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Barriers to Sexuality for Individuals with Intellectual and Developmental Disabilities: A Literature Review

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Abstract: Individuals with intellectual and developmental disabilities (ID/DD) experience multiple barriers that may prevent them from understanding and exploring their own sexuality. These barriers prevent them from achieving the same autonomy and quality of life as their peers. This research synthesis focuses on 13 articles published between 2000 and 2013 that explored sexuality of individuals with ID/DD. Analysis of these articles produced common barriers that individuals with ID/DD experience. Implications for practice are discussed.

Despite the recent focus on quality of life for individuals with intellectual and developmental disabilities (ID/DD) and an emphasis on full inclusion, relatively little is known about issues of sexuality for this population. Individuals with ID/DD face many barriers during their development into and in adulthood, including accessing their own sexuality. Unfortunately, the barriers that individuals with ID/DD face are often reinforced by the lack of attention and common misconceptions regarding sexuality and sexuality education.

There are multiple explanations for this lack of attention to sexuality. Common social misconceptions may reinforce myths that portray individuals with disabilities as incapable of being sexually active, incapable of understanding the complexities of sexuality, or even deny the existence of sexuality as a part of their lives (Murphy & Elias, 2006). Another explanation may be the assumption "that adolescents with moderate disabilities could not participate in education to attain the skills that would lead to any acceptable form of quality of life" (Harader, Fullwood, & Hawthorne, 2009, p.18). Unfortunately, these myths and barriers often deny individuals with ID/DD equitable access to sexuality education that could help these individuals to lead a fully autonomous and fulfilling life inclusive of their sexuality.

A place to begin dispelling these myths is by clearly defining and describing components of sexuality. Murphy and Elias (2006) have suggested that definitions of sexuality should include gender-role socialization, physical maturation and body image, social relationships, as well as future social aspirations. More broadly, the National Information Center for Children and Youth with Disabilities has defined human sexuality as, sexuality knowledge, beliefs, attitudes, values and behaviors of individuals (1992). The Sexuality Information and Education Council of the United States (SIECUS) defines sexuality "as multifaceted, having biological, social, psychological, spiritual, ethical, and cultural dimensions" (Gougeon, 2009). For the purpose of this paper we choose to view sexuality as defined by the SIECUS. Using a multifaceted definition of sexuality helps highlight the scope of topics included in sexuality education.

Comprehensive sexuality education empowers individuals with ID/DD to enjoy personal sexual fulfillment and protect themselves from abuse, unplanned pregnancies, and sexually transmitted infections (Murphy & Young, 2005). Unfortunately, individuals with ID/DD have not been provided the same opportunities (Boehning, 2006; Cabe & Cum-

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mins, 1996) and access (Hamilton, 2002) to learn and make decisions about sexuality as typically developing peers. "Considering that adolescents with and without disabilities have been found to be experiencing similar age of onset and rates of sexual activity there is obvious need for equitable sexuality education availability" (Tice & Harnek Hall, 2008, p. 48). Excluding individuals with ID/DD from sexuality education is not a viable option for full inclusion into all aspects of life.

Review of the previous sexuality research indicates that individuals with ID/DD experience multiple barriers to achieving full autonomy over their sexuality. The barriers in place threaten an individual's knowledge, experiences, and decision-making surrounding sexuality. This further restricts an individual's overall quality of life (QOL). Viewing sexuality of individuals with ID/DD through a QOL framework provides the opportunity to promote full citizenship and autonomy.

Framework and Theoretical Foundation

Societal inclusion and equitable access are key concepts within the quality of life framework. Schalock, Gardner, and Bradley (2007) state:

> At its core the Quality of Life (QOL) concept makes us think differently about people at the margin of society and how we might bring about change at the organizational, systems, and community levels to enhance people's personal well-being and to reduce their exclusion from the societal mainstream. (p. 3)

This framework requires us to ensure that all individuals receive the opportunity for education along with relation and identity exploration (Siebers, 2012).

Individuals who support QOL for individuals with ID/DD can promote the concept of intimate citizenship. Intimate citizenship is defined as "the control (or not) over one's body, feelings, relationship: access (or not) to representations, relationships, public spaces, etc; and socially grounded choices (or not) about identities, and gender experiences" (Siebers, 2012, p. 38). Stated otherwise, intimate citizenship is the control over one's body and choices made in context with that body. Intimate citizenship is aligned with the concept of citizenship; "a person's full membership in a community, with a choice of participation or non-participation in a said community, and with access to knowledge that would enable such a person to make well-informed decisions in all areas of life" (Gougeon, 2009, p. 279).

From an intimate citizenship perspective, individuals with ID/DD need to have full access and participation in decisions regarding all aspects of sexuality (e.g., relationships, identity development, and sexual orientation). That access spans not only to sexuality education but also to the greater realm of everyday life. Unlike other aspects of adulthood such as employment, postsecondary education, or independent living, decisions about sexuality are more likely to be scrutinized (World Health Organization Guidance note, 2009), and the lack of equal access becomes more prevalent for individuals with ID/DD. The idea that individuals with disabilities should have access to full citizenship is not new; however, when it comes to access to sexuality, what once was a black and white issue becomes grey for some (Harader et al., 2009).

