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Youth and Parent Perspectives on Sexual Health Education for People with Intellectual Disabilities

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Abstract

Youth with intellectual disabilities face barriers to receiving sex education including the lack of educational tools accessible for multiple cognitive and emotional learning styles. We conducted exploratory research to gather input from a diverse group of youth with disabilities and their guardians about needed learning modalities and sexual health content areas. Three focus groups were conducted with youth ages 17–28 years ($n=14$) and three with parents ($n=16$). An applied thematic analysis of the transcripts resulted in three structural codes related to topics of greatest interest for youth sexuality education, teaching tools and methods, and needs for ancillary parent education and support to help youth access information and health care. We identified a total of ten themes associated with the three structural codes. Next steps will be to create educational resource prototypes that are responsive to focus group input for testing in further research.

Keywords Intellectual disabilities · Sexuality · Exploratory research · Learning tools · United States

Introduction

To develop and implement best practices in sexuality education for youth with intellectual disabilities, it is critical to hear directly from them. As a result of limited sexual and reproductive health (SRH) educational resources, people with intellectual disabilities often lack vital information about sexual health, as well as the skills needed for decision making and navigating relationships [1, 2]. Compared to neurotypical youth, youth with intellectual disabilities are less informed about sexuality and relationships and have fewer exposures to social situations that can support them in understanding social norms outside the classroom [3]. People with intellectual disabilities are also more likely to report that they want more sexuality information than they currently have [4]. Inequities in SRH information and care

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can result in disproportionate impacts of unplanned pregnancies, sexually transmitted infections, and sexual victimization on youth with intellectual disabilities [5–9]. Intersections of race, class, gender, and other social categories compound these inequities [4].

Thus, there is a need for sex education content and specialized learning tools for youth with intellectual disabilities, including content that will support youths' rights to self-determination and meet their diverse learning needs. We used focus group research methods to gather input from youth with intellectual disabilities regarding what SRH content areas they would most like to learn about, and their preferred teaching methods and educational tools to convey SRH information. Given the significant role that parents play in the lives of youth with intellectual disabilities, we sought their perspectives as well. Our primary research question was: What sexuality information do adolescents and young adults with mild to moderate intellectual disabilities, and their parents, report as most needed? Sub-questions within this focus were: What content areas are most important? What learning resources and modalities are desired to convey this information, and in what contexts do they want new learning tools to be available?

Sexuality Education Resources for Youth with Intellectual Disabilities

As a normal part of growth and development, youth and adults with intellectual disabilities experience sexual desires and behaviors as diverse as that of the broader population [10, 11], yet there are barriers to ensuring they receive developmentally appropriate SRH education [12–15]. Reviews of SRH interventions for people with intellectual disabilities have described the key features and limitations of existing interventions [8, 16–20]. These include the lack of theoretical foundations and rigorous evaluation methods to assess program efficacy. Reviewers have also noted that educational programs lack comprehensiveness by often focusing narrowly on abuse prevention [17], although Black and Kammes [16] observed a shift in programming scope from abuse prevention to broader relationship-building skills after 2010. Comprehensive sexuality education encompasses a spectrum of topics such as sexual and reproductive anatomy, puberty and adolescent development, consent, relationships, contraception and pregnancy, among others; and should support learners to build content knowledge and apply related skills [21].

Additionally, youth input has been lacking in the planning of sexuality education programs [16]. There are some exceptions, including the Healthy Relationships on the Autism Spectrum (HEARTS) intervention [22], Elevatus, and National Council on Independent Living curricula. Existing feedback from adolescents with intellectual disabilities and their parents has repeatedly stated the need for tailored sexual risk reduction interventions such as adapted instructions and teaching tools [23]. In a review of 11 sexuality education programs for people with intellectual disabilities, Travers and colleagues [19] identified the use of methods such as lectures and didactic presentations, interactive methods such as Q&A, role play, guided practice, and group discussions. Social stories are an additional method that has been researched to some degree. A multi-method study to develop four social stories to be integrated into a sexuality and relationship training program concluded that professionals at adult care facilities could effectively use them with women with intellectual disabilities [24]. Further research on the benefits of using social stories shows they can help individuals and parents prepare for and manage opportunities to engage in healthy and satisfying sexual

lives [25]. However, no studies have systemically evaluated program components to assess their degree of effectiveness.

The Role of Parents

Parents play an important role in facilitating sexual education for youth with intellectual disabilities. They are often responsible for providing information on relationships and sexuality and may need and want guidance on how to provide age and developmentally appropriate education for their child with intellectual disabilities [26]. Yet, research has found that many parents do not receive training about the sexual development of youth with intellectual disabilities, and perhaps consequently, do not feel confident or communicate needed information to their children [27, 28]. Further, Eyres et al. [29] outline parents' stated needs for clear communication between schools, service agencies, and parents about what information is communicated and what educational strategies are available for learning sexuality information.

Research has suggested parents of youth with intellectual disabilities are concerned predominantly with keeping their children safe from risks associated with sexual behaviors or from sexual abuse. In a study assessing parents' expectations of a sex education program for youth with developmental and cognitive disabilities, participants denied that their child is interested in sex and expressed fear of their child being pregnant or sexually abused as main concerns [23]. Parents, along with youth with developmental and cognitive disabilities, professionals, and healthcare providers, expressed the need to include parents in the development of sex education programs, and to create a program for parents to have access to the information to work with youth at home. A 2012 study by Pownall et al. [30] found that mothers of youth with intellectual disabilities prioritized discussing safety issues with their child more than other sexuality topics, whereas mothers of youth without disabilities found peer pressure, contraception, and STDs were considered most important. These findings underscore the need for parents of children with intellectual disabilities to receive education and training on facilitating more comprehensive sexuality education to their children.

