

Narratives of Personal Health and Sexual Education Experiences of Emerging Adults with
Disabilities

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ACADEMIC ABSTRACT

Disabled communities' sexualities have been historically oppressed. Currently in the United States, public school curricula do not include inclusive sexual education and students with disabilities are often left out of classrooms that discuss any amount of personal health and sexual education. Research on the disabled population is filled with samples of non-disabled individuals imposing their opinions for a population that they do not belong to. The purpose of this study was to understand how emerging adults with disabilities learned about personal health and sexuality. Individuals with varied disabilities were intentionally included to add breadth to the research field. Narrative interviews captured individuals' lived experiences. The final sample consisted of eight individuals (75% female, 87% white, mean age of 21.5). After analyzing interviews using thematic narrative analysis, four story types were generated. Findings highlighted the lack of formal supports and access to adequate, relevant information about sexuality for disabled communities, as well as informal sources of information, like families and media. Findings also emphasized people's agency in seeking out information on their own, as well as variability in people's readiness and use of information about sexuality. Individuals' disability symptoms and personal characteristics need to be considered when crafting universally applicable personal health and sexuality education. There are also opportunities for theoretical integration of disabilities and sexuality research.

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GENERAL AUDIENCE ABSTRACT

People with disabilities have historically been left out of policy and research related to sexuality. Governments and societies around the world have taken personal health choices and sexual decisions away from disabled communities. Furthermore, people with disabilities are not taught about bodily changes, romantic relationships, and safer sex practices. I gathered stories of lived experiences of personal health and sexual education from people with different disabilities in order to present variation of experience. Participants shared their journeys learning about their own personal health and sexuality during their lifetimes; equally as important, participants reflected on the inadequacy and failure of formal and informal resources, like schools and medical providers. To provide accurate health and sexuality information that disabled communities can use, families, schools, and healthcare providers need to understand the experiences of people with disabilities and ways that disabilities and sexuality intersect.

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Story Types with Supportive Thematic Breakdown by Participants		
Participant Names	Story Types	Supportive Themes
P1: Stacy P4: Jude P5: Brandy	1. Self-Guided Journey	Failure of Formal School PHSE and School Support Mixed Parental Guidance Failure of Medical Providers Feeling Separate from Peers Actively Seeking PHSE
P2: Gabrielle P3: Amie P6: Alice	2. Experience is the Best Teacher	Unhelpful School Sex Education Reactive Discussions with Family Members Vicarious Learning Personal Experiences Influence of Media
P7: Cecelia	3. Personal Health Matters More	No School Sex Education Sexual Information Was Not a Priority Prioritized Personal Health Familial Support Learning to Personally Advocate Prominence of Disability
P8: Drew	4. “2 Ears and 1 Mouth”	Dating and Sex Were Not His Top Priorities Supportive Family Present, but Unhelpful, School Sex Education Peers with Similar Values The Absence of Sexuality and Disability Interaction

Introduction

“Sexuality is often the source of our deepest oppression; it is also often the source of our deepest pain. It’s easier to talk about and formulate strategies for changing discrimination in employment, education, and housing than it is to talk about our exclusion from sexuality and reproduction.” -Anne Finger (1992), disability activist.

Too often policies, curricula, and practices do not consider the voices and opinions of the populations that they seek to help. Minorities are historically left out of giving their own perspectives on research that affects their population. Disabled voices are frequently missing from research about how to meet the needs of disabled people (Stafford, 2017; Vlachou, 2004). As Anne Finger alludes to in the quote above from “Forbidden Fruit”, the exclusion of disabled voices from discussions of sexuality is a source of oppression. While research on personal health and sexual education (PHSE) for disabled individuals exists, very few of these studies - if any - include what disabled communities actually want and are not receiving (Treacy et al., 2018; Alexander & Taylor Gomez, 2017; Turner & Crane, 2016). Not including disabled voices in research can lead to nondisabled views, biases, values, and opinions being pushed on this population ineffectively and/or harmfully (Rioux, 2001). Reducing sexual health disparities in disabled populations necessitates listening to what people with diverse disabilities say they need in their PHSE experiences.

The terms “disabled people” and “people with disabilities” will be used interchangeably (Dwyer, 2022) throughout this study. This word usage is intentional as different disabled communities use each terminology, and the study seeks to capture disability as its own category

rather than separating each type of disability. It is important to acknowledge that the author understands that this terminology is an individual's choice; using both identifying phrases, it is my hope to represent as much of the disabled community as possible. Furthermore, in this paper, I use the official federal/legal definition of disability: "An individual with a disability is defined by the ADA as a person who has a physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such an impairment, or a person who is perceived by others as having such an impairment" (Americans with Disabilities Act Amendment Act, 2008).

Theoretical Framing

Multiple theoretical perspectives can inform research on PHSE among adolescents with disabilities. My own research perspective highlights the liberation of people with disabilities and their right to experience consensual, fulfilling, and pleasurable sexual relationships. Therefore, I align myself with theories related to disability and sexuality that highlight these rights, empower disabled voices and experiences, and critique the social and cultural circumstances that infringe on personal autonomy. These theories include the widely-accepted social model of disabilities, crip theory of sexuality, and the integration of sexuality theory, specifically citing the normative framework of sexuality development (Tolman & McClelland, 2011).

The social model of disabilities offers a general guiding framework of appropriate ways to view disabilities in context. This is a widely accepted model within this research field because it does not include the deficit perception that has historically accompanied disability diagnoses. Contrary to the social model, the medical model of disabilities fixates on the deficit perception, or the belief that disabilities are internal and exist to be cured. My research acknowledges the

historical use of the medical model, but does not align with the beliefs or framework. The social model categorizes disabilities and impairments with the inclusion of environmental, social, and economic barriers put in place by societies (Burchardt, 2004; Shakespeare, 2006). Societies create barriers that everyone encounters daily though not every body can overcome. The individual is, thus, disabled by, or because of, the environment. Unlike models that view disabilities as internal deficits, the social model does not view disabilities as existing within an individual. The individual's developed identity is created/influenced by such outside barriers as well. A conclusion drawn from the model is, if an individual exists within an environment that is totally accessible, then they would not be considered disabled because they are able to exist/perform without the challenges that barriers provide. As it applies to the current study, the social model proposes that disabled people are not inherently less sexual or less able to participate in sexual activities. Rather, due to the lack of comprehensive and inclusive PHSE, disabled individuals are put at a disadvantage when it comes to personal health and intimacy.

Crip theory of sexuality relates to the social model of disabilities as both reconsider traditional, ableist views of disabilities in ways that serve and empower disabled communities. As a branch of crip theory (2006), McRuer's crip theory of sexuality (2011) offers a place for sexuality inclusion in disability research. Crip theory of sexuality considers (and reconsiders) disabled peoples' rights and pleasures, while including how they may be assisted by the state/legislative bodies (to the desire of the disabled community; McRuer, 2011). This promotion of independence and emphasis on rights and pleasures of individuals with disabilities serves as a guide to analyze and represent the community in a humanized, enlightened way. Where crip theory challenges the idea of a stark difference between being able-bodied and disabled, crip theory of sexuality goes further and also challenges the idea that there is a stark difference

between what is viewed as sexual functioning and not sexual functioning. Crip theory of sexuality reconsiders sexual desire, performance, and abilities to scope wider than sexual function and penetrative sexual intercourse. Investigating how individuals living with disabilities learn about and experience sexuality and intimacy gives more context to the complexities of specific needs and ways of expressing, exploring, and enjoying sexuality.

Finally, normative framework of sexuality development is relevant when considering the process and trajectory of becoming a sexual being. Normative framework of sexuality development (Tolman & McClelland, 2011) proposes that sexuality is normal, expected, and necessary for an individual to develop as a sexual person across adolescence. Under their framework, the term “sexuality” includes multiple behavioral and cognitive domains, such as sexual behaviors, safer sex, sexual identity, and attitudes toward sexuality. Although this theory does not abide by developmental timelines or benchmarks, it implies a typicality in sexuality development and leaves room for assumptions of atypical ways of sexuality development. We address this limitation of the framework alongside the findings of this study within our discussion.

Previous research has used normative framework of sexuality development to investigate aspects of sexuality development with disabled adolescents (Dewinter et al., 2013). In their narrative review of autism and sexuality development, Dewinter and colleagues (2013) discuss normal and positive aspects of developing sexual selfhoods, behavior, and socialization among adolescents on the autism spectrum. While work like Dewinter and colleagues is an important first steps to situating disabilities research with sexuality frameworks, using specific disabled populations limits the impact such research could have across the disabled population.

Historical Mistreatment of Disabled Peoples' Sexuality

The historical intersection of disability and sexuality contains extreme examples of actions that infringe on the sexual rights of people with disabilities. Consistent with theories of disability and sexuality, cultural misunderstandings about disabled people made it difficult for them to navigate sexuality in a healthy and independent manner. People with disabilities were institutionalized for decades where their human rights were neglected and violated. Forced sterilization and segregation from society restricted the reproductive rights of disabled people in the United States and globally (Buck vs. Bell, 1927; Gomez, 2012; Kempton & Khan, 1991). The eugenics movement argued that “forced sterilization was in society’s best interest” (Pham & Lerner, 2001).

Related to the historical issue of sterilization is the prevalence of sexual abuse. Sterilization and denial do not prevent sexual abuse. Sexual abuse can be widely defined as any unwanted sexual behavior or sexual act that is forced upon another without their consent (Gill, 2010). The disabled population has historically high rates of sexual abuse compared to other populations (Gomez, 2012). In the 1980s, record rates of institutional abuse led to deinstitutionalization. Through this legislatively-driven process in which communal residences for disabled individuals were closed, thousands of residents were moved out of harmful institutions and back to immediate caregivers, group homes, halfway houses, and independent living facilities (Ben-Moshe, 2020). However, institutions were not the only places where abuse took place. Although statistics on current rates of abuse vary, in their systematic review of research on sexual abuse of children with disabilities, Klebanov and colleagues (2023) found that children with disabilities were two to four times more likely to be sexually abused compared to children without disabilities. The prevalence of sexual abuse across 24 countries for young girls

with disabilities was 8% to 31% and for young boys with disabilities was 3% to 17% (Kelbanov et al., 2023; Finkelhor et al., 2014).