Sexuality of individuals with ID/DD has not been a major focus for the disability field. The lack of attention on an important topic makes a review of the current research necessary to provide researchers and practitioners with information that can advance practices to ensure programs and practices include access to sexuality for individuals with ID/DD. This research synthesis will examine the barriers to accessing sexuality experienced by individuals with ID/DD. The overarching research question we posed was: "What are the barriers that individuals with ID/DD face when accessing sexuality and sexuality education?" Answering this question will lay a foundation for creating a state of equitable access to sexuality.

Method

A research synthesis was conducted to examine the published research educational practices and perceptions of sexuality for individuals with ID/DD. Using a quality of life framework, the current study describes barriers that have been experienced by individuals with ID/DD in gaining knowledge of sexual-

ity, sexuality-related topics, and experiencing relationships. For the purpose of this research, we define sexuality broadly to include biological, social, psychological, spiritual, ethical, and cultural dimensions (Gougeon, 2009). Using this definition captures the multiple dimensions of sexuality and allows the literature review to look beyond access to only biological sex education, for example.

Multiple steps were taken to identify the articles included for this review. Our first step was identifying databases to search. PsychInfo, PubMed, and ERIC were identified as the three publication databases because they are commonly used for sexuality, education and disability related scholarship. A cross-disciplinary publication search was important so that information gathered from multiple academic communities could be considered for this particular synthesis. PsychInfo was the database that produced the majority of relevant publications.

Our next step was to identify the search terms for our review. The primary search terms used in each database included either *intellectual disabilities* or *developmental disabilities* (the population in focus for this literature review) and additional search terms were: *disability, sex education, sexuality, sexual orientation, adolescent,* and *young adults with disabilities*. This search yielded 32 publications across the databases queried. We expanded our search terminology to include: *decision-making, puberty,* and *sexuality education*, which yielded additional articles. By consistently using *intellectual* and/or *development disability* we were able to select studies focused on the population of interest.

After identifying our search terms, we identified the range of dates for this literature review. We limited the scope to include only literature published between 2000 and 2013. This timeframe was chosen for a several reasons. First, the search would result in the most current information available in regards to sexuality and intellectual/developmental disabilities. Second, this recent research reflects current societal trends and attitudes towards sexuality, and in addition is reflective of current special education practices. Lastly, whereas other literature reviews such as those conducted by Gougeon (2009) and McGuire and Bayley (2011) were specific to individuals with autism spectrum disorder or perceptions of caregivers; this review included information about individuals with all intellectual and developmental disabilities, and also expanded on topics which produced a different set of articles to review. Upon completing the database search, we conducted a second source search identified additional studies from the references of the articles found in our initial search for any additional articles to be included in the synthesis.

Our fourth step was to exclude articles that were not peer reviewed. During this step we also read for evidence of the quality indicators for qualitative (Brantlinger, Jimenez, Klingner, Pugach, & Richardson, 2005) and single-case designs (Horner, Carr, Halle, Odom, & Wolery, 2005). For example, one quality indicator for single-case research is the establishment of "three demonstrations of the experimental effect at three points in time through demonstration that behavior change covaries with manipulation of the independent variable between baseline and intervention phases" (Horner et al., 2005, p. 168). Although quality indicator rules may vary in qualitative research Wolcott (1990) advises "to be reasonable and not apply the quality indicators in an arbitrary or intolerant manner" due to some "unique and unconventional reporting formats" (as cited in Brantlinger et al., 2005, p. 202). If articles did not meet with reservation (e.g., three points of data versus five points of data during a single-case phase) or higher, on the quality indicators as judged by the researchers, they were excluded from this literature review.

Lastly, we did not exclude any article due to participant age. Our research synthesis is focused on barriers to accessing sexuality and sex education. We believe these barriers can be experienced across the life span and did not identify age as an inclusion/exclusion criterion. Furthermore, for articles to be included in this synthesis, the research conducted in each article had to address individuals' with ID/DD access to sexuality, sexuality education, and/or knowledge of sexuality. Fifty-three total articles were found in our search. Only 13 articles met all of our inclusion criteria (see Table 1).

