



Volume 11, Issue 2, 2016

reSearch

A collection of research reviews on rehabilitation topics from NARIC and other information resources.

Revisiting Sex, Sexuality, & Disability: The Past 10 Years

In this edition of *reSearch* we revisit the topic of sexuality, intimacy, and people with disabilities a topic we covered in 2010. Individuals with disabilities have the same emotional and physical sexual drives as the people without disabilities. However, issues of sexual intimacy and disability remained unaddressed for many years. Individuals with disabilities seeking intimacy face psychosocial barriers such as stereotyping, a lack of adequate information, negative societal and cultural attitudes regarding sexuality and disability, and often lack the proper education and resources to prepare for intimate relationships.

Individuals with disabilities may be perceived as being asexual or hyper-sexual (i.e. sexually inappropriate). The stereotyping of individuals with disabilities as non-sexual or hyper-sexual beings has exaggerated misconceptions about the impact of an individuals' disability on his or her sexual functioning. Only recently, has information on sexuality, intimacy, and sexual functioning become part of the rehabilitation process of individuals with disabilities (i.e. spinal cord injury, traumatic brain injury, developmental disabilities, amputation, etc.).

Support organizations and unique social networking sites like Disaboom and ilivewithadisability.com offer opportunities for more interaction and education. Furthermore, the continued popularity of online dating has given rise to sites geared specifically for individuals with disabilities, including datedisabled.com, datingdisabled.net, disabledcupid.com, disabledpassions.com, whispers4u.com, and nolongerlonely.com.

All of this has contributed to increased research on sexuality and disability from clinical aspects to health promotion. It also may have helped in dispelling some of the myths and misconceptions at work within and outside of the community.

This edition of *reSearch* provides a 10 year "snapshot" of research on sexuality, intimacy, and disability. This "snapshot" presents research related to sexuality and intimacy among individuals with moderate to severe disability. The combined search terms for this edition of *reSearch* included: Sex, Sexuality, Intimacy, and Disability (Severe, Significant). A listing of near 200 additional descriptor terms between the NARIC, ERIC, and the PubMed databases can be found at the end of this document.

A search of the REHABDATA database resulted in 144 documents published between 2006 and 2016; and 11 international research that may have been collected by CIRRIE between 2008 and 2010. The ERIC and PubMed database searches resulted in 43 documents between 2007 and 2016 and 66 documents between 2006 to 2016; respectively.

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NIDILRR Funded Projects Related to Sex, Sexuality, & Disability

In addition to document searches, we searched our NIDILRR Program Database to locate grantees/projects related to sex, sexuality, and disability. While no current projects addressed these topics directly, we identified several on directly-related topics (i.e., health, independent living, participation, and self-management). The search resulted in 11 currently funded projects. Project information and their publications are offered as additional resources for our patrons.

Advanced Rehabilitation Research Training Program on Health and Functioning of People with Disabilities

Project Number: 90AR5024

Phone: 781/736-3928.

Email: slp@brandeis.edu.

Internet Safer and Stronger Program for Men with Disabilities (Men's SSP)

Project Number: 90IF0056 (formerly H133G130207)

Phone: 503/725-9602

Email: oschwald@pdx.edu.

A Lifestyle Intervention Targeting Enhanced Health and Function for Persons with Chronic SCI in Caregiver/Care-Receiver Relationships: Effects of Caregiver Co-Treatment

Project Number: 90DP0074

Phone: 305/243-3628

Email: mnash@med.miami.edu.

The Menopause Transition in Women with Traumatic Brain Injury

Project Number: 90IF0047 (formerly H133G130011)

Phone: 734/763-0153

Email: clairez@umich.edu.

Motivating Self-Management Through Multi-Media Health Promotion

Project Number: 90DP0073

Phone: 406/243-2992

Email: craig.ravesloot@mso.umt.edu.

Rehabilitation Research and Training Center on Developmental Disabilities and Health

Project Number: 90RT5020

(formerly H133B130007)

Phone: 800/996-8845 (V), 312/413-0453 (TTY)

www.rttcd.org.

healthmattersprogram.org.

Research and Training Center on Community Living for People with Intellectual Disabilities

Project Number: 90RT5019

(formerly H133B130006)

Phone: 612/624-6328

Email: rtc@umn.edu.

rtc.umn.edu.

Research and Training Center for Pathways to Positive Futures: Building Self-Determination and Community Living and Participation

Project Number: 90RT5030

(formerly H133B140039)

Phone: 503/725-8313

Email: rtcpubs@pdx.edu.

www.pathwaysrtc.pdx.edu.

twitter.com/pathwaysrtc.

www.facebook.com/pathwaysrtc.

RRTC on Developing Optimal Strategies in Exercise and Survival Skills to Increase Health and Function

Project Number: 90RT5027

(formerly H133B140012)

Phone: 312/238-4864

Email: eroth@ric.org.

www.ric.org/research/centers/dosesses.

Safe@Home: A Self-Management Program for Individuals with Traumatic Brain Injury and Their Families

Project Number: 90IF0052

(formerly H133G130149)

Phone: 404/603-4269

Email: nicole_thompson@shepherd.org.

The University of Michigan Advanced Rehabilitation Research Training Program in Community Living and Participation

Project Number: 90AR5020

(formerly H133P140005)

Phone: 734/963-5600

Email: angellee@umich.edu.

pmr.med.umich.edu/education-training/fellowships/advanced-rehabilitation-research-training-program.

Why do I see different grant numbers?

In 2014, President Obama signed the [Workforce Innovation and Opportunity Act \(WIOA\)](#) into law. As part of WIOA, the institute changed its name from the National Institute on Disability and Rehabilitation Research (NIDRR) to the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) and moved from the Department of Education to the Administration for Community Living (ACL) at the Department of Health and Human Services. Approximately 250 active grants received new ACL grant numbers and all new grants funded under NIDILRR have only an ACL grant number. For more information about NIDILRR/ACL grant numbers please visit: <http://naric.com/?q=en/content/about-nidilrracl-grant-numbers-0>.



Documents from NARIC's REHABDATA search listed are listed below:

2016

(2016). ***MSKTC headlines: January 2016.***

NARIC Accession Number: O20319

Project Number: H133A110004

ABSTRACT: Newsletter from the Model Systems Knowledge Translation Center (MSKTC) provides information about spinal cord injury (SCI), traumatic burn injury (TBI), and burn injury model systems. In this issue: (1) the MSKTC produced a webinar titled Using Social Media to Promote Your Research; (2) the MSKTC releases new factsheet: SCI and Sexuality; (3) the Northern New Jersey SCI System Center has posted the podcast, Integrating Yoga into a Plan of Care for Individuals with Spinal Cord Injury; (4) call for nominations of papers for the 2015 Rosenthal Award; (5) the Spaulding-Harvard TBI Model System Center is recruiting participants for its Multicenter Evaluation of Memory Remediation after TBI with Donepezil study; (6) burn model system researchers to participate at the American Burn Association 48th Annual Meeting; and (7) upcoming events.

