REVIEW OF DISABILITY STUDIES: AN INTERNATIONAL JOURNAL
Vol. 19 Issues 3 & 4 (2024)

The Right to Love and Be Loved:

Sexual Health Education for Students with Intellectual and Developmental Disabilities

Anne Stair[1] and Andrew Roach[2]

[1]Cherokee County School District, Georgia

[2] Department of Counseling & Psychological Services, Georgia State University

Abstract

Although there has been notable progress in educational inclusion for students with intellectual and developmental disabilities (I/DD), they generally receive inadequate sexual health education. This paper outlines the historical factors for this gap, current practices in sexual health education, and related outcomes for this group of students.

Keywords: sexual health education, intellectual and developmental disabilities, social connection

The Right to Love and Be Loved:

Sexual Health Education for Students with Intellectual and Developmental Disabilities

People with disabilities and their families have experienced a long history of discrimination, mistreatment, and exploitation. The fight for social justice and civil rights for individuals with disabilities has resulted in legislation providing legal protections, especially with regards to education and employment (e.g., Americans with Disabilities Act [ADA], 1990; Individuals with Disabilities Education Act [IDEA], 2004; The Rehabilitation Act, 1973). These legislative acts have promoted significant positive changes in the way people with disabilities access public spaces, receive healthcare, and participate in education. However, there remain notable opportunities for improvement across a variety of life domains. This is especially true regarding sexual health education because people with disabilities often report diminished opportunities to engage in intimate relationships and increased risk for sexual abuse and assault.

The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (American Psychiatric Association, 2013) defines intellectual disability (ID) as a disorder that includes deficits in intellectual and adaptive functioning that have been observed since early childhood. Similarly, IDEA defines ID as “significantly subaverage general intellectual functioning, existing concurrently with deficits in adaptive behavior and manifested during the developmental period” (IDEA, 2004). In both the DSM-5 and IDEA definitions, intellectual functioning encompasses mental abilities such as reasoning, problem solving, planning, and abstract thinking. Conversely, adaptive functioning includes the skills needed for daily living such as communication, social skills, and self-care in home and community settings.

Developmental disabilities are a larger group of conditions typically identified in early childhood that persist throughout the lifespan; ID is one common form of developmental disability. Developmental disabilities often include impairments in physical, learning, language, or behavioral functioning. These impairments may adversely affect day-to-day functioning and require supportive services and intervention (Zablotsky et al., 2019). It is estimated that one in six children in the United States has been diagnosed with a developmental disability, and approximately 1.48% of male children and 0.90% of female children are diagnosed with an ID (McPartland et al., 2016; Zablotsky et al., 2017).

Due to the noted cognitive and adaptive functioning concerns experienced by people with intellectual and developmental disabilities (I/DD), they can encounter barriers to developing and maintaining intimate relationships, despite experiencing the same desire for intimacy and romance as their typically developing peers (Sala et al., 2019). Moreover, people with I/DD are too often presumed to be asexual or disinterested in meaningful interpersonal and sexual relationships, despite sexual expression being a significant part of human development and well-being (Treacy et al., 2018). As Ladau (2021) notes, individuals with disabilities are frequently viewed as “childlike, breakable, undesirable, damaged goods who are unfit to be sexually active or sexualized” (p. 134). In fact, individuals with I/DD frequently indicate a desire to establish meaningful interpersonal connections, while also confirming they have trouble finding romantic partners and maintaining intimate relationships (Schaafsma et al., 2017).

Considering these challenges, the American Association on Intellectual and Developmental Disabilities (AAIDD) and the ARC released a joint position statement indicating that people with I/DD have “inherent sexual rights that must be affirmed, defended, and respected” (AAIDD, 2008). Similarly, Articles 23 and 25 of the Convention of the Rights of Persons with Disabilities (CRPD) outline the rights of people with disabilities to access information, education, and medical supports needed to facilitate their sexual and reproductive health (Perez-Curriel, et al, 2023). Moreover, Individuals with I/DD have the right to engage in safe, fulfilling interpersonal relationships (VanDyke, McBrien, & Sherbondy, 1995). In short, healthy sexuality and intimate relationships are a consideration in establishing satisfactory quality of life; conversely, experiences of social isolation and loneliness are consistently associated with diminished physical and emotional well-being (Pitonyak, 2003).

Disability Rights and Legislation

People with disabilities have a long history of being excluded from and ostracized in community settings. Changes with regards to the treatment and perceptions of people with disabilities have occurred primarily due to the activism of people with disabilities and their families. The Rehabilitation Act was passed in 1973, providing protection against discrimination in federal programs and services, as well as any program or service receiving federal funding. In 1990, the Americans with Disabilities Act (ADA) expanded discrimination protections for people with disabilities and clarified that they have the same rights and opportunities as others to participate in public life. These rights extend to employment, school, transportation, and all public and private places.

Public Law 94-142 (P.L. 94-142) passed in 1975, guaranteeing a free and appropriate education to all children with a disability (U.S. Department of Education) Passage of P.L. 94-142 provided protection and support for children and adolescents with disabilities who had been excluded completely from the public education system. As outlined in the law, all schools receiving federal funding need to accommodate the needs of the students with disabilities, including providing appropriate instructional materials and supports. The Individuals with Disabilities Education Act (IDEA), originally passed in 1990 and reauthorized in 2004, is considered landmark legislation that ensured students with disabilities had the same rights as their peers without disabilities (IDEA, 2004). Of note, the commitment to provide students with disabilities access to a free and appropriate public education (FAPE) through special education services was reaffirmed by IDEA 2004. These services are developed to meet their individual needs with the goal of further education, employment, and independent living. Per IDEA 2004, the effectiveness of education interventions and supports must be assessed or evaluated. and that evidence-based practices must be used in teaching students with disabilities (SIECUS, 2014). Given these legislative provisions, implementation of a comprehensive sexual health education program to teach students with I/DD about sexuality and healthy relationships is not only supported by research, but one could argue is also mandated by federal law.

