Intellectual disability and sexuality: The missing link

Megan Hoorn

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Intellectual disability and sexuality: The missing link

Abstract
Research literature documents the varied perspectives of caregivers, educators, health professionals, community members, and family members regarding intellectual disability and sexuality. Many aspects of disability and sexuality, even intellectual disability and sexuality, are well documented. But what are the perspectives and experiences regarding sexuality of those who have intellectual disabilities? There is a void when it comes to the voices of people labeled as having intellectual disabilities regarding their own sexuality; their perspectives have not been described. This research study explores the existing literature that discusses the perspectives of others (parents, caregivers, educators, medical professionals, the general community, etc.) and then takes it one step further, to research the perspectives and experiences of people who have intellectual disabilities about sexuality. A common slogan in the disability rights movement, "nothing about us without us," captures the intent of this research, as the existing research has such limited information about the opinions of those with intellectual disabilities. Individuals labeled as having intellectual disabilities can, and should, be a part of these discussions about their own sexuality. If people with disabilities are to be fully and truly included in society, these conversations must include them, and take their opinions and experiences into account when planning for service, supports, and educational curriculums for people with intellectual disabilities.

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Table of Contents

Abstract ................................................................................................ 3
Introduction ............................................................................................ 4
Exploring the Perspectives of People without Intellectual Disabilities............. 4
    Parents/Caregivers ........................................................................... 4
    Professionals: Physicians and Educators ................................................. 7
    General Community ........................................................................ 9
    Common Themes ........................................................................... 10
    What is missing? ........................................................................... 11
Method................................................................................................ 11
    Participants .................................................................................. 12
    Research Procedures ....................................................................... 12
Results ................................................................................................ 13
    Gender ....................................................................................... 14
    Sex ............................................................................................ 14
    Sexuality .................................................................................... 15
    Negative Perceptions ...................................................................... 16
    Positive Perceptions ........................................................................ 17
    Disability and Sexuality .................................................................. 19
    Disability and Gender .................................................................... 20
    Relationships ................................................................................ 21
    Parenting .................................................................................... 23
    Religion ...................................................................................... 24
    Sex Education .............................................................................. 25
Discussion ............................................................................................. 27
    The Impact of Society ..................................................................... 27
    We’re More Alike than Different ...................................................... 28
    The Need for Education .................................................................... 29
    The Significance of Words Unspoken ................................................ 31
Future Considerations .............................................................................. 32
References ............................................................................................ 34
Abstract

Research literature documents the varied perspectives of caregivers, educators, health professionals, community members, and family members regarding intellectual disability and sexuality. Many aspects of disability and sexuality, even intellectual disability and sexuality, are well documented. But what are the perspectives and experiences regarding sexuality of those who have intellectual disabilities? There is a void when it comes to the voices of people labeled as having intellectual disabilities regarding their own sexuality; their perspectives have not been described. This research study explores the existing literature that discusses the perspectives of others (parents, caregivers, educators, medical professionals, the general community, etc.) and then takes it one step further, to research the perspectives and experiences of people who have intellectual disabilities about sexuality. A common slogan in the disability rights movement, “nothing about us without us,” captures the intent of this research, as the existing research has such limited information about the opinions of those with intellectual disabilities. Individuals labeled as having intellectual disabilities can, and should, be a part of these discussions about their own sexuality. If people with disabilities are to be fully and truly included in society, these conversations must include them, and take their opinions and experiences into account when planning for service, supports, and educational curriculums for people with intellectual disabilities.

Keywords: sex, inclusion, cognitive impairment, disability, education, special education
Introduction

Sexuality is something that many, perhaps even most, people take for granted, something that is assumed to be, and typically manifests as an intrinsic part of what makes up an individual. So what happens when that sexuality is limited? Discriminated against? Questioned? Eliminated completely? The realm of disability and disability rights begins to bring some of these questions to the surface. While physical disability and sexuality has become an accepted topic of discussion and exploration, less research has been done in regards to intellectual or developmental disabilities. People with disabilities are often metaphorically neutered, in that their sexuality is minimized, forgotten about, and marginalized by the people in their life and by society as a whole (Kallianes & Rubenfeld, 1997, Kroll & Levy Klein, 1992, Shakespeare, 1999, Shakespeare, 2000, Sheerin & Sines, 1999, Tepper, 2000). But why? It is apparent that barriers exist between these two topics of sexuality and intellectual disability (ID). Sexuality in relation to is a taboo, but also incredibly important, topic to be addressed (Hahn, 1981, Kempton & Kahn, 1991). In a review of existent research literature surrounding the topic of ID and sexuality, many studies discuss the perspectives of parents, caregivers, staff, educators, medical professionals, and even the general community.

Exploring the Perspectives of People without Intellectual Disabilities

Parent and Caregiver Perceptions

One major societal group that has been discussed in research literature demonstrates the perspectives of caregivers and parents of individuals labeled as having ID. Brown and Pirtle (2008) categorized the perceptions of caregivers into four different sets of beliefs, based on a survey done with forty individuals who were either parents or
INTELLECTUAL DISABILITY AND SEXUALITY

professional caregivers of individuals with ID including advocates, supporters, regulators, and humanists.

