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ORIGINAL PAPER

Educators' Attitudes and Beliefs Towards the Sexuality of Individuals with Developmental Disabilities

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Abstract This study presents educators' attitudes and beliefs towards the sexuality of adolescents and adults with developmental disabilities. Open-ended, structured interviews were conducted with five Teachers in a School Program and five Instructors in an Adult Day Services Program at an educational facility for individuals with medically complex developmental disabilities. Results indicate that educators hold a positive view towards providing sexuality education and access to sexual expression for persons with developmental disabilities. Educators viewed sexuality as a basic human right, yet expressed concerns regarding capacity to consent to and facilitation of sexual activity. This study is an initial step to understanding barriers preventing the delivery of sexuality education to this underserved population.

Keywords Attitudes · Consent · Developmental disabilities · Sexuality education

Introduction

Individuals with developmental disabilities comprise a vulnerable population at risk for victimization, pregnancy and sexually transmitted infections [1, 2]. Providing the tools to express their needs and enhance understanding of sexuality can facilitate prevention of sexual abuse, promote normalization and greatly improve quality of life. Caregivers' and parents' attitudes regarding sexual expression as a basic human right for persons with developmental disabilities have been examined [2–4], but minimal attention has been afforded to educators' views. The current study addressed this gap by examining educators' attitudes and beliefs towards the sexuality of individuals with developmental disabilities.

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Persons with developmental disabilities have long been stereotyped as asexual beings, childlike and naïve [5]. Ironically, they also have been regarded as sexual deviants, unable to control their sexual urges. Despite research evidence suggesting that individuals with developmental disabilities do engage in sexual activity [1], and are no more likely to be arrested for sexual offenses than their nondisabled peers [2], misperceptions regarding their sexuality persist. These misperceptions have led to numerous barriers preventing individuals with developmental disabilities from acquiring adequate sexuality education and social acceptance as sexual beings. In essence, failure to provide sexuality education may lead to deprivation of fulfilling social experiences. Research has shown that sexual socialization processes of individuals with developmental disabilities are linked to societal norms and are strongly influenced by the attitudes of parents and caregivers [6]. Lack of exposure to typically developing peers as role models coupled with repressive attitudes and failure to educate individuals with developmental disabilities on sexuality, specifically concepts of public versus private behaviors and inappropriate personal touches, may escalate their vulnerability to sexual predators [7].

Primary responsibility for the sexuality education of children with developmental disabilities is typically relegated to parents. However, parental fears of generating ideas that may lead to experimentation, denial of their child's developing sexuality, and lack of knowledge and skills about how to best present this type of information are among the many obstacles parents face in the role of sexual educator [8]. Parents understand the need to provide sexuality education but are often extremely cautious and avoid or delay such education until the high school years [9, 10]. Thus, while parents are perceived to be the most logical choice as sexuality educators, they often do not fulfill this role. For individuals with developmental disabilities who are placed in residential facilities, caregivers or professional educators are the more likely sources for providing information on sexuality-related topics.

Education professionals have long been perceived as responsible for providing school-based sexuality education. Currently, 32 states and the District of Columbia mandate that public schools provide HIV education; the majority also mandates sexuality education as part of the curriculum [11]. However, for students with disabilities, this responsibility is routinely diverted to ancillary professionals such as nurses and social workers. Lack of administrative support, limited appropriate training modules, and confusion about role responsibilities impede delivery of sexuality information to students with disabilities by the education professionals who may be best suited to teach such material [12]. It is not surprising then that a review of the limited literature reveals conflicting conclusions with regards to educators' overall attitudes towards sexuality education for individuals with developmental disabilities. Aunos and Feldman [13] suggest that while educators generally have a positive attitude towards sexuality education for disabled populations, few serve in this role or have taught such programs themselves. In addition to insufficient transparency regarding whose domain the responsibility of sexuality education falls, this service gap may also be the result of a dearth of programs that have been subjected to evaluation processes for individuals with developmental disabilities [7]. Howard-Barr et al. [14] concluded that despite the more inclusive overall societal attitude towards accepting the sexuality of individuals with developmental disabilities, educators continue to hold conservative viewpoints and do not understand this population's needs. Contributory factors to conservative viewpoints include a lack of training and competence to deliver sexuality education programs coupled with a perceived lack of administrative and parental support. Additional studies that elucidate existing barriers are needed to develop effective policies and interventions that will support educators in providing sexuality education to

individuals with developmental disabilities. Toward this end, three overarching research questions guided this study:

