following recommendations focus specifically on the needs of YWD.

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A. Policy Recommendations

- Approve and require curricula adapted or created for YWD that align with the National Sex Education Standards to be taught in LEAs.
- Emphasize use of curricula and materials developed by or in collaboration with diverse groups of people with disabilities, and in general follow the motto “nothing about us without us.”
- Research is needed on what makes sexuality and relationships education effective for diverse YWD. People with disabilities can contribute a great deal as equitable decision-making partners in this research.
- Include positive representations of disability in all aspects of CSE (e.g., curriculum, visual aids, models, activities, presentations, panels, instructors, etc.).
- Develop a grant program to fund public, private, and charter schools and school districts as they provide CSE programs for YWD. This includes effective training for teachers about how to use education materials.
- Develop a grant program to train, retain, and deploy people with disabilities as sexuality and relationship educators for YWD. Similarly, support peer-to-peer education programs that pay people with disabilities to educate others about sexual health and consent.
- Expand access to professional development for teacher and staff employed by facilities serving YWD to learn about developmentally appropriate CSE for YWD.
- Expand access to professional development for sexuality educators and school staff serving in this role to learn about the needs of YWD and developmentally appropriate CSE for YWD.
- Include YWD in definitions of cultural competence when drafting sex education policies.
- Recognize and support the autonomy of YWD in all policies affecting the population. Incorporate supported decision-making in sex education, therapy, and sexual violence prevention efforts.
- Mandate that YWD begin receiving sex education at the same time and as often as their peers without disabilities.
- Most experts agree that sex education should occur early and often. Base content on age rather than on developmental abilities. Disability impacts how content is taught but not what content is taught.
- The criminal justice system must learn about and use ADA law and accommodations, especially as it relates to the sexual health, rights, and relationships of people with disabilities.
- Training about YWD is needed for sex educators, sex therapists, sexual assault prevention staff, and sexual assault response teams (e.g., nurses).

Example State Legislation

While the regulatory language that is used in sex education concerning disability varies greatly depending on the state, states that include disability often address it in the same vein: by addressing the different student populations for whom the curriculum must be accessible. To advance sex education nationwide, advocates must take further action to ensure their state sex education requirements include affirming language that ensures YWD receive comprehensive sex education. [California Education Code § 51930-51939](#), known as the California Healthy Youth Act, offers an exemplary model other states may follow to advance sex education curriculum for YWD:



(d) (1) Instruction and materials shall be appropriate for use with pupils of all races, genders, sexual orientations, and ethnic and cultural backgrounds; pupils with disabilities; and English learners.

...

(3) Instruction and materials shall be accessible to pupils with disabilities, including, but not limited to, the provision of a modified curriculum, materials and instruction in alternative formats, and auxiliary aids."

While this policy offers a more advanced definition of inclusive sex education, states must continuously work to expand their policies to further include the needs of YWD. Further, educators and school officials must work to ensure that YWD begin receiving sex education at the same time and as consistently as their peers without disabilities.

In addition to implementing more advanced sex education policies that incorporate the needs of YWD, schools and districts must ensure educators and staff employed by facilities serving YWD receive substantial support in implementing developmentally appropriate comprehensive sex education (CSE) for YWD. This can be achieved through professional development training on educating students with cognitive and physical disabilities. Through the implementation of such trainings, educators will be appropriately equipped to teach sex education to students with a variety of needs.



B. In Practice

This section is an overview of some curricula available for teaching comprehensive sex education to YWD.

FLASH Lesson Plans for Special Education

A free curriculum for middle and high school students created by Seattle's Public School District, created by education and public health specialists and medical professionals (English). Updated in 2008-2011. Includes lesson plans for facilitators, PowerPoints, and useful appendices (e.g., letters to parents, assessment tools).

Making a Difference for Youth with Cognitive Impairments Set

A curriculum for high school students created for students with mild cognitive impairment, emphasizing postponing sexual activity. Includes facilitator guide, activity set (cards, posters, handouts), curriculum DVDs. English, \$299.

Sexuality Education for People with Developmental Disabilities

A curriculum for high school students and adults with intellectual and developmental disabilities created by Katherine McLaughlin, MEd (elevatus.com). Includes a facilitator manual with tips for common challenges, curriculum with 22 lesson plans including handouts and teaching tools, and prompts for allowing participants to practice skills like understanding public and private situations. Covers internet safety, social media, gender identity and expression, and abuse prevention. English, \$299.