Advocates for Youth has provided guidance for parents on supporting the sexuality education of youth with intellectual disabilities, specifically in assisting youth to identify credible, accurate sources to use when seeking information on their own and routinely initiating discussions on sexuality to make conversations easier and more comfortable [31]. They recommend providing parents with a combination of training on how to teach sexuality and relationships to youth and including parents in the development of their child's sexual health program. Yet we were unable to find examples in the research literature about parents' inclusion in the development or planning of sexuality education curricula and resources. We sought their perspectives for our current project in order to address this gap.

Study Purpose and Context

The purpose of this study was to collect data about learning needs and tools to support the sexual and reproductive health of youth with mild to moderate intellectual disabilities. The results provide exploratory information from youth with intellectual disabilities and their parents, to add to the knowledge base described above. Further, the results will be used

to inform a larger project to create new learning tools for youth with intellectual disabilities and their parents. This larger project involves a multidisciplinary network of experts in intellectual disabilities and sexuality education gathered to develop and test innovative sexuality education programming for youth aged 16–24 years with mild to moderate intellectual disabilities. An additional advisory board of adolescents and adults with intellectual disabilities, parents of youth with intellectual disabilities, and advocates was created to provide ongoing input and accountability for the work of the network. Together these groups make up the Sexual Health Innovation Network for Equitable Education with youth with intellectual disabilities– otherwise known as Project SHINE. Project SHINE is located, and this research was conducted, in New York City.

Our specific population of focus was youth ages 16–24 diagnosed with a mild to moderate intellectual disability as defined by criteria from the fifth edition of the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM-5) [32] and the American Association on Intellectual and Developmental Disabilities [33]. We chose to focus on youth with mild to moderate intellectual disabilities because they are best suited to utilize SRH services and benefit from health interventions that require some degree of independence and ability to consent. People with mild to moderate intellectual disabilities have abilities to communicate and socially function with limited to moderate ongoing support [34].

Methods

Design and Participants

We conducted an exploratory research study using focus groups to collect data and applied thematic analysis methods to understand what adolescents and young adults with mild to moderate intellectual disabilities, and their parents, perceive as the most needed content areas for sexuality information; what learning resources and modalities are desired to convey this information; and in what contexts they want these learning tools to be available. We chose to conduct focus groups because of the opportunity they create for peer interaction and sharing. We thought it was likely that at least some youth participants would have little to no direct experience of sexuality education they could use as a reference point when responding to questions about interests and needs in this area, and thus that hearing peers' experiences could be helpful in making the concept of sexuality education less abstract for some.

The Project SHINE network members (including self-advocates, and interdisciplinary professionals from social science, education, law, social work, and public health) provided input about recruitment, measures, data collection, and data interpretation by reviewing study flyers, discussion guides, and preliminary findings and by giving input into the use of focus groups as a data collection method (i.e., group sizes and compositions). Such an approach has been recommended as a best practice in health care research, especially with underserved groups [35]. Further input was provided by Project SHINE Advisory Board members (people with intellectual disabilities and parents/guardians of people with intellectual disabilities, and others working in the disability field; these groups are not mutually

exclusive). To be clear, SHINE network and Advisory Board members were not themselves participants in the research.

We recruited youth and parents from the client base of five New York City organizations serving racially and ethnically diverse people with intellectual disabilities. Organizations were part of the Project SHINE Network. Youth with intellectual disabilities were purposively recruited for three, mixed gender focus groups: one each for youth aged 16–19 and 20–24 years who were referred by service providers, and one for youth aged 18 to 30 who were affiliated with a self-advocacy organization. Inclusion criteria for youth were: (1) 16–30 years old, (2) currently receiving supportive services related to a diagnosis of mild to moderate intellectual disabilities (with or without a co-occurring condition), (3) living at home or in residential treatment, (4) able to speak and read in English; (5) able to participate in a video call from a private location without supportive assistance from another person, and (6) able to verbally communicate in a group discussion about the topic of sexual and reproductive health. A total of 14 youth participated who ranged from 17 to 28 years of age. Nine identified as men and five as women. All identified as having an intellectual disability. Six youth were living with a guardian or independently and eight were living in a residential group home. Gender, racial and ethnic identities are shown in Table 1.

Parents were purposively recruited for three focus groups, one facilitated in English and two facilitated in Spanish (directly, not through an interpreter). In New York City, immigrated youth who are not native English speakers are engaged in school-based English language learning, and conducting focus groups in Spanish is not necessary to reach these youth. However, parents who have immigrated as adults may have ongoing limited English proficiency and we wanted to capture this cultural variation in our sample. Staff members from the Project SHINE Network organizations were given a recruitment flyer to give to clients who they knew met the inclusion criteria. These staff also received a recruitment instruction sheet/script to explain basic information about the study. Inclusion criteria for parents were: (1) age 18 or older, (2) parenting (or the legal guardian of) a person between ages 12 and 30 with a diagnosis of mild to moderate intellectual disability, (3) able to speak and read in English or Spanish, and (4) able to participate in a video call from a private location. Sixteen parents (not matched to the youth participants) participated in focus groups, seven were caring for youth between the ages of 12–15 and nine were caring for youth with intellectual disabilities between the ages of 16–19. Gender, racial and ethnic identities are shown in Table 1.

Interested youth and parents were phoned by a research team member within five days of initial recruitment in order to obtain informed consent. Youth with legal guardians provided signed informed assent, and their guardians provided signed consent (electronic signatures

Table 1 Youth and parent gender, racial and ethnic identification

Characteristic	Youth n=14	Parent n=16
Gender identity		
Woman	5	15
Man	9	1
Race/ethnicity		
Latinx	4	11
Black	5	4
White	4	1
Multiracial	1	0

obtained via a confidential DocuSign account). A total of 48 prospective participants were referred to the research team; of these, 33 provided consent prior to the focus groups and 30 total youth and parents participated. Table 2 presents a summary of the focus group compositions and sizes. In the context of the COVID-19 pandemic, groups were conducted virtually via Zoom with two facilitators, one to lead the discussion and the second to assist individuals with platform features if needed. Focus group participants received a $40 electronic gift card as an incentive after the group was completed. Information to determine eligibility and demographics (age, race/ethnicity, gender) was collected at the time of recruitment.

