Let's Talk About Sex and IDD: A Qualitative Analysis of the Perspectives of Secondary General Education Health Teachers on Necessary Supports for Teaching Sex Education to Young Adults with Intellectual and Developmental Disability

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by

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ABSTRACT

Adolescents with intellectual and developmental disabilities (IDD) tend to receive inadequate comprehensive sex education (CSE). This problem could be addressed by providing sex education taught by general education health teachers to students with IDD in high school, a cost-effective yet underutilized and under researched service model. This qualitative study sought to determine the types of support health teachers need to effectively teach CSE to adolescents with IDD and to identify any misconceptions they have about the sexuality of individuals with IDD. Nine health teachers from 3 public school districts in Northeastern Pennsylvania were studied using a revised version of the Attitudes to Sexuality Questionnaire – Individuals with an Intellectual Disability (ASQ-ID) and semi-structured interviews. Data was analyzed by cross-case pattern analysis to generate a list of recommendations for local districts on how best to support their existing health teachers in the implementation of formal CSE for young adults with IDD. The three primary supports participants need are (1) support from special education staff, (2) assistance in developing the curriculum and adapting instruction, and (3) additional training. With these supports, general education health teachers can provide effective CSE to adolescents with IDD so they can be equipped with the relationship and sexuality knowledge and skills necessary to lead safe, fulfilling lives.

DEDICATION

To MJ for inspiring me

To GW for motiving me to be the best I can be

To Mema and Nick for making it all possible

To Willy for the unconditional love

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CHAPTER 1: INTRODUCTION

Imagine if, even as an adult, you were never given the opportunity to experience a romantic relationship or sexual gratification. Furthermore, imagine if every time you tried to discuss or inquire about your desires and need for companionship, even with trusted adults, you were silenced. Would you be able to realize a truly fulfilling life? For most adults, romantic relationships and sexuality are an important, albeit complicated, part of existence without which one's quality of life would suffer. However, for most adults with intellectual and developmental disabilities (IDD), the opposite is true. Throughout the world, few adults with IDD are given the knowledge, skills, freedom, or support to engage in desired romantic and sexual relationships (Paulauskaite et al., 2022). Most are discouraged from even verbally expressing sexual desire or romantic interest. This denial of personal freedom has been occurring for generations and has proven, lifelong negative implications for individuals with IDD.

Context

Treatment of Individuals with IDD

In recent decades, many improvements have been made in the treatment, education, and independence of individuals with IDD. The Civil Rights movement of the 1960s—which championed equality for black Americans—also inspired other marginalized groups to seek equitable treatment, including supporters of individuals with disabilities (Treacy et al., 2018; SIECUS, 2021; Aron & Loprest, 2012). This first manifested in the closure of institutions that had previously housed individuals with IDD, usually in deplorable conditions. The next step towards normalization for individuals with disabilities came from legislation like The Rehabilitation Act of 1973, the Education for All Handicapped Children Act of 1975—which later became the Individuals with Disabilities Education Act (IDEA), as it is still known today—and the Americans with Disabilities Act of 1990. These laws require equal treatment for

individuals with disabilities, including those with IDD, in public settings, such as schools and workplaces.

Today, many children and young adults with IDD in the United States are educated in general education classrooms in public schools alongside their nondisabled peers. This is due in large part to the 1997 amendment of IDEA, which required that students with disabilities be educated in the least restrictive environment (LRE) meaningfully possible with the support of supplementary aids and services (Aron & Loprest, 2012). The Independent Living Movement, with its focus on person-centered planning and giving individuals with disabilities agency over their lives, continues the trend towards increased independence and self-advocacy today (National Council for Independent Living (NCIL), 2023; Bambara & Brantlinger, 2002). However, despite these advances in education, working, and living conditions, individuals with IDD are still at a disadvantage in acknowledging their sexuality and engaging in romantic relationships (Bernert, 2010). As Bambara and Brantlinger (2002) attest, "In addition to satisfying needs for employment, and a comfortable and secure place to live, people have pressing needs for companionship, friendship, sexual expression, sexual identity, and intimate relationships. It is in this third domain of life that human needs for people with disabilities remain largely unfulfilled" (p. 5).

Sexuality of Individuals with IDD

The importance of this third domain to the lives of individuals with IDD is overlooked and undervalued. Despite legislation mandating equitable treatment and the trend toward normalization, misconceptions and stigmas regarding the sexuality of individuals with IDD persist (Keshav & Huberman, 2006). Individuals with IDD are still not viewed as equal citizens because of their disability (Bogart & Dunn, 2019; Scior, 2016; Howard-Barr et al., 2005). One example of this are the stereotypical views many hold of their sexuality. Keshav and Huberman

(2006) identify three commonly held myths about the sexuality of individuals with IDD: they have uncontrollable sexual urges that predispose them to deviance, they are asexual and disinterested in romantic relationships, or they are childlike and therefore not capable of sexual thoughts. None of these myths are true for most individuals with IDD. Views of individuals with IDD as childlike or asexual are based on assumptions that, due to their cognitive limitations, their physical development is also delayed. This is also false; most individuals with IDD develop physically on pace with their nondisabled peers (Keshav & Huberman, 2006). Concerningly, these erroneous views are used to justify failure to recognize the sexuality of, and to provide sex education for, young adults with IDD. Rather than viewing sex education as something that young adults with IDD should be taught at a level appropriate to their ability like other subjects, it is viewed as something one must be ready for (Barnard-Brak et al., 2014). They are rarely deemed ready.

Failure to provide sex education to young adults with IDD is an endemic problem with far-reaching implications. As Schmidt et al. (2021) summarize:

> The current context for SE is impeded by values and cultural issues, parental attitudes toward their child's sexuality, a lack of organizational policies and standards, and limited professional education or societal bias, which unintentionally oppress people with IDD because they inhibit the provision of [CSE] (p. 6).

Lack of sex education—combined with lack of caregiver and peer support which is common for individuals with IDD (Schmidt et al., 2021; McDaniels & Fleming, 2018; Kammes et al., 2020; Howard-Barr et al., 2005; Sexuality Information and Education Council of the United States (SIECUS), 2021)—results in a lack of sexuality and relationship skills and knowledge. This lack of knowledge is then used to justify denying individuals with IDD the opportunity to express their sexuality and sometimes the ability to consent to consensual sexual activity (Wolfe, 2002).

The ability to consent to sexual acts rests on an understanding of what a person is agreeing to. Therefore, the prevailing logic is that if individuals with IDD don't understand sex, they can't consent to it (Onstot, 2019). In turn, if they don't engage in sexual acts, they are protected from harm (Perske, 1972). This logic is flawed. A lack of sexual knowledge makes individuals with IDD more susceptible to sexual abuse and less likely to report it (Sullivan & Knutson, 2000). However, sex education is proven to reduce engagement in risky sexual behaviors (Society for Adolescent Health and Medicine (SAHM), 2017; Santelli et al, 2017; World Health Organization (WHO), 2015) and increase the likelihood of reporting sexual abuse (Keshav & Huberman, 2006).

Sex Education in the United States

The World Health Organization argues that sexual health, including access to adequate sex education, is a human right, one that cannot be denied by caregivers or government policies (WHO, 2015). The SAHM (2017) specify, "Sexual and reproductive rights are grounded in a constellation of fundamental human rights guarantees, including the right to life, health, access to accurate health information, privacy, information, freedom from discrimination, and freedom from cruel, inhumane, and degrading treatment—among others" (p. 402). Unfortunately, in the United States the provision of sex education in general is inconsistent due to a lack of federal guidelines and funding (Lindberg & Kantor, 2022; SIECUS, 2021). Instead, this important responsibility is left up to individual states and local districts to mandate and fund. Sometimes it is a politically charged issue, with conservatives tending to favor abstinence-only or abstinence-until-marriage education (Eisenberg et al., 2013). However, most Americans support sex education in secondary schools, and 85% of those who do favor more comprehensive sex education (Planned Parenthood, 2018).

According to Future of Sex Education (FoSE, 2020), comprehensive sex education (CSE) goes beyond avoiding sexual activity and includes "knowledge and skills relating to human development, relationships, decision-making, abstinence, contraception, and disease prevention" (p. 60). Studies have shown that sex education is most effective prior to the start of sexual activity, therefore CSE ideally includes providing age-appropriate sex education early and continually (Goldfarb & Lieberman, 2021; FoSE, 2020, SIECUS, 2021). CSE has been proven effective throughout the world, resulting in positive outcomes such as delayed initiation of sexual activity, reduced incidence of sexually transmitted infection (STIs), and fewer unintended pregnancies (WHO, 2015). In addition to achieving traditional sex education aims, CSE has been shown to improve self-advocacy, communication, and relationship skills (Goldfarb & Lieberman, 2020; WHO, 2015). Despite this overwhelmingly positive evidence, while nearly 60% of students in the US received some form of sex education between 2011 and 2019 (SIECUS, 2021, p. 20), only around 50% of young adults in the US received more comprehensive sex education (Linberg & Kantor, 2022, p. 292). SAHM (S017) reports an unfortunate decrease in the percentage of American students receiving CSE versus abstinence-based sex education between 1985 and 2017.

Sex Education for Individuals with IDD

The results of CSE could be even more beneficial for individuals with IDD. Several of the social skills that individuals with IDD often struggle with—some of which could lead to serious repercussions in adulthood—are covered in CSE programs. This is especially true when considering that most individuals with IDD lack adequate access to same-aged, nondisabled peers to learn relationship skills and sexuality knowledge from informally (McDaniels & Fleming, 2018), and many lack caregiver support in fostering and supporting their sexuality (Kammes et al, 2020). For example, failing to understand boundaries or being able to identify

appropriate audiences and settings for certain behaviors can result in instances of inappropriate touching or exposure. These instances worsen public perception of individuals with IDD and can have legal consequences (Wolfe, 1997).

Individuals with IDD tend to be under constant supervision, even into adulthood, and they sometimes rely on others to assist with hygiene, toileting, and dressing needs. As such, they may not realize that they have a right to control what they and others do to their bodies (Howard-Barr et al., 2005). This makes them more susceptible to abuse. Sullivan and Knutson (2000) found that children with disabilities are 3.14 times more likely to experience sexual abuse than nondisabled children, and children with IDD are more likely to experience multiple types of abuse than other children with disabilities (p. 1265-1266). Understanding one's body, how it works, and the correct terminology for various body parts is essential to noticing and accurately reporting health concerns and abuse.

Still, only 44.6% of students with IDD received any sex education, making them the least likely of any federal disability category to receive sex education (SIECUS, 2021, p. 20). Not only does this deny them equal access to the experience of romantic relationships and sexuality, which are hallmarks of human existence, it puts them at increased risk of harm and unintended sexual misconduct. As Keshav and Huberman (2006) insist, "[R]egardless of the physical, mental or emotional challenges they face, young people have feelings, sexual desire, and a need for intimacy and closeness. In order to behave in a sexually responsible manner, each needs skills, knowledge and support" (p. 3). The reauthorization of IDEA in 2004 requires that students with disabilities be educated using evidence-based practices. Evidence overwhelmingly supports the benefits of CSE for all students, especially those with IDD. It is now up to researchers and service providers—like federal and state education departments, local districts, and outside support agencies—to determine the best way to implement this necessary service (Curtis &

Stoffers, 2023; Schmidt, Brown & Darragh, 2020; Barnard-Brak et al., 2014; Blanchett & Wolfe, 2002; Howard-Barr et al., 2005; McDaniels & Fleming, 2018; Schmidt et al., 2021).

Statement of Problem

It is well established that young adults with IDD do not receive comprehensive sex education (CSE) at the same rate as their nondisabled peers. The resultant lack of relationship and sexuality knowledge and skills has negative lifelong implications, such as increased susceptibility to sexual victimization and barriers to establishing wanted romantic relationships, which can have long term effects on their quality of life and mental health. When provided, existing sex education for young adults with IDD is typically characterized by inconsistency in onset of delivery, delivery method, topics covered, and staff responsible. The responsibility typically falls on special education (SPED) teachers, who have expertise in working with students with disabilities but lack the training required to teach CSE effectively. With the trend toward including students with disabilities in general education settings mandated by IDEA, general education health teachers are increasingly being suggested for the job. Previous research supports this recommendation. However, it is unclear whether general education health teachers have the experience or training required to deliver CSE to the unique population of young adults with IDD effectively.

Significance of Study

Much research has been done into the perspective of various groups on the sexuality of individuals with IDD. The views of parents and caregivers have been explored to better understand the ways in which they view their child with IDD, how they address the topic of sexuality, and the role they expect schools to play (Schmidt et al., 2021; Kammes et al., 2020; Swango-Wilson, 2011; Oakes & Thorpe, 2019; Bernert & Ogletree, 2013; Couldrick et al., 2010; Cuskelly & Bryde, 2004). The perceptions of special education professionals—including

teachers, administrators, support staff, and residential workers—have been analyzed to determine their past experiences, current practices and concerns, and future recommendations regarding the sexuality and sex education of individuals with IDD (Couldrick et al., 2010; Wolfe, 1997; Howard-Barr et al., 2005; Schmidt et al,. 2021; Curtis & Stoffers, 2023; Wilkenfeld & Ballan, 2011; Oakes & Thorpe, 2019; Kammes et al., 2020; Swango-Wilson, 2008; Cuskelly & Bryde, 2004). The general public has been surveyed to assess how understanding and accepting they are of the sexuality of individuals with IDD (Cuskelly & Gilmore, 2007; Cuskelly & Bryde, 2004; Tamas et al, 2019). Even the observations and recommendations of healthcare providers regarding the sexual health of individuals with IDD have been considered (Schmidt et al, 2021).

General education health teachers have been suggested as well-positioned to provide sex education to young adults with IDD in school (Howard & Barr et al., 2005; Curtis & Stoffers, 2023). Their perspectives on barriers to and best practices for delivering quality sex education generally have been assessed (Eisenberg et al., 2010; Eisenberg et al., 2013). However, their perspective regarding the sexuality of individuals with IDD and their confidence to teach comprehensive sex education to young adults with IDD has yet to be explored. Under IDEA, school districts have an obligation to provide evidence-based instruction to students with disabilities. In absence of additional funding dedicated to CSE for students with disabilities, districts will likely need utilize existing faculty to provide this important service. Providing effective, evidence-based CSE in accordance with IDEA will require school districts to provide adequate training and support for their general education health teachers. Understanding the perspectives, experiences, and confidence level of general education health teachers regarding young adults with IDD will enable districts to do so.

Purpose

This qualitative study sought to investigate the perspectives of secondary general education health teachers on the sexuality of individuals with intellectual and developmental disability (IDD) to discover any biases or misconceptions that need to be addressed and to determine what support and training they feel they need to deliver comprehensive sex education (CSE) to this population effectively. This data was used to generate a list of recommendations for local districts on how best to support their existing secondary general education health teachers in the implementation of formal comprehensive sex education for young adults with IDD.

Research Questions

- What types of supports do secondary general education health teachers need to effectively teach CSE to adolescents with IDD?
    - What are the perspectives of secondary general education health teachers on CSE for adolescents IDD?
    - What training, if any, have secondary general education health teachers received specific to teaching individuals with IDD?
    - How prepared are secondary general education health teachers to teach CSE to adolescents with IDD?

Theoretical Framework

People with IDD, like all people, have inherent sexual rights. These rights and needs must be affirmed, defended, and respected (The Arc of the United States and the American Association on Intellectual and Developmental Disabilities, 2021, p. 1).

Individuals with IDD often desire physical relationships and companionship but encounter barriers in achieving them. As Terzi (2005) describes, “When the whole capability of the person in achieving her valued ends is thereby compromised, impairment and disability become matters of justice” (p. 215). More broadly, the provision of sex education to individuals with IDD is a social justice issue because it concerns how a person’s traits may deny them access to just, equitable treatment (Terzi, 2005). More narrowly, the issue can be addressed by disability theory because it is rooted in the need to ensure equitable recognition and treatment of individuals with disabilities, so they have what they need to live a fulfilling life. The two predominant views of disability—the medical model and the social model (Bogart & Dunn, 2019)—are contrary but both problematic (Terzi, 2005). The medical model is problematic because it places too much emphasis on fixing those with disabilities and not enough on addressing societal barriers that make disability more impairing (Bogart & Dunn, 2019; Terzi, 2005). The social model is problematic because, by viewing disability as just another aspect of human diversity devoid of inherent limitations, it fails to acknowledge that some limitations caused by disability are still limiting regardless of society’s level of accommodation (Terzi, 2005).

The capability model, based off Amartya Sen’s Nobel Prize-winning theory of economics, has recently been applied to disability theory. It addresses weaknesses in the medical and social models in that it considers both the individual with a disability and society. The focus is on giving individuals with disabilities choice and autonomy. In terms of disability, this requires consideration of what an individual values, the limitations to achieving that valued end resulting from disability, and the support necessary to overcome said limitations to realize a fulfilling life (Bajmócy et al, 2022). When considering how best to support individuals with disabilities using the capability model, one must consider the freedoms the individual will have

in the future, not the freedoms (s)he has now (Terzi, 2005). So, although adolescents or young adults with IDD may not yet have interest in engaging in romantic and sexual relationships, it is reasonable to assume they may as an adult. So, they should be provided with the comprehensive sex education necessary to do so safely and responsibly.

Both the medical model of disability and the biological view of sex promote ableism, the act of looking down on or excluding people because of their disability, even when unintentional (Bogart & Dunn, 2019; Dunn, 2019; FoSE, 2020). As Bernert explains (2010), the medical model is problematic when framing the sexuality of individuals with IDD because, "The perception that ID equals dysfunction creates linear thinking that persons with ID are incapable of managing their sexuality" (p. 139). He goes onto explain how environments that are based on individuals' disabilities, such as group homes and day programs, further contribute to the denial of sexual freedom due to nearly constant staff oversight and behavioral restrictions meant to keep individuals with IDD safe (Bernert, 2010). Overprotectiveness towards individuals with disabilities, while well-intentioned, is misguided and denies them what Perske (1972) termed the "dignity of risk," the right to choose to engage in potentially harmful experiences safely. The biological view of sex is similarly problematic for individuals with IDD. Conceptualizing sex as solely a means of procreation positions it as something that only normal, nondisabled people should do and further serves to exclude individuals with IDD from the experience (Onstot, 2019). Instead, Couldrick and colleagues (2010) argue for the use of The Recognition Model when addressing the sexuality of individuals with disabilities in various settings, from healthcare to social services to education. The Recognition Model involves recognizing that individuals with disabilities are sexual beings, giving them explicit permission to discuss sexuality in an appropriate setting, and providing them with support to achieve their sexual goals (Couldrick et al., 2010).

The biological view of sex is also problematic in general because it frames the purpose of sex as procreation rather than pleasure. As Tepper (2000) describes, “The pleasurable aspect of sex in our culture has been largely ignored, vilified, or exploited” (p. 285). The negative repercussions of this view are myriad and pervasive. For one, it makes acknowledgement and discussion of sex for pleasure taboo and can have mental health implications for those who do not abstain. Also, it is discriminatory in that it reinforces the idea that sex is only for heterosexual couples. Stigmatizing the notion of sex for pleasure has in part resulted in billions of dollars of funding in the United States going towards abstinence-based sex education programs, which have proven to be ineffective (Santelli et al., 2017; Society for Adolescent Health and Medicine (SAHM), 2017). On the contrary, comprehensive sex education (CSE) is proven effective (Santelli et al, 2017; SAHM, 2017). The wealth of evidence disproving the effectiveness of abstinence-based sex education programs is so great that many health practitioners and the SAHM now recommend CSE. The updated position of the SAHM (2017) is, “Sexuality education should be comprehensive, medically accurate, and culturally competent; promote healthy sexuality; and prepare young people to make healthy sexual decisions” (p. 400). Some even argue that failing to provide adolescents with complete, accurate sexual health information is a violation of human rights (Santelli et al., 2017; SAHM, 2017; WHO, 2015). All adolescents, whether disabled or not, are entitled to effective, comprehensive sex education so they can live safe, fulfilling romantic lives.

Research Design

The design of this study is pragmatic and follows tenets of generic qualitative inquiry rather than adhering to a specific qualitative methodology. It utilizes a “cross-sectional interview-based design” supported by supplementary questionnaire data (Smith et al., 2011). All teachers who consented to participate were administered two data collection measures

separately: a virtual questionnaire and a semi-structured interview. True to qualitative inquiry, the driving data for this study is qualitative interviewing. Supplementary close-ended questionnaire data is used to contextualize, confirm, and enhance interview findings, but it is of secondary importance to interview data and is not the primary focus of the study. The questionnaire—a researcher-revised version of the *Attitudes to Sexuality Questionnaire - Individuals with an Intellectual Disability (ASQ–ID)*—assessed participants' perceptions of the sexuality of individuals with IDD and elucidated any common misconceptions participants held about the sexuality of individuals with IDD.

Delimitations

Certain delimitations were set by the researcher to focus the scope of the study. The target population of secondary general education health teachers was selected to fill a gap in the existing research. This group is often mentioned as being well positioned to teach CSE to young adults with IDD, but their perspectives have yet to be explored. Instead, the focus has been on the perspectives of parents, special education staff, and the public (Cuskelly & Bryde, 2004; Cuskelly & Gilmore, 2007; Tamas et al, 2019). The decision to focus on research sites local to Northeastern Pennsylvania was guided by the lack of federal guidelines and funding for CSE, which leaves the responsibility to plan for and fund CSE up to state governments and local districts (Planned Parenthood, 2023). The ASQ-ID questionnaire was selected as a secondary data collection method because, although it is close-ended, it is an established measure that has been used in previous studies on the perception of the sexuality of individuals with IDD (Cuskelly & Bryde, 2004; Cuskelly & Gilmore, 2007; Tamas et al, 2019). Finally, the decision was made to utilize generic qualitative inquiry guided by pragmatism, rather than a specific qualitative methodology like grounded theory, to prioritize the problem over the methodology.

Definition of Terms

Special Education Teacher – A special education teacher is one whose primary purpose is to educate and support students with disabilities and to support other non-special education faculty and staff, such as general education teachers, in doing so. They are certified in special education and specialize in understanding the needs of diverse learners and utilizing instructional strategies and techniques to meet those needs.

General Education Teacher - A general education teacher is one whose primary purpose is to educate all students. While general education teachers typically have students with disabilities in their classes, they usually do not have specialized training in how best to support students with diverse learning needs. General education certifications vary, but general education teachers specialize in a content area, such as health, or a specific grade level, such as third grade. The term general education is often used interchangeably with the term regular education.

Health Teacher - A health teacher is a teacher who is certified to teach health class, a component of which is sex education. Other topics often include healthy eating, exercise, self-care, and substance abuse avoidance. Often, health teachers are primarily physical education (a.k.a. gym) teachers who also teach health classes. The Pennsylvania Department of Education (PDE, 2023) requires, “Every student in a primary (generally grades K-3), intermediate (generally 4-6), middle school (generally grades 7-9) and senior high (generally 10-12) programs must be provided with planned instruction that is aligned with academic standards in health and physical education” (PDE). In Pennsylvania, there are two possible health teacher certifications: Health Education PK-12 or Health and Physical Education PK-12.

Secondary Teacher – Secondary teachers are teachers of middle and high school, which typically spans grades seven through twelve. Their students are generally adolescents and young adults, ages thirteen through twenty-one.

Least Restrictive Environment (LRE) - LRE is a tenet of 1997 amendment of the Individuals with Disabilities Education Act (IDEA), which governs the education of students with disabilities in the United States. As stated in IDEA (2015), LRE requires, "[T]o the maximum extent appropriate, children with disabilities, including children in public or private institutions or other care facilities, are educated with children who are nondisabled" (Sec. 300.114(a)(2)(i)). This means that students with disabilities must have the opportunity to take part in all aspects of the general education setting, including classroom, peers, curriculum, and teachers, as much as meaningfully possible with specially designed instruction and supplementary aids and services. All of this must be provided at no cost to students or families. The enactment of LRE is commonly referred to in schools as inclusion.

Specially Designed Instruction (SDI) – The Pennsylvania Training and Technical Assistance Network (PaTTAN, 2018) of the PDE's Bureau of Special Education defines specially designed instruction as "adapting, as appropriate, the content, methodology, or delivery of instruction to address the unique needs of the student that result from the student's disability and to ensure access of the student to the general education curriculum" (p. 33). Often, SDI is carried out in the general education classroom. It can include things like providing picture supports for reading passages, breaking assignments into smaller chunks, frequently checking for understanding, and allowing extra time for tests and assignments.

Supplementary Aids and Services - The PaTTAN (2018) defines supplementary aids and services as, "aids, services, and other supports that are provided in regular education classes, other education-related settings, and in extracurricular and nonacademic settings, to enable students with disabilities to be educated with nondisabled students to the maximum extent appropriate" (p. 34). This includes things like the support of a paraprofessional, access to a counselor or social worker as needed, speech and language therapy, occupational therapy,

physical therapy, services for the Deaf and hard of hearing and visually impaired, and special transportation. It can also include adjustments to the typical general education curriculum, such as providing an adapted textbook, modifying an assignment, or utilizing different grading criteria. All necessary SDI and supplementary aids and services must be provided at no cost to students and families.

Free Appropriate Public Education (FAPE) - FAPE is another tenet of IDEA. As stated in IDEA (2015), FAPE requires, "A free appropriate public education must be available to all children residing in the State between the ages of 3 and 21, inclusive, including children with disabilities who have been suspended or expelled from school" (Sec. 300.101(a)). FAPE impacts schools in two main ways: (1) schools most provide any supplementary aides or services a student needs to make measurable progress at no cost to students or families, including private school tuition and transportation when local districts cannot provide an adequate education, and (2) students with disabilities must receive a meaningful education appropriate to their level that allows them the opportunity to make measurable progress.

Intellectual and Developmental Disabilities (IDD) – Intellectual disability (ID) is a type of developmental disability (DD); prior to 2010, ID was referred to as mental retardation (MR). IDD includes people with intellectual disability (ID) and/or developmental disabilities (DD). The Arc of the United States and the American Association on Intellectual and Developmental Disabilities (2021) define DD as:

> a group of lifelong conditions that emerge during the developmental period and result in some level of functional limitation in learning, language, communication, cognition, behavior, socialization, or mobility. The most common DD conditions are [ID], Down syndrome, autism, cerebral palsy, spina bifida, fetal alcohol syndrome, and fragile X syndrome (footnote).

The severity of IDD is typically classified as mild, moderate, or severe.

Sexuality – Sexuality has a variety of meanings. For this study, sexuality will be used according to the definition provided by McDaniels and Fleming (2018), who explain, "Sexuality is greater than just participation in sexual relationships; it encompasses sexual knowledge, beliefs, attitudes, and behaviors" (p. 29). This includes individuals' level of interest in sexual expression, even asexuality, and their understanding of what it means to be a sexual being. The World Health Organization (WHO, 2015) expands on that definition, adding, "Sexuality is a central aspect of being human throughout life" (p. 5).

Comprehensive Sex Education (CSE) – Generally, sex education curricula fall on a spectrum of topic coverage between most inclusive, which is referred to as CSE, and least inclusive, which is referred to as abstinence-only education or abstinence-until-marriage education. CSE goes beyond the traditional, narrow, biologically based conception of sex solely for procreation, the purpose of which is to avoid the risks of sex like unintended pregnancy and sexually transmitted infection (STI). Instead, CSE takes a more holistic approach. The breadth of topics covered varies, but according to the *National Sex Education Standards* (FoSE, 2020), CSE includes "knowledge and skills relating to human development, relationships, decision-making, abstinence, contraception, and disease prevention" (p. 60). This can include topics like masturbation, consent, sexual identity, and sexual orientation, but always goes beyond simple avoidance of sex and the associated risks.

Summary

There is a proven need for comprehensive sex education (CSE) for individuals with IDD in the United States to allow them to live their most fulfilling adult lives and to help keep them safe from harm. This study sought to fill a gap in the existing research by investigating the perspectives of secondary general education health teachers on the sexuality of individuals with

IDD, their experiences and comfort level with teaching that population, and the training and support they feel they would need to do so effectively. The topic of sex education for individuals with IDD is both a social justice issue and disability studies issue. It was investigated according to the tenets of generic qualitative inquiry and utilizing a cross-sectional interview-based design. The results were used to generate actionable recommendations for local districts to implement to enable them to take advantage of their existing general education health teachers to effectively deliver this much needed service to young adults with IDD.

The next chapter provides a more detailed description of the treatment of individuals with IDD in society. It also describes varying perspectives on the sexuality of individuals with IDD, such as those of individuals with IDD themselves, special education staff, and caregivers. Then, it explains the provision of sex education in the United States in general. Finally, it provides evidence for the need for CSE for individuals with IDD and best practices for delivering CSE to young adults with IDD, including topics to cover and who best to deliver.

CHAPTER 2: REVIEW OF THE LITERATURE

Purpose

This qualitative study sought to investigate the perspectives of secondary general education health teachers on the sexuality of individuals with intellectual and developmental disability (IDD) to discover any biases or misconceptions that need to be addressed and to determine what support and training they feel they need to deliver comprehensive sex education (CSE) to this population effectively. This data was used to generate a list of recommendations for local districts on how best to support their existing secondary general education health teachers in the implementation of formal comprehensive sex education for young adults with IDD.

Research Questions

- What types of supports do secondary general education health teachers need to effectively teach CSE to adolescents with IDD?
    - What are the perspectives of secondary general education health teachers on CSE for adolescents IDD?
    - What training, if any, have secondary general education health teachers received specific to teaching individuals with IDD?
    - How prepared are secondary general education health teachers to teach CSE to adolescents with IDD?

Need for the Study

Individuals with IDD in Society

Prior to the adoption of the term intellectual disability in 2010, individuals with IDD were termed mentally retarded, a word now fraught with negative connotations. The *Diagnostic*

and Statistical Manual, 5th Education (DSM-5) of the American Psychiatric Association (2013) describes IDD as:

> deficits in general mental abilities, such as reasoning, problem solving, planning, abstract thinking, judgement, academic learning, and learning from experience...[which] result in impairments of adaptive functioning, such that the individual fails to meet standards of personal independence and social responsibility in one or more aspects of daily life. (p. 31)

In 2017, 6.99% of children in the United States had a developmental disability diagnosis (Zablotsky & Blumberg, 2017). The severity level of IDD varies and is classified into three broad categories: mild, moderate, and severe.

The United States does not have a proud history of the treatment of individuals with IDD. Prior to the 1960s, most individuals with IDD were institutionalized in facilities that were later deemed unfit. As summarized in the Sexuality Information and Education Council of the United States's (SIECUS) publication *Comprehensive Sex Education for Youth with Disabilities: A Call to Action* (2021), the Civil Rights Movement was the beginning of positive change for individuals with IDD. By 1967, most facilities were closed, and integration into private homes and schools became the norm, although students with IDD were still not included to the degree they are today. The enactment of the Handicap Children Act in 1975—which later became the Individuals with Disabilities Education Act (IDEA)—was the beginning of inclusion as we now know it, the practice of including students with disabilities in the general education classroom alongside their nondisabled peers. IDEA guaranteed students with disabilities a right to a free and appropriate public education (FAPE) in the least restrictive environment (LRE) meaningfully possible with adequate specially designed instruction and supplemental aids and services.

IDEA was reissued in 2004 and continues to govern special education to this day. In 1990, protections for individuals with disabilities were extended beyond public schools with the issuance of the Americans with Disabilities Act (ADA), which mandated that individuals are not discriminated against based on their disabilities. As Grove et al. (2018) explain, “These landmark pieces of legislation sought to create a culture and society where individuals with disabilities had expanded access and opportunities to pursue their dreams and a better quality of life.” (p. 314) Part of a full, satisfying adult life is being able to establish and maintain healthy romantic relationships, and in this area individuals with IDD are still at a disadvantage. Children and adolescents with IDD are more likely to be sexually abused and less likely to receive sex education than their nondisabled peers (Sullivan & Knutson, 2000; SIECUS, 2021). As adults, individuals with IDD are less likely to have opportunities and support to engage in desired healthy romantic relationships (Bernert, 2010; Kammes et al., 2020).