Advocates included parents and caregivers who were “strong supporters of human rights for the individual with an intellectual disability” (Brown & Pirtle, 2008, p.66). These advocates supported sex education, including the moral implications; and they were supportive of marriage for individuals with ID, as well as reproduction. They were in complete opposition to sterilization of individuals with ID. They did not, however, agree with a supportive attitude toward homosexuality (Brown & Pirtle, 2008).

The second category was that of supporters. Supporters expressed viewpoints in support of sex education and sexuality. They were against non-marital sex, but also did not view individuals with ID as capable of marital relationships (although they did not feel strongly enough about this to push these feelings upon individuals with ID). They were also strongly anti-sterilization (Brown & Pirtle, 2008).

Regulators were those who showed strong support for educating individuals with ID concerning sex. However, they also supported extensive birth control measures, including sterilization in order to prevent the birth of offspring with ID.

The final category, humanists, included the strongest supporters of human rights for individuals with ID. They strongly supported sex education, including birth control methods, as they believed that “individuals with intellectual disabilities should be allowed to participate in sexual activities and marriage with procreation if desired” (Brown & Pirtle 2008, p.68). This study showed that the perspective of parents and caregivers is largely based upon their personal belief system regarding sexuality, which is then passed along to individuals with ID. Even the advocates, the most accepting and
open-minded of the parents and caregivers surveyed, were not supportive of homosexuality for individuals with ID. This has an important impact on the education and services provided (Brown & Pirtle, 2008).

In a study by Swango-Wilson (2008), a survey compared nondisabled individuals’ beliefs regarding their own and their peers’ sexuality, with that of individuals with ID. This study found that while caregivers deemed public and private displays of affection and safe sex appropriate for individuals with ID, they believed prolonged public kissing, anal sex, and risky sex to be inappropriate for individuals with ID. A significant difference arose in perceptions of sexual behavior for caregivers and their peers compared to the same sexual behavior for individuals with ID. This implies that it is viewed as more appropriate for those without ID to participate in these sexual behaviors than for those with ID. Swango-Wilson concluded that “successful sexual programs for the individuals with ID must first address the attitudes and perceptions of the primary caregivers” (2008, p.79). Similar to the results of Brown and Pirtle, the individual perceptions of caregivers are assumed to have a direct relationship with the quality of sexual education for individuals with ID. If there is an assumption that successful sexual programs must first address the attitudes of caregivers, then that places the attitudes, wants, and needs of individuals who actually have disabilities in a place of lower priority.

Pownall, Johada, and Hastings (2012) completed a study of mothers’ perceptions of sexuality, comparing mothers of children with ID and mothers of children without ID. There were many significant differences found between the two groups, notably, that mothers of children with ID felt it necessary to educate their children about different aspects of sexuality than mothers of children without ID. Mothers of children with ID felt
that it was more important to discuss pleasure and masturbation, while mothers of children without ID felt that it was more important to discuss abstinence, STDs, and peer pressure. Mothers of children with ID had less positive attitudes about the ability of their child to make responsible decisions and were more cautious regarding the sexuality of their child. Mothers of children with ID also felt that the education system should have more of a role in the sex education of their child (Pownall et al., 2012). All three of these studies showed that the perceptions and perspectives that parents hold regarding sexuality tend to be passed on through their education of their children with ID.

**Professionals: Educators and Physicians**

While parents and caregivers are primary stakeholders in the lives of those with ID, professionals often make up a fairly large and important category as well. For the purposes of this review of the literature the term “professionals” includes educators as well as general practitioners (GPs). McCarthy studied the prescription of contraception for women with ID (2011). 92% of GPs felt that women with ID had less understanding of their contraceptive choices than women without ID. 60% of the GPs in the study did not use any specialized materials (such as pictures, pamphlets, diagrams, videos, etc.) to inform women with ID about their contraceptive choices (McCarthy, 2011). Most of the GPs in this study said that they would discuss the contraceptive choices with the caregiver of the patient. They also stated that they would potentially seek to involve parents, guardians, caregivers, advocates, partners, and even friends and neighbors in the decision making process: “It is difficult to see how these at the bottom of the list would ever have an appropriate role to play in discussions about a woman’s need for contraception” (McCarthy, 2011, p. 342). Clearly, doctors who prescribe contraception to
women with ID often work indirectly with the patient, through a parent, caregiver, or others. Perhaps increased education and support, as well as increased coordination would make this process more effective and meaningful, for both providers, as well as patients (McCarthy, 2011).

The sex education of students with ID raises several issues, one of which is the prevalence of disagreement about who is responsible for that education. Wilkenfield and Ballan (2011) sought to identify educators’ attitudes and beliefs toward the sexuality of individuals with ID. They found that educators stressed the importance of autonomy and the fact that sexuality is a basic human right. Educators also addressed the issue of “capacity to consent” and the necessity of preserving autonomy, while simultaneously preventing victimization. These topics certainly deserve consideration, however very few sexuality education programs fully address these concerns. There was also a general disapproval toward pregnancy for individuals with ID (Wilkenfield & Ballan, 2011). Disapproval toward pregnancy for certain individuals is not new within the field of disability rights, but remains an important issue. Historically individuals with disabilities were involuntarily sterilized, an issue still widespread even today. Educators believed that students with ID should receive the same sex education as students without disabilities. Some educators felt that the family should be responsible for initiating the discussion of sexuality, and all stated that the school plays a major role in sexuality education. Meanwhile, many parents feel that the school should play a bigger role in sex education for their children. Many of the educators stated that sex education was a necessity, but seemed reluctant to take responsibility for that role, indicating that perhaps
more training needs to be done for educators in this particular area (Wilkenfield & Ballan, 2011).