Measures and Data Collection

A structured focus group guide [36] was used to facilitate discussions about the kinds of sex education resources and topics that could be helpful to youth with mild to moderate intellectual disabilities. We created one guide for youth groups and a separate guide for parent groups, however they were parallel in the flow of topics with minor wording or question differences. For example, youth were asked, "What would help you learn new information about how your body works?", whereas parents were asked, "What kinds of educational materials would be helpful to teach youth or would help you talk to your children about sexual development and anatomy?" Groups were asked to discuss their opinions about what youth with intellectual disabilities should know about sexuality (with probes about anatomy, reproduction, birth control, and relationships). We probed about specific topics given best practices for comprehensive sexuality education, but also provided opportunities for focus group participants to name other topics of importance. Participants were also asked to share ideas about ways to best convey the information with probes about the use of written materials, visual and hands-on tools, and interactive games. In the groups with youth, we screen-shared slides with visual aids to augment verbal comprehension and used closed captioning [37]. Instructions to group participants were to answer all questions about "youth" with the definition of "adolescents and youth ages 16–24 years old with an intellectual and/or developmental disability." Therefore, all subsequent references to "youth" should be understood in this way.

Groups were conducted via Zoom, lasted 90 min, and were conducted by two facilitators. Participants were asked to remain on camera during the group and use the chat only when necessary to ask for any help or clarification to ensure engagement in an interactive dialogue. The groups with Spanish speaking parents were conducted in Spanish by fluent facilitators (i.e., not via an interpreter). Positionality of the researchers was presented to all groups at the start of discussion, which was described in relation to the mission and purpose of Project SHINE (also provided on their website).

Table 2 Focus group composition summary

Group Name	Sampling Strategy	Number of Participants
Youth Group 1	Youth ages 16–19	6
Youth Group 2	Youth ages 20–24	4
Youth Group 3	Intellectual disability self-advocates, ages 18–30	4
Parent Group 1	English speakers	7
Parent Group 2	Spanish speakers	3
Parent Group 3	Spanish speakers	6

Analyses

Verbatim transcripts in English were created from the Zoom recording closed captioning transcript feature. Research staff downloaded and cleaned these transcripts for accuracy by reviewing the text in conjunction with the video recording. Zoom did not support closed captioning in Spanish, therefore, transcripts for the two groups conducted in Spanish were created with a two-step process: one research staff member created a verbatim transcript in Spanish using the recording of each group, and then a second staff member translated the transcript from Spanish to English. Responses were labeled with participant IDs to facilitate comparison of interview participants' responses. Transcripts were then uploaded into Dedoose software for coding. We treated the six youth and parent transcripts as a single dataset because the discussion guides for youth and parents were closely aligned with one another.

We analyzed each transcript using applied thematic analysis methods as described by Guest, MacQueen, and Namey [38]. First, three different coders (one assigned to each transcript) conducted structural coding of the focus group transcripts, segmenting text using a total of nine a priori codes aligned with the structure of the discussion guides. These codes were outlined in a codebook with a code name associated with a particular discussion topic, a brief definition, and scenarios for use. Because the discussion guides for youth and parents followed a similar flow of topics, we used a single codebook for both transcript types. We used a fractured approach to applying codes – for example, if content related to "parent educational needs" was discussed in relation to a question that did not ask about parent needs directly, the "parent needs" code was still applied to the content. Structural coding allowed us to find content within each transcript that should be further analyzed in service of Project SHINE's most immediate priority: creating accessible sex education tools for youth with intellectual disabilities and accompanying resources for parents.

Next, we analyzed the segments associated with three structural codes (SRH topics for youth education, teaching methods and tools for youth, and parent educational needs) to identify emergent themes. Identifying repetition – by multiple participants within a single group as well as across groups – was our primary strategy to define themes. After an initial reading of all the transcript segments (exported from Dedoose into summary documents), three coders met to discuss their perspectives on emergent themes and identify a set of thematic codes. Finally, the coders used Dedoose to apply the agreed-upon thematic codes to the transcript segments. Table 3 displays the themes associated with each structural code. In the Results section below, subheadings correspond to the structural codes and associated themes. We present quotations that illustrate each theme.

Results

SRH Topics for Youth Education

Four thematic areas emerged from both youth and parents related to what they thought was most important for youth to learn about: (1) Anatomy and puberty, (2) Consent, boundaries, and sexual victimization, (3) Reproduction and birth control, and (4) Relationships and dating safety.

Table 3 Structural codes and themes related to sexuality education needs	Structural Code	Themes
	Topics for youth education	1. Anatomy and puberty content addressing both physical and emotional changes was prioritized by youth and parents 2. Learning about consent and boundaries highly valued by both youth and parents to minimize risks of victimization 3. Youth highly interested in learning about reproduction and birth control 4. Youth highly interested in learning about relationships and dating safety
	Teaching methods and tools	1. Need to be useful across contexts 2. Visual aids in general are highly valued, but preferences on specific vary 3. Hands-on tools would support teaching and learning 4. Games and scenario-based/storytelling learning are promising for both group and individual education
	Parent educational needs	1. Workshops would be utilized by some parents but may not work for all 2. Individualized, professional support to parents and their youth should complement workshops and may be preferred by some

Anatomy and puberty content addressing both physical and emotional changes was prioritized by youth and parents

The most frequently discussed theme in both youth and parent groups was the need for youth with intellectual disabilities to learn about sexual body parts and how they work, including pubertal processes and the mechanics of sexual behavior. This was true across genders and youth ages. Youth participants across groups named needing to know about genital shapes and sizes, managing body hair and odor, and menstruation, and that changes are a "normal" or "natural" part of growing up.

Learning about emotions emerged as an area of needed education in conjunction with bodily changes and sexual functioning. For example, this Youth Group 2 participant shared:

> I think that [youth with intellectual disabilities] need to know more about how [body changes] feel. And that, because I know certain people, especially those who are on the higher functioning end of the spectrum, struggle with hypersensitivity, and to educate them on how those feelings are normal, but you know how to be more responsible with those feelings and managing them, in a healthy, physical and safe way, focusing on like arousal and controlling it and being aware of the sensations that come along with that… …Yes, as well as how to manage and control them properly so that, that person can get the most out of the quality of life and in a relationship or marriage.