Table 1

Research on sexuality and sexuality education for persons with ID/DD

Authors/Date/Title	*Sample*	*Research Design*	*Results*	*Summary*
Bedard, C., Zhang, H. L., & Zucker, K. J. (2010). Gender identity and sexual orientation in people with developmental disability. Sexuality and Disability, 28, 165–175. doi:10.1007/s11195-010-9155-7	32 participants (16 males and 16 females) 20–64 years old. All had developmental disabilities —Functioning level ranged from borderline intelligence to high moderate level of developmental disability.	Descriptive study to survey and compare. Complete 5 questionnaires (demographics (10 questions), sexual orientation (Erotic Response and Orientation Scale), sexual history, recalled childhood gender identity, and adult gender identity). Comparisons were made regarding their sexual orientation and gender identity, as well as differences based on their diagnosis that may not have been related to their developmental disability.	Self-identification of their sexuality matched with the EROS scale. There was not a greater increase in Gender Identity Disorder with those with DD.	There was a range of gender identity and sexual orientation in individuals with developmental disabilities.
Bernert, D. J., (2011). Sexuality and disability in the lives of women with intellectual disability. Sexuality and Disability, 29, 129–141. doi:10.1007/s11195-010-9190-4	14 women, intellectual disabilities, 18–89 Y.O. 21% African American, 71% European American, 7% Native American, all participants had assistance or lived in an assisted living.	Ethnographic study. Sexual autonomy, disability identification. Talked about their sexuality and how sexuality functioned in their lives.	1) Most women functioned within disability-centered environments without having a disability identity, 2) most women expressed an adult identity that resulted in their expectations of sexual autonomy. 3) Most women experienced sexuality limitations because of protective policies and programs.	"The perception that intellectual disability equals dysfunction creates linear thinking that persons with intellectual disabilities are incapable of managing their sexuality, whether accurate or inaccurate to their actual experiences." Individuals in the study see themselves as adults, and NOT having intellectual disabilities.
Dukes, E., & McGuire, B. E. (2009). Enhancing capacity to make sexuality-related decisions in people with an intellectual disability. Journal of Intellectual Disability Research, 53, 727–734. doi:10.1111/j.1365-2788.2009.01186.x	4 participants (two male and two female). 22–23 years old.	Single-subject design. Individually tailored sex education adapted from *Living Your Life*. Multiple baseline design. Four target areas: knowledge of sexual safety practices, knowledge of the physical self, knowledge of sexual functioning, and knowledge of choices and consequences in sexual matters.	The results indicate that all four participants improved their knowledge in all targeted areas as measured by an increase in the number of SCEA items correctly answered after the intervention.	The aim of the study was to apply an intervention to the area of sexual knowledge in order to determine if capacity to make sexuality-related decisions could be improved.
Esmail, S., Darry, K., Walter, A., & Knupp, H. (2010). Attitudes and perceptions towards disability and sexuality. Disability and Rehabilitation, 32, 1148–1155. doi:10.3109/09638280903419277	32 Participants 18 years +, placed in 1 of 4 focus groups. Each F.G. had 6–8 people. Focus groups were divided into: service providers, visible disabilities, invisible disabilities, general population.	Phenomenological research. Short documentary film on sexuality and disability. Explore themes in sexuality and disability in the four focus groups	1) Stigma of being labeled as asexual, 2) Difference between visible and invisible disabilities and stigma, 3) people living with disabilities could benefit from formal, accurate sexual education information and resources.	Primary aim: describe the current societal perceptions and attitudes surrounding sexuality and disability and to understand the basis of these views. Secondary aims included determining how social stigma differs between individuals living with visible and invisible disabilities.