**General Community**

Societal norms, expectations, and opinions play an important role in the lives of every individual. Cuskelley and Gilmore (2007) conducted a study of 261 adults from the general community and found that all respondents held negative attitudes towards parenthood for individuals with ID. This is a theme that seems to run through the perceptions of professionals, caregivers, and the community. It was also found that sexual freedom is viewed as acceptable for people without ID as compared to those with ID. Despite these slightly negative attitudes, however, overall community attitudes toward the sexuality of people with ID were generally positive (Cuskelley & Gilmore, 2007). Societal expectations and opinions for people with disabilities impact many different areas of life, and if people in the general community who do not have disabilities perceive themselves as having more sexual freedom than those with disabilities, individuals with disabilities will struggle to have equal sexual freedom compared to their nondisabled peers.

Franco, Cardoso, and Neto (2012) completed a study of 454 college students, specifically medical, psychology, and architecture students. This study compared responses about students' perceptions of the sexuality of people with ID, based on the field the students were pursuing. Overall, attitudes toward sexuality were quite positive; however when questions related to how, when, and with whom are introduced, the conversation changes and the attitudes become less positive. This study also compared perceptions of students who had regular contact with someone with ID with those who
had less experience with people with ID. Those with frequent contact with people with ID generally had more negative attitudes. Psychology students demonstrated the most positive attitudes regarding sexuality of people with ID of the three groups studied. In relation to marriage and reproduction all three groups were less positive, but in regards to sex education all three groups were quite positive (Franco et al., 2012). This is a theme consistent with parents, professionals, as well as general community participants.

Common Themes

There were several themes that arose from exploring the perceptions of different categories of people who participate in the lives of people labeled as having ID. In general, there is actually a fairly positive view of sexuality, and sex education for people with ID. However, when the details of this discussion arise, more negativity appears. There is a significant gap between the beliefs of caregivers, parents, professionals, and the general community and the execution of these beliefs. While everyone agreed that sex education was absolutely crucial, there was very little agreement as to who should be responsible for delivering sex education. Educators felt that it should be families; families felt that it should be educators. GPs felt that it should not be their responsibility. Sexuality education that is actually provided may be inadequate due to this lack of agreement.

It is also important to note that the sex education delivered by parents and caregivers is likely to be impacted, and perhaps limited, by their personal views. It is essential that people with ID receive education that is impartial and complete and is not limited to the beliefs of the parent or caregiver. Another important note is the significance that overarching cultural perspectives have on this issue. For example, as was revealed in
a study by Franco et al (2012), people who were close to someone with an ID tended to have more negative views of sexuality and ID than people who did not have a close relationship with someone with an ID. The existing research literature all seems to state a general positive perception of sexuality for individuals with ID; however, further work needs to be done before this perception and attitude can be realized in education, prescription, supports, and recognition of sexuality as a whole.

**What is missing?**

Perhaps the most significant and apparent theme among all of these research studies, is the lack of information and lack of opinions from individuals who are actually labeled as having ID. This is important. This is necessary. We cannot, as a society, truly be inclusive until we include people with disabilities in these conversations. We cannot be inclusive until we have broken down the barriers that still exist between those with and without disabilities. We must recognize disability, but be willing to look past it, and discuss realities and possibilities. We need to knock down the taboo surrounding disability and sexuality. We need to break down the barriers to education, healthcare, and basic human rights. The conversation should be about people with disabilities, but it needs to INCLUDE people with disabilities. Why have people with ID been excluded from these conversations about their own sexuality?

**Method**

A qualitative, ethnographic research study was completed, interviewing individuals labeled as having ID (including Down syndrome, cerebral palsy, autism, and others). The focus of this research was to study the perspectives on sexuality of people who are labeled as having ID so that services, supports, and education may be more
directly catered toward their needs, as well as including them in the conversation and ensuring that their voices are heard. This concept is commonly referred to by disability activists as ensuring “nothing about us without us.” The perspectives of people actually labeled as having ID should be the first, and loudest voices acknowledged in discussions of disability and sexuality that directly impacts their own lives.

Participants

Eight participants took part in this research study. Participants were all between 18 and 35 years of age, with the majority being between 18 and 30, and all were labeled as having ID, alongside other disabilities that included cerebral palsy, Down syndrome, and autism. All participants identified themselves as heterosexual and cisgender. All participants also identified themselves as either white or African American. There were participants who identified themselves as having a female gender identity, as well as participants who identified themselves as having a male gender identity; however, the majority of participants had male gender identities. The sample was a convenience sample, with most participants being recruited through word of mouth, and through the local school district’s transition classrooms. All participants were from the same geographical area, part of a metropolitan region in the northern Midwest of the United States. Recruitment letters were sent out to participants and their guardians describing the research procedures and goals. Participants were given the option to withdraw from the study at any time, and could choose not to answer any of the questions if they felt uncomfortable doing so.
Research Procedures

A single, face-to-face, semi-structured interview was used, allowing for participants to expand upon questions and share their experiences in their own way. Interviews lasted approximately one hour. Interviews were completed by a single, white, middle-class, female interviewer familiar with ID. Topics covered during the interviews included masturbation, sex, sexuality, sex education, marriage, family, relationships, and the intersection of disability and sexuality. Important considerations allowed for during the interviewing process were issues surrounding abuse, marriage and family, sterilization, expressing sexuality, obtaining consent, victimization, and education. These topics commonly come up when discussing disability and sexuality, and while there were no specific questions during the interview process about all of these topics, awareness of the prevalence of these issues and familiarity with potential implications ensured adequate preparation for potential discussions that might arise. Consent and assent were obtained from participants, as well as from guardians as necessary. All consent forms were physically signed, and discussed thoroughly with participants prior to the interviews. The interviews were video recorded, and then transcribed. Participants were informed of all research procedures and purposes. The University Human Subjects Review Board approved all research procedures.