Sexuality for All Abilities

Sexuality for all Abilities is curriculum developed for and used by special education teachers to provide sexuality education to students primarily with cognitive delays, rigid thinking patterns, impulse control issues, developmental delays, and processing issues but can be used for students of all abilities. This curriculum was created using universal design principles. This curriculum breaks down the heart of what is most important for all students to understand about healthy relationships and sexuality. The pacing of the curriculum can be adjusted according to needs of the students in the class. There are built-in accommodations and modifications to the curriculum, as well as a section for frequently asked questions and areas of possible confusion. Sexuality for All Abilities targets areas of transition that can be used to support student IEP goals such as teaching self-advocacy, personal safety, healthy relationships, and public and private behaviors.

The Safety Class

The Safety Class, which is an interactive, structured, eight-session, weekly face-to-face group program facilitated by the Rural Institute (RI), was found feasible for implementation in an efficacy study. Working in partnership with the intellectual disability community through all phases of the project helps ensure the relevance, inclusion, and accessibility of The Safety Class.⁵⁹

Other resources available at <http://www.med.umich.edu/yourchild/topics/disabsex.htm>



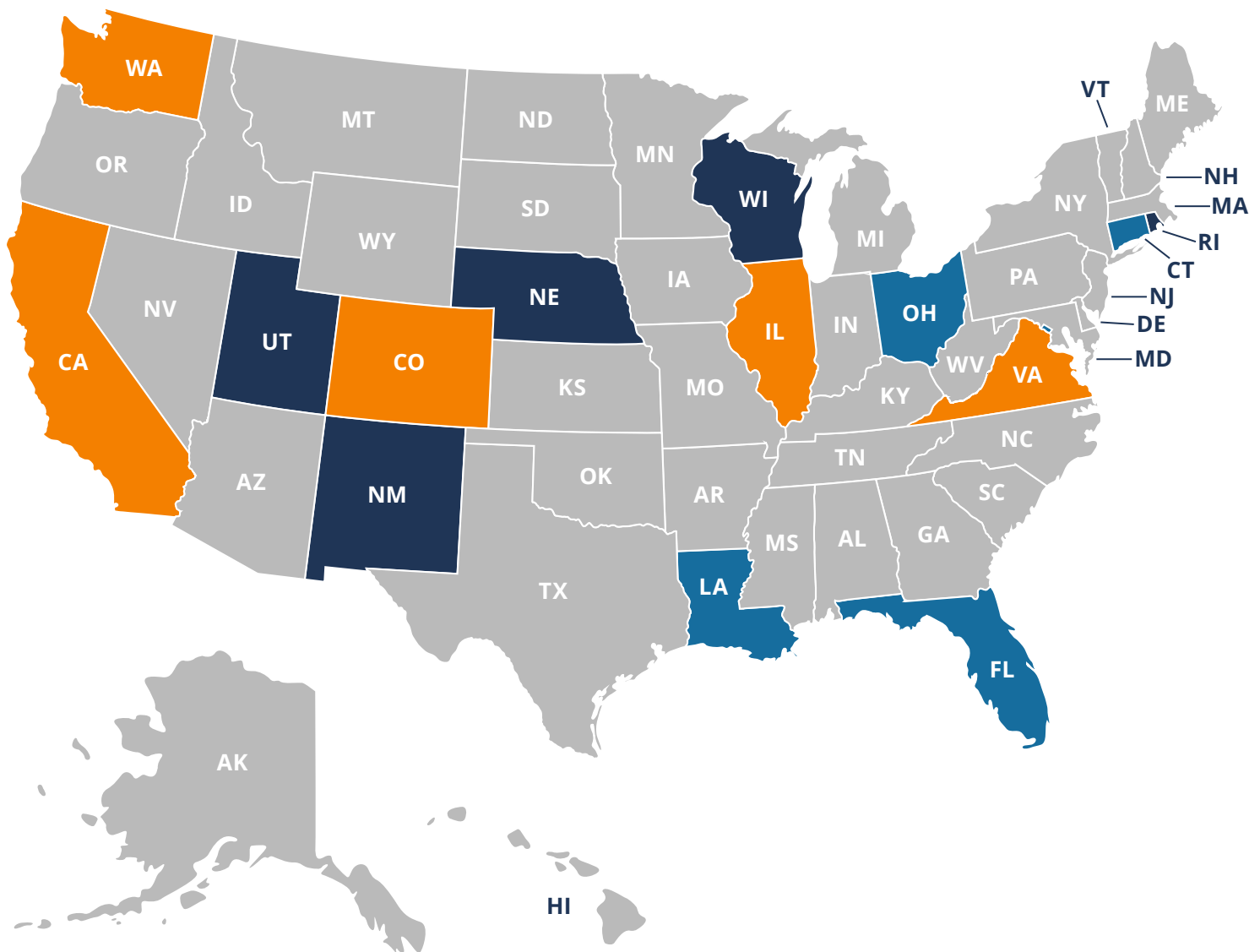
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Appendix