The Crime Victims with Disabilities Act in 1998 represented recognition that individuals with disabilities are more likely to be victimized than their nondisabled peers, including an increased risk of sexual abuse (SIECUS, 2021). Efforts have been taken to protect individuals with IDD from sexual victimization, but the result of many of these protective policies and measures is a lack of sexual autonomy on the part of individuals with IDD. There is a misconception that cognitive functioning is representative of an individual’s maturity level or capacity for independence. Onstot (2019) found that court systems and caregivers often get to make decisions about the ability of individuals to consent to sexual activity by objectively assessing their mental capacity. So, while there are many misguided policies in place intended to protect individuals with IDD from sexual harm by prohibiting them from sexual relationships, there are no laws in place in the United States to protect their sexual rights (Onstot, 2019).

Rather than attempting to shield individuals with IDD from romantic relationships to keep them safe, there should be comprehensive programs and supports in place to help individuals with IDD make smart choices to keep themselves safe (SIECUS, 2021). Some programs have been designed specifically for individuals with IDD, such as the Circles and Positive Choices curricula, but more research is needed to determine their effectiveness (Blanchett & Wolfe, 2002; Graff et al, 2018; Faught et al, 2020). Unfortunately, when sex education is provided to this population it is typically inadequate, either in frequency, duration, method of instruction, or content. Usually, sex education for individuals with IDD is focused on preventing the dangers of sexual activity and not on fostering healthy, fulfilling romantic relationships (McDaniels & Fleming, 2018).

Perspectives on the Sexuality of Individuals with IDD.

Enmeshed in the troubling history of the treatment of individuals with IDD in the United States is the normalized denial and repression of the sexuality of individuals with IDD, which is based largely on myths and misconceptions (Onstot, 2019). The institutionalization of individuals with IDD prior to the 1960s included policies and practices that minimized and suppressed their expressions of sexuality, including frequent separation of genders and, at times, forced birth control and sterilization (Faught et al., 2020; SIECUS, 2021). Although the practice of institutionalization has largely ended, individuals with IDD still lack the romantic and sexual freedom that adults without disabilities typically enjoy. Despite the improvements in integration and recognition of individuals with IDD, there is still a history of misinformation that surrounds IDD, such as that if people with IDD reproduce, they will spread their condition (Onstot, 2019).

Perspectives of Individuals with IDD. Bernert (2010) studied the perspectives of adult women with IDD and found that policies intended to protect women with IDD held them back and prevented them from living their fullest lives. The women—most of whom were living in a

residential facility—expressed the feeling that their lives were centered around their disability because they relied on others for access to transportation, habitation, vocation and socialization. Rules and policies prevented them from establishing and maintaining romantic relationships, such as not allowing displays of affection, requiring couples to be married before living together, requiring a chaperone on dates, and only being able to socialize in common areas unless they have parent permission. While the women acknowledged their lack of autonomy in practice, they still viewed themselves as women first, disabled second, and they became upset when others got in the way of their sexual freedom. As a result, they felt compelled to assert their independence whenever possible, which at times resulted in risky behavior, such as engaging in sex in a restaurant bathroom (Bernert, 2010). These experiences are common for adults living in a group home and are not things typical adults must contend with. They prove that individuals with IDD do not have the access to sexual freedom and romantic relationships to which they are entitled.

The group home staff in Bernert's (2010) study described the adult women's behavior around romantic relationships as immature—such as changing significant others rapidly, bickering with housemates, and gossiping about each other—and they used that explanation to further infantilize the women and justify why they weren't prepared to handle adult relationships. However, rather than being a sign of incapacity, this is an indicator that these women are lacking the skills needed to engage in safe, healthy, mature relationships. These are skills they could acquire with proper training and practice, which is further evidence of why CSE early and often is so important.

In another study exploring the perspectives of adult women with IDD, Bernert and Ogletree (2012) found that most of the women were sexually inexperienced and had negative views of sex, even those who had been sexually active. These negative views were based on fear of the dangers of sex, such as contracting an STI or getting pregnant, and stem from previous

formal or informal sex education they had received from school, caregivers, and staff. For some, negatives views also stem from previous negative experiences with sex, such as abusive relationships and sexual assault. One staff member was quoted as saying, “When have they had an opportunity to have a positive experience? I mean, they’re not educated about it. They don’t have the right place to do it. So how are they going to see sex as positive?” (p. 246). This reinforces the importance of CSE that goes deeper than simply preventing the negative outcomes of sex and teaches how to have and enjoy healthy romantic and sexual relationships that are the basis for most fulfilling adult lives. It also reiterates the need for paradigm and policy shifts that do a better job of balancing protecting individuals with IDD from sexual harm with ensuring their right to sexual freedom (Bernert, 2010).

Perspectives of Special Education Staff. Adolescents and adults with IDD typically require the support of many specialized staff members to learn, live and work as independently as possible. In public schools, this can include special education teachers and administrators, paraprofessionals (also known as support staff), nurses, and related service providers, like speech therapists, physical therapists, and occupational therapists. In Pennsylvania, students with IDD can continue to receive educational services until their twenty-second birthday, as recently updated in the Pennsylvania Department of Education’s (PDE) Individuals with Disabilities Education Act (IDEA) regulations, effective September 5, 2023 (PDE, 2023). As they approach adolescence and grow closer to adulthood, outside agency support typically begins. This can include vocational support in the form of work assessments, job shadows, and job coaching. It can also include behavioral health services, such as individual, school-based, and family-based counseling. In addition, it can include support for independent living, such as transportation and assistance navigating the community and assistance finding a supported living arrangement. These services are often provided by the county in which the individual resides. When K-12

educational services end on a student's twenty-second birthday, agency services become the primary support for individuals with disabilities outside of their families. As adults, individuals with IDD who do not have the skills and abilities necessary to maintain competitive or supported employment often participate in day programs for adults with disabilities. Those whose families are not able or willing to house them in adulthood often end up in group homes. In these cases, support staff take on the role of caregiver.

A substantial body of research exists on the perspectives of different professionals working with individuals with IDD at various life stages, from adolescence to adulthood, on the sexuality of the population, both in the United States and abroad. Many common themes have emerged from this research. Overwhelmingly, special education teachers feel reluctant to teach CSE topics for several reasons, including lack of specialized sex education training (Howard-Barr et al, 2005; Gerchenovitch & Rusu, 2019; Tamas et al., 2019; Schmidt et al., 2021, Curtis & Stoffers, 2023), lack of clear consistent policies and standards governing sex education (Schmidt et al, 2021), and concerns about lack of parental support (Cuskelly & Bryde, 2004; Wilkenfeld & Ballan, 2011; Schmidt et al., 2021, Curtis & Stoffers, 2023). Some also hold misconceptions about the sexuality of individuals with IDD or are encumbered by their own religious beliefs and/or sexual values (Gerchenovitch & Rusu, 2019; Schmidt et al., 2021). One special educator described how some educators convey "a 'weird overextension that all sex is bad and if anyone ever touches you it's wrong'" (Schmidt et al., 2021, p. 4).

Rather than providing formal, proactive sex education, many special education professionals report providing reactive sexuality information in response to statements of misinformation, questions, or inappropriate behavior (Schmidt et al., 2021). Many special education teachers also cover sex education topics informally as part of other content areas, especially those topics related to social skills (Schidt et al., 2021). But most feel unprepared to

teach the topic formally and worry about discussing such a sensitive topic in the absence of clear guidelines regarding their role in the sex education of individuals with IDD. The lack of preparation and guidelines for supporting the sexual health needs of individuals with IDD is a worldwide problem. Tamas et al. (2019) from Serbia acknowledge this shortcoming and state:

> It is recommended that the education of professionals on the subject of sexuality of person with ID be intensified within the existing educational, health, and social security institutions… Professionals should be given clear guidelines for dealing with specific situations associated with the manifestation of sexual behavior of persons with ID, as well as for educating and counseling their parents on the subject (p. 255).

However, an overwhelming majority of special education professional studied support formal sex education for individuals with IDD (Wilkenfeld & Ballan, 2011; Gerchenovitch & Rusu, 2019; Schmidt et al, 2021; Curtis & Stoffers, 2023). Middle or high school are commonly suggested as an appropriate time to begin providing formal sex education to individuals with IDD, although some special education professionals feel it should begin even earlier, and most agree supports should be lifelong (Wilkenfeld & Ballan, 2011; Gerchenovitch & Rusu, 2019).

Many special education professionals studied have expressed concern about parents' role in the sexuality of individuals with IDD. Parents' attitudes towards the sexuality of individuals with IDD are commonly cited as a barrier to providing adequate CSE (Cuskelly & Bryde, 2004; Wilkenfeld & Ballan, 2011; Schmidt et al., 2021, Curtis & Stoffers, 2023). Generally, it is believed that families and schools share responsibility for effectively educating young people with IDD about sexual health and relationships, while parents are also primarily responsible for providing them with adequate privacy and appropriate outlets for safe sexual exploration and romantic relationships (Wilkenfeld & Ballan, 2011). Studies have shown that parents and

professionals tend to have differing views and levels of acceptance regarding the sexuality of individuals with IDD (Cuskelly & Bryde, 2004; Tamas et al., 2019). This is problematic because, as Cuskelly and Bryde (2004) explain, “A difference in values around sexuality and its expression may make it difficult for the two groups to work together and may produce a sense of confusion around sexual mores and behavior for individuals with [IDD]” (p. 260). Special education teachers’ common reluctance to take on the role of providing sex education coupled with the importance of parent involvement provide support for the idea of a team approach to CSE for individuals with IDD, including special educators, parents and others, like regular education health teachers and nurses (Wilkenfeld & Ballan, 2011; Schmidt et al., 2021).

Although special education professionals studied overwhelmingly support some type of formal sex education for individuals with IDD, there is a lack of consensus regarding what topics should be covered. This lack of consensus stems from a difference in the types of romantic and sexual behaviors deemed appropriate for individuals with IDD by special education staff, which varies based on several factors such as the professional’s role, age, and personal and religious background (Wolfe, 1997; Gerchenovitch & Rusu, 2019). The severity of the individual’s IDD is also a factor in determining when to provide sex education and what topics to cover, with a reduction in the sex education topics perceived as important as severity of IDD increases (Wolfe, 1997). Nearly all special education teachers agree that individuals with IDD should be taught social and relationship skills, including boundaries, consent, and managing emotions (Wolfe, 2997; Howard-Barr et al., 2005; Cuskelly & Bryde, 2004). Many feel that sexual behavior should be covered in some capacity (Howard-Barr et al, 2005; Wilkenfeld & Ballan, 2011). There is a lack of consensus among special education professionals as to whether the concept of sexual pleasure, including masturbation and contraception, should be taught to individuals with IDD (Wolfe, 1997; Howard-Barr et al, 2005; Wilkenfeld & Ballan, 2011). Most special education

professionals studied do not believe individuals with IDD should procreate due to concerns about their inability to care for a child when they often struggle to independently care for themselves and concerns for their personal health and wellbeing due to their own medical issues (Wolfe, 1997; Wilkenfeld & Ballan, 2011). However, many support marriage between consenting individuals (Wolfe, 1997; Wilkenfeld & Ballan, 2011). It is also widely agreed that individuals with IDD require specialized curricula and teaching strategies, much like they do for other content areas (Wilkenfeld & Ballan, 2011).

Inclusive post-secondary education programs (IPSE) at traditional colleges and universities are a relatively new post-secondary option for higher functioning young adults with IDD. Oakes and Thorpe (2019) investigated the perceptions of young adults with IDD enrolled in one such program and their support staff, and they identified the following common themes in student responses:

> limited knowledge of sexual health and sexual health resources; lack of interest in sexual health for now; awkwardness and lack of comfort in talking about sexual health; wanting support with sexual health from friends and/or support staff; ideas for improving sexual health programs; barriers to participation in sexual health programs; and autonomy. (p. 592)

Staff agreed that students lacked adequate sexual health knowledge and that students were uncomfortable discussing the topic, likely due to having internalized that the subject is taboo and not to be discussed. Evidence that both older adults and young adults with IDD were lacking in sexual health knowledge shows that this is a persistent, lifelong problem that is not currently being addressed in adolescence or in adulthood.

Although all staff members in this study believed young adults with IDD have a right to sexual freedom and indicated they are comfortable discussing sex and relationships with students, Oakes and Thorpe (2019) did find that students and staff tend to be more uncomfortable discussing sexual health topics with the opposite sex, especially for male staff members and female students. This finding highlights the need for clearly defined guidelines outlining the roles and expectations of staff regarding addressing sexual health concerns and needs with students so that staff members don't have to fear accusations of impropriety.

Sex Education in the United States

Although there is widespread public support for sex education in schools, there are no nationally accepted sex education standards (Lindberg & Kantor, 2022; Planned Parenthood, 2018). As a result, there is immense variation in the topics covered and amount of sex education provided from state to state and district to district (Lindberg & Kantor, 2022). There is also no federal funding provided for CSE (SIECUS, 2021). Instead, the limited funding available is earmarked for pregnancy-prevention programs only (Lindberg & Kantor, 2022). So, funding CSE falls on states. The United States Department of Health and Human Service's Office of Disease Prevention and Health Promotion state in their Healthy People 2030 framework for improving the health and well-being of all Americans—including those from historically disadvantaged groups, such as those with disabilities—that they have a goal to "increase the proportion of adolescents who get formal sex education before 18 years of age," but their data indicates "little or no detectable change" in this area between 2015-2017 and 2017-2019 (Office of Disease Prevention and Health Promotion, n.d.). This lack of national standards and federal funding for sex education indicate that sex education is not a priority in the United States, even for nondisabled students. Organizations like Sexuality Information and Education Council of the United States (SIECUS) and Advocates for Youth are attempting to change that with the

issuance of their recommended *National Sex Education Standards*, which were recently updated in 2020.

CSE is now the recommended form of sex education for all students, including those with IDD (SIECUS, 2021). The National Sex Education Standards, recently updated in 2020, include the following topics: "Consent and Healthy Relationships, Anatomy and Physiology, Puberty and Adolescent Sexual Development, Gender Identity and Expression, Sexual Orientation and Identity, Sexual Health, [and] Interpersonal Violence" (FoSE, 2020, p. 9). However, comprehensive sex education is not widely provided (McDaniel & Fleming, 2018). Instead, many states and district still provide outdated education focused primarily on preventing pregnancy and covering topics like contraceptive use and abstinence. McDaniels and Fleming (2018) describe, "Considering the contentious nature of sexual health education within the public education landscape, it is not surprising that for students with intellectual disabilities, access to education, information and appropriate curricula is seriously lacking." (p. 29). While the general lack of adequate comprehensive sex education is a problem for all students, it is an especially pernicious problem for individuals with IDD because they often lack the ability and opportunity to gain informal sexual health information from sources like the internet and their friends the way their nondisabled peers do.

Need for Comprehensive Sex Education (CSE) for Individuals with IDD

While inclusion of individuals with IDD into residential, educational, and vocational settings with their nondisabled peers was a positive and necessary change, it comes with repercussions and obligations. For instance, the increased visibility of individuals with IDD also makes them more susceptible to harm by people who want to take advantage of their limitations (Bernert, 2010). It also means that unintentional inappropriate sexual behaviors can result in stigmatizing views of the population, thereby hurting efforts at inclusion (Wolfe, 1998). These

are some of the many reasons why sex education is so important for this population. The increased inclusion of students with IDD in public schools equates to an increased responsibility to provide sex education for students with IDD. An increasing number of young adults with IDD are also attending inclusive post-secondary education programs at typical colleges and universities, which presents an additional opportunity for further sex education and relationship building (Oakes & Thorpe, 2019). Yet, in the United States students without IDD are more likely to receive sex education than those with IDD (Barnard-Brak et al., 2014). Curtis and Stoffers (2023) examined and described the current "eclectic landscape of sex education for people with [IDD]" in the United States (p. 15). They identified seven common service models and found that, when provided, sex education for individuals with IDD is characterized by a lack of consistency in providers, funding, age of onset, content, frequency, and duration (see Table 2.1). High-school based sex education was the least common service model identified, although it is a promising model worthy of further consideration (Curtis & Stoffers, 2023).

Table 2.1

Service Delivery Models [of Sex Education for Individuals with IDD] and Definitions

Service Model	Definition	Funding
Disability programs	Community-based agencies offering services to support individuals with disabilities. As one component of these programs, sex education services are provided to consumers, or sometimes the agency is contracted by nearby schools to provide sex education.	Grants; Donors; agency funds; Medicaid
Small businesses	For-profit enterprises that design and potentially market sex education curricula. Schools and organizations often hire these businesses to provide sex education to individuals with disabilities.	Contracts with schools and organizations; Medicaid; out-of-pocket fee; sale of curriculum; consultations and trainings
University-based educators	University faculty who either provide sex education instruction to students with disabilities in post-secondary programs or offer sex education programs to community partners and conduct research on implementation.	University-based funds and fees; Medicaid; research grants

Clinic-based board-certified behavior analysts (BCBAs)	Clinics that provide behavior services rooted in applied behavior analysis. Some clinic-based BCBAs focus exclusively on sex education, while others offer comprehensive behavior support that may include sex education for individuals who demonstrate this need.	Medicaid or private insurance billing; out-of-pocket fee
Public health not-for-profits	Organizations that provide education and sexual health services for community members with and without disabilities.	Grants (e.g., Office for Violence Against Women and Department of Health and Human Services)
Mental health therapists	Clinicians who provide mental health services to clients and may support victims and perpetrators of sexual violence. Sex education may be offered as part of these services.	Medicaid or private insurance billing; out-of-pocket fee
High school-based educators	Educators based in high school settings who support students with disabilities and provide sex education instruction to these students as part of their job.	School-based funding

From "Service models for providing sex education to individuals with intellectual disabilities in the United States," from Curtiss, S. L. and Stoffers, M., 2023, *Journal of Intellectual Disabilities*, p. 7. (https://doi.org/10.1177/17446295231164662). Copyright 2023 by Curtiss, S. L. and Stoffers, M.

Barriers to Providing CSE for Individuals with IDD. There have been improvements in the provision of post-secondary education and training, vocational skills and supports, and independent living services for individuals with IDD, but sexual and romantic freedom is an area that has yet to be achieved for those with IDD (Kammes et al. 2020). Although sexual knowledge and freedom for individuals with IDD is more about enabling them to enhance their quality of life through fulfilling relationships than it is about sex, the two are often intertwined (Bambara & Brantlinger, 2002). As Brodwin and Frederick (2010) conclude, "If society accepts that sexual expression is a natural and essential part of human existence, then perceptions that deny sexuality for [persons with disabilities] refute a basic right of expression." (p. 40) The preconceptions of staff and caregivers often result in barriers to individuals with IDD being able to have adult relationships. For example, many special education teachers fail to see students

with IDD as autonomous beings capable of or interested in sexual relationships (Howard-Barr et al., 2005; Kammes et al., 2020). Special education teachers are often more likely to recommend providing sex education to individuals with milder forms of IDD because those students are better outward communicators, but that is not a predictor of their capacity for comprehension.

As Barnard-Brak et al. (2014) explain:

> [E]very student has the potential to benefit from some form of sex education as long as the instructional trials are matched to the individual student's strengths and weaknesses, just like in any other educational content area. The goal is that sex education not be viewed as a question of "Are they ready to learn this information?" but instead be approached as another skill that needs to be taught through an IEP. (p. 93)

Sadly, politics and policies influence whether CSE can be provided, often limiting the provision of sex education for individuals with disabilities to preventing negative outcomes such as pregnancy, STIs and abuse, if provided at all (Curtis & Stoffers, 2023). Some educators and staff members who support sex education for individuals with IDD are still reluctant address the topic and answer questions due to the stigma surrounding the discussion of sexual topics with students (Kammes et al., 2020).

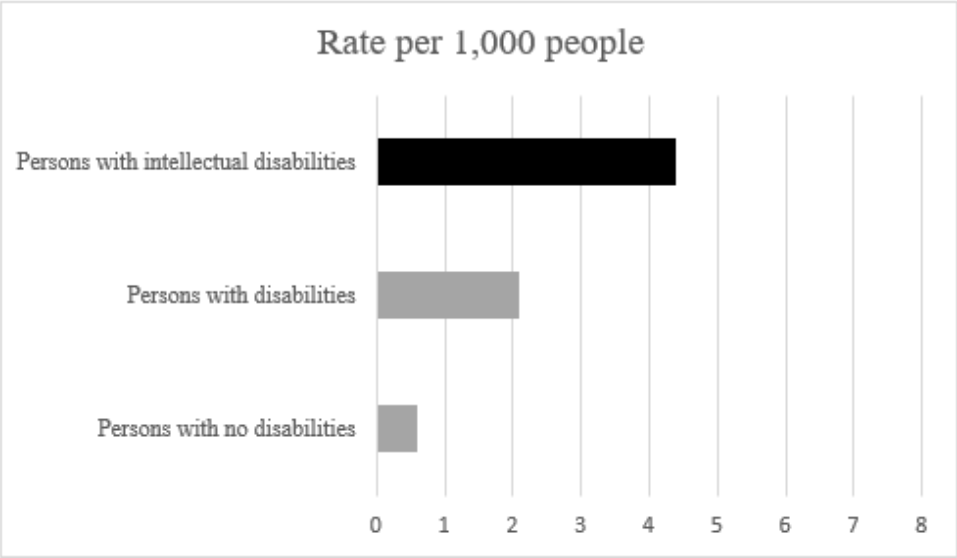
Dangers of Failing to Provide CSE to Individuals with IDD. For individuals with IDD, not having any trusted adults to discuss sexual health and relationship topics with is especially detrimental because they typically lack access to informal outlets for sexual health information, such as nondisabled peers and the internet (Kammes et al., 2020). Turning to the Internet and social media for sexual health information is particularly problematic because individuals with IDD lack the ability to accurately assess the reputability of online sources and the authenticity of people they meet online (McDaniels & Fleming, 2018). The presence of

predatory individuals online makes the internet another avenue in which individuals with IDD are vulnerable to exploitation and abuse. In addition, the same lack of social skills that typically prevent individuals with IDD from developing friendships with their nondisabled peers can have additional negative repercussions. For example, not understanding personal space can result in getting too close or touching people, which could cause conflict and, in some instances, constitute a crime.

Individuals with IDD are more likely to be sexually abused than their nondisabled peers. An NPR investigation into Pennsylvania state and federal crime data in 2018 found that individuals with IDD are seven times more likely than nondisabled individuals to report being sexually abused (see Figure 2.1). The actual prevalence is likely higher because these crimes are believed to often go unreported (Shapiro, 2018). NPR's Joseph Shapiro (2018) states "there is an epidemic of sexual abuse against people with intellectual disabilities. These crimes go mostly unrecognized, unprosecuted and unpunished. A frequent result was that the abuser was free to abuse again. The survivor is often re-victimized multiple times" (para. 24).

Figure 2.1

Sexual Assault Rates Among People with Intellectual Disabilities, 2011-2015



Note: Data from the Bureau of Justice Statistics, National Crime Victimization Survey, Special Tabulation. From *The Sexual Health Epidemic No One Talks About,* Joseph Shapiro, 2018 (https://www.npr.org/2018/01/08/570224090/the-sexual-assault-epidemic-no-one-talks-about). Copyright 2018 by NPR.

Keeping individuals with IDD safe is crucial but preventing them from engaging in romantic relationships and sexual activity does not guarantee their safety. It does, however, deny them experiences that are essential to the human experience and to a fulfilling adult life (Onstot, 2019). It is unacceptable for individuals with IDD to refrain from romantic relationships and sexual activity out of fear of judgement or punishment, misinformation about negative consequences, and lack of knowledge about how to do so safely. Some argue it is more unsafe to continue to deny individuals with IDD the opportunity to realize their bodily autonomy. As SIECUS (2021) explains:

> Some [youth with disabilities] are taught to accept that adults will touch their bodies to care for them, often without asking...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 youth with disabilities targets for sexual victimization. (p. 12)

The best way to counter those experiences and give individuals with IDD back their personhood and right to sexual freedom is to empower them with the knowledge and skills necessary to make smart sexual health and relationship choices so they can avoid dangerous experiences and enjoy the benefits of safe, fulfilling ones.

Best Practices for Sex Education for Individuals with IDD

Individuals with IDD, like all individuals, vary greatly in their abilities and skills, so sex education needs to be individualized to the needs of each learner. While substantial research has been done to date on best practices for delivering CSE to individuals with mild IDD, little to no research has been done on individuals with moderate to severe IDD; this is an area in need of investigation. In the meantime, the findings of existing studies can be used to plan the provision and delivery of appropriate, meaningful CSE that effectively increases the sexual knowledge and relationship skills of individuals with IDD. These best practices can be broken down into two broad categories: structural/planning recommendations for the provision of CSE and instructional recommendations and strategies.

Planning Recommendations

In terms of planning for the provision of CSE for individuals with IDD at a national, state, district, or even school level, experts agree that sex education should be offered early and often (FoSE, 2020; Howard-Barr et al., 2005; Schmidt et al., 2021; Schmidt, Brown & Darragh, 2020; SIECUS, 2021). While there is some disagreement as to whether elementary or middle school is best, so long as the curriculum and instruction are appropriately designed, individuals with IDD should begin receiving CSE as early as their nondisabled peers (SIECUS, 2021). Additionally, CSE should be proactively provided to all individuals with IDD as part of their course of study and not reserved as a reaction to instances of misconduct or to address misinformation (Schmidt et al., 2021). Although cognitively and socially delayed, individuals with IDD typically develop physically in line with their nondisabled peers. However, individuals with IDD may express interest in sex and romantic relationships later in life. So, in addition to starting early, experts also agree that relationship and sexual health education and support should be provided repeatedly and continuously into adulthood and throughout the life of individuals

with IDD (Schmidt et al., 2021; SIECUS, 2021). Lifelong provision of sex education and support would also help individuals maintain their sexual health because it could include information on things like preventative care for breasts and female and male reproductive organs.

One way to provide consistent reinforcement of CSE topics is to incorporate sexual health and relationship topics into various content areas, not just health class (Goldfarb & Lieberman 2021). Acquiring the knowledge and skills necessary to ensure sexual health and fulfilling relationships are so integral to life satisfaction that some argue providing adequate sex education is part of meeting the transition planning requirements for young adults with IDD (McDaniels & Fleming, 2018). Transition planning is mandated to begin at age 14 in the state of Pennsylvania. As McDaniels and Fleming (2018) explain, "For individuals with disabilities, the processes of effective transition include development of a variety of adult roles—often conceptualized as working, living, and participating in the community." (p. 29). Part of living a fulfilling adult life is being sexually healthy and able to have satisfying relationships. The same competencies in self-advocacy, self-determination, boundaries, and other social and interpersonal skills that are necessary to establishing and maintaining adult relationships would benefit individuals with IDD in the workplace and the community, too (McDaniels & Fleming, 2018). As such, sex and relationship knowledge and skills proficiency should be prioritized as a part of the transition planning process that is assessed and worked towards just like the other transition focus areas: independent living, post-secondary education and training, and employment.

Another consideration for planning for the provision of CSE for individuals with IDD is how to structure the course. For individuals with IDD to receive the maximum benefit from CSE, instruction needs to be designed and delivered in a way that meets their unique needs. Substantial research has been conducted to date on best practices for providing CSE to individuals with mild IDD. While some argue that CSE for individuals with IDD should be inclusive and take place in

classroom settings with their general education peers (SIECUS, 2021), to appropriately tailor the curriculum to the needs and abilities of individuals with IDD and to maximize their comfort level in asking questions, sex education is one area where instruction should be delivered via small-group direct instruction (McDaniels & Fleming, 2018; Schmidt, Brown & Darragh, 2020). However, the expertise of general education health teachers should be utilized in collaboration with special education teachers to deliver meaningful, effective sex education to young adults with IDD (Schmidt et al., 2021; SIECUS, 2021).

Instructional Recommendations

Those providing sex education to individuals with IDD must first choose a curriculum. Rowe et al. (2018) encourage collaboration when selecting a curriculum, such as between special education teachers and general education health teachers. The curriculum should be based on the *National Sex Education Standards* (FoSE ,2020; Schmidt et al., 2021; SIECUS, 2021). It is widely accepted that sex education should not be fear based—focusing solely on the dangers of sex and how to prevent pregnancy and STIs—and instead include well-rounded coverage of topics related to sexuality and healthy relationships, including social skills instruction (Blanchett & Wolfe, 2002; Onstot, 2019). Rowe et al. (2018) recommend using a planning tool to guide careful selection, such as the Curriculum Evaluation Tool developed by SIECUS as part of their *Guidelines for Comprehensive Sexuality Education*, to ensure that the curriculum truly is comprehensive (2004). Additionally, an effective CSE curriculum for individuals with IDD should include clearly stated prerequisite skills, assessment of prior knowledge to tailor instruction, measurable goals and objectives, and opportunities for continuous assessment. Lessons should also follow the principles of strong instructional design, such as including a distinct structure with opportunities for accessing prior knowledge, providing new instruction, guided practice, independent practice and follow-up, and adapting instruction to meet the needs

of each learner as in Universal Design for Learning (Blanchett & Wolfe, 2002; Rowe et al. 2018; Grove et al., 2008). Although research has yet to support a single CSE curriculum as being ideal for individuals with IDD, a lot has been discovered about the specific topics that should be covered and best practices for doing so.

Once an appropriate CSE curriculum is chosen, there are many evidence-based practices that can be utilized to maximize effectiveness for individuals with IDD. Generally, they are the same best practices that benefit learners with IDD in other content areas as well. Instructional materials should be modified to include representations of individuals with disabilities (Blanchett & Wolf, 2002; SIECUS, 2021). The reading level of instructional materials should be adjusted to meet the abilities of the learners and paired with visuals to aid comprehension (Graff et al., 2017; Schmidt, Brown & Darragh, 2020; SIECUS, 2021). Instruction should be multimodal to engage all learning styles (Blanchett & Wolfe, 2002; Schmidt, Brown & Darragh, 2020). For example, videos can be used to reinforce concepts and made available to students to rewatch later to aid in comprehension (Curtis & Stoffers, 2023; Oakes & Thorpe, 2019). Carefully selected examples from popular culture can supplement instruction and increase relevance and student engagement (Rowe et al., 2018).

In addition to adapting materials and lessons, specific instructional practices and activities have been proven to increase the effectiveness of sex education for individuals with IDD. Once rapport has been established, instructors of sex education for individuals with IDD need to set clear expectations for high standards of behavior, such as age-appropriate maturity, early on and clearly establish when and with whom it is okay to discuss sexuality related topics outside of class (Rowe et al., 2018). Additionally, they need to correct misconceptions and clearly teach even commonly assumed material, such as that only women get periods (Blanchett & Wolfe, 2002). When learning new concepts and skills, role playing is extremely beneficial—

especially for topics such as relationship skills, consent and assertiveness—because it provides opportunities for students to practice what is learned in a safe, structured environment with immediate feedback (Blanchett & Wolfe, 2002; Graff et al., 2018; SIECUS, 2021). Hands-on activities are also necessary for learners with IDD, such as practicing using feminine hygiene products or condoms (Schmidt et al., 2020).

Role of Parents

Another area where there is a wealth of existing research is the role of parents in the sexual wellbeing and autonomy of individuals with IDD. Experts agree that parents should be included in the sexual education of their children with IDD (Curtis & Stoffer, 2023; McDaniels & Fleming, 2018). They also require training and support in how to best navigate the sexual health and romantic relationships of their children with IDD (Kammes et al., 2020; McDaniels & Fleming, 2018). Parents are overwhelmingly more involved in the romantic lives of their children with IDD than those of nondisabled children. Understandably, they have concerns about their children with IDD being sexually victimized, and some fear their children with IDD will unintentionally commit sexually inappropriate behavior, such as unwanted touching (Kammes et al., 2020). As a result, they often allow their children with IDD relatively little free, unsupervised time alone or with possible romantic partners. In addition to being unnecessarily repressive, failing to provide adults with IDD with romantic freedom can backfire and result in risky behavior (Bernert, 2010). Therefore, it is important to help parents understand the sexuality of their children with IDD so they can balance their efforts at protection with supporting their child's healthy sexual development and establishment of fulfilling relationships (Bernert, 2011; Kammes et al., 2020).