Unfortunately, most middle and high school students with I/DD do not receive adequate education regarding sexual health and intimate relationships. In fact, the sexuality of young people with I/DD it too often perceived as troublesome behavior that must be modified or extinguished, instead of being viewed as typical expression of the human need for intimacy (Sala et al., 2019). Further, parents/guardians of youth and young adults with I/DD generally report they want to provide this education to their children but often avoid the topic due being unsure about what to talk about, when it is appropriate to talk about it, and how to modify information about relationships and sexuality so that their children will understand the concepts (Frank & Sandman, 2019).

Education about healthy relationships and sexuality is essential due to increased risks experienced by the I/DD population, including sexual assault, interpersonal violence, and victimization (Ward et al., 2013). For example, the United States Department of Justice reported that people with I/DD are sexually assaulted at a rate seven times that of people without disabilities (Inskeep, 2018). The U.S. Justice Department also disclosed that it estimated between 68% and 83% of women with I/DD have been sexually assaulted (Murphy & Elias, 2006). Further, researchers have consistently indicated that children with I/DD are at increased risk for sexual abuse as compared to typically developing peers. For example, Sullivan and Knutson (2000) reported that children with ID were four times more likely to be sexually abused than children without ID. Similarly, Skarbek et al. (2009) reported that children with disabilities are 3.4 times more likely to be sexually abused than children without disabilities. An increased risk for being victims of sexual violence also has been documented for adolescent girls with physical disabilities or persisting health problems

(Treacy et al., 2018). Taken together, these data demonstrate that students with disabilities (including those with I/DD) are significantly more likely to experience sexual abuse or assault (Alriksson-Schmidt et al., 2010). Education regarding healthy relationships, biological functions of their bodies, and sexuality is imperative for people with I/DD to understand and protect themselves (Treacy et al., 2018).

Social Connections and Social Support

Research also demonstrates that people with I/DD have smaller social networks that often consist of mostly family members and support staff. People with I/DD report social relationships and feelings of connectedness are missing from their lives, resulting in social isolation and loneliness (Emerson & McVilly, 2004; Knox & Hickson, 2001). Froese et al. (1999) reported that 81% of participants with ID in their study expressed a desire for more friendships and 65% reported wanting a chance to develop a “best friend” relationship. In terms of intimate relationships, Blum at al. (1991) indicated that over 70% of their study’s participants with developmental disabilities endorsed a hope to get married, although only 7% of respondents reported having the opportunity to maintain a consistent relationship with a close friend. In accordance with these findings, participants in a study completed by Robertson et al. (2001) stated their friendship networks consisted of approximately two people, excluding service providers. Similarly, Ward et al. (2013) found that participants had a social network consisting of approximately four people, and that number often included professionals who worked with participants. These studies reflect the critical need for people with I/DD to develop the skills to initiate and maintain close interpersonal relationships.

Social inclusion is a broad construct that may be more easily defined by what it is not: the exclusion of others based on specific characteristics such as race, gender, socioeconomic status, or disability. Inclusion of youth with I/DD requires removal of barriers and provision of supports to allow them to participate in all areas of life to their full capacity. Adolescents with disabilities often experience challenges with social inclusion including difficulties making friends; limited opportunities to engage in leisure, play, and community activities; and diminished social interactions in the classroom setting (Frazee, 2003; Koller et al., 2018). Consistent with these findings, Pijl et al. (2008) reported that up to 25% of students with disabilities were rejected by their peers, did not have friends, and did not engage with a subgroup within their class as compared to only 8% of their peers without disabilities. Students with disabilities are at increased risk for social isolation and bullying, both of which result in a variety of poor outcomes (Koster, et al., 2010). Social isolation and bullying can lead to a diminished sense of school belonging, obstacles to participation in social activities, poor motivation, low self-concept, and difficulties in academic performance (Asher & Coie, 1990). While these concerns are relevant for any student experiencing peer rejection, students with I/DD appear to be particularly vulnerable.

Although they experience challenges around social inclusion, it also appears that adolescents with I/DD do identify peers in their class or school as being their friends. Matheson et al. (2007) found that being in the same class or school was an important defining characteristic of a friendship. This becomes problematic for students with disabilities as they leave K-12 education and experience loneliness associated with this transition period (Foley et al., 2012). Unfortunately, Snowdon (2012) reported limited integration and social supports were in place for adolescents with disabilities as they grow into adulthood. Services for this population generally focused on outcomes related to employment, postsecondary education, and community inclusion, but did not address other aspects important to quality of life such as friendships, dating, and intimate relationships (Carter et al. 2010; Haber et al. 2015).

Biggs and Carter (2016) found that parents of transition-age youth with I/DD reported lower ratings of their child's psychological well-being (e.g., feelings of positive emotions and satisfaction with life) and social support/peer relationships (e.g., quality of interaction and support between the child and peers) compared to typically developing peers. Among participants in Biggs and Carter's study, the lowest rated life domain was social support and peer relationships. Similarly, in a study conducted with young adults aged 17 to 20 years, participants with ID reported that their most significant worries included being bullied, making and keeping friends, losing a caregiver, and not being successful in life (e.g., passing driving tests). In comparison, their peers without disabilities reported that their most significant worries included getting a job, lack of extra money, failing, and making decisions that would affect their future (Forte et al., 2011). Implementation of effective interventions to support the development of interpersonal skills and relationships is critical not only for school-age children with I/DD, but for transition-age youth as well. Thus, as they transition through the lifespan, development of the skills necessary to form and maintain friendships and intimate relationships is imperative for the overall mental and physical health of people with I/DD.

Sexual Health Education in the United States

Sexual health education in the United States has evolved into two different approaches: abstinence-based sexual health education and comprehensive-based sexual health education. These two approaches affect how sexual health education looks in practice. For example, dependent upon the approach, the role and type of sexual health education in schools can vary with regards to how much time is devoted to various topics and the breadth of content covered. Approaches to sexual health education generally are guided (and sometimes mandated) by federal and state funding. Specifically, if funding sources endorse abstinence-based approaches, then the enacted curriculum will be in line with this orientation.

