Sexuality in Transition Planning
Annotated Bibliography
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What is Sexuality in Transition Planning?

Sexuality has been defined as "companionship, friendship, sexual expression, sexual identity, and intimate relationships" (Bambara & Bratlinger, 2002). People with disabilities have many obstacles as they transition to adulthood, including developing and understanding their own sexuality (Sinclair, Unruh, Lindstrom, & Scanlon, 2015). These can include the perception individuals with disabilities have about their own sexuality, the perception of others regarding the sexuality of people with disabilities, and the knowledge of sexuality by individuals with disabilities among others. Sexuality in transition planning seeks to overcome this obstacles through explicit planning in order to more fully develop a student’s sexuality.

Why is Sexuality in Transition Planning Important?

Sexuality is in transition planning is important because it ties into the larger issue of quality of life. For some time now, quality of life for individuals with disabilities has been recognized as an important issue. In that time multiple definitions have been established, and each definition includes interpersonal relations as a critical piece (Schalock, 2000). In 2002, Bambara and Bratlinger noted that although progress has been made for individuals with disabilities with regards to quality of life, their sexuality needs remain largely unaddressed by society and educators. Recent publications indicate this is still an issue for individuals with disabilities (East, & Orchard, 2014; Sinclair, Unruh, Lindstrom, & Scanlon, 2015). As a result, the purpose of this annotated bibliography is to provide resources for individuals, educators, families, and other related personnel in the area of sexuality and individuals with disabilities.

References:

What Does the Literature Say About Sexuality in Transition Planning?

Many articles have been published on the topic of sexuality in transition planning. The following sections will provide a reference and a brief synopsis of articles published on this topic. The articles are divided into two basic categories. The first is “Journals or Special Issues.” This group consists of (a) journals dedicated to the topic of sexuality, or (b) special issues of other journals that are dedicated to the topic. The second category consists of articles appearing in various publications that are not dedicated exclusively to this topic.

Journals or Special Issues

Editor: S. Hough.
- This peer-reviewed journal is devoted entirely to the psychological and medical aspects of sexuality in rehabilitation and community settings. Sexuality and Disability provides original scholarly articles addressing the psychological and medical aspects of sexuality in relation to rehabilitation. Publishing up-to-date articles, case studies, clinical practice reports, and research and survey data reports, this international quarterly offers the latest developments in the areas of sexuality as it relates to a wide range of disabilities. Contributions address consumer issues; clinical and research progress; community programs; independent living programs; guidelines for clinical practice; contemporary developments in special programs in sex education and counseling for people with disabilities.

This special issue of Research & Practice for Persons with Severe Disabilities was dedicated to sexuality and individuals with disabilities. Articles included:

   a. Provides an overview of current issues in the field of special education with regards to sexuality and people with disabilities. Includes brief descriptions of each article and key themes found across articles.

   a. Discusses importance of developing positive attitudes toward people with disabilities and their sexuality. Describes attributes of healthy human service systems, highlights importance of strong self-advocacy by people with disabilities, and explains harmful effects negative attitudes can have on people with regards to disability and sexuality.

   a. Highlights lack of research on topic of sexuality and women with developmental disabilities. Explores various issues women with developmental disabilities experience with regard to sexuality including lack of access to gynecological healthcare and sex education, limited choices regarding reproductive options, and the impact of negative stereotypes. Provides recommendations to address these issues.

   a. Describes Behavioral Risk Management, a wrap-around, community-based program that addresses the needs of males with disabilities who exhibit inappropriate sexual behaviors.

   a. Evaluates 12 curricula that were recommended by the Sexuality Information Education Center of the United States for students with disabilities. Criteria includes goals/objectives and scope and sequence, curriculum concepts, instructional methods, curriculum development and evaluation techniques, and suggested adaptations for diverse learners.

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**model program.** Research & Practice for Persons with Severe Disabilities, 27, 58-68.

a. Describes findings from several surveys and a program that was developed based on findings for adults, parents, and professionals.


a. Describes a qualitative study conducted with adults with disabilities, living in Belgium, regarding their perceptions of sexuality. Findings suggest that although there is no one type of relational-sexual experience, a lack of support for building relationships exist. Additional findings suggest that the circumstances of people's lives, including structural, attitudinal, and organizational barriers appear to shape the perceptions. Provides implications for service professionals.


a. Discusses lack of institutional policies with regards to homosexuality for individuals with disabilities.


a. Provides an overview of a session that was conducted at the TASH conference on generating ideas on how to support individuals with disabilities who are homosexual. Suggestions include working with organizations dedicated to helping homosexuals to be more inclusive.