1. What are educators' attitudes and beliefs about sexuality related issues for individuals with developmental disabilities?
2. Are there differences in the attitudes and beliefs of Instructors in an Adult Program and Teachers in a School Program towards sexuality related issues?
3. How might sexuality education best be delivered to children and adults with developmental disabilities?

Methods

In order to fully explore the research questions, in-depth interviews were conducted. In-depth interviews are highly useful for exploratory qualitative research [15], in part because they provide investigators with access to others' experiences through narration of personal stories from which investigators can then develop insights [16]. A comprehensive review of the empirical research on sexuality and developmental disabilities led to the formulation of a structured interview protocol that included 37 questions. Examples of questions include: (a) "Describe any instances where students in your classes exhibited interest in sexuality related matter?", (b) "What do you believe are appropriate ways for individuals with developmental disabilities to express their sexuality?", (c) "In thinking about your role as an Instructor/Teacher what are your feelings about addressing sexuality related issues with your class?" and (d) "What ideas, suggestions or changes would you recommend for the way sexuality is addressed currently in the day program you work in?" Interview questions were open-ended and probes such as "tell me more" or "can you give me an example" were used to further elicit information. Eight of the questions focused on demographics.

Participants

A non-probability, convenience sample of educators was obtained to document the classroom experiences regarding sexuality and disability. Purposeful sampling allows for selection from a population that has familiarity with the material an investigator is interested in studying [16]. Participants included: Teachers in a School Program for children ages three through 21 and Instructors in an Adult Day Services Program for men and women over age 21 at a facility for individuals with medically complex developmental disabilities located in the Northeast. Teachers have a minimum of a Bachelor's Degree with appropriate state-mandated certifications and Instructors have a Bachelor's Degree and experience working in the Human Services field. Teachers work with classes of middle school to high school aged students with varying cognitive and functional capacities ranging from a developmental age of less than 12 months (i.e. sensory level of function) to IQs of less than 70. Instructors with the adult population have a larger proportion of higher cognitively functioning individuals in their classes, with the majority in the moderate to mild range of intellectual disability. All students have multiple physical disabilities in addition to cognitive impairments with common diagnoses of spastic quadriplegia due to Cerebral Palsy and various genetic disorders.

Participant recruitment consisted of verbal announcements at staff meetings and direct outreach by phone and email to Instructors and Teachers. A total of sixteen educators

volunteered to participate, approximately 55% of educators employed at the facility. To ensure an adequate sample size, data was systematically collected to the point of thematic saturation [16], which occurred after the tenth interview. Five interviews with adult Instructors and five interviews with Teachers were completed. Interviews were conducted by the Principal Investigator, who is a social worker at the facility and a social work doctoral student. The interviews averaged approximately 60 minutes in duration. Interviews were audio-taped and transcribed, then checked for accuracy. All interviews occurred in the social worker's office during the work day. No monetary compensation was provided. Institutional Review Board approval was obtained from both Rutgers University and through the Ethics Board at the facility in which the research occurred.

Data Analysis

To determine emergent themes from participant's interviews, data analysis consisted of evaluating the content of interviews across cases. Content analysis is a mechanism of analyzing text to make sense of the qualitative material and ultimately identify recurring foci [16]. This method has the advantage of being unobtrusive and is a relatively expedient mechanism to analyze a significant amount of text [17]. Open coding was used, which involved the identification of themes and categories in the data and placing a preliminary label on them. Themes were identified through an iterative process in which the researchers alternated between asking questions about the data and returning to the data to verify and compare their notes.

Results and Discussion

Instructors from the Adult Day Services Program range from 30 to 50 years of age. Their average age was 37. Two are community instructors who take their classes on trips in the surrounding neighboring environment and three were primarily stationed in classrooms in the facility. The four female and one male Instructor had Bachelor's degrees in either Psychology or Sociology, one Instructor had also earned a Masters in Behavioral Health.

