

Perceptions of Reproductive Rights among Young Adults with Disabilities

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Abstract

Background: The perception that people with disabilities are asexual and lack reproductive rights has existed in the United States since the early 1900s. In the early 1900s in the U.S., approximately 42,000 institutionalized people with disabilities were lawfully sexually sterilized as a result of the Eugenics Movement. The state of California was responsible for one-third of all sterilizations during the Movement. **Purpose:** This study aimed to assess the perceptions of reproductive rights among young adults with disabilities. **Methods:** Purposive and snowball sampling was used. Twelve semi-structured interviews with eight young adults with various mental health, physical, intellectual/developmental, and learning disabilities were conducted. **Results:** Participants reported that their ability to have sex and their reproductive rights were commonly questioned by peers and professionals. Some internalized asexual stereotypes and questioned whether they should reproduce due to the potential that they might pass on a disability or burden their children with their own disability. Others confidently reported their desire to bear their own children. **Conclusion:** The asexuality stereotype of people with disabilities is pervasive and continues to be present in society today. It is important that professionals reflect on their own biases toward the reproductive rights of people with disabilities.

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Keywords: Reproductive rights; disability; sterilization; asexuality

Introduction

The perception that people with disabilities are asexual and lack reproductive rights has existed in the United States since the early 1900s. Any sexual behavior exhibited by people with disabilities has often been considered unacceptable, unsafe, or inappropriate (Shandra & Chowdhury, 2012). In the early 1900s approximately 42,000 institutionalized people with disabilities in the United States were lawfully sexually sterilized in the Eugenics Movement (Stern, 2005). The main focus of the Eugenics Movement was to prevent sexual reproduction of the intellectually and mentally unfit. The state of California was responsible for one-third of all sterilizations; most of which had diagnoses now known as schizophrenia and intellectual disability (Stern, 2005). The Supreme Court case *Buck v. Bell* in 1927, which confirmed the constitutionality of sterilization of people with disabilities, was never overturned and many states passed laws prohibiting marriage among people with disabilities. Today more than 39 states, including California,

prohibit or restrict marriage among people with disabilities (Neuhaus, Smith, & Burgdorf, 2014). This dark history can be juxtaposed with today's society in which people with disabilities are just as likely as others without disabilities to experience pregnancy and parenting in or outside of marriage (Höglund, Lindgren, & Larsson, 2012; Shandra, 2011). Though progress is slow in recognizing that people with disabilities are just as likely to have children, the State of California repealed the state's sterilization law in 1979 (Stern, 2005). Very recently, California's Healthy Youth Act passed that mandates adapted sex education for students with disabilities (AB-329 Pupil Instruction: Sexual Health Education, 2015). This may represent a new era of reproductive rights among young adults with disabilities. This study aimed to assess the perceptions of reproductive rights among young adults with disabilities who have primarily grown up after most state sexual sterilizations laws were repealed. The purpose of this study is to understand the lived experience of young adults with disabilities today related to reproductive rights.

Methods

Design

A phenomenological design, including qualitative interviews, was chosen to explore or investigate the lived experience of young adults with disabilities related to reproductive rights (Padgett, 2008). The study received Institutional Review Board approval to conduct the study from a mid-sized public university in southern California.

Sample

Participants were recruited by purposive and snowball sampling starting with a presentation at a university disability club meeting at a public, mid-size university in southern California in spring of 2016. Disability status and diagnoses were self-described. The sample consisted of people with mental illnesses, intellectual/developmental disabilities, and learning disabilities (Table 1). Written informed consent was obtained from participants, which were all over the age of 18.