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- This special issue of the TASH newsletter was dedicated to exploring the sexuality of people with disabilities including the following articles:


a. Discusses the history of oppression of sexuality for individuals with disabilities. Provides recommendations for how to plan socio-sexuality curricula for people with disabilities including providing instruction by knowledgeable personnel, providing a comprehensive scope of topics, and using best practices.

a. Provides recommendations for parents when dealing with sexuality and their children with disabilities. Recommendations include: increasing supervision, recognizing sexuality is normal and healthy, allowing dreams about marriage and children.

   a. Provides a first hand account of two self-advocates (one gay and one not) and their experiences with people who are gay and have a disability.

   a. Discusses the definition of consent and how it applies to individuals with disabilities and sexuality. Recommends that people with disabilities be involved at the policy-making level of how consent is defined for sexuality and people with disabilities.

Other Articles


- Examines behaviors and perceptions of young adults with learning disabilities with regards to sexual activity.
- Offers findings that indicate about half the young adults engaged in sexual behaviors that potentially put them at risk for contracting AIDS/HIV. Additionally, the majority of young adults indicated they had received AIDS education in school.


- Surveyed and compared people with a developmental disability regarding five areas related to sexuality (i.e., demographics, sexual orientation, sexual history, recalled childhood gender identity and adult gender identity).
- Results showed that most subjects perceived themselves as heterosexual (87%), followed by those that saw themselves as bisexual or questioning (9.7%) and lastly those that reported that they were interested in same sex partners (3.2%). Four subjects scored within the range to indicate that they had gender identity dysphoria (GID). No differences were found for diagnostic category.
- One case study was presented to aid in better understanding of a transgendered individual.
The authors recommend that professionals rule out the possibility of ambivalence about gender and sexual issues caused by social and life experiences, and (b) gender identity and/or sexual identity of individuals with disabilities must be honored as we do with the general population.


- Explored how sexuality was experienced among 14 adult women with intellectual disabilities.
- Most of the women (a) functioned within disability centered environments without having a disability identity, (b) expressed an adult identity that resulted in their expectations of sexual autonomy, and (c) experienced sexuality limitations because of protective policies and programs.


- The authors used data from the survey Life and Health—Young People 2005, which was completed by 3,084 adolescents attending mainstream schools in Sweden to examine adolescent sexuality.
- They found: (a) that 15-16 year old youth with disabilities report a significantly higher rate of sexual debut than adolescents with no disabilities; (b) the sexual debut in youth with and without disabilities is related to mental health, school exposure, and substance use; and (c) there is a strong relationship between sex and substance use among all adolescents.


- Based on findings from a participatory research study conducted with Zulu-speaking youth with physical and visual disabilities in KwaZulu-Natal, the authors argue that young people with disabilities construct their sexual identity similarly to other non-disabled youth.


- This literature review explores sociological theories of disability, gender, and sexuality. Theories of disability that incorporate discussions of gender and sexuality were used for the analysis. The theories used were organized in the
following categories: social constructionist theory, feminist and gender theory, queer theory, and resistance theory.


- A meta-synthesis of empirical and nonempirical literature analyzed journal articles and book chapters addressing the intersection of disability, [homo]sexuality, and gender identity/expression.
- The articles and chapters emphasized the diversity of lesbian, gay, bisexual, and transgender youth with disabilities (e.g., cultural, linguistic, sexual, abilities, disabilities, related service needs), noting that most LGBT youth with disabilities possess multiple stigmatized identities as sexual/gender minorities and young people with disabilities.


- Examines the effects of "Living Your Life", a sexuality curriculum that was adapted for adults with Intellectual Disabilities.
- Indicates the curriculum, when adapted for the specific individuals, was effective in increasing individuals' capacity to make sexuality-related decisions.


- The authors conducted a qualitative study to explore the development and challenges associated with emergent sexuality, identity formation, and self-image among Canadian adolescents with physical disabilities.
- Results indicate that while adolescents with physical disabilities face the same challenges related to identity, self-image, and social acceptance as those without disabilities, many of these issues are often ignored or overlooked by the adults in their lives.

• This study examined the experiences and challenges of sex education for adolescents with physical disabilities. Data were gathered from adolescents with physical disabilities, their parents, and health professionals working with the population.
• Results reveal that youth with physical disabilities do not receive the formal and informal sexuality education needed to make educated decisions regarding their sexual health and intimate relationships. This is due to the fact that parents, educators, and health professionals divert the responsibility of sex education to others they think are more qualified.