Abdo, C.H.N., Battistella, L.R., Bellucci, C.H.S., Bruschini, H., de Bessa Jr., J., de Carvalho, F.L., de Souza, D.R., Filho, J.E.C., Filho, T.B., Gomes, C.M., Miranda, E.P., Scazufca, M., & Srougi, M. (2016). **Evaluation of sexual dysfunction in men with spinal cord injury using the male sexual quotient.** *Archives of Physical Medicine and Rehabilitation*, 97(6), 947-952.

NARIC Accession Number: J73974

ABSTRACT: Study assessed different aspects of sexual function in men with spinal cord injury (SCI) using the Male Sexual Quotient (MSQ), a newly developed tool to assess sexual function and satisfaction. A total of 295 adult men with SCI for more than 1 year were assessed from February to August 2012. Patients completed the MSQ questionnaire and the Sexual Health Inventory for Men (SHIM). Performance in various domains of sexual function was evaluated using the MSQ and SHIM questionnaires. Erectile function, ejaculation, and orgasm

were the most severely affected domains. The median MSQ score was 40 and the median SHIM score was 5. The diagnostic properties of the two instruments were similar in the discrimination of sexually active subjects. The area under the receiver operating characteristic curve was .950 for the MSQ and .942 for the SHIM. There was a strong correlation between the two instruments. Different domains of sexual function are severely impaired in men with SCI, although their sexual interest remains high. The MSQ and SHIM scores strongly correlate, but the MSQ provides a more comprehensive assessment of sexual dysfunction in male patients with SCI.

Burke, M.A., Dispenza, F., Gaudet, M.M., Sewell, M.H., & Viehl, C. (2016). **A model of affirmative intersectional rehabilitation counseling with sexual minorities: A grounded theory study.** *Rehabilitation Counseling Bulletin (RCB)*, 59(3), 143-157.

NARIC Accession Number: J73429

ABSTRACT: This modified grounded theory study identified the professional character traits and specific practices that rehabilitation counselors considered effective when working with sexual minorities (i.e., lesbian, gay, bisexual, queer [LGBQ]) living with chronic illnesses and/or disabilities. A total of 12 certified rehabilitation counselors were individually interviewed. Interviews were transcribed and recursively analyzed with a research team. Trustworthiness and credibility were ensured via in-depth member checking, researcher triangulation, and collection of rich descriptions from participants. A substantive model of rehabilitation counseling was constructed from the interviews, with affirmative intersectionality as the core category. Affirmative intersectionality was viewed as the facilitating agent exercised by the participants to promote action and change with their clients, whether the counseling goals of the client were vocational, psychological, or health-related. Four supporting categories were also constructed, including professional attributes, alliance, intersectional sensitivity, and intersectional interventions. Details regarding the model are provided, as well as discussion on educational and supervision implications, study's limitations, and future research implications.

Hammond, F.M., Hanks, R.A., Maestas, K.L., Papadakis, M.R., & Sander, A.M. (2016). **Multicenter study of sexual functioning in spouses/partners of persons with traumatic brain injury.** *Archives of Physical Medicine and Rehabilitation*, 97(5), 753-759.

NARIC Accession Number: J73809

Project Number(s): H133A070042, H133A070043, H133A080044, H133A120020, H133A120035, H133B090023

ABSTRACT: Study investigated sexual functioning and its predictors in spouses/partners of individuals with traumatic brain injury (TBI). Participants were 70 adults with complicated mild to severe TBI admitted to 1 of 6 participating TBI Model Systems inpatient rehabilitation units and their spouses/partners who were both living in the community and assessed at 1 year after injury. Outcome measures included the Derogatis Interview for Sexual Functioning Self-Report and the Global Sexual Satisfaction Index. Analysis revealed that 20 percent of spouses/partners of adults with TBI reported sexual dysfunction, and 44 percent reported dissatisfaction with sexual functioning. Sixty-two percent of spouses/partners reported a decrease in sexual activity during the year after injury, 34 percent reported a decrease in sexual drive or desire, and 34 percent indicated that sexuality was less important in comparison to preinjury. Greater sexual dysfunction in spouses/partners was associated with older age and with poorer sexual functioning in the person with TBI. Rehabilitation professionals should provide education on the potential impact of TBI on sexual functioning for both the individuals with TBI and their spouses/partners, and integrate the assessment of sexual functioning into their clinical assessment, making appropriate referrals for therapy.

2015

(2015). *Consumer testing on sexuality and sexual functioning after SCI factsheet: Topic guide for consumer interviews.*

NARIC Accession Number: O20337

Project Number: H133A110004

ABSTRACT: Document provides procedures for conducting consumer testing of the fact sheet titled "Sexuality and Sexual Functioning After SCI." It guides the interviewer through the evaluation process and includes questions to ask the consumer participant. This testing is designed to assess whether the fact sheet provides the target audience with the information they need.

(2015). *MSKTC headlines: February 2015.*

NARIC Accession Number: O19965

Project Number: H133A110004

ABSTRACT: Newsletter from the Model Systems Knowledge Translation Center (MSKTC) provides information about spinal cord injury (SCI), traumatic brain injury (TBI), and burn injury model systems. In this issue: (1) resource highlight: Understanding Spinal Cord Injury (2-part series); (2) the New England Regional SCI Center (NERSCIC) and the Spaulding-Harvard SCI Model System present the next Knowledge-in-Motion webcast, Sexuality after SCI; (3) NERSCIC model system publication selected as winner of the Vogel Award; (4) NERSCIC Model System Researcher to present at the American Occupational Therapy Association's annual conference; (5) model systems researcher presented at the International Neuropsychological Society; (6) resource highlight: Traumatic Brain Injury and Acute Inpatient Rehabilitation factsheet; (7) TBI Model Systems Represented at the 2015 Brain Injury Awareness Day; (8) resource highlight: Sleep Problems after Burn Injury factsheet; (9) MSKTC testing Burn Model Systems' draft logo with consumers; (10) MSKTC seeks parents of children with burn injury to test two factsheets; and (11) upcoming events.

Arias-Pardo, A.I., de la Barrera, S.S., Ferreiro-Velasco, M.E., Montoto-Marques, A., Otero-Vilaverde, S., & Rodriguez-Sotillo, A. (2015). **Sexual satisfaction in women with spinal cord injuries.** *Spinal Cord (formerly Paraplegia)*, 53(7), 557-560.