Table 1.

| Demographic Characteristics of the Sample (n=8) | | |
|---|----|---------|
| | M | Range |
| Age | 25 | 22 - 29 |
| | n | % |
| Gender | | |
| Male | 3 | 37.5 |
| Female | 5 | 62.5 |
| Race | | |
| Caucasian | 5 | 62.5 |
| Mexican | 2 | 25.0 |
| Ghanian | 1 | 12.5 |
| Disability | | |
| Attention-Deficit Hyperactivity Disorder | 1 | 12.5 |
| Anxiety | 1 | 12.5 |
| Autism Spectrum Disorder | 1 | 12.5 |
| Borderline Personality Disorder | 1 | 12.5 |
| Dyslexia | 2 | 25.0 |
| Obsessive Compulsive Disorder | 1 | 12.5 |
| Schizophrenia | 1 | 12.5 |
| Irritable Bowel Syndrome* | 1 | 12.5 |
| Parent's Birth Country | | |
| USA | 5 | 62.5 |
| Mexico | 2 | 25.0 |
| Ghana | 1 | 12.5 |

*Co-occurring medical diagnosis that participant reported as a disability.

Measures

Twelve interviews with people with various disabilities ($N = 8$) were conducted in spring and fall 2016. Each participant had an initial interview with the option of a follow-up interview; only four participants did a second interview. All interviews were conducted by the 1st author, a college student at the time of the interviews. The interviewer is perceived to be a tool in phenomenological methods; thus, it is critical to know how the participants may have related to the interviewer (Padgett, 2008). In this study, it appeared that the participants felt very comfortable sharing their feelings with the interviewer since she may have been viewed as a peer to the participants. Individual interviews were conducted using a semi-structured interview script (Appendix 1). Interviews were 42 minutes on average with a range from 21 minutes to an hour and five minutes. Probing questions were used to encourage participants to extrapolate on their original descriptions of experiences, such as “Can you provide an example of that?”. To maintain anonymity, each participant was assigned a unique ID number and nickname once they signed the consent form and was only referred to by their ID number or nickname during data collection and analysis.

Analysis

All interviews were audio-recorded and professionally transcribed verbatim. Consistent with phenomenology, bracketing was conducted in which the interviewer reflects on use of herself as a tool during the interview. Content analyses were conducted to identify major themes and subthemes in the data. Themes and subthemes were given weight based on the use of stories, emotionality, and specificity (i.e. personal nature) of the examples offered. All three authors read through each interview and identified themes. All authors met to discuss themes and create a codebook, which consisted of vocabulary that met criteria for each theme as determined by the authors' discussion. No qualitative software was used.

Results

Asexuality and reproductive rights were discussed in numerous occasions using emotion and in-depth examples. These topics were continuously mentioned alongside one another by all participants except one.

Asexuality

The young adults believed that society viewed people with disabilities as asexual and that this is a “*misconception*”, a common term used by participants. Aba reflected on others asking her, “*do you feel anything down there? Or really invasive questions, almost like I’m subhuman...it was weird...like I was a science project.*” Mason echoed this different treatment of people with disabilities: “*They’re [people with disabilities] not viewed as sexual objects. People look at them with kind of pity.*” The ability to have sex and be sexual was related to having a good relationship by one of the participants. Mia shared that society feels like: “*oh they must not have good relationships cuz they don’t have sex.*”

It was mentioned by participants that professionals and family members have influence on their development of sexual and reproductive health and intimate partnerships. Olivia spoke about sexual education in a general education classroom. She explained that her teacher told the class “*I’m gonna teach you about abstinence, and then I’m gonna tell you that if you are gonna have sex you really should have sex with someone that you love.*” However, Mia reported that her Mom only believed in abstinence education: “*I don’t think my mom would’ve let me take home a book on how to be sexually active.*”

Aba spoke of her experience as an individual with a disability in a special education classroom who was developing feelings for a fellow individual with a disability:

...(M)y first crush in preschool...I would hold his hand during story time... the teacher would always try to discourage it- well, first ‘cuz we were in preschool and another ‘cuz she didn’t know how it was gonna be like ‘cuz we both had

disabilities... I always felt like she would try to keep us apart. It was a Special Ed class, so I think that she’s been trained.