Teachers in the School Program range from 42 to 57 years of age. Their average age was 50.2. One male and four female Teachers were interviewed. Four teachers had Bachelor's degrees in Special Education, one had a degree in Accounting. Several Teachers had advanced degrees; one had two Masters degrees, one a Law degree and another was completing a Ph.D. The average length of time Teachers were employed with a special education population was 12.4 years; 3.8 years for Instructors. All Instructors and Teachers in this sample are of non-Hispanic White ethnicity.

Using the analytic strategy described earlier, three themes were identified across educators' responses: (1) Sexuality as a basic human right, (2) Capacity to consent, and (3) Need for sexuality education.

Sexual Expression is a Basic Human Right

A primary theme that emerged from these data is the fundamental human right of sexual expression. The majority of respondents suggested sexuality is a *normal and natural* part of being human and a definitive *need* to achieving intimacy and fulfillment for individuals with developmental disabilities. Instructors consistently stressed the importance of autonomy, with comments such as "*I want this person to do what he wants, it's a right*"

and "*I think they have every right to do it*." Others delineated the continuum of rights, as noted by a Teacher who stated "*whether it's marriage, sexual intercourse whatever, it's their decision*." Moreover, respondents made comparisons between the nondisabled and individuals with developmental disabilities, delineating commonalities to further aver the normalcy of the right to sexual expression for all. As Instructors shared, "*The commonality we all have as people; we all have the same life emotions and challenges*," and "*Let them have their fun-they're adults, let them like anyone else*." One Teacher stated, "*Well, I don't think that they're any different than a normal person, normal people do it, so if there is a safe way for the person to satisfy their needs and it's… I don't see anything wrong with it for them*."

Sexuality was explicated and normalized as a need from both a physical and an emotional perspective. An Instructor noted "*They want to have that emotional connection… what they really want [is] gratification but [with a focus on the] emotional aspect*." Another Instructor observed how individuals with developmental disabilities appear to differentiate between the emotional/romance aspect of relationships and physical sexuality: "*To them a romantic relationship is holding hands, a kiss on the cheek, as for actual sexual relations there is not [what we think of as intimate sexual relations] because to them they think that [holding hands and kissing] is really intimate. That is their definition of romance*". Another Instructor stressed the level of knowledge and skills regarding the physical aspects students were interested in by stating: "*The whole class wants to talk about porn, kissing, intimate actual sexual intercourse, positions they can get into, vibrators*." Educators reflected on the physical and emotional aspects in experiencing sexuality and relationships and considered implications for helping individuals with developmental disabilities to achieve satisfactory life experiences.

Educators also framed sexuality requiring systemic understanding of self and society to understand sexual rights: "*Regarding sexual relationships… requires a lot of self examination, in some ways we have to serve them to their best interest to help them in achieving their full potential and where does sexuality fit into that, are we the judge of that? We have to explore as a society more*." Another Instructor lamented *"[sexuality] a natural thing and it's foreign to most people here… I think human rights- necessary to make sure, but sad too… Natural thing for most people but made into an issue here*." Educators appear to be frustrated by and struggle with their students' experience of their own sexuality as a basic human right and society's role in mediating this process.

Capacity to Consent

A second theme identified is the individual's ability to demonstrate capacity to consent. Review of research in this area acknowledges three widely recognized components used in evaluating a person's capacity to consent to sexual activity: knowledge, rationality and voluntariness [18–20]. The dilemma is how to accurately and appropriately determine these components in a population who cannot be assessed by current conventional tools. The onus often falls on the caregiver or guardian to protect and preserve the safety of the individual without devaluing his or her basic human right to participate in intimate experiences. Although no interview questions specifically addressed one's capacity to consent, all educators referred to this construct as a key issue causing concern. Educators addressed the need for maintaining balance to preserve one's autonomy and right to participate and experience sexuality while preventing victimization. As one Teacher observed, "*If it can be determined it's consensual it would be appropriate. People are at different levels of functioning who can and cannot make choices. [We] need to protect*

them in case they don't want to participate." Teachers and Instructors verbalized concern about individuals' ability to handle emotional components of a physically intimate relationship. As one Teacher described, "*It's a necessary component… they are maturing at an almost 'normal' rate and sexuality and emotions are something they have to deal with.*" An Instructor further elucidated this concept, "*If both [partners have] mental capacity to consent, it is okay for them to have a sexual relationship. [They should have] understanding of all the ramifications; like if you're going to have sexual relations [that may lead to] lot deeper emotions and stuff and [they need to] be able to handle the emotions…*"