In addition, parental support is beneficial to—and may even be required for—the provision of CSE for young adults with IDD. Parents can be their child's biggest sexual health

educator and role model, but they often refrain from addressing this topic with their child with IDD due to the misconception that lack of sexual health information will protect them from sexual victimization and other undesired outcomes of sex (Howard-Barr et al., 2005). Instead, parents often wait until they feel their child with IDD is ready to learn about sex, but sometimes by that time it is too late to protect them from harm (Kammes et al., 2020). When parents do discuss sex with their child with IDD, they likely focus more on discouraging sex than how to engage in sex safely (Kammes et al., 2020).

Interestingly, Schmidt, Brown and Darragh (2020) found that parents of children with IDD are more likely to support sex education in schools than parents of nondisabled children, likely due to their discomfort and lack of certainly about how best to address the topic with their children themselves. Some parents also realize that, because their children lack access to informal sexual knowledge gained primarily through socializing with nondisabled peers, without formal sex education in schools, parents would be left to fill the gap (Kammes et al., 2020). However, like most parents, they want the formal sex education their child receives to align with their family values (Kammes et al., 2020; Rowe et al., 2018). For families who are reluctant to allow their child with IDD to receive sex education, it can be helpful to convey to them the safety reasons for learning about sexual health and relationships (Curtis & Stoffer, 2023). As is the case with CSE for adolescents in general, some parents fear learning about sexual health and relationships will result in increased sexual behavior. Yet, as is also the case for adolescents in general, that has not been found to be the case.

Even for adolescents and adults with IDD who do receive formal CSE, they often do not have access to the privacy and social opportunities that promote sexual freedom. Kammes et al. (2020) explain, “Parents also struggled with the duality of understanding the vulnerability of their adult, while also recognizing their normative sexual drives and desires” (p. 680). This is

another reason why it is important to collaborate with families in the sex education of their child with IDD. The more families are educated and included, the more they will buy in to the benefits of sex education and the more they will continue to support efforts for sexual health and relationships at home, leading to improved outcomes for individuals with IDD (Curtis & Stoffer, 2023; Kammes et al., 2020). Kammes et al. (2020) studied the experiences of parents of children both with and without IDD and found that having other parents of adult children with IDD as mentors to help them navigate this challenging area would be beneficial.

Topics to Cover in Comprehensive Sex Education

Sex education for all should be comprehensive and based on the *National Sex Education Standards* (FoSE, 2020), but there are topics which individuals with IDD require additional focus. Much research has been done in this area, and a review of the existing research yields a thorough list of topics. Although the focus of CSE needs to go beyond elucidating the negative consequences of sex and how to avoid them—as it has been for too long—individuals with IDD do still need to know what the possible consequences of sex are so they are equipped to avoid those that are unintended. While the idea of contracting a sexually transmitted infection (STI) or getting pregnant from unprotected sex are common knowledge for most adolescents, even those who have not received formal sex education, this knowledge cannot be assumed for individuals with IDD (Blanchett & Wolfe, 2022). Clear, explicit instruction needs to be provided in contraception use to prevent pregnancy and the use of condoms to prevent STIs (Bernert & Ogletree, 2013; Blanchett & Wolfe, 2002; Graff et al., 2018; Schmidt, Brown & Darragh, 2020). In addition to how to prevent unwanted pregnancy, Schmidt, Brown and Darragh (2020) recommend including information on healthy pregnancy, such as not smoking while pregnant. Of course, instruction on sexual intercourse should be preceded by coverage of the anatomy and physiology of reproductive organs (Barnard-Brak et al., 2014; FoSE, 2020; Grove et al., 2018),

puberty and sexual development (FoSE 2020); menstruation (Graff et al., 2018); genital hygiene (Barnard-Brak et al., 2014; Blanchett & Wolfe, 2002; Grove et al., 2018); and sexual health and wellness (Blanchett & Wolfe, 2002; FoSE, 2020; Graff et al., 2018).

Deficits in social skills are common in individuals with IDD, so special attention to the skills necessary to establish healthy relationships is a must (Bernert & Ogletree, 2013; Blanchett & Wolf, 2002). The following areas should be thoroughly reinforced: setting and respecting boundaries and personal space (Bernert & Ogletree, 2013; Blanchett & Wolfe, 2002; Faught et al., 2020; SIECUS, 2021), communicating clear relationship expectations, and expressing desires (Bernert & Ogletree, 2013; Goldfarb & Lieberman, 2021). This includes explicit instruction in the notion of consent (FoSE, 2020; SIECUS, 2021). In a study by Graff et al. (2018) of young adults with IDD in an inclusive post-secondary education program, "healthy relationships, information on red flags in relationships, and gender specific health care" were identified by participants as the most beneficial topics.

Individuals with IDD are seven times more likely to be sexually assaulted than those without IDD (The Arc, 2023), so there needs to be targeted instruction in types of abuse and abuse prevention (Graff et al., 2018; SIECUS, 2021), recognizing safe and unsafe relationships (Barnard-Brak et al., 2014; Blanchett & Wolfe, 2002; Graff et al., 2018; Schmidt, Brown & Darragh, 2020), and how to seek help when needed (Blanchett & Wolfe, 2002; Howard-Barr et al., 2005). Additionally, individuals with IDD need to be empowered to realize their bodily autonomy and make decisions for their own bodies and relationships (Bernert & Ogletree, 2013; SIECUS, 2021). This is particularly important for individuals with IDD because they often rely so heavily on help from adults—sometimes for things like hygiene, toileting and feeding—that they may not realize that they are in control of their own bodies, and they get to decide who does and does not touch them (SIECUS, 2021). They need to be taught and encouraged to assertively

advocate for themselves, particularly with partners, healthcare providers, and caregivers (Blanchett & Wolfe, 2002; Howard-Barr et al., 2005; SIECUS, 2021).

For CSE to truly be comprehensive, the uncomfortable, sometimes controversial topics need to be covered as well. Individuals with IDD are often taught that private areas, such as breasts and genitals, are no touch zones, so they often don't realize that the desire to and act of touching their own genitals in an appropriately private place is normal and acceptable. So, the concept of masturbation needs to be taught (Blanchett & Wolfe, 2002). In addition to learning that it is normal to pleasure themselves, individuals with IDD should be taught that it is normal to desire and engage in sexual intercourse for pleasure with consenting adults (Blanchett & Wolfe, 2002; Goldfarb & Lieberman, 20210). It is widely established in the professional community that it is unacceptable to teach abstinence only or abstinence until marriage. As Goldfarb and Lieberman (2021) argue, "[T]he focus on sexual behavior as problematic itself eliminates the opportunity for young people to explore and experience normal, healthy, safe, and pleasurable sexual activity" (p. 23). Another topic that has been historically omitted from formal CSE and needs to be included is acknowledgement and acceptance of different sexual orientations and gender identities (Blanchett & Wolfe, 2002: FoSE, 2020).

CSE can be viewed as an element of social emotional learning (SEL) (Goldfarb & Lieberman 2021). The Collaborative for Academic, Social, and Emotional Learning (CASEL) describes SEL as:

> the process through which all young people and adults acquire and apply the knowledge, skills, and attitudes to develop healthy identities, manage emotions and achieve personal and collective goals, feel and show empathy for others, establish and maintain supportive relationships, and make responsible and caring decisions. (n.p.)

Similarly, CSE is about helping students develop knowledge and skills that will enable them to establish and maintain healthy relationships and make responsible sexual choices.

Who Best to Deliver Sex Education to Young Adults with IDD

One area where the research into sex education for individuals with IDD is lacking is who best to provide such education. Much like there is a lack of nationally accepted sex education standards and a lack of federal funding for CSE, there is also a lack of consensus and clear guidelines about what qualifications are necessary or recommended to teach sex education to individuals with IDD. As Curtis and Stoffers (2023) report, "[L]ittle is known about who teaches sex education to individuals with [IDD] or about the structural organization that allows these sex educators to implement sex education instruction on a sustainable basis" (p. 2). There is disagreement in the field of education over the primary importance of special education expertise versus content area knowledge (Curtis & Stoffers, 2023). Though, most experts agree that meaningful, effective CSE for individuals with IDD requires collaboration between special education and general education health professionals (Barnard-Brak et al., 2014; Curtis & Stoffers, 2023; SIECUS, 2021). Regardless of who delivers CSE to individuals with IDD, they need adequate training and support (Blanchett & Wolfe, 2002).

Curtis and Stoffers (2023) conducted an analysis of service models currently used to provide sex education to individuals with IDD, and they identified seven common models: "(1) disability programs, (2) small businesses, (3) university-based educators, (4) clinic-based board-certified behavior analysts (BCBAs), (5) public health not-for-profits, (5) mental health therapists, and (7) high school-based educators" (p. 6). The facilitators in all seven service models were experienced, highly trained sex educators. High school-based educators were the smallest group represented, and all of the high school-based educators reviewed in this study were special education teachers; none were general education health teachers. Several of the

models utilized a “short-term, drop in approach” that was found to be problematic because those educators lacked knowledge of the students and had limited time to build rapport and cover content (Curtis & Stoffers, 2023). In their review of currently implemented sex education programs for young adults with IDD, Schmidt, Brown and Darragh (2020) discovered that a variety of professionals teach sex education, including “researchers, therapeutic staff, behavioral specialists and psychology doctorate students, certified trainers..., professionals with a bachelor’s or master’s degree in psychology or social services or organizations serving individuals with disabilities” (p. 445). Agency representatives may take over once students leave high school (McDaniels & Fleming, 2018).

When it is provided in public schools, sex education for individuals with IDD is typically taught by special education teachers. Barnard-Brak et al. (2014) suggest special education teachers can best determine individual risk factors for sexual abuse and recommend accommodations and modifications that may be needed for students with IDD to get the most out of sex education. Though many special education teachers feel unprepared to teach formal CSE to young adults with IDD—and many are reluctant to take on an additional role—most special education teachers already do address relationship and sexuality education, such as personal safety, social skills, and hygiene (Howard-Barr et al., 2005). If special educations teachers were to assume a more formal role in the provision of CSE for individuals with IDD, they would need additional training to confidently teach it and ideally to collaborate with other professionals, such as general education health teachers (Howard-Barr et al., 2005; McDaniels & Fleming, 2018; Schmidt et al., 2021).

In the *National Sex Education Standards*, Future of Sex Education (FoSE) (2020) affirms, “Teacher training is the most significant indicator in determining the quality of sex education instruction and confidence and comfort with teaching sex education” (p. 13).

Unfortunately, there is a pervasive lack of adequate training; most special education teachers lack training in sex education, and most health teachers lack training in special education (McDaniels & Fleming, 2018). Schmidt, Brown and Darragh (2020) reviewed the implementation of existing sex education programs for individuals with disabilities and found that instructors typically had to meet an additional training requirement to teach the subject, ranging from hours to days long. SIECUS (2021) reports that health teachers are now receiving more training in teaching individuals with disabilities, but still only half of general education health teachers in the United States have any special education training.

While collaboration between special education teachers and general education health teachers is key to providing quality sex education for young adults with IDD in public school, inclusion of students with IDD in the general education classroom with their nondisabled peers is not suitable for sex education because individuals with IDD require such differentiated instruction and an environment where they feel comfortable asking questions and where misconceptions can be discovered and corrected (McDaniels & Fleming, 2018). Clayton et al. (2018) suggest that the best sex educators for individuals with IDD are those who are already skilled in teaching sex education and have received recent professional development (PD) because recent receipt of sex education PD was shown to result in more topics covered. So, general education health educators appear to be some of the best qualified professionals to deliver this important instruction.

Summary

Great strides have been made towards improving the lives of individuals with intellectual and developmental disabilities (IDD) over the past 70 years, but failure to recognize their right to romantic relationships and sexual expression is one area that is still lacking. Prevailing misconceptions about the sexuality of individuals with IDD—such as that they are asexual and

not interested in romantic relationships, they lack the skills to be in an adult relationship, or that they are hypersexual and should be prevented from engaging in sexual relationships because such conduct will result in deviancy—have led to individuals with IDD being largely overlooked for the receipt of sex education. Additionally, policies and practices that govern the education and support services of individuals with IDD reflect these myths in their suppression of individuals' with IDD access to opportunities for socialization and privacy to engage in romantic relationships that are routinely available to nondisabled adolescents and adults.

The negative implications of lack of relationship and sexuality education and opportunity are well-established in the literature. The first step to helping individuals with IDD realize their human right to healthy sexuality and romantic relationships is to discover and implement best practices for providing effective, meaningful, evidence based CSE for individuals with IDD. Adolescents with IDD are often educated in public schools and often attend classes with their nondisabled peers taught by general education teachers. Considering there is no federal funding, and inconsistent state funding, for CSE, the most practical option is to utilize existing general education health teachers in public secondary schools to teach sex education to adolescents with IDD where they are.

Special education teachers specialize in working with individuals with disabilities but lack expertise in teaching sex education and are often responsible for too many other tasks to take on an additional role. General education health teachers possess the content area expertise to teach sex education, but they often lack training and experience working with individuals with IDD. So, collaboration between the two is necessary to deliver the best possible sex education programming for adolescents with IDD. This qualitative study seeks to investigate the perspectives of secondary general education health teachers on the sexuality of individuals with IDD to discover any biases or misconceptions that need to be addressed and to determine what

support and training they feel they would need to deliver sex education to young adults with IDD effectively.

The next chapter explains the qualitative methodology underpinning this study and the methods used to collect and analyze data. It describes the sites participants were recruited from, the sample of teachers studied, the type of information collected and how, and the data analysis process, including a discussion of methodological strengths and weaknesses. Additionally, it details the measures the researcher took to increase trustworthiness and the ethical considerations involved in this study and the steps taken to address them. Finally, it explains how the results from this study will be used and distributed.

CHAPTER 3: METHODS

The previous chapter gave a historical overview of the treatment of individuals with IDD in the United States and detailed the relevant literature to date on the topic of sex education for individuals with IDD and the barriers to adequate, equitable delivery. This chapter will outline the qualitative methodology and methods that were undertaken to investigate the perspectives of secondary general education health teachers on the sexuality of individuals with intellectual and developmental disability (IDD) to discover any biases or misconceptions that need to be addressed and to determine what support and training they feel they need to deliver comprehensive sex education (CSE) to this population effectively. It will also explain how collected data was analyzed and synthesized to inform recommendations for local districts on how best to support their existing secondary general education health teachers in the implementation of formal CSE for young adults with IDD.

All methodology and methods were selected to provide insight into this study's research questions:

- What types of supports do secondary general education health teachers need to effectively teach CSE to adolescents with IDD?
    - What are the perspectives of secondary general education health teachers on CSE for adolescents IDD?
    - What training, if any, have secondary general education health teachers received specific to teaching individuals with IDD?
    - How prepared do secondary general education health teachers feel to teach CSE to adolescents with IDD?

Research Sample

Purposeful Sampling

Qualitative research utilizes purposeful sampling to obtain a sample that will elicit the type of information needed to explore the issue in question (Bloomberg, 2023; Creswell & Creswell, 2018; Patton, 2015). This study aims to fill a gap in the existing research by investigating the perspectives of secondary general education health teachers, a group that is often referenced in the literature as being well-positioned to teach CSE to young adults with IDD, but whose perspectives have yet to be explored. Previously, the focus has been on the perspectives of the public, parents, special education faculty and staff, and individuals with IDD themselves (Cuskelly & Bryde, 2004; Cuskelly & Gilmore, 2007; Tamas et al, 2019). Since the study concerns a specific target population, a group characteristic sampling strategy was required (Patton, 2015). Homogeneous sampling was utilized to select a subgroup of similar teachers to investigate commonalities in their experiences and perspectives (Patton, 2015; Bloomberg, 2023). All participants were general education teachers who held current Pennsylvania teaching certificates in either Health Education PK-12 or Health and Physical Education PK-12 and had taught at least one general education high school health class. Years of teaching experience and experience teaching students with special needs were not considered.

Sample Size

It is well-established that generic qualitative research focuses on depth of coverage rather than breadth and generalizability, so large sample sizes are not a requirement or even often the goal (Baker & Edwards, 2012; Bloomberg, 2023; Patton, 2015; Roberts & Hyatt, 2019). As Bloomberg (2023) explains:

> Essentially, the goal of qualitative research is not to produce ‘truths’ that can be generalized to other people or settings but rather to develop descriptive context-relevant

> findings that make it possible for readers to decide whether similar processes can apply to their own settings and communities (p. 75).

There is little concrete guidance regarding adequate sample sizes for qualitative studies, and experts provide conflicting guidelines based on qualitative epistemology and research purpose, such as whether publication is the goal.

A traditional measure of adequate qualitative sample size is data saturation. Patton (2015) describes:

> The analyst brings closure to the process when sources of information have been exhausted, when sets of categories have been saturated so that new sources lead to redundancy, when clear regularities have emerged that feel integrated, and when the analysis begins to 'overextend' beyond the boundaries of the issues and concerns guiding it (p. 556).

However, Baker and Edwards (2012) note that data saturation cannot be assessed until a study is already underway, and often there is a need to clearly delineate aspects of study design like sample size prior to beginning a study, such as when seeking institutional review board (IRB) approval.

One suggestion is to instead consider a balance of outside factors, such as time and resources allotted and need for IRB approval, and inside factors, such as theory, methodology, and purpose (Baker & Edwards, 2012). In other words, when designing a qualitative study, the goal is to strike a balance between the number of participants necessary to gather sufficient depth of data and still reasonably conduct the study. Baker and Edwards (2012) also advise qualitative researchers to focus more on the quality of data collected than that quantity, which is inherent in the word qualitative. For this study, a minimum of ten participants were sought to generate enough interview data to clearly address the research questions while still being manageable for

a single novice researcher. Twenty-eight potential participants were contacted. Nine participants completed the questionnaire, and eight participants completed the semi-structured interview. One teacher signed the informed consent form but, upon viewing the questionnaire, felt he did not know enough about individuals with IDD to continue his participation in the study. Three additional teachers expressed interest but were not eligible because they have never taught in high school.

Research Setting

There are no federal laws governing the provision of sex education. Rather, states and local governments must determine their own guidelines for if and how to provide sex education (Planned Parenthood, 2023). Additionally, the provision of sex education is a controversial, oftentimes political, topic, especially in more conservative areas (Planned Parenthood Action Fund, 2023). Because the goal of this study is to make research-based, actionable recommendations that school districts can implement utilizing existing resources (general education health teachers) to provide a much-needed service (CSE) to their adolescents with IDD, this study has a local focus. Participants were recruited from three school districts—two rural and one suburban—in Lackawanna, Pike, and Wayne Counties in Northeastern Pennsylvania. All three districts are part of the Northeastern Educational Intermediate Unit (NEIU) 19. Together these districts cover more than 700 square acres and serve more than 6,000 students K-12 districtwide. According to the Future Ready PA Index (2023), the student body of all three districts is primarily white (82%) and, on average, 10.8% Hispanic, 2.6% Black, 3.4% two or more races, 0.8% Asian, 0.2% Native American/Alaskan Native, and 0.1% Native Hawaiian or other Pacific Islander. On average, 60.7% are economically disadvantaged, 0.7% are designated English language learners (ELL), 0.9% are homeless, and 0.4% are in foster care. On average across all three districts, 23.9% receive special education services; this is above the

Pennsylvania state average of 18.5% of students per district receiving special education services in the 2021-2021 school year (Christ, 2022)

Site Permission. Research sites often have "gatekeepers" whose assistance or permission are needed to gain access to the site and potential study participants (Creswell & Creswell, 2018, p. 185). In the case of public-school districts, gatekeepers could be district superintendents, building principals, school boards, or even district-specific IRBs. The public school districts utilized in this study each required site permission be granted by their district superintendent to recruit teacher participants using school e-mail addresses and to possibly conduct interviews during non-instructional times of the school day, such as during teacher preps. Permission was obtained by e-mailing each superintendent to provide a brief overview of the study, including an explanation of why the site was chosen, a summary of activities to be conducted, any potential disruptions to the site, how and where findings will be reported, what potential gains might come from participation, and any possible ethical issues and related protections (Creswell & Creswell, 2018). The researcher also received site permission from two neighboring districts; recruitment e-mails were sent to their secondary health teachers but yielded no participants. Site permission was obtained prior to IRB approval because it was needed for the IRB process, but no recruitment or data collection occurred until after IRB approval was granted. Two other neighboring districts were contacted but did not respond to requests for site permission.

Information Needed

Bloomberg (2023) asserts that qualitative studies require the following types of data be collected: "contextual, demographic, and perceptual" (p. 270). Contextual information provides an understanding of the setting in which participants live or work (Bloomberg, 2023). For this study, contextual information was collected during interviews via questions about participants' past experiences teaching health to students with disabilities and any education or training they

had received specific to teaching students with disabilities. Demographic information identifies participants by characteristics relevant to the study (Bloomberg, 2023). For this study, demographic information was collected as part of an online questionnaire. Patton (2015) recommends asking demographic questions on questionnaires instead of during interviews because interviews should concentrate on eliciting thorough, descriptive responses, not short answers. Demographic information collected consisted of years of experience teaching health, years of experience teaching students with disabilities, grades taught, education, and teaching certification.

Perceptual information describes peoples' experiences, thoughts, and opinions and is the most valuable form of information in qualitative research (Bloomberg, 2023). For this study, perceptual information was collected from each participant via two methods: a virtual questionnaire and a semi-structured interview. The questionnaire—a researcher-revised version of the *Attitudes to Sexuality Questionnaire - Individuals with an Intellectual Disability (ASQ–ID)*—assessed participants' perceptions of the sexuality of individuals with IDD and elucidated any common misconceptions participants held about the sexuality of individuals with IDD via close-ended questions with Likert-scale response options. Perceptual information was also collected during interviews with questions regarding participants' confidence level to teaching individuals with IDD and the support and training they feel they would need to do so effectively. In summary, two data collection methods—questionnaires and interviews—administered to all participants were used to collect the necessary contextual, demographic, and perceptual information.

Research Methodology and Design

The design of this study is pragmatic and follows tenets of generic qualitative inquiry rather than adhering to a specific qualitative methodology. This allows the researcher to select

methods with complementary strengths and weaknesses to best achieve the study's intended purpose of generating a list of actionable recommendations that school districts can implement to utilize their existing high school health teachers to provide CSE to young adults with IDD. The concept of combining research strategies to achieve a study's purpose goes by many names including critical multiplism and methodological pluralism (Patton, 2015). Many scholars endorse the notion of seeking the best research design without forcing a study to fit a particular methodology (Smith et al. 2011; Patton, 2015; Roberts & Hyatt, 2019). Howard-Barr et al. (2005) explain, "Qualitative research...could provide a deeper understanding of what respondents need to provide adequate, comprehensive sexuality education to special education students" (p. 104). Qualitative inquiry has been the primary method of investigation used when researching the sexuality of individuals with IDD due to the complex nature of the topic and the myriad intervening factors.

In addition to the challenge of distinguishing between qualitative designs with dozens to choose from and a lack of agreed upon descriptions, a criticism of methodologically driven qualitative design is that researchers sometimes get so focused on the research paradigm that that lose sight of the purpose of the study, which negatively influences the outcome (Smith et al., 2010; Patton, 2015). Even worse, attempting to adhere to a specific qualitative methodology can result in unconscious bias in the form of rejecting strategies, and even findings, that do not suit the goal of the research design (Patton, 2015). Instead, Patton argues, "Being practical and flexible allows one to eschew methodological orthodoxy in favor of *methodological appropriateness* as the primary criterion for judging methodological quality, recognizing that different methods are appropriate for different situations" (p. 97).

Specific qualitative methodologies were considered—namely constructivist grounded theory because it is influenced by social justice theory and aims to question and investigate the

inequitable and unfair treatment of marginalized groups—but were discarded because none fit the research questions and purpose precisely. For instance, grounded theory utilizes qualitative interviewing as its main data collection method, but it requires theoretical sampling, which is not necessary to produce the homogenous sample required to answer this study's research questions. Grounded theory is also constructed around the idea of generating theory based exclusively on data, but much is already known about the lack of sex education for individuals with IDD and the reasons for the inequity. While this study is exploring the perspectives of a different target population than previous studies, it does have a conceptual framework to build from. A convergent mixed methods design was also considered because questionnaire data is collected in addition to qualitative interviews. It was rejected because the driving data for this study is qualitative interviewing. Although questionnaire data is also collected, Bishop and Herron (2015) argue that Likert-scale responses are not true quantitative data due to their inability to be accurately mathematically quantified. Supplementary close-ended questionnaire data is used to contextualize, confirm, and enhance interview findings, but it is not the focus of the study and undergoes no true quantitative statistical measures.

Researchers like Patton (2015) and Tracy (2010) espouse tenets of quality qualitative inquiry regardless of specific methodology. Qualitative inquiry is naturalistic in that it takes place in applied settings without researcher manipulation of variables. It is also a holistic approach that involves discovering the full picture of the subject of inquiry. As Patton (2015) explains, "The qualitative inquirer consciously works back and forth between parts and wholes, aiming to understand the complex, interwoven constellations of variables in a sorting-out and then putting-back-together process" (p. 76). Participants' meanings are the focus of qualitative inquiry; the researcher serves only to give purpose and context to them. All aspects of thoughtful qualitative design converge towards a deep understanding of the topic of inquiry (Smith et al.,

2011). Other tenets include purposeful sampling, thick description and reflexivity, to be addressed later in this chapter.

Pragmatism, although typically associated with mixed methods, involves the practical search for answers and requires investigating practical research questions based on real-world problems and selecting practical methods based on real-world concerns of fit and feasibility (Patton, 2015). As existing research has shown, the sexuality of individuals with IDD is underacknowledged and individuals with IDD are underserved in the area of sex education. The negative implications of a lack of CSE for individuals with IDD are myriad and lifelong, making this an issue that demands attention. A pragmatic approach is well-suited to this issue because its driving goal is actionable results.

Overview of Methods

IRB Approval. Obtaining approval from the institutional review board (IRB) was the first step in conducting this study, as it is in any research using human subjects. This took place in Fall 2023. The Slippery Rock University (SRU) IRB determined that this study falls into the exempt category. In January 2024, the researcher applied for and obtained a protocol change to increase the recruitment rate. The following changes were made to the study design: (1) the informed consent, questionnaire, and interview scheduling process were streamlined into one user-friendly Qualtrics form, and (2) one of the eligibility requirements was changed from having taught high school health in the past two years to having ever taught high school health.

Recruitment. Upon obtaining IRB approval, because site permission had already been obtained as part of the IRB approval process, participant recruitment began. All participants were recruited from three districts in Northeastern Pennsylvania. Homogeneous sampling was utilized to select a subgroup of similar teachers to investigate commonalities in their experiences and perspectives (Patton, 2015; Bloomberg, 2023). Only those who held current Pennsylvania

teaching certificates in either Health Education PK-12 or Health and Physical Education PK-12 and had taught at least one general education high school health class were included.

Recruitment occurred by contacting teachers who met the inclusion criteria via their school e-mail with a form e-mail briefly explaining the topic of the study and providing a link and a QR code to a Qualtrics form that asked questions to determine if interested candidates were eligible and then linked to the informed consent form with more detailed study information. Teachers were given the researcher's contact information and encouraged to reach out with any questions or concerns. E-mail was selected as the best method of communication with potential participants because it is a common and often preferred method of communication for teachers (Bloomberg, 2023). Teachers who indicated interest and met the eligibility requirements were asked to digitally sign the informed consent and consent to audio recording forms via Qualtrics. It was made clear that even if participants did not consent to have their interviews audio recorded for the purpose of audio transcription, their input was still valuable. Only one participant declined to have their interview recorded.

Data Collection. This study utilizes a "cross-sectional interview-based design" supported by supplementary questionnaire data (Smith et al, 2011). All teachers who consented to participate were administered two data collection measures separately: a virtual questionnaire and a semi-structured interview. True to qualitative inquiry, the driving data for this study was qualitative interviewing. Supplementary close-ended questionnaire data was used to contextualize, confirm, and enhance interview findings, but it was of secondary importance to interview data and is not the primary focus of the study.

Questionnaire. After digitally signing the informed consent and consent to audio recording forms via Qualtrics, participants were taken to the questionnaire—a researcher-revised version of the *Attitudes to Sexuality Questionnaire - Individuals with an Intellectual Disability*

(ASQ–ID)—and asked to complete it independently and honestly (see Appendix B). The researcher obtained permission to revise and use this measure from the co-creator, Dr. Monica Cuskelly, via e-mail in July 2023. The ASQ-ID consists of close-ended questions with Likert-scale response options. It assesses participants' perceptions of the sexuality of individuals with IDD and elucidates any common misconceptions participants hold about the sexuality of individuals with IDD. This revised questionnaire also contained additional demographic questions regarding participants' years of health teaching experience, years of experience teaching students with disabilities, grades taught, education, and teaching certification. Once each participant completed the ASQ-ID, they were taken to a scheduling screen where they could select a date, time, method (in-person or via Zoom) and place, if applicable, for the semi-structured interview.

Interviews.

Interviews were scheduled for Winter 2023. Participants were given the option to participate in person or via video conferencing. Video conferencing was provided as an optional interview method because it is a tool most teachers are comfortable and proficient using after being forced to do so during COVID-19 school closures. (Bloomberg, 2023; Oliffe et al., 2021) It may also encourage participation for those who are reluctant to meet in person (Oliffe et al., 2021). All interviews conducted, whether in-person or via video conferencing, were guided by a researcher-designed semi-structured interview protocol (see Appendix A). The protocol also consisted of introductory information, including a review of informed consent, and closing procedures (Jacob & Furgerson, 2012; Patton, 2015). All interview questions align with at least one of the study's research questions (see Table 3.1). However, in keeping with the flexibility and emergent design characteristic of qualitative research in general, the researcher was free to probe and question further as deemed necessary.

Table 3.1

Interview and Research Question Alignment Matrix

Interview Question	Research Question			
	What types of supports do secondary general education health teachers need to effectively teach CSE to adolescents with IDD?	What are the perspectives of secondary general education health teachers on CSE for adolescents IDD?	What training, if any, have secondary general education health teachers received specific to teaching individuals with IDD?	How prepared do secondary general education health teachers feel to teach CSE to adolescents with IDD?
1. What is your experience teaching students with IDD? If you have experience what subjects (health or physical education) did you teach?	X	X		
2. What training have you had specific to teaching special education students? Was it specific to teaching sex education?			X	
3. What training have you have specific to teaching students with IDD? Was it specific to teaching sex education?		X	X	
4. How would you feel if you were asked to , or told you would be, teaching an adapted health class to students with IDD, including sex education? If concerned, what would your concerns be?	X			X
5. How qualified do you feel to teach se education to students with IDD without any additional training? If not, what training do you feel you would need to do so effectively?				
6. If you were to teach health to students with IDD, what support would you want from a special education teacher in or out of the classroom? What support would you want from a special education paraprofessional, like a classroom assistant, in the classroom?	X			

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All interviews, whether conducted in-person or via video conferencing, were also audio recorded with participant permission using either a mobile device (in-person) or the automatic recording feature (video conferencing), except for that of the participant who opted not to be recorded. Except for that interview, the researcher did not take detailed notes during interviews because it detracts from being able to facilitate the interview, build rapport, and note nuances, such as in body language (Patton, 2015). However, the researcher did briefly note on the interview protocol important wording and points in case audio recording failed (Patton, 2015; Creswell & Creswell, 2018). Immediately following each interview, audio recordings were downloaded to the researcher's personal computer and backed up to a personal, password-protected cloud storage account (OneDrive). Also following each interview, the researcher conducted an "immediate post interview review," noting details, thoughts, and observations in a research journal (Patton, 2015, p. 471).

Audio recordings were then transcribed using an automatic transcription service (Bloomberg, 2023). The researcher confirmed each transcription by listening to the audio recording and comparing it to the transcription, word for word, correcting and adding notes of emphasis and relevant body language as needed (Bloomberg, 2023). To enhance credibility, each participant was given the opportunity for participant verification, a form of member checking that consists of participants reading the transcription of their interview to verify that it accurately portrays their intended meaning. Once transcriptions were researcher and participant verified, they were prepared for preliminary coding and memoing by importing them into Microsoft One Drive.

Data Analysis.

Once all questionnaires were completed, the results were analyzed using descriptive statistics to identify trends and averages in participants' perceptions of the sexuality of

individuals with IDD and common misconceptions they hold about the sexuality of individuals with IDD. Findings were used to refine the semi-structured interview questions as needed. Later, they were also compared with semi-structured interview data during its analysis to contextualize, confirm and enhance interview findings.