The history of abstinence-based education can be traced to beliefs about the need to reform sexual sin in the United States and England in 1724 with the publication of *Onania*, a written work referencing the Bible and "the sin of wasting man's seed" (Treacy et al., 2018, p. 67). This work has been attributed with influencing cultural views and laws prohibiting masturbation and oral sex and viewing sex as a sin against God to be performed only for procreation (Cornog & Perper, 1996). These beliefs influenced political campaigns, educational practices, and public health efforts during the 1800s. Social reformers (e.g., Sylvester Graham and John Kellogg) suggested sexual activity was immoral and separately authored anti-masturbation literature to be disseminated to the public during this time (Carter 2001; Cornog & Perper, 1996). Consistent with this theme, the National Education Association (NEA) passed a resolution supporting "moral education" in schools in 1892 (Treacy et al., 2018). Negative views of sexuality persisted well into the twentieth century and continue to play a part in culture, laws, politics, values, and norms in the United States.

Margaret Sanger, the founder of Planned Parenthood, also played a significant role in the early beginnings of comprehensive sexual education. Sanger, a nurse, opened the first birth control clinic in the United States in Brooklyn, New York in 1916. She published the first scientific journal about contraception, the *Birth Control Review*, and opened the Birth Control Clinical Research Bureau in Manhattan, the mission of which was to make contraception available to women and to collect data in order to improve the safety and effectiveness of the contraceptive devices being provided (Treacy et al., 2018; Cornog & Perper, 1996; Planned Parenthood, 2014).

Following Sanger's work in the field of comprehensive sexual education and family planning, an abundance of sexual health information was published in the early 1900s, including research articles, books, and pamphlets. The early focus of sexual health education was deterrence of disease, as it was perceived that education about personal sanitation and hygiene in schools might assist in prevention of disease (Carter, 2001). Developments in the medicine and related fields, including confirmation of the first effective treatment of syphilis (i.e., discovery of penicillin) and identification of the hormones involved in the human reproductive system, further increased the push for sexual health education in schools (Treacy et al., 2018; Cassell & Wilson, 1989). Two organizations were developed and tasked with ongoing improvement and growth of comprehensive sex education in public schools and higher education institutions. In 1964 and 1967 respectively, the Sexuality Information and Education Council of the United States (SIECUS) and the American Association of Sex

Educations, Counselors, and Therapists (AASECT) were formed (Seruya, Losher, & Ellis, 1972; Cornog & Perper, 1996; SIECUS, 2014).

The first funding initiatives for sexual health education occurred in the 1980s, starting with the Adolescent Family Life Act under Title XX of the Public Health Service Act (Advocates for Youth, 2014). This legislation provided funding to educate adolescents about the dangers of premarital sex. Education efforts also focused on promoting adoption subsequent to an unplanned pregnancy rather than abortion (Cassell & Wilson, 1989; SIECUS, 2014, 2016). In 1996, $50 million in annual funding was allocated to abstinence-based sexual health education programs through welfare reform policies and amendment to the Maternal and Child Health Block Grant (Advocates for Youth, 2014; Williams, 2006).

Currently, every state in the United States allocates funds for public schools to implement sexual health programs. However, this provision of funds has resulted in ongoing and combative discourse between parties endorsing abstinence-based education and those favoring more comprehensive sexual education (Treacy et al., 2018). A significant amount of research exists examining the effectiveness of both comprehensive sexual education and abstinence-based programs. For example, 56 studies evaluating the outcomes of abstinence-based sexual education and comprehensive sexual education were reviewed by Kirby (2008). Abstinence-based sexual education programs strongly encourage refraining from sexual behavior outside of marriage to avoid the risk of pregnancy and sexually transmitted diseases (STDs). While comprehensive sexual education emphasizes that abstinence is the safest choice, topics of discussion include methods of contraception such as condoms and birth control pills, sexual anatomy, pregnancy, risk of STDs, and places to seek sexual health care (e.g., Planned Parenthood). Multiple studies have reported abstinence-based programs do not delay participants from engaging in sex nor were there any positive effects on sexual behavior (Kirby, 2008; Stanger-Hall & Hall, 2011; Trenholm et al., 2007). Conversely, research indicated comprehensive sexual health education programs resulted in a significant increase in participants' use of condoms and contraception and delayed participants' initiation of sexual relations (Kirby, 2008; Trenholm et al., 2007). Furthermore, Kohler et al. (2008) demonstrated a 50% lower risk of teen pregnancy associated with comprehensive sexual education as compared to abstinence-based sexual education.

Santelli and Kantor (2008) made a strong argument that scientific evidence does not support abstinence-based sexual education to decrease unwanted outcomes of adolescents' sexual behavior and that the influence of politics and ideology have resulted in the undermining of best approaches to sexual education. There are significant ethical and human rights concerns about the provision of incomplete and inaccurate sexual health information. Government agencies and policymakers have an obligation to provide accurate information (and to prevent dissemination of inaccurate information) to the public. Despite this, abstinence-based programs in schools are restricted in the information they can provide to students (e.g., limited or no information about condoms and contraception), and are expected to promote scientifically questionable ideas such as potential links between early sexual behavior and mental health issues. Placing limits on the approved topics that can be discussed through these programs increases risks for students by withholding accurate information they need to protect their own health. Further, it presents an ethical dilemma for program facilitators, forcing them to refrain from sharing potentially lifesaving information or risk losing funding by violating policy requirements (Santelli & Kantor, 2008). In discussing the legislative mandate for abstinence-only programs, Treacy et al. (2018) stated:

> The paradox here is that funding does not support the evidence-based practice. At a time in education when all instructional practices must be identified as an evidence-based practice, funding follows the less effective practice; therefore, denying both students with and without disabilities access to evidence-based sexual health education. (p.71)