Parents also raised learning about anatomy and sexual functioning as a top concern in both English- and Spanish-speaking groups. They highlighted the importance of medically accurate vocabulary; as a Parent Group 3 participant shared:

> I think the first thing you should do is inform the person that you are going to work with, let's call him a boy in this case, of his organs first, because sometimes they know what organs they have, what their function is, what care he should he have for his body, for his sexual organs, what kind of cleaning he needs.

Masturbation was also specifically raised in all parent groups as an important area for education; as a Parent Group 3 participant said, "They touch and it's a stimulation for them." Parents in Group 1 discussed concerns that their children had received shaming messages about masturbation, with one saying, "I know some people would say we shouldn't be teaching our kids to masturbate, but our kids are, I think, more likely to be ashamed, and not realize this is natural, and that disturbs me." Menstruation was also named as an important topic because as one Parent Group 1 participant put it, "They should be prepared for when [menstruation] happens. Sometimes it happens later, sometimes it happens very early and can be difficult for a younger child to manage and understand."

Congruent with what emerged from the youth groups, parents also expressed concern about connecting social-emotional learning to bodily changes and sexual functioning. For example, a Parent Group 1 participant said:

> I think part of the education program other than showing the body parts, is that our children are going through hormonal changes, and as a result they are going to have certain reactions, certain needs and desires, and I think whatever education we do for them is to make sure that they understand these feelings are normal, and just give them some kind of, not parameter, but how to externalize those feelings, how to manage those desires, without having to infringe on somebody else's sexuality.

Learning about consent and boundaries was highly valued by both youth and parents to minimize risks of victimization

Youth and parents both expressed a lot of concern about understanding how to give and receive sexual consent. Fears of victimization or of being accused of perpetrating a sexual offense arose as the predominant motivating factor. This also arose for youth across all ages and from both young men and young women, as exemplified in the following exchange between participants in Youth Group 2:

> Female youth: [We should learn about] how to identify abuse, sexual abuse and relationships, and who to call. I think that there should be a lot of education on that.
> Male youth A: Number one rule, and this is something I learned from my mother, and this is the number one rule, and this is final: When a girl says no at any time you will immediately back off. You can talk about it, you can say, 'Listen, I'm sorry. Can we talk about this? I don't know why you said no, are you not ready yet?' But the moment she says no, back off. The number one rule is you have to back off. Period.
> Male youth B: When the person says no.
> Male youth A: Right.
> Male youth B: When they're not ready, you have to be able to be accepting.
> Male youth A: Even, even if you're on top of it, ready to do it.

One Parent Group 1 participant described the need for differentiating boundary violations that are abusive and ones that are not, saying, "There's being touched where you need to call the police and then there's being touched where it's an annoyance but you can let that go. They really need things explained in a more granular way." Parents wanted their children to know that consent was theirs to give and their boundaries should be respected, with one parent stressing that this was especially important because, "I find a lot in special education that they really teach our kids to please others…it is very important for them to understand that, yes, doing a good job of doing the right thing doesn't necessarily mean that they have to accept for people to do things to them as well. So, they need to understand that they too have to give consent for someone to touch them or do anything to them."

Concerns about the role of racial bias in accusations against youth with intellectual disabilities arose in Parent Group 1 as well, as exemplified in the following quotation:

> We talked about consent around the criminal justice system. You know, he went to a mostly white private school and he wanted to go to the fraternity parties, and I was like dude, if you're in a room with one of these white girls and whatever she says happened when you guys were in that room together, they're gonna believe her. Of course, they made them go through mandatory consent classes that they make all the kids go through and a lot of his thought was like, 'Oh my god, people didn't know that if a woman is unconscious, you shouldn't be kissing her?' But it was always, for me, around being mindful of the criminal justice system around consent […] constantly drumming into him, people don't see you the way you see yourself. They look at you and see a six-foot tall black guy with dreadlocks. And they're not going to [think], 'Oh he didn't mean to do that and maybe he just brushed against her butt.' They're going to assume the worst and so, you need to recognize that and be ready for that, before it happens.

Some youth and parents made more general statements about public versus private behaviors and boundaries without explicitly using consent terminology, but fear of being accused of sexual assault was still predominant. As a young man in Youth Group 3 stated, "You should also know the boundaries of what you should not do and what is [and] mainly to be aware of and be careful of. Around this time everyone's doing the 'Me Too' part and there's a lot of that on social media so you always have to be careful of what you do to anybody, women or men, and just be careful what to do 'cause you don't know what will happen and you just have to watch out for things…in a relationship or friendship or anything." A Parent Group 3 participant shared this concern related to masturbation for her son, saying, "I would redirect him to his room, you have to do something in your room, and he has to be there alone, and I try to redirect him to a more appropriate place for him. I try to redirect him […] to find privacy, to avoid whatever misunderstandings."

A Parent Group 1 participant summarized what she saw as key messages for youth with intellectual disabilities:

> We all have body parts. They perform different functions. One of them is to help us feel good. However, we don't touch anybody. We don't proposition anybody. We don't expose ourselves to anybody, and relationships take a while to build.

Youth were highly interested in learning about reproduction and birth control

Youth expressed interest in learning about pregnancy and a range of birth control methods. A female participant in Youth Group 1 described key education points as, "You should know about pregnancy. You need to take a pregnancy test. Like a woman, if they get pregnant with their partner and having a baby for nine months, or you skip your, you miss your period." Other youth in this group described wanting to learn about fertility ("the processes of checking in on sperm count, egg count"), condoms, and effectiveness of birth control methods ("We need every single thing for both genders and how effective it is, how to use it, how it works, like the pros and cons of all of them"). A participant in Youth Group 2 expressed a similar sentiment, wanting to learn "the risks and like the side effects of taking birth control, what kind of unpleasant or side effects was to be expected when you take it, so that you can make an informed decision of whether you think that's good for you or not physically."