NARIC Accession Number: J72207

ABSTRACT: Study identified the factors that affect the degree of sexual satisfaction in a sample of women with spinal cord injury (SCI). Participants were 32 women with American Spinal Injury Association (ASIA) A-D spinal injuries, between the ages of 18 and 65 years, who completed rehabilitation therapy and lived in the community in the north-west of Spain. When comparing the group of women who were sexually active with those who were not, variables such as age, neurological level, time since the SCI, ASIA or Spinal Cord Independence Measure score, urinary incontinence, chronic pain and spasticity were not related to sexual activity. The only factors that were found to be related to sexual activity were not having a stable partner and a lack of sensation in the genital area. Improving sexual satisfaction, information and specific programs during rehabilitation can help women with SCI explore and investigate new erotic possibilities, thereby improving their self-esteem and social relationships.

Bonfils, K.A., Firmin, R.L., Salyers, M.P., & Wright, E.R. (2015). **Sexuality and intimacy among people living with serious mental illnesses: Factors contributing to sexual activity.** *Psychiatric Rehabilitation Journal (formerly Psychosocial Rehabilitation Journal)*, 38(3), 249-255.

NARIC Accession Number: J72383

ABSTRACT: Study explored relationships between mastery (perception of control of one's life and future), sexual self-esteem (perceptions of one's capacity to engage in healthy sexual behavior), sexual attitudes (permissive ideas about sexuality), and perceived importance of relationships/ sexuality and number of sexual partners. A secondary analysis of survey data from 401 adult participants living with a severe mental illness in the Indiana Mental Health Services and HIV-Risk Study was conducted. Analysis of covariance (controlling for marital status) compared those with 0 partners, 1 partner, or multiple partners over the past 3 months on the dependent variables of mastery, sexual self-esteem, sexual

attitudes, and perceived importance. Participants with more permissive attitudes, greater perceived importance, and higher mastery were more likely to be sexually active with multiple partners. Self-esteem did not differentiate groups. Given the key role of sexual satisfaction in quality of life and the high rates of sexual risk behavior in this population, it is important that clinicians systematically assess mastery, perceived importance, and attitudes about sexuality when working with consumers diagnosed with a severe mental illness. Individually tailoring existing interventions on the basis of consumers' levels of mastery, related to self-efficacy for implementing changes in life, could improve long-term outcomes for these programs.

Corkill, H.A., Goutos, I., & Pandya, A.A. (2015). **Sexual function following burn injuries: Literature review.** *Journal of Burn Care and Research (formerly Journal of Burn Care & Rehabilitation)*, 36(6), e283-e293.

NARIC Accession Number: J72798

ABSTRACT: Article reviews the existing knowledge on sexual function following burn injuries. The authors describe the various tools used to assess post-burn sexual function and analyze a number of parameters can affect the quality of sexual life following burn injuries. These factors include age at the time of injury, location, and severity of the burn as well as coping mechanisms employed by the individual survivor. Addressing issues of intimacy relies on awareness, education, and a holistic approach on behalf of the multidisciplinary team members. Important parameters in addressing sexual function issues relate to when, who, and how these issues are raised and managed. The authors conclude by providing recommendations for health professionals as to how to best address these sensitive intimate issues in burns rehabilitation.

Couwenhoven, T. (2015). *Boyfriends and girlfriends: A guide to dating for people with disabilities.*

NARIC Accession Number: R09355

ABSTRACT: This guidebook provides information about dating and relationships for teens and adults with intellectual and/or developmental disabilities. It explains the do's and don'ts of dating and validates normal, age-appropriate desire for companionship and romance.

Dekker, R., Dijkstra, P.U., Enzlin, P., Geertzen, J.H., & Versschuren, J.E. (2015). **People with lower limb amputation and their sexual functioning and sexual well-being.** *Disability and Rehabilitation*, 37(3), 187-193.

NARIC Accession Number: J71100

ABSTRACT: Study explored how people with a lower-limb amputation experience (changes in) their sexual functioning and sexual well-being. Semi-structured interviews were conducted with 26 individuals with a lower-limb amputation. Thematic analysis of the data resulted in eight themes derived from the interviews: importance and description of sexuality; changes in sexual functioning; changes in sexual well-being; practical problems concerning sexuality; self-image; feelings of shame; role of the partner; and communication about sexuality with professionals. Participants in this study indicated some problems concerning sexual functioning and/or sexual well-being. Some of these problems were of practical nature, and participants would have appreciated some information about how to handle these kinds of sexual problems. However, such information should not be given at the beginning of the rehabilitation process, since at that time, sexuality is not a priority for all patients.

Dillaway, H., Fritz, H.A., & Lysack, C.L. (2015). **“Don't think paralysis takes away your womanhood”: Sexual intimacy after spinal cord injury.** *American Journal of Occupational Therapy (AJOT)*, 69(2), 6902260030.

NARIC Accession Number: J71370

ABSTRACT: This article presents the findings from an in-depth qualitative study of the sexual and reproductive health experiences of 20 women with spinal cord injury (SCI) in or around Detroit, MI. The results reaffirm existing literature documenting the sexual consequences of life after SCI and suggest new areas of inquiry important for better addressing sexual concerns across the lifespan. Specifically, the findings suggest a need to consider the variable effects of SCI on sexual intimacy in relation to a person's developmental trajectory, the appropriate timing of sexual education, the need to expand conceptualizations of sexual intimacy, and the ways SCI may affect sexuality in later life.

Duong, J., & Stanley, I.H. (2015). **Mental health service use among lesbian, gay, and bisexual older adults.** *Psychiatric Services (formerly Hospital and Community Psychiatry)*, 66(7), 743-749.

NARIC Accession Number: J72125

ABSTRACT: Study assessed mental health service use among lesbian, gay, and bisexual (LGB) and heterosexual older adults and determined the mediating role of nonspecific psychological distress, excessive alcohol use, and self-perceived poor general medical health. Data from the 2011 New York City Community Health Survey were analyzed. The analytic sample comprised 5,138 adults aged 50 years and over. Logistic regression modeling was used to examine associations between sexual orientation (LGB versus heterosexual) and past-year mental health service use (counseling or medication), adjusting for sociodemographic and clinical characteristics. Mediation analyses using bootstrapping were conducted. Results showed that 23.9 percent of LGB and 13.1 percent of heterosexual older adults reported receiving counseling in the past years. In addition, 23.4 percent of LGB and 14.7 percent of heterosexual respondents reported taking psychiatric medication in the past year. LGB respondents were significantly more likely than heterosexuals to have received counseling and psychiatric medication. Psychological distress, excessive alcohol use, and self-perceived poor general medical health did not mediate the association between sexual orientation and mental health service use.