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Table 1: State Laws, Policies, and Resources Related to Accessible Sex Education



Key:

- Sex Education Must be Accessible
- Health Education Must be Accessible
- State-Provided Resource (guidelines not enforced by law)

Accessibility notes:

Connecticut

State-Provided Resource

Connecticut's Guidelines for the Sexual Health Education Component of Comprehensive Health Education include advanced discussion of sex education for students with disabilities.

District of Columbia (D.C.)

State-Provided Resource

D.C.'s 2017 Sexual Health Curriculum Review's Health Education Curriculum Analysis Tool and Physical Education Curriculum Analysis Tool are designed to be appropriate for students regardless of disability.

Florida

State-Provided Resource

Florida's 2014 Next Generation Sunshine State Standards-Health Education include access points for students with significant disabilities. However, the standards do not have the force of the law.

Illinois

Sex Education Must be Accessible

Individuals admitted to a developmental disability facility in Illinois must have access to sex education and related resources according to Public Act 101-0506.

Louisiana

State-Provided Resource

The 2011 Louisiana Health Education Handbook states that quality health education provides guidance for maintaining a healthy lifestyle for all individuals, including those with disabilities.

Nebraska

Health Education Must be Accessible

The Nebraska Health Education Framework states that schools must accommodate a diversity of student abilities, disabilities, cultural backgrounds, interests, and other factors that affect student performance in school.

New Mexico

Health Education Must be Accessible

New Mexico Administrative Code § 6.31.2.7 defines general education curriculum as the "same curriculum that a public agency offers for non-disabled children. For New Mexico public agencies whose non-special education programs are subject to department rules, the general curriculum includes the content standards, 6.31.2 NMAC 3 benchmarks, and all other applicable requirements of the Standards for Excellence (Chapter 29 of Title 6 of the NMAC) and any other department rules defining curricular requirements." Administrative Code § 6.29.6, which defines the Health Education Standards for Excellence, includes sex education.

Ohio

State-Provided Resource

Ohio's Learning Standards—Extended for Science include topics related to sex education.

Rhode Island

Health Education Must be Accessible

Rhode Island's [Rules and Regulations for School Health Programs](#) state that health education instruction and materials shall be age appropriate for use with students of all races, genders, sexual orientations, ethnic and cultural backgrounds, and students with disabilities. Rhode Island schools are required to include Family Life and Sexuality in their health education course.

Utah

Health Education Must be Accessible

Utah [Administrative Code R277-700-7](#) requires a student with a disability served by a special education program to demonstrate mastery of the Core Standards. This includes the Utah Core Standards for Health Education, which mandates sex education.

Virginia

Sex Education Must be Accessible

Enacted in 2020, the Virginia Department of Education must establish guidelines for IEP teams to use while developing IEPs that include age and developmentally appropriate instruction on sexual health and personal boundaries.

Washington

Sex Education Must be Accessible

Washington's [comprehensive sex education mandate](#) requires sex education to be accessible to all students regardless of their protected class status under [chapter 49.60 RCW](#).

Wisconsin

Health Education Must be Accessible

Wisconsin [Statute § 118.019\(2d\)](#) prohibits human growth and development instruction from discriminating against YWD.

State-Provided Resource

Wisconsin's [Human Growth and Development: A Resource Guide to Assist School Districts in Policy and Program Development and Implementation](#) includes 10 tips and recommended resources for talking about sexuality with children who have developmental disabilities.