Some comments from youth seemed to reflect messages they received about risks associated with sexual behavior. In Youth Groups 1 and 2, youth used terms such as "consequences" and "dangers" when discussing sexuality, for example in the following exchange between Group 2 participants:

> Female youth: Well, sometimes when you have sex, I feel like you have to use like condoms and stuff like that. If you really wanted to, having a baby is fine, but you have to make sure that you're ready for it, you know.
> Male youth: Also, I think the dangers of teen pregnancy and abortions are very [important for] including in one of the topics for educating people.

Further, in reply to the facilitator asking Youth Group 2 participants, "What do you wish you had learned more about [when you were in your teens]?", a male participant responded, "Abortion…and having more education about those things to help you make practical decisions in the future, if you were to run into that situation."

Parents were more limited in their conversation specifically about reproduction and birth control. This may represent more discomfort with the topic compared to other topics such as anatomy, or that most were caring for male youth with intellectual disabilities. Parents more frequently mentioned the importance of learning about proper condom use than other birth control methods. But reproduction and pregnancy prevention were discussed in general terms as exemplified in the following quotation from a Parent Group 3 participant:

> How can I help him too when he has, because many have girlfriends and I say, how do I explain to them how to prevent pregnancy, in addition to infectious diseases, help them to also protect themselves that there is no pregnancy? Because it's a responsibility that not everyone is going to be able to manage. So, there are many situations within love that they are not going to be able to handle, so to explain to them little by little to avoid a future major problem.

Youth were highly interested in learning about relationships and dating safety

One theme that emerged from youth groups, but not from parent groups, was wanting educational content about the how-tos of dating. Youth expressed wanting to learn about how to call someone you like, ask for a date, what to do if someone breaks up with you, how to meet someone online, and how to know if someone likes you or wants to have sex. These topics are more in the social skills arena than sexual and reproductive health knowledge, and they arose repeatedly across all youth age groups and genders. A male participant in Youth Group 1 captured this in a nutshell, saying, "I suggest we need to establish [learn about] all the types of sexual relationships; like one night stand, decent dating relationships and relationships that can go even further." Another male participant in the same group said he wants to learn how to ask, "If you could go out with me, or do you want to date me, you know, those type of questions." A male participant in Youth Group 2 expressed wanting to know about whether somebody likes you and "how to interpret the verbal and non-verbal cues."

The following exchange from Youth Group 1 shows participants expressing a need for education about the progression from asking for a date to having a sexual relationship with someone:

> Male youth A: What about consent, if the person, if you ask the person to date you then the person might either say no or yes. Or they might tell you to wait for a bit because they have come out of a relationship, and they need a little more time. So, they might either say no, maybe, or yes. But you have to be careful not to push it because next thing you know the person might not be interested in you anymore.
> Male youth B: Yeah, I was saying that they [youth in general] should learn to not go immediately into that type of relationship, like, get to know each other more and everything before moving on to the next step because if you rush things your partner might not like it and it go downhill after, and fixing something like that would be difficult. So, they should know that it's always better to be patient and get to know your partner more.

One topic that emerged only in Youth Group 2 was how experiences of pornography could impact relationships. One male participant put it this way: "Another thing that I would say has to be prioritized is the difference between porn and actual sex." A second male participant shared, "Porn really shouldn't be something that you get into 'cause it could distort a lot of your views on sexual intimacy and relationships. [You should] educate more about pornography versus actual sexual intercourse and understanding what the purpose of [sexual intercourse] is, that it's more than just recreation, you know, you're bonding with someone on a very deep emotional level, and there's risks with that."

This same participant in Youth Group 2 expressed a unique concern related to disability:

> I also feel like that you have to really know your partner and know the person you know that you're married to or your companion on a deeper intimate level. You need to trust them. So, it can have communication, you know about sex and relationship should also be talked about more on how people should talk about that with their families and maybe even if their spouses or their girlfriends; learning how to communicate

about those because that's a very, that could be a very touchy subject, especially for someone in a relationship and in if they have a disability, of any kind.

Similar to the discussions of consent, safety and fear of victimization arose repeatedly in discussions of dating. A female participant in Youth Group 3 made reference to this when sharing key messages about dating and relationships, saying, "I would probably say taking it slow, don't rush into something right away. Then, like don't say I love you just yet, wait to get to know the person first and, like, be careful who you talk to there's a lot of sexual predators out there." Referring to educational messages, a male participant in Youth Group 1 said, "They should probably like describe the types of healthy relationships during dating… …Like sometimes relationships can't go too well and it can get abusive sometimes or it just may take a toll on you and something bad, might want to break up, stuff happens, just to try to talk it out with that partner."

Further, online safety was a specific concern, which was often expressed briefly as wanting to learn about "online dating safety" or "dating online is dangerous." For example, this female participant in Youth Group 1 said, "Also, it's hard to find [a date] right now, like this coronavirus. You gotta do online dating, it's really crazy to do that." However, this male participant in Youth Group 1, who said that someone you're dating should not "want your personal information such as your social security number," also outlined a number of his fears in more detail:

> Yeah, if you can't find a girl that you like yourself or if you like somebody, but that person has already been taken, you can always go to one of those dating apps on your phone or look on the computer. But I must warn you, you have to be careful with these dating apps, because sometimes it can turn out dangerous…Sometimes that person might be a gang member, or a serial killer, or a murderer. Sometimes that person might use that dating app to set up a robbery, or a killing. Yeah, and you don't want any of that. Because then it could end up in tragedy. You might end up getting killed or hospitalized.

Teaching Methods and Tools

During the course of the discussions, facilitators inserted questions about ways that youth with intellectual disabilities could be supported in learning about the different sexual and reproductive health topic/content areas. Therefore, input about methods, tools, and where/how to learn about sexual health information was elicited throughout the discussion. Facilitators would begin with open-ended questions (e.g., "If you wanted to learn about how the body changes during puberty, what would help you learn the best?") and then follow up to seek opinions on specific types of tools depending on the flow of the conversation. No methods or tools were discussed that were unique to one sexual and reproductive health content area or another. Rather, similar themes emerged across content areas, and were similar across youth and parent groups.