Table 1—*(Continued)*

Authors/Date/Title	*Sample*	*Research Design*	*Results*	*Summary*
Galea, J., Butler, J., Iacono., T., & Leighton, D. (2004). The assessment of sexual knowledge in people with intellectual disability. Journal of Intellectual and Developmental Disability, 29, 350–365. doi:10.1080/13668250400014517	96 adults (54 males, 42 females) with intellectual disability, ranging from 18–57 years old. 75% reported mild disability, 22% reported moderate	Explore the sexual knowledge of people with an intellectual disability as assessed on the knowledge section of the ASK. Scores from the QKQ were compared against each other scores of the different questions.	Participants scored relatively well (in relation to scores on other sections) on knowledge of parts of the body, assessing public and private parts and places, masturbation, relationships, protective behaviors, pregnancy and birth, legal issues regarding sexuality (illegal behaviors). Participants scored relatively poorly on knowledge of puberty, menstruation, menopause, sexuality, safer sex practices, sexual health–screening tests, sexually transmitted infections, legal issues regarding sexuality (rights) and in particular, the area of contraception.	There was only a significant difference between males and females in regards to knowledge of menstruation. "Overall, participants had limited knowledge of safe sex practices, sexually transmitted infections, contraception, and, in particular, sexual health screening. These results suggest that either participants are not involved in appropriate sex education programs, these topics are not being taught, or the information that is presented is not being understood or retained."
Garwood, M., & McCabe, M. (2000). Impact of sex education programs on sexual knowledge and feelings of men with mild intellectual disability. Education and Training in Mental Retardation and Developmental Disabilities, 35, 269–283.	6 adolescent and young adult men.	Participants were given the Sexuality knowledge, experience, feelings and needs scale for people with intellectual disability (Sex Ken-ID) Pre and Post tests. Participants had 6–10 sessions of sex education in a community health setting.	The hypothesis that participants from each of the sex education programs would attain greater sexual knowledge at the completion of the programs, compared to program entry, was only moderately supported. Despite increases in knowledge for both groups in most sexuality areas at post-test, such increases were mainly of a minimal degree.	There needs to be more individualized sex education for people with intellectual disabilities. Parents and caregivers have influence on individuals with intellectual disability view of sexuality.
Healy, E., McGuire, B. E., Evans, D. S., & Carley, S. N. (2009). Sexuality and personal relationships for people with an intellectual disability. Part 1: Service-user perspectives. Journal of Intellectual Disability Research, 53, 905–912. doi:10.1111/j.1365-2788.2009.01203.x	5 focus groups were conducted (3 groups separated by age [13–17 years, 18–30 years, 31+] and then by gender [20 male, 12 female]) 32 participants total.	Employed a focus group method that encouraged open and frank discussion of sexuality issues. Asked questions 1) general views regarding sexual and relationship experiences of people with an ID, 2) The experiences of participants with regard to relationships and sexuality, 3) Aspirations in terms of personal relationships and sexuality.	It appears that participants demonstrate a clear understanding of companionship, trust and the reciprocal nature of relationships and its positive effects on self-esteem; they aspire to marriage and children; endorse the sexual activity of masturbation; understand the need for privacy and request greater tolerance from careers.	Discussion points from the groups 1) Personal relationships, 2) Relationships within the service or facility, 3) masturbation, 4) sexual intercourse, 5) sex education, 6) contraception, 7) privacy, 8) rules, 9) the future. "Provision of sex education training &promotion of positive attitudes towards appropriate sex expression is critical to the realization of sexual autonomy.
Lofgren-Martenson, L. (2004). "May I?" About sexuality and love in the new generation with intellectual disabilities. Sexuality and Disability, 22(3), 197–207.	13 Youth, 13 staff and 11 parents.	Ethnographic/qualitative study. Observations were taken at dances, and interviews were administered to young adults, staff members and parents.	The consequence is that staff members and relatives frequently act as "new obstacles or institutional walls" despite the fact that the old institutional obstacles have been removed.	Parents and care-takers now have control over what individuals with intellectual disabilities can do. There is no room for exploration for these individuals. There is still a sense of "fear" to let individuals with disabilities explore their sexuality.

Table 1—*(Continued)*

Authors/Date/Title	*Sample*	*Research Design*	*Results*	*Summary*
Lofgren-Martenson, L. (2012). "I want to do it right!" A pilot study of Swedish sex education and young people with intellectual disabilities. Sexuality and Disability, 30, 209–225.	9 Females, 7 males. Age range 16–21.	Qualitative interviews, with a guiding analysis of an interactionist perspective on sexuality.	A restrictive script is geared toward informants with intellectual disability.	It is unclear for participants to know what should be covered in sexuality education and by whom it should taught.
O'Callaghan, A. C., & Murphy, G. H. (2007). Sexual relationships in adults with intellectual disabilities: Understanding the law. Journal of Intellectual Disability Research, 51,197-206. doi:10.1111/j.1365-2788.2006.00857.x	60 adults [mean age = 37.6] and 60 young people [ages 16–18]. All participants had intellectual disability.	This is a qualitative inquiry to identify what individuals with ID know about the laws relating to sexuality. 30 questions were developed by the researchers for the participants to answer.	There were significant differences between the to groups: adults with ID had a very limited understanding of the general laws relating to sexuality (e.g., age of consent, incest, abuse), as well as the law relating to sexuality and ID (e.g., whether they could have sexual relationship, whether they were allowed to marry, what protection they should expect from the law). Young people showed a better understanding, both for general laws and for those relating specifically to adults with ID.	It is necessary to educate individuals with ID further on the laws that are in place to protect them. At this point more education is necessary.
Swango-Wilson, A. (2011). Meaningful sex education programs for individuals with intellectual/developmental disabilities. Sexuality and Disability, 29, 113–118. doi:10.1007/s11195-010-9168-2	Individuals with DD/CD: 23–43 years of age, 2 male and 1 female. Parents of DD/CD: 3 mothers. Profession: health educator, counselor, administrator. Health care professional: 2 nurses, 1 physician.	Ethnographic, qualitative study. Interviews of parents, health care professionals, individuals with DD/CD, and care staff.	Parents identified a common theme of denial and fear. Professionals–theme of safety and legal ramifications. Health professionals–theme to protect them from sexually transmitted diseases. CD/DD wanted to know relationship knowledge.	There is a discrepancy between "parents & professionals" and individuals with DD/CD.