Results

Within the realm of disability studies and special education, who better to ask and receive information from than individuals labeled as having disabilities themselves? Upon completion of the interviews with participants numerous themes became clear, including gender differences, perspectives on education, participant demographics,
perceptions of sexuality, ideas surrounding marriage and family, the intersection of race, religion, and/or gender, and the intersectionality of disability and sexuality.

**Gender**

The gender differences among participants are certainly noteworthy. The majority of participants identified as male. This may be, to some extent, due to there being more men than women labeled as having ID in our society, especially African American men. While additional women were asked to participate, they either declined, or their guardians declined to have them participate. The discomfort with even having a conversation about sex and sexuality among women with ID asked to participate is significant. Why were they more hesitant to have these conversations? This may be indicative of a difference in sex education between men and women, and perhaps men are taught to be more comfortable with sex and sexuality than are women. An attitude difference may also exist between men and women, where men are simply more comfortable with sex and sexuality than women. It is important to keep in mind the education and societal expectations that many women receive about their own sex and sexuality. While sex is everywhere in the media, many women's sexuality is discouraged, minimized, and often treated as inappropriate. Women are also more likely to experience sexual abuse or sexual assault, and as such, victimization may be viewed as more of a concern for women than it is for men (Stromsness, M., 2008). While difficult to know why these gender differences occurred when collecting data, many factors can, and should, be considered regarding these differences.
Sex

During conversations surrounding the topic of sex specifically, many participants identified sex with marriage and with having children. One participant stated, “When a man and a woman are together, and they have sex to create a baby while they’re sleeping.” Another described sex as “it means you have kids.” and yet another stated “if you want to have a baby, that’s the perfect way to do it.” While sex and having children certainly have a strong connection, only a few individuals mentioned anything about sex for pleasure or about sex as an integral part of their lives. Several participants explained that sex should only accompany marriage, and that one is supposed to wait until marriage before having sex.

Still, one participant described sex this way: “sex is when kissing, making out, the humping, and it’s having fun. Yeah, I’ve had that before.” This is one example of an individual who defined sexual intercourse very differently from the more standard definition. Another individual described “I don’t do it on the first date. When she ready, she’ll let me know. When I’m ready, I’ll let her know. Then I’ll put on some soft music, first I’m going to cook though, then put on some soft music, start hugging, kissing, next thing you know we having sex.” Several individuals stated that they had had sex and some several stated that they were interested in having sex, and several did not demonstrate knowledge of sex or sexuality, and were not sure how to describe sex beyond the description “it’s inappropriate.” Clearly experiences and perspectives of sex varied, both extremely positive, extremely negative, and everywhere in between.
Sexuality

Viewpoints and understanding of sexuality were also fairly consistent among participants. Many participants stated that while they personally did not identify as homosexual, they felt that people “should be able to be with whoever they want, and should be able to marry whoever they want.” Attitudes toward homosexuality were overall very tolerant and accepting among many of the participants. One person explained “it don’t bother me, but I think it’s awkward.” Another described sexuality in this way, “sexuality is like, what you like. It’s what you prefer. It doesn’t really matter. It doesn’t affect you as a person, it’s just what you like. You shouldn’t be judged for what you like, or for how you act. It shouldn’t stop anyone from doing whatever they want to do.” Contrasting this more open-minded and accepting viewpoint, there were also individuals who stated that sexuality was inappropriate or that they did not know what it meant, and several individuals also described sex and sexuality as synonyms, without differentiating sex as an action from sexuality as a part of identity and humanity. Participants consistently identified heterosexuality and homosexuality, however, only one participant mentioned bisexuality, and no one made any mention of asexual, queer, or transgender sexual identities. This also has educational implications. If students are never taught about the spectrum of sexuality and the ways in which sexuality may not necessarily be heteronormative, it may be more difficult to recognize and appreciate one’s own sexuality. Especially if individuals with ID are not being taught about aspects of sexuality outside of our heteronormative culture, the expectation that they can have a broad, healthy, and objective understanding of their own sexuality is unrealistic.
Negative Perceptions

An interesting note was the number of negative perceptions that individuals had regarding sex and sexuality, especially surrounding masturbation and non-marital sex. Masturbation most commonly had negative reactions both verbally and nonverbally. All participants seemed very uncomfortable discussing masturbation, and visually were much more nervous with this discussion. Many participants denied masturbatory behaviors, and some even went so far as to say “never do it,” and “no... no.” This vehement refusal to accept masturbation as a healthy and normal part of sexuality leads one to believe that perhaps many individuals were simply taught that masturbation is inappropriate, rather than being taught the appropriate ways, locations, and situations in which masturbation can be a positive and healthy part of an individual’s sexuality. Two participants stated that masturbation make them feel good, however neither was willing to elaborate or share their opinions beyond these statements, and both showed visible signs of discomfort and nervousness when asked these questions. Non-marital sex also was often addressed as inappropriate. One participant described sex outside of marriage as unsafe sex and bad sex.