Despite evidence indicating that comprehensive sexual health education results in more positive outcomes than abstinence-based programs, most funding for sexual health education is provided to public schools for abstinence-only programs (Advocates for Youth, 2014; Kirby 2008; Kohler et al., 2008; Santelli & Kantor, 2008; SIECUS, 2014, 2016; Treacy et al., 2018; Trenholm et al., 2007). The National Conference of State Legislatures (2020) reported that as of March 2020, 29 states require public schools to teach sexual health education and 22 states dictate that if sexual health education is provided, it must be medically accurate. However, definitions of “medically accurate” vary significantly. Definitions are often vague and use terminology such as *age-appropriate*, *dissemination of factual information*, *respects community values*, *stress moral responsibility*, *technically accurate*, etc. Parent/guardian rights also come in to play in many instances, as 25 states require parent/guardian notification if sex education is provided, five states require parent/guardian consent for sex education to be provided, and 36 states allow parents/guardians to opt-out completely of sex education for their children. Shapiro and Brown (2018) found only 11 states included the concepts of healthy relationships, sexual assault, and consent in their state policies and education standards. This suggests that the majority of public school students in the United States are not receiving instruction through their schools' sexual health education program regarding healthy and unhealthy relationships, dating and relationship violence, or negotiating consent.

Policies Regarding the Sexuality of Individuals with I/DD

Based on reported research, students with disabilities frequently have been excluded from education about sexual health throughout the twentieth century. Historically, many individuals with disabilities were placed in institutions where they did not receive instruction in reading, writing, or mathematics, much less sexual health information (Barnard-Brak, Schmidt, Chestnut, Wei, & Richman, 2014; Cassell & Wilson, 1989; Murphy & Young, 2005; Preston, 2013). Eugenic beliefs and practices were a significant factor in American history and culture from the late 19th century until World War II. By the early 1900s, many American universities, scientists, and professionals promoted eugenic ideology and actively supported eugenics-inspired legislation. The American Eugenics Society and prominent eugenicists in the United States not only endorsed restriction of immigration to the United States for those viewed as inferior, but also advocated for the sterilization of American citizens considered to be "insane, retarded, and epileptic" (Bruinuis, 2006, p. 7). In 1927, the U.S. Supreme Court ruled in favor of a statute for the "compulsory sterilization of the unfit for the protection and health of the state" (Bruinius, 2006, p. 7). This allowed for government and private agencies to sterilize people with disabilities (American Academic of Pediatrics, 1999). This ruling was reversed in 1942 when the U.S. Supreme Court declared procreation to be a human right. Despite this, 28 states still had sterilization laws two decades later. Twenty-six of those states included compulsory sterilization in order to prevent reproduction by people with disabilities (Stein & Dillenburger, 2016). Further, it should be noted that guardians of people with disabilities *can still* choose to have their child sterilized if they prove "good reason" (American Academy of Pediatrics, 1999). Stern (2005) reported that thousands of people continued to be sterilized through the late 1960s and into the mid-1970s as many academic and medical professionals continued to promote eugenics as a public health issue. Specifically, those with mental illness, physical or medical disabilities, or behaviors viewed as immoral (e.g., pregnancy out of wedlock) were seen as threats to American society, and this ideology was promoted and accepted as it was supported by trusted medical and mental health professionals.

Political views and legislation at the federal and state levels have significant effect on policies and perceptions in both in school and community contexts. In many instances, funding is provided to promote only certain policies and to support implementation of only certain curricula. Hence, understanding the history of disability law is a critical piece in understanding perceptions of people with I/DD as competent, autonomous individuals. Disability law also has significant consequences for educational programming for people with I/DD, which includes access to educational resources and services.

Sexual Health Education and Individuals with Disabilities

Research suggests there is not a consistent, evidence-based sexual health education program currently being implemented in U.S. schools for any students regardless of disability status. Wolfe and Blanchett (2002) found that while there were sexual education curricula recommended for use with people with disabilities, materials were designed to be used with a broad range of individuals and were not specific to the needs of specific subgroups of participants (i.e., deaf students, students with I/DD, etc.). Sexual health education programs provided for students with disabilities often focus on the biological aspects of sexual health and behavior, while the emotional aspects of romantic relationships receive little, if any, attention (Knox & Hickson, 2001; Shakespeare et al., 1996). Given the previous discussion regarding the desire of people with disabilities to engage in intimate relationships, the lack of guidance regarding appropriate dating and romantic behaviors is concerning.

Further, McDaniels and Fleming (2016) reported that many of the sexual health education programs recommended for implementation with people with I/DD were not comprehensive but focused on limited topics in isolation (e.g., sexual abuse or STD prevention). A critical piece missing from many of these educational materials was ecological validity, or rather the practical application of these skills in real-world contexts. While delivering sexual health education content and increasing knowledge of participants is critical, teaching participants how to successfully apply learned skills requires an additional level of implementation and skill on the part of educators/program facilitators (McDaniels & Fleming 2016).

The Community Advisory Group of the Sexual Health Equity for Individuals with Intellectual/Developmental Disabilities (SHEIDD) project conducted a review of seven curricula designed to address healthy relationships and sexuality education for people with I/DD (Kayser et al., 2018). Of these, five programs were specifically designed to target the school-age population and to be delivered in school or community settings while two of the programs were designed to be delivered to adults in community or agency settings. Several, though not all, of these programs were found to have strengths including affirming that people with disabilities are sexual beings and use of a variety of teaching strategies and materials. However, many of these programs were lacking in regards to including information about transgender and non-binary people, adaptations to account for participants' cultures and their influence on relationships and sexual health, information about contraception and STDs, and information about parenting rights and relationships. This review suggested that programs designed specifically for the I/DD population to teach sexual health and relationship education continue to be inadequate in several significant areas.

Conclusion

People with disabilities have a long history of discrimination, mistreatment, and exploitation. Moreover, people with disabilities, including school-age children and adolescents with I/DD, are often excluded from activities and supports that comprise a well-rounded, socially connected life. While many students with I/DD are enrolled in their neighborhood schools with their peers, true inclusion continues to be absent in too many cases. Students with disabilities, including those with I/DD, experience rejection, exclusion, isolation, and bullying at higher rates than their peers without disabilities. They also experience barriers to activities that their peers without disabilities freely access (e.g., participation in extracurricular programs and recreational activities). Social connectedness is a vital component of the human experience and has been linked to both physical and mental health. Yet lack of friendships and intimate relationships remain a primary concern reported by people with I/DD and their families. This becomes even more problematic once students with I/DD leave the school setting and transition into young adulthood, where the social support that was provided in the school setting is completely absent.