Table 1—*(Continued)*

Authors/Date/Title	*Sample*	*Research Design*	*Results*	*Summary*
Swango-Wilson, A. (2009). Perception of sex education for individuals with developmental and cognitive disability: A four-cohort study. Sexuality and Disability, 27, 223–228. doi: 10.1007/s11195-009-9140-1	3 individuals with ID/DD based on the AAMR definition, met the criteria of being able to verbally communicate and engage in a question/answer relationship.	Qualitative inquiry to identify what individuals with ID/DD expect from a sex education program	Three themes. 1) Development of friendships [it is the meaning of trust that seems to challenge the ID/DD participant's judgments.] 2) development of lasting relationships and marriage. 3) self-intimacy	
			Recommendations for sex education include: 1) mix gender classes, 2) classes that focus on practical ways to develop relationships, 3) inclusion of class section for caregivers separate from class for ID/DD participant, 4) practice skills in different settings (homework), 5) continue to give information of safe sex practices but don't make that the main focus, and 6) include information on how to safely report abuse from care givers.	Focus of sex education programs to include: friendship, relationships, and safe sex behaviors.
Wilkenfeld, B. F. & Ballan, M. S. (2011). Educators' attitudes and beliefs towards the sexuality of individuals with developmental disabilities. Sexuality and Disability, 29, 351–361.	16 teachers who work with youth younger than age 21 and 5 instructors who work with youth older than 21.	Qualitative in-depth interviews. An review of the literature regarding sexuality and developmental disabilities informed the questions asked to participants.	Educators hold a positive view towards providing sexuality education and access to sexual expression for persons with developmental disabilities.	Viewed sexuality as a basic human right, yet expressed concerns regarding capacity to consent to and facilitation of sexual activity.

Nine of the thirteen articles used qualitative research methodology to explore and describe barriers that impact access to sexuality for individuals with ID/DD. Three studies were descriptive research utilizing survey methods and questionnaires. One article used a single subject design to show a functional relationship between sexuality knowledge acquisition and sexuality decision-making (measured by a sexual knowledge scale) and individualized sexuality education for each participant.

Data Analysis

To answer our original research question, "what are the barriers that individuals with ID/DD face when accessing sexuality and sexuality education?" we treated each study, as it's own unit, that is, "ensuring that each study contributes equally to the overall synthesis result" (Cooper, 1998, p. 98). To identify barriers we examined themes within each article. We reviewed each article to identify a theme that represented the culmination of the article's findings, as suggested by Cooper (1998).

After each article was analyzed, we used pattern coding for further analysis. First level pattern coding can be described as grouping of qualitative data into smaller categories (Miles, Huberman, & Saldaña, 2013). Pattern coding was used to review the abstracts of the included literature. Pattern coding was additionally used to review the results sections of each included publication. Once pattern coding was completed, codes from individual article abstracts and results were cross-referenced for code agreement. Cross-referencing was used to verify that the codes used for each article (abstract and results) were consistent with each other.

Three themes emerged from our pattern coding. The majority ($n = 11$) of articles included the theme of attitudes and perceptions of individuals with intellectual and developmental disabilities on sexuality. Just over half ($n = 7$) of the articles included the theme of attitudes and perceptions of others (parents, caretakers, general public) on sexuality and disability. A smaller number ($n = 5$) of articles included the theme of knowledge of individuals with ID/DD on sexuality. Every article indicated a desire to describe the current landscape for individuals with intellectual and developmental disabilities.

Each theme represents a culmination of our pattern coding. Similar to our thematic pattern coding, specific barriers emerged from the qualitative data reported in each article. Barriers are what an individual with ID/DD experiences or perceives. Each barrier was then mapped (Miles et al., 2013) to fit within one of three themes previously defined. For example, in a study asking parent's perceptions of their child with ID/DD sexuality, one parent opined, "their child was not interested [in sex]," (Swango-Wilson, 2009, p. 226). This statement would be mapped under the theme that included the perceptions of others about individuals with ID/DD and their sexuality.

Results

The reviewed studies revealed multiple barriers faced by individuals with ID/DD to accessing their sexuality and sexuality education in three major themes. The three themes are: a) perceptions of others about individuals with ID/DD and their sexuality, b) perceptions of individuals with ID/DD about their own sexuality, and c) sexuality knowledge of individuals with ID/DD. We summarize the literature of these three themes below. Within each theme we identify the barriers to accessing sexuality and sexuality education for individuals with ID/DD.

Theme 1: Perceptions of Others about Individuals with ID/DD and their Sexuality

The first theme focuses on perceptions of other people (e.g., parents, caregivers, service providers) about sexuality for individuals with ID/DD. Over half of the articles ($n = 7$) included in this synthesis asked care providers about their perceptions. One identified barrier is that parents and caregivers demonstrate a range of misunderstanding in regards to the sexuality of individuals with ID/DD (Esmail, Darry, Walter, & Knupp, 2010; Swango-Wilson, 2009). Parents and caregivers in multiple studies reviewed held the misperception that individuals with ID/DD are asexual. In one case, a parent of a child with ID/DD stated to researchers that "their child was not interested [in sex]," even if the parent recognized

that sex was an important part of life in general (Swango-Wilson, 2009, p. 226). When researchers in another study questioned a participant without a disability about a relationship with an individual with a disability, the participant responded by saying they would not want to begin a relationship with someone with a disability for fear of becoming a caregiver to the individual with a disability (Esmail et al., 2010).