Many individuals also had negative perceptions of sex and sexuality in general. Multiple participants stated that it was inappropriate, bad, and uncomfortable. Along with many of these negative statements regarding sex, they also generally stated that they were unsure about, or did not know how to answer questions. Several individuals also had nonverbal behavior indicating that they were uncomfortable with the topics, including actions such as laughing, shaking their heads fervently, putting their heads in their hands,
pausing, hesitating, and shrugging. Along with a lack of adequate information, understandably, comes confusion, discomfort, and other associated negative emotions.

Positive Perceptions

On the other hand, several individuals did have more positive perceptions of sex and sexuality in general. Several participants stated that sex is a natural thing, and that it has got to happen and everyone goes through it. Additionally people said that it makes them comfortable, it is having fun, they liked it, and that it does not bother them. Several individuals brought up “making out” during conversations about sex and sexuality saying “my favorite is making out, tongue in mouth.” One individual described their experience saying “So we went in the room, I did it. Came out smiling. That was how I got my first relationship.” Sex was also associated with love and marriage more than once, and was considered more positive within the marital and love context.

Individuals who stated that they had previously had sexually intimate relationships had more positive perceptions of sex and sexuality than individuals who had not previously experienced sexually intimate relationships. Additionally, individuals who had previously had sexually intimate relationships had a better knowledge of sex and sexuality as a whole, and were generally comfortable having conversations about these topics.

Across these themes of both negative and positive perceptions, it appears that race as well as gender may play a role. Of the African American individuals interviewed, the majority had more positive views of sex and sexuality, whereas whites seemed more hesitant to discuss sex and sexuality, and were more likely to have negative and inaccurate perceptions.
Beyond that, women who agreed to participate in the interview seemed to be more comfortable discussing sex and sexuality than men. However, this may have been a consequence of having a female interviewer for all participants regardless of their gender identity. These women may have also been more comfortable with sex and sexuality in general, because they elected to participate, whereas several other women declined to even participate in the study. Race and gender certainly play a role in sexuality for all individuals. The intersection of how race and gender may also interact with disability and could create additional themes and uncover more consistencies across individuals. Along with these intersections of various different identities, it is important to remember that all people likely identify with more than one social group, and that intersections among and across groups play a significant role in all people’s lives, regardless of their ability status.

Disability and Sexuality

The intersection of disability and sexuality brought up a discussion about which almost all participants had strong opinions. It was evident that there were connections between the two for them, and not necessarily positive connections. Many individuals stated that it was harder to date because they have a disability. One participant described this by saying

I feel like you don’t see a lot of people with disabilities that have relationships. It’s kind of hard to be in a relationship and have a disability at the same time. You’re trying to deal with having a disability, and also being in a relationship. I don’t know why people with disabilities don’t have relationships, it’s just, that’s how it works.
Another individual mentioned that they noticed that people with disabilities only date each other. This has implications about the opportunities for individuals with disabilities, and the expectations they place on themselves, as well as expectations and assumptions ascribed to them by others. One participant discussed his own relationship saying,

So, once you get out there and other people can see us dating, but when they see us closer, when you get out there and are dating with disabilities and all, and when people see us they think we're just like them, but when they get closer, they find out that we have a disability and they take advantage of us.

After discussing the ways in which they felt that disability might interfere with sexuality, the majority of participants mentioned that they are the same as anyone else, and can date and be sexually active the same as everyone else. Like many disability rights issues, this suggests that the obstacles that these individuals have encountered in their romantic, dating, and sexual lives have more to do with restrictive environments, restricted expectations, and a lack of opportunity imposed upon them by nondisabled people than the obstacles associated with their diagnoses.

It is evident that the individuals interviewed had all experienced some form of ableism against them in their dating and sexual lives, and further felt that it was important to note that they are the same as anyone without a disability, have the same biological needs, and should be treated as such. The societal barriers between people labeled as having ID and their own sexuality are tall and wide, and far from being broken down.
Gender and Disability

Beyond disability and sexuality, a few participants also identified connections between gender and disability, and how gender role expectations, along with disability, can create additional struggles for individuals with disabilities. One man explained this as

...If a girl has a disability, it doesn’t really affect them because they’re girls. Guys will talk to them anyways, because they are girls. But with guys it’s different… Sometimes I wish I was a girl. It’s easier being a girl. You shouldn’t say bad things about girls or talk about girls or say anything bad about them or hurt their feelings or anything because they have low feelings. I feel like the rules of being a girl, you shouldn’t say anything bad about them. Guys shouldn’t be like, ‘oh she’s not smart she’s dumb’ because everybody get on your case about why you say that about her. You shouldn’t disrespect or talk about girls, and if you do, then somebody will say something you and say ‘why you say that about her’ and it’s going to be a problem. But for boys, it’s like guys and girls can say stuff about it because there’s not really any rules, because they’re dudes and they should be able to take it because they ‘don’t have feelings,’ they don’t really have feelings, they don’t really care.