Oppressive practices such as forced sterilization perpetuated the mentality that disabled individuals were not fully human, a stigma that then was used as justification for maltreatment and neglect. Misperceptions of people with disabilities' sexuality have been a common reason for not providing the population with sexual knowledge. This population is often thought of as asexual, having no sexual feelings or desires (Barbareschi & Wu, 2022; Michielsen & Brockschmidt, 2021). The idea that the entire disabled population is asexual is untrue as all people go through sexuality development and experience desires. Additionally, people with disabilities are also often thought of as needing protection (Michielsen & Brockschmidt, 2021). Challenges of being overprotected can range from not being given any information about the topic to never gaining independence, which leads to increased vulnerability because individuals do not learn their own rights to bodily autonomy. Vulnerability increases the risk of victimization and unhealthy sexual practices like STI transmission and unplanned pregnancies (Michielsen & Brockschmidt, 2021). False perceptions like these result in dehumanizing an entire group of already marginalized people.

The Current State of PHSE for Disabled Communities

As of 2019, 38 out of 50 states in the U.S. mandate sexual education in schools, and only eight of those states include all components of comprehensive education (Scholars Strategy Network, 2019). Comprehensive education teaches that sexuality is normal and a healthy part of life, provides students with sufficient information in order to make their own choices of sexual expression and practice, and covers a wide variety of shame-free topics, like relationships,

human development, and sexual health and expression (Scholars Strategy Network, 2019).

Receiving comprehensive sexual education is important for understanding intimacy and sexuality development. The type of education and students are taught varies, but students with disabilities are often not included in sexual education classes (Scholars Strategy Network, 2019). Failing to provide sexual and health education to students with disabilities is an overlooked violation of the Individuals with Disabilities Education Act (IDEA) (2004). The IDEA provides all individuals with disabilities a right to free, appropriate public education that is tailored to their needs.

Special Needs programs in public schools are the most commonly used way to provide such education, though it is not specifically required by the IDEA to provide sex education for students with disabilities. Comprehensive universal education about personal health and sexuality is necessary for all groups of people and therefore should be included in tailored education for students with disabilities. Consistent with crip theory of sexuality's emphasis on rights and autonomy, the exclusion of people with disabilities from sex education is another way that society fails to consider the sexual rights of the population.

Although disabled communities need to have their sexual autonomy and rights validated and protected through sexuality education, this need is not being met. In the United States, public middle and high schools typically incorporate sexual health into their overall health education (Brener et al., 2019). According the 2018 CDC Health Profiles, key comprehensive topics for sexual health education, such as sexual health practices, STIs/STDs, family planning/resources, and relationship skills are taught in 43% of high schools and 18% of middle schools across the United States. This report does show the number of public schools receiving and lacking formal PHSE; the report does not, however, show the types of students in those schools that are being taught (e.g., mainstream vs. Special Ed).

In the absence of school-based PHSE, adolescents with disabilities may rely on family members and community programs to learn about health and sexuality. Families and caregivers typically acknowledge that sexual education needs to be taught, but do not know the best ways to teach it (Gray, et al., 2021). Gray and colleagues found that even though children with cerebral palsy were at risk for abuse, families frequently discounted the likelihood of abuse due to the child's disability. Since not all family members know how to educate youth about PHSE, some resources, like conversation models and question guides, have been created to assist with such conversations (Couwenhoven, 2007).

More research on interventions of PHSE for disabled communities exists outside of the United States. In Japan, a research team found that sexual education programs for individuals with intellectual disabilities increased knowledge of personal and sexual health (Hayashi et al., 2011). After conducting interviews directly with disabled youth, a pilot study of Swedish sex education found that what would be most helpful for the young disabled population is an adapted model for PHSE that is consistent with varying individual circumstances (Löfgren-Mårtenson, 2012).

Consequences of Inadequate PHSE

As a direct consequence of not receiving effective PHSE, people with disabilities are made more vulnerable to sexual abuse. Studies show that the risk of victimization is significantly higher for men and women with disabilities than nondisabled people across their lifespans (Basile, et al., 2016; Harrell, 2017; Mailhot, et al., 2021). The lack of sexual health education can also lead to health problems. There is a higher risk of STIs/STDs for disabled individuals (Mabusi & Kivuma, 2021).

Not being taught about personal health and sexuality is harmful. Knowledge about sexual activity gives all people more control and more understanding about what goes on around them or to them. Not knowing about sex and personal health does not change the ambiguity, confusion, and negative impacts that survivors of sexual abuse experience. A study conducted by McCarthy and Thompson (2010) with 185 people with intellectual disabilities found that although abuse was revealed by the survivors themselves, they were unaware of the social meaning of it – they were aware that *something* had occurred to them, but not that those acts were inappropriate, without consent, and sexual in nature. Nonetheless, all victims felt ambivalent and/or negative feelings towards the perpetrators and what they had done to them.

Not all sexual activity is unwanted, though. People with disabilities experience the same sexual desires that nondisabled people do (Loeser, et al., 2018). The difference, however, is that people with disabilities sometimes have less knowledge of what is happening to their bodies and how to protect themselves and others because they are not taught appropriate PHSE (Klebnov et al., 2023). That means while engaging in consensual sexual activities, some people with disabilities may not know how to protect themselves from things like STIs/STDs and pregnancy (Mabusi & Kivuma, 2021). Access to proper healthcare is also much more challenging for adults with disabilities - another way that society places barriers on sexual rights of the population (Greenwood & Wilkinson, 2013). So, even if equipped with knowledge, accessing the required materials to prevent unwanted outcomes of sex is difficult.

Additional barriers to sexual expression repress disabled individuals. Alienation, stigmatization, and discrimination are all ways that societal systems attempt to extinguish sexuality for this population (Campbell, 2017). Ableist views embedded in policies, laws, and supports harm the disabled community they set out to serve. A direct result of ableist influences

is internalized ableism, which is the projection of negative ableist feelings onto people with disabilities who then internalize and believe them to be true (Jun, 2018). Internalized ableism is incredibly damaging to disabled individuals.

Barriers to PHSE for Disabled Communities

Even though there has been some headway made for improving PHSE targeted for disabled communities, current research has only provided limited insights into the PHSE needs of people with disabilities. One barrier to addressing disability and sexuality is limited use of disabled voices in research and policy. Stafford (2017) writes about emancipating the oppressed voices of young individuals with disabilities. The article discusses how young disabled individuals are not used as active participants in research covering their own population. Stafford's work supports earlier claims by Kitchin (2000) that disability research has been and still is dominated by non-disabled voices. This lack of representation seems to be a theme within disability research - not using the population as actual participants in research studies, other than to measure symptomatology (ex: Saez-Suanes et al., 2022; Bassichi et al., 2005).

If research does not sample disabled communities, who is representing the disabled community in literature? For the most part, literature on PHSE targets parents and clinicians (Fogel, 2021; Vlachou, 2004). As a direct result, inexperienced and ableist ideas are inserted into regulations and supports for the disabled population. Family members, clinicians, and caretakers have become the voices and experts of the community. Centering the voices of caregivers and providers takes out the involvement of disabled individuals altogether. Although it is important to provide caretakers with supportive guides to assist in caregiving, resources should be *made for* individuals with disabilities and serve as supportive tools for aids and caretakers.

Efficacy and perceptions of PHSE are useless if not inclusive of the perspectives from the population of interest. How can a program be assessed if not by the population it serves? It is the duty of researchers in disabilities studies to use participants of the population they seek to serve with their work (Stafford, 2017). Using disabled individuals as participants in studies about disability will lead to proper representation.

Another barrier to more expansive research combining disability and sexuality is the tendency to target populations with singular, specific types of disabilities. Disabilities are diverse and the disabled community is not monolithic. Research tends to focus on specific types of disabilities and disabled groups which leads to generalizations and segregated experiences amongst the greater disability community. By including multiple types of disabilities in a study, researchers can compare and contrast the lived experiences of various disabled communities. In their literature review of available PHSE resources for people with disabilities, Treacy and colleagues (2018) provided a useful table with various books and sources to use as educational tools for families and individuals with specific disabilities. Researchers have investigated the ways people with intellectual disabilities may effectively learn about PHSE topics (Schaafsma, et al., 2015; Löfgren-Mårtenson, 2012; Hayashi, et al., 2011); the fertility/infertility, sexual health, and STIs/STDs prevalence of people living with cystic fibrosis (Brown et al., 2019; Frayman & Sawyer, 2015; Etherington et al., 2012; Havermans et al., 2011), and the education and sexuality of people with Down Syndrome (Gokgoz et al., 2021; Awaru et al., 2020; Bononi et al., 2009; Couwenhoven, 2007). Previous research has provided depth to specific areas of disability and sexuality research; this study intentionally sought to provide breadth to the research field.

Although generalizability was most likely not the goal of past researchers, focusing research on a few specific types of disabled individuals leaves room for the assumption that

findings can apply to all disabled communities. What is appropriate for individuals with intellectual disabilities may not serve individuals with non-intellectual disabilities or individuals with co-occurring disabilities (i.e., diagnosis of intellectual disability along with other non-intellectual disabilities). This study intentionally included PHSE experiences of individuals with multiple types of disabilities to show the variability of current experiences. While acknowledging the need for PHSE for individuals of all abilities, there needs to be specific curricula that assists with unique and overlapping disability needs. Topics and lessons within PHSE should then vary based on the unique populations that are being educated.

The Present Research

PHSE is vitally important because everyone - regardless of “ability” - goes through biological changes that impact their day-to-day actions, interactions, feelings, thoughts, and desires. The goal of this study was to understand the PHSE experiences of emerging adults with disabilities. Personal stories of the lived experiences of PHSE not only tell us *what* is being taught, but *how* this information is being communicated and how effective it is. Retrospective narratives gave insight to the perception of PHSE from people living with disabilities based on how stories were told, thus giving researchers more information about the strengths, gaps, and needs of adolescents with disabilities when it comes to PHSE. Our sample intentionally had participants with multiple types of disabilities and symptoms to represent unique and shared experiences of PHSE and sexuality development across the disabled population. The results of this study add breadth to the research field. A narrative, qualitative approach was used to honor the experiences of people with disabilities and center their voices while empowering them and promoting an inclusive, accurate representation of PHSE (Smith-Chandler & Swart, 2014; Gerber, 2006; Hartley & Muhit, 2003).

Research Question 1: How do emerging adults with various types of disabilities experience personal health and sexual education?