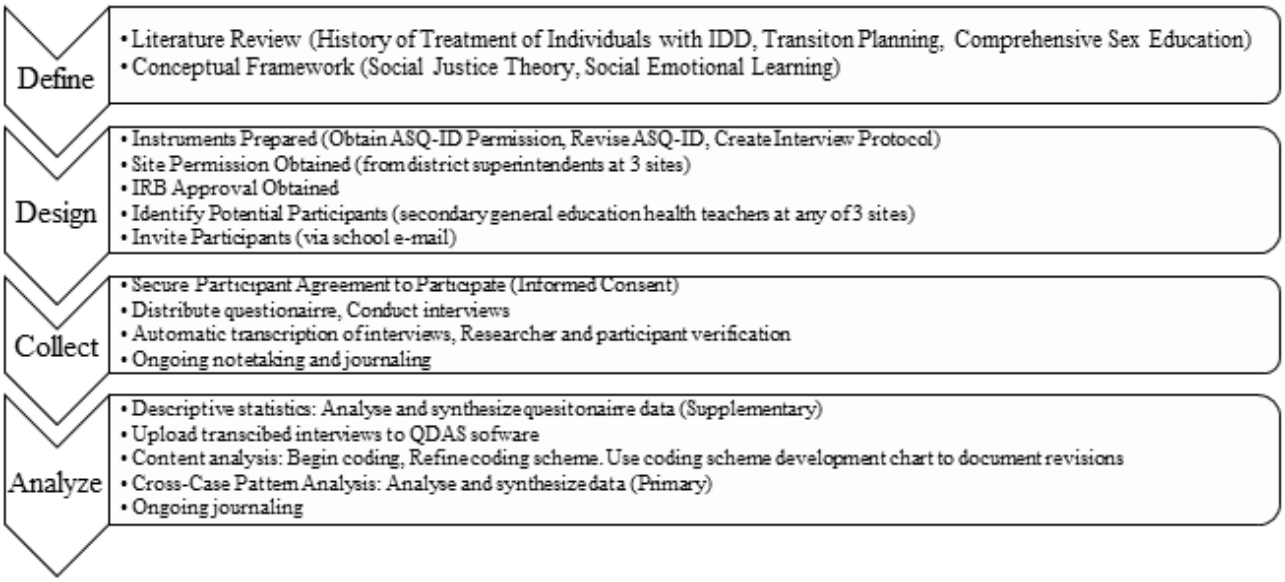
True to qualitative inquiry, preliminary interview data analysis was not an entirely separate phase of research, rather it began as interviews were completed and continued in more detail once all interviews had concluded. Once transcriptions were researcher and participant verified, they were prepared for preliminary coding and memoing by importing them into Microsoft OneDrive. There is no universally accepted procedure for analyzing qualitative data (Bloomberg, 2023). For this study, interview data was analyzed using general content analysis methods with the goal of specific cross-case pattern analysis (Patton, 2015). The bulk of interview data analysis and overall data synthesis were conducted in early spring of 2023.

Summary.

See Figure 3.1 for a summary of the methods used in this study.

Figure 3.1

Research Methodology Flowchart



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Data Collection

All participants were administered two data collection measures separately: a virtual close-ended questionnaire and a semi-structured interview (except one participant who only completed the questionnaire and did not respond to multiple attempts to schedule an interview). Multiple data collection methods increase rigor and deepen understanding (Patton, 2015). Use of multiple methods is also a form of triangulation that contributes to enhanced trustworthiness and increases the likelihood of achieving data saturation, thereby demonstrating an adequate sample size (Bloomberg, 2023). Although interviews were the primary data collection method and the questionnaire provided only supplemental information, the questionnaire was administered first. Developing an accurate understanding of the support and training participants need to effectively teach CSE to young adults with IDD requires all participants to complete both data collection methods because each serves a distinct purpose. The questionnaire captures demographic

information and perceptual information about the sexuality of young adults with IDD while the interview captures contextual information and perceptual information about participants' confidence and comfort level with teaching CSE to young adults with IDD. A virtual questionnaire is quicker and easier to administer than an interview, so the questionnaire was administered first. Findings were used also to refine the semi-structured interview questions as needed.

Questionnaire

A questionnaire was used in this study to provide supplemental information on the perceptions of participants. Prior to being interviewed, participants were administered a virtual, revised version of the ASQ–ID to assess their overall perceptions of the sexuality of individuals with IDD and identify any commonly held misconceptions. The questionnaire also included demographic questions about participants' years of experience teaching health, years of experience teaching students with disabilities, grades taught, education, and teaching certification. It was digitized using Qualtrics and began after participants provided informed consent to participate in the study but prior to being scheduled for an interview.

Rationale. This measure was chosen because it has been evaluated and used in several studies throughout the world investigating the perception of the sexuality of individuals with IDD. The ASQ-ID was developed by Cuskelly and Bryde in 2004 for their study comparing the attitudes of parents, staff members and the public on the sexuality of adults with IDD in Queensland, Australia. They developed the measure by combining components of other established measures. Eight different sexuality-related topics are covered— "sexual feelings, sex education, masturbation, personal relationships, sexual intercourse, sterilization, marriage, and parenthood"—with four questions on each topic (p. 258). Steps were taken to increase the validity of the measure, including updating the language, evenly combining positively and

negatively worded statements, randomizing the order of the questions, and utilizing a six-point Likert scale. Cuskelly and Bryde (2004) determined that the overall measure has high test-retest reliability and high internal consistency. When administered by Cuskelly and Bryde (2004):

> The introduction to the community questionnaire asked respondents to answer each item 'with respect to individuals with a moderate intellectual disability,' while that given to staff and parents asked respondents to consider 'an adult with moderate support needs and an Intelligence Quotient of 40-55' when answering the questionnaire (p. 258).

The original measure can be found in the appendix of Cuskelly & Bryde's 2004 publication. More recently, the ASQ-ID was used in a similar study comparing attitudes of the general public towards the sexuality of individuals with IDD with those of staff members and parents in Serbia (Tamas et al., 2019) and in a study comparing the attitudes of parents on the sexuality of their adult children with IDD versus that of their nondisabled adult children in the United States (Kammes et al., 2020).

The ASQ-ID was later revised by Cuskelly and Gilmore in 2007. Several changes were made, including the addition of gender-specific language to enable researchers to determine if people have different perceptions of the sexuality of men versus women with IDD. Cuskelly and Gilmore (2007) explain their rationale for the addition of three new questions:

> [T]he first was intended to tap into the idea that individuals with ID have little interest in sex (the 'perpetual child' view), the second addressed the stereotype that this group are unable to control their sexual urges, and the third asked about the capacity of individuals with ID to maintain an emotionally intimate relationship (p. 215).

While the researcher primarily used the original version of the ASQ-ID for this study, these new questions were included because they address common stereotypes of the sexuality of individuals with IDD that, if possessed by general education health teachers, need to be corrected.

Permission to use the measure for this study was obtained from Dr. Cuskelly via e-mail in July 2023. This researcher revised the original measure by adding the updated questions from the 2007 revision—while still maintaining gender-neutral language—and removing questions related to marriage because they don't suit the purpose of this study. Demographic questions were also added. The language of the instructions was changed to say respond to each item "with respect to individuals with a moderate intellectual disability, such as those in a Life Skills class" to reflect what general education teacher participants would likely understand. In addition, it was digitized for virtual delivery using Qualtrics. Like the original and the revision, this measure also uses a six-point Likert-scale response option ranging from one, strongly disagree, to six, strongly agree, with a higher score representing a more liberal/accurate perception of the sexuality of individuals with IDD.

Strengths and Weaknesses. While questionnaires do not generate the complexity of data that interviews do, they have benefits. They are a preferred way of collecting demographic information because they prevent the need to ask short-answer questions during interviews (Patton, 2015). In addition, participants may be more comfortable sharing information on sensitive topics on questionnaires than face-to-face (Bloomberg, 2023). Regardless of the question topics, questionnaires can be distributed in a variety of ways, are unobtrusive, user-friendly, and typically have quick response times (Bloomberg, 2023). Questionnaires can be and often are administered virtually, and when done so they are even more user-friendly and result in even quicker response times (Bloomberg, 2023). The data generated by questionnaires requires less time and effort to analyze than interview data because it does not need to be transcribed or coded, and when administered virtually data analysis is even easier. They are also inexpensive because they do not require the transportation and manpower that interviews sometimes do (Bloomberg, 2023).

Despite the benefits, questionnaires are sometimes rushed through by participants, which can impact the accuracy of the answers received, and there is typically no opportunity on a questionnaire for participants to clarify their answers. The use of interviews in conjunction with a questionnaire addresses one of the primary weaknesses of questionnaires, which is that participants do not get an opportunity to elaborate. Because participants will all be interviewed individually after they complete the ASQ-ID, they will have an opportunity to share anything they did not get to share on the questionnaire.

Interviews

Interviewing is the primary data collection method in this study. After participants completed the ASQ-ID, they were scheduled for an interview. Interviews were semi-structured, both to satisfy IRB requirements to clearly explain research procedures and to allow flexibility to ask probing and follow-up questions as needed. Interviews were guided by a researcher-designed semi-structured interview protocol. All interview questions align with at least one of the study's research questions (see Table 3.1). The interview protocol also included opening and closing instructions (Jacob & Ferguson, 2012; Patton, 2015). Opening instructions consisted of an introduction to the researcher and the study, a notification of audio recording, and an informed consent reminder, including the option to end the interview at any time (Jacob & Ferguson, 2012; Patton, 2015). Closing instructions included giving participants a final opportunity to add any final thoughts and the provision of researcher contact information in case they thought of any questions or information they'd like to add (Jacob & Ferguson, 2012; Patton, 2015). On average, interviews were approximately 30 minutes long.

To encourage participation and maximize participant comfort, participants had the choice of being interviewed in-person or via video conferencing (Oliffe et al., 2021). Video conferencing was included as an option because it is a common technology for many teachers,

especially following its prolific use during COVID-19 school closures in 2020 (Oliffe et al., 2021; Bloomberg, 2023). All interviews were conducted either outside of school hours or during non-instructional time, such as teacher prep. Those who chose an in-person interview were immediately sent a confirmation e-mail with the date, time, and location of the interview. In-person interviews were conducted at the participant's school of work or at a mutually agreed upon neutral location with sufficient privacy. Those who chose a virtual interview were sent a Zoom link with the date and time. They were asked to be in an area free from distraction. They were encouraged, but not required, to have their camera on during the interview (Bloomberg, 2023). All participants were e-mailed a reminder twenty-four hours before their scheduled interview.

All interviews—except for one because the participant declined to be recorded—were audio recorded using either a mobile device (in-person) or the automatic recording feature (video conferencing). Participant permission for audio recording was collected in writing via a consent to audio record form and verbally before the interview began. Participants were aware that they could pause or stop the recording at any time. Except for the interview that was not recorded, the researcher took minimal notes during interviews to focus on giving participants undivided attention and facilitating the interviews. Immediately following each interview, audio files were downloaded to the researcher’s personal computer and backed up to a personal, password protected cloud storage account (OneDrive). Also following each interview, the researcher conducted an “immediate post interview review,” noting details, thoughts, and observations in a research journal (Patton, 2015, p. 471).

Rationale and Strengths and Weaknesses. Qualitative interviews differ from other interview types, such as journalistic and diagnostic interviews (Patton, 2015). They are essential to qualitative inquiry because they allow researchers to investigate perceptions and experiences

they cannot see for themselves (Patton, 2015). Although semi-structured interviews are less flexible than open-ended interviews and may hinder the natural flow of communication, they still involve asking open-ended questions and allow probing for deeper responses. Using semi-structured interviews over unstructured or structured interview allows the researcher to balance the structure and accountability required of the IRB with the spontaneity and flexibility of naturalistic inquiry at the heart of qualitative research.

The use of a detailed interview protocol in semi-structured interviewing makes it easy for the researcher to ensure all necessary topics have been covered in the interview and to control the interview and keep it moving. It also makes the comparison of responses during analysis, as in the cross-case pattern analysis used in this study, easier because each participant is asked the same questions in the same order. As Patton (2015) cautions, a drawback to interviewing is, "[T]he quality of information obtained during an interview is largely depending on the [skill of] the interviewer" (p. 427). Fortunately, the uniformity of semi-structured interviews reduces interview effects and bias and is more manageable for novice interviews who lack interview skill and experience.

Conducting interviews virtually introduces additional challenges, such as the interviewer missing out on nuances realized when physically with the interviewee, the possibility of distractions and interruptions for both parties, and the occurrence of technical difficulties. However, there are benefits to virtual interviewing, especially in a post-COVID world in which many people are already familiar with the technology, especially those in the teaching field. Oliffe et al. (2021) investigated the pros and cons of virtual interviewing and discovered that people tend to be more comfortable talking about sensitive issues in virtual interviews when they are in the comfort of their chosen environment and have the distance a screen provides. This

addresses one of the shortcomings of traditional interviewing, which is that people may be reluctant to share sensitive or personal information with a stranger.

Data Analysis

Questionnaire Data

Although closed-ended questionnaires like the ASQ-ID are typically viewed as quantitative data points, the distance between response items on a Likert-scale are not equal, as Bishop and Herron (2015) explain, so measures with a Likert-scale response option are not true quantitative measures. They give the example:

> [N]o investigator would express the mean of a Likert-response item as 'Strongly Agree and a half'. But, after these descriptors are converted to numbers, investigators are comfortable doing just that; in fact the results might be (improperly) expressed as 'Strongly Agree.523' (Bishop & Herron, 2015, p. 298).

Likewise, the information gathered from these questionnaires was not subject to any true statistical measure. Bloomberg (2023) recommends analyzing any quantitative data promptly before moving onto the primary data analysis in a qualitative study. Once all questionnaires were completed, each participant was assigned a pseudonym (ex: Teacher A, Teacher B, etc.). Descriptive statistics were then used to identify trends in participants' perceptions of the sexuality of individuals with IDD, such as how accepting they are of individuals with IDD as sexual beings and if they hold any common misconceptions regarding the sexuality of individuals with IDD. As Bloomberg (2023) describes, "[I]n qualitative research, reporting the findings means that data from all sources are seamlessly woven to provide an overall integrated and holistic presentation" (p. 329). This information was used in conjunction with the results of the qualitative interviews to inform future support and training recommendations for general education health teachers who will be teaching sex education to young adults with IDD.

Interview Data

Like many aspects of qualitative research, there is no single standard way of conducting data analysis (Patton, 2015; Bloomberg, 2023). There is no concrete test of statistical significance for qualitative data, so it is up to the researcher to break down, analyze, and construct meaning from the data (Patton, 2015). Patton (2015), a foremost qualitative researcher and self-declared pragmatist, refers to typical qualitative analysis as content analysis. Some researchers have a more restrictive view of content analysis as a superficial method of counting instances of words and phrases, rather than true analysis and meaning making (Patton, 2015). They instead use the term thematic analysis (Nowell, 2017; Bloomberg, 2023). However, as Patton clarifies, "[*C*]*ontent analysis* refers to any qualitative data reduction and sense-making effort that takes a volume of qualitative material and attempts to identify core consistencies and meanings" (p. 541). So, this researcher uses the term content analysis to refer to the general procedure of making meaning from qualitative data. The process of qualitative analysis proceeds from the general to the specific (Creswell & Creswell, 2018). In this study, raw interview data was analyzed generally using content analysis and then more specifically using cross-case pattern analysis to determine commonalities in the amount of training and experience participants have, their willingness to and comfort level teaching CSE to individuals with IDD, and the training and support they need to do so effectively.

Also, unlike in quantitative research, qualitative analysis is not a separate phase of research that occurs after data collection has concluded. It is a continuous process that begins as data is collected and continues in a cycle as codes are created and refined and patterns are discovered. Immediately following each interview, audio recordings were downloaded to the researcher's personal computer and backed up to a personal, password protected cloud storage account (OneDrive). Also following each interview, the researcher conducted an "immediate

post interview review," noting details, thoughts, and observations from the interview in a research journal (Patton, 2015, p. 471). All data—such as notes and audio recordings—were labeled with the previously assigned pseudonyms and dated. Audio recordings were transcribed soon after completion using an automatic transcription service (Bloomberg, 2023). The researcher then confirmed each transcription by listening to the audio recording and comparing it to the transcription, word for word, correcting and adding notes of emphasis and relevant body language as needed (Bloomberg, 2023). To enhance credibility, each participant was given the opportunity for participant verification, a form of member checking that consists of participants reading the transcription of their interview to verify that it accurately portrays their intended meaning. Once transcriptions were researcher and participant verified, they were prepared for preliminary coding by memoing.

Broadly, qualitative content analysis consists of data reduction, categorization, and reorganization. Data reduction began with reading over all the data and taking preliminary notes to get an overall feel for the data (Bloomberg, 2023; Patton, 2015; Creswell & Creswell, 2018). Then, coding of the data began. Codes can be developed inductively, meaning they are developed from the data; they can be developed deductively, meaning they are predetermined based on previous research or a preexisting framework; or they can be a combination of the two (Creswell & Creswell, 2018). For this study, codes were both inductively generated. Quotations are the raw data of interviewing (Patton, 2015), so care was taken to keep participants' words intact. Once coding was complete, categorization and reorganization occurred as coded data was sorted into categories and moved until patterns were developed and data saturation was reached (see Appendix C and Appendix D). Then, interpretation, also known as synthesis, began.

Bloomberg (2023) explains:

> Whereas analysis splits data apart, synthesis is the process of pulling everything together: (a) how the research questions are answered by the findings, (b) how the findings from interviews are supported from all other data collection methods, (c) how findings relate to the literature, (d) how findings relate to the researcher's initial assumptions about the data. (p. 300)

Two sources guide qualitative data analysis and interpretation: the data itself and the research questions, which are based on review of the existing literature (Patton 2015). Keeping a reflexive journal and conducting analytic memoing throughout the analysis process provided an audit trail to ensure trustworthiness (Bloomberg, 2023). All analysis and interpretation was done by the researcher.

Issues of Trustworthiness

Trustworthiness is especially important to pragmatists because it determines the likelihood that the results of a study will be put to practical use. A defining characteristic of pragmatism is that a study is only meaningful when it is useful (Patton, 2015). In qualitative research, trustworthiness generally involves four considerations originally termed by Lincoln and Guba in 1985: credibility, dependability, confirmability, and transferability (Nowell, 2017; Bloomberg, 2023). Some researchers assign different names to these concepts, but the overarching ideas are the same (Tracy, 2010; Patton, 2015). Credibility is the degree to which all facets of the topic have been explored and the researcher's portrayal of the topic matches the data gathered (Nowell, 2017; Bloomberg, 2023). It is similar to reliability in quantitative research. Confirmability is the degree to which interpretation accurately reflects the data collected in an unbiased manner (Nowell, 2017: Bloomberg, 2023). In other words, if another researcher conducted the same study on a similar sample, they would reach similar conclusions. Dependability is the alignment between a study's design and purpose (Nowell, 2017; Bloomberg,

2023). A well-designed study demonstrates dependability when the design framework, data collection methods and analysis techniques allow the researcher to answer the research questions. It is similar to validity in quantitative research. Transferability is the usefulness of the study and its findings to other applications and settings (Nowell, 2017; Bloomberg, 2023). It is similar to generalizability in quantitative research. Bloomberg (2023) notes, "Although qualitative researchers do not expect their findings to be generalizable to all other settings, it is likely that the lessons learned in one setting might be useful to others" (p. 304). Transferability is determined by the reader. The researcher can enhance transferability by making the study's methods and findings clear so readers can decide if it is transferable to areas of interest to them. These four tenets of trustworthiness were addressed in this study by triangulation, transparency measures, and demonstrations of reflexivity.

Triangulation

Triangulation is one way of accomplishing credibility, confirmability, and transferability. It is the use of multiple methods, data sources, or theories, to ensure that all facets of the topic have been explored. An additional benefit of triangulation is that it helps achieve data saturation, even with a small sample size (Bloomberg, 2023). This study utilized triangulation of data collection methods (see Table 3.2). All but one participant completed both a questionnaire and an interview; each method provided different types of information, and each has complementary strengths and weaknesses. The ASQ-ID collected demographic information, assessed participants' perceptions of the sexuality of individuals with IDD, and elucidated any common misconceptions participants held about the sexuality of individuals with IDD. Although questionnaires don't give participants the opportunity to elaborate, they are good for collecting demographic information and they often make it easier for participants to share their perspectives on sensitive issues, like sexuality. All but one participant partook in a qualitative interview

regarding their past experiences teaching health to students with disabilities, education and training they'd had specific to teaching students with disabilities, their confidence level to teach CSE to individuals with IDD, and the support and training they feel they would need to do so effectively. Although interviews rely on interviewer skill to collect quality information and sometimes make it difficult for participants to share about sensitive topics, they gave participants in this study an opportunity to elaborate and share information they may not have gotten the opportunity to share on the questionnaire. Additionally, having participants complete the questionnaire prior to scheduling interviews likely got them thinking about the sexuality of individuals with IDD so they could consider the topic prior to being interviewed.

Table 3.2

Triangulation Matrix

Research Questions	Data Source	
	Questionnaire	Interview
What types of supports do secondary general education health teachers need to effectively teach CSE to adolescents with IDD?	X	X
What are the perspectives of secondary general education health teachers on CSE for adolescents IDD?	X	X
What training, if any, have secondary general education health teachers received specific to teaching individuals with IDD?		X
How prepared do secondary general education health teachers feel to teach CSE to adolescents with IDD?		X

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Transparency

Demonstrating transparency is a way of addressing credibility, confirmability, and dependability. One way transparency was upheld was through the maintenance of a research journal. Journaling conducted throughout the study included post-interview reflections and justification of decisions made throughout the data collection and analysis process—including consideration of disconfirming cases. All participants were given the opportunity to complete member checks, in the form of participant verification of their interview transcription, to ensure accuracy and transparency in the expression of their ideas. Any experiences and ideas participants expressed that were contrary to the patterns discovered in cross-case analysis were addressed to ensure completeness in reporting. As Creswell and Creswell (2018) support, "Because real life is composed of different perspectives that do not always coalesce, discussing contrary information adds to the credibility of an account" (p. 201). Analytic memoing

conducted during data analysis also contributed to transparency by providing clear evidence for coding and categorization decisions that ultimately resulted in the findings of the study. All these forms of documentation contributed to an audit trail that clearly traces all the steps of the research process (Nowell, 2017). Thick description used in the reporting of the findings, , including purposeful use of direct quotes, conveyed the depth of perceptions and experiences portrayed by participants that formed the basis of the researcher's final recommendations.

Reflexivity

Reflexivity means being continually aware of how the researcher influences data collection and analysis. It is a way of enhancing trustworthiness by bolstering credibility and confirmability. In this study, reflexivity is evidenced in study design, journaling, and analytic memoing. The study design reflects reflexivity in the inclusion of two research sites in which the researcher is unfamiliar to balance the possible impacts of also including the researcher's place of employment. This chapter also later includes a consideration of the researcher's positionality, which is a demonstration of reflexivity. Journaling and analytic memoing conducted during data collection and analysis also provide a record of the reflections, considerations, and decisions of the researcher throughout the study (Nowell, 2017; Bloomberg, 2023).

Ethical Considerations

In the United States, the principals of research ethics are based on the Belmont Report, which outlines three ethical considerations for research with human subjects: respect for persons, beneficence, and justice (NCPHSBBR, 1979). As an additional safeguard, research on human subjects is also governed by institutional review boards (IRBs) who approve and monitor projects. To obtain IRB approval, and before any recruitment or data collection can be done, researchers must prove that they have addressed the ethical considerations outlined in the Belmont Report. There are three levels of IRB review—exempt, expedited, and full—each based

on the possible risk to human subjects and each with different reporting requirements. Due to the minimal risk to human subjects in this study, exempt IRB approval was granted in the Fall of 2023.

Respect for Persons

Despite the minimal risk to human subjects involved in this study, all the ethical considerations presented in the Belmont Report were considered by the researcher. Respect for persons was primarily addressed through informed consent, which is an IRB requirement for research with human subjects. Informed consent requires that potential participants be given the opportunity to make an informed decision about whether to participate in a study. It also requires researchers to make it clear to participants that they may cease participation in a study at any time and that no negative repercussions will befall them if they choose not to participate or to terminate participation. The principal of informed consent includes ensuring people are capable of understanding the information provided to them and are capable of consenting; all of the participants in this study were college educated and none were from a vulnerable population, so no additional steps had to be taken in this regard.

Informed consent for this study was provided twice and collected via digital signature and confirmed verbally by participants. All information required by the IRB and best practice was included, such as important details about the study, expected benefits, reasons to participate, potential harm, and methods of assuring confidentiality (Patton, 2015). Teachers who expressed interest by clicking the link or scanning the QR code in their e-mail and who answered yes to all eligibility questions were then taken to a digital version of the informed consent form where they could sign digitally and consent to the study or choose not to participate. They were offered the researcher's contact information in case they had any questions. A statement of informed consent was also built into the interview protocol as part of the introductory information (Jacob &

Furgerson, 2012; Patton, 2015). Additionally, participants who were interviewed virtually had to click a recording acknowledgement before Zoom would allow the recording to begin.

Beneficence

Beneficence is concerned with maximizing harm and minimizing risk. Informed consent documents address the concept of beneficence by including statements of expected benefits and potential harm. The target population for this study was secondary general education health teachers, and the aim was to generate recommendations for local districts on how best to support their existing secondary general education health teachers in the implementation of formal comprehensive sex education for young adults with IDD. So, the participants could benefit directly from the results of the study by receiving increased training and support.

In general, potential harms from participation in research could be physical, emotional, psychological, reputational, or financial. Although the issue of sexuality and sex education may be uncomfortable for some people, all the participants in this study were health teachers, so they were likely comfortable discussing sex education and related topics. Both data collection methods participants underwent in this study are low risk. Questionnaires are a preferred data collection method for sensitive information, and one was utilized in this study. Interviews are sometimes uncomfortable for participants but allowing participants in this study to choose the method, virtual or in-person, and the location gave them control to choose the setting most comfortable to them.

Sometimes there is a risk that participants may suffer backlash from others, such as coworkers or their employer, for participating or not participating in a study. In this case, administrators of the sites participants were recruited from did not know which teachers chose to participate, so there was no chance of employer backlash. Additionally, all recruitment and

potentially all data collection took place virtually and was done outside of school hours if desired, so there was little possibility of coworkers discovering who participated.

Many measures were taken to ensure participant privacy. As Bloomberg (2023) explains, "There are two aspects to [privacy]: First, the freedom to identify the time and/or circumstances under which information is shared or withheld from others. Second, the right to decline receiving information they do not want" (p. 307). To address the first aspect, all data, including correspondence, was kept private so only the research had access to it. E-mails, like those for recruitment, were sent from a password protected account that only the researcher has access to. Virtual questionnaire data, audio recordings, and interview transcriptions were also collected and stored via password protected software that only the researcher has access to. Participants were contacted once with an opportunity to verify their interview transcriptions. Finally, participants were contacted once at the conclusion of the study with an abridged version of the results.

Steps were also taken to ensure confidentiality during data collection and analysis and during reporting. Pseudonyms were assigned to participants (ex: Teacher A, Teacher B, Teacher C, etc.) immediately after they completed the questionnaire. Participants were referred to by their pseudonyms for the rest of the study. Although the use of homogenous sampling means that all the participants had specific characteristics, which could make them easily identifiable, recruiting participants from multiple research sites reduced the likelihood of participants being identified. The researcher also took care not to provide enough demographic information about any single participant in reporting to allow identification (Bloomberg, 2023).

Participants also knew from the informed consent document and statement that they could terminate their participation in the study at any time for any reason without repercussion. This is another way of minimizing harm because it ensures that if participants do suffer unforeseen adverse effects, they do not need to continue participation. Finally, participants

received the researcher's contact information during recruitment and were provided it again during the closing of the interviews, so they could contact the researcher with any concerns or to report any negative effects.

Justice

The principle of justice as presented in the Belmont Report (1979) refers to fairness. One way researchers can ensure fairness is by ensuring that they carefully consider who is benefitting from their research so that their subjects do not incur potential harms while others reap the benefits (NCPHSBBR, 1979). The target population for this study is secondary general education health teachers, and the aim is to generate recommendations for local districts on how best to support their existing secondary general education health teachers in the implementation of formal comprehensive sex education for young adults with IDD. In this respect, the Belmont principal of justice is satisfied because the participants could benefit directly from the results of the study by receiving increased training and support. Although the subjects of this study are not from a vulnerable population, the impetus for the study is to benefit individuals from a vulnerable population: those with IDD. An important aspect of fairness is equitable treatment and representation, which concerns the language used when discussing certain characteristics of individuals. This is especially relevant when discussing individuals with IDD because the previous term for this population was mentally retarded, a term that is now used in such a derogatory way that it was replaced. The APA (2020) states, "The overall principle for using disability language is to maintain the integrity (worth and dignity) of all individuals as human beings" (136). One way this is achieved is by using person-first language. This researcher is mindful to always use person-first language when referring to individuals with disabilities, such as the phrase "young adults with IDD" rather than "IDD young adults".

Researcher Positionality

In qualitative research, the researcher is the primary data collection and analysis instrument because the collection, analysis, and interpretation of data are all conducted by and at the discretion of the researcher without the mathematical support of quantitative statistical measures to fall back on. As such, it is vital for the researcher to acknowledge their position in relation the research site and participants as well as any biases they have that may have impacted the study. As Bloomberg (2023) elaborates:

> The EdD or dissertation in practice model, more so than with traditional PhD dissertations, assumes the researcher holds close personal connections to the research site, participants, and contexts, with the researcher holding a vested interest in resolving the professional problem of practice within their place of employment in the presence of colleagues. For this reason, the full disclosure of the researcher's positionality becomes all the more important (p. 140).

Having a vested interest in the topic of study, so long as it is realized and accounted for, is a benefit of qualitative research because it results in a deeper engagement and understanding. Many of the same techniques used to enhance trustworthiness can also be used to account for researcher positionality.

Reflexivity and transparency in methods are demonstrated through a clear audit trail, journaling, analytic memoing and attention to disconfirming cases. Creswell & Creswell (2018) extend the concept of reflexivity, adding, "This aspect of the methods is more than merely advancing biases and values in the study, but how the background of the researchers actually may shape the direction of the study" (p. 182). A desire to improve the lives of individuals with IDD is driven by the researcher's personal and professional experiences. As the child of a parent with IDD, the researcher has experienced firsthand the consequences of the lack of sexual

recognition, education and support for the sexuality of individuals with IDD. The researcher was raised by her grandparents because her parent with IDD lacked the knowledge, skills, and support to maintain a healthy adult relationship, care for an infant and raise a child. The researcher has also taught young adults with IDD for the past five years and has experienced and helped counsel students through their lack of relationship and sexuality knowledge and skills. These experiences result in a vested interest in improving sex education offerings for young adults with IDD.

Additionally, one of the research sites is the researcher's place of employment. Creswell and Creswell (2018) refer to this as "backyard research" and recommend taking conscious steps to prevent conflict of interest and increase trustworthiness. Although the researcher works with some of the participants, none of them are subordinates of the researcher (Bloomberg, 2023). However, the study design reflects reflexivity in the inclusion of two research sites in which the researcher is unfamiliar to balance the possible impacts of including the researcher's place of employment. Journaling and analytic memoing conducted during data collection and analysis also provide a record of the reflections, considerations, and decisions of the researcher throughout the study (Nowell, 2017; Bloomberg, 2023).

In studies involving qualitative interviewing, researchers must also consider how they will be perceived by participants to encourage an equal balance of power. Patton (2015) recommends striving for empathic neutrality, which he defines as, "[U]nderstanding a person's situation and perspective without judging the person—and communicating that understanding with authenticity to build rapport, trust, and openness" (p. 57). Following the advice of Patton (2015), the interview protocol was carefully designed to increase researcher rapport and participant comfort and to encourage open answering. Experience and behavior questions were asked first because they are relatively easy to answer and non-controversial. Then, opinion and

feeling questions were asked because they are easier for participants to answer once experiences are recalled. Demographic questions were asked on the questionnaire so the researcher could focus on asking open-ended questions and encouraging deep responses during interviews. Follow-up questions and reinforcing body language were also used to increase the depth of responses. The illustrative examples format of questioning was used throughout the interview to lessen participants' fear of judgement. Prefatory statements were utilized to keep participants aware of and comfortable with the flow of the interview. Attempts to clarify misunderstandings were limited to two per topic to prevent participant frustration when misunderstandings did occur. At the conclusion of the interview, participants were given an opportunity to share any final thoughts and were provided with the researcher's contact information in the event of additional questions or comments to emphasize that their input is valued.