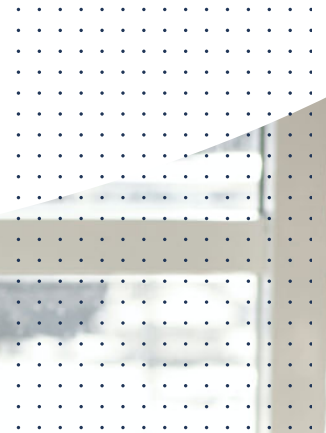
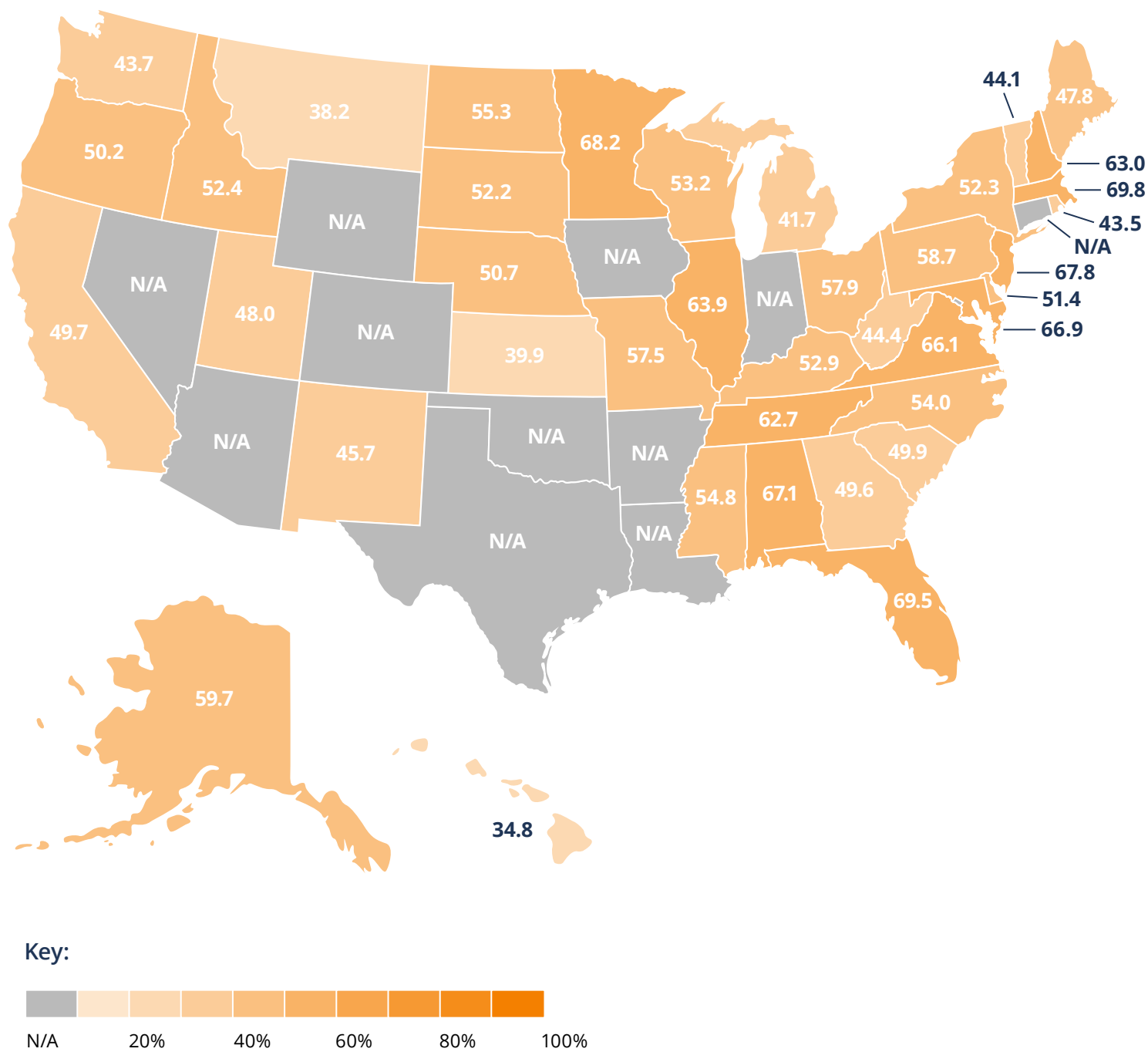