The eloquence of this description is notable, because it brings up the issue of gender role expectations for both women and men, and identifies important themes of expectations and assumptions about disability and ableism as well.

Male participants were more likely to say that they had previously dated, or would like to date a woman without a disability, whereas women participants were more apt to say that they would be more comfortable dating someone with a disability. Societally, are
we more comfortable with men with disabilities dating women without disabilities? Is there a stigma associated with women with disabilities dating someone without a disability? Socially constructed gender roles and expectations may have an impact on the ways and types of relationship dynamics that are generally expected and accepted for individuals with disabilities. Navigating the topics of consent and comfort when it comes to relationships where one person has a disability and another does not, brings up additional questions and concerns as far as the extent to which disabled voices are heard.

**Relationships**

Participants were all much more comfortable with talking about relationships than they were when talking about topics more closely related to sex and sexuality, whether discussing different kinds of relationships, dating, previous relationship experiences, or stories about other people’s relationships. Many shared experiences that they had in romantic relationships, both positive and negative, and described the advantages and disadvantages of being in a romantic or dating relationship with another person. One participant said

That’s like another person that you have to deal with. So you have to deal with like their problems, and also your problems too, and if they are going through stuff you have to go through it with them. That’s like the bad part of it. At the same time, you have the good parts. You hang with them, you might go see a movie. You do stuff with them so you not bored out of your mind. It’s having a friend, but not really.

Beyond more generic descriptions of relationships, several participants brought up the importance of respect for the other person in the relationship, especially if the
relationship becomes sexually intimate. This was a theme mostly among the male participants, mentioning that you have to respect a woman’s feelings and where she’s coming from. Only one participant described a successful relationship, and all participants described negative aspects of dating alongside the positive aspects.

One woman stated that people she had previously dated, who were also labeled as having disabilities, “didn’t know what to do with women really, it seems like they don’t understand something about it, like they don’t know how to make the relationship survive.” This statement that may be related to ability status, but may also be a common sentiment among women in the general population as well. Further, this statement regarding her previous partners’ not knowing or understanding what they were doing may also be yet another example of how sex education for individuals with disabilities is inadequate in multiple areas.

**Parenting**

During discussions on marriage, sex, and sexuality, the topic of parenting arose. The majority of participants said that they would like to have children in the future, when they got married. Many participants who were 20-28 years old stated that they would like to wait to get married and have kids after they were in their 30’s.

Everyone that mentioned a desire to have children also mentioned ways in which that would create lifestyle changes. For instance, one person said that “if you want to go hang out with your friends that’s single and you can’t go hang out with them because you know, you got a kid, and you’re married now, so you got responsibilities to do.” Another participant mentioned the need to have a babysitter when they got married, so that there was someone to take care of children when they were not home.
One woman discussed adoption, saying that she had seen movies about childbirth, and it was painful. She stated that it would be difficult for her to adopt kids, saying “I’m pretty sure that’s pretty hard for me, because of disability and stuff. It makes me a little bummed.” This comment seemed to have little to do with her disability, but rather to be about institutional barriers. She felt that because of her disability, she would not be allowed to adopt children. Previous literature brought up the notion that many people involved in the lives of people with disabilities are uncomfortable with the idea of people with ID reproducing and parenting their own children (Brown & Pirtle, 2008, Wilkenfield & Ballan, 2011, Franco, Cardoso, & Neto, 2012).

People who actually have ID present a different side of this issue. Participants all expressed an interest in having children, and also described the extent of the responsibilities that come along with having children. However, there seemed to be a certain hesitancy among participants, in that they did not feel prepared or have the skill set to raise children. Perhaps nondisabled people should shift their focus toward developing programs and supports that might assist individuals with disabilities in learning about, understanding, and executing effective parenting, instead of merely suggesting that parenting is wrong, bad, or concerning for individuals who have intellectual disabilities.

**Religion**

What role does religion play in regards to ID and sexuality? Many participants identified sex as something that should be reserved for marriage, a viewpoint often associated with certain religious beliefs. However, only one individual identified as practicing a religion consistent with these beliefs:
If you’re not married, don’t have a kid, and if you’re married you can have kids. When a man and a woman sleep together and they’re not married, it’s not safe sex. Marriage is when a man and a woman are together forever. You don’t break that commitment. In the Bible, it says that two are together as one.

Religion, to some extent, can strongly impact one’s beliefs and standards about sexuality, regardless of disability status (Cochran, J., Beeghley, L., 1991). However, it was unclear whether the association of sex with marriage was made totally because of religious reasons, or because that was simply how sex and sexuality was taught by principal educators, regardless of religious background. Another person stated, “Basically you’re supposed to wait until you get married, but you don’t.” While sex and marriage had evident connections among many of the participants, the reasoning for why sex and marriage had such strong connections were not necessarily clear. Educationally, as well as societally, this is an injustice to individuals with intellectual and other disabilities: when sex education focuses on sex within the context of marriage only, especially when many people with disabilities may face institutional challenges when choosing to get married in the first place, their sexuality becomes limited.

Sex Education

Perhaps the most significant theme that arose from the interviews was one regarding sex education. While everyone stated that they had learned about sex and sexuality, many individuals had inaccurate information about sex and sexuality. Several stated that their primary mode of education was somewhere other than school, and that the education that they did receive at school was not beneficial. Participants described their learning experiences saying that they learned from parents, cousins, “homies,”
school, friends, and independent research online, by watching movies, and “from the hood and street talking.”