Educational tools should be useful across contexts

Youth and parents mentioned that new learning tools meeting the multi-modal and sensory needs of youth with intellectual disabilities should be useful across the contexts of school-based and workshop learning, one-to-one counseling with a professional, and at home as self-directed learning. One male participant in Youth Group 2 described, "I did learn from school, but it was mostly during like my counseling meeting that I would have. Yeah, that was the only place I learned a lot from knowing guys and how their body works and how women's body works and pregnancy." A Parent Group 3 participant said:

> I also think that it must be a combination between home and school […] because those are the places where our children spend most of their time. And also involve professionals. For example, in occupational therapy, it's the therapist that should give more information about the body and environments. I think we should involve professionals too. It would be a lot of different environments that we should take into account, but of course the home would be the priority.

Youth and parent participants also suggested tools should be available in both online and print formats whenever possible. "Make sure it's on multiple platforms like phones and laptops and all kinds of things, because [our children] access information at different times, through different platforms," said a Parent Group 1 participant. It was noted that availability of multi-modal tools would aid in the need for repetition of information and generalization of learning. As a Parent Group 2 participant explained, "As much as one speaks to [my son], by the morning it's already forgotten what one said, as children who have autism or other disabilities – it's difficult that they retain everything that someone says. So, one must repeat and repeat every day."

Visual aids in general are highly valued, but preferences on specifics vary

Youth and parents both said visual aids were crucial components of any sexual and reproductive health teaching tool. Illustrated diagrams and photographic images were both suggested as useful, especially for learning about anatomy, but opinions were mixed about which would be better, as demonstrated in this discussion from Youth Group 1:

Facilitator: What would be helpful to understand the ways people's bodies are different?

Male Youth A: Drawings and videos, like labels, I guess […] probably making it interactive to show the function.

Male Youth B: Or just show the words.

Facilitator: Should it be drawings or actual photographs with the different names of the body parts?

Male Youth C: Photographs.

Male Youth B: I would say you have to do like the scientific ones that actually show, like medical versions of them. And then the drawing version of them because mostly drawings are a better way to explain it, rather than the actual real pictures.

Female Youth A: I want to see the real picture, that's what I want to see.

Parents also had mixed opinions about illustrated versus photographic images. Some said their children may not engage with or be willing to ask questions about photographic images, while others said animations may not appeal to older youth. But in general, parents emphasized the importance of visual aids. The following quotation from a Parent Group 3 participant typifies this sentiment:

It's important in general for all our children, visuals, because even though they're verbal, visuals reinforce the learning [...] I would start with something basic, showing them parts of the body with their appropriate names, because sometimes one gives it a nickname and when difficult situations happen for them, it's difficult for them to express it as, how one would say in a complete sentence. They can specify a word, that's it, and one understands as parents, but if there is someone external that they don't know, it's more difficult for them to understand what they're referring to or what situation they are going through. So, for me, it would be good to have something visual that shows them body parts with specific names so that for a given situation if they are feeling some discomfort or if they feel something different in their bodies, to express it in an appropriate manner and that is understandable for [people other than their parents].

Videos were named as another important visual aid by youth and parents, for at least three reasons: (1) because they can show interactive processes, (2) because they can be viewed multiple times to reinforce learning, and (3) because they can be watched at one's own pace. As a Parent Group 3 participant explained with regard to the latter two points:

If you don't hear or understand what they said [in a video], you have the possibility to see it again and again [...] and then you can say to the child, 'how we saw in the video,' you can model how you would do such a thing, and the video stops and questions are asked, because each child will learn in a different way according to the disability, but in a way where you can also adapt to the rhythm of the child.

Youth participants suggested videos about dating, relationships, choosing a birth control method, and putting on a condom. Parents suggested videos would be useful for the same topics, and as a Group 1 participant explained, would be especially useful "to illustrate the whole dynamic of relationships." She continued:

[Our children] work very well with visual stuff so I don't know if anything, just audible or that you listen to, or anything that they have to read would really have an impact. I think it has to really be illustrated, again, through animation, for them to understand. I think it's easier for them to understand this whole concept of consent and understanding, okay, your rights and where my freedom begins or whatever that phrase was. So, I think that's probably the best way to go in that sense, you know, and they have to be reminded constantly reminded of it until they really capture it and keep it in mind.

Hands-on tools would support teaching and learning

In all youth and parent groups, there was agreement that hands-on tools, or the concept of a hands-on toolkit, would effectively support learning. If it was not mentioned spontaneously, the facilitators probed specifically about this concept, and while no participant disagreed with its usefulness, no one indicated such tools had been made available to them in the past. Moreso than did the youth participants, parents made suggestions for hands-on tools. For example, in Parent Group 1, the following suggestions emerged:

> Parent A: I think maybe like a model or a doll or something […] I would think that a visual would be a good thing, like, okay, this is how you put a condom on. So maybe like a model of a penis and a condom and how to put it on, or if it's a female condom, how to use it.
> Parent B: I would agree on having an actual human model.

A Parent Group 3 participant suggested, "That would be great if there was an application for our children, that would be like, for example, *what do you need to shower?* But it has to be a doll or figures obviously, not something so explicit. The child would choose shampoo or the towel. And tell the [body] parts also by their name, first the anus, what do I know [like a game]." Another parent in this group said a toolkit or bundle of different hands-on materials for home would be "informative and practical for the parents [also], and that the child isn't learning alone."

Games and scenario-based/storytelling learning are promising for both group and individual education

Further, tools should incorporate scenario-based learning such as story-telling and problem-solving. A Youth Group 2 participant suggested "social stories or role playing stories […] where it puts you in the scene, where you're filling in the blank, kind of like what would you do? Or giving the person a scenario especially and including visual aids in that as well. How would you react, how would you handle this? And then giving some multiple choice." This echoed a suggestion from a Youth Group 1 participant, who said, "scenarios could help with different – like with answers, like how they would react in the moment, or life in a certain point in their lives it might happen like that. That would be good."