Table 2: Percentage of Secondary Schools in Which the Lead Health Education Teacher Received Professional Development During the Two Years Before the Survey on Teaching Students with Physical, Medical, or Cognitive Disabilities According to the 2018 School Health Profiles

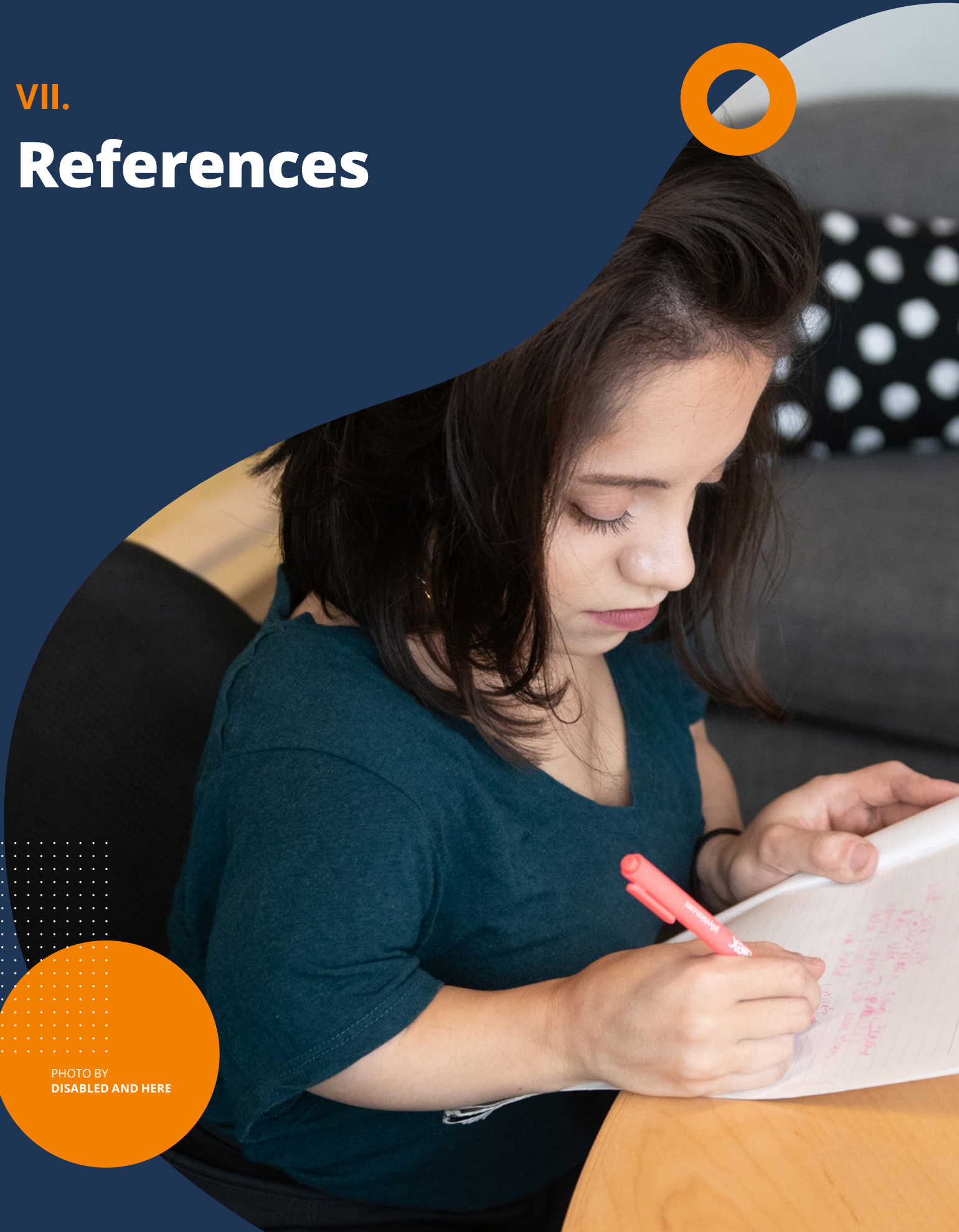


VII.

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