Respondents suggested that capacity to consent was a critical issue that incorporated *privacy rights* and *facilitation issues.* An individual's right to privacy is a pervasive concern in institutional settings where most of the population shares rooms with at least one roommate. Respondents noted that privacy and time to address sexual needs are definitive rights that have been largely unacknowledged to date. As one Instructor suggested "*Regarding roommates-time and place to set up for them to do it [e.g., masturbation]… it's difficult in this environment because they're not really allowed to-I feel they should be allowed [to masturbate]… to have a room to go fool around in-[but there is] no privacy-privacy is an issue*". Another Instructor reflected on a resident's need for time to masturbate "*… provide him with time… …several [nondisabled] people [are] allowed their private time.*"

Educators agreed that sexuality education should help individuals with developmental disabilities understand the distinctions between public and private sexual behaviors. What is considered appropriate—publicly or privately—with regard to time and place is a cornerstone of most sexuality education curricula [21]. Differentiating between socially appropriate public behaviors and those defined as private is a difficult concept for individuals who have many aspects of their private lives controlled by caregivers. In addition, lack of appropriate social role models further complicates their ability to make this discrimination [1]. As one Teacher stated *"… it's an absolute necessity… (they) have to know what they are not supposed to do in public*." Educators believe the knowledge to act in accordance with social mores can facilitate the integration of individuals with developmental disabilities within mainstream society and contribute to the dissolution of societal misperceptions related to sexual behavior (e.g., the belief that individuals with developmental disabilities are sexually deviant).

Facilitation of sexual activity for those who have significant physical disabilities was another important issue noted by respondents. Preparing individuals with disabilities for sexual activity (e.g., removing clothes, positioning, and retrieving erotic materials) is considered less problematic than direct participation with stimulation (e.g., a personal assistant placing her/his hands on the consumer's hands to guide stimulation, helping two clients with disabilities stimulate each other) [22]. One Instructor recounted "*It hurts me… because they can't have that. I tell them to talk to their families or their social workers, one guy wanted a dildo, he'd need someone to help him, but that's a huge line to cross, how can you ask someone to do that?*" A Teacher stated "*How independent is the individual going to be in the act, one partner helping the other that's fine-but if there needs to be a third party… I think there's unchartered waters, I would hope we've started to kind of map out…*" While supporting the individual's right to self-determination in experiencing sexual intimacy, educators are conflicted about the implications that facilitation of sexual activity poses for caregivers. Interestingly, all educators acknowledged approval of sexual intercourse and marriage for this population as long as capacity to consent was determined and sexual activities occurred in an appropriate place, at an appropriate time.

Need for Sexuality Education

Overall, educators noted that accurate sexual information will help maturing individuals with developmental disabilities engage in safe and socially appropriate relationships and experiences. Uniform agreement among both Teachers and Instructors was evidenced regarding the following three categories: (1) the value of providing sexuality education to students; (2) the need for sexuality education to begin during the school years; and (3) techniques for the delivery of a sexuality education curriculum.

Educators were emphatic about the value of sexuality education in minimizing risk and enhancing functionality among persons with developmental disabilities. As one educator exclaimed in response to a question regarding the need for sexual education in the population "*definitely a must, important they understand what's socially acceptable, consequences for having relations with no protection, pregnancy, stds and that kind of thing even though they are developmentally disabled… if they have enough cognition to understand they have these desires and wants, (they) need to know how to protect themselves*!" Instructors and Teachers asserted this population should receive the same sexuality education curriculum as nondisabled or mainstreamed students with disabilities, citing an understanding of sexuality as a necessary component for self-development and citizenship.