Limitations and Delimitations

Limitations include those inherent in qualitative inquiry and those specific to the methods selected for this study. Local sampling could limit readers' perception of transferability, but generalizability is not the goal of qualitative research and the decision to focus sampling locally is well-justified by current sex education policies and practices and well-suited to the purpose of developing actionable recommendations for districts to implement. The use of a questionnaire as a data collection method limits participants' ability to elaborate, so a questionnaire was used only to gather supplementary perceptual and demographic data. The primary data collection method was qualitative interviewing. Recruiting participants from the researcher's place of work could result in those participants being less open and honest in their responses (Bloomberg, 2023). So, potential participants were also recruited from four other research sites (although only two additional sites yielded participants).

Certain delimitations were set by the researcher to focus the scope of the study. The target population of secondary general education health teachers was selected to fill a gap in the existing research. This group is often mentioned as being well positioned to teach CSE to young adults with IDD, but their perspectives have yet to be explored. Instead, the focus has been on the perspectives of parents, special education staff, and the public (Cuskelly & Bryde, 2004; Cuskelly & Gilmore, 2007; Tamas et al., 2019). The decision to focus on research sites local to Northeastern Pennsylvania was guided by the lack of federal guidelines and funding for CSE, which leaves the responsibility to plan for and fund CSE up to state governments and local districts (Planned Parenthood, 2023). The ASQ-ID questionnaire was selected as a secondary data collection method because, although it is close-ended, it is an established measure that has been used in previous studies on the perception of the sexuality of individuals with IDD (Cuskelly & Bryde, 2004; Cuskelly & Gilmore, 2007; Tamas et al., 2019). Finally, the decision was made to utilize generic qualitative inquiry guided by pragmatism, rather than a specific qualitative methodology like grounded theory, to prioritize the problem over the methodology.

Presentation of Results

This study was conducted as the dissertation requirement for a Doctor of Special Education degree, so the results were shared with selected Slippery Rock University faculty and students as well the researchers' dissertation committee, both during the research process and after completion. The researcher may also seek publication in the future. As far as sites and participants go, the superintendent and director of special education of each site and the participants were provided with an abridged version of the findings of this study and the resultant recommendations for utilizing secondary general education health teachers to teach sex education to high school students with IDD. They were also given the option to receive a digital copy of the entire dissertation at their request.

Summary

This study aimed to fill a gap in the existing research by investigating the perspectives of general education health teachers, a group that is often referenced in the literature as being well-positioned to teach CSE to young adults with IDD, but whose perspectives have yet to be explored. Previously, the focus has been on the perspectives of the public, parents, special education faculty and staff, and individuals with IDD themselves (Cuskelly & Bryde, 2004; Cuskelly & Gilmore, 2007; Tamas et al, 2019). Since the study concerned a specific target population, a group characteristic sampling strategy was required (Patton, 2015). All participants were general education teachers who held current Pennsylvania teaching certificates in either Health Education PK-12 or Health and Physical Education PK-12 and had taught at least one general education high school health class. Because the goal of this study was to make research-based, actionable recommendations that school districts can implement utilizing existing resources (general education health teachers) to provide a much-needed service (CSE) to their adolescents with IDD, this study had a local focus. Participants were recruited from three school districts in Northeastern Pennsylvania.

The design of this study was pragmatic and followed tenets of generic qualitative inquiry rather than adhering to a specific qualitative methodology. A pragmatic approach is well-suited to this issue because its driving goal is actionable results. Generic qualitative inquiry was chosen over a specific qualitative methodology, like grounded theory, to prioritize the problem over the methodology. It also allowed the researcher to select methods with complementary strengths and weaknesses. This study utilized a “cross-sectional interview-based design” supported by supplementary questionnaire data (Smith et al, 2011). True to qualitative inquiry, the driving data for this study was qualitative interviewing. Supplementary close-ended questionnaire data was

used to contextualize, confirm, and enhance interview findings, but it was of secondary importance to interview data and was not the primary focus of the study.

Trustworthiness was achieved via purposeful sampling, reflexivity, triangulation of methods, member checks, the maintenance of an audit trail, and use of thick description. All three ethical considerations outlined in the Belmont report were addressed in the study design and reporting. This study posed minimal risk—mainly just possible discomfort discussing sexuality and sex education—but it has the potential to yield great benefits in the form of increased training and support for secondary general education health teachers and improved sex education programming for young adults with IDD.

The next chapter explains the findings of this study. It describes the demographics of study participants, explains how data was analyzed and how themes were generated, and details participants' perspectives on the sexuality of individuals with IDD, their feelings on CSE for young adults with IDD, their willingness and preparedness to teach CSE to this population, and the supports they need to do so effectively.

CHAPTER 4: RESULTS AND FINDINGS

The previous chapter outlined the qualitative methodology and methods that were undertaken to investigate the perspectives of secondary general education health teachers in this study. It also explained how collected data was analyzed and synthesized to inform recommendations for local districts on how best to support their existing secondary general education health teachers in the implementation of formal comprehensive sex education (CSE) for young adults with intellectual and developmental disabilities (IDD). This chapter explains the findings of this study. It describes the demographics of study participants, further explains how data was analyzed and how themes were generated, and details participants' perspectives on the sexuality of individuals with IDD, their feelings on CSE for young adults with IDD, their willingness and preparedness to teach CSE to this population, and the supports they need to do so effectively.

It is well established that individuals with IDD need access to better information regarding relationships and sexuality; they do not receive sex education at the same rate as their nondisabled peers to the detriment of their safety and well-being. With the increase in students with IDD in the general education setting since the enactment and subsequent reauthorizations of the Individuals with Disabilities Education Act (IDEA), general education teachers have become likely candidates to provide this instruction. So, this qualitative study sought to investigate the perspectives of secondary general education health teachers on the sexuality of individuals with IDD to determine if they hold any common biases or misconceptions that need to be addressed and to determine what support and training, they need to deliver CSE to this population effectively. This study was conducted according to the tenets of generic qualitative inquiry and

utilized a cross-sectional interview-based design supplemented by questionnaire data.

The target population for this study was secondary general education health teachers because their perspectives had yet to be explored in previous research on the topic. Participant recruitment was focused on research sites local to Northeastern Pennsylvania due to the lack of federal guidelines and funding for CSE, which leaves the responsibility to plan for and fund CSE up to state governments and local districts (Planned Parenthood, 2023). The results were used to generate actionable recommendations for local districts on how best to support their secondary general education health teachers in the implementation of formal CSE for young adults with IDD so they can utilize their existing faculty to deliver this much needed service to young adults with IDD.

Demographics

For this study, a minimum of ten participants were sought to generate enough interview data to clearly address the research questions while still being manageable for a single novice researcher. Twenty-eight potential participants from five school districts were contacted. Nine participants completed the questionnaire, and eight participants from three school districts completed the semi-structured interview. One teacher signed the informed consent form but, upon viewing the questionnaire, felt he did not know enough about individuals with IDD to continue his participation in the study. Three additional teachers expressed interest but were not eligible because they have never taught in high school.

The nine participants who completed at least one study component had between 6 and 21 years of experience teaching health, for an average of 16.9 years of teaching experience. For special education in particular, participants had between 3.5 and 21 years of teaching experience, for an average of 14.1 years of experience teaching special education students. However, most participants specified that this experience was primarily from having special education students

included in their general education classes and was not necessarily specific to teaching self-contained classes or to teaching students with IDD. All participants have taught high school and all but one currently still does. Most have also taught middle school grades, and a few participants have taught elementary school grades. All participants hold current Pennsylvania teaching certifications in Health & Physical Education, PK-12 or K-12. Slightly more than half of the participants have a master's degree in a related field, the rest hold a bachelor's degree (see Table 4.1).

Table 4.1

Participant Demographics

Participant	Years of Teaching Experience	Years of Experience Teaching Health	Years of Experience Teaching Special Education Students	Grade(s) Taught	Highest Post-Secondary Degree Earned & Field	Pennsylvania Teaching Certification(s)
Teacher A	8	8	8	9-12	B.S. in Kinesiology	K-12 Health and PE Driver Education
Teacher B	17	17	17	6-12	M.S. Health Education	PK-12 Health PK-12 Health & PE
Teacher C	16	16	16	5-12	B.S. in Exercise, Sport & Health Education	K-12 Health & PE Driver Education
Teacher D	21	21	5	6-12	M.S. in Classroom Technology	K-12 Health & PE Driver Education
Teacher E	6	6	3 ½	K,2,9,10,11,12	B.S Health and PE	Health and PE
Teacher F	16	16	16	K-12	M.S. in Classroom Technology	Health and PE
Teacher G	21	21	21	11	M.S. in Classroom Technology	K-12 Health and PE
Teacher H	23	20	23	6, 9, 11, 12	M.S. in Kinesiology	Health and PE
Teacher I	21	21	17	7-12	B.S. Health & PE	K-12 Health and PE

All participants were recruited from three school districts—two rural and one suburban—in Lackawanna, Pike, and Wayne Counties in Northeastern Pennsylvania. The researcher also received site permission from two neighboring districts; recruitment e-mails were sent to their secondary health teachers but yielded no participants. Two other neighboring districts were also contacted but did not respond to requests for site permission. All three participating districts are part of the Northeastern Educational Intermediate Unit (NEIU) 19. Together these districts cover more than 700 square acres and serve more than 6,000 students K-12 districtwide. According to the Future Ready PA Index (2023), the student body of all three districts is primarily white (82%) and, on average, 10.8% Hispanic, 2.6% Black, 3.4% two or more races, 0.8% Asian, 0.2% Native American/Alaskan Native, and 0.1% Native Hawaiian or other Pacific Islander. On average, 60.7% are economically disadvantaged, 0.7% are designated English language learners (ELL), 0.9% are homeless, and 0.4% are in foster care. On average across all three districts, 23.9% receive special education services; this is above the Pennsylvania state average of 18.5% of students per district receiving special education services in the 2021-2021 school year (Christ, 2022).

Results

Primary Research Question

What types of supports do secondary general education health teachers need to effectively teach CSE to adolescents with IDD? Overall, this study sought to determine the type of supports secondary general education health teachers need to effectively teach CSE to adolescents with IDD. To answer this question, participants completed a questionnaire and answered semi-structured interview questions.

The questionnaire—a researcher-revised version of the *Attitudes to Sexuality Questionnaire - Individuals with an Intellectual Disability* (ASQ-ID)—measures participants' level of agreement with statements about the sexuality, romantic freedom, sexual expression, and sex education of individuals with IDD. (The researcher received written permission from the co-creator of the ASQ-ID, Dr. Monica Cuskelly, to use and revise it.) Taken as whole, the ASQ-ID helps assess how liberal or conservative participants' views are towards the sexuality of individuals with IDD. It also includes statements of common misconceptions held about the sexuality of individuals with IDD—such as that they lack sexual desire or are overly sexual and lack control—to identify misconceptions participants hold that may indicate a need for specific training.

The ASQ-ID is scored by assigning a point value from one to six to participants responses on a six-point Likert scale with higher scores indicating more liberal views toward sexuality. Response options on the Likert scale are strongly disagree, disagree, somewhat disagree, somewhat agree, agree, and somewhat disagree. On the revised version used for this study, there were twenty-two statements with nine statements reverse scored. ASQ-ID responses were analyzed for overall ratings (liberal versus conservative), patterns, discrepancies, and ratings on misconception statements.

During the interview, participants were asked questions about their experience teaching special education generally and to students with IDD specifically, how they would feel if told they were teaching an adapted health and sex education class, what concerns they would have, and what support they would want from special education professionals. Interview responses were then automatically transcribed, researcher and participant verified, read over, and separated according to which research question they address. The researcher then began the process of content analysis, specifically focused on cross-case pattern analysis. Using OneNote, responses

were inductively coded and illustrative quotations were flagged. Once the data was initially coded, the codes were categorized and collapsed until the following themes were identified (see Appendix C, Appendix D, and Appendix E).

Special Education Support. All teachers interviewed stated that they would need support from a special education teacher to teach CSE to students with IDD effectively. However, the type and level of support desired varied. Five of the teachers interviewed would be open to co-teaching an adapted health and sex education class with a special education teacher, and two of those teachers would prefer it. Teacher G, who co-taught an adapted health and sex education class last school year for the first time, explained:

> Does that mean I couldn't do it by myself? No, I think I could. But it was *way way* better with the two of us there, because we did tag team it. We did, 'Okay, this is your strength. You take this piece. Now flip it back to me. I take this piece...'

Three of the teachers interviewed would prefer to teach an adapted health and sex education class on their own but would still like support from a special education teacher outside the classroom, primarily in planning instruction. Teacher C, who has little experience teaching students with IDD, stated, "I think it would be great to have a special ed. teacher in the building that I could go to with questions. Or if I was working on building something, specifically partnering with them." All teachers interviewed stated that they would require support from a special education teacher to develop the curriculum for an adapted health and sex education class and in modifying assignments to the individual needs and levels of the students in the class.

Paraprofessionals are a common fixture in special education settings and serve various roles, but working with paraprofessionals is not something many general education teachers are accustomed to. Teachers interviewed had varying opinions on paraprofessionals in the classroom. Most participants distinguished personal care assistants who work one-on-one with

individual students, such as those supporting students with challenging behaviors, from instructional paraprofessionals, sometimes called classroom assistants. As explained by Teacher C:

> My experience right now if I've had someone in the classroom is that they can't help me. You know, they're just there for the students? So, if it was somebody who could actually help, then that would be ideal. If it was, you know, the situation where it's like, 'I'm here to help these particular students that need one-on-ones,' then that's not always helpful...

Most teachers interviewed realize the need for and are largely accepting of one-on-one personal care assistants.

However, teachers had varying views on classroom assistants. Five teachers stated they want the support of a classroom assistant. Two teachers stated they would try having a classroom assistant but are not sure if it would be beneficial. Oppositely, Teacher H, who has taught several adapted health and sex education classes in the past, was adamant that she does not want the support of a paraprofessional, stating:

> I don't like extra people in my classroom. Unless it was something where the kid had extreme behavioral issues that would distract me from being able to teach the other kids. But other than that, no, I like to have my class as my class.

For the most part, teachers who were reluctant to have a classroom assistant felt that way due to either a self-proclaimed lack of experience working with an assistant or to negative experiences working with an assistant in the past.

Those who have become accustomed to working with classroom assistants or who have had positive experiences with assistants in the past were more open to having one in the future. Teacher B described how one of the paraprofessionals in her previous adapted health and sex education class was skilled at reading aloud expressively, which helped students to better

understand assignments, especially those about relationships and emotion. She went on to say, “I love the [paraprofessionals] in my class. I think they’re part of the reason that my class is so successful.” Teacher B shared that any extra support person in the classroom provides another adult for students to potentially connect with and go to with questions or concerns, which is beneficial for all, even general education peer helpers. Most participants acknowledged that it depends on the individual classroom assistant if they are helpful.

The most common reason for wanting a special education staff member in the classroom was because special education staff know the students better than general education teachers do. Teacher B stated, “I would feel more comfortable having someone to kind of feed off of who's maybe around them more than me.” Teacher E, who has taught adapted health and sex education in the past, elaborated that it is beneficial to have a special education staff member in class with him to support discussions, ask questions they know students may have, make connections to things happening outside the classroom, and reinforce and hold students accountable for things taught in health class outside of class (e.g. personal space, public versus private behavior, hygiene, etc.).

Administrator Support. Some teachers also expressed the importance of having support from building and district-level administration when taking on an endeavor like teaching an adapted health and sex education class. Teacher G, who co-taught an adapted health and sex education class for adolescents with IDD for the first time last school year, stated that they could not have gotten this new class started without the support of their administration. Specifically, she explained how necessary it was for her and the special education teacher to have time to write curriculum together over the summer to have a common planning period at least once a week while teaching the course, stating:

> To be honest, I don't think there could have been a better set up because it's all well and good to meet over the summer and come up with your plans. But until you're in it you don't know what you don't know. So, I think the fact that we had that one period a week where it was set in stone. 'This is what we're doing. This is what we're talking about.' I feel like I don't know how we could have made that any better.

Ensuring teachers' schedules are compatible to co-teach a course and have a common planning period and compensating teachers for curriculum writing all require administrative approval and support.

Additionally, several teachers mentioned that they would want to have a set curriculum prior to teaching an adapted health and sex education course so if a parent had a concern about the appropriateness of a topic being covered, they would have an approved curriculum to refer to. Administrative support would be necessary to support teachers if challenges to the topics covered arose. Teacher F added that she feels it should be a joint effort between teachers, administrators, and parents to determine what topics will be covered.

Curriculum. All teachers interviewed discussed the importance of having a curriculum prior to teaching a new course like adapted health and sex education, and they all mentioned the need for special education teacher support in creating and adapting said curriculum. Some teachers stated they would prefer to utilize a pre-made adapted health and sex education curriculum designed specifically for students with IDD, especially when teaching the course for the first time. Others stated they would prefer to modify the curriculum they use for their existing general education health classes with the help of a special education teacher but felt it would be useful to have an adapted curriculum designed specifically for students with IDD for use as a guide and an additional resource. Teacher D, who has taught adapted PE but never adapted health and sex education, stated, "I think it could be a combination of what we do in our regular

class with, you know, stuff that would be probably more geared towards their level or what would benefit them." Teacher G, who cotaught adapted health and sex education for the first time last year, explained:

> We did mirror the unit of health of what our traditional units were...However it was presented differently...We did use [Positive Choices] curriculum that we had found online geared towards this population...It gives a lot of good diagrams, good information, good ideas on how to present this. We didn't do everything in the book...We did base it heavily on this.

Regardless of where it comes from or how it is developed, several teachers stated that a well-defined curriculum framework of topics to cover is important for several reasons: to pass along to future teachers who may teach the course, to ensure the course achieves its desired purpose, and to protect themselves from potential parent backlash.

Training. Nearly all of the teachers interviewed stated that they do not currently receive enough, if any, in-service health training—especially related to special education—and are open to any training available, be it in-house or off-site. A few teachers stated they prefer off-site training, like that offered recently by the Northeastern Educational Intermediate Unit (NEIU), because they find it helpful to see how other teachers, schools and districts do things. As Teacher B described, "I like those trainings...I always like to hear what other people are doing...I find that very helpful." Teacher G also stated, "I'm always open to seeing some other person's idea of what would be appropriate." However, preferred training topics varied.

Some teachers interviewed would prefer to receive training on individuals with IDD in general and strategies for teaching them. Teacher H, who has taught adapted health and sex education several times in the past, described:

> I think additional training would be good. I don't think it needs to be like a grad course in it. But, getting taught some stuff or some tricks or things. Something like that I think would be helpful because I don't know a lot about all of their different things they have going on with them, I guess.

Others would prefer to receive more targeted training on sex education for adolescents with IDD. Teacher G, who also has prior experience teaching adapted health and anticipates doing so again in the future, stated:

> Specific to life skills, I would love there to be a training...in particular just about presenting sexual education information to students. I would absolutely attend that. I would absolutely love it, and... I would take from that. And I would use what would apply to my students and what I feel they would benefit from.

Unfortunately, participants report that they rarely, if ever, see training like this offered.

Five statements on the ASQ-ID relate to misconceptions commonly held about the sexuality of individuals with IDD. Participants' responses to these statements revealed that most do not hold these misconceptions. On those addressing the misconception that individuals with IDD are hypersexual and prone to deviance, most participants disagreed at least somewhat with the statement, "Adults with IDD are more easily stimulated sexually than people without IDD," and all but one participant disagreed at least somewhat with the statement, "Individuals with IDD have stronger sexual feelings than nondisabled individuals." On statements addressing the misconception that individuals with IDD are asexual and uninterested in sex, all participants disagreed at least somewhat with the statements, "Individuals with IDD have less interest in sex than nondisabled individuals," and "Adults with IDD typically have fewer sexual interests than people without IDD." All participants also disagreed at least somewhat with the statement, "Adults with IDD are unable to develop and maintain and emotionally intimate relationship with

a partner," indicating that they understand that individuals with IDD are capable of establishing romantic relationships.

Reflection and Revision. Three of the teachers interviewed had previously taught an adapted health and sex education class for students with IDD, and they all reflected on things that worked in the past and things that they would like to improve upon. Teacher G reflected:

> Especially as our first attempt at doing this, I think we knew we were gonna learn a little bit about what it's going to look like...Certainly with any class, you do it once and then you say, 'Okay, we're gonna make this happen. We're gonna skip this part next time.'...This is my first year doing it. I am learning. I know I'm going to get better at it.

One of the teachers interviewed currently teaches an adapted physical education class for individuals with IDD, and he too reflected on things he would like to do differently going forward.

Secondary Research Question 1

What are the perspectives of secondary general education health teachers on CSE or adolescents with IDD? To answer the primary research question, it is necessary to understand the perspectives of secondary general education health teachers on CSE for adolescents with IDD. This question was also answered using data collected from participants' responses to the ASQ-ID and their answers to semi-structured interview questions. In addition to the previous questions relating to the primary research question, participants were also asked about training they have received on teaching special education students generally and students with IDD specifically. The same data analysis procedures were used to determine the answer to this question as were used for the primary research question to identify patterns in teachers' perceptions.

Additionally, to get a clearer picture of participant' understanding of and openness to the sexuality of individuals with IDD, the researcher separated the statements on the ASQ-ID into

categories during data analysis and calculated sub scores for each participant and average overall sub scores (see Table 4.2). The romantic freedom category consists of statements about intimate and non-sexual relationships. The sexuality category consists of statements about the sexual interests and feelings of individuals with IDD. The sex education category consists of statements about when to discuss sex education with individuals with IDD, what topics should be covered, and the role that sex education plays. The sexual expression category consists of statements about physical expressions of sexuality like masturbation and intercourse.

Table 4.2

ASQ-ID Statements by Category

Sexuality • Adults with IDD typically have fewer sexual interests than people without IDD. • Sterilization should be used as a means of inhibiting sexual desire in individuals with IDD. • Adults with IDD are more easily stimulated sexually than people without IDD. • Individuals with IDD have stronger sexual feelings than nondisabled individuals. • Generally, individuals with IDD are able to make the distinction between sexual thoughts and sexual actions. • Individuals with IDD have less interest in sex than nondisabled individuals.
Sexual Expression • Sexual intercourse should be allowed between consenting adults with IDD. • Sexual intercourse should be discouraged amongst adults with IDD. • Masturbation should be discouraged among adolescents with ID. • Masturbation in private for adolescents with IDD is an acceptable form of sexual expression. • Masturbation should be taught to individuals with IDD as an acceptable form of sexual expression in sex education courses. • It is a good idea to ensure privacy at home for individuals with IDD who wish to masturbate.
Romantic Freedom • Provided no unwanted children are born and no one is harmed, consenting adults with IDD should be allowed to live in a heterosexual relationship. • Consenting adults with IDD should be allowed to live in a homosexual relationship if they so desire. • Adults with IDD should be allowed to engage in non-sexual romantic relationships. • Adults with IDD are unable to develop and maintain an emotionally intimate relationship with a partner.
Sex Education • Discussions on sexual intercourse promote promiscuity in adolescents with IDD. • Sex education for adolescents with IDD has a valuable role in safeguarding them from sexual exploitation. • Advice on contraception should be fully available to individuals with IDD whose level of development makes sexual activity likely. • It is best to wait for the individual with IDD to raise questions about sexuality before discussing the topic with him/her. • Sex education for adolescents with IDD should be compulsory. • It is best not to discuss issues of sexuality with people with IDD until they reach puberty.

Need For Sex Education. All the teachers interviewed stated that sex education is necessary for adolescents with IDD, regardless of their cognitive level. And all teachers who completed the ASQ-ID agreed at least somewhat with the statement, “Sex education for adolescents with IDD should be compulsory.” However, participants’ ideas on what should covered varied, with some favoring less comprehensive sex education than others.

Teachers interviewed provided several reasons why they feel sex education is necessary for students with IDD. The most stated reason is that individuals with IDD need access to correct information about relationships and sexuality. Specific areas participants feel adolescents with IDD need instruction in are how their bodies and those of the opposite sex work, appropriate behavior for public versus private settings, and prerequisite knowledge that health teachers typically assume teenagers already have but many with IDD lack, such as hygiene. Teacher B, who currently teaches adapted PE, explicitly stated the need to correct misinformation found on online sources, like YouTube, explaining, "I think a lot of times they are just left like to be on their iPads and stuff like that." Another reason why participants feel sex education is needed for young adults with IDD is that they need a safe place to discuss sexuality-related topics. Teacher H stated that one of the reasons why sex education should be taught by someone other than a special education teacher is so students with IDD have an additional trusted adult they can talk to about such issues.

Participants unanimously agreed that one important reason why an adapted health and sex education class for adolescents with IDD is necessary is that those who are included in general education health classes are not fully benefitting, usually because the information is presented in a manner that is over their heads. Teacher G described:

> From my experiences in a regular ed classroom, where I would have that population of [IDD] students in here with their aides and just wondering sometimes, you know, I'm talking to 17-year-old, 18-year-old students...They're sitting in here getting this information that I'm presenting to this age category, and technically they are that age, but you could clearly see that there was a need. A lot if it was just 'whoop!' [gesturing over her head]. It wasn't even something that was resonating with them at all. And that's not

> helpful...We know there's a need, like it just doesn't fit. If it doesn't fit, then they're not taking away what they need to take away.

Openness to and Understanding of Sexuality of Individuals with IDD. All teachers interviewed stated that they are supportive of romantic and sexual freedom for individuals with IDD. Teacher H—who has taught adapted health and sex education several times and whose score on the ASQ-ID indicates the most liberal views of all participants—explained:

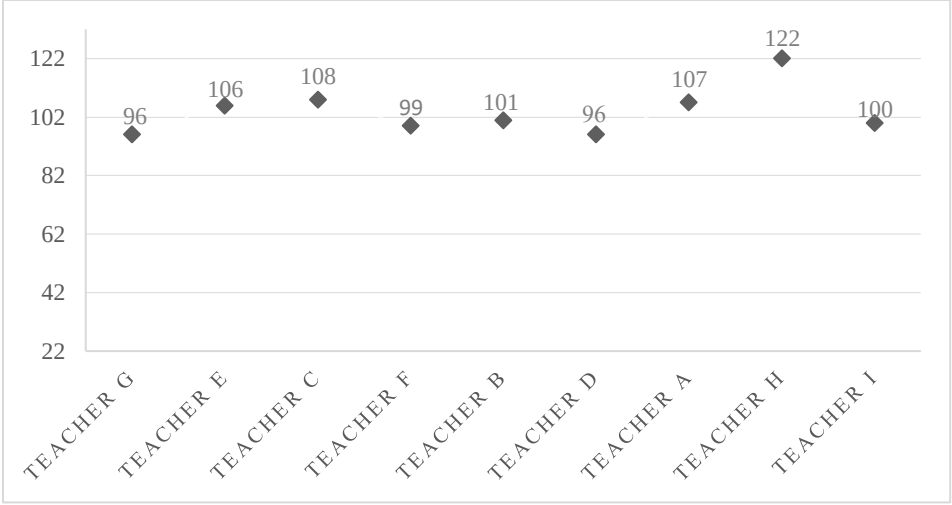
> I think it's an important thing that they need to learn because they're human just like anybody else and they've got the hormones, they've got the feelings, they just even more so need to know exactly what's appropriate and not appropriate for them.

All teachers who completed the ASQ-ID agreed at least somewhat with the statement, "Sexual intercourse should be allowed between consenting adults with IDD." However, participants' responses to the ASQ-ID questionnaire did illustrate some limiting beliefs about the sexuality and sexual freedom of individuals with IDD, such as masturbation.

Participants' overall scores on the ASQ-ID questionnaire reveal that, on average, participants hold liberal views of the sexuality of individuals with IDD (average score of 103.9 out of 132). Taken individually, all but one participant's score (ranging from 96 to 108) indicated liberal views, with the remaining teacher's score (122) indicating strongly liberal views (see Figure 4.1). In descending order, participants' average sub scores indicate liberal views on sex education for individuals with IDD (31.2 out of 32) and somewhat liberal views on the romantic freedom (30.3), sexuality (26.7), and sexual expression (26.4) of individuals with IDD (see Figure 4.2). Participants ratings for each statement were also averaged to determine which statements were rated most conservatively and most liberally on average.

Figure 4.1

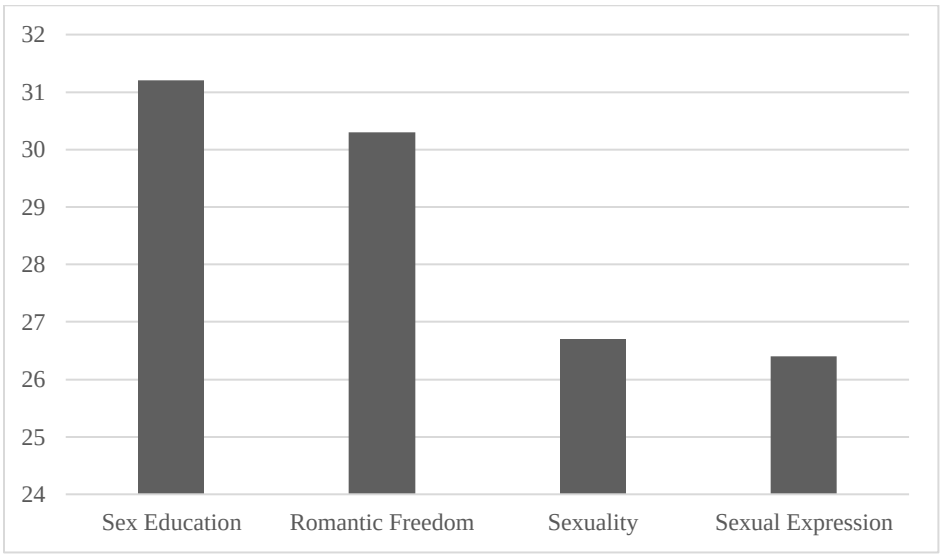
ASQ-ID Scores by Participant



Note: Scores are out of a maximum of 132 points. The higher the score the more liberal the participants' view on the sexuality of individuals with IDD.

Figure 4.2

Average ASQ-ID Sub Scores



Note: Sub scores are out of a maximum of 32 points. The higher the score the more liberal the participants' views.

The eight lowest rated statements were from the sexuality and sexual expression subcategories. The five lowest were characterized by inconsistent scores, meaning participants

ratings were spread out between three or four ratings on the Likert scale and were not clustered to one side towards general agreement or disagreement. The statement with the lowest average rating—indicating participants have a somewhat conversative view on the statement—was "Masturbation should be taught to individuals with IDD as an acceptable form of sexual expression in sex education courses." Participants' ratings on this statement were very inconsistent, with four participants rating in the agreement range and five rating in the disagreement range. The next lowest rated statement on average, which also had inconsistent responses, was, "Generally, individuals with IDD are able to make the distinction between sexual thoughts and sexual actions." Six participants' ratings fell in the agreement range, and four fell in the disagreement range. The following statements all had similarly inconsistent ratings and were among the lowest rated on average: "Adults with IDD are more easily stimulated sexually than people without IDD," "Masturbation in private for adolescents with IDD is an acceptable form of sexual expression," and "Individuals with IDD have stronger sexual feelings than nondisabled individuals."

All but one of the top five highest rated statements were from the sex education category; the other was from the romantic freedom category. The highest rated statement, on average, was, "Advice on contraception should be fully available to individuals with IDD whose level of development makes sexual activity likely." All participants agreed at least somewhat with this statement. All participants also agreed at least somewhat with the statements: "Sex education for adolescents with IDD has a valuable role in safeguarding them from sexual exploitation," and "Adults with IDD should be allowed to engage in non-sexual romantic relationships." All participants disagreed or strongly disagreed with the statement, "Discussions on sexual intercourse promote promiscuity in adolescents with IDD." And, all disagreed at least somewhat with the statements, "It is best to wait for the individual with IDD to raise questions about

sexuality before discussing the topic with him/her," and "Sterilization should be used as a means of inhibiting sexual desire in individuals with IDD." Due to the reverse scoring of some statements, these ratings all indicate more liberal views on these issues.