• A qualitative study to describe current perceptions and attitudes towards sexuality and disability, and how social stigma differs between individuals living with visible and invisible disabilities.
• Results indicate individuals with disabilities are commonly viewed as asexual.
• The authors attribute a lack of information and education on sexuality and disability as a major reason for the stigma associated with disability and sexuality.


• A survey of family and staff working with people with intellectual disabilities was conducted to assess the attitudes towards sexuality of people with an intellectual disability.
• Results indicated staff were: (a) more inclined to openly discuss issues of sexuality with individuals with intellectual disability; (b) to identify environmental factors as barriers to discussions of sexuality, as opposed to characteristics of the individuals with intellectual disability; (c) were more likely to support engagement in intimate and non-intimate relationships of individuals with intellectual disability; and (d) more closely matched to ideological developments on sexuality and disability.
• The authors conclude there is still a need to provide staff and family with opportunities for dialogue and ongoing training in the area of sexuality.

In this paper the author argues for the need for a critical pedagogical approach to sexuality education in order to educate individuals with intellectual disabilities on sexuality.

The reason identified is twofold. First, sexuality education for individuals with intellectual disabilities has been inadequate, making it an ‘ignored curriculum’. Second, students with intellectual disabilities are often excluded from interactions with peers that could lead to them incidentally learning the material.


This article reviews selected research on the sexuality, sexual knowledge, and sexual behaviors of individuals with autism spectrum disorders over 20 years.

The following themes are identified: the importance of sexuality in the lives of individuals with autism, the discourse of problematic sexuality, and the difficulty in translating knowledge into practice.


This paper reviews several gynecological issues for young women with significant disabilities and the anxiety that accompanies them. These issues include menstruation, contraception, sexual abuse, pregnancy, access to information, and medical issues related to reproductive hormones (e.g., cyclic seizure, behavioral challenges, osteoporosis).


This article addresses the lack of information on sexuality given to adolescents with moderate disabilities. It looks at legal factors, societal norms and attitudes that contribute to the issue, how these adolescents are often victims of inappropriate sexual beliefs and attitudes, and how professionals can promote positive sexual attitudes and behaviors with these adolescents.

• This study used focus groups to examine the sexual knowledge, experiences, aspirations, and perceived impediments to sexual autonomy of people with intellectual disabilities.
• Results indicated individuals had an understanding of their sexual rights and the barriers to sexual autonomy, with individuals under 18 having a more rudimentary understanding. Additionally, family and staff attitudes influenced the views on sexuality of individuals with intellectual disability.
• As such, the authors conclude that sex education training and support for appropriate sexual expression is necessary for individuals with intellectual disability to achieve sexual autonomy.


• This study examined the sexual behavior of adolescents and young adults with autism spectrum disorder who lived in group homes. The caregivers in the group homes administered the Interview Sexuality Autism, and reported a variety of sexual tendencies.


• The authors of this study compared the responses of two groups of individuals to the Interview Sexuality Autism-Revised, adolescents and young adults (a) with borderline/mild mental retardation and autism spectrum disorder and (b) with borderline/mild mental retardation but without autism spectrum disorder. Similarities and differences are reported.


• Offers suggestions on how to deal with problematic masturbation for individuals with developmental disabilities.
• Includes guidelines on how to teach appropriate time and place.

This study examined the practices of pediatricians regarding sexuality for individuals with autism spectrum disorders. An online survey was completed by pediatricians who regularly care for the population. Results indicated that some, but not all sexuality topics were discussed (10.9 out of 26). Common barriers to comprehensive sexuality care cited were logistics, discomfort of parents and pediatricians, lack of training, and the absence of information and materials to facilitate sexuality care for this population.


This qualitative study used a phenomenological approach to analyze the experiences of eight mothers of children with and without intellectual disabilities. The mothers were asked to contrast their experiences of supporting both groups’ as their sexuality development. Individuals without disability were given increasing autonomy as they made this transition, whereas the dependence of individuals with intellectual disabilities hindered this process.


This study looks at the sexual and pregnancy experiences of students with disabilities through interviews with thirteen school social workers.

Results showed the social workers counseled pregnant and parenting adolescents with disabilities on various topics including whether they were pregnant, making decisions related to pregnancy, and decisions about sex. Identified barriers were cognitive impairments, emotional challenges, sexual abuse history, a wish to fit in, communication issues, self-esteem issues, and impulsivity.

Recommendations are made regarding sexual health services for adolescents with disabilities.