Research Question 2: What do the stories of emerging adults with various disabilities suggest about their satisfaction with their experiences of PHSE?

Method

Recruitment

Recruitment took place between August 2022 and February 2023. Participants were recruited through advertisements and word of mouth in and around Blacksburg, Virginia and Niagara University, New York. As both towns are home to college campuses, there was a robust population of emerging adults. Advertisements and announcements were also made in classes related to sexuality and/or disability. Inclusion criteria required participants to be between ages 18-24 and have at least one diagnosed disability from a medical professional. Having different types of disabilities represented captured a more representative population of emerging adults with disabilities' (e.g., physical, psychiatric, congenital, emotional, acquired, etc.). People with intellectual disabilities were not included in the sample because of logistical barriers to obtaining consent and, since the main population being recruited were students on college campuses, they were less likely to be recruited.

Participants

When working with vulnerable, previously exploited communities, it is vital to consider the best ways research can support participants (Shivayogi, 2013; Pyer & Campbell, 2012). Narrative research methods in disabilities studies empower individuals with disabilities and promote inclusive, accurate representation, which was the investigator's goal (Smith-Chandler

and Swart, 2014; Gerber, 2006). This was accomplished through open-ended and participant-led conversations, summarizing information with participants during interviews so they could correct possible misinterpretations, and reflexive work by the investigator to consciously keep preconceptions out of data. In this way, participants were involved in research collection *and* analysis. Privacy was maintained through deidentification of transcripts and correspondences.

Eight participants completed semi-structured narrative interviews over Zoom. Participants' mean age was 21.5 (range 18 - 25). The sample included six women, one man, and one person who identified as non-binary. A large majority of the sample was Caucasian ($n = 7$) and one participant was Black/African American. Not all participants disclosed their sexual identities ($n = 4$), but of those who did: one identified as bisexual, two identified as heterosexual, and one identified as queer. All participants were students; three participants were graduate students and five were undergraduate students. The following are all of the disabilities that participants identified with: type one diabetes ($n = 2$), bilaterally deaf ($n = 1$), hearing impaired/partial deafness ($n = 1$), Attention Deficit/Hyperactivity Disorder ($n = 5$), Generalized Anxiety Disorder ($n = 2$), Obsessive Compulsive Disorder ($n = 1$), Crohn's disease ($n = 1$), autistic ($n = 1$), disordered eating ($n = 1$), thyroid disease ($n = 1$), a herpes diagnosis ($n = 1$), and acquired neurological disabilities ($n = 1$). Several participants had comorbid disabilities, so no disability listed was mutually exclusive.

Procedure

Individuals interested in the study contacted the investigator through email. Once eligibility was determined, each participant met with the investigator and participated in a virtual

semi-structured interview on the Virginia Tech Zoom platform. All interviews were audio recorded and consent was obtained before proceeding with protocol questions.

Each interview followed a narrative methodological structure where content of each experience was key, so probing questions were based on capturing PHSE experiences more wholly. Participants were asked to begin by explaining their personal meaning of sex education (“When I say sex education, what do you think of?”). Then, they were asked to tell the story of how they learned about personal health and sexuality development (“I want you to think of your journey with PHSE as a story with characters and plotlines, etc. Whenever you are ready, please share your story with me.”) Once the participant finished their narrative, the interviewer asked probing questions that were dependent on the story each participant told. In order to provide more detail, participants responded to questions about their perceptions of experiences, the influential characters that they mentioned, turning points in their story, and their overall satisfaction with their PHSE journeys. Member checking is not advised for narrative interviews outside of interviews because the content of one’s story can change based on their environment, reflection, and how questions are presented (Holloway & Freshwater, 2007). Thus, the investigator asked clarifying and interpretive questions during interviews to ensure accurate interpretation of participant experiences.

Data Analysis

After the interview was complete, the investigator transferred the audio recordings to a university secure virtual location. The investigator transcribed audio recordings verbatim and de-identified them for participants’ privacy. Recordings, transcripts, and memo files were also labeled with ID numbers and aliases.

The raw data (interviews) were analyzed using thematic narrative analysis (Riessman, 2008). Thematic narrative analysis focuses on the content of participants' stories, deconstructs each narrative during analysis and thematic generation in order to identify core narratives, and then reconstructs segmented stories to present narratives as they were told. The goals of this method are to preserve the essence of participants' stories, focus on *what* is being said (vs how or to whom), and to identify the core of each narrative or story types being told. At the end of analyses, story types present the different ways participants experienced the phenomena and help situate individual narratives in relation to other participants' (Josselson & Hammock, 2021). My goal for analyses was to first identify themes and then construct story types that reflected the themes in the data.

Story types were essential to the study because stories are powerful. Stories are ways of synthesizing information. People make sense of their experiences through memories and recounts of their stories. Therefore, the type of stories that are shared when describing PHSE reflect memorable, unique experiences. A person's disability adds a layer of context around their story as it affects how they interact with others, their environment, and sometimes themselves.

All eight interview transcripts went through sequential readings (guided by Josselson & Hammock, 2021), which is traditional in narrative analysis, for familiarization. The investigator, who conducted each interview, was also the primary coder for each transcript. For this study, the first three rounds of coding focused exclusively on content of the narrative and identifying themes. Initial codes were based on thematic content and the overall structure or pattern of the narrative (example codes: "PHSE not present in school"; "Failure/Distrust of Medical Providers"; "Self-led Journey"). The investigator used initial codes to define themes throughout each transcript, which led to segmentation within the data. Then, the following two read throughs

focused more on key voices, characters, and important influences within the narrative (example codes: “Peer Pressure”, “Messages from Parents”, “Media was a PHSE tool”). Once a codebook was generated and comprised of each transcripts’ themes, the investigator identified similarities or links between transcripts. This began story type generation. At this point during analysis, the investigator unsegmented transcripts to preserve the context of codes (Riessman, 2008).

The investigator kept memos during the analysis (see Appendix II for example) that reflected on their position in the data as well as thoughts, feelings, and observations. A co-investigator assisted in the latter half of analyses. Together, the investigators discussed, debated, and ultimately collaborated on story type construction based on themes found in the data. Four story types were constructed across the eight narratives based on shared or unique experiences, similarities, and differences in experiences across the eight participants.

Positionality

The investigator identifies as a cisgender, heterosexual woman with multiple invisible disabilities with a background in qualitative research and interviewing. The research team has expertise in developmental research, disabilities studies, and qualitative research. In order to present the data, findings, and relevance for the study in the most effective way, the investigator sought the advice and guidance of research team members during the entire process of the research study.

Findings

Using thematic methods for narrative analysis, four story types were discovered from the stories of the eight participants: (1) “The Self-Guided Journey”, (2) “Experience is the Best Teacher”, (3) “Personal Health Matters More”, and (4) “Two Ears, One Mouth”. Each story type held combinations of unique experiences of participants and shared experiences across

participants. Below, each story type is described along with the role of disabilities and sources of sexual information (or lack of information), like schools, families, and medical providers.

The Self-Guided Journey

As the name of this story type implies, the three participants that experienced “The Self-Guided Journey” actively educated themselves on personal health and sexual topics after not receiving the information they needed from authority figures. Although some participants described PHSE resources that attempted to educate them and some resources that failed to provide accurate support, all three participants who described this story type needed to find their own communities and educational resources in order to accumulate all of the PHSE information they needed. One key characteristic of this story type that was different compared to other narratives was that each participant emerged as the main character in their story - they were actively involved in every step of their PHSE journey.

Interestingly, each participant who described this story type was diagnosed with a disability after childhood. Most of the sex education that they discussed took place before their disabilities were recognized/diagnosed. Another characteristic of these participants’ narratives was that their disability symptoms were woven throughout their entire narrative. All three had clear reflections about how their disabilities impacted their personal health, romantic relationships, and sexual lives.

Failure of Formal School PHSE and School Support

Public school PHSE was unhelpful and fear-based for these participants. The curriculum they experienced was neither inclusive nor comprehensive.

We all had the same class and it was a mix of health education until we had the class for a few weeks. And then we had sex education as a part of the health course of the PE class that we had. And again, it wasn't very inclusive. I want to say they really only teach you how a woman can get

pregnant. And basically, that's it, the sex, organs and reproductive system. Sometimes he would go into a little bit of detail like when a woman can get pregnant, they can still get pregnant during their period. And that's basically it. It seemed like some very informative things that he was telling us. But again, thinking back on it, you realize that it was mainly two gendered males and females that you're always thinking about. And they never talk about the emotional aspects of it either. And there was literally no discussion at all as far as disability. (Stacy)

Brandy reflected on how school sex education failed to give her social and communication skills that would have helped in relationships later in her life.

I realized that sex ed in high school does a lot of fear stuff. So, I felt very afraid of a lot of STIs. But one thing that I lacked was the ability to communicate, especially with people I was hooking up with, about my boundaries ... I think [my struggle with communicating to sexual partners] is a combination of not being explicitly taught self-advocacy in childhood and kind of struggling with that in general. I'm a certified people-pleaser, so that you know just all of those things together I think, really came together to influence some not so great decision-making on my part.

Jude echoed the other two participants in their desire for more comprehensive, inclusive sex education in public school. Jude added how the exclusion of non-heterosexual information left them without key information that would have been helpful given that they are queer and non-binary. Aside from PHSE, Jude's school system stopped providing physical accommodations and support once their acquired disabilities became less visible:

[There was] absolutely no queer representation or no disability representation at all [in school sex education]. I think everyone at least in my class did not have a physical disability that was visible or apparent. So, it just wasn't at the forefront of anyone's mind...

People were really good when I had these physical indicators of injury, but once those physical indicators were gone, like I still have- I developed a neurogenic stutter... and my memory was still pretty awful, and I could do assignments but I needed more time. But I could do all the things, and thankfully a lot of it came back, but once the physical indicators were gone, it was like 'Oh, Jude's

healed, like Jude's fine' when I was not fine by any stretch of the imagination. So yeah, it was this really weird mix of like physical indication versus invisible disability plus not wanting us to sue the school system [for the injuries] and my mom being a special education teacher and trying to keep me on track. So, it was a lot all wrapped up together, which, like, had some very interesting implications for, like, how people handled everything ... like, once all the physical indications of disability were gone [the accommodations were gone too].