A second barrier is the lack of consistency across providers on what topics and how to approach educating individuals with ID/DD regarding their sexuality. Their perceptions varied depending on the role the service provider had in his/her interaction with individuals with ID/DD. Across professional and personal roles there was no consensus as to what should be the primary goal of discussing sexuality and sex education with the individuals with disabilities they serve.

Physicians and health professionals were concerned about covering topics such as pregnancy, sexually transmitted diseases, and other reproductive health matters (Esmail et al., 2010). Independent living center service providers were concerned about the safety of their clients and feared legal ramifications from parents for unapproved sexual behaviors even though the individuals they cared for were over eighteen years of age (Bernert, 2011; Esmail et al., 2010). Parent responses seemed to be more focused on sexual abuse and unwanted pregnancy; for example, "I fear sexual abuse . . . he is so trusting" (Swango-Wilson, 2009, p. 226) and "if she had a baby I don't think I could raise another one" (Swango-Wilson, 2009, p. 226). The views of service providers and parents resulted in restrictions on relationships and personal encounters for individuals with ID/DD (Bernert, 2011; Esmail et al., 2010; Swango-Wilson, 2009). In contrast, the majority of the teacher and instructor responses were supportive of individual's with disabilities rights in accessing sexuality (Wilkenfeld & Ballan, 2011). One teacher commented, "I want this person to do what he wants, it's a right." Another instructor stated, "Whether it's marriage, sexual intercourse whatever, it's their decision."

The third barrier identified was lack of responsibility to educate individuals about sexuality. Parents are identified as the primary sexual educators for their children for individuals with and without disabilities (National Information Center for Children and Youth with Disabilities, 1992). Yet, there is lack of understanding of what and how much sexuality education does and does not occur at home. Although instructors who worked with young adults over the age of 21 felt comfortable assuming the role as sex educator for individuals with ID/DD, high school teachers were less inclined to take on that responsibility (Wilkenfeld & Ballan, 2011).

Theme 2: Perceptions of Individuals with ID/DD about their own Sexuality

The second theme was individuals' with ID/DD own perceptions on sexuality and the current policies that regulate access to their sexuality or sexuality education. The barriers mapped under this theme were found in the majority (n = 11) of the articles used in this synthesis. A study that used co-ed focus groups, with participants separated by age (i.e., ages 18–30, and 31 years or older) documented a clear lack of control over relationships and sexuality related decisions for individuals with intellectual disabilities (Healy, McGuire, Evans, & Carley, 2009). Lack of control over their own relationships is yet another barrier.

One participant in a study that focused on individuals' with ID/DD general views regarding sexual and relationship experiences stated, [care givers think] "we shouldn't (have relationships) because they [care givers] think we don't realize what we're doing" (Healy et al., 2009, p. 908). Another participants in the same study reported, "her mother doesn't want her to have a boyfriend and I don't think that's fair; I'd like to bring her home, but I can't; no she wouldn't approve" (Healy et al., 2009, p. 908). Healy and colleagues reported that a participant was "caught red handed in bed together" and his feelings were "that's not fair," (2009, p. 908) because of the lack of privacy for he and his girlfriend.

Another barrier is individuals with ID/DD often display a lack of understanding of how to engage in sexuality and access sexuality education. Many participants in these studies wanted to know about how to start relationships as well as understand safe sex practices.

The 2009 article by Swango-Wilson that questioned participant's views of sex education curriculum reported that participants were asking questions such as, "How do you make a relationship with just one girl?" and "How to keep from getting AIDs [sic] or other sickness" (p. 226). In the Swango-Wilson (2011) study, participants wanted to know, "How to learn how to [use] proper techniques and stuff" and "show how to get relationships going" (p. 117). Lofgren-Martenson (2012) inquired, "What is sex education to you?" to participants with intellectual disabilities. Responses included, "No idea. . .but having sex, I think" and "love."

Theme 3: Sexuality Knowledge of Individuals with ID/DD

The lack of research on knowledge of sexuality is reflected in that only five articles in this synthesis addressed this topic. A lack of sexuality knowledge is an additional barrier that individuals with ID/DD face. Sexuality knowledge was measured in the identified studies using a variety of instruments and assessments. Researchers used focus groups, individual interviews, and multiple sexuality knowledge scales (Assessment of Sexual Knowledge, The Sexual Consent and Education Assessment Scale, Sexual Knowledge, Experience and Needs Scale, and Erotic Response and Orientation Scale) to measure the acquired knowledge of participants with ID/DD. Overall, the results demonstrated individuals with ID/DD had less knowledge about sex and sexuality than their non disabled peers (Dukes & McGuire, 2009; Galea, Butler, Iacono, & Leighton, 2004; Cabe & Cummins, 1996; Swango-Wilson, 2011).