Willingness to Teach Adapted Sex Education. All teachers interviewed were willing to teach adapted health and sex education to adolescents with IDD. A couple of the teachers interviewed were even eager to teach health and adapted sex education and are disappointed they do not have the upcoming opportunity, in part because they were concerned that the teacher who will be teaching it will not do so effectively. Most were willing but somewhat apprehensive and admittedly need training and support to do so confidently. As Teacher A explained:

> I think there needs to be an adapted health class or there should be. Um, I'd have no problem teaching it. My only, not even a concern, my only, like, hesitation would just be my, you know, the lack of training in it. Um, but I definitely think it needs to be offered to them.

Those interviewed who have taught adapted health and sex education to individuals with IDD in the past shared contradictory opinions on how best to structure aspects of the course based on their experience. Teacher G chose not to separate genders for discussion about male and female body parts and experiences and felt strongly that that was the right choice. She stated:

> We presented it as, 'Everybody can know this. It's not a bad thing to know this.'...I think the mindset was...we're gonna be talking about things that have to do with girls. We're gonna be talking about things that have to do with boys. And it's okay. You can know. You can know what's going on, even though it may not affect you directly. There's nothing wrong with knowing that.

Teacher H—who has taught the class twice and has tried teaching it both ways—felt strongly that it is better to separate classes by gender for certain topics. She explained:

> It think it was good for that group to be separated into male and female. I felt like especially the boys were less goofy and less embarrassed about topics that we talked about because I think they're impacted more with sex ed, you know, just with uncontrolled erections, you know, all of that kind of stuff that goes with it. So, I thought it was better teaching them segregated than altogether and, you know, doing relationships you could bring them back together again, but for the sex part of it.

Despite their differences in opinion, both teachers did emphatically agree that it is important for both genders to know about each other.

Several teachers who have worked with students with IDD in the past in some capacity spoke about the varying ability levels amongst students with IDD and the need to differentiate even already adapted materials accordingly. Teacher G explained that when she taught adapted health and sex education last year, "Within that class itself, even though it was a life skills health class, we still had different levels of ability. So, anything that we would create, oftentimes I would create at least two versions of it, sometimes three versions." Two teachers stated they believe it would best to separate students with IDD into leveled classes, at least for some topics, so that material can be presented at a level that is appropriately complex for students with mild to moderate IDD without being too complex for students with moderate to severe IDD and vice versa.

Parental Role. Parents of children with IDD tend to have more involvement in the lives and relationships of their adolescent and adult children with IDD than parents of nondisabled children (Kammes et al., 2020). So, the role of parents in the sex education of adolescents with IDD came up in several interviews, specifically whether parents should have a say in the topics covered and whether they should be able to opt their children out of sex education. This issue is

especially complicated when considering that students with IDD can, and often do, remain in high school until age 22, so may legally be adults themselves (PDE, 2023).

About half of teachers interviewed had not considered the roles of parents, but those who had held contrasting views. Two teachers felt strongly that parents should not be able to opt their children out because students are entitled to information about their bodies. Teacher B stated, “I think if you’re teaching kids how to make healthy choices in all aspects of life, there shouldn’t be an opt out.” In contrast, Teacher F felt strongly that parents should have a say in what is covered and should be able to opt their children out of specific topics or of sex education altogether. Other teachers who discussed the issue mentioned sending home letters to parents notifying them of the intent to cover certain topics and wanting to follow whatever policy would be used if the parent of a general education student had the same concern.

Secondary Research Question 2

What training, if any, have secondary general education health teachers received specific to teaching individuals with IDD? To answer the primary research question, it was also necessary to understand what, if any, existing training secondary general education health teachers have had specific to teaching individuals with IDD. This question was answered using data collected from participants’ responses to semi-structured interview questions. Participants were asked about training they have received regarding teaching special education students generally and students with IDD specifically, both in college (pre-service training) and since becoming a teacher (in-service training). The same data analysis procedures were used to determine the answer to this question as were used for the primary research question to identify patterns in teachers’ experiences.

Pre-Service Training. Most participants reported taking an adapted physical education (PE) course in college focused on addressing the physical mobility of individuals with special needs. Health and sex education were not part of this adapted PE course. As teacher C described:

> It was more PE. It was a lot of, like, ways to differentiate your lesson, especially if there was, like, safety concerns or balance, like equipment that you would need to order or implement into the program...like, sensory items to be able to differentiate in the phys. ed. setting.

Two participants who went to the same university explained that planning adapted physical activities, like swimming, for adults from a local group home was part of their adapted PE course. Only Teacher A reported college training related to teaching health to special education students; it was "a section or two" of one course, did not address sex education, and was not specific to students with IDD. Teacher G reported receiving no special education training in college, saying, "I'm graduated like in the late nineties. I don't think [special education] was heavily played upon back then".

In-Service Training. Half of the teachers interviewed stated that they have received few trainings specific to their discipline since becoming a teacher and none have been specific to special education. Referring to general health and PE training, Teacher H explained:

> We don't have to keep up on anything really. I mean, we learn K to 12—or actually three years to eight years of age—how to teach them how to do things with appropriate steps. So, once you know that it's not like the kids change, right?

Teacher G, who has been teaching for more than twenty years, recalled:

> I cannot recall a training specific to a life skills population...There were a few trainings on sexual education. There were a few trainings on how to present relationships. I remember

going to a training, and I believe the actual training itself was on a life skills curriculum. However, they named it life skills, but it was really for the general population.

She attributed the lack of training opportunities in recent years to a decrease in available funding. Two of the teachers interviewed had received training on special education, but it was not specific to health or sex education. Teacher F received training several years ago on how special education students are more likely to be abused and how to discuss the topic with them. Teacher E completed TACT (Therapeutic Aggression Control Techniques)-2 restraint training "just in case." Two participants reported receiving no training specific to their discipline since becoming a teacher.

Secondary Research Question 3

How prepared are secondary general education health teachers to teach CSE to adolescents with IDD? To answer the primary research question, it was also necessary to understand how prepared general education health teachers feel to teach CSE to individuals with IDD. This question was also answered using data collected from participants' responses to semi-structured interview questions. Participants were asked about how they would feel if they were asked to, or told they would, be teaching an adapted health and sex education class for students with IDD and what concerns, if any, they would have about doing so. The same data analysis procedures were used to determine the answer to this question as were used for the primary research question to identify patterns in teachers' experiences.

Special Education Experience. All teachers interviewed were accustomed to having special education students included in their general education classes. Half of the teachers interviewed had experience teaching adapted physical education to students with IDD. Three of the teachers interviewed had experience teaching adapted health and sex education to students with IDD (to varying degrees of comprehensiveness). Teacher J expressed interest in the study

and signed the informed consent form but chose to discontinue participation upon viewing the ASQ-ID questionnaire because he felt he had insufficient experience with students with IDD to have an opinion.

Feelings About Teaching Adapted Sex Education. None of the teachers interviewed felt qualified to teach CSE to students with IDD without additional training or support, even those who have taught adapted PE or health classes before. Most teachers stated that they felt somewhat qualified because they are comfortable with the content but are uncertain about how best to adapt it for and deliver it to the unique population of students with IDD. For example, Teacher F said she felt "medium qualified" given her current training and experience. And teacher B stated:

> I would say that I would be 50% qualified. Just because, like, I feel like I know. But, I mean, the students in the life skills classroom again, even in phys ed, are so...like, the spectrum is so huge. You know, I have kids that are just so far apart in what they know and can do. I think if I had to start tomorrow, I'd say 50%. If you gave me a little time, it would be more, but I feel confident that I could do it.

Teacher E, who previously taught adapted health and sex education a few years ago and found out he will be teaching it again next year, felt "nervous" and "uncertain." All teachers interviewed, even those who have taught adapted courses in the past, expressed that they would need additional support to teach CSE to students with IDD confidently and effectively. While specific responses varied, the three primary supports participants would like to receive are (1) support from special education staff, (2) assistance in developing the curriculum and adapting instruction, and (3) additional training.

Findings

Overall, general education teachers are understanding and supportive of the sexuality of

young adults with IDD, acknowledge the need for an adapted health and sex education course for this population, and are willing to teach it. Unfortunately, they lack the knowledge, experience and support needed to do so confidently and effectively.

Primary Research Question

What types of supports do secondary general education health teachers need to effectively teach CSE to adolescents with IDD? To teach CSE to adolescents with IDD effectively, special education teachers need (1) support from special education staff members and administrators, (2) a set curriculum, and (3) training to improve their knowledge and skills regarding students with IDD. Those who have taught adapted sex education before need to reflect on the successes and shortcomings of their past experiences and make necessary revisions.

Need for Special Education and Administrative Support. Although general education health teachers would likely be able to teach an adapted health and sex education class to students with IDD without any additional support, it appears that teachers would be most effective with the support of special education staff members in and out of the classroom. General education health teachers have the content area expertise needed to teach CSE, and special education teachers have pedagogical knowledge and the knowledge of individual students, which can vary greatly even within a class of students with IDD. Teacher G explained how, in her experience teaching students with IDD, "[The special education teacher], knowing these kids very well, would be like, 'Okay, they need this', and the paras as well. They already know which students, you know, kind of need, which."

All participants in this study agreed that they would require and appreciate special education teacher support outside the classroom to effectively plan and adapt sex education lessons for adolescents with IDD. This coincides with the findings of previous studies, like that

by Barnard-Brak et al. (2014) which found that general education teachers and special education teachers should collaborate to provide the most effective CSE for young adults with IDD. Several teachers in this study also agreed that they would be open to special education support in the classroom, such as co-teaching. Of the few participants who have co-taught an adapted health class in the past, most felt it was the ideal way to teach this subject to the unique population of students with IDD. Almost all teachers interviewed would also welcome the support of a paraprofessional inside the classroom because paraprofessionals are also knowledgeable about the students and how best to support them.

In addition to special education staff, some schools utilize similar-aged general education students as peer helpers in adapted elective classes to provide both support and socialization opportunities for special education students. This also provides general education students experience working with people with disabilities, which is especially beneficial for those who are interested in working in a public service field like education or healthcare. A few participants spoke about the benefit of having peer helpers in adapted PE. However, most participants agreed that sex education for students with IDD should be self-contained. This allows students with IDD to feel comfortable asking questions and to receive differentiated instruction at their level; it allows instructors to spend more time on topics for which students may lack the prerequisite knowledge common in general education students. So, it is unclear whether peer helpers would be similarly helpful in an adapted health and sex education class.

Administrator support is key to ensuring many of the required supports for general education teachers are put in place. At the most basic level, administrator approval is typically required to develop any new course. Logistically, administrators would likely need to facilitate any necessary changes to the schedule to allow general education health teachers and special education teachers to co-teach if desired. They would also need to authorize compensation for

curriculum writing time for special education teachers and general education health teachers and/or to purchase a premade adapted curriculum. The adapted health and sex education curriculum would also likely need to be approved by an administrator, especially because sex education is a sensitive topic and any parent concerns would likely need to be fielded by an administrator. Several participants expressed the importance of feeling supported by administration if a concern did arise if expected to cover truly comprehensive sex education topics with students with IDD.

Need for Curriculum. Participants had varying views on how best to develop an adapted health curriculum, but it appears that a predetermined curriculum—or at the very least a solid framework of topics to cover—would be essential. First and foremost, having a curriculum that all general education teachers who teach adapted health are expected to follow would establish consistency and go a long way towards making sure that the coverage is truly comprehensive. Some participants' interview and questionnaire responses indicated that they have reservations about the appropriateness of some topics for students with IDD, such as sexual orientation, birth control, and masturbation. As Schmidt et al. (2021) found, "values and cultural issues may be overcome by addressing the need for specific sex education standards and guidelines" (p. 6) Teacher H explained the importance of a curriculum framework, saying, "If it ended up being somebody else who's not as comfortable teaching that topic, it at least gives them a guideline of what has been talked about or discussed previously and basically is a safe topic to teach about because its written down and you have activities handy."

Having a curriculum would also help ensure that topics are covered that may not be part of the general education health curriculum because high school students typically already know the information, such as hygiene and public versus private behavior. It would also provide a buffer for teachers if there was ever a concern that the information covered is not appropriate for

students with IDD. Health teachers would probably need the expertise of special education teachers to effectively develop an adapted health and sex education curriculum, so providing general education health teachers and special education teachers curriculum writing time to plan together would be beneficial.

Need for Training. In addition to wanting the support of special education staff, all teachers interviewed expressed feeling unprepared to teach students with IDD. This is consistent with reporting by the Sexuality Information and Education Council of the United States (SIECUS, 2021), who surveyed fourteen schools and found that less than half reported providing professional development for health teachers on "teaching students with physical, medical, or cognitive disabilities" between 2016 and 2018 (p. 18). Fortunately, all teachers interviewed expressed openness attending any training that would better prepare them to teach CSE to students with IDD. This is consistent with findings by Eisenberg et al. (2010), who found that health teachers are interested in professional development to make up for the lack of training received previously and to meet new job demands because in the health education field there is "general recognition that teaching excellent sex education require[s] training in both content and pedagogy" (p. 341). Clayton et al. (2018) found that professional development may be helpful for all teachers of sex education. As teacher C explained, teachers would like training on, "How I would have to, adapt, I guess, work? Or even the way I'm delivering instruction, you know, like, what level would I need to change?"

Need for Reflection and Revision on Past Offerings. Even with adequate support, a strong curriculum, and additional training, it is probable that any adapted sex education course offered will not be perfect. Reflecting on and revising as needed is an essential part of teaching. Teachers need to be open to reflecting on things that went well and things that did not and revising as needed in future offerings. As Teacher G explained, "Next time always is a work in

progress, and you're learning things." She and the other two participants who had previously taught adapted sex education reflected on their experience. In the future, these teachers noted they would like to have a more established curriculum, to adjust their pacing so they can make sure they have enough time to cover all the topics desired, and to learn more about students with IDD so they can adapt the course to meet the needs of students with differing levels of cognitive functioning. These reflections highlight the importance of ensuring that, even once schools begin offering an adapted health and sex education class for students with IDD, teachers, schools, and districts continue to reflect on what worked and what did not work and revise as needed.

Secondary Research Question 1

What are the perspectives of secondary general education health teachers on CSE for adolescents with IDD? Generally, teachers interviewed felt adapted health and sex education is necessary for young adults with IDD for many reasons and are willing to teach it provided they have adequate support.

Need for Sex Education. Participants were largely supportive of sex education for adolescents with IDD, which reinforces the findings of previous research. Barnard-Brak et al. (2014) found that most general education teachers support sex education for individuals with IDD. As teacher B described, "I think, like, knowledge is power. I think they need to know things, like, just because they may have an intellectual disability doesn't mean their bodies don't work and aren't gonna feel the same thing as somebody else's." On the ASQ-ID, all participants agreed at least somewhat with the following statements: "Sex education for adolescents with IDD should be compulsory," "Sex education for adolescents with IDD has a valuable role in safeguarding them from sexual exploitation," and "Advice on contraception should be fully available to individuals with IDD whose level of development makes sexual activity likely." Additionally, all participants disagreed at least somewhat with the statements, "It is best not to

discuss issues of sexuality with people with IDD until they reach puberty," "It is best to wait for the individual with IDD to raise questions about sexuality before discussing the topic with him/her," and "Discussions on sexual intercourse promote promiscuity in adolescents with IDD." These questionnaire responses, along with participants' interview responses, indicate that all are in favor of some form of sex education for adolescents with IDD, although the level of comprehensiveness favored varied.

Participants provided several reasons why they feel an adapted health and sex education class is necessary. Some participants noted that young adults with IDD do not have much of the same knowledge about sexuality and relationships as their same-aged peers, and research confirms this (McDaniels & Fleming, 2018). A few participants also noted that a sex education class would provide students with IDD a safe space to discuss sexuality and related topics, which is something they do not always have access to. As Teacher H explained, "I think it should be a separate topic that they then are comfortable just talking to that teacher." This is important because research has shown that adolescents and adults with IDD do not have access to the same informal sources of information on relationships and sexuality that most nondisabled people do (McDaniels & Fleming, 2018). They often lack exposure to typical peers to discuss these topics with, and SIECUS reports they are vulnerable to misinformation online because they often lack the skills necessary to decipher relationship and sexuality information found on the Internet and to distinguish reliable from unreliable information (2021).

Having a health teacher teach sex education, rather than a special education teacher, gives students with IDD another trusted adult they can talk to about the subject. Research has shown that individuals with IDD are often discouraged from discussing sex and related topics by the adults overseeing them (teachers, support staff, parents, caregivers, etc.) (Schmidt et al., 2021).

Having experienced this herself with students with IDD in the adapted PE class she teaches, Teacher B exclaimed, “Someone’s got to be okay with talking about it!” This sentiment coincides with the recognition model of sexuality, which underscores the importance of recognizing individuals with IDD as sexual beings and giving them explicit permission to discuss sexuality in an appropriate setting, like a health class (Couldrick et al., 2010).

In line with what Eisenberg et al. (2013) discovered about health teachers largely supporting the coverage of a wide range of topics in general education courses, even those that are controversial, most teachers indicated support for comprehensive sex education for young adults with IDD. However, a few participants expressed concern that some CSE topics may be inappropriate for adolescents with IDD, even those recommended by the *National Sex Education Standards* (FoSE, 2020). For example, Teacher G admitted that she did not cover some topics, like sexual orientation and birth control, when she cotaught adapted health education last year because she was not sure they were appropriate for young adults with IDD. She also stated that she gives her general education health classes the opportunity to write down questions they have about relationships and sexuality at the start of the course so she can ensure she covers any topics they have questions about, but she did not provide this opportunity to students with IDD. She explained, “That is not something I did with the life skills students and I’m not sure that means I would never do it. I just don’t know that’s appropriate.” Similarly, Teacher F shared concerns about teaching more sensitive topics, like masturbation, and expressed apprehension about whether such topics should be covered in school or by parents or healthcare providers.

Previous research has addressed the impact of teachers’ personal values on their coverage of sex education topics. Wolfe (1997) advised, “Professionals must be aware of personal values and the effect they may have on the individual with whom they work” (p. 88). Especially when teaching sex education, Wolfe (1997) suggests that educators need to be careful that their

personal values are not preventing them from providing students with the information and skills they need to engage in potentially risky activities like sex safely, which could deny them the 'dignity of risk' to which they are entitled (Perske, 1972). As outlined by the capability model of disability, educators are responsible for giving young adults with IDD the information and skills they need to make autonomous decisions about their personal lives (Bajmócy et al., 2022). The impact that teachers' personal values can have on whether students receive the comprehensive sex education to which they are arguably entitled (Eisenberg, 2013), and which has been proven effective (Santelli et al., 2017), is a concern that should be addressed by adopting recommended sex education standards and an approved curriculum (Schmidt et al., 2020) and offering teacher training. Although not all participants were entirely supportive of truly comprehensive coverage of sex education topics for young adults with IDD, they admittedly do not know much about the population of individuals with IDD and are open to learning more.

One participant stated:

> With the survey you had, I do think it brought to light the fact that I don't necessarily know a lot of those answers. So, you're gonna see a lot of mine are right in the middle cause I'm like, 'Okay, I don't know.' So, I absolutely see. I thank you for doing what you're doing because I see how, yes, there's a lot more things that I still need to learn to get, you know, at the top of my game with this class (Teacher G).

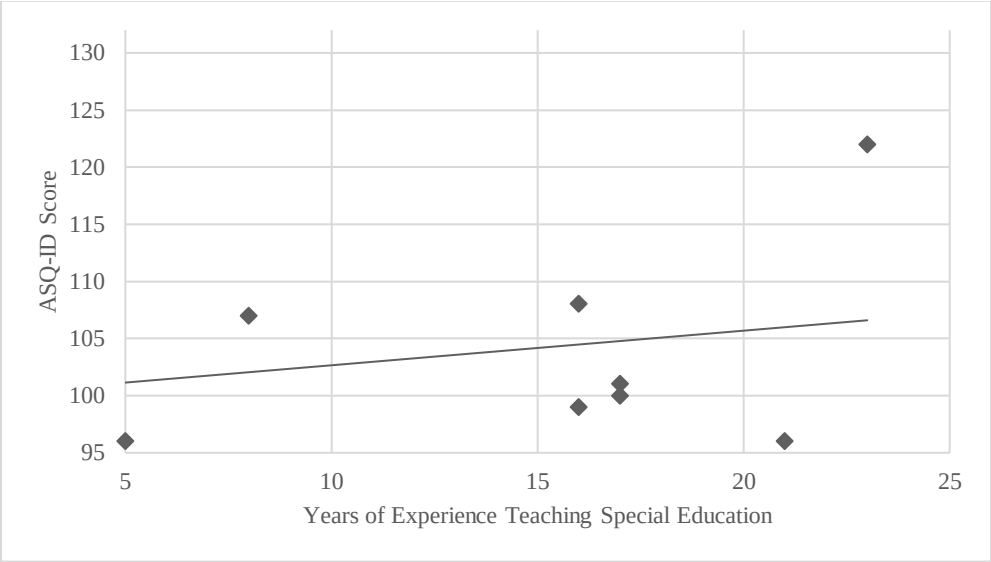
Open to and Understanding of Sexuality of Individuals with IDD. Generally, participants' responses revealed that they are open to and understanding of the sexuality of young adults with IDD. They did not express any of the common misconceptions measured on the ASQ-ID—such as that individuals with IDD are disinterested in sex or are hypersexual and prone to deviance—and their interview responses indicate broad acceptance of the sexuality of individuals with IDD. For example, when speaking of other professionals who have prevented

students with IDD from engaging in the same romantic behavior as their nondisabled peers, Teacher B stated, “Like, they’re not allowed to have the same kind of feelings that everybody else has, so, like, I think that’s kind of, like, doing them a great injustice, you know?” This is an unexpected finding; it was anticipated that general education teachers would hold some of these misconceptions and that future in-service training would need to correct them. Additionally, participant’s responses suggest that they are understanding and accepting of differences in sexuality among individuals with IDD and that they do not hold the heteronormative views found amongst staff working with young adults with IDD in some previous studies like that by Oakes and Thorpe (2019). All participants agreed at least somewhat with the statement “Consenting adults with IDD should be allowed to live in a homosexual relationship if they so desire.” However, it is worth noting that participants may have agreed to participate in this study due to experience or interest in working with students with special needs, so they may be more likely to hold more favorable views than the average general education teacher.

When participants’ overall scores on the ASQ-ID were examined in relation to their years of experience teaching special education students in any capacity, the researcher discovered a slight positive correlation between more liberal views on the sexuality of individuals with IDD and more experience teaching special education students, as illustrated by the upward trend line in Figure 4.3. This suggests that the more teachers work with students with special needs, the greater their understanding of the sexuality of the population. This finding contradicts with previous research by Tamas et al. (2019), who also utilized the ASQ-ID and found that the general public tends to hold more liberal views on the sexuality of adults with IDD than special education professionals and parents.

Figure 4.3

Relationship Between ASQ-ID Score and Years of Experience Teaching Special Education



One area where some participants exhibited less-accepting views is masturbation. Two of the statements on the ASQ-ID about masturbation were among the five lowest rated statements on average. Several participants disagreed with the statement, "Masturbation in private for adolescents with IDD is an acceptable form of sexual expression." And, most participants disagreed with the statement, "Masturbation should be taught to individuals with IDD as an acceptable form of sexual expression in sex education courses." Although participants did reveal during interviews that the latter statement confused them because they were unsure if it was suggesting that teachers should teach students *how* to masturbate—which Teacher F said is more the responsibility of parents and healthcare providers—lower average scores on these statements suggest that participants are not completely accepting of masturbation, even in private, among individuals with IDD. However, a shortcoming of the ASQ-ID is that it does not compare participants' views on the sexuality of individuals with IDD with their views on the sexuality of those without IDD, so the researcher is unable to determine if participants hold conservative views on masturbation in general or only for those with IDD. Curiously, the only other

masturbation-related statement on the ASQ-ID was, on average, rated more liberally, with all but one participant disagreeing at least somewhat with the statement, “Masturbation should be discouraged among adolescents with ID.” It is possible that participants make a distinction between discouraging the behavior, which could make adolescents feel shame and guilt, and feeling the behavior is unacceptable without directly saying anything discouraging, which would not influence the individual.

Willing to Teach Adapted Sex Education. Despite most teachers interviewed feeling underprepared to teach adapted sex education, all teachers interviewed expressed willingness to teach adapted sex education and a few even expressed eagerness to do so. This finding is important because, although teachers would likely teach any class assigned to them for which they are certified, willingness and eagerness will likely result in better effort than if doing so compulsorily. As teacher C expressed, “I'm very much somebody that would wanna make sure I'm doing what's best for my students regardless of how they come in the room.” When examining common service models of sex education for individuals with IDD, Curtis and Stoffers (2023) did not find general education instruction to be one that is commonly used. The willingness of general education teachers in this study to take on this important responsibility reinforces the notion that general education instruction may be an overlooked sex education model with exciting potential. However, it is again worth noting that teachers may have been more likely to participate in this study if they have an interest working with special education students, so that may not be reflective of general education health teachers on average.

Participants who had prior experience teaching adapted health and sex education to adolescents with IDD offered differing opinions on how best to structure the course, including whether to separate male and female students when covering overtly sexual topics and how best to differentiate for the varying ability levels found even among students with IDD. One teacher

felt that there should be various levels of adapted health and sex education classes, just like classes in content areas like English and math are commonly leveled so material can be taught at a level that is accessible even to the lowest level learners without sacrificing the depth of coverage that is beneficial to higher level learners. As Teacher H explained:

> I think having it leveled would definitely be helpful and it wouldn't have to be leveled with everything—you know, like relationships, touching in public and stuff that could be the same—but getting into, you know, nocturnal emissions and actual sex, that might need to be more differentiated.

In contrast, another teacher felt that the class content should be such that all students will benefit and feel comfortable regardless of their level. These statements indicate a potential difference in perception about what and how information should be covered depending on the severity of students' IDD.

This is consistent with the findings of Wolfe (1997), who determined that teachers and administrators tend to feel that engaging in romantic and sexual behavior is less appropriate for students with more severe disabilities. This suggests that teachers are more likely to think that students with more severe IDD are less in need of information about comprehensive sexuality-related topics, which is untrue. As Wolfe (1997) also discovered, "Secondary students with moderate and severe disabilities did display sexual behavior including masturbation, touching, kissing, and interest in sexuality" (p. 86). Differentiation is certainly necessary for the various ability levels in a self-contained classroom, but, regardless of which approach to differentiation is taken, it is important to ensure that all students are receiving the same comprehensive sex education and that lower-level students are not receiving less comprehensive information. While some adolescents with more severe disabilities may display a seeming lack of interest in sexuality and romance, in accordance with the capability model of disability professionals need

to prepare students for the freedoms they may want in the future, not only the freedoms they want now. This is another reason adopting established instructional standards, such as the *National Sex Education Standards* (FoSE, 2020), and having an approved comprehensive curriculum is important (Schmidt, 2021).

Consider Parental Role. Most participants had not considered parents' role in sex education for secondary students; parents wanting to opt their children out of specific topics, or out of sex education entirely, is not an issue that they have often, if ever, encountered when teaching general education health and sex education. However, this is a pressing issue when considering sex education for young adults with IDD, one the researcher has personally experienced in her role as a high school special education teacher. This is further complicated by the fact that students with IDD can continue to receive school-aged services until the age 22 in Pennsylvania (PDE, 2023), meaning some high school students with IDD are legal adults who are entitled to make their own decisions about their education under the law (although parents often obtain guardianship over them (Onstot, 2019). Half of the participants had an opinion on the issue, and of those about half of them felt that parents should, at minimum, have a say in the topics covered. However, the two participants who were eager to teach sex education to students with IDD felt strongly that parents should not be able to opt students out, which is consistent with their conviction about the importance of sex education for students with IDD.

Some, like the World Health Organization (WHO, 2015) and Eisenberg et al. (2013) argue that sex education is a right. According to social justice theory—the basis of which is that all individuals are entitled to equitable treatment, regardless of differences like ability level (Terzi, 2005)—if sex education a right for nondisabled individuals, it should also be a right for individuals with IDD and parents should not be able to opt their young adult children out no matter their disability. Some studies have found that the practice of allowing parents to opt

students with IDD out of sex education is detrimental. As Kammes et al. (2020) report, parents' fear of their child getting mistreated and/or acting inappropriately and their discomfort around their adult child with a disability's sexuality result in intentional and unintentional barriers to relationships and sexual expression, oftentimes limiting even discussion about sexuality-related topics. Having nowhere to go for reliable information about one's body and sexuality is problematic for any young person, but it "may have an amplified effect on an individual with intellectual disability as they may not receive this information elsewhere" (Kammes et al., 2020, p. 682). They suggest providing training to parents on how to address the topic to discourage avoidance. Regardless of how parent input is addressed, it is important that the issue is considered and planned for when developing an adapted health and sex education course. This can be done using some of the same strategies Schmidt et al. (2021) recommend to ensure that teachers' values do not affect the comprehensiveness of sex education topics covered: by following established professional standards and a predetermined curriculum that is supported by school and district administration.

Secondary Research Question 2

What training, if any, have secondary general education health teachers received specific to teaching individuals with IDD? Participants have had little, if any, training in teaching students with IDD. The training they have received has been primarily focused on adapted PE and physical mobility, has not been related to classroom instruction or sex education, and occurred while they were in college prior to becoming teachers. Most teachers studied have not received any special education training and little training specific to sex education since becoming a teacher. It is unclear whether training on sex education for individuals with IDD is not being offered or whether teachers simply are not aware of it.

This is consistent with the findings of previous research into health teacher training in general. Eisenberg et al. (2010) determined that health teachers feel their previous training has been inadequate. It is also consistent with previous data on special education training for health teachers specifically. SIECUS (2021) reports that the median percentage of health teachers throughout the United States who have received training on “teaching students with physical, medical or cognitive disorders” has increased over the past decade, but it is still only 52.4% on average nationally (p. 18) and only 58.7% on average in Pennsylvania (p. 35). Fortunately, teachers unanimously expressed openness to additional training opportunities and most added that they would not feel prepared to teach an adapted sex education class without additional training. This is a welcome finding because teacher training can address two of the four barriers to sex education for individuals with IDD identified by Schmidt et al. (2021) “values and cultural issues" and “limited professional education or societal biases” (p. 3).

Secondary Research Question 3

How prepared are secondary general education health teachers to teach CSE to adolescents with IDD? All teachers interviewed have had experience teaching special education students in inclusive classes, which have primarily been PE classes. Most of them also have some experience teaching students with IDD in adapted PE, but this has also been primarily in the PE setting. Few participants have experience teaching students with IDD in a classroom setting, such as an adapted health and sex education class. This is consistent with the common sex education service models for individuals with IDD identified by Curtis and Stoffers (2023). They did not find general education instruction to be a model that is commonly used (Curtis & Stoffers, 2023). However, this avenue should be investigated further because cost is often a barrier to offering special education services and utilizing existing general education health

teachers—who appear to be open to the prospect—would make it possible to offer sex education to young adults with IDD at little to no added cost to districts.

Unprepared to Teach Students with IDD. Overall, participants feel confident in their knowledge of sex education content but feel unconfident to teach it to the unique population of students with IDD without additional support. This is consistent with the findings of Schmidt et al. (2021), who also found that educators do not feel prepared to teach CSE to individuals with IDD. While specific responses varied, the three primary supports participants would like to receive are (1) support from special education staff, (2) assistance in developing the curriculum and adapting instruction, and (3) additional training.

Summary

Teachers interviewed are generally open to and understanding of the sexuality of individuals with IDD. They feel adapted sex education is necessary for young adults with IDD for many reasons and are willing to teach it provided they have adequate support. However, participants have had little, if any, training in teaching students with IDD. By and large, the training they have received has been focused on adapted PE and physical mobility, not related to classroom instruction or sex education, and occurred while they were in college, prior to becoming teachers. To teach CSE to adolescents with IDD effectively, special education teachers need (1) support from special education staff members and administrators, (2) a set adapted curriculum, (3) training to improve their knowledge and skills regarding students with IDD. After teaching an adapted health and sex education course, teachers need to reflect on the successes and shortcomings of the experience and make necessary revisions in the future.