Mixed Parental Guidance

Although Stacy, Jude, and Brandy had similar feelings about their school-based sexual education, they had different experiences with family sexual socialization. Stacy's parents were caring and held opinions about dating or sexual behaviors, but they did not communicate or converse about PHSE topics with her. There was no conversation even when she experienced concerning changes in her menstrual cycle.

I did not learn much from my family. My dad tries to tell me about how emotionally I should only deal with people who make you feel good and things like that. But, like, to have [a sex] conversation with my dad, just is like- it just didn't happen. Not that I don't trust him, but we don't have that kind of relationship where I could just talk to him about sex. And then my mother, she's funny too, like we just don't talk about it. But there was an incident where I was, like, seeing a boy and I was about 17 and it was a hard, toxic situation. So toxic that, like, I had skipped my period for a whole month and we weren't having sex or anything like that. But it was close to the point where [my mom] felt like, 'Oh, you haven't had your period.' Like, I had gone to the nurse and then she told me that I should tell my mother. So, I told her and she was so upset with me. And we went to the gynecologist and she put me on the pill. That was literally the whole thing. Like I was fine after that, but it was such a stressful situation. And it was a toxic situation. It took a toll on my body and I just did not have my periods that month. And so, it was a really scary and hard situation, but me and my mother, we didn't really talk much about it at all. She just put me on birth control and then that was it. Yeah. So, my parents did not really give me a lot of sex education.

Brandy's parents did not have conversations about sexuality, but they provided resources for her to learn from and safer sex mechanisms, like condoms and birth control, when she needed them:

I remember, my parents are very passive people, and my sex ed at home consisted of coming home from school one day, and I found, like, three books on my bed about sex. They were great. They were really good resources, I think one of them was published by the American Pediatrics Association. One of them was more informal, and had, like, illustrations in it, and I don't remember what the other one was, but it was pretty much understood that I could ask any questions that I needed to, but my parents didn't want to start the conversation...

I got the depo shot and then started dating my high school boyfriend, who I later had sex with. I remember my mom found condoms in my dresser, and she was like, "Hey, just wanted you to know I know you've had sex. We don't need to talk about it," and I was like, "Great."

In contrast to Stacy and Brandy's lack of communication from parents about sex, Jude had an open, communicative relationship with their mother when it came to personal health and sexuality. Their mother grew up with no PHSE communication in her family, so she made the active choice to be open with Jude when they were ready to have those discussions.

My mom was always very good about having those conversations, if and when I needed them, or when I had questions she answered them. I don't really remember what those questions were, but she was always very receptive and happy to answer them in developmentally appropriate ways.

Feeling Separate from Peers

Although this was not a part of Stacy's PHSE story, both Jude and Brandy felt separated from their peers because of disability-related health outcomes. Brandy explained how delayed puberty was a symptom of her Crohn's disease, so when her friends' bodies and hormones were changing and they were becoming interested in dating and romantic relationships, she felt behind:

I was undiagnosed for so long. I had an extremely delayed puberty, and I think that that was a huge influence on my sex education, because I felt very behind all of my peers. Throughout high school especially [I felt behind because] I didn't get my period until I was 16, and that was a time where I started hearing sex talked about more around me. So, there is kind of like that disjointedness, I guess, where I was dealing with all of these health things and it was causing my puberty to be delayed. I felt like crap all the time. Just no energy. I couldn't really keep any nutrients down. And then all my peers were talking about sex like it was this fun thing, you know, and I was just, like, I don't see anywhere that fits in my life just because of all the issues I was dealing with, so that that I think is really important when it comes to my journey with all of that is just being very physically behind my peers developmentally.

Jude experienced almost the opposite when they went through puberty before their peers. Although their puberty was not related to any diagnosis, early breast development led to being sexualized by peers, particularly boys, and Jude turned towards their hyperfixation on academic achievement to mediate anxiety. Jude self-identified as autistic and having ADHD and explained how “it was kind of like the chicken or the egg thing”: hyperfixation on school work helped ease the anxiety about sexuality development and peer treatment, but their sexuality development and academic success caused unwanted peer treatment that led to anxiety.

The sexualization that came from like little teenage boys who thought that they were being funny and made the comments around like, “Oh, did you get a boob job?” I think at that point in time academic validation became that much more important because I wanted to be seen as more than just like my body, which I think is really interesting...

It was an awful cycle of being perceived as like a woman in a way that was very restrictive and made me want to achieve highly, but I was already achieving highly. So it was just like this awful circle, until, like I broke like, and I never felt comfortable with how people were perceiving me from a gender perspective.

Jude and Brandy demonstrated connections between disability and sexuality development in different ways, illustrating the bidirectional links between these processes. Sexuality development can be influenced by disability symptoms, as Brandy discussed, just as disability symptoms can be influenced by one's sexuality development experiences, as Jude discussed. The interaction between disability characteristics was also apparent in the second story type, "Experience is the Best Teacher," that is described below.

Failure of Medical Providers

All three participants described various failures of medical providers, specifically doctors and nurses. Each had doctors that provided unclear or incorrect information regarding their diagnoses and how their sexual or health related circumstances may be affected. Participants' inadequate healthcare experiences for sexuality were also tied to inadequate healthcare broadly. For example, Stacy explained how her journey with birth control began with a doctor providing her with a "one-size-fits-all" advice model that was not actually helpful in reality for people living with diabetes:

Like with the Depo shot, I noticed that I had to use a lot of insulin...If I want to get back on some kind of birth control, I would have to do the trial and error and just see what's right for me. As far as [doctor name], my OB-GYN, she was telling me the shot is like the best thing for a diabetic and it's amazing. It's like it's a one size fits all or something like that. She was basically telling me I should have been able to perfectly live with the Depo shot. And that was not correct at all because my blood sugar was so high for the longest time, and I realized that it was [because of] the depo and I had to wait three months for it to get out of my system. And so yeah, a lot of things where- a lot of these doctors they think it's like a one size fits all for everything that comes with diabetes and even the nurses when I felt like my feet were hurting or tingling, she would tell me, "Oh, that's not like that's weird." That's not something that I've ever heard of before. But I've talked to other

diabetics and they're like, "Oh yeah, like you might want to make sure you're doing better, like you're keeping up with your insulin because that could be the start of neuropathy in your hands and feet." And so yeah. Like when you ask those kinds of questions, they think they just give you an answer that they gave everyone else, but it just does not work that way...

I feel like in health care settings, it's a little cut and dry. They tell you what they tell you in bulk. They told me to stay away from pastry, stay away from all this stuff only on good occasions, like happy occasions when you want to eat things like that. And so, when I actually looked up, there was like Beyond Type One that's like a website for type one diabetes like Nick Jonas was like a part of it or something like that. And so, I did learn a lot from it. However, it was like a source that I didn't find from an actual doctor.

Unhelpful information from doctors about sexual health mirrored dissatisfying medical experiences about disabilities. Jude experienced misdiagnoses that led to not receiving helpful treatment options.

I was very, very anxious. So, I was on anti-anxiety [medication]. In hindsight, it was like a lot of it was probably ADHD that was terribly misdiagnosed. They also almost misdiagnosed me with borderline personality disorder, because I was describing kind of like, not the highs and lows, but like more or less the highs and lows of ADHD, where it's like I super hyper focus and like I don't have any energy. And they, like, they didn't ask good enough probing questions to like, get at any of it, cause like I had great grades like I was like, despite all these injuries like I still had like A's and B's, and like as a child, I was a perfectionist like very stereotypical, like female presenting ADHD that no one caught, because that's not like how we perceive like ADHD in children because all the studies are based off of like small boys. So, the medication helped a lot with like, my, like, the anxiety that came alongside ADHD, but like I still was always kind of like, have like this little bit of anxiety, because, like, I wasn't actually being treated with what I needed to be treated for.

When visiting the doctor for medical advice about painful penetrative sex, Jude received heteronormative information about solutions for penile-vaginal sex that did not

apply to them, like using condoms and unclenching vaginal muscles. They attempted the process of IUD insertion and withdrew consent mid-procedure due to pain and did not get an IUD. After negative interactions with doctors, Jude experienced a turning point in their story when they realized that there were other paths to finding PHSE information that were more specific to their sexuality development. Jude has not returned to gynecologists' offices since because they were able to find helpful sexual and gender information on their own.

Have I been to a gynecologist since? No. Should I? Yes... So, yeah, I think, just like all in all, there is like lack of affirmation of like sexuality, gender, or like experience in general prevents people from wanting to go to the doctor, which then leads to future challenges with health, because you're not engaging in preventative practices like pap smears, blood, tests, etc, etc, etc. So, you don't wanna go to the doctor and then, like you're potentially screwed later on, because you could have caught something earlier. And I know that, and I still don't go, so I think that speaks volumes.

Brandy explained her "pattern of distrust of doctors" throughout her interview. It began in her adolescence when she questioned how her diagnosis of Crohn's disease would affect her ability to have children and her doctor responded: "Why are you thinking about having kids right now? You're in high school." Then, when she went on birth control, her nurses did "everything in their power to make it the worst experience possible".

Interviewer: What do you mean in their power?

Brandy: So, my doctor prescribed it, but it was always the nurses that would administer the shot. And they would do things, so I would go by myself to get the shot without my parents, and that was just kind of at a convenience, not because I didn't want them there. I would go, and the nurses would use the largest needle possible. I didn't find out until I'd already been getting the shot for 2 years that it could go in my arm, and you didn't have to use, you know, a 16-gauge needle, which

is a massive needle. They would require that I get the shot done in my thigh, so they made me get undressed in order to take this shot and they used a huge needle. Any time I requested to have the shot [then] a couple of days earlier or later than the exact date that was 3 months past the other one they'd make me take a pregnancy test, or they tell me I'd have to come back and do it another time. So, just things like that made the experience awful.

She hypothesized how the reactions of nurses and doctors could have been due to the southern United States cultural context, which she perceived as unwelcoming to sexually active young women. Whatever the reasoning, she confided that it felt like she “was being punished for needing something” which led her to stop raising questions to medical providers and seek answers herself.

Actively Seeking PHSE

Because teachers, family, and medical providers lacked PHSE information that was relevant to their lives, all three of these participants sought out their own answers to questions and sexual/health inquiries. Jude’s turning point (as described above) was when they realized that authority figures, specifically doctors and medical care providers, could not give them all of the information specific to their sexuality development. Brandy had the same pattern of distrust with medical care providers that solidified her inability to rely on them as sources of PHSE.