Instructors and Teachers suggested various time frames for the initiation of sexuality education ranging from birth through high school. Most deferred to the specific cognitive level of the individual as a guide for when information should be provided, but regardless of cognition, all noted that students should receive sexuality education by the onset of puberty and no later than the start of middle school. While some educators believed the family should be responsible for initiating discussion of sexuality, all stressed that the school had a major role in providing sexuality education—both independently and as a supplement to support families.

Educators proposed a multisensory approach to deliver sexuality education to persons with developmental disabilities. Awareness of and sensitivity to the different cognitive styles for learning is clearly demonstrated by those who recommended the use of diagrams, pictures, manipulatives and auditory stimuli. Educators stressed the importance of deconstructing the material to a form that students could comprehend given their sensory and cognitive abilities. Introducing material creatively is a skill set that educators regularly employ when teaching individuals with developmental disabilities. As indicated by the following observations "*visual learners, visual and concrete, diagrams, videos" and "role playing with dolls… and the auditory. My class is receptive not expressive so you would have to give them something to express it with…*," educators understand that their students have unique capacities which may differ from conventional educational paradigms.

Despite their general acceptance of sexual intercourse and marriage for individuals with developmental disabilities, educators unanimously expressed ambivalence or disapproval towards pregnancy. Their belief that individuals with developmental disabilities cannot function independently and care for themselves invokes profound implications with regards to giving birth and raising a child. As one Instructor reflected "*If [pregnancy] happened, it's very intense… they would have to know what a huge responsibility it would be if they had children. They can't care for themselves how can they care for another being… it wouldn't be the greatest decision.*" Another Instructor stated "*I don't think it's fair to have somebody who is disabled themselves and can't take care of themselves… I don't mind sex but the pregnancy is not fair to the child…*" Apprehensions about having children were matched with health concerns for the individual who would experience

pregnancy. One Teacher reflected "*I have concerns… about their frailness and pregnancy… much of our population is medically fragile*." The physical and medical limitations of the population inspire reflective commentary in this domain perhaps even superseding the educators' concerns about cognitive limitations.

Differences Between Groups

The major differences identified in the responses between Teachers and Instructors address perceptions of their *role* as sexuality educators. Instructors appeared open and willing to assume the role of sexuality educator for students with developmental disabilities. As one Instructor related "*… I think it's good and important for them to express their feelings. Instructors should feel comfortable in talking about that. It's educational-they don't have friends outside of here that they can go talk to about it, we're instructors, mentors*".

However, the majority of Teachers did not view educating students about sexuality as their professional responsibility. Teachers defined their roles in a more traditional capacity as authority figures with a specific mission to teach a prescribed core curriculum. They perceived formal sexuality education to be beyond the scope of their expertise, which may be due, in part, to limited academic or employment-based training and preparation about this topic area. Instead, they relegated this task to other school-based professionals or family members. As one Teacher observed, "*We have the nurse and the Phys Ed. Teacher teaching them health issues… I don't feel it's my role*". Another Teacher noted "*… (it) should start at home, but if they live here, nurses, PCAs (personal care assistants)… people who do their ADLs (activities of daily living), should be the nurses… they should overtake the caregivers' role… don't think it should be the teachers… don't dress them. Don't have intimacy with them.*" These comments suggest that sexuality education is better left to professionals whose training, experience, and routine tasks prepare them to function in that role. This would likely include social workers, psychologists, and those who attend to the personal care activities of individuals with developmental disabilities. Without a clearly delineated policy about the provision of sexuality information to students, Teachers appear reluctant to serve in this role.

Conclusion

This investigation contributes to a limited body of research on educators' perceptions about barriers to sexual expression and views about sexuality education for adolescents and adults with developmental disabilities. Because educators play a central role in the delivery of sexuality information, their attitudes and beliefs act as filters for sexuality topics communicated to their students. Our findings support previous research in this context [14] that suggests lack of clarity defining role and responsibilities as a sexuality educator and apprehension about providing sexuality education may served as obstacles for Teachers and Instructors. Yet overall, educators exhibited positive attitudes towards sexuality in this population.