Aba also spoke of a female high school friend who used a wheel chair who was dating a boy who also used a wheel chair and was non-verbal. During physical education (PE) class, the female friend would talk to Aba about her future being married to and having children with her boyfriend. Aba described that after PE class, the female friend’s aide would say: “*If she says it again, don’t encourage her. Don’t sell her a dream.*” Aba expanded, “*She (the aide) would tell her (the female friend), ‘Now you know you’re not gonna have kids.’ ...I don’t know why she would do that. I don’t know...but she was discouraging her from that.*”

Reproductive Rights

The young adults reflected upon the topic of reproductive rights, specifically pertaining to individuals with disabilities. Santiago asked during the interview, “*Should we, people with disabilities, have sex?*” He told a story about a fellow friend of his “*I noticed something strange about (the friend). Now they (the friend and his significant other) have a baby, and this baby has a disability.*” This was also mirrored by Noah; he explained that a common question he is asked is “*‘With your illness, do you really feel that you should be having sex and everything?’ ... I mean cuz that can lead to babies and babies can—and with the illness you can pass it on, so.*” Aba spoke of sterilization and forced adoption: “*I’m just like, ‘Really?’ You going to tell me what I can do with my body, while these girls out here having babies don’t even want it, but people with disabilities who in stable relationships and who love each other want to have kids but can’t have kids because why?*”

Participants also reflected upon having their own children. During the interviews, Aba, Santiago, and Olivia all expressed interest in having children in the future. Aba explained that she would like to have children of her own one day because “*all kids love their parents, and they’re gonna realize that they had you because they love each other and then they want to have a*

combination of themselves in one person.” Valentina demonstrated a struggle with her desire to have a child. She asked *“Is it selfish to have a kid?...even if your kid doesn’t have a disability, are you putting that burden on that kid to one day take care of you because you have a disability...?”* Mia explained, *“Maybe one day, if I’m in the right mindset, I’ll have children. I gotta’ be in the right mindset though. Cuz my borderline will be a huge problem and it’s able to be passed down, so if I’m not in a healthy relationship and I raise a kid with my genes in a shitty relationship, they gonna’ get my problems. I cannot do that to them.”*

Discussion

An association between asexuality and reproductive rights was present in the interviews of young adults with various disabilities. The idea of asexuality reportedly came from multiple sources including: the general population, peers, and professionals, such as teachers. Participants’ sexual abilities and reproductive rights were questioned by others. In addition, participants questioned their own reproductive rights viewing themselves as a risk for passing on a disability to their child or burdening their child with a parent with a disability, while others confidently wanted to exert their ability to bear and raise children.

Appendix 1

Table 1. Interview Script

| Question | |
|----------|--|
| 1 | In your opinion, what are your best qualities? |
| 2 | How do you define intimacy? |
| 3 | How do you define sexual health? |
| 4 | In your own words, what are the top three most common misconceptions the general population has regarding persons with disabilities and their sexuality? |
| 5 | What are your feelings, thoughts, and /or reactions to the concept: “Everyone wants intimacy.” |
| 6 | Tell me about your disability. |
| 7 | Tell me about an experience that impacted how you think about intimacy in relation to your disability. |
| 8 | What is the most common question, or comment you have heard regarding your disability and the topic of sexuality and intimacy? |
| 9 | Imagine you are giving a speech to other college students who have disabilities, on the topic of sexuality, what would the title be, and why? What would the purpose of the speech be? |
| 10 | Has having a disability affected or influenced your love life? If so, how? Is this positive? Negative? Both? If not, what advice would you give to someone whose disability has negatively affected their love life? |

It was an unexpected finding that the young adult participants in this study experienced the stereotype of asexuality. This demonstrates the possible pervasiveness of the asexuality stereotype for people with disabilities. According to our participants and consistent with previous research, sexual behavior exhibited by people with disabilities continues to be considered inappropriate to society in general as well as professionals (Shandra & Chowdhury, 2012).

Limitations

This study has a small sample size due to its qualitative nature. Phenomenological research often sacrifices breadth for depth. Generalizability is limited due to the small sample size used.

Conclusion and Future Research

In conclusion, young adults with disabilities in this study questioned their rights to have children. This has implications for health and education professionals. Future research should be conducted that continues to explore feelings of young adults with disabilities on reproductive rights to see if the findings in this study are common among different and larger samples.

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