Similar to Jude and Brandy, Stacy explicitly connected her lack of PHSE in school and from doctors to her needing to find her own answers regarding sexuality and health. She described early in her narrative a time she asked a teacher about periods while in a sex education class and he had dismissed the question altogether. This experience started her on a path of not being able to discuss her sexuality development with authority figures. Stacy’s thoughtful reflection made her turning points, or narrative climaxes, that much clearer upon analysis.

As far as sex education, everything that I've learned, that I've known about, is something that I've

had to learn on my own. It's not something that I've learned even like in [school] ... Although I didn't learn that much about disability and sex education [growing up], what I have learned on my own has been pretty good. I tried to take everything one day at a time. I just do what I can and not think too much about what could happen if I don't take care of myself... My experience is that I do what I can with the information that I'm given because I seek out that information.

Finally, the internet was an educational tool in all three of these PHSE journeys. Jude discovered gender and sexuality information through YouTube videos and other internet platforms. It was on the internet that they learned about trans health, non-binary identities, and sexual activity options, like engaging in kink, for individuals with varying abilities.

I ended up consuming more and more information [on the internet about] like kink communities and like trans communities, and like different abilities, just like so I had all those tools in my toolbox, like, if someone ever were to need them. Sometimes they have been super necessary and helpful, and sometimes it's like, why, why do I know this thing? It's cool that I know this thing in case it ever comes up? But is it ever really gonna be necessary? Probably not. So, yeah. So, a lot of informal sex education existed for me... I was able to find a majority of what I needed in some way, shape, or form. I just had to get really, really creative about the avenues in which I searched for those things.

Stacy also found a helpful community online of people with her same diagnosis. They were able to give her advice about birth control options and outcomes, which her doctors proved to be unaware of.

I had to learn a lot of what I know about my disease through other people on Facebook and on Twitter. I found a really good community on Twitter about having diabetes...I found [useful sexual health information] from my type one diabetes groups. And so, they talked about different birth controls you can use as a type one diabetic.

Experience is the Best Teacher

Now, I think I'm very educated, but that came from experience and from asking questions that I didn't even know how to ask at the time when I was being educated. I didn't...like, nobody educated me enough to find the questions or know what questions to ask or know what questions were important. So, I think now, I mean, it's taken many years and sexual experiences to actually figure out how to navigate sexual relationships and just being smart and safe and stuff. I think so now I'm at a point that I'm happy with. (Amie)

In the second story type, three participants learned about sex and personal health through experiences with others, or vicariously through others, or after an experience happened and each participant raised questions. This is different from the “Self-Guided Journey” story type because participants were not actively seeking sexual knowledge in order to educate themselves. Additionally, where participants who experienced the “Self-Guided Journey” described themselves as the main characters of their story and having turning points where they took initiative in their sexual journeys, participants who described the “Experience is the Best Teacher” story type seemed more passive within their stories, soaking in the things that happened to them and around them. Personal, shared, and others’ experiences served as “teaching”, or lessons on PHSE. Their friends, siblings, romantic partners, and media were important characters in their narratives. Alice’s reflection encapsulates the role of others in PHSE: “even though my school didn't teach me that much like the media and the people that I'm surrounded by taught me like a ton.”

For the participants who described this story type, their disabilities were woven into their stories, though not as apparent as those from “The Self-Guided Journey”. None of these participants highlighted their disabilities within their narratives during formal sex education. Rather, the influence of disabilities emerged towards the middle and end of their interviews when describing experiences that they later learned from. Describing their disabilities and

symptoms near the end of interviews showed how participants who described this story type had not considered previously how their disabilities impacted their sexuality development; in contrast, in “The Self-Guided Journey”, participants had clear reflections on the intersection of disabilities and PHSE experiences. In this way, formal education was not nearly as helpful in their disability lives as lived experiences.

Unhelpful School Sex Education

If sex education was present in school, it was not sufficient to equip participants with the tools/social skills they needed. Formal education was conceptual and did not provide practical guidance for navigating the challenges of sexual and romantic relationships. Insufficient school PHSE was one way that the “Experience is the Best Teacher” story type was similar to “The Self-Guided Journey”.

One participant did not receive any school-based PHSE. Alice described how her class “got to the first day [of formal PHSE] when they were talking about the organs. And then our heater broke in our school and it was the end of the semester, so we just never finished the class.” Although Alice did not receive any formal PHSE, she hypothesized that it would have been abstinence-based:

I went to a Catholic middle school, so I'm pretty sure they would have not been like, “Go and do your thing, just be safe.” I'm pretty sure it's not what the Catholic Church then or I'm sure now is really preaching. I'm sure it would have been, “Hey, here's all these things so you know about it, but you need to wait until marriage because that's what's expected of you.” I'm pretty sure that's what I would have been taught just because I went to a Catholic school.

Early in her interview, Amie proposed that more comprehensive PHSE would have been helpful to her as she managed her disability:

I think a lot of people with ADHD and other disabilities might not have the social skills to adapt to, like, navigate that type of situation. . . And [what is being taught in school] I mean that's not

really helpful when you have to figure out what to do in an awkward situation. I think that that's really important and that there should definitely be some education on that, especially for people who might struggle because I think anxiety sometimes causes me to just shut down when I'm in an extremely uncomfortable position. And just like maybe something I'd be able to do when I wasn't super anxious. I'd be able to navigate that situation, but if I'm super anxious about a situation, it becomes a lot harder to navigate my way through a situation.

Reactive Discussions with Family Members

Conversations with family members, particularly parents, occurred in response to sexual situations instead of proactive discussions before participants became sexually active. This contributed to the narrative of “Experience is the Best Teacher” as participants were having sexual or personal health related experiences before having discussions around what those experiences may be like. Amie, for example, described her first conversation with her mother about periods after she got her first period:

But anyways, so yeah, very little sex education at that point. Then once I got my period, because my mom got her period when she was a junior in high school, she got hers really late, so she didn't think that she's going to have to talk to me until eighth grade. So, she hadn't talked to me about it. But then like after I got my period, I went and talked to her about it and she explained all of that and what to do with tampons and pads.

Then, Amie had a similar encounter with her mother after engaging in sexual activities:

Amie: I mean, like once I started having sex, and once my sister started then my mom- Like, sometimes my mom would just say to be safe. She put us on birth control and stuff. But yeah, not much. No. I mean, we didn't have conversations much about other things besides just, you know, be safe.

Interviewer: Okay. And those conversations came up after- after you started having experiences? So, like your mom talked about periods after you got your period?

Amie: Yes.

Interviewer: And about sex after you've had sex?

Amie: Yeah.

In another story, Gabrielle described indirect sexual communication with her parents and conversations after she became romantically involved:

Like in middle school and we didn't, it was not like, alright, we're gonna sit down and we're going to have this like my parents were, like, they're kinda like easy-going. Not easy-going but, like, they pay attention and care and look at what we're doing. Like, I have a younger brother who was also deaf. Yeah. It's just like they were just like No, I didn't say anything till later unless I started talking- until I started talking about guys [and dating] ...

The conversation of sex in general, like it was indirect. Like when we were just talking or we'd be watching TV and it'd be like jokingly. My dad [would say] "That's what she said". Or like jokes like that. So, we understood the concept of it because of that.

Alice had similar, comfortable communication with her mother, but after having experienced dating and beginning sexual activities, like kissing and fondling:

I think around like my sort of figuring things out and like freshman year in high school, like, I'm sure my mom and I were watching something and she's like, "Do you know how this works?" And I was kinda like, "Yeah, but you can kind of give me the run?" and she gave me a very quick rundown on how it works, but it's a very quick thing just because I don't think it was really that uncomfortable for her but for me I just learned about it. It was a very uncomfortable conversation to be having with my mom as a 14-year-old girl who was very new to the whole thing. Like she's been obviously more open about that now as I've done stuff [with my boyfriend].

Vicarious Learning

In addition to personal experiences, these participants learned about personal health and sexuality vicariously or socially from siblings and peers. Gabrielle spoke about not being "the

sexual type” in high school and learning about dating once her friends were romantically involved:

I didn't really, like, [I wasn't] the sexual type. Like I just kinda didn't think about that. I was more focused on my schooling studies, like, I had my friends. I got a big group of friends and I had guy friends too, but it wasn't like a big deal to me. But then I guess around junior year is when I started getting interested in [romantic relationships], you know, because of my friends. I don't know if it was like peer pressure necessarily, but it was just like, 'Okay, I'm getting older, like, I'm about to go to graduate.' Like, I don't know. Like, I feel like just learning from others is what helped me the most understand how things work.

Similarly, Amie's sister began dating before she did and her curiosity led her to raise questions:

Interviewer: And then so was she just, [your sister] was just around and you ask questions or-

Amie: I feel like it was more of her telling me stories I didn't really need to know. But I had questions about those stories.

Interviewer: So, hearing about her experiences?

Amie: Yes. And then Just being curious. Like how does that work? Like what did you do? Like Are you pregnant? Like stuff like that.

Personal Experiences

Participants who described this story type had personal experiences that taught them about their sexuality overlapped with disability symptoms.

Relationships and sex “clicked” for Alice as she entered high school and her peer group began talking about sexual taboo topics more openly. Once she began dating, she experienced anxiety, panic attacks, and eventually developed an eating disorder. She had to then learn how to communicate and respond in sexual scenarios once her disability symptoms arose. One example Alice told was about a time when she was in a car with her boyfriend and he attempted to kiss her:

So, my system was just overstimulated and he was trying to make a move [to kiss me]. And I was just like, and I basically was like staring at his joystick and he was like, “Are you okay?” And I was like, “No you need to drive or distract me because I think I'm starting to get an anxiety attack.” So, if we're driving and I didn't really know what was making me anxious because I was like, “Oh, maybe it's the ice cream or it's just this kid [trying to kiss me].” Then he was like, “Hey, am I the reason you're anxious? Like you're afraid to do anything physical with me”. And I was like, “Yes, honestly like I am because this is intimidating. I'm not even sure how I feel about all this. Like this is all happening very quickly.” Like he came over to my house and we hung out, made out and I was just kinda like, I don't really enjoy this. And I was like If this is what kissing and making out is like, I thought this was supposed to be nice and magical and I'm not feeling that at all.