This study looked at the dating and sexual experiences of minority youth with disabilities via interviews with high school social workers.
Among the aspects discussed are (a) family beliefs and practices, (b) socioeconomic status, (c) special education, (d) historical influences, and (e) aspects of adolescents’ lives that demonstrated resilience in dating and sexuality.


This study examined the experiences of sexual education of youth with intellectual disability between 16 and 21 years of age. Sixteen young people with intellectual disabilities were interviewed.

The results showed that sex education for youth with intellectual disabilities is restrictive in that it focuses on risks, avoiding topics of pleasure, desire, and intimacy. Additionally, critical pedagogical methods can form a professional teaching model for sex education for youth with intellectual disabilities.


This study examined the opportunities and barriers for youth with intellectual disabilities to sexually express themselves.

Results show young gay individuals with intellectual disabilities were found to be an invisible group, and the opportunities to sexually express oneself is dependent on the attitudes and behaviors of those surrounding them.

The authors stress the importance of teaching this population about different sexualities, and suggest more research on homosexuality and bisexuality and intellectual disability without a heterosexual starting point.


Describes a comprehensive approach to supporting sexuality for adults with mental retardation.

Suggests a person-centered approach combined with individualized assessments and programs.

Offers suggestions on the role adult service agencies can play in supporting sexuality for adults.


doi:10.3109/09638280902846368
• This study used an adapted version of the South African You Risk Behaviour Survey to compare the sexual behaviors of youth with and without physical disabilities in Cape Town, South Africa.
• Results indicate that adolescents with disabilities engage in risky sexual behaviors and are at the same risk of contracting HIV as their peers without disabilities.
• The authors conclude that youth with disabilities must be included in research and activities to promote sex education.


• Investigates sexual knowledge of people with physical disabilities, people with a mild intellectual disability, and people without disabilities.
• Indicates individuals with intellectual disabilities had less knowledge and more negative attitudes about sexuality than individuals with physical disabilities.
• Indicates individuals with physical disabilities had less knowledge and more negative attitudes about sexuality when compared to individuals without disabilities.


• This study examined how social and environmental factors affect individuals with intellectual disabilities vulnerability to adverse sexual health outcomes.
• Interviews and focus groups were conducted with 10 LGBT youth with intellectual disabilities.
• Participants reported that limitations on their sexual autonomy led to riskier sexual behavior such as having sex in places they were not comfortable and a decreased likelihood to practice safer sex.
• As such, while attempting to protect this population, the limiting of sexual autonomy by authority figures could be leading to riskier sexual behavior.


• This review of literature focused on relationships and sexuality for people with intellectual disability.
• Summarized findings reveal a need for better education for caregivers to facilitate discussion of sexuality in order to improve sexuality education at the
practice level. Second, restrictive attitudes prevail regarding this topic. Finally, although many programs are now available on this topic, they require rigorous evaluation.

Nichols, S., & Blakeley-Smith, A. (2010). 'I'm not sure we're ready for this ...': Working with families toward facilitating healthy sexuality for individuals with autism spectrum disorders. *Social Work in Mental Health, 8*(1), 72-91. doi:10.1080/15332980902932383

- This study incorporated two components. In the first, focus groups were used to gather data on the concerns of parents in regards to the sexuality development of their children with autism spectrum disorders. The second examined the effectiveness of a parent sexuality-education curriculum. Results are discussed.


- This study examined the characteristics of people with learning disabilities who also cross-dress or have gender dysphoria. Anonymized data from a specialist were reviewed to gather the data.
- Demographic and mental health characteristics were reported.
- Several recommendations were made including that people with learning disability could benefit from a person centered understanding when dealing with these topics and that longer assessments may be appropriate prior to hormone and surgical interventions.


- This study looked at the views of mothers on adolescent sexual development. Two groups of mothers were compared, those with children with intellectual disabilities and those with children without intellectual disabilities.
- Both groups felt the topic of sexuality was important to address.
- Mothers of children with intellectual disabilities were: (a) more cautious about topics such as contraception, intimate relationships, and readiness for sexual education; (b) had concerns about sexual vulnerability; and (c) had discussed fewer topics with their child.

• This article reviews factors that contribute to youth with developmental disabilities developing sexual aggression as well as the effects of early identification and intervention on the youth’s self-concept and behavior.

• Recommendations are made for school social workers to facilitate safety in the schools and healthy functioning for the youths.


• This article documents a girl’s sexual experiences through her mother’s point of view. It addresses learning disability, sexual experimentation, education, governance, and responsibility. The intent is to provide insight into the challenges inherent in addressing the sexuality of youth with learning disabilities.