Gan, C., McKerral, M., Moreno, A., & Zasler, N. (2015). **Experiences, attitudes, and needs related to sexuality and service delivery in individuals with traumatic brain injury.** *NeuroRehabilitation*, 37(1), 99-116.

NARIC Accession Number: J73323

ABSTRACT: Study explored the experiences, attitudes, and needs related to service delivery regarding sexuality issues in individuals with traumatic brain injury (TBI). Thirty-eight community-dwelling adults who had completed a post-acute TBI rehabilitation program completed a questionnaire adapted to individuals with TBI addressing experiences, attitudes, and needs regarding sexuality and service delivery. Respondents reported a low frequency of specific discussions with their treating clinician(s)

about sexual and reproductive health issues, as well as many unmet needs regarding sexuality. None of the participants considered discussion about these issues to be inappropriate. They reported more favorable attitudes towards discussing sexual health topics compared to actual service delivery with family physicians, general practitioners, psychologists, and other health care professionals. These individuals with TBI desired more openness about discussing sexual concerns. The findings are discussed in terms of the clinical implications to meet the individuals' needs regarding sexual concerns after TBI.

Heiman, E., Haynes, S., & McKee, M. (2015). **Sexual health behaviors of Deaf American Sign Language (ASL) users.** *Disability and Health Journal*, 8(4), 579-585.

NARIC Accession Number: J72509

ABSTRACT: Study explored the self-reported sexual health behaviors of Deaf American Sign Language (ASL) users. Data from 282 Deaf participants, aged 18 to 64 years, who participated in the 2008 Deaf Health Survey were compared with weighted data from a general population comparison group of 1,890 adult respondents to the 2006 Adult Health Survey. Four sexual health-related outcomes were examined: abstinence within the past year; number of sexual partners within the last year; condom use at last intercourse; and ever tested for HIV. Descriptive analyses were performed, including stratification by gender, age, income, marital status, and educational level. Results showed that Deaf respondents self-reported higher numbers of sexual partners over the past year compared to the general population. Condom use was higher among Deaf participants. HIV was similar between groups, though HIV testing was significantly lower among lower income, less well-educated, and female Deaf respondents. Findings suggest that Deaf ASL users have a sexual health risk profile that is distinct from that of the general population.

Jensen, M.P., McMullen, K., Molton, I.R., & Smith, A.E. (2015). **Sexual function, satisfaction, and use of aids for sexual activity in middle-aged adults with long-term physical disability.** *Topics in Spinal Cord Injury Rehabilitation, 21*(3), 227-232.

NARIC Accession Number: J72828

Project Number(s): H133B080024, H133B130018

ABSTRACT: Study examined sexual function, sexual satisfaction, and sexual aid use among middle-aged individuals with long-term physical disabilities (LTPD). A total of 576 middle-aged adults with LTPD completed a cross-sectional survey that included measures of sexual activity, function, and satisfaction. Analyses evaluated the: (1) prevalence of reported sexual dysfunction and rates of sexual aid use among individuals with LTPD; (2) associations between sexual satisfaction, dysfunction, and the use of aids; and (3) physical and psychological predictors of sexual satisfaction separately for men and women living with LTPD. Consistent with studies of able-bodied adults, results indicated that sexual function was the strongest predictor of satisfaction. However, depression also predicted sexual satisfaction for women. Use of aids for sexual activity varied by disability type and was generally associated with better function. The lowest levels of sexual satisfaction were reported by men with SCI. These findings emphasize the importance of sexual activity in adults aging with physical disability, especially for those aging with SCI.

Johnson, K.L., & Pebdani, R.N. (2015). **Rehabilitation counseling students report on training and sexuality.** *Rehabilitation Counseling Bulletin (RCB), 58*(3), 173-175.

NARIC Accession Number: J70902

Project Number: H133P080008

ABSTRACT: Study surveyed 312 rehabilitation counseling students on how much training they received on sexuality during their education. Results indicated that less than half of the participants reported receiving graduate-level training on sexuality, and nearly one-third of the participants received training on sexuality during their undergraduate education. Implications for research, training, and practice and limitations of the study are discussed.

Lindstrom, L., Sinclair, J., & Unruh, D. (2015). **Barriers to sexuality for individuals with intellectual and developmental disabilities: A literature review.** *Education and Training in Autism and Developmental Disabilities - ETADD (formerly Education and Training in Developmental Disabilities; Education and Training in Mental Retardation and Developmental Disabilities), 50*(1), 3-16.

NARIC Accession Number: J70962

ABSTRACT: This literature review examined the barriers that individuals with intellectual and developmental disabilities (ID/DD) experience that may prevent them from understanding and exploring their own sexuality. Thirteen articles published between 2000 and 2013 that explored sexuality of individuals with ID/DD met the inclusion criteria. Analysis of these articles revealed multiple barriers faced by individuals with ID/DD to accessing their sexuality and sexuality education in three major themes. The three themes are: (1) perceptions of others about individuals with ID/DD and their sexuality, (2) perceptions of individuals with ID/DD about their own sexuality, and (3) sexuality knowledge of individuals with ID/DD. Within each theme, the authors identify the barriers to accessing sexuality and sexuality education for individuals with ID/DD. These barriers prevent them from achieving the same autonomy and quality of life as their peers. Implications for practice are discussed.

McEntee, B., McGrady, M., Schoen, B., & Vaughn, M. (2015). **Addressing disability stigma within the lesbian community.** *Journal of Rehabilitation, 81*(4), 49-56.

NARIC Accession Number: J72948

ABSTRACT: Article explores how stigma intersects with both the disability and the lesbian communities. Despite decades of research reporting the consequences of stigma facing non-dominant groups in areas including sexual orientation and disability, lesbians continue to encounter attitudinal and environmental barriers that threaten their general health and quality of life. It is important to examine and understand the impact of the intersection of multiple threats individuals encounter as a result of their membership in multiple marginalized groups. This article examines the body of research that investigates the processes and challenges associated with

being lesbian with a disability in pursuit of the basic tenets of life. Recommendations for rehabilitation counselors and training programs are discussed.

Nevedal, A., & Sankar, A. (2015). **The significance of sexuality and intimacy in the lives of older African Americans with HIV/AIDS.** *The Gerontologist*, 5(1), 1-11.

NARIC Accession Number: J73716

Project Number: H133P090008

ABSTRACT: Study explored older African Americans' experiences of living with HIV/AIDS. Thirteen seropositive African Americans aged 50 and older completed one semi-structured in-depth interview on life course expectations and experiences of living with HIV/AIDS. Interview transcripts were analyzed using standard qualitative coding and thematic analysis. Responding to broad, open-ended questions about the impact of HIV on life course expectations, participants emphasized how HIV limited their ability to experience sexuality and intimacy. Two major themes emerged, damaged sexuality and constrained intimacy. Older African Americans' discussions of living with HIV focused on the importance of and the challenges to sexuality and intimacy. Findings highlight a need for screenings, interventions, and sources of support for older African Americans with reduced well-being because of challenges and losses to sexuality and intimacy after an HIV diagnosis.