A key component to the achieving and maintaining quality of life is engagement in healthy intimate and romantic relationships. While the AAIDD and the ARC joint statement indicates people with I/DD have "inherent sexual rights that must be affirmed, defended, and respected" (American Association on Intellectual and Developmental Disabilities [AAIDD], 2008), most middle and high school students with I/DD do not receive adequate education regarding sexuality and healthy relationships. This exclusion could be due to people with I/DD being perceived of as asexual, as incapable of developing and maintaining romantic relationships, or as uninterested in romantic relationships. However, in previous research conducted by Blum et al. (1991), people with disabilities have expressed they desire engagement in intimate relationships and think about marriage and having children just as many of their peers without disabilities do.

The type of sexual health education program delivered in schools is driven by competing ideologies: abstinence-based sexual health education and comprehensive-based sexual education. While overwhelming research indicates the positive outcomes of comprehensive-based sexual health education (e.g., safe-sex practices, delayed initiation of sex), abstinence-based education is the most common form of sexual education being taught in schools. The promotion of abstinence has deep roots in religious and moral beliefs, leading to significant political and financial support for implementation of these programs. Furthermore, students with I/DD are often excluded from sexual health education altogether. When this education is provided, it tends to focus on the biological aspects of sexual health, while failing to address topics such as developing and maintaining intimate relationships, dating behavior, healthy versus unhealthy relationships, and negotiating consent. One could argue that, because IDEA dictates evidence-based practices must be utilized in teaching students with disabilities, implementation of a comprehensive sexual education program to teach sexual and relationship health to students with I/DD is both supported by research and mandated by federal law.

Based on a review of the literature, there is not a consistent, evidence-based sexual health education program being implemented in U.S. schools for students with and without disabilities. While there are sexual education curricula recommended for use with people with disabilities, these materials are designed to be used with a broad range of individuals rather than specific subgroups of participants (i.e., deaf, I/DD, etc.) and focused on topics in isolation (e.g., sexual abuse or STD prevention). The aim of these programs is to increase the knowledge of participants, and while that is vitally important, a key component missing from these programs is providing opportunity for participants to successfully apply learned skills in real-world contexts. While these programs demonstrate distinct areas of strength (e.g., affirmation that people with disabilities are sexual beings and use of various instructional strategies and modalities), they often lack inclusion of information about transgender and non-binary people, adaptations to account for participants' cultures and their influence on relationships and sexual health, information about contraception and sexually transmitted diseases, and information about parenting rights and relationships (Kayser et al., 2018).

Overall, available educational materials designed to address sexual health and relationships with students with I/DD are severely lacking in many critical ways. Furthermore, implementation of effective sexual health education programs for students with I/DD is absent from most school settings. As outlined in the joint position statement by AAIDD and the ARC: "All people have the right within interpersonal relationships to develop friendships and emotional and sexual relationships where they can love and be loved" (AAIDD, 2008). Because healthy sexuality and intimate relationships strongly influence individuals' quality of life and well-being, policymakers and educators must work in earnest to provide quality programming and supports in this area. To that end, we propose the following action steps:

1. *Develop and implement sex-positive training for educators who work with students with I/DD.* Goodley (2017) notes, "erotophobic attitudes and excessive repression suppress discussions about sex and pervade professional beliefs about disabled people." For example, professionals in Colarossi et al. (2023a) reported discomfort talking about sexuality and the desire to learn how discuss sexual

health with youth “in unbiased, fact-based, non-judgmental ways” (p. S154). As such, professional development efforts must address both professional knowledge and attitudes about sexuality.

2. *Promote creation and dissemination of sexual health education curricula address the specific needs of youth with I/DD.* Educators who were interviewed as part of Colarossi et al.’s (2023a) study endorsed the need for “accessible teaching tools, with videos and hands-on toolkits” (p. S158). In a separate study, interviews with youth with I/DD and their families identified a variety of instructional supports that should be integrated in sexual health education programs, including visual aids, hands-on learning activities, social stories, and case scenarios (Colarossi et al., 2023b). Program developers might utilize CAST’s Universal Design for Learning (UDL) Guidelines (CAST, 2018) to develop instructional materials that are maximally accessible for *all* students, including students with I/DD.
3. *Coordinated advocacy efforts from educators, families, and individuals with disabilities to impact state- and district-level policies regarding sexual health education*. In particular, IDEA mandates regarding research-based practices should be leveraged to advocate for comprehensive sexual health education for students with I/DD. Schools should be expected to implement programs that address not only abstinence and human physiology but also include topics like dating, negotiating consent, and using contraception (Perez-Curiel et al., 2023).

References

Advocates for Youth. (2014). *This history of federal abstinence-only funding.* https://www.advocatesforyouth.org/wp-content/uploads/storage//advfy/documents/fshistoryabonly.pdf

Albrecht, G. L. (Ed.). (2006). Encyclopedia of disability (Vol. 1). Sage.

Alirksson-Schmidt, A. I., Armour, B. S., & Thibadeau, J. K. (2010). Are adolescent girls with a physical disability at increased risk for sexual violence? *Journal of School Health, 80*(7), 361-367. https://doi.org/10.1111/j.1746-1561.2010.00514.x

American Psychiatric Association, D. S. M. T. F., & American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders: DSM-5* (5th ed.). https://doi.org/10.1176/appi.books.9780890425596

American Association on Intellectual and Developmental Disabilities. (2008). *Sexuality.* https://aaidd.org/news-policy/policy/position-statements/sexuality#.WujCRk2WxGE

Asher, S. R., & Coie, J. D. (Eds.). (1990). *Peer rejection in childhood*. CUP Archive.