Games were mentioned as a way to engage youth in conversations that can be awkward and hard to introduce without a context. A Youth Group 3 participant suggested a board game. Participants in Youth Group 2 considered the following ideas:

> Male Youth A: What I was thinking now that we brought the topic of role plays and scenarios, I was thinking of doing like a *Jeopardy!* themed type game where everyone could give an answer and you say, how close is this person to this answer?
> Male Youth B: That's actually not a bad idea, and that's interactive where you can get a lot of people involved, that could even be something that's going in a health class. […] Now here's an interesting question. What do we all think, would an individual sense be better, or would it be better to have it in a group scenario?

Female Youth A: I think it depends on how you feel about talking in front of a group, or if you're more comfortable talking one-on-one or even with like three people in the room […] because some people may feel uncomfortable about talking about either something personal or just in general, and they might just want to speak to someone alone.

Parent Group 1 participants responded very favorably to the idea of a game; as one said, "I think it engages them and makes them ask more questions." Specific suggestions were for a video game or something with a cartoon or entertainment component. One Parent Group 1 participant shared, "You know the thing that's difficult for them is to see the way that their actions look to other people. So I often will bring up scenarios and sort of gamify it, in keeping with social learning and social interaction learning." Another parent from Group 1 said, "When they're younger, books are good, but when they're older and doing a lot of their own things, it has to be something that presents the information more quickly – a video, or a game or something like that, that can hold their attention, because they're no longer sitting in our laps." Parents in Group 2 also mentioned using game-playing as a strategy to teach concepts to their children; as one participant said, "Them playing, they will assimilate [knowledge] better."

Echoing the above exchange from Youth Group 2, where youth discussed the use of games for group or individual learning, parents also suggested that video games could work well for youth who would find it challenging to learn about sexual and reproductive health in a group setting. For example, this Parent Group 1 participant discussed what she thought would best work for her son, saying, "My son is sort of ashamed and extraordinarily uncomfortable. You couldn't drag him screaming and kicking…to a group where there's going to be role play and talk about sex with other kids. For the kids who are more like him, a video game or something where they are exposed, they can just go on their own, would be better."

Parent Educational Needs

In the discussions about SRH educational needs of youth with intellectual disabilities, parents repeatedly raised that they, too, were in need of support and training to help them talk to their children about their bodies and sexuality because it was part of their parental role to do so. Participants in Parent Group 1 highlighted a particular need for parents to be educated about sexual orientation, gender identity, and gender expression, including transgender and nonbinary identities. They also mentioned needing help with the social-emotional aspects of sexuality in conjunction with information about anatomy and reproduction. As one Parent Group 1 participant explained:

For me the reproductive and healthcare part of it is so much easier – there's less emotion with it. Like for [my son] at least there was. Like you can talk about the practical, you have to use condoms because of sexually transmitted diseases, and how sexual health is just part of regular health and taking care of yourself. Like that stuff is much more cut and dried then around friendships and relationships and whether people like you or not.

Workshops would be utilized by some parents but may not work for all

Participants described wanting parenting workshops and support from professionals, although we heard this more from Spanish-speaking parents than English-speaking ones. This difference could be because resources to support primary Spanish speakers are scarcer and/or due to cultural taboos related to discussions of sexuality, as was suggested by the participants. As one Parent Group 2 participant said, "I believe that there should be more chats, but more than anything for us the parents…it would be an excellent idea that we as Hispanic parents have more chats and we open our minds up more on sexuality…We're not very open to sexuality like other cultures, so we need like a little bit more help in this situation."

Individualized, professional support to parents and their youth should complement workshops and may be preferred by some

Parents in Groups 2 and 3 mentioned wanting help from professionals such as therapists or shared past experiences getting support from professionals already connected to their youth, like speech therapists and teachers. One Parent Group 3 participant stressed the importance of both individual and group workshop support for parents, mentioning that "sometimes there are people, well I speak for my partner, are hard-headed, that don't want to go to these workshops" but would be open to talking with a counselor on an individual or family basis.

Discussion

Using qualitative research methods, we gathered ideas for sexuality education resources from 14 youth with mild to moderate intellectual disabilities and 16 parents. Four priority education content areas emerged from our focus group discussions: (1) Anatomy and puberty, (2) Consent, boundaries, and sexual victimization, (3) Reproduction and birth control, and (4) Relationships and dating safety. While the first two of these four content areas were priorities for both youth and parents, reproduction, birth control, relationships, and dating safety were predominantly discussed by the youth with intellectual disabilities. Some of the safety concerns youth share likely reflect conditioning from their parents and other adults in their lives. Our focus group participants identified visual aids such as videos and diagrams, hands-on tools such as anatomical models or dolls, and games and scenario-based learning exercises as most desired to support SRH learning. Such methods and tools can be used in combination with one another – for example, scenario-based learning can be embedded into a video, and anatomical models can serve as both tactile and visual aids – and as we heard from participants, should be made available for use across different settings such as home, school, and supportive services environments.

This study also found that parent and youth perspectives were closely aligned for topics of greatest importance as well as needed educational tools and strategies. Parents discussed their own needs for training about how to communicate sexuality information to their children, but the youth in our groups did not mention the need for the adults in their lives to improve their skills in this area. This could be because the youth focused more on their own ability to independently learn new information and ask trusted adults when needed. Further, while this study was not designed to specifically focus on cultural differences, we did find

that Spanish speaking parents with limited English proficiency (LEP) were very similar to English speaking parents in terms of their concerns and the importance they placed on youth receiving accurate and preventative sexuality information. What was noteworthy was those parents with LEP expressed far more concern about their inability to access Spanish language educational resources for parents including written materials and in person services such as parenting classes and support groups or workshops.