It was also evident that many participant’s beliefs about sexuality were strongly influenced by whomever taught them about sex and sexuality. For instance, individuals who primarily learned about sex and sexuality from their peers, tended to have more positive viewpoints. Individuals who learned about sex and sexuality from their parents or from school, tended to have more negative perceptions.

The suggestion that sex education is not sufficient, especially for individuals with ID, is no surprise. Research has been done that suggests that abstinence only education, which is most commonly used in the United States is not effective, even at the general education level (Pittman, V., Gahungu, A., 2006). Further research suggests that when disability is a factor, educators often feel unqualified, and uncomfortable with broaching some of the crucial topics for discussion (Wilkenfield & Ballan, 2011). While curriculums have been developed for teaching individuals with disabilities about sexuality, these programs rarely receive support or funding locally or federally (Dailard, C., 2001, Gougeon, N., 2009).

Participants often stated “I don’t know” in response to questions, especially about sex, sexuality, and masturbation. Even from the answers that participants did give surrounding these topics, it is evident that the education that they received could hardly be considered comprehensive, with negativity common as a focus. No individuals explained sexual intercourse accurately, indicating their limited information and experience. The consistency with which individuals did not have accurate knowledge about sex and sexuality suggests that regardless of the reasoning, education about healthy
sexuality is lacking and requires further focus during school, development, and discussions with parents or caregivers.

Many participants stated that they had never heard of sexually transmitted infections. Several people stated that it was important to “be careful” if they were going to participate in sexually intimate activities. The only form of birth control or protection mentioned by any of the participants were condoms. If individuals receive the education to “be careful,” this needs to go further. Why do you need to be careful? What does protection protect against? When and how should you say “no” to someone if you are uncomfortable? What does being careful look like? These are all important discussions, and many participants missed out on them. Sex education needs to be very explicit, honest, and direct, and many times (even in general education settings) students do not have a full understanding of what they are learning. In order for accurate knowledge to be conveyed, educators and other adults need to be comfortable with having these conversations in explicit, open-minded, objective ways.

Discussion

The Impact of Society

The impact that society has on the sexuality of people with ID became clear as a result of this research study. Many participants described how having a disability has a negative impact on dating and sexually intimate relationships. They also described the ways in which gender roles and expectations interact with ability status, and how that can have negative implications in society. Further, individuals emphasized that they are the same as anyone else, and should be treated as such. These comments and stories highlight, perhaps, the greatest injustice with regards to the sexuality of people with ID.
People with ID want to be treated with equality among their peers, and yet every person had a story or comment about how society views them differently because of their disability, and how that interferes with their own sexuality.

Further, the voices that are predominant in current research literature are not the voices of people who have disabilities. They have not been treated with the equality and respect that is deserved. If any other minority was treated with such disregard for their own opinions, there would be outrage, and yet, this seems to be completely acceptable within the field of disability and sexuality. Society as a whole discriminates against people with disabilities in countless ways, only a few of which fall within the category of sexuality. This discrimination has gone on continuously throughout history, and while the disability rights movement has come a long way from where it started, there is still much work to be done. There is no reason that people with ID cannot be included in these conversations about themselves; indeed, it is essential that they be included. Even though this study only described the perspectives and stories of eight individuals, their voices should count for far more, and they should be a significantly larger and louder part of these conversations than other individuals. Parents, caregivers, staff, the general community, and professionals should not have more of a say about the sexuality of people with disabilities than those people who have been labeled as having ID themselves.

**We’re More Alike than Different**

An important lens through which to view this research is by comparing it to the general community of people who have not been labeled as having an ID. Many of the themes that arose may have been similar to themes that would arise in a study about
sexuality for the general population. Gender differences certainly exist for all individuals, regardless of ability status. Differences in religious beliefs also strongly impact the ways in which people view sexuality, just as they did in this study. To some extent, sex education is lacking for all individuals, not just individuals who are labeled as having ID. Everyone has experiences to share about relationships, marriage, and parenting. Everyone is impacted by societal expectations and assumptions that are made about the social groups with which they identify. Many of the issues that have been discussed are not unique to people who have ID. People with disabilities experience the same world, and the same things as nondisabled people; as such, they should be treated with equality and justice in all aspects of that world. Unfortunately, this is often not the case. We must note these similarities and differences, and further, notice how the differences may have more to do with the way the world is structured than with differences inherent to a diagnosis of ID.

The Need for Education

In order to more effectively educate individuals with ID regarding sex and sexuality, results from the present research project, as well as others, need to be taken into consideration. Previous research studying the perspectives of parents, caregivers, staff, professionals, and educators brought up concerns about consent, ability, childbearing, marriage, and safety. Many of these perspectives also included an emphasis on a need for sex education, and also had positive perceptions regarding sex education for individuals with disabilities. However, it is clear that many people with ID need sexuality education that is more comprehensive in all areas, including basic anatomy and physiology, descriptions of relationships, when sex and sexuality are appropriate, what
consent is, how to use birth control and why, the importance of healthy sexuality, and the idea that sex is something that can be done for pleasure, not simply for reproduction.