The results suggest a trend towards positive attitudes for sexual rights of individuals with developmental disabilities. Most notably, marriage was viewed favorably, reflecting a shift from previous findings [23]. However, pregnancy continues to be viewed less positively, a finding consistent with current literature [24, 25]. With profound concern about the health and well-being of women with developmental disabilities, it is important to explore whether educators' beliefs about pregnancy in this population might impact the

delivery of information on the topic and, in turn, impede prevention and sexual health promotion efforts for women.

Consent capacity is another potential barrier to healthy sexuality for this population. Creating a "capacity to consent to sexuality" instrument that captures the multisensory needs and abilities of individuals with moderate to severe developmental disabilities is warranted. Individuals who are verbally or physically unable to communicate their desires for sexual activity may still be capable of consenting to sexual activity.

Once capacity to consent is established other issues may arise. When a person is physically disabled and unable to experience sexuality without assistance, there is a need for facilitation [26]. This need for 'facilitation' was another identified theme. This issue has potential to become both a moral and ethical dilemma for guardians and caretakers. Policy and procedure manuals in most residential settings fail to address this topic which leads to educators' concern for clients' rights as well as apprehension and unanswered questions as to who, if anyone, should assist with facilitation.

Uniform agreement about these topics among the Teachers and Instructors who participated in this study reveals a basic concern for the populations' ability to experience an important aspect of their socio-sexual development. Yet, one major difference between the groups' responses prevailed, namely their perception of *role definition as* sexuality educators. Instructors regarded this aspect as part of their routine responsibilities while Teachers voiced discomfort about providing sexuality education to their students. Perceptions about roles between the two groups may be partially attributed to age differences. Instructors were significantly younger than Teachers and closer in age to their adult students. Instructors reported a greater tendency to identify with their students. As one Instructor observed *"… [I am the] same age as they are, [students] look at me like a friend, someone they can talk to.*" This finding is consistent with previous research that has shown age related factors impact attitudes and beliefs towards sexuality in this population. Older adults have been associated with more conservative attitudes towards sexuality than younger adults [25, 27]. Other possible explanations that require further research include differences in their level of professional preparation to teach sexuality education, the impact of perceived administrative level of support and self-efficacy and competence in providing instruction on sexuality-related topics.

Another reason for the differences among Instructors' and Teachers' attitudes may be due in part to the difference in functional and developmental levels of the students with whom they work. Students in the Adult Day Services Program had higher cognition and ability to engage in emotional relationships than students in the School Program whose developmental levels were considerably lower. Sexual activity for most school aged students consists of sensory oriented activities such as masturbation. Sophisticated social/emotional relationships including romance and intimacy do not appear to be issues for students in the school program.

This qualitative exploratory study provided important information about the attitudes and beliefs of a subset of educators, but some limitations should be noted. This study did not examine beliefs and attitudes as predictors of action, an important concept that requires further inquiry. Due to the small sample size, the findings cannot be generalized to all educators. Nevertheless, the identified themes are understudied in the literature and merit further examination. Follow-up focus groups or interviewee review of the data could have confirmed and expanded upon the findings. Finally, study participants were nonHispanic White. Exploring attitudes across racial and ethnic groups to garner a more reflective sample of educators in contemporary society is needed.

Implications for Future Research

Educators at residential facilities are specially trained to teach individuals with developmental disabilities and adapt curricula and instructional techniques that are effective with this population. However, sexuality is often a neglected focus. Educators require training in human sexuality to impart this information in an appropriate format and unbiased manner. Many of the educators who participated in this study provided suggestions for creative teaching techniques but Teachers seemed reluctant to assume the responsibility of administering such a curriculum. A multidisciplinary team approach that includes an educator, nurse, social worker and personal care attendant may be indicated. Future research should explore the training needs of educators to ensure they are able to select the most appropriate material and instructional techniques to embed sexuality education into existing curriculum and teach it in natural environments. Studies should assess the impact of training and formal education on educators' knowledge, attitudes, and self-efficacy beliefs towards sexuality education for individuals with medically complex developmental disabilities. Students with developmental disabilities require specific knowledge and skills to make safe, healthy and informed decisions regarding issues of sexuality and sexual expression. Skilled educators can be instrumental in their achievement.

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