A study by Galea et al., (2004), found in relation to other scores on the Assessment of Sexual Knowledge test, participants with ID/DD had poorer scores than their typically developing peers on topics relating to puberty, menstruation, menopause, sexuality, safer sex practices, sexual health, sexually transmitted diseases, contraception and legal issues regarding sexuality. Another study found that individuals with ID/DD had less knowledge than their peers without disabilities in areas such as dating and intimacy, sexual interaction, contraception, pregnancy, abortion and childbirth, sexually transmitted diseases, masturbation, and homosexuality (Garwood & McCabe, 2000). In the study by Healy and colleagues (2009), participants with ID/DD in their focus groups were incorrect in their understanding of masturbation and contraception. In the only study that asked participants about their sexual orientation, it was noted that the participants who identified as heterosexual or homosexual scored correspondingly on the Erotic Response and Orientation Scale, which demonstrated that they understood their own sexual orientation (Bedard, Xhang, & Zucker, 2010).

Only one study identified for this synthesis examined if an increase in knowledge about sex and sexuality in individuals with ID/DD would occur after an individualized sex education intervention. The intervention used an individualized sex education curriculum for the four participants in the single-subject study. Each participant was labeled with moderate intellectual disability, two participants were twenty-two years old and the other two were twenty-three years old. Dukes and McGuire (2009) used the Sexual Consent and Education Assessment Scale (SCEA) as a measure of knowledge acquisition. Their participants demonstrated mastery of sexuality information by answering more questions on the SCEA correctly after the intervention as compared to baseline, and at a six-month follow-up. "As higher scores on the SCEA are correlated with a greater capacity to make sexuality-related decisions, the results of the study demonstrated that capacity was improved through sexuality education" (Dukes & McGuire, 2009, p. 732).

Discussion

This research review provides in-depth information and helps to illuminate the barriers that individuals with ID/DD experience accessing their sexuality and sexuality education. The research also informs how individuals with ID/DD understand sex and sexuality and touches on the ability of these individuals to make sexuality related decisions. Although there has been a paucity of research on this topic, the studies reviewed help to answer the research question, "What are the barriers that individuals with ID/DD face when accessing

sexuality and sexuality education?" Three themes emerged from the literature. The first theme focused on the perceptions of others about individuals with ID/DD and their sexuality, which included barriers such as the denial of sexuality and what and how to teach sexuality related topics. The second theme reported what an individual's own perceptions of sexuality are (e.g., starting a relationship, and safe sex practices). The third theme focused on individuals with ID/DD knowledge of sexuality, which was previously researched using sexuality knowledge scales.

Our review discovered multiple barriers that impact access to sexuality information and experiences for individuals with ID/DD. As expected, parents and caregivers have a variety of perceptions regarding their children's sexuality. This is indicative of "the perception that intellectual disability equals dysfunction creating a linear thinking that persons with intellectual disabilities are incapable of managing their sexuality" (Galea et al., 2004, p. 138). Parent's denial or fear of their child's sexuality is one of the barriers that must be overcome, if individuals with ID/DD are to make their own decisions about their sexuality. Lack of understanding regarding sexuality can lead to misinformation, misconceptions, and prejudice towards individuals with disabilities (Esmail et al., 2010). Other articles measured sexual knowledge through different instruments, consistently showing that individuals with ID/DD have less knowledge about sex and sexuality than their peers without disabilities.

Implications for Practice

Although this literature provided evidence that individuals with ID/DD have less access to their sexuality and sexuality education, these barriers can be overcome by focusing on policies, intervention research, and subsequent practices for individuals with and without disabilities. In this section we apply a multilevel approach to demonstrate how focusing on access to sexuality and sexuality education needs to occur across federal, state, residential, classroom, and individual levels. To support an individual's quality of life and their access to sexuality and sexuality education, change needs to occur on all levels.

National Policy Arena. The Individuals with Disabilities Education Act (IDEA, 2004), mandates free and appropriate public education as well as planning for transition aged youth in areas of employment, post secondary education, and when applicable, independent living. Therefore, these broad federal requirements for special education should also support sexuality education in preparing students with ID/DD for full quality of life.

The introduction of the common core standards can be seen as a starting point providing a consistent education standard across states. In addition to the common core standards, the American School Health Association (ASHA), American Association for Health Education (AAHE), National Education Association Health Information Network (NEAHIN), and The Society of State Leaders of Health and Physical Education (SSLHPE), have developed National Sexuality Education Standards that cover core content and skills for kindergarten through twelfth-grade. In the Future of Sex Education (FoSE) 2011 report, these organizations state the purpose of the national standards, "is to provide clear, consistent and straightforward guidance on the *essential minimum, core content* for sexuality education that is developmentally and age-appropriate for students in grades K-12" (p. 6).

This same report also identified that "teens that received comprehensive sexuality education were 50 percent less likely to report a pregnancy than those who received abstinence only education" (FoSE, 2011, p. 7). While these national standards provide general guidance for sexuality education they "generally do not address special needs students. . .or students with any of the other unique attributes of a given classroom or setting" (FoSE, 2011, p. 8). Changes in national curricula, such as the National Sexuality Education Standards to include differentiated and individualized instruction for individuals with ID/DD is absolutely necessary so all students may gain access to sexuality education.