Seeman, M.V. (2015). **The role of mental health services in addressing HIV infection among women with serious mental illness.** *Psychiatric Services (formerly Hospital and Community Psychiatry)*, 66(9), 966-974.

NARIC Accession Number: J72962

ABSTRACT: This literature review explored how mental health services can best prevent and treat HIV infection in women with serious mental illness (SMI). The Google Scholar database was searched using the terms "HIV," "serious mental illness," and "women" to identify recent articles addressing the topic of HIV infection among women with SMI. Of the 500 relevant papers retrieved, 82 were included based on their state-of-the-art findings. Women with SMI at risk of HIV were found to be an especially vulnerable group. The evidence suggests that dis-

ussion of the modes of viral transmission reduces the risk of infection in this population, as do psychoeducation; long-term antipsychotic medication; adherence therapy; community treatment orders; prevention of domestic violence and homelessness; disbursement of financial entitlements; provision of psychotherapy and social support; cognitive rehabilitation; promotion of abstinence, monogamy, or reduction in the number of sexual partners; access to and training in the use of condoms; prophylaxis with vaginal microbicides and oral antiretroviral drugs; prompt diagnosis and treatment of sexually transmitted diseases; across-the-board offers of HIV testing; and preservation and monitoring of reproductive health. For HIV-positive individuals, comprehensive treatment measures have included prompt HIV treatment, long-term retention in care, supervision of medication adherence and drug interactions, rapid management of substance use disorders and all other comorbidities as well as drug side effects, and preclusion of professional stigmatization. This literature review provides evidence to recommend effective combinations of strategies to prevent and treat HIV within mental health services.

Sidana, A. (2015). **Information product testing: Results from cognitive testing of sexuality and sexual functioning after spinal cord injury factsheet.**

NARIC Accession Number: O20338

Project Number: H133A110004

ABSTRACT: Report presents the results of the cognitive testing of a factsheet on sexuality and sexual functioning after spinal cord injury (SCI). The factsheet was created for consumers with SCI as well as their families and caretakers. Trained interviewers used a semi-structured interview protocol to conduct cognitive testing on the factsheet through telephone interviews lasting about 60 minutes. Five SCI survivors were interviewed. The testing results are organized by the sections in the factsheet. Overall, Comprehension for this factsheet was high and participants found the factsheet helpful, reacting positively to the majority of the information in the factsheet. Participants appreciated that the factsheet contained information "applicable to almost everyone who would read it" and was written by a "scientific organization [using] ordinary words" and a tone that "normalized" discussion of sex after SCI. Par-

ticipants generally related to and agreed with the information in the factsheet, describing it as “helpful” and “accurate,” and stated that none of the information in the factsheet made them uncomfortable or contained any “triggers.” Participants considered the factsheet to be written for someone who was recently injured as well as “anyone with SCI who has any questions about sexuality.”

Smith, A. (2015). *New paper: The importance of sexual function, satisfaction, and use of aids for sexual activity.*

NARIC Accession Number: O20091

Project Number: H133B130018

ABSTRACT: This document summarizes research examining sexual functioning and satisfaction with sexual activity among individuals with physical disabilities as they age. A total of 368 middle-aged adults with physical disabilities completed a cross-sectional survey that included measures of sexual activity, function, and satisfaction. Results indicated that, consistent with studies of able-bodied adults, sexual function was the strongest predictor of satisfaction. However, depression also predicted sexual satisfaction for women. Use of aids for sexual activity varied by disability type and was generally associated with better function. Lowest levels of sexual satisfaction were reported by men with spinal cord injury.

2014

Arnold, C.K., Friedman, C., Owen, A.L., & Sandman, L. (2014). **“Remember our voices are out tools:” Sexual self-advocacy as defined by people with intellectual and developmental disabilities.** *Sexuality and Disability*, 32(4), 515-532.

NARIC Accession Number: J73476

Project Number: H133B140046

ABSTRACT: Study examines how people with intellectual and developmental disabilities (IDD) define and experience sexuality in the context of their identities as self-advocates. The nominal group technique was used to gather data from 35 male and female adult self-advocates with IDD. Analysis revealed that self-advocates described sexual self-advocacy as relating to knowing and respecting themselves, respect for others, choices, speaking up, having their rights respected, getting information, healthy relationships, and interdependence.

They also explained facilitators that would increase their sexual self-advocacy such as expanding access to information and sexual health services, removing systemic barriers, educating others, increasing access to counseling, and developing opportunities for sexual expression. This study is significant because it expands the research on sexual self-advocacy by bringing the sexuality and self-advocacy literatures together, reinforcing the value of people with IDD as legitimate sources of information about their own experiences. It also provided a sustainable and accessible research method for working with people with IDD.

Barker, D., Brown, L.K., Crosby, R., DiClemente, R.J., Donenberg, G.R., Hadley, W., Lang, D.M., Lescano, C., & Oster, D. (2014). **Project STYLE: A multisite RCT for HIV prevention among youths in mental health treatment.** *Psychiatric Services (formerly Hospital and Community Psychiatry)*, 65(3), 338-344.

NARIC Accession Number: J68836

ABSTRACT: This randomized controlled trial (RCT) examined the efficacy of family-based and adolescent-only HIV prevention programs in decreasing HIV risk and improving parental monitoring and sexual communication among youths in mental health treatment. A total of 721 adolescents (ages 13 to 18 years) and their caregivers from mental health settings in three cities were randomly assigned to one of three theory-based, structured group interventions: family-based HIV prevention, adolescent-only HIV prevention, and adolescent-only health promotion. Interventions were delivered during an all-day workshop. Assessments were completed at baseline and three months post intervention. Compared with those in the health intervention, adolescents in the HIV prevention interventions reported fewer unsafe sex acts, greater condom use, and greater likelihood of avoiding sex. They also showed improved HIV knowledge and self-efficacy. The family-based intervention, compared with the other interventions, produced significant improvements in parent-teen sexual communication, parental monitoring, and parental permissiveness. Findings of this RCT indicated that HIV prevention interventions reduced sexual risk behavior over three months in a large, diverse sample of youths in mental health treatment and that the family-based intervention improved parental monitoring and communication with teens about sex.

Barnard-Brak, L., Chestnut, S., Richman, D., Schmidt, M., & Wie, T. (2014). **Predictors of access to sex education for children with intellectual disabilities in public schools.** *Intellectual and Developmental Disabilities, 52*(2), 85-97.