The racial diversity of this study's sample is rare in the literature. Our sample was too small to draw conclusions based on racial differences, but our results do show that parents are concerned about an increased likelihood of Black youth with intellectual disabilities being accused of a sexual offense or treated more harshly for a social boundary violation. All parents and many youth discussed their fear of sexual victimization and of being accused of sexual perpetration (both due to cognitive difficulties understanding consent, social norms and boundaries), but their vulnerabilities are enhanced by intersecting identities of race, gender and disability.

This study's findings align with and bolster a set of recommendations that emerged following a community needs assessment conducted as part of the Sexual Health Equity for Individuals with Intellectual/Developmental Disabilities (SHEIDD) project in Multnomah County, Oregon [39]. Based on a series of surveys and focus groups with youth (ages 18–21) with intellectual disabilities and their family and professional support people, the project's guidelines for supporting youth with intellectual disabilities include "think of teaching about body parts as a starting point, not the end point" and "make sure young people know their relationship, sexual, and reproductive rights." Furthermore, the guidelines call for "strengthening skills by teaching sexual health education in many ways, including videos, modeling, role-play, and one-on-one support" and emphasize the importance of communication, boundary-setting, and decision-making skills. As others have noted, incorporating multimodal teaching strategies is a best practice for working with youth with intellectual disabilities [17]. Games such as the SeCZ TaLK board game [40] and social stories [24] have shown promise in other exploratory research.

In the present study, parents expressed interest in building their own knowledge and skills to discuss SRH with the youth in their lives and in having access to resources they could use with their youth at home. Earlier focus group research studies with parents of youth with intellectual disabilities similarly found they were open to SRH education opportunities for their youth and keenly interested in building their own communication skills [29, 41]. Some, but not all, parents in our study expressed a desire for more support from the professionals providing services to their youth, which could entail providing direct counseling or education to the parent (e.g., a support group for parents of youth with intellectual disabilities) or referring the parent to trusted informational resources or tools (e.g., books and websites). There are multiple ways to implement a parent engagement practice for youth sexuality education, and our findings suggest that using a variety of methods could support engagement of parents who are diverse with regard to their attitudes, values, and learning styles as well as their children's specific disability.

The present study makes a unique contribution given that the research literature on sexuality education resources for youth with intellectual disabilities has included minimal reporting on formative or up-front input from youth with intellectual disabilities and their parents that can be used to design and develop resources. In fact, several scholars have noted that program and resource descriptions are often missing key information such as

the rationale behind design decisions, details on implementation of teaching methods and techniques, and evidence of their efficacy [18, 19, 42]. This study gathered valuable information about priority educational content and the methods and tools best suited to teaching that content, from the perspectives of youth with mild to moderate intellectual disabilities and their parents. It also prioritized recruitment of racially and ethnically diverse parents and youth through social service agencies that served people with fewer socioeconomic resources to access educational services or special learning tools. Input that comes from multiple perspectives is essential to ensure that final products successfully meet community needs, and supports Project SHINE's vision of inclusive and equitable access to SRH information and care for youth with intellectual disabilities.

Limitations

Our research has several limitations. With regard to the sample, a relatively small number of youth and parent participants were recruited via a network of organizations committed to increasing access to sexuality education resources for youth intellectual disabilities; all are based in New York State and predominantly serve people within New York City, which is a uniquely rich environment for disability support and other social and sexual health services. All but one of our participating parents were women and as a group, they may have more positive attitudes about sexuality education for youth with intellectual disabilities than parents who did not participate. Further, several were parenting youth who are younger than our priority age group of 16–24, which could skew how they prioritized sexual health learning topics, in particular (i.e., greater interest in anatomy and puberty content).

We conducted virtual focus groups and ensured that participants could engage in the discussions both privately and independently, yet our research exhibits some of the limitations associated with focus group research. Specifically, participants could have felt pressure to limit sharing their true opinions in the group context [43], which may be of particular concern for youth with intellectual disabilities. Further, the virtual format may have excluded youth and parents with more limited access to technology, or youth with mild to moderate intellectual disabilities who require in person support and/or additional communication support. Excluding these perspectives could mean our findings do not generalize to these youth, although we did work closely with the network of participant-referring organizations to minimize these limitations by clarifying the eligibility criteria and creating support for technology and language access (in addition to creating opportunities to engage with Project SHINE outside of the research context). Within the actual group discussions, the facilitators would repeat questions, ask whether further explanations of a question were needed, check in individually with quieter participants, normalize the possibility of disagreement (e.g., by asking, "Does anyone have a different opinion?"), and encourage use of the chat feature for participants to share additional thoughts as the discussion moved on to new topics. We note as a further limitation that results validation was done only with the SHINE network members, not directly with focus group participants using a member checking approach.

Next Steps

Our findings have implications for practitioners in the sexuality education and disability support fields more generally, but also for Project SHINE specifically. Our next steps will

be to create educational resource prototypes that are responsive to focus group input. Our group of stakeholders, including self-advocates (youth and adults with disabilities), parents/caregivers, and those working in the disability field (noting these groups are not mutually exclusive) met to review these data and after engaging in a series of human-centered design thinking activities, decided as a group to make a toolkit of materials focused on sexual anatomy and bodily autonomy. By starting with this topic, we can test materials and build other content areas using lessons learned. The toolkit will be responsive to the information gathered through these focus groups and notably be multi-modal and multi-use. Youth with disabilities will be able to use the tools on their own if desired, and with other peers, parents, their support professionals, or within small or large groups. The components will include an interactive glossary with detailed images, choose-your-own adventure style game, bank of realistic stories from self-advocates on bodies and sexuality, reflection and discussion questions, and resources on how to use the toolkit and where to go for more accessible information. Over time, we hope to integrate a 3-D model into the toolkit, but given the technical skill required to build such a tool in the way envisioned by our members, this component will take additional time and partnership. The components are being built by a group of SHINE Network and Advisory Members, including youth with disabilities in a group called the Design Collective. Prototypes will be tested for acceptability, feasibility, and comprehension before finalizing and further evaluating for learning outcomes.

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