State. At the time this article was written, there were no federally mandated sexuality education curricula for students in either general or special education. States have the overall decision-making power as to what form of sexuality education students receive. While nationwide there is a shift to focus on com-

prehensive sexuality education, there are still many states and regions that receive funding to provide abstinence only sexuality education (SIECUS, 2011). Parents and advocates can inform their representatives about the need for a comprehensive sexuality education program inclusive of individuals with ID/DD and ask them to support comprehensive sexuality education in their schools. Contacting local school boards can also promote change in the sexuality curriculum individuals with ID/DD receive.

Residential. Although individuals with ID/DD are less likely to live independently than nondisabled peers, it is important to recognize that those who live on their own or in residential facilities should have access to their sexuality. As was noted, in some residential facilities it is prohibited for residents to engage in physical relationship due to residential policies. One suggestion is for residential facilities to include sexuality education courses to cover topics that are important to their residents and align residential policies to the education delivered (e.g., opportunities for dating and healthy relationship building activities).

School and Classroom-based. High school teachers and school personnel can also provide access to sexuality education for individuals with ID/DD. Lumley and Scotti (2001) suggest a team approach including parents, educators, and care providers that use person centered planning for sexuality education. They suggest the team have:

> "five essential goals in mind: a) having a presence and participating in the community, b) acquiring and maintaining interpersonal relationships, c) expressing preferences and choices, d) having the chance to fulfill respected positions and live with dignity, and e) continuing development of personal competencies" (p. 111).

Using such a person centered planning approach aligns with the outcomes orientation of the Quality of Life framework, and the sense of citizenry, self-control, and equitable access advocated by disability studies theorists (e.g., Siebers, 2012; Hamilton, 2002).

Additionally, as part of the person-centered planning process, it is critical to include key stakeholders in the individual's life (e.g., caretakers, parents, and physicians) and learn about what individuals with ID/DD want in a relationship and the best way for them to achieve their goals. This will provide for the most educated and informed plans so that individuals can feel supported in searching for and maintaining healthy relationships. Teachers and other school personnel can be advocates by finding appropriate sex education curricula. In addition, they can educate parents who may not view their children as sexual beings, and explain the importance of sexuality education. Research shows that with education individuals with ID/DD can make more informed sexuality related decisions, producing positive outcomes (Dukes & McGuire, 2009).

Individual. Teachers can also promote an individual's self-determination and self-advocacy skills. These skills are indicators of overall quality of life (Schalock, Gardner, & Bradley, 2007). Self-determination and self-advocacy skills can also be used for an individual to identify what sexuality education they prefer. Our results indicate that there is a wide range of topics that could be covered and that some topics are more important (e.g., beginning a relationship) to some people than other topics (e.g., the functions of my sexual organs). Lastly, acknowledge that individuals with ID/DD are sexual beings. Individuals with ID/DD have the same desires as their peers without disabilities and they should have the right to access this important part of their life.

Limitations

As is the case with many under-investigated research topics, most of the research reviewed was exploratory in nature and utilized some form of qualitative methodology to gain further understanding and insight on such a sensitive issue. Qualitative methodology is preferred when trying to gather in depth information about a specific phenomenon (Patton, 2002), but this method also has limitations. Due to the specific population and the small sample sizes used by most researchers, external validity is of concern if researchers want to use the findings for empirically based intervention development.

Another limitation of the studies we reviewed was a noticeable absence of questions regarding sexual orientation, as well as lesbian, gay,

bisexual, and transgender participants. Dukes and McGuire (2009) acknowledged that, "same sex relationships were not part of the sex education program and is not an area assessed in the SCEA (Sexual Consent and Education Assessment) – this is clearly a deficit in the intervention program that should be addressed in future studies" (p. 734). Studies by Bernert (2011), Esmail et al. (2010), Galea et al. (2004), and Swango-Wilson (2011), don't include lesbian, gay, bisexual or transgender people or the topic of sexual orientation either. One article by Lofgren-Martenson (2004) noted that expression of homosexual behavior was usually redirected by a caretaker or was affirmed as a friendship over a relationship between individuals of the same gender.

Due to the sensitive nature of the topic being studied there could also be a limitation regarding the selection of participants. Most participants in these studies were recruited in independent care facilities, or by postings on vocational rehabilitation centers' message boards or other community centers. All of the participants had to be willing to discuss sex and sexuality related issues, which may have led to biased samples. Additionally, the sensitivity of the topic could have had an impact on individuals' responses in focus groups or interviews, because sexuality is a "value-laden topic," which could cause distorted or filtered responses to questions (Esmail et al., 2010).

Conclusion

This research synthesis has addressed the topics of sexuality research and the barriers individuals with ID/DD face in accessing sexuality. These barriers have an impact on how individuals perceive their own sexuality, their knowledge of sex and sexuality, and their quality of life and subsequent outcomes for adult life. It is important that we address these barriers across multiple levels (e.g., policy, residential, school) so individuals with ID/DD can become knowledgeable and make informed decisions regarding their own sexuality and ultimately enhancing their overall quality of life.

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