NARIC Accession Number: J68810

ABSTRACT: Study analyzed data from the National Longitudinal Transition Study-2 to identify variables that predicted whether individuals with intellectual disability (ID) received sex education in public schools across the United States. Results suggested that individuals without ID receiving special education services were only slightly more likely to receive sex education than students with mild ID (47.5 percent and 44.1 percent, respectively), but the percentage of students with moderate-to-profound ID that received sex education was significantly lower (16.18 percent). Analysis of teacher opinions and perceptions of the likelihood of the students benefiting from sex education found that most teachers indicated that students without ID or with mild ID would benefit (60 percent and 68 percent, respectively), but the percentage dropped to 25 percent for students with moderate-to-profound ID. Across all students, the only significant demographic variable that predicted receipt of sex education was more expressive communication skills. The findings are discussed in terms of ensuring equal access to sex education for students with ID in public schools.

Bellamkonda, E., & Zollman, F. (2014). **Relationship between employment status and sexual functioning after traumatic brain injury.** *Brain Injury, 28*(8), 1063-1069.

NARIC Accession Number: J69131

Project Number(s): H133A070043, H133A080044, H133B090023, H133P080007

ABSTRACT: Study investigated whether correlations exist between employment status and sexual functioning in people with traumatic brain injury (TBI). Participants were 146 community dwelling adults either enrolled in the TBI Model Systems sexuality study database or admitted to Rehabilitation Institute of Chicago with a primary diagnosis of TBI between 2004 and 2006. Data collected included employment status, annual income, Derogatis Inter-

view for Sexual Functioning Self Report (DISF-SR) sum and sub-scale scores, Global Sexual Satisfaction Index (GSSI). Participants were grouped according to employment status. No significant difference was found in GSSI scores between employed, unemployed or students/volunteers; however, lower income marginally correlated with lower GSSI scores. Marginally significant lower DISF-SR Sexual Cognition sub-group scores were found in unemployed versus employed. Lower annual income also correlated with lower DISF-SR sum scores, sexual cognition/fantasy, orgasm/ejaculation, and sexual drive and relationship scores. Results indicated that lower-quality sexual functioning and satisfaction was present in subjects with TBI and concomitant unemployment or lower annual income. Efforts are needed to increase awareness among the TBI population and rehabilitation professionals of the potential impact unemployment or financial stress has on sexual functioning and satisfaction.

Boston, Q., & Pitt, J.S. (Eds.). (2014). **International rehabilitation points of impact.** *Journal of Applied Rehabilitation Counseling (JARC), 45*(2), 1-52.

NARIC Accession Number: R09287

ABSTRACT: Articles in this special journal issue highlight international trends in rehabilitation counseling. Topics include: disability and the Asian culture; investigating educators' views of sexuality, HIV and AIDS education in working with students with disabilities in South African schools; vocational rehabilitation in Uruguay; preparing global leaders in rehabilitation; disability in India: the role of gender, family, and religion; and an international collaborative cross-cultural teaching project between the United States and Taiwan. Individual articles may be available for document delivery.

Boutot, E., Tincanci, M., Travers, J., & Whitby, P.S. (2014). **Alignment of sexuality education with self-determination for people with significant disabilities: A review of research and future directions.** *Education and Training in Autism and Developmental Disabilities (formerly Education and Training in Developmental Disabilities; Education and Training in Mental Retardation and Developmental Disabilities)*, 49(2), 232-247.

NARIC Accession Number: J69201

ABSTRACT: Article explores the ways in which self-determination and sexuality education for people with significant disabilities are aligned. The authors conducted a systematic review of sexuality education intervention research for this population and found significant gaps related to self-determined sexuality. Sexual development is a complex but vital part of the human experience. People with significant disabilities are not excluded from this principle, but often may be prevented from receiving high-quality and comprehensive instruction necessary for a healthy sexual life. The functional model of self-determination emphasizes increasing knowledge, access to environments, and positive self-perceptions and may be an effective framework for the delivery of sexuality education to people with significant disabilities. Suggestions for sexuality education for people with significant disabilities as well as barriers are presented and implications for stakeholders and future research are discussed.

Cantor, J.B., Goldin, Y., Gordon, W.A., Spielman, L., & Tsaouides, T. (2014). **Sexual functioning and the effect of fatigue in traumatic brain injury.** *Journal of Head Trauma Rehabilitation*, 29(5), 418-426.

NARIC Accession Number: J69860

Project Number(s): H133A020501, H133A120084

ABSTRACT: Study examined specific aspects of sexual functioning (frequency, desired frequency, importance, and satisfaction) and their relationship to fatigue in individuals with traumatic brain injury (TBI) compared with those without brain injury. The relationship of demographic variables, emotional well-being, and health-related quality of life to sexual functioning was also explored. Data were collected through administration of self-report measures and interviews as part of a larger study of post-TBI fatigue. Two hundred twenty community-dwelling adults with self-reported mild-to-severe TBI and 83

individuals without brain injury completed the following measures: the Participation Objective, Participation Subjective, (a measure of community integration); the Fatigue Assessment Instrument and the Global Fatigue Index (fatigue); the Beck Depression Inventory (depression), and the Medical Outcomes Study 36-Item Short-Form Health Survey (health-related quality of life). Several aspects of sexual activity (frequency, desired frequency, and importance) were closely related to specific features of fatigue among individuals with TBI. Women with TBI reported lower frequency and lower importance of sex than men. In individuals without brain injury, the impact of fatigue was limited to the frequency of sexual activity with no sex differences observed. The findings suggest that fatigue plays a different role in the subjective experience of sexual activity for men and women with TBI than for those without brain injuries.

das Nair, R., Dyer, K. (2014). **Talking about sex after traumatic brain injury: Perceptions and experiences of multidisciplinary rehabilitation professionals.** *Disability and Rehabilitation*, 36(17), 1431-1438.

NARIC Accession Number: J69723

ABSTRACT: Study explored rehabilitation professionals' perceptions and experiences of discussing sexuality with service-users who have had a traumatic brain injury (TBI). The data were collected using focus groups with teams of rehabilitation professionals that already work together. Purposeful sampling was used to recruit 24 participants from two local National Health Service trusts and from a national charity. A semi-structured interview schedule was used to guide the discussion about post-TBI sexual issues. Focus group data were transcribed verbatim and analyzed using thematic analysis. Six main themes emerged from the analysis: (1) sexuality after TBI is a specialist issue; (2) sexuality is a sensitive subject; (3) practicalities of discussing sexuality; (4) roles and responsibilities; (5) dilemmas about risk and vulnerabilities; and (6) organizational and structural issues. The findings suggest that a more proactive approach to addressing sexuality issues be taken by incorporating sexuality into assessments and by having sexuality information available for service-users. Support for professionals is also needed in the form of the development of policy, on-going training, and supervision.