The following chapter explains the practical implications of these findings on policy and professional practice, including a list of actionable recommendations local districts can follow to utilize their existing general education health teachers to teach adapted health and sex education

to young adults with IDD. Then, it provides recommendations on how to continue to address this important issue in future research.

CHAPTER 5: RECOMMENDATIONS

The previous chapter explained the findings of this study. It described the demographics of study participants, explained how data was analyzed and how themes were generated, and detailed participants' perspectives on the sexuality of individuals with intellectual and developmental disability (IDD), their feelings on comprehensive sex education (CSE) for young adults with IDD, their willingness and preparedness to teach CSE to this population, and the supports they need to do so effectively. This chapter explains the practical implications of these findings on policy and professional practice, including actionable recommendations local districts can follow to utilize their existing general education health teachers to teach adapted health and sex education to young adults with IDD. Then, it provides recommendations on how to continue to address this important issue in future research.

Secondary students with IDD need access to better information regarding relationships and sexuality to improve their safety and well-being. With the increase in students with IDD included in the general education setting mandated by Individuals with Disabilities Education Act (IDEA), general education teachers are likely to be tasked with providing this instruction, yet their perspective has not been explored in previous research on this topic. So, this qualitative study investigated the perspectives of secondary general education health teachers on the sexuality of individuals with IDD to discover what support and training they need to deliver CSE to this population effectively. Participants were recruited from research sites in Northeastern Pennsylvania because there are no federal guidelines or funding for CSE. Instead, the responsibility of providing sex education is left to state governments and local districts (Planned Parenthood, 2023). It was conducted using generic qualitative inquiry methods and a cross-

sectional interview-based design supplemented by questionnaire data. The following research questions were explored:

- What types of supports do secondary general education health teachers need to effectively teach CSE to adolescents with IDD?
    - What are the perspectives of secondary general education health teachers on CSE for adolescents IDD?
    - What training, if any, have secondary general education health teachers received specific to teaching individuals with IDD?
    - How prepared are secondary general education health teachers to teach CSE to adolescents with IDD?

Review of Findings

Teachers interviewed are generally open to and understanding of the sexuality of individuals with IDD. They feel adapted sex education is necessary for young adults with IDD for many reasons and are willing to teach it provided they have adequate support. However, participants have had little, if any, training in teaching students with IDD. By and large, the training they have received has been focused on adapted PE and physical mobility, not related to classroom instruction or sex education, and occurred while they were in college prior to becoming teachers. To teach CSE to adolescents with IDD effectively, special education teachers need (1) support from special education staff members and administrators, (2) a set adapted curriculum, (3) training to improve their knowledge and skills regarding students with IDD. After teaching an adapted health and sex education course, teachers need to reflect on the

successes and shortcomings of the experience and make necessary revisions in the future.

Conclusions

Understanding and Accepting of Sexuality of Individuals with IDD

Surprisingly the general education health teachers in this study did not appear to hold common misconceptions about the sexuality of individuals with IDD. Although not all participants were entirely supportive of truly comprehensive coverage of sex education topics for young adults with IDD, they admittedly do not know much about the population of individuals with IDD and are open to learning more. Overall, they are understanding and accepting of the fact that young adults with IDD are sexual beings with romantic and sexual interests and urges much like their nondisabled peers. Contrary to the researcher's expectations, addressing misconceptions about the sexuality of individuals with IDD does not necessarily need to be incorporated into training for this group of teachers. However, as noted in chapter four, it is possible that the teachers who participated in this study chose to do so because they have an interest in special education, so it is possible that their views are more accepting than those of general education health teachers on average.

Pre-service teacher training in colleges and universities and in-service professional development training in and for schools should still include information on correcting misconceptions and should be guided by the recognition model of sexuality and the capability model of disability. The recognition model of sexuality emphasizes recognizing that individuals with disabilities are sexual beings, giving them explicit permission to discuss sexuality in an appropriate setting, and providing them with support to achieve their sexual goals (Couldrick et al., 2010). The capability model as applied to disability theory focuses is on giving individuals with disabilities choice and autonomy by considering the freedoms the individual will have in the future, not the freedoms (s)he has now (Terzi, 2005; Bajmócy et al, 2022). This means that

although not all adolescents or young adults with IDD may express an interest in engaging in romantic and sexual relationships, it is reasonable to assume they may as an adult. So, they should be provided with the comprehensive sex education necessary to do so safely and responsibly.

Additionally, it is important for states and local districts to adopt CSE standards, like the *National Sex Education Standards* (FoSE, 2020), and an adapted health and sex education curriculum to ensure that students with IDD receive comprehensive sex education coverage. Comprehensiveness and consistency in coverage are important for students because they need and are entitled to adequate information about relationships and sexuality to live safe, fulfilling lives. Adopting standards and a curriculum will help guarantee that adapted health and sex education courses are not diluted by the values of the individuals teaching the course (Schmidt et al., 2021). It is also important for teachers because (1) they need to know what material should be covered to achieve the aim of the course, even if staffing changes, and (2) they need to have clear, well-established guidelines to fall back on if they are ever challenged about the appropriateness of the topics they are covering by parents or others.

Need for Adapted Sex Education

The teachers interviewed for this study have noticed that students with IDD who have been included in general education health and sex education courses have not fully benefitted. Often general education health and sex education courses are taught at a level that is not accessible to them because they move too quickly and do not cover all of information that students with IDD need. Health teachers have reported that at times students with IDD were removed from their inclusive general education health and sex education classes during some or all sex education topics, either by their special education teacher or by parent request. Teachers have noticed how this lack of sexuality and relationship knowledge and skills sometimes results

in students with IDD engaging in problematic behavior, such as inappropriate touching. They also note that students, especially those with IDD, are accessing information online that is incorrect or that they do not understand. Health teachers understand that young adults with IDD need a trusted adult to talk to about sexuality and related topics and a safe, appropriate place to do so.

For these reasons, the best way to meet the need for CSE for students with IDD is to offer an adapted health and sex education course. It should be taught by someone other than a special education teacher—who is already one of the few adults many students with IDD have regular access to in school—or an outside agency representative—who is not always around or easily accessible for students to talk to and who districts have no authority over if they are unhappy with the coverage. High schools need to offer adapted health and sex education course taught by a general education health teacher for students with IDD and it needs to be offered consistently.

Districts who are not providing adequate sex education for students with IDD need to prioritize this need. According to the IDEA (2015), school districts have an obligation to provide evidence-based instruction to students with disabilities, and evidence overwhelmingly supports the benefits of CSE for all students (Santelli et al, 2017; SAHM, 2017). There is currently no federal or Pennsylvania state funding dedicated to CSE, so providing effective, evidence based CSE in accordance with IDEA will likely require local districts to utilize their existing general education health teachers, who will need additional training and support to do so. This includes adopting comprehensive sex education standards and an adapted health and sex education curriculum, providing the necessary logistic support to make it fit into teachers' and students' schedules and to ensure it is offered regularly, and developing a common sense parent opt-out policy that balances potential parent concerns with students' right to autonomy and sexual health information, especially since some students with IDD remain in high school until age 22 when

they are legally adults (PDE, 2023). States and local districts should also consider adding relationships and sexuality to the transition planning process—which in Pennsylvania must begin once a special education student turns 14—as part of the independent living consideration. Transition planning is discussed each year at a student's annual IEP meeting, which would provide an opportune time to discuss the issue, be transparent about the adapted health and sex education course and address parental concerns.

Willingness

The general education health teachers in this study are all willing to teach an adapted health and sex education course—a few are even eager to do so—but they do not feel entirely qualified to do so because they lack special education training and experience. The few participants who had previously taught adapted health and sex education had largely positive feelings about the experience but admitted they still have room to improve and more to learn. So, while general education health teachers appear willing to teach adapted health and sex education, they acknowledged that they would need support in and out of the classroom to do so effectively. Again, it is possible that the teachers who participated in this study chose to do so because they have an interest in special education, so it is possible that they are more willing to teach adapted health and sex education than general education health teachers on average.

Districts should attempt to utilize teachers interested in teaching adapted health and sex education whenever possible. Teachers who are interested in and invested in what they are teaching are more likely to be dedicated and effective. Especially when offering a new course, it is important to have teacher buy-in. For example, of the three teachers in this study who had previously taught adapted health and sex education, the two who reported positive experiences were the ones who were interested in teaching it and sought it out and they are both eager to

teach it again. The one who was assigned to teach it did not have a good experience the first time and is “uncertain” and “nervous” about teaching it again next year.

To teach adapted health and sex education confidently and effectively to students with IDD, general education health teachers require training, curriculum, and support. Ideally, districts should provide teachers with in-service training on how to teach sex education to young adults with IDD prior to having them teach an adapted health and sex education course. All teachers interviewed were open to all training opportunities, including having a trainer come in and attending outside training. Several companies and organizations, like Among Friends, Elevatus, Ease (Empowerment, Advocacy & Sexuality Education), and Geisinger’s Autism & Developmental Medicine Institute, offer teacher training specific to teaching sex education to students with IDD. Planned Parenthood offers a free online teacher training course “to help make sex education more accessible and inclusive for students with disabilities” (Planned Parenthood, 2023). Districts should provide special education training to all their secondary general education health teachers, not just those who may teach adapted health and sex education soon, so that all teachers are prepared in the event of a staffing change. They should also record the training or offer it on a reoccurring basis to ensure that newly hired teachers are trained as well.

If hiring a trainer to come in, districts could offset the cost by inviting neighboring districts to send their health teachers as well. Districts may also want to consider having one of their teachers or special education administrators trained as a sex education trainer so that person can offer reoccurring trainings in house. Elevatus offers a virtual three-day sexuality educator and trainer course for anyone who works with students with IDD that “will give [them] the curriculum, tools, and skills [they] need to teach sexuality education classes and lead staff/parent trainings” (Elevatus, n.d.). Although it requires a larger upfront cost, districts would then not need to pay outside trainers repeatedly to offer reoccurring trainings.

Lack of Experience

Few teachers in this study have had experience teaching students with IDD in a classroom setting. Most only have experience teaching special education students in general education health and PE classes, and these are typically not students with IDD. A few teachers in this study have had experience teaching students with IDD in adapted PE and a few have taught adapted health and sex education in recent years. Most of those who have taught adapted health and sex education sought out the course because they knew there was a need.

Usually, general education health teachers do not get many opportunities to interact with students with IDD, especially in a classroom setting. When they do get the opportunity, it is often in an adapted PE class and focused on physical mobility. Much like general education content area teachers (i.e. math, science, English, social studies, foreign language, etc.) teach the same level of classes year after year, typically the same general education health teacher teaches the adapted classes year after year. All general education teachers need opportunities to gain experience working with students with varying needs and ability levels, including IDD. For health teachers specifically, this could include things like inviting students with IDD to an open gym to play games, pushing into special education classes to do lessons on health-related topics like nutrition and first aid, and helping with Special Olympics and Unified Sports. The more general education teachers are exposed to students with IDD, especially in the classroom setting, the more comfortable they will feel around them and eventually teaching them. If multiple health teachers are willing and interested in teaching adapted health and sex education, they should all get the opportunity to do so on a rotating basis so they can gain further experience teaching students with IDD.

Need for Training

All teachers interviewed received little to no special education training, especially specific to teaching health and sex education or students with IDD, either in college or since becoming a teacher. General education health teachers need more training on teaching health and sex education to special educations students in general and students with IDD specifically. This needs to occur in colleges and universities so incoming general education health teachers are better prepared to teach students with special needs and it needs to occur in local school districts so current teachers can improve their knowledge and skills.

Colleges and universities need to do a better job of preparing future health teachers to teach students with special needs outside of the PE setting. Many participants reported taking a mandated adapted PE course in college focused on physical mobility for students with disabilities. This is a good start because it often exposes pre-service teachers to individuals with IDD, but health teachers need to be prepared to teach special education students of varying ability levels in the classroom setting as well. Colleges and universities should also offer a course on teaching health and sex education to special populations that is required for pre-service general education health teachers.

School districts also need to make up for the shortcoming in special education classroom training health teachers are receiving in college by offering in-service training on how to teach health and sex education to special education students, including those with IDD. If school districts are not offering meaningful trainings specific to their discipline or if health teachers have an area that they want to learn more about, teachers and department chairs should seek out such trainings and petition their districts to enable them to attend. If districts know teachers are interested in and willing to apply what they learn in a training, they may be more likely to provide them with the time and resources necessary to attend.

Need for Support from Special Education Staff and Administration

General education health teachers want and need support from special education staff if teaching adapted health and sex education. Due to their lack of training and experience, they do typically not feel comfortable enough with students with IDD to teach them effectively on their own. They are unsure how to adapt their instruction, assess comprehension, and differentiate for the variety of ability levels found in a class of students with IDD. For maximum effectiveness and longevity, districts need to set general education teachers up for success when first teaching an adapted health and sex education course, so they have a good experience and want to teach the course again. General education health teachers need to be allotted curriculum writing and planning time with a special education teacher who is familiar with students with IDD and the ability to consult with that teacher as needed while teaching the course. In the classroom, they need instructional support from a paraprofessional who is knowledgeable about the students. Because general education teachers often are not accustomed to working with paraprofessionals, it is important to make sure the paraprofessional's role in the classroom is clearly defined and written out, so both the health teacher and the paraprofessional understand their role and what is expected of them.

Administrator support is also crucial when offering a new course, especially one on a controversial topic like sex education. Administrators should provide logistic support by ensuring there is room in the schedule for the course to be offered on a reoccurring basis and for the general education and special education teacher to have a common planning time. Administrators should provide financial support by authorizing necessary training, curriculum material, and curriculum writing time for the general education and special education teacher. Finally, administrators should provide instructional support by encouraging the adoption of CSE

instructional standards, being knowledgeable about the curriculum and topics covered, and supporting teachers if anyone challenges the appropriateness of the course.

Need for Adapted Curriculum

Although willing to teach adapted health and sex education for students with IDD, teachers interviewed are unsure what topics to cover, how much time to spend on each topic, and how to successfully modify their lessons because they are unknowledgeable about the needs of students with special needs. Some also have concerns about whether all sex education topics are appropriate for young adults with IDD. General education health teachers need at minimum a well-developed framework of topics to cover before taking on an adapted health and sex education course, but many would prefer a well-developed curriculum.

At the state level, states should adopt a policy requiring CSE for all students, regardless of ability level. Currently, Pennsylvania does not require schools to provide sex education other than to teach about STD (sexually transmitted disease) prevention via abstinence, and there is no specific requirement to include students with disabilities (SIECUS, 2023). Ideally, Pennsylvania and all states would adopt more comprehensive, inclusive sex education legislation like Washington state did in 2020. Their sex education policy states, “By the 2022-23 school year, all schools must provide comprehensive sexual health education (CSHE) to all students. All students includes any student enrolled in a district or public charter school, such as those in special education programs, online learning or alternative learning experiences, etc.” (Washington OSPI, n.d., Implementation Requirements).

At the district level, school districts should provide a carefully selected adapted curriculum designed for students with IDD that health teachers could either use in its entirety or use as a guide to modify and supplement their existing health and sex education curriculum. This curriculum should be based on approved the *National Sex Education Standards* (FoSE, 2020)

and be approved by school and district administration, so they are knowledgeable about the topics included and prepared to defend them if challenged by parents or anyone else. There are several adapted sex education curricula available, both paid and free, including Friendships and Dating by Oregon Health and Science University (OHSU), Positive Choices by Oak Hill Relationship and Sexuality, Relationships Decoded, and Sexuality Education for People with Developmental Disabilities by Elevatus. SIECUS (2004) provides a useful Curriculum Evaluation Tool to guide careful selection of a CSE curriculum as part of their *Guidelines for Comprehensive Sexuality Education* that helps to ensure that the curriculum selected truly is comprehensive.

Even with an adapted curriculum, health teachers will still need special education teacher support to adapt the lessons and activities to accommodate the various ability levels within an IDD class and paraprofessional support in the classroom to deliver the material effectively. The special education teacher of students with IDD should meet with the health teacher assigned to teach adapted health and sex education prior to the start of each offering of the course to share specific areas of need and concern for that specific group of students, such as topics to cover and histories of abuse. Just like in any class, every class of students with IDD is different and has different backgrounds, needs, and ability levels.

Need for Reflection and Revision

Even the teachers in this study who have taught adapted health and sex education in the past are not entirely confident that the course accomplished its intended purpose. There are things they want to do differently in the future, and there are still things about sex education for students with IDD that they are unsure about and want to learn more about. No course is ever perfect the first time it is offered. Teachers learn from doing. They see how things go and reflect on what went well and what they should change in the future. Each group of students is also

different. Not all lessons work well for all groups of students, even when all those students have IDD. There is variation in student needs and ability levels from class to class and even student to student.

Developing a strong, effective, comprehensive adapted health and sex education class for young adults with IDD is a work in progress. Like any other class, the first iteration will likely not be perfect. General education health teachers, along with special education teachers and paraprofessionals, need to reflect on what worked well and what did not throughout the course and at the end of each semester or school year. General education and special education teachers then need to work together to develop a plan to revise going forward, enlisting the help of an administrator as needed, like for scheduling issues.

Districts should start by providing as much support as possible for general education health teachers initially so they can start with a strong foundation for success. However, administrators need to clearly convey to all parties—general education teachers, special education teachers, paraprofessionals, and even students and parents to begin with—that the development of an adapted health and sex education course is a learning experience and a work in progress. Flexibility is key. They need to clearly establish the expectation that all staff members involved will discuss and reflect and that revisions will be made as needed. Ideally, districts will have adopted instructional CSE standards, like the *National Sex Education Standards* (FoSE, 2020), so it also needs to be clear that certain topics must be covered, even if they are difficult or uncomfortable, but teachers can work together to brainstorm ways to improve delivery if concerns arise about the effectiveness of specific lessons and units. It is also important that general education health teachers and special education teachers consult at the beginning of each new course offering to discuss the incoming group of students and any areas of need or concern.

Consideration of Parental Role

Most general education health teachers interviewed have not considered parents' role in the sex education of their children or whether parents should have the ability to opt their children out of specific topics or of sex education altogether. It is not something that has come up often, if ever, in their experience with general education students, so most were unsure what their state or district policy is. Those who did have an opinion had conflicting views. Districts need to balance providing information that young adults with IDD need and are entitled to with being sensitive to the needs and concerns of parents and caregivers. School and district administrators need to support teachers' and students' rights if parental questions or concerns arise.

Most states have either parent opt-out or opt-in policies for sex education. Opt-out policies are more conducive to students' sexual rights because they allow more students access to needed sexual health information (SIECUS, 2018). As summarized by SIECUS (2023), Pennsylvania has an opt-out policy for sex education which means, "School districts must publicize the fact that parents and guardians can review all curriculum materials. Parents and guardians whose principles or religious beliefs conflict with instruction may excuse their children from the programs" (para. 1). Although parents can legally opt their children out of sex education for personal or religious reasons, school districts need to strategies to minimize the number of young adults with IDD who are prohibited from receiving sexual health information in this manner. For one, districts need to adopt established instructional standards for CSE and an established adapted health and sex education curriculum to make it clear that topics being presented in adapted health and sex education are sound and not based on individual teachers' whims.

Also, districts should notify parents of their intent to provide instruction in sexuality and related topics so parents do not feel these issues are being discussed without their knowledge,

which will help lessen possible feelings of untowardness. This notice should also state the proven effectiveness of CSE over abstinence-based education and should include a list of topics that will be covered, and resources parents can access if they would like to discuss them at home as well. There are many online and printable resources available for free to help guide parents in discussing relationships and sexuality with their children of all ages. Amaze.org, American Sexual Health Association (ASHA), Awk Talk, Advocates for Youth, Nemours Kids, Planned Parenthood and Sex Ed Rescue all have resources dedicated to parents. Additionally, the Parent Educational Advocacy Training Center (PEATC) has published a free helpful, disability-specific parent resource called *Let's Talk About Sex: Students with Disabilities and Their Sexual Health - A Toolkit for Parents of Students with Disabilities.* District special education departments should also offer training for parents on the sexual development of children with IDD, how and when to approach sexuality-related topics at home and the importance of doing so. Such training should be offered on a regular basis, perhaps biannually, so parents of children approaching adolescence can attend. Several companies and organizations offer sexuality and sexual health training tailored to parents of students with IDD including Among Friends, Ease, and Elevatus.

As suggested earlier, sex education should also be added to the independent living section of students' transition plans, which are discussed annually at IEP meetings once students turn 14. This is an opportune time to discuss student and family goals regarding relationships and sexuality, be transparent about the adapted health and sex education course, and address parent questions and concerns. In their *Toolkit for Parents of Students with Disabilities*, the PAETC presents a useful tool called My Child's Action plan that can be used to structure discussion and planning around students' personal care, dating skills, and sexual health, including identifying concerns, setting goals, developing an action plan, and establishing a support system. This

should be incorporated into the annual transition planning assessment process, at least for high-school aged students.

Recommendations for Further Research

To better understand the scope of the problem, future studies should investigate the prevalence of the receipt of sex education among young adults with IDD specifically in United States public schools. Barnard Brak et al. (2014) suggest that a nationally representative study of the receipt of sex education by students with IDD is necessary to provide a deeper understanding of the scope of the issue and to propel large-scale change. Because sex education is often a politicized topic, changes to sex education legislation often do not make it through state governments. For politicians to see how important the need to improve the provision of sex education for young adults with IDD is, they need to see how serious the problem is by seeing how few students are receiving this needed service. In addition to investigating what percentage of secondary students with IDD in the U.S. have received sex education, future studies should also investigate whether or not any sex education received included comprehensive coverage of the topics recommended by the *National Sex Education Standards* (FoSE, 2020): "Consent and Healthy Relationships, Anatomy and Physiology, Puberty and Adolescent Sexual Development, Gender Identity and Expression, Sexual Orientation and Identity, Sexual Health, [and] Interpersonal Violence" (p. 9).

To reduce the potential impacts of teachers being more likely to participate in a study like this if they already have interest in or experience with students with IDD, this study should be repeated with measures taken to expand the success rate of participant recruitment. These measures could include: (1) expanding eligibility to include any secondary health teachers, including those who teach middle school, (2) expanding the geographic location to include more regions of the state or states altogether, (3) simplifying the time commitment required to

participate by eliminating the interview and adding open-ended questions to the questionnaire, and (4) eliminating repetitive questions on the ASQ-ID portion of the questionnaire and rewording questions that participants found confusing. The researcher recommends running a pilot of future iterations of the questionnaire to identify and address any areas of concern or ambiguity prior to the outset of the study.

To better assess the potential impact of health teachers' personal values and views on the sexuality of individuals with IDD on their delivery of sex education to students with IDD, this study should be repeated with measures taken to compare participants' views on the sexuality of young adults with IDD with their views on the sexuality of typical young adults. For example, participants' responses to the ASQ-ID in this study indicated some more conservative views on masturbation, indicating that they were not entirely accepting of masturbation as a form of sexual expression for individuals with IDD. However, the ASQ-ID only measures participants' perspectives on the sexuality of individuals with IDD, so it is impossible to tell if they hold more conservative views on masturbation in general or whether their reservations are specific to individuals with IDD. This is an important distinction because if their reservations are specific to individuals with IDD, any training they receive in preparation for teaching adapted health and sex education should include reinforcing that masturbation in private is a natural, healthy form of sexual expression for all people, regardless of disability. If they hold reservations about the appropriateness of CSE topics like masturbation for all people, that is a larger issue that needs to be addressed differently to ensure that their personal values do not impact the sex education instruction they are providing for all students.

Conclusion

Great strides have been made towards improving the lives of individuals with IDD over the past seventy years, but failure to recognize their right to romantic relationships and sexual

expression is one area that is still lacking. The negative implications of lack of relationship and sexuality education and opportunity are well-established in the literature, including increased susceptibility to sexual victimization and barriers to establishing wanted romantic relationships, which can have long term effects on their quality of life and mental health. When provided, existing sex education for young adults with IDD is typically characterized by inconsistency in onset of delivery, delivery method, topics covered, and staff responsible. The first step to helping individuals with IDD realize their human right to healthy sexuality and romantic relationships is to discover and implement best practices for providing effective, meaningful, evidence based CSE for individuals with IDD. Considering there is no federal funding, and inconsistent state funding, for CSE, the most practical option for public schools is to utilize existing secondary general education health teachers to teach sex education to adolescents with IDD where they are.

Special education teachers specialize in working with individuals with disabilities but lack expertise in teaching sex education and are often responsible for too many other tasks to take on an additional role. General education health teachers possess the content area expertise to teach sex education, but they often lack training and experience working with individuals with IDD. So, collaboration between the two is necessary to deliver the best possible sex education programming for adolescents with IDD. This qualitative study investigated the perspectives of secondary general education health teachers on the sexuality of individuals with IDD to determine what training and support they need to deliver sex education to young adults with IDD effectively. The data was used to generate a list of recommendations for local districts on how best to support their existing secondary general education health teachers in the implementation of formal CSE for young adults with IDD.

Overall, general education teachers are understanding and supportive of the sexuality of young adults with IDD, acknowledge the need for an adapted health and sex education course for

this population, and are willing to teach it. Unfortunately, most general education health teachers lack the knowledge, experience and support needed to teach such a course confidently and effectively. School districts should offer adapted health and sex education courses taught by a general education health teacher on a regular basis so all students with IDD can take it at least once during their high school career. To ensure that all health teachers are prepared to teach it, colleges and universities should broaden the special education courses required of pre-service health teachers to include an adapted health and sex education course, and school districts should offer in-service training on teaching sex education to students with IDD to all existing general education health teachers. Training should adhere to the capability model of disability and the recognition model of sexuality by affirming that individuals with IDD have romantic and sexual desires and are entitled to the knowledge, skills and support necessary to engage in relationships safely. In addition, colleges, universities, and local districts should provide informal opportunities for all health teachers to gain experience with students with disabilities.

States who have not already should pass more comprehensive, inclusive sex education requirements. In the meantime, local school districts should adopt the *National Sex Education Standards* to ensure comprehensive, evidence-based coverage. They should also provide for a quality, comprehensive adapted health and sex education curriculum. When offering an adapted health and sex education course, districts should utilize general education teachers who are interested in teaching adapted health and sex education whenever possible. If more than one teacher is interested, they should allow each to teach the course on a rotating basis. Outside the classroom, districts should ensure planning and consultation time before, during, and after the course offering for health and special education teachers to collaborate. Inside the classroom, districts should provide an instructional paraprofessional to support health teachers and ensure well-defined roles for each. During and after each course offering, districts should encourage

active, collaborative, and continuous collaboration between the health and special education teachers to reflect and revise as needed.

Districts should balance parent concerns with the students' right to autonomy and sexual health by adopting common-sense opt out policies. If challenges to the appropriateness of topics covered arise, administrators should support teachers in their effort to provide students with accurate, comprehensive information about their bodies and sexual health. To keep an open line of communication with parents, district special education departments should begin mandating sexuality and sexual health be included as part of the independent living section of transition planning, especially for high-school aged students. They should notify parents of the intent teach sex education and the topics to be covered and provide resources and training for parents to continue the discussion at home.

Future studies should investigate the prevalence of sex education for students with IDD in public secondary schools in the U.S. and topics covered to determine how many students are adequately receiving this needed service and how many are missing out. In addition, this study should be repeated with changes made to (1) expand the success rate of recruitment, which would account for potentially positively skewed perspectives, and (2) to compare the perspectives of general education health teachers on the sexuality of students with IDD versus that of their typical peers to establish whether reservations in participants' views of the sexuality of individuals with IDD are attributable to their views on persons with disabilities or their views on sexuality.

In the words of disability activist and self-advocate Anne Finger, "Sexuality is often the source of our deepest pain. It's easier for us to talk about and formulate strategies for changing disability discrimination in employment, education and housing than to talk about our exclusion from sexuality and reproduction" (Kennedy Krieger Institute, 2024, para. 5). Researchers

worldwide have been talking about the inequitable treatment of individuals with IDD regarding relationships and sexuality for decades. It is time to remedy this exclusion by enacting strategies to improve adolescents' and young adults' with IDD access to comprehensive sex education. Using the recommendations resulting from this study (see Appendix F), school districts can make positive change in the lives of students with disabilities now by utilizing their existing secondary general education health teachers to provide CSE for students with IDD.

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APPENDIX A: SEMI-STRUCTURED INTERVIEW PROTOCOL

Before we begin, I'd like to review the information in the consent document you signed prior to participation. The purpose of this study is to determine what support and training general education health teachers feel they would need to deliver comprehensive sex education to young adults with intellectual and developmental disability, known as IDD, confidently and effectively. You've already completed a virtual questionnaire and are about to participate in an individual interview in the format of your choosing, either in-person or via video conferencing. I asked that you choose a time and a place free of distractions, and we agreed upon here and now.

This interview will take approximately an hour to complete. Risks from this research include potential discomfort and possible breach of confidentiality or privacy, although care will be taken to prevent any such breaches. The study will result in recommendations for local districts on how best to support their existing secondary general education health teachers in the implementation of formal comprehensive sex education for young adults with IDD. This would likely benefit general education health teachers and students with IDD, although I have no knowledge of immediate plans to implement any such program locally. Most importantly, taking part in this research project is voluntary. You do not have to participate, and you can stop at any time without repercussions. Do you have any questions? Do you still wish to participate?

To give you my full attention, I will be taking minimal notes throughout the interview. Instead, I will be audio recording our conversation to transcribe and code later. Once your transcription is complete, I will contact you via e-mail with an opportunity to verify that it accurately conveys your perspective. Do you consent to having our conversation audio recorded? If so, please state your consent once I press record.

Intellectual and developmental disability, or IDD, was previously referred to as mental retardation. IDD "result[s] in some level of functional limitation in learning, language, communication, cognition, behavior, socialization, or mobility. The most common DD conditions are [ID], Down syndrome, autism, cerebral palsy, spina bifida, fetal alcohol syndrome, and fragile X syndrome" (Arc, 2021, Footnote). The severity of IDD is typically classified as mild, moderate, or severe. Students with IDD are often in self-contained classes, known as "life skills."

1. First, I'm going to ask you about your personal experiences working with students with IDD. Although most general education teachers are accustomed to having special education students in their classes, students with IDD are often in self-contained classes, often called "life skills," with less exposure to general education teachers. What is your experience teaching students with IDD?
    a. If you have experience, what subjects (health or physical education) did you teach?
2. Next, I'd like to ask about your teacher training. Despite most general education teachers having special education students in their classes, some have never received any special education training while others have either taken classes in college or received on-the-job training on teaching special education students. What/ training have you had specific to teaching special education students?
    a. Was it specific to teaching sex education?
3. What training have you had specific to teaching students with IDD in particular?
    a. Was it specific to teaching sex education?
4. Next, I'd like to ask you about your personal feelings on the issue of health and sex education for adolescents with IDD. Some participants have been open to the idea of

teaching an adapted health class to this population, and others have been more reluctant. How would you feel if you were asked to, or told you would be, teaching an adapted health class for students with IDD, including sex education?

   a. If concerned, what would your concerns be?

5. How qualified do you feel to teach health and sex education to students with IDD without any additional training?

   a. If not totally, what type of training do you feel you would need to do so effectively?

6. Special education teachers can support students and teachers in many ways, from modifying assignments, to collaborating with the general education teacher outside the classroom, to reviewing material with students after class, to pushing in during instruction. If you were to teach health to students with intellectual disabilities, what support would you want from a special education teacher in or out of the classroom?

   a. What support would you want from a special education paraprofessional, like a classroom assistant, in the classroom?

7. What, if anything, would you like to add?

If you think of anything you would like to add or have any questions or concerns, please contact me at (845)800-4505 or jcb1029@sru.edu. Once your transcript is complete, I will email you a copy for you to verify if you would like. Once the study is complete, I will e-mail you a copy of the findings.

APPENDIX B: ATTITUDES TO SEXUALITY – INDIVIDUALS WITH AN INTELLECTUAL DISABILITY (ASQ-ID) - REVISED 2023

This questionnaire is a revised version of the ASQ-ID (Cuskelly & Bryde, 2004) and the ASQ-ID Revised (Cuskelly & Gilmore, 2007). It is used and revised with permission from Dr. Monica Cuskelly. It was administered digitally via Qualtrics.