Amie reflected on how her unique combination of anxiety and ADHD symptoms made giving and asking for consent challenging. Consistent with previous research (McCarthy & Thompson, 2010), consent can be a problem for people with disabilities because individuals may not have the cognitive understanding as to what consent is or why it is important in sexual interactions, or they may lack the social comfortability to ask or give consent while in sexual scenarios. During youth and adolescents, people with disabilities need to be taught what consent is and provided with strategies of helpful, accessible ways to ask for/give consent. For Amie specifically, communicating about personal boundaries was uncomfortable during sexual scenarios:

[With my] combined anxiety and ADHD, I think there was a part of being scared to ask questions and then a part of not really being observant enough about, you know, like, I don't know, just not putting enough focus on the sex education that I did receive -the little sex education that I did receive ... It's kind of depressing, but I feel, like, with my anxiety, I kind of struggle to speak up when maybe I didn't have any interest in a guy. Like if he's touching me or something [I don't like] and like I just, like, run off or take off and not handle that in a correct way, where maybe

somebody else would have [handled it differently] because they would have said, “Screw you!” or something like that and said I’m just like, “Oh God, what do I do?” Just, you know, not handling that correctly necessarily.

Gabrielle’s personal experiences with disability and interacting with others diverged from Amie and Alice’s experiences. She explained how, even though she was Deaf, having cochlear implants allowed her to “pass”, or appear more able-bodied, and hear more. And while passing did not directly affect her sexual experiences, Gabrielle explained how she came from a “socially open home” where her parents normalized talking to others about her Deafness:

When people asked me about it, I’m very like, you know, big on wanting to tell everything about it ... I see myself as normal. If you were to put it- like not normal. But when you go out like yeah, like people are like they’re like, Oh, you’re deaf? Like I just got a new job on campus and my manager didn’t know for like two weeks. Like I told him, he was like, “What!” Then I was like, “Yeah, I was like, I honestly just wanted to wait to see how long you’d have to figure that out. I thought you would have noticed.”

Influence of Media

Like the participants in the “self-guided journey,” various media platforms served as educational tools for relationships and dating for these participants as well. For Gabrielle, the media’s influence was a continuation of socially learning from friends over an online platform. She also explained how shifts in societal messaging and cultural changes set the tone for the type of media she consumed:

We had like people started- because we had the school dances and like there was Instagram and Snapchat became a thing. So, people were posting stuff and then high school people started to get into alcohol, underage drinking and drugs. So that comes out like people post stuff about that ...

[The media is] definitely more influential now like definitely since 2020 with all the queer and the LGBTQ awareness and all that, which I fully support. But like all that definitely makes a big

difference with all sexuality and learning about that. Because now it's like education too. It's being a big influence on that as well because people are trying to figure out how to properly teach it without, you know, with [university] doing the whole pronoun thing. Now, that's a whole big deal. I feel like that's definitely a big change.

The influence of the media continued in Alice's interview. She described how 'smut books' and porn taught her about personal grooming and sexual activities. Learning from the media was not always positive, though, as it enforced gendered stereotypes and contributed to her disordered eating.

I've gotten more experienced with, I've watched a lot of different YouTubers or different people because people are getting more comfortable about the conversation topic and talk about what things to have, when things don't have, what things you think are good for it but are, and how to properly take care of yourself down there. So, I am very aware of that. And I'm trying to, I'm in a pretty good place, some pretty good rhythm with that now ...

I'd watched a ton of media. I read a lot of smut. It's what it's called, I guess, like smut books and stuff like that. I watched porn as well, which gave me kind of graphic yet unrealistic descriptions of what things would be like.

While Gabrielle and Alice reflected on how media impacted the PHSE journey, Amie's story did not include media influences. This was one way that her journey diverged from the others within the same story type.

Personal Health Matters More

The third story type, "Personal Health Matters More", reflects the experiences of one participant, Cecelia. Compared to other participants and story types, Cecelia appeared to be in the beginning stages of her journey with PHSE. Romantic and sexual relationships with other people had not been priorities to Cecelia; in contrast, from a very young age, personal health was

a top priority in her life. At seven years old, Cecelia was diagnosed with a brain tumor and grew up consciously trying to avoid comorbidities.

Sexual Information Was Not a Priority

Cecelia shared that she had not acquired sexual information. She described herself as not open or ready to learn about sexuality:

I feel like if I'm not open to be receptive to learning about it and it's not my top priority, then that's just kinda where a disconnect could be in it. So, if I'm not ready to learn about it, then I just won't worry about it. So that's probably also why I just don't have so much information about it because I'm not asking questions either.

Not seeking out or being receptive to PHSE put Cecelia at the beginning of her PHSE journey.

Where other story types presented narrative climaxes and turning points, Cecelia's interview revealed that she was in the early stages of learning about PHSE. Her narrative truly showed how sexuality is *not* a linear experience where everyone develops at the same time and pace.

No School Sex Education

Her formal education in school settings included personal/general health, but not comprehensive sexual information.

Cecelia: We took like general health and high school, but more so focused on drugs, I guess, and alcohol usage within those classes.

Interviewer: So, they didn't talk about like periods or pregnancies or safe sex?

Cecelia: No. Not really.

Familial Support

Cecelia did report open communication with her mother and support with personal health goals from sisters. So, even though their conversations were not focused on topics like sexuality, Cecelia felt comfortable and open when communicating with her family members.

Interviewer: What about have you ever had those kinds of conversations with your family members?

Cecelia: Kind of with my mom, I guess. Like I have, um, three other sisters. It's like they've talked about periods and stuff, but that's something that's part of one of my health issues is that I don't really get that, so I don't focus on that aspect of it. Then that's just about it. None of us have boyfriends, so our minds don't focus, right to like sex and safe sex techniques because that's not our main focus, I guess.

Her sisters were also not currently dating, so they were also not a source of direct or indirect learning about sexuality or romantic relationships. Cecelia's sisters were, however, sources of "influence and encouragement" on her personal health.

I guess none of them have ever had a boyfriend. So, nothing really like dating wise, I guess. I guess like for my sisters, I've learned about the menstrual cycle and stuff and just because they get it. So, they've kinda told me like, oh, this is what to expect or this, and that, that's what should be happening. Then for my health-wise. My sisters are all pretty healthy. And luckily they don't have much medical stuff. And so, they'll help teach me different things about like what's the best choice on what to eat and let's go to the gym together. We are active together, I guess.

Prominence of Disability

Cecelia was diagnosed with a brain tumor in childhood and worried about comorbidities over the course of her life. Because of this awareness, she developed open communication with doctors and family members, and learned to advocate for herself in medical settings. Although her disability did not directly guide her sexual education experiences, it did influence her attention and care to learning about personal health.

So, I guess personal health started at a pretty young age just because when I was diagnosed with cancer, I was only seven. And so, prior to that, I had gone to doctors and like I struggled with weight problems. And so, I started to like, take control of my health then to try and combat

gaining weight. And then later found out that I was diagnosed with cancer. And then I guess just from there, I started taking health into my own hands and trying to figure out, well how can I decrease the chances of getting other diseases and how can I better help myself overcome the disease I already had.

Two Ears, One Mouth

One participant experienced the final story type, which was named after an in-vivo code that explained his view on PHSE: “Two Ears, One Mouth”. Similar to “Personal Health Matters More”, the participant experiencing this final story type did not prioritize sexuality or dating even though there were supportive influences that provided PHSE knowledge, like family members and peers. However, contrary to “Personal Health Matters More”, “Two Ears, One Mouth” held themes of learning about sexuality and dating during adolescence. This story type also differed from “Experience is the Best Teacher” because formal and informal avenues of PHSE information provided Drew with enough accurate knowledge; however, he has not needed such information in his personal life. Instead, Drew prioritized his religion, well-being, and quality of life above romantic or sexual relationships.

[PHSE information] was a lot of in one ear out the other sort of a thing of like in a sense like denial, kind of like, “Okay, I’ve already heard this before, let’s move on” type of a thing... I’m definitely the person that I live by the model we have two ears and one mouth sort of a thing. So, listen before you speak.

Drew held confidence and satisfaction in the amount of PHSE he had acquired over time, but he has not had much need for it because dating and sexuality are not among his top priorities. He explained how he took in and adsorbed PHSE information during his adolescence. Internalized ableism and “special” treatment were also hallmarks to this story type that were not present in other participants’ journeys.

Dating and Sex Were Not His Top Priorities

For Drew, dating and sexuality have not been top priorities. He acquired PHSE from multiple sources and had access to open conversations about things like puberty, dating, and sexuality; however, he did not seek out information or raise inquiries of his own.

I'm also very strong in my religious beliefs ... So, I've kind of always prioritized that above everything and said, You know, I'm not even going to really like, I take [relationships and sex] to heart, but I'm also like- it's a little lesser priority over my religion and my religion is weighted anyway, that's going to hold the value over it ... truthfully I'm just prioritizing myself.

Peers with Similar Priorities

Drew described his friend group as having the same priorities as him. This meant that they were not focusing on relationships and sex, and he was less prone to peer pressure because he was not presented with it.

I would say friends that share the similar viewpoint to me, of just like [dating and sex] is not super important, like we're not going to really engage in it anyway, like, to a good extent.

Positive, Supportive Family

Drew also described having open conversations with family members that equipped him with knowledge about dating and sexual activities. He felt comfortable in these conversations, but he was not the one seeking or applying the information.

I definitely had the at-home talk to like not just, you know sex-related. Just, you know, you should be or might be experiencing [puberty changes] and you can talk to us. One thing I will say about my family is that we are very close, very integrated, you know, we're a very tight knit family. So, my parents expressed from early on, you know, talk to us, you know, we've all been through similar experiences that we all go through the same life development and all that. So, you know, be free and willing to talk to us about whatever you're going through and we can help you out or we can reference you to something or whatever.

Present, but Unhelpful, School Sex Education

The formal sex education that Drew received was fear-based or abstinence only. He reported not retaining much information though because it did not apply to his life.

Essentially, [teachers] say abstain, but obviously, that's somewhat unrealistic as you go farther and farther into life, they're like just be protected with it. You know, how to use condoms and all that and just kind of know again, just know kinda consequences that could go with whatever you whatever actions you take.