Hajiaghababaei, M., Javidan, A.N., Khalifa, D.A., Khoei, E.M., Koenig, H.G., Pakpour, A.H., & Sa-beri, H. (2014). **Female sexual dysfunction in patients with spinal cord injury: A study from Iran.** *Spinal Cord (formerly Paraplegia)*, 52(8), 646-649. NARIC Accession Number: J69767

ABSTRACT: Study assessed the prevalence of female sexual dysfunction (FSD) following spinal cord injury (SCI), compared sexual function and sexual distress between females with SCI and gender-matched healthy controls, and identified risk factors associated with FSD among women with SCI. A total of 105 Iranian female patients with SCI provided sociodemographic information and completed the Female Sexual Function Index, Hospital Anxiety and Depression Scale and Female Sexual Distress Scale-Revised questionnaire. The average age was 41.0 years. Women with SCI reported significantly higher levels of sexual dysfunction compared with normal controls. Approximately, 88 percent of SCI patients reported at least one type of sexual dysfunction, whereas only 37 percent of healthy controls reported sexual dysfunction. Lack of vaginal lubrication was reported more frequent in SCI patients compared with controls. Women with SCI reported a significantly higher level of sexual distress compared with healthy women. Sexual dysfunction was observed to be significantly higher in older patients, those with less education, patients with complete lesions, those with sexual distress and patients who were anxious and depressed. Findings suggest that sexual dysfunction is highly prevalent among Iranian women with SCI. Sexual dysfunction is associated with age, education, symptoms of depression and anxiety, and level of injury. Sexual counseling during the rehabilitation period may help to prevent sexual dysfunction following SCI.

Harcourt, D., & Mathias, Z. (2014). **Dating and intimate relationships of women with below-knee amputation: An exploratory study.** *Disability and Rehabilitation*, 36(5), 395-402.

NARIC Accession Number: J68821

ABSTRACT: Study investigated the experiences of dating and intimate relationships among women who use a below-knee prosthesis. Four women took part in semi-structured online interviews. The transcripts were analyzed using interpretative phenom-

enological analysis. Five themes were identified: (1) Revealing and Exposing: Disclosing the Amputation and Prosthesis; (2) Judging and Judged: Internal Fears and Self-Doubt; (3) Trusting and Accepting: Good Guy/Bad Guy Elimination; (4) Taking it Further: The Need for Depth; and (5) Realization: Accepting and Feeling Accepted. Participants described how, despite negative feelings towards their appearance and body image, they chose not to conceal their prosthesis when dating. Rather, it was used as a means of screening potential partners in their search for deep and meaningful relationships. Realizing that others were not prejudiced towards people who use a prosthesis had helped them become more comfortable with their own prosthesis. These findings suggest that facilitating contact with other below-knee amputees and, in some cases specialist support, could help those who are struggling with the challenges they face regarding dating and intimate relationships. They also highlight the need for researchers and clinicians to give more attention to these important aspects of amputees' lives.

Hasson-Ohayon, I., Hertz, I., Kravetz, S., & Vilchinsky, N. (2014). **Attitudes toward the sexuality of persons with physical versus psychiatric disabilities.** *Rehabilitation Psychology*, 59(2), 236-241.

NARIC Accession Number: J68733

ABSTRACT: Study examined whether involvement of people with either a physical or psychiatric disability in a sexual relationship moderates the relation between their type of disability and attitudes toward them. After reading one of six randomly assigned vignettes, 195 university students filled out a semantic differential-based attitude scale. The six vignettes consisted of a male with either a physical disability, a psychiatric disability, or no disability, who was either involved or not involved in a sexual relationship. The attitudes scale consisted of 31 items that referred to 5 characteristics of the men portrayed in the vignettes: personality, sociality, occupation, intelligence, and ethics. Results showed an interaction between type of disability and involvement in a sexual relationship was found for two subscales of the attitudes scale, occupation and intelligence. Involvement in a sexual relationship was found to generate more positive attitudes when the target person had a physical disability but more negative attitudes

when he had a psychiatric disability. Involvement in a sexual relationship seems to work in favor of people with a physical disability because of the association of such a relationship with normality and adaptation. However, attributing such a relationship to individuals with a psychiatric disability seems to be stigmatic.

Lichtenberg, P.A. (2014). **Sexuality and physical intimacy in long-term care.** *Occupational Therapy in Health Care*, 28(1), 42-50.

NARIC Accession Number: J68312

ABSTRACT: Article reviews the current literature on sexuality and aging, examines some of the clinical practices and guidelines regarding sexual expression in long-term care, and presents two case examples. Because older adults in medical rehabilitation and long-term care settings present with significant frailties, and often significant neurocognitive disorders, it makes it difficult for occupational therapists and other staff to evaluate the capacity of an older adult resident to participate in sexual relationships. A semi-structured interview and decision tree is presented to assist therapists in making careful and informed decisions and thereby balancing the needs for protection with the needs for autonomy. Recommendations for long-term care facilities and the implications for occupational therapy practitioners are discussed.

Lynch, E., & McGrath, M. (2014). **Occupational therapists' perspectives on addressing sexual concerns of older adults in the context of rehabilitation.** *Disability and Rehabilitation*, 36(7), 651-657.

NARIC Accession Number: J69000

ABSTRACT: Study explored occupational therapists' perspectives on addressing sexuality in the context of rehabilitation services for older people. Data were collected through 5 focus groups conducted among 22 occupational therapists working with older people. Data were analyzed using content analysis. Results indicated that occupational therapists in this study rarely addressed sexuality in the context of rehabilitation services for older people. Three major categories emerged in relation to barriers to current practice in this area: (1) the influence

of culture on decisions regarding whether or not to address sexuality, (2) perceived competence and confidence to address sexuality, and (3) the impact of resources regarding the inclusion or exclusion of sexuality from rehabilitation. Although sexuality is increasingly considered an important and relevant aspect of successful aging, the extent to which healthcare professionals are prepared to address sexual concerns identified by older people is less clear. If new expectations of healthy ageing are to be met, healthcare professionals must acknowledge the importance of sexuality and be prepared to be involved in sexual health management.

Seymour, L.M., & Wolf, T.J. (2014). **Participation changes in sexual functioning after mild stroke.** *Occupation, Participation and Health (OTJR) (formerly The Occupational Therapy Journal of Research)*, 34(2), 72-80.