Balaji, A. B., Claussen, A. H., Smith, D. C., Visser, S. N., Morales, M. J., & Perou, R. Social support networks and maternal mental health and well-being. *Journal of Women's Health, 16*(10), 1386-1396. https://doi.org/10.1089/jwh.2007.CDC10

Barnard-Brak, L., Schmidt, M., Chestnut, S., Wei, T., & Richman, D. (2014). Predictors of access to sex education for children with intellectual disabilities in public schools. *Intellectual and Developmental Disabilities, 52*(2), 85-97.

https://doi.org/10.1352/1934-9556-52.2.85

Biggs, E. E. & Carter, E. W. (2016). Quality of life for transition-age youth with autism or intellectual ability. *Journal of Autism and Developmental Disorders, 46,* 190-204. https://doi.org/10.1007/978-1-4614-6435-8_102218-1

Blanchett, W. J. & Wolfe, P. S. (2002). A review of sexuality curricula: Meeting the sexuality education needs of individuals with moderate and severe disabilities. *Journal of the Association for Persons with Severe Handicaps (JASH), 27*(1) 43-57. https://doi.org/10.2511/rpsd.27.1.43

Blum, R., Resnick, M., Nelson, R., & Germaine, A. (1991). Family and peer issues among adolescents with spina bifida and cerebral palsy. *Pediatrics, 88*, 280-285.

Bruinius, H. (2006). *Better for the world: The secret history of forced sterilization and America's quest for racial purity.* Vintage Books.

Cacioppo, J. T., Hawkley, L. C., Crawford, L. E., Ernst, J. M., Burleson, M. H., Kowalewski, R. B., Malarkey, W. B., William, B., Cauter, E., & Bernston, G. (2002). Loneliness and health: Potential mechanisms. *Psychosomatic Medicines, 64*(3), 407-417. https://doi.org/10.1097/00006842-200205000-00005

Committee on Bioethics. (1999). Sterilization of minors with developmental disabilities. *Pediatrics, 104*(2), 337-340. https://doi.org/10.1542/peds.104.2.337

Carter, E. W., Ditchman, N., Sun, Y., Trainor, A. A., Swedeen, B., & Owens, L. (2010). Summer employment and community experiences of transition-age youth with severe disabilities. *Exceptional Children, 76,* 194-212.

https://doi.org/10.1177/001440291007600204

Carter, J.B. (2001). Birds, bees and venereal disease: Toward an intellectual history of sex education. *Journal of the History of Sexuality, 10*(2), 213-249. https://doi.org/10.1353/sex.2001.0022

Cassell, C. & Wilson, P. M. (1989). *Sexuality education.* Garland Publishing, Inc.

CAST. (2018). *Universal Design for Learning Guidelines version 2.2*. http://udlguidelines.cast.org

Cohen, S. (2004). Social relationships and health. *American Psychologist,* 676-684. https://doi.org/10.1037/0003-066X.59.8.676

Cohen, S., Doyle, W. J., Skoner, D. P., Rabin, B. S., & Gwaltney, J. M., Jr. (1997). Social ties and susceptibility to the common cold. *Journal of the American Medical Association, 277,* 1940-1944. http://dx.doi.org/10.1001/jama.1997.03540480040036

Cohen, S., Underwood, L. G., & Gottlieb, B. H. (Eds.). (2000). Social support measurement and intervention: A guide for health and social scientists. Oxford University Press.

Collier, K. L. (2023, May 31-June 2). Sexual and reproductive health education for youth with intellectual disabilities: A mixed methods study of professionals' practices and needs [presentation]. 31st Annual Meeting of the Society for Prevention Research (SPR), Washington, D.C.

Cornog, M. & Perper, T. (1996). *For sex education, see librarian: A guide to issues and resources.* Greenwood Press.

Education for All Handicapped Children Act of 1975. Education for All Handicapped Children

Act of 1975, 20 U.S.C. §§ 1401-1461 (1975).

Emerson, E. & McVilly, K. (2004). Friendship activities of adults with intellectual disabilities in supported accommodation in Northern England. *Journal of Applied Research in Intellectual Disabilities, 17*, 191-197. https://doi.org/10.1111/j.1468-3148.2004.00198.x

Eng, P. M., Rimm, E. B., Fitzmaurice, G., & Kawachi, I. (2002). Social ties and change in social ties in relation to subsequent total and cause-specific mortality and coronary heart disease incidence in men. *American Journal of Epidemiology, 155,* 700-709. http://dx.doi.org/10.1093/aje/155.8.700

Foley, K.-R., Dyke, P., Girdler, S., Bourke, J., & Leonard, H. (2012). Young adults with intellectual disability transitioning from school to post-school: A literature review framed within the ICF. *Disability and Rehabilitation*, *34*, 1747–1764. https://doi.org/10.3109/09638288.2012.660603

Forte, M., Jahoda, A., & Dagnan, D. (2011). An anxious time? Exploring the nature of worries experienced by young people with a mild to moderate intellectual disability as they make the transition to adulthood. *British Journal of Clinical Psychology, 50,* 398-411. https://doi.org/10.1111/j.2044-8260.2010.02002.x

Frank, K. & Sandman, L. (2019). Supporting parents as sexuality educators for individuals with intellectual disability: The development of the home B.A.S.E curriculum. *Sexuality and Disability, 37,* 329-337. https://doi.org/10.1007/s11195-019-09582-7

Froese, P., Richardson, M., Romer, L. & Swank, M. (1999). Comparing opinions of people with developmental disabilities and significant persons in their lives using the individual supports identification system (ISIS). *Disability & Society, 14*, 831-843. https://doi.org/10.1080/09687599925920

Goodley, D. (2017). *Disability studies: An interdisciplinary introduction.* Sage.