But then throughout middle school, I guess it was kinda the same thing like you have just a certain education that I guess it's, I would say very similar to elementary school. Where, you know, the consequences here, the, the action that can be taken, the consequences that go with it. And how to protect yourself against STD or STI and all that sort of thing. Um, and again, I would say like, I've internalized that a little bit more but it was still like a, alright, this isn't going to pertain to me for a little bit.

As you go from middle school to high school, your sex education, like yeah, they still kinda teach it. My personal opinion [schools] don't teach it well. They definitely undervalue [sex education] and they can do a better job at it. But they do teach it.

Drew's narrative held the most prominent examples of internalized ableism, which affected his overall educational experiences, although he did not specifically describe whether it affected his PHSE. At first, he described how prominent his impaired hearing was during his childhood because his hearing aids were visible and he had additional support in instructional settings. He described receiving special treatment and being coddled by educators, family, and peers.

Especially when I was young, I would definitely say I had a special treatment like all throughout elementary and I would say especially as I got to like middle school...I did have a hearing aid and all of that, especially up until like seventh grade at least. And not only that, but throughout

elementary school my teachers would have some sort of necklace/microphone I guess, but it was like a very fancy necklace [with a microphone]. So, when they spoke, it literally went directly in my ear like somebody would just be talking at a normal volume... It was basically to the point where like all my classmates knew about it. Like all my classmates knew that it kind of pointed me out to everyone. I was never bullied or anything, like, I never had that negative treatment, but it definitely made it to where everyone was like, “Alright, he has that. He's the kid [who can't hear]” sort of a thing. And I would definitely say that it impacted a little bit of just how some people treated me, like, again no one ever bullied me or anything. But they always kind of, I guess, even outside of the house, [everyone] coddled me.

Although he did not describe it affecting his sexuality development or education, internalized ableism influenced how Drew presented himself as he transitioned between grade levels. By high school, in an attempt to “pass” amongst his peers, Drew wore his hearing aids less often.

And I would say that looking back at it and I'll be completely honest with you, I never thought about this until actually just sharing this [in the interview]. But looking back at it, that might be the reason why when I went to high school, I just ditched my hearing aids. I didn't want to stand out. I just wanted to fit in and conform and all that. Well, I kind of said to myself I would rather deal with only hearing 75% of the conversation and not standing out than having this advantage of hearing [like everyone else] ... I was known as the person that had the hearing aid and I kinda internalized it and the standing out sort of a thing.

The Absence of Sexuality and Disability Interaction

Finally, the absence of sexuality and disability intersections in Drew's narrative became apparent in data analysis. Although Drew explained his disabilities and how they affected his life and some experiences, he did not describe any time when his disabilities affected intimate or sexual interactions with others. Teachers, family members, and peers did not change the way they interacted with him due to his symptoms or diagnoses.

Having no interaction between sexuality and disability symptoms may have been due to the deprioritization of sexual relationships and Drew's ability to "pass", similar to how Gabrielle passed while using cochlear implants in the second story type "Experience is the Best Teacher".

Discussion

The findings from this study provide a glimpse of possible ways individuals growing up with disabilities learn about personal health and sexuality. Participants' experiences showed that, as is common in general populations (e.g., Davies et al., 2023), formal sources of PHSE information such as schools and medical providers did not provide accurate or adequate PHSE. When formal educators proved unhelpful and unsupportive, individuals looked toward informal support from family members, peers, and media. An added challenge for individuals growing up with disabilities was discovering how their unique symptoms interacted with their sexuality development. Disability symptoms played a role in individuals' sexuality development and intimate experiences with others. Disabilities also influenced ways that others interacted with participants. This study illustrates how varied disability characteristics inform young adults' journeys seeking PHSE information and expand on current research of sexuality and disability by giving further insight to diverse experiences of sexuality development of disabled adolescents.

Formal and Informal Sources of PHSE

Our findings show similarities between the PHSE experiences of people with disabilities and the general population. Unfortunately, exposure to poor or nonexistent sex education in schools, uninformed medical providers, and uncomfortable conversations with family members about sex are common experiences among youth (Davies et al., 2023). Participants in this sample had the added challenge of finding helpful and informed educators who could advise on the interaction of their sexuality development and specific disability symptoms.

Some participants described not having received PHSE in schools. When they did receive sex education, it was fear-based, largely focused on abstinence, and not inclusive. Similar to our

findings, in a longitudinal study from 2015-2019 in the United States, researchers found that 53% of female adolescents and 54% of male adolescents had received sexual education, and, of those who received sexual education, 81% of female adolescents and 79% of male adolescents reported specifically receiving “say no to sex” (abstinence-based) education (Guttmacher Institute, 2022). All of our participants expressed a desire for more universal, comprehensive PHSE from schools, which is consistent with previous research that found that adolescents want PHSE education that is focused on comprehensive sexuality (Formby & Donovan, 2020; Coll et al., 2018).

Having diagnosed disabilities adds an extra layer of context around PHSE experiences because there are other formal supports that provide health information specific to symptoms, like medical providers. Doctors and other medical providers were another formal way that individuals’ sexuality, development, and disabilities intersected. When participants had a more open dialogue with their doctors, they were more likely to ask questions and communicate about their disabilities and sexuality. Some participants described receiving inaccurate information from doctors and experiencing judgmental interactions with medical providers, which was particularly important to individuals who told “The Self-Guided Journey” narrative. These findings were consistent with previous research that explains how difficult finding a well-trained, understanding medical professional can be for the disabled population (Barbareschi & Wu, 2022).

For the individuals who experienced inadequate PHSE information from authority figures, like schools and medical providers, informal educators held great influence. Family members appeared in every story type, whether it was as helpful supporters or unhelpful, inadequate resources. Regardless of ability status, previous research has shown that family

members, especially parents, do not always know how to talk about sexuality development (Kaestle et al., 2021). This was apparent in multiple stories as some parents indirectly discussed sexuality or actively avoided sexual discussions. A lack of useful and accessible materials for informal PHSE that caregivers and families can provide disabled loved ones with is a barrier to PHSE for disabled communities. Even though literature with guides, advice, and practices about teaching PHSE exists for families of youth with disabilities (Fogel, 2021; Frank & Sandman, 2019; Nichols et al., 2009; Phelps, 2009; Couwenhogen, 2007), we hypothesize that such resources are not being used by caregivers because they are not disseminated widely from providers and are not entirely accessible. Our findings also showed the influence of siblings when it comes to learning about personal health and sexuality. Consistent with previous literature (Kaestle et al., 2021; Killoren & Roach, 2014), participants' siblings were supportive, positive resources for sexual information and sexuality development conversations.

Many participants learned about sexuality and the role of their disabilities in their sexuality from the media. Our findings add to the evidence of previous research that has begun to describe how media such as television, websites, and social media can be important educational tools for adolescents and young adults with disabilities during their sexuality development (Ahrens et al., 2023; Hole et al., 2022; Friedman et al., 2014). Our participants described media avenues to learning about personal health and sexuality development like reading books and pamphlets, using the internet to access pornography, and joining online organizations for people with their shared disabilities and symptoms. Our findings indicate that media remain important for people with disabilities and are influences in young people's lives.

The internet has the potential to help and harm young people depending on the reliability of web pages and content creators. Experiences with cybersexual violence victimization and

pornography use in adolescence can be associated with risky sexual behaviors, like lack of condom use, birth control use, and substance use (Rivas-Koehl et al., 2023). Online sexual health content that focus on PHSE for disabled populations exist, however not all media and webpages are accessible nor do they provide accurate sexuality and health information that serves the diverse needs of disabled adolescents (Ahrens et al., 2023; ²Crehan et al., 2023). So long as the information on web pages is accurate and developmentally appropriate, the internet could be a great source to aid in teaching children and adolescents PHSE that is more tailored to their individual needs, like disability symptoms and personal readiness. Guardians, parents, and influential adults also have opportunities to involve themselves in media consumption, through parental monitoring and open conversations, which can support healthy adolescent sexuality development (Rivas-Koehl et al., 2023).

Sexuality Development in the Context of Disability

The timing of when individuals learned about PHSE was just as important as the sources they learned from. Journeys to acquiring PHSE information were not linear nor did they follow a progressive developmental path. Contrary to prior research that suggests differences in timing of sexual experiences may not be significant for people with disabilities (¹Crehan et al., 2023), our findings clearly show how disability symptoms can influence the timing of readiness to receive PHSE. For example, Brandy's Crohn's disease delayed her puberty. Other participants, like Drew and Cecelia, were focused on their health and not their sexual or romantic relationships when they received formal PHSE. Individuals' disabilities informed their developmental journeys. Even if adolescents with disabilities receive comprehensive PHSE that is relevant to their needs, that education will not be helpful if they are not developmentally at the point where

such information would be applicable. Therefore, simply providing PHSE during adolescents is not enough – the timing of when it would be most appropriate must be considered as well.

Personal readiness and priorities were additional motivators for acquiring sexual information. While some participants were ready to receive PHSE information, others were not. These findings contribute to current literature on disability and sexuality by adding more context, examples of lived experiences, possible sexuality development trajectories, and identifying helpful vs. unhelpful ways adolescents with disabilities are experiencing PHSE. Our examples of diverse PHSE experiences are helpful in recognizing current barriers to accessing resources and pitfalls in established systems (ex: having some type of sex education in schools is not enough, especially when that education is abstinence-based and does not account for differences in sexuality development); our story types show similarities and variability in experiences between people at similar ages with different disabilities and personal characteristics.

Furthermore, where disability came into all participants' PHSE stories - and where it did not – suggested the extent to which participants perceived their disability interacting with their lives. For example, the three participants who told a Self-Guided Journey had clear reflections on how their symptoms and diagnoses affected their sexuality development and the way others interacted with them. Their PHSE stories included disability reflections from start to finish. This was not the case for all of the participants, though. When reflections on the intersection of disability symptoms and sexuality came near the end of participants' stories, it was more in response to probing questions rather than spontaneous as participants had not thought about the connections before. For example, in "Experience is the Best Teacher", Amie began the interview by sharing her story and experiences learning about sexuality, and only started tying her ADHD symptoms to sexual experiences near the end of the interview when she realized that her

experiences were intertwined with her symptoms. When reflections of the intersection between disability and sexuality development were not as present until the end of participants' stories, it was clear that they did not originally consider their disability to impact their PHSE journey. Although some disability symptoms have more impact on a person's life, diagnoses are only a piece to an individual's life and interact with every part of who they are - including how they develop sexually and interact with others. Our findings add to the current literature that emphasizes diversity in disabilities and experiences with sexuality (Barbareschi & Wu, 2022; Loeser et al., 2018). Specifically, our findings demonstrate how disability symptoms and personal characteristics impact individuals' sexuality development in different ways even when participants were in a similar age range and stage of life.