While everyone seems to believe that sex education is crucial, results of this study would suggest that education is not actually occurring. If individuals with ID are unsure of what to even call their genitals (as several were), how can they stand up for themselves? If a woman does not know the proper way to talk about her vagina, how can she accurately protect herself against abuse? If adults are unsure of how to use a condom or other forms of protection, and the appropriate times to use such items, how can they be expected to have safe sex? If individuals have never been taught that sex is a healthy part of their lives, and is not necessarily solely linked with reproduction, how can they make that a successful aspect of their lives?

Many participants expressed interest in having sex, but because so many of the other people in their lives are uncomfortable with sexuality for people with intellectual and other disabilities, their sexuality, by extension, becomes limited. Sexuality should not be limited for these individuals, and everyone deserves access to comprehensive education on the topic. Issues of consent, victimization, abuse, marriage, raising a family, and other concerns raised by caregivers and professionals are still relevant. However, if all of these important topics were addressed during sex education, the taboo and the associated concerns might be dispelled through open, honest, and direct conversations, with curriculum designed to include these additional discussions.

Yet another concept to focus upon is the concern that many participants felt that they had been discriminated against in their sexual and dating lives because of their disabilities, and that disability status has an impact on sexuality and relationships. Many
said that disability should not make a difference, that they wish they were treated the same as anyone else, and that sexuality and sexual relationships are the same for disabled people as they are for nondisabled people. The socially constructed ableism that is described by these participants regarding sexuality and disability stands out as a call to action for society as a whole to become more open-minded and more willing to accept differences among other humans, whether at the level of disability, race, socioeconomic status, sexuality, or education level. Societally, it is time to listen to the voices of disabled people. Nondisabled people should not be making decisions and filling in the gaps in conversations with their own voices.

The Significance of Words Unspoken

Up until this point, the results and discussion have focused on verbal communication during interviews. Beyond the verbal communication that occurred during interviews lies another aspect: nonverbal communication. Verbal communication is only one facet of communication, and may not always be the best form. In moving forward with this study, and with future discussions, the impact of nonverbal communication, and the impact of words that were not said during interviews are also important. What did participants choose not to share, if anything? Which questions did participants not know how to answer? What is the story behind responses such as “no,” “inappropriate,” “not sure,” and “don’t know”? The eloquent verbal communication and stories shared by people who primarily communicate through spoken language should not outweigh the stories and experiences that were shared in fewer words. While some participants shared their experiences in great detail, others had much less to talk about. It is crucial that the meaning of the words not spoken is considered. The words not spoken
out loud may be the most powerful. The brevity of statements that some people gave, or even the lack of responses to certain questions, is significant research data in and of itself. This field of research in the area of disability requires that every detail be noted, and that every form of communication is just that, communication. This research cannot simply be interpreted based on the eloquent quotes from individuals who had much to share, but should be interpreted mindfully, acknowledging the significance of the experiences of those who had less to say.

An important ellipsis has begun to be filled in by these verbal descriptions of experiences, opinions, and perspectives of people who have ID. But the work does not end here. This ellipsis will be more fully explored and uncovered when the voices of people who do not communicate verbally are heard. For many people with ID, verbal communication is not their primary mode of communication. How have these individuals experienced sex and sexuality?

Unfortunately, the participants for this study consisted of individuals whose primary mode of communication is verbal speech. Individuals who use more varied modes of communication were asked to participate, but either they or their guardians declined. This area of ID perhaps stands out as the area in which the most research needs to be completed. Just because someone does not communicate verbally, the standard mode of communication for our society, does not invalidate or devalue the power of their stories and experiences. The quietest voices may often be the loudest, but are hidden behind a form of communication foreign to those of us who solely communicate verbally.
Future Considerations

This is only the beginning of this crucial research. There are many more conversations to be had, and much research to be done. The sample size for this study was fairly small, and an increased sample size would surely allow for further analysis and allow for more findings. Beyond this, the sample size consisted almost entirely of men. It would be helpful for future projects to include more women in the discussion.

Another consideration to keep in mind would be to match the gender of the interviewer with the identified gender of the participants. This might allow for more honest discussions, and perhaps more elaboration on certain topics. It would also be helpful to have a broader range of ability included in interviews, including people who are nonverbal and use alternative communication modes, as well as including people who have physical and intellectual disabilities. It may also be helpful to have a broader age range included.

Further research studies could explore the intersectionality of race, religion, gender, region, and sexuality. Having individuals who identify as different races and religions, outside of Christian, White, and African American would allow for many more themes to develop. Expanding to include participants from different locations would also allow for further investigation as to the impact that geographic location may have on this topic.

All individuals in this study identified as cisgender and heterosexual coincidentally. By expanding this research to include people with ID who identify as transgender, homosexual, bisexual, or asexual, even further themes may be drawn.
Beyond considerations for future research, and ways in which this study could have been expanded upon, there are also many implications for future practice and policy. It is evident from this study that sexuality education must be improved, especially for those labeled as having ID. Research can and should be done, investigating the current sexuality education curriculum being used for individuals with ID, and further, developing stronger curriculum for future use.

Above all else, one future consideration is clear: more conversations are necessary. This research cannot end here. These conversations need to continue to include individuals labeled as having ID, as well as other disabilities, and should be progressive and productive toward allowing individuals with ID to have more positive, and educated sexual lives and experiences.
References


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