Haber, M. G., Mazzotti, V. L., Mustian, A. L., Rowe, D. A., Bartholomew, A. L., & Fowler, C. H. (2015). What works, when, for whom, and with whom: A meta-analytic review of predictors of postsecondary success for students with disabilities. *Review of Educational Research*, *86*(1), 123-162. https://doi.org/10.3102/0034654315583135

Holt-Lunstad, J., Robles, T. F., & Sbarra, D. A. (2017). Advancing social connection as a public health priority in the United States. *American Psychologist, 72*(6), 517-530. http://dx.doi.org/10.1037/amp0000103

Holt-Lunstad, J. Smith, T. B., & Layton, J. B. (2010). Social relationships and mortality risk: A meta-analytic review. *PLoS Medicine, (7)*7, e1000316. https://doi.org/10.1371/journal.pmed.1000316

Individuals with Disabilities Education Act of 2004, 20 U.S.C. §§ 1400-1415 (2004).

Kayser, A., Alpert, B., Toevs, K, & Ramachandan, D. (2018). *In their own words: Guidelines for supporting the sexual health of young people experiencing intellectual/developmental disabilities.* Multnomah County Health Department. https://multco.us/school/sexual-health-youth-developmental-disabilities

Kiecolt-Glaser, J. K., & Newton, T. L. (2001). Marriage and health: His and hers. *Psychological Bulletin, 127,* 472-503. http://dx.doi.org/10.1037/0033-2909.127.4.472

Kirby, D. (2008). The impact of abstinence and comprehensive sex and STX/HIV education programs on adolescent sexual behavior. *Sexuality Research and Social Policy, 5*(3), 18-27. https://doi.org/10.1525/srsp.2008.5.3.18

Knox, M. & Hickson, F. (2001). The meanings of close friendship: The views of four people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 14*, 276-291. https://doi.org/10.1046/j.1468-3148.2001.00066.x

Kohler, P. K., Manhart, L. E., & Lafferty, W. E. (2008). Abstinence-only and comprehensive sex education and the initiation of sexual activity and teen pregnancy. *Journal of Adolescent Health, 42*(4), 344-351. https://doi.org/10.1016/j.jadohealth.2007.08.026

Koller, D., Le Pouesard, M., Rummens, J. A. (2018). Defining social inclusion for children with disabilities: A critical literature review. *Children and Society, 32*, 1-13. https://doi.org/10.1111/chso.12223

Koster, M., Pijl, S. J., Nakkhen, H., Van Houten, E. (2010). Social participation of students with special needs in regular primary education in the Netherlands. *International Journal of Disability, Development and Education, 57,* 59-75. https://doi.org/10.1080/10349120903537905

Ladau, E. (2021). *Demystifying disability: What to know, what to say, and how to be an ally.* Ten Speed Press.

Laidlaw Foundation. (2003). *Thumbs up! Inclusion, rights and equality as experienced by youth with disabilities*. Laidlaw Foundation.

Matheson, C., Olsen, R. J., & Weisner, T. (2007). A good friend is hard to find: Friendship among adolescents with disabilities. *American Journal on Mental Retardation*, *112*, 319–329.

McDaniels, B. & Fleming, A. (2016). Sexuality education and intellectual disability: Time to address the challenge. *Sexuality and Disability, 34*, 215-225. https://doi.org/10.1007/s11195-016-9427-y

McPartland, J.C., Law, K., & Dawson, G. (2016). Autism spectrum disorder. In H. Friedman (Ed.), *Encyclopedia of Mental Health* (2nd ed.). Academic Press.

Murphy, N. A. & Elias, E. R. (2006). Sexuality of children and adolescents with developmental disabilities. *Pediatrics, 118*(1), 398-403. https://doi.org/10.1542/peds.2006-1115

Murphy, N., & Young, P. C. (2005). Sexuality in children and adolescents with disabilities. *Developmental Medicine & Child Neurology, 47,* 640-644. https://doi.org/10.1111/j.1469-8749.2005.tb01220.x

National Coalition for Sexual Health (2019). *Goals.* https://nationalcoalitionforsexualhealth.org/about/goals-values

National Conference of State Legislatures (2020). *State policies on sex education in schools.* https://www.ncsl.org/research/health/state-policies-on-sex-education-in-schools.aspx#sex%20ed%20and%20states

Pijl, S. J., Frostad, P., & Flem, A. (2008). Social position of pupils with special needs in regular schools. *Scandinavian Journal of Educational Research, 52*(4), 387-405. https://doi.org/10.1080/00313830802184558

Preston, M. (2013). “Very, very risky”: Sexuality education teachers’ definition of sexuality and teaching and learning responsibilities. *American Journal of Sexuality Education, 8*(1-2), 18-35. https://doi.org/10.1080/15546128.2013.790223

Pérez-Curiel, P., Vicente, E., Morán, M. L., & Gómez, L. E. (2023). The right to sexuality, reproductive health, and found a family for people with intellectual disability: A systematic review. *International Journal of Environmental Research and Public Health, 20*(2), 1587. https://doi.org/10.3390/ijerph20021587

Pitonyak, D. (2003) *Loneliness is the only real disability: Implications and recommendations for policymakers* [handout]. National Association of Developmental Disabilities Directors 2003 Annual Meeting. http://dimagine.com/wp-content/uploads/2018/03/NASDDS.pdf

Repke, A., & Ipsen, C. (2019). Differences in social connectedness and perceived isolation among rural and urban adults with disabilities. *Disability and Health Journal, (13).* https://doi.org/10.1016/j.dhjo.2019.100829

Robertson, J., Emerson, E., Gergory, N., Hatton, C., Kessissoglou, S., Hallam, A., & Linehan, C. (2001). Social networks of people with mental retardation in residential settings. *Mental Retardation, 39*, 201-214.