• This study looked at the extent to which HIV education has reached people with disabilities and the challenges for professionals in providing HIV prevention education in South Africa.

• A survey was given to 34 schools for individuals with special needs and interviews were conducted with 21 staff members of these schools.

• Staff acknowledged the importance of HIV prevention education for individuals with disabilities. Challenges reported were communication barriers, discomfort about sexuality and disability, disagreements about what content is appropriate, and fears of promoting sexual activity.

• A need for a sex education program that is tailored to individuals with special needs was identified.


• Promotes sexuality education for students with disabilities be integrated into the general curriculum.

• Discusses teaching strategies, issues in developing a curriculum, and traits of successful sex education teachers.

• This study interviewed high school social workers to examine their needs and concerns in serving students with disabilities in the areas of dating and sexual health.
• Results are interpreted through Bronfenbrenner’s ecological systems theory. Challenges are identified within the mesosystem, exosystem, and macrosystem.
• Recommendations are made for social work education, policy, and programs for adolescents with disabilities.


• This study used regression analyses to examine the relation between disability and (a) first type of sexual relationship, (b) amount of discussion of birth control, and (c) desire for pregnancy.
• Using the National Longitudinal Survey of Youth (1997) a sample of 2,729 racially diverse girls who were between the ages of 12 and 24 at first sexual intercourse.
• Results suggest that disability status is important to consider with respect to sexuality as differences were revealed between the experiences of participants with and without disabilities, as well as differences between participants of different disabilities.


• This review summarizes 13 studies that examined the sexuality of individuals with intellectual and/or developmental disabilities.
• Common barriers are identified and implications for practice are made.


• This study examined the expectations for sex education of (a) individuals with developmental and cognitive disability, (b) parents of this population, (c) professionals working with this population, and (d) health care professionals who contact this population.

• This study interviewed three individuals with intellectual/developmental disabilities to obtain information on their expectations of a sex education program.
• Themes emerged including methods of education and the need for future sex education programs to include the topics of friendship, relationships, and safe sex.


• Presents information on promoting sexuality to individuals with Autism Spectrum Disorder (ASD) including preventing sexual abuse, facilitating relationships, preventing challenging behavior, and promoting health and hygiene.
• Includes guidelines on instruction including what should be taught (including how to incorporate skill selection into the IEP planning process) and who should teach it.


• The study examined the effectiveness of a board game (SeCZ TaLK) to facilitate communication on sexuality in youth with chronic conditions.
• Eight-five participants played the board game and completed a questionnaire. Results showed 81% of participants believed the board game facilitated discussions about sexuality and intimate relationships, which 85% of participants thought were important to have.
• The authors recommend professionals use interventions like SeCZ TaLK to promote these discussions with youth with special health care needs.


• Provides an overview of a sexuality education program for individuals with moderate to severe intellectual disabilities.
• Offers suggestions on who should deliver the instruction, what type of instruction to deliver, and how to deliver it.

Wazakili, M., Mpofu, R., & Devlieger, P. (2009). Should issues of sexuality and HIV and AIDS be a rehabilitation concern? The voices of young South Africans with
physical disabilities. *Disability & Rehabilitation*, 31(1), 32-41. doi:10.1080/09638280802280619

- This study examined the experience of sexuality and HIV/AIDS of youth with disabilities with the added purpose of determining the appropriate role for rehabilitation professionals in addressing this topic. Sixteen participants completed in-depth interviews followed by discussions in focus groups.
- Most participants had received rehabilitation for their physical impairment, but the topics of sexuality and HIV/AIDS were not addressed.
- The authors conclude that rehabilitation professionals should expand their practice to include promoting health sexual and reproductive health for youth with disabilities.


- This study used open-ended, structured interviews with ten educators from a facility for individuals with medically complex developmental disabilities to explore their attitudes and beliefs on the sexuality of adolescents and young adults with developmental disabilities. Five educators were from the school program and five were from the adult day service program.
- The educators had a positive view of sexuality education, seeing it is a human right. However, they had concerns about capacity to consent to and facilitate sexual activity.


- Offers an instrument, the Sexuality Education Protocol, to systematically evaluate sex education curricula.


- Describes ways to apply ABA principles to teaching sociosexual education to students with autism.
- Offers suggestions on which content areas should be included and effective teaching practices.

- Examines educators' perceptions of sex education curricula for students with moderate to severe disabilities.
- Offers suggestions on how to infuse sex education into existing curricula and transition plans.