Eligibility

A Qualitative Analysis of the Perspectives of Secondary General Education Health Teachers on Necessary Supports for Teaching Sex Education to Young Adults with Intellectual and Developmental Disability

Dr. Jessica Hall-Wirth, Ed. D., jessicahall-wirth@sru.edu, (724) 738-2085
Mrs. Jessica C. Baton, M. Ed., jcb1029@sru.edu, (845) 800-4505

Thank you for your interest in this study!

To participate, you must be:

- -a teacher who holds current general education Pennsylvania teaching certificates in either Health Education PK-12 or Health and Physical Education PK-12, and
- -has taught at least one high school health class.

Taking part in this research project is voluntary.

Please answer the questions below to ensure you are eligible to participate.

Do you hold a current general education Pennsylvania health teaching certificate?

- ○ Yes
- ○ No

Have you taught at least one high school health class?

- ○ Yes
- ○ No

Sorry. You are not elibilge to particiapte in this study. Thank you for your interest!

If you have any questions, please contact Jessica Baton at jcb1029@sru.edu or (845) 800-4505.

Informed Consent

You are eligible to participate! Thank you again for your interest in this study. Please read over the study details below and indicate if you would like to proceed with participation.

Slippery Rock University of Pennsylvania

CONSENT TO PARTICPATE IN RESEARCH

A Qualitative Analysis of the Perspectives of Secondary General Education Health Teachers on Necessary Supports for Teaching Sex Education to Young Adults with Intellectual and Developmental Disability

Dr. Jessica Hall-Wirth, Ed. D, jessica.hall-wirth@sru.edu, (724) 738-2085
Mrs. Jessica C. Baton, M. Ed., jcb1029@sru.edu, (845) 800-4505

Important Information about the Research Study

Things you should know:

- -The purpose of the study is to determine what support and training regular education health teachers feel they would need to deliver comprehensive sex education (CSE) to young adults with intellectual and developmental disability (IDD) confidently and effectively.

Have you taught at least one high school health class?

- ○ Yes
- ○ No

Sorry. You are not elibilge to particiapte in this study. Thank you for your interest!

If you have any questions, please contact Jessica Baton at jcb1029@sru.edu or (845) 800-4505.

Informed Consent

You are eligible to participate! Thank you again for your interest in this study. Please read over the study details below and indicate if you would like to proceed with participation.

CONSENT TO PARTICPATE IN RESEARCH

A Qualitative Analysis of the Perspectives of Secondary General Education Health Teachers on Necessary Supports for Teaching Sex Education to Young Adults with Intellectual and Developmental Disability

Dr. Jessica Hall-Wirth, Ed. D, jessica.hall-wirth@sru.edu, (724) 738-2085
Mrs. Jessica C. Baton, M. Ed., jcb1029@sru.edu, (845) 800-4505

Important Information about the Research Study

Things you should know:

- -The purpose of the study is to determine what support and training regular education health teachers feel they would need to deliver comprehensive sex education (CSE) to young adults with intellectual and developmental disability (IDD) confidently and effectively.

- -If you choose to participate, you will be asked to complete a virtual questionnaire and participate in an individual interview, in-person or via video conferencing. The questionnaire will take approximately 15 minutes. The interview will take approximately an hour at a date and time convenient to you.
- -Risks or discomforts from this research include potential discomfort and possible breach of confidentiality or privacy.
- -The study will result in recommendations for local districts on how best to support their existing secondary regular education health teachers in the implementation of formal comprehensive sex education for young adults with IDD. This would likely benefit regular education health teachers and students with IDD.
- -Taking part in this research project is voluntary. You do not have to participate, and you can stop at any time.

Please take time to read this entire form and ask questions before deciding whether to take part in this research project.

What is the Study About and Why are We Doing it?

The purpose of the study is to determine what support and training regular education health teachers feel they would need to deliver comprehensive sex education (CSE) to young adults with IDD confidently and effectively.

What Will Happen if You Take Part in This Study?

If you agree to take part in this study, you will complete a virtual questionnaire, which will take approximately 15 minutes. At the end of the questionnaire, you will schedule an interview at a date and time that is convenient for you. You will have the option to participate virtually or in-person, either at your school of work during non-instructional time or at an agreed upon neutral location after school hours. The interview will last approximately one hour. It will be audio recorded for transcription and data analysis purposes. You will have the opportunity to verify the transcription of the audio recording for accuracy. Information collected will not be linked to any other data.

Questionnaire questions will ask you to rate how strongly you agree or disagree with statements about the sexuality of individuals with IDD, such as, “Young adults with an intellectual disability should be allowed to engage in non-sexual romantic relationships.”

Interview questions will cover topics such as previous education or training you have had specific to teaching students with disabilities and what support and training you feel you would need to do so confidently and effectively.

How Could You Benefit From This Study?

You or other health teachers might benefit from being in this study because you could one day receive improved training and support. Students with IDD could also benefit from this study by receiving improved sex education.

What Risks Might Result From Being in This Study?

You might experience some risks from being in this study. They are discomfort and breach of privacy or confidentiality. Sexuality and sex education may be a sensitive for some people so you may experience discomfort in discussing this topic, and interviews are sometimes uncomfortable for participants due to lack of familiarity with the interviewer. However, you will be able to choose your preferred interview method, virtual or in-person, so you can choose the setting most comfortable to you.

Anytime personal data is collected, there is a risk that it could be compromised. There is also a risk that potential participants will not want to be contacted regarding study participation. However, a number of steps will be taken to protect your privacy. All e-mail correspondence will come from a password protected account that only the research has access to. All virtual data will be stored on a password protected cloud account that only I have access to and accessed via my personal, password protected laptop, which will be stored in the my locked home office when not in use along will all hard copies. You will only be contacted twice to invite participation. Once you express interest, a maximum of two contact attempts will be made to obtain your participation in this study. Then, a maximum of two contact attempts will be made to reschedule the interview if the initial time and date is unsuccessful. At the conclusion of the study, you will be contacted once with an abridged version of the results.

There is a slight risk that others could find out about your participation in this study. However, a number of steps will be taken to prevent your identity from being discovered. No administrators or employees of the district will be infromed which teachers are participating. Additionally, all recruitment and potentially all data collection will take place virtually and can be done outside of school hours, which minimizes the chance of

coworkers knowing who is participating. A pseudonyms will be assigned to you (ex: Teacher A, Teacher B, Teacher C, etc.) immediately after you complete the questionnaire, and participants you will be referred to by your pseudonyms for the rest of the study, including during reporting. Although all participants are high school health teachers, which makes them more easily identifiable, participants are being recruited from multiple districts, which reduces the likelihood of you being identified. We will also take care not to provide enough demographic information about you in the research report to allow identification.

How Will We Protect Your Information?

We plan to publish the results of this study. To protect your privacy, we will not include information that could directly identify you.

We will protect the confidentiality of your research records by sending all e-mail correspondence from a password protected account that only we have access to. WE will store all virtual data on a password protected cloud account that only we has access to, and it will ony be accessed via our personal, password protected devices, which will be stored in a locked location when not in use along with all hardcopies, such as notes. Your name and any other information that can directly identify you will be stored separately from the data collected as part of the project.

No administrators or employees of the district will be infromed which teachers are participating. Additionally, all recruitment and potentially all data collection will take place virtually and can be done outside of school hours, which minimizes the chance of coworkers knowing who is participating. A pseudonyms will be assigned to you (ex: Teacher A, Teacher B, Teacher C, etc.) immediately after you complete the questionnaire, and participants you will be referred to by your pseudonyms for the rest of the study, including during reporting. Although all participants are high school health teachers, which makes them more easily identifiable, participants are being recruited from multiple districts, which reduces the likelihood of you being identified. We will also take care not to provide enough demographic information about you in the research report to allow identification.

What Will Happen to the Information We Collect About You After the Study is Over?

We will not keep your research data to use for future research or other purposes. Your

name and other information that can directly identify you will be deleted from the research data as part of the project.

What Other Choices do I Have if I Don't Take Part in this Study?

If you choose not to participate, there are no alternatives.

Your Participation in this Research is Voluntary

It is totally up to you to decide to be in this research study. Participating in this study is voluntary. Even if you decide to be part of the study now, you may change your mind and stop at any time. You do not have to answer any questions you do not want to answer. If you decide to withdraw before this study is completed, your previously completed responses will not be included in the data analysis or findings.

Contact Information for the Study Team and Questions about the Research

If you have questions about this research, you may contact:

Dr. Jessica Hall-Wirth, jessica.hall-wirth@sru.edu, (724) 738-2085

or

Mrs. Jessica Baton, jcb1029@sru.edu, (845) 800-4505

Contact Information for Questions about Your Rights as a Research Participant

If you have questions about your rights as a research participant, or wish to obtain information, ask questions, or discuss any concerns about this study with someone other than the researcher(s), please contact the following:

Institutional Review Board
Slippery Rock University
104 Maltby, Suite 302 Slippery Rock, PA 16057
Phone: (724)738-4846
Email: irb@sru.edu

Your Consent

By selecting the first option below and digitally signing, you are agreeing to be in this study. Make sure you understand what the study is about before you sign. We will give you a copy of this document for your records. We will keep a copy with the study records. If you have any questions about the study after you sign this document, you can contact the study team using the information provided above.

I understand what the study is about and my questions so far have been answered. I agree to take part in this study. I understand that I can withdraw at any time. A copy of this signed consent form has been given to me.

- ○ I consent, begin the study.
- ○ I do not consent, I do not wish to participate.

By signing below, I indicate that the participant has read and to the best of my knowledge understands the details contained in this document and has been given a copy.

Printed Name of Investigator: Jessica Baton
Date: January 18, 2024
Signature of Investigator:

Audio Recording Consent

We request to audio record your interview as part of our study. We specifically ask your consent to use this material to transcribe the content of your interview for data analysis. You will have an opportunity to view and verify the transcript of your interview for accuracy. Your audio recording will be labeled using a pseudonym assigned to you separate from any identifying information. Only we, the researchers, will have access to your audio recording; it will not be shared with anyone else. Your audio recording will be destroyed once your interview is transcribed and verified or once the study is complete, whichever comes first.

Regarding the audio recording of your interview, please select one of the following options and sign on the next screen:

PLEASE NOTE: Should you choose not to allow your voice to be recorded, we can still benefit from your inclusion as a research study participant.

- ○ I do give consent for my interview to be audio recorded for the purpose of transcription.
- ○ I do not I do give consent for my interview to be audio recorded for the purpose of transcription.

Please sign your full name.

Questionnaire

Thank you for agreeing to participate in this study! I appreciate your time and input.
Please complete the following questionnaire.

Demographics
The purpose of this section is to collect demographic information. Your name will only be used to connect your questionnaire answers with your interview transcript. You will be assigned a pseudonym for the purpose of this study, and your identity will not be disclosed to anyone other than the researchers.

First Name

Last Name

Years of Teaching Experience

Years of Experience Teaching Health

Years of Experience Teaching Special Education Students

Grade(s) Taught

Highest Post-Secondary Degree Earned & Field
(ex: B. S. in Exercise Science)

Pennsylvania Teaching Certification(s)

Preferred contact method (e-mail address or phone number).

Perceptions

The purpose of this section is to understand your perception of the sexuality of individuals with intellectual and developmental disabilities (IDD). Please answer these questions honestly.

These questions are adapted from the original and revised versions of the ASQ-ID and used with permission from the co-creator, Dr. Monica Cuskelly.

When answering these questions, please imagine an individual with IDD with an IQ below 70. As students, these individuals are typically in a self-contained "Life Skills" class and may participate in activities like Special Olympics.

	Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree
Provided no unwanted children are born and noone is harmed, consenting adults with IDD should be allowed to live in a heterosexual relationship.	○	○	○	○	○	○
Consenting adults with IDD should be allowed to live in a homosexual relationship if they so desire.	○	○	○	○	○	○
It is best to wait for the individual with IDD to raise questions about sexuality before discussing the topic with him/her.	○	○	○	○	○	○
Adults with IDD should be allowed to engage in non-sexual romantic relationships.	○	○	○	○	○	○
Sterilization should be used as a means of inhibiting sexual desire in individuals with IDD.	○	○	○	○	○	○

When answering these questions, please imagine an individual with IDD with an IQ below 70. As students, these individuals are typically in a self-contained "Life Skills" class and may participate in activities like Special Olympics.

	Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree
Masturbation should be discouraged among adolescents with ID.	○	○	○	○	○	○
Discussions on sexual intercourse promote promiscuity in adolescents with IDD.	○	○	○	○	○	○
Masturbation in private for adolescents with IDD is an acceptable form of sexual expression.	○	○	○	○	○	○
Generally, individuals with IDD are able to make the distinction between sexual thoughts and sexual actions.	○	○	○	○	○	○
Sex education for adolescents with IDD has a valuable role in safeguarding them from sexual exploitation.	○	○	○	○	○	○

When answering these questions, please imagine an individual with IDD with an IQ below 70. As students, these individuals are typically in a self-contained "Life Skills" class and may participate in activities like Special Olympics.

	Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree
Sexual intercourse should be allowed between consenting adults with IDD.	○	○	○	○	○	○
Adults with IDD are unable to develop and maintain an emotionally intimate relationship with a partner.	○	○	○	○	○	○
Individuals with IDD have stronger sexual feelings than nondisabled individuals.	○	○	○	○	○	○
Individuals with IDD have less interest in sex than nondisabled individuals.	○	○	○	○	○	○
Masturbation should be taught to individuals with IDD as an acceptable form of sexual expression in sex education courses.	○	○	○	○	○	○

When answering these questions, please imagine an individual with IDD with an IQ below 70. As students, these individuals are typically in a self-contained "Life Skills" class and may participate in activities like Special Olympics.

	Strongly Disagree	Disagree	Somewhat Disagree	Somewhat Agree	Agree	Strongly Agree
Sex education for adolescents with IDD should be compulsory.	○	○	○	○	○	○
Adults with IDD typically have fewer sexual interests than people without IDD.	○	○	○	○	○	○
Adults with IDD are more easily stimulated sexually than people without IDD.	○	○	○	○	○	○
Advice on contraception should be fully available to individuals with IDD whose level of development makes sexual activity likely.	○	○	○	○	○	○
Sexual intercourse should be discouraged amongst adults with IDD.	○	○	○	○	○	○
It is a good idea to ensure privacy at home for individuals with IDD who wish to masturbate.	○	○	○	○	○	○
It is best not to discuss issues of sexuality with people with IDD until they reach puberty.	○	○	○	○	○	○

Interview Scheduling

What date are you available for an interview? It will take less than an hour.

- ○ 2/1/24
- ○ 2/2/24
- ○ 2/3/24
- ○ 2/4/24
- ○ 2/5/24
- ○ 2/6/24
- ○ 2/7/24
- ○ 2/8/24
- ○ 2/9/24
- ○ 2/10/24
- ○ 2/11/24
- ○ 2/12/24
- ○ 2/13/24
- ○ 2/14/24
- ○ 2/15/24
- ○ 2/16/24

What time(s) are you available on this date?

Would you prefer a virtual interview or an in-person interview?

- ○ Virtual via Zoom
- ○ In-Person at School or Another Public Place

If in-person, what public place would would you like to meet for an interview?
(ex: school, library, coffee shop, etc.)

APPENDIX C: CODING SCHEME DEVELOPMENT CHART & CODING SCHEMA

The first coding wave of the interview transcripts (and notes for the participant who declined to be recorded) produced 24 codes. The second wave of coding included 13 codes.

Phases of Development	Changes in Coding Scheme
2/19/24. Initial coding scheme developed after initial review of transcripts and relevant literature	The initial coding scheme was inductively developed based on the first review of the transcripts. 24 initial codes were created.
2/24/24. Based on review of initial codes and redundancies, codes were merged or removed.	Several codes were redundant or irrelevant to the research, so the codes were merged or removed. 13 codes resulted.

Coding Schema

The initial coding process for the research results yielded the 24 codes, which then was distilled into 13 codes:

Initial Coding Scheme	Final Coding Scheme
1. RQ 1: Paraprofessional support	1. RQ1: Special education support
2. RQ1: SPED teacher support	2. RQ1: Administrator support
3. RQ1: Curriculum	3. RQ1: Curriculum
4. RQ1: Training	4. RQ1: Training
5. RQ1: Administrator support	5. RQ1: Reflection/revision
6. RQ1: Reflection/revision	6. RQ2: Need for SE
7. RQ2: Need for SE	7. RQ2: Openness understanding of sexuality of IDD
8. RQ2: Willingness to teach	8. RQ2: Willingness to teach
9. RQ2: Openness to/Understanding of sexuality of IDD	9. RQ2: Parental role
10. RQ2: Reasons for need	10. RQ3: Pre-service training
11. RQ2: Parental role	11. RQ3: In-service training
12. RQ2: How best to structure	12: RQ4: SPED experience
13. RQ3: Pre-service SPED training	13: RQ4: Feelings about teaching
14. RQ3: Pre-service SPED PE only	
15. RQ3: No pre-service SPED training	
16. RQ3: In-service SPED training	
17. RQ3: In-service gen. ed. training only	
18. RQ3: No specialized in-service training	
19. RQ4: SPED experience level	
20: RQ4: Need SPED teacher support	
21: RQ4: Need curriculum	
22: RQ4: Need paraprofessional support	
23: RQ4: Need training	
24: RQ4: Feelings about teaching	

Adapted from *Completing Your Qualitative Dissertation: A Road Map from Beginning to End*, L. D. Bloomberg, 2023, Appendix P (online), Copyright 2023 by SAGE Publications, Inc.

APPENDIX D: DATA SUMMARY CHARTS

	Primary Research Question																	
	Special Education Support				Administrator support			Curriculum			Training			Reflection and Revision	
Participant	Co-teach with SPED teacher	SPED teacher support to adapt curriculum	No paras except behavior	Para support	Curriculum writing time, , Scheduling, Parent concerns	Common planning period	Addressing parent concerns	Set framework	Pre-made adapted curriculum	Hybrid curriculum	Teaching students with IDD	Teaching CSE to students with IDD	Observe others	Overall	Topic by topic
Teacher A		X		X	X				X		X	X			
Teacher B	X	X		X	X					X			X		
Teacher C	X	X		X	X				X		X				
Teacher D	X	X		X				X		X	X	X	X		
Teacher E	X	X		X					X						
Teacher F		X		X	X		X	X	X						
Teacher G	X	X		X	X	X				X	X	X	X	X	X
Teacher H		X	X		X			X			X	X			
Frequency	5	8	1	7	6	1	1	3	4	3	5	4	3	1	1

Secondary Research Question 1																																
Participant	Need for SE										Openness to/Understanding of sexuality of IDD	Willingness to teach						Parental Role														
	Necessary	Should be for all	Lacking in gen. ed. too	Comprehensive	Less Comprehensive	Topics should be covered before HS	Bust misinformation	Safe space to discuss sex	Inclusive SE is insufficient		Generally supportive	Willing	Eager	Want to do it well	Feel unprepared	Lacking training	Personal connection	Parental say in topics	Parent opt out possible	No parent opt out												
Teacher A	X											X			X	X															
Teacher B		X	X	X			X	X			X		X				X			X											
Teacher C		X		X								X		X	X	X															
Teacher D												X			X				X												
Teacher E					X		X				X	X																				
Teacher F	X					X	X		X		X	X						X													
Teacher G	X	X			X				X				X						X												
Teacher H			X	X			X	X	X		X	X								X											
Frequency	3	3	2	3	2	1	3	2	3		4	6	2	1	3	2	1	1	2	2												

Participant	Secondary Research Question 2								Secondary Research Question 3									
	Pre-service training				In-service training				SPED experience			Feelings about teaching						
	Part of a class	Separate class	PE only	No SPED training	Rarely get health/PE training	General SPED training	Gen ed PE only	No training	Only in inclusion	Adapted PE	Adapted health/SE	Somewhat qualified	Room for improvement	Nervous	Know material but not population	Need help to differentiate	Need curriculum	Need SPED support	Need training
Teacher A	X							X	X			X			X	X		X	
Teacher B		X	X				X			X		X							
Teacher C		X	X					X		X					X		X	X	
Teacher D		X	X		X					X								X	
Teacher E		X	X			X				X	X			X					
Teacher F		X	X			X			X			X					X		X
Teacher G				X	X						X		X						
Teacher H		X	X		X						X								
Frequency	1	6	6	1	3	2	1	2	2	4	3	3	1	1	2	1	2	3	1

Adapted from *Completing Your Qualitative Dissertation: A Road Map from Beginning to End*, L. D. Bloomberg, 2023, p. 349, Copyright 2023 by SAGE Publications, Inc.

APPENDIX E: THEME DEVELOPMENT CHART

Primary Research Question: What types of supports do secondary general education health teachers need to effectively teach CSE to adolescents with IDD?

Theme	Selected Categories	Selected Codes
Need for special education teacher, paraprofessional, and/or administrator support	Special education support	Co-teach with SPED teacher, SPED teacher support to adapt curriculum, No paras except behavior, Para support
	Administrator support	Curriculum writing time, Common planning period, Addressing parent concerns
Need set curriculum	Curriculum	Set framework; Pre-made adapted curriculum; Hybrid
Desire training to improve their knowledge and skills regarding students with IDD	Training	Teaching students with IDD generally, Teaching CSE to students with IDD specifically, Observe others
Need to reflect on past offerings and revise as needed	Reflection/Revision	Overall, Topic by topic

Theme	Selected Categories	Selected codes
Are generally understanding and accepting of the sexuality of young adults with IDD and feel adapted sex education is necessary for many reasons	Need for SE	Necessary, Should be for all, Lacking in gen. ed. too, Comprehensive, Less comprehensive, Topics should be covered before high school, Bust misinformation, Safe space to discuss sex, Inclusive SE is insufficient
	Openness to and understanding of sexuality of IDD	Generally supportive
Are willing to teach with necessary supports	Willingness to teach	Willing to teach, Eager to teach, Want to do it well, Feel unprepared, Lacking training, Personal connection
	How best to structure	Self-contained, Separate genders, Do not separate genders, Adapt for levels within class, Separate classes further by level

Unsure about what parental role is or should be	Parental role	Parental say in topics covered, Parent opt out possible, No parent opt out

Secondary Research Question 1: What are the perspectives of secondary general education health teachers on CSE for adolescents IDD?

Secondary Research Question 2: What training, if any, have secondary general education health teachers received specific to teaching individuals with IDD?

Theme	Selected Categories	Selected Codes
Lack training in SPED	Pre-service training	Part of a class, Separate class, PE only, No SPED training
	In-service training	Rarely get health/PE training, General SPED training, Gen. ed. PE only, No training

Secondary Research Question 3: How prepared are secondary general education health teachers to teach CSE to adolescents with IDD?

Theme	Selected Categories	Selected Codes
All have experience with SPED students in inclusive classes but less have experience with students with IDD in a self-contained classroom setting	SPED experience	Only in inclusion, Teaches/taught adapted PE, Taught adapted health/SE

Feel confident in the content area but require support to teach students with IDD	Feelings about teaching	Somewhat qualified, Room for improvement, Nervous, Know material but not population, Need to differentiate even in adapted class, Need curriculum, Need SPED support, Need training

Adapted from *Completing Your Qualitative Dissertation: A Road Map from Beginning to End*, L. D. Bloomberg, 2023, p. 369, Copyright 2023 by SAGE Publications, Inc.

APPENDIX F: SCHOOL DISTRICT RECOMMENDATIONS

How to Best Utilize General Education Health Teachers to Teach Sex Education to Students with Intellectual and Developmental Disabilities (IDD)

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Young adults with IDD do not receive comprehensive sex education (CSE) at the same rate as their nondisabled peers. The resultant lack of relationship and sexuality knowledge and skills has negative lifelong implications, such as increased susceptibility to sexual victimization and barriers to establishing wanted romantic relationships, which can have long term effects on their quality of life and mental health. Districts who are not providing CSE for students with IDD need to prioritize this need. However, without additional funding dedicated to CSE for students with disabilities, districts will likely need to utilize existing faculty to provide this important service.

Results of this study indicate that general education health teachers notice the need for adapted health and sex education and are willing to teach it provided they have adequate training and support. The following recommendations will help districts successfully offer adapted health and sex education for students with IDD while minimizing additional costs.

- **Adopt comprehensive sex education standards.** It is important for school districts to adopt comprehensive sex education standards, like the *National Sex Education Standards*, to ensure that the course covers all information students need. This is best for students because it helps guarantee that the topics covered are not affected by the values of the teacher teaching the course. It is also important for teachers because (1) it lets them know what material should be covered to achieve the aim of the course, even if staffing

changes, and (2) it provides clear, well-established guidelines to fall back on if they are ever challenged about the appropriateness of the topics they are covering. Under the IDEA, school districts have an obligation to provide evidence-based instruction to students with disabilities, and evidence overwhelmingly supports the benefits of comprehensive sex education (versus abstinence-based education) for all students.

  - **Resources:** *National Sex Education Standards*

- **Utilize a sex education curriculum designed for students with IDD**. It is also important for school districts to carefully select a comprehensive sex education curriculum designed to meet the needs of students with IDD. This also helps to ensure comprehensiveness and consistency in coverage so students receive the information they need to live safe, fulfilling lives. This curriculum should adhere to the *National Sex Education Standards.*

  - **Resources:** There are several adapted sex education curricula available, both paid and free, including Friendships and Dating by Oregon Health and Science University (OHSU), Positive Choices by Oak Hill Relationship and Sexuality, Relationships Decoded, and Sexuality Education for People with Developmental Disabilities by Elevatus. SIECUS (2004) provides a useful Curriculum Evaluation Tool to guide careful selection of a CSE curriculum as part of their Guidelines for Comprehensive Sexuality Education that helps to ensure that the curriculum selected truly is comprehensive (p. 89-99).

- **Regularly offer a self-contained adapted health and sex education class.** The best way to meet the need for CSE for students with IDD is to offer an adapted health and sex education course taught by someone other than a special education teacher. Having a health teacher teach sex education, rather than a special education teacher, gives students

with IDD another trusted adult they can talk to about the subject. Offering it as a self-contained class helps students with IDD to feel comfortable asking questions and to receive differentiated instruction at their level, and it allows instructors to spend more time on topics for which students may lack the prerequisite knowledge common in general education students and to differentiate instruction to the appropriate levels. It needs to be offered consistently so all students get the opportunity to take it at least once during their high school career.

- **Discuss relationships and sexuality as part of the transition planning process.** By high school, local districts should add relationships and sexuality to the transition planning process as part of the independent living consideration. Transition plans are discussed annually at student IEP meetings., which offers an opportune time to discuss student and family goals regarding relationships and sexuality, to be transparent about the adapted health and sex education course, and to address parent questions and concerns.
    - **Resources:** In their *Toolkit for Parents of Students with Disabilities*, the PAETC presents a useful tool called My Child's Action plan that can be used to structure discussion and planning around students' personal care, dating skills, and sexual health, including identifying concerns, setting goals, developing an action plan, and establishing a support system. This should be incorporated into the annual transition planning assessment process, at least for high-school aged students.
- **Utilize interested teachers whenever possible**. Districts should attempt to utilize teachers interested in teaching adapted health and sex education whenever possible. Especially when offering a new course, it is important to have teacher buy-in because teachers who are interested in and invested in what they are teaching are more likely to be dedicated and effective. If multiple health teachers are interested in and willing to teach

adapted health and sex education, they should all be given the opportunity to do so on a rotating basis.

- **Provide specialized in-service training to all general education health teachers.** School districts should provide teachers with in-service training on how to teach sex education to young adults with IDD prior to having them teach an adapted health and sex education course. It should be provided to all secondary general education health teachers—not just those who are likely to teach adapted health and sex education soon—so that all teachers are prepared in the event of a staffing change. It should also be recorded or offered on a reoccurring basis so newly hired teachers can be trained as well. If hiring a trainer to come in, districts could offset the cost by inviting neighboring districts to send their health teachers as well. Districts may also want to consider having one of their teachers or special education administrators trained as a sex education trainer so that person can offer reoccurring trainings in house.
    - **Resources:** Several companies and organizations, like Among Friends, Ease (Empowerment, Advocacy & Sexuality Education), Elevatus, and Geisinger's Autism & Developmental Medicine Institute. offer teacher training specific to teaching sex education to students with IDD. Planned Parenthood offers a free online teacher training course on sex education for students with disabilities.
- **Create opportunities for teachers to gain experience with students with IDD.** All general education teachers need opportunities to gain experience working with students with varying needs and ability levels, including IDD. For health teachers specifically, this could include things like inviting students with IDD to an open gym to play games, pushing into special education classes to do lessons on health-related topics like nutrition and first aid, and helping with Special Olympics and Unified Sports. The more general

education teachers are exposed to students with IDD, especially in the classroom setting, the more comfortable they will feel around them and eventually teaching them.

    - **Resources:** Special Olympics Unified Sports

- **Facilitate collaboration with the special education teacher of students with IDD.** Allot curriculum writing and planning time for the general education health teacher(s) who is expected to teach adapted sex education to meet with a special education teacher who is familiar with students with IDD before and during the course. Even with an adapted curriculum, health teachers will still need special education teacher support to adapt lessons and activities to accommodate the various ability levels within a life skills class. The special education teacher of students with IDD should continue to meet with the health teacher assigned to teach adapted health and sex education prior to the start of each offering of the course to share specific areas of need and concern for that specific group of students, such as topics to cover and histories of abuse.
- **Assign a paraprofessional to provide support in the classroom.** In the classroom, general education health teachers would benefit from instructional support from a paraprofessional who is knowledgeable about students with IDD. Because general education teachers often are not accustomed to working with paraprofessionals, it is important to make sure the paraprofessional's role in the classroom is clearly defined and written out, so both the health teacher and the paraprofessional understand their role and what is expected of them.
- **Administrators must provide support as needed.** Administrators can provide logistic support by ensuring there is room in the schedule for the course to be offered on a recurring basis and for the general education and special education teacher to have a common planning time. Administrators can provide financial support by authorizing

necessary training, curriculum material, and curriculum writing time for the general education and special education teacher. Administrators can provide instructional support by supporting the adoption of CSE instructional standards, being knowledgeable about the curriculum and topics covered, and supporting teachers if anyone challenges the appropriateness of the course.

- **Encourage continuous reflection and revision.** General education health teachers, along with special education teachers and paraprofessionals, need to reflect on what worked well and what did not throughout the course and at the end of each semester or school year. The teachers then need to work together to develop a plan to revise going forward. Administrators need to clearly convey to all parties that the development of an adapted health and sex education course is a learning experience and a work in progress. They need to clearly establish the expectation that all staff members involved will continually discuss, reflect, and revise as needed, during the course and after each subsequent offering.
- **Support the needs of parents and students.** Although Pennsylvania parents can legally opt their children out of sex education for personal or religious reasons, school districts need to enact strategies to minimize the number of young adults with IDD who are prohibited from receiving sexual health information because research shows that school is the primary source of sex health information for students with IDD.

  Adopting established instructional standards and an adapted sex education curriculum will make it clear that the topics being covered are evidence-based and not based on individual teachers' whims. Districts should also notify parents of their intent to provide instruction in sexuality and related topics so parents do not feel these issues are being discussed without their knowledge, which will help lessen feelings of

untowardness. This notice should also state the proven effectiveness of CSE over abstinence-based education and should include a list of topics that will be covered, and resources parents can access if they would like to discuss them at home as well. District special education departments should also offer training for parents on the sexual development of children with IDD, how and when to approach sexuality-related topics at home and the importance of doing so. Such training should be offered on a regular basis, perhaps biannually, so parents of children approaching adolescence can attend.

- **Resources:** There are many online and printable resources available for free to help guide parents in discussing relationships and sexuality with their children of all ages. Amaze.org, American Sexual Health Association (ASHA), Awk Talk, Advocates for Youth, Nemours Kids, Planned Parenthood and Sex Ed Rescue all have resources dedicated to parents. Additionally, the Parent Educational Advocacy Training Center (PEATC) has published a helpful, disability-specific parent resource printable resource called *Let's Talk About Sex: Students with Disabilities and Their Sexual Health - A Toolkit for Parents of Students with Disabilities*. Several companies and organizations offer sexuality and sexual health training tailored to parents of students with IDD including Among Friends, Ease, and Elevatus.