Theoretical Implications

These findings challenge dominant theoretical understanding of adolescent sexuality development by adding the complexity and individualized nature of disability. As discussed in the introduction of this paper, the most relevant theories to our study from both disabilities studies and sexuality research, as described above, are the social model of disabilities, crip theory of sexuality (McRuer, 2011) and the normative framework of sexuality development (Tolman & McClelland, 2011). The social model of disabilities provides a framework for crip theory of sexuality, so crip theory of sexuality will dominate this discussion.

Crip theory of sexuality converges and clashes with normative framework of sexuality development. Both frameworks propose that developing sexuality is a healthy part of development; however, normative framework of sexuality attempts to generalize the sexuality developmental experience, whereas crip theory of sexuality considers a more individualized path. The sexuality developmental proposal set forth by of the normative framework of sexuality

leaves room for assumptions of typicality and suggests that what is common for sexuality development is the “correct” way to develop. However, people at the same age do not always experience the same trajectory of sexuality development, as shown in the findings of this study. Sexuality development occurs across the lifespan, but the timing of changes in physical, behavioral, and cognitive aspects of sexuality cannot be generalized due to unique, individualized characteristics and circumstances.

Both crip theory of sexuality and normative framework of sexuality were relevant to understanding and interpreting our findings; however, neither theory completely captures the reality of sexuality development for disabled people. The findings from our study push against normative, linear, and progressive sexuality development because disabilities and individual symptoms can either speed up or slow down sexuality development. Our findings are similar to how crip theory of sexuality urges societies to reconsider the sexual rights and pleasures of people with disabilities, though it adds a developmental component to the theory (McRuer, 2011). Currently, crip theory of sexuality has been influential for policy and advocacy purposes. What is missing from the theory, though, is a sexuality developmental component that could potentially guide researchers and health professionals in the varied and healthy ways that disabled people experience sexuality development. Researchers could build and strengthen this young theory by integrating the sexuality development of people with disabilities. A developmental addition to crip theory of sexuality could be achieved by considering and investigating developmental processes and trajectories of disabled populations from childhood to older adulthood. This would not be an attempt to generalize or set development expectations for the disabled population, but rather highlight multi-directional pathways of sexuality development. Adding a sexuality development component to crip theory of sexuality would

guide researcher questions, studies, and work that focuses on empowering disabled voices and experiences.

The findings and implications from this study should push researchers to expand crip theory of sexuality by adding a developmental focus. Normative framework of sexuality offers an opportunity for crip theory of sexuality to further develop and grow into a fuller theoretical tool. Under the additions to crip theory of sexuality, sexuality development of people with various disabilities should be considered a healthy, non-generalizable part of life with individual trajectories. Expanding the theory would be beneficial for multiple domains of research, like gender studies, sexuality studies, intersectional research, etc. (Mery Karlsson & Rydström, 2023).

Social Policy Implications

Linearity in sexuality development should not be expected nor should it be expected that people at the same age are in the same stage of sexuality development. Our participants expressed how unhelpful the timing and expectations of sexual milestones were, and how useless some of their PHSE was due to the fact that it did not affect their life at that time since they were not physically and/or emotionally ready for sexual relationships. Therefore, sexual education in formal settings should not assume someone's readiness to receive PHSE information. A universally designed sexual education would be most beneficial to younger populations, regardless of ability status. Universal design refers to an environment that is accessible and helpful to every body, regardless of ability status. Universal design principles have been applied in sexuality surveys and research for disabled individuals (Wilds, 2022), though this research area is not expansive and needs further exploration. Our findings reinforce the need for more existing efforts for universally designed PHSE. A universally designed PHSE would provide

everyone with accessible, useful knowledge that they can apply in social and romantic relationships. Accessible, helpful PHSE that includes instruction about varied abilities would empower individuals to learn at their own pace a wealth of sexual information that pertains to both the general population and their specific needs. The next step for researchers should be gathering ample amounts of sexual information, desires, and lived experiences of people who grew up with or acquired disabilities, and then distributing accessible and helpful information to supporters and resources for all disabled communities.

Individualization within disabilities and disability presentation exists. Medical providers, especially those providing diagnoses, need to have more PHSE information for individuals with disabilities, and recognize that a one-size-fits-all model is unrealistic and not helpful. Research has shown that medical providers have mixed comfort levels and little knowledge about the sexuality of people living with disabilities (Crehan et al., 2023; Holmes et al., 2014; Shindel et al., 2010). To fix this problem for medical providers and patients, providers that interact with disabled communities should be using researched experiences of sexuality development and advice that is directly from the communities they serve. Formal educators, specifically school teachers, need to have more education when it comes to children with disabilities. There should not be an assumption that children with disabilities are asexual nor that they develop at the same time as every other child.

Limitations

As with any research study, my study held some limitations. The sample was mostly white (87.5%) and composed of women (75%). Qualitative narrative analysis traditionally has smaller sample sizes in order to preserve the nuances of participants' stories and not generalize experiences (Josselson & Hammock, 2021). However, since this study had eight participants, it

did not capture all possible experiences of learning about PHSE of individuals growing up with disabilities. Additionally, all of the participants experienced mainstream schooling, which meant there were no experiences shared from individuals that went through Special Education programs in public schools or home-schooling. Since non-mainstream students experience different classroom settings and lecture content, their experiences learning about personal health and sexuality are likely to have a different set of complexities compared to those in our sample (Treacy et al., 2018; Löfgren-Mårtenson, 2012). Future researchers should strive to capture additional PHSE narratives from a more diverse sample of individuals with disabilities.

My sample had various types of disabilities represented and it did not include anyone with an intellectual disability. We recognize that not including individuals with intellectual disabilities limits the variability of PHSE experiences. Previous literature has specifically highlighted the experiences of sexuality among people with intellectual disabilities (Schaafsma, et al., 2015; Löfgren-Mårtenson, 2012; Hayashi et al., 2011). Future researchers interested in the intersection of PHSE and disabilities should include lived experiences of people with intellectual disabilities in their sample.

Conclusion

Emerging adults with disabilities were not represented in classroom PHSE, but they experienced agency in seeking out information from additional sources such as media and families. Although our findings presented individuals' agency in seeking out and acquiring helpful PHSE information, it should not be left to the individual - especially during childhood or adolescence - to educate themselves on sexuality and health related topics. Young people growing up with (and without) disabilities need to have helpful educators from multiple outlets, like families, medical providers, peers, schools, etc. Additionally, this study presents

opportunities to expand theoretical understanding of sexuality development in the context of disability. Inclusive design for sexual education is not only an issue for people with disabilities and, if implemented across the United States, would greatly benefit younger generations' sexual knowledge.

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Appendix I

Notes for Interview Researcher

Research Question 1: How are emerging adults with various types of disabilities experiencing personal health and sexual education?

Research Question 2: What do the stories of emerging adults with various disabilities suggest about the satisfaction of their experiences of PHSE?

Explicit information: exchange of PHSE information, lack of PHSE information, when and how information is delivered, periods of growth/transitions between points of learning

Implicit information: how they tell their story (things they include or don't include), differences in tone and speed of speaking, body language

Interview Protocol

Introduction to interview: Thank you for agreeing to be a part of this study. With this research, I want to learn about how people with various types of disabilities experience Personal Health and Sexual Education.

I want you to think of your journey with PHSE as a story, where the first chapter is your first experience with sexuality and personal health and the final chapter is where you are now. Could you tell me about your experiences with this, starting with your first experiences with your own sexuality and how and when your knowledge of PHSE has changed over time?

Additional questions:

- Tell me the story of ways you experienced personal health and sex education
 - Could you tell me about your first experiences with your own sexuality?
 - Who taught you about sex education?
- Tell me about ways you learned about your own personal health or sexuality in general

- Who taught you?
- When did you learn?
- Thinking back to the idea of your journey as a story, how many chapters would yours have? What would separate each section? (AKA- what would the turning points be?)
- On a scale of 1-10, how satisfied are you with your experiences with personal health and sexual education?
 - Tell me why it is high/low/mediocre?
 - If high: why?/what experiences made you this satisfied?
 - If low: what could have been different to make you more satisfied with these experiences?

Based on context of individuals, possible questions:

- If no formal education about PHSE: have you learned at all about your own personal and sexual health?
 - If so: where? From who? How? When?
- How does your disability fit into your story?

Appendix II

Investigator Memo 2 (After First Reading)

Originally, I had made the note that this may have been a self-guided journey; this was not the case now that I have read this again. This participant had reactive conversations with her mother (and stepdad to some extent), learned alongside her friends and then became a peer educator herself, and learned with her boyfriend as they experienced this for the first time together. Her school clearly failed her in that they decided not to continue with ANY type of sexual education after the HEATING BROKE the first day! I found that to be wild! She was able to speculate that they would have taught abstinence-based education because it was a Catholic, all-girls school, though.

After listening to it again and reading the transcript, I forgot that she brought up gendered stereotypes! That was the first thing that stuck out to me because it had slipped my mind. There was a lot going on in this story though, beyond just the story type. She spoke a lot about stereotypes in media and society, specifically about how women should “hide” or “keep secret” their sexual desires/activities and then how women *should* look (skinny/thin). There were biases coming from her family as she went on dates – her stepdad gave her self-defense lessons before going to the drive-in! I think this observation goes beyond the scope of the current study, but could be something to keep in mind for a potential secondary analysis.

Related to her disabilities/symptoms: she talked about casual relations that brought anxiety attacks, how OCD tendencies dictate her life everywhere except from the bedroom (so maybe looking for some escape from her reality there?), and how her disordered eating mixed with medication played a role in healthy and unhealthy relationships and stereotypes. There was more interaction between disability symptoms and sexual experiences that I will pay more attention to during the next read through.

I think it is important to note that I really enjoyed this interview and related to this participant. Although we do not have the same story nor experiences, I saw myself in some of the same contexts as her. I am wondering if this is why I thought this interview was so intriguing? Her story was her own, but I do want to make note of seeing myself in some of what she said because I actively want to separate that bias I have moving forward.