Sala, G., Hooley, M., Attwood, T., Mesibov, G., & Stokes, M. A. (2019). Autism and intellectual disability: A systematic review of sexuality and relationship education. *Sexuality and Disability, 37,* 353-382. https://doi.org/10.1007/s11195-019-09577-4

Santelli, J. S., & Kantor, L. M. (2008). Introduction to special issue: Human rights, cultural, and scientific aspects of abstinence-only policies and programs. *Sexuality Research and Social Policy, 5*(3), 1-5. https://doi.org/10.1525/srsp.2008.5.3.1

Schaafsma, D., Kok, G., Stoffelen, J. M. T., & Curfs, L. M. G. (2017). People with intellectual disabilities talk about sexuality: Implications for the development of sex education. *Sexuality and Disability, 35*(21-38). https://doi.org/10.1007/s11195-016-9466-4

Seruya, F. C., Losher, S., & Ellis, A. (1972). *Sex and sex education: A bibliography.* Bowker Company.

Shakespeare, T., Gillespie-Sells, K., & Davies, D. (1996). Identity and Imagery. In T. Shakespeare, K. Gillespie-Sells & D. Davies (Eds.), *The sexual politics of disability: Untold desires.* Cassell.

Shapiro, S. & Brown, C. (2018). *Sex education standards across the states.* Center for American Progress.

Shattuck, P. T., Orsmond, G. I., Wagner, M., & Cooper, B. P. (2011). Participation in social activities among adolescents with an autism spectrum disorder. *PLoS One, 6,* e27176. https://doi.org/10.1371/journal.pone.0027176

SIECUS: Sexuality Information and Education Council of the United States. (2014). http://siecus.org

SIECUS: Sexuality Information and Education Council of the United States. (2016). *Federal programs cheat sheet.*

SIECUS: Sexuality Information and Education Council of the United States. (2020).

https://siecus.org/wp-content/uploads/2020/01/Georgia-PDF.pdf

Siperstein, G. N., Parker, R. C., & Norins Bardon, J. (2007). A national study of youth attitudes toward the inclusion of students with intellectual disabilities. *Exceptional Children, 73*(4), 435-455. https://doi.org/10.1177/001440290707300403

Skarbeck, D., Hahn, K., & Parrish, P. (2009). Stop sexual abuse in special education: An ecological model of prevention and intervention strategies for sexual abuse in special education. *Sexuality and Disability, 27*(3), 155-164. https://10.1007/s11195-009-9127-y

Smith, S. G., Zhang, X., Basile, K. C., Merrick, M. T., Wang, J., Kresnow, M., Chen, J. (2018). The National Intimate Partner and Sexual Violence Survey (NISVS): 2015 Data Brief – Updated Release. Atlanta, GA: National Center for Injury Prevention and Control, Centers for Disease Control and Prevention.

Snowdon, A. (2012). *Strengthening Communities for Canadian Children with Disabilities.* The Sandbox Project: Toronto, ON.

Stanger-Hall, K. F. & Hall, D. W. (2011). Abstinence-only education and teen pregnancy rates: Why we need comprehensive sex education in the U.S. *PLoS ONE 6*(10), e24658. https://doi.org/10.1371/journal.pone.0024658

Stein, S. & Dillenburger, K. (2016). Ethics in sexual behavior assessment and support for people with intellectual disability. *International Journal on Disability and Human Development, 16*(1), 11-17. https://doi.org/10.1515/ijdhd-2016-0023

Stern, A. M. (2005). Sterilized in the name of public health. Race, immigration, and reproductive control in modern California. *Journal of Public Health, 95*(7), 1128-1138. https://doi.org/10.1016/S0145-2134(00)00190-3

Sullivan, P. M. & Knutson, J. F. (2000). Maltreatment and disabilities: A population-based epidemiological study. *Child Abuse and Neglect, 24*(10), 1257-1273. https://doi.org/10.1016/S0145-2134(00)00190-3

Swango-Wilson, A. (2011). Meaningful sex education programs for individuals with intellectual/developmental disabilities. *Sexuality and Disability, 29*, 113-118. https://doi.org/10.1007/s11195-010-9168-2

Taft, A., Hegart, K., Ramsay, J., Feder, G., Carter, Y., Davidson, L., & Warburton, A. (2009). Screening women for intimate partner violence in health care settings (Protocol). *Cochrane Database of Systematic Reviews 2008.* https://doi.org/10.1002/14651858.CD007007

Treacy, A. C., Taylor, S. S., & Abernathy, T. V. (2018). Sexual health education for individuals with disabilities: A call to action. *American Journal of Sexuality Education, 13,* 65-93. https://doi.org/10.1080/15546128.2017.1399492

Trenholm. C, Devaney, B., Fortson, K., Quay, L., Wheeler, J., & Clark, M. (2007). *Impact of four Title V Section 510 abstinence education programs: Final report.* Mathematica Policy Research, Inc.

Van Dyke, D., McBrien, D., & Sherbondy, A. (1995). Issues of sexuality in Down syndrome. *Down Syndrome Research and Practice*, *3(2)*, 65-69. https://doi.org/10.3104/reviews.53

Ward, K. M., Atkinson, J. P., Smith, C. A., & Windsor, R. (2013). A friendships and dating program for adults with intellectual and developmental disabilities: A formative evaluation. *Intellectual and Developmental Disabilities, 51*, 22-32. https://doi.org/10.1352/1934-9556-51.01.022

Ward, K. M., Windsor, R., Atkinson, J. P. (2012). A process evaluation of the friendships and dating program for adults with developmental disabilities: Measuring the fidelity of program delivery. *Research in Developmental Disabilities, 33,* 69-75. https://doi.org/10.1016/j.ridd.2011.08.016

Williams, M. E. (2006). *Sex: Opposing viewpoints.* Greenhaven Press.

Zablotsky, B., Black, L. I., Blumberg, S. J. (2017). Estimated prevalence of children with diagnosed developmental disabilities in the United States, 2014-2016. *NHS Data Brief, (291)*,1-8. https://www.ncbi.nlm.nih.gov/pubmed/29235982

Zablotsky, B., Black, L. I., Maenner, M. J., Schieve, L. A., Danielson, M. L., Bitsko, R. H., Blumberg, S. J., Kogan, M. D., & Boyle, C. A. (2019). Prevalence and trends of developmental disabilities among children in the United States: 2009-2017. *Pediatrics, 144*(4). https://doi.org/10.1542/peds.2019-0811