NARIC Accession Number: J68769

ABSTRACT: Study explored the extent to which people with mild stroke experience changes in participation in sexual activity post stroke. A cross-sectional study was completed with 13 adults who were 6 to 18 months post mild stroke. Participants completed an assessment battery over the telephone that included the modified Quality of Sexual Function scale, the Stroke Impact Scale (SIS), and the Patient Health Questionnaire-9, a measure of depression. Correlational analyses were performed to examine the relationships among sexual functioning, the impact of stroke, and depression. Results indicated that participants experienced mild problems with sexual functioning. Sexual dysfunction post stroke was highly correlated with all of the domains on the SIS. Several participants reported that they would have liked more information about sexual functioning post stroke. These findings suggest that individuals with mild stroke are experiencing decreased participation in sexual activities post stroke and would like more information from healthcare professionals about the potential for sexual changes.

Sullivan, J.E. (2014). **Information/education page: Sexuality after traumatic brain injury.** *Archives of Physical Medicine and Rehabilitation*, 95(9), 1801-1802.

NARIC Accession Number: J69600

Project Number(s): H133A060070, H133A120020, H133B090023

ABSTRACT: Article describes common sexual problems after traumatic brain injury and offers ways to improve them.

Travin, M. (Ed.). (2014). *SCI Access*, 22(2), Fall 2014.

NARIC Accession Number: O19657

Project Number: H133N110002

ABSTRACT: Newsletter of the University of Michigan (UM) Spinal Cord Injury (SCI) Model System provides information on research briefs, treatment, and social issues for individuals with SCI. This issue focuses on interpersonal relationships. Topics include: acceptance and change: new ways to deal with difficult thoughts and feelings; perspectives of dating from people with SCI; sexuality and SCI; UM SCI Model System alumni news; in memory of Glenn Bates; and upcoming events.

2013

(2013). **Quick review of model system research: Predictors of sexual functioning and satisfaction 1 year following traumatic brain injury: A TBI model systems multicenter study.**

NARIC Accession Number: O19491

Project Number: H133A110004

ABSTRACT: This study investigated predictors of sexual dysfunction in people with traumatic brain injury (TBI) and the relationship of these predictors to dissatisfaction with sexual function at one year after injury. Participants in this study were 255 individuals who received acute rehabilitation in a TBI Model Systems center. The study found that older age, more severe injury, and female gender were associated with a greater likelihood of sexual dysfunction at 1 year after TBI. Depression was also predictive of worse sexual satisfaction but not sexual functioning. On the other hand, better social participation was linked to lower sexual dysfunction. The findings indicate that lack of motor and cognitive

independence did not necessarily imply sexual dysfunction. The results show that specialized assessments and services may be required to help address the needs of those that may be at a higher risk for sexual dysfunction.

Arango-Lasprilla, J.C, Gan, C., McKerral, M., & Moreno, J.A. (2013). **Sexuality after traumatic brain injury: A critical review.** *Neurorehabilitation*, 32(1), 69-85.

NARIC Accession Number: J66272

ABSTRACT: Article reviews the literature on traumatic brain injury (TBI) and sexuality. A general review of the concept of sexuality and the neurological correlates of sexual function are proposed as a framework to understand the cognitive, behavioral, and physical effects of TBI on sexuality and sexual function. Studies are classified according to the participants enrolled and findings are presented from the professional's, the survivor's, the patient/partner's, and the non-injured spouse's perspectives. Results are discussed taking into account methodological limitations and knowledge gaps. Next, implications for sexual rehabilitation for individuals with TBI are discussed. Finally, suggestions for future research and their pertinence for improving rehabilitation outcomes are considered.

Bishop, L., Clancy, C., Hillinger, M., & Stein, J. (2013). **Sexuality after stroke: Patient counseling preferences.** *Disability and Rehabilitation*, 35(21), 1842-1847.

NARIC Accession Number: J67335

ABSTRACT: Study examined patient preferences for counseling related to sexuality after stroke. Two hundred sixty-eight patients from a stroke registry were provided an anonymous paper or online survey. Thirty-eight patients completed the survey, which collected demographic information and assessed respondents' sexual dysfunction, fatigue, depression, and functional independence. In addition, subjects were queried about stroke-related sexual dysfunction and their preferences for counseling and education materials. Most respondents (71 percent) identified sexuality as a moderately to very important issue in their post-stroke rehabilitation. Sexual dysfunction was common, with 47 percent of respondents indicating that their sexual function had declined since

the stroke. Eighty-one percent reported receiving insufficient information about sexuality post-stroke, and the majority (60 percent) expressed a preference for receiving counseling regarding sexuality from a physician. A substantial portion (26.5 percent) of patients wanted to receive counseling prior to discharge from a hospital or rehabilitation center, with 71 percent wishing to receive counseling within 1 year post-stroke.

Dekker, R., Dijkstra, P.U., Enzlin, P., Geertzen, J.H.B., & Verschuren, J.E.A. (2013). **Sexuality in people with a lower limb amputation: A topic too hot to handle?** *Disability and Rehabilitation*, 35(20), 1698-1704.

NARIC Accession Number: J67324

ABSTRACT: Study investigated whether and by whom sexuality is discussed in amputation departments of rehabilitation centers and hospitals. The study focused on whether professionals received questions about sexuality from their patients with a lower-limb amputation and whether they addressed sexuality themselves. The study also analyzed whether the knowledge and comfort level, approach and attitudes toward sexuality of the professionals influenced receiving questions from patients and addressing sexuality themselves. An online questionnaire, including questions on self-perceived sexuality competence and the Knowledge, Comfort, Approach and Attitudes towards Sexuality Scale, was completed by 166 professionals. Results indicated that 78 percent of the professionals had not received questions about sexuality from their patients and 67 percent had not addressed sexuality. Self-perceived knowledge about sexuality and self-perceived ability to recognize sexual problems increased the odds of receiving a question about sexuality and the odds of addressing this issue. Findings suggest that sexuality is rarely discussed by professionals in the amputation department. It is, however, the responsibility of the professional to do so. By addressing sexuality in a systematic way and discussing this as a common topic, professionals "give permission" to patients and other team members to discuss eventual sexual problems or concerns.

Downing, M.G., Ponsford, J.L., & Stolwyk, R. (2013). **Factors associated with sexuality following traumatic brain injury.** *Journal of Head Trauma Rehabilitation*, 28(3), 195-201.

NARIC Accession Number: J66443

ABSTRACT: Study examined the relationship between sexuality following traumatic brain injury (TBI) and a range of demographic (age, gender); injury-related (time since injury, posttraumatic amnesia duration, independence in activities of daily activities [ADLs]); and post-injury (antidepressant use, depression, and self-esteem) variables. Participants included 986 individuals with predominantly moderate to severe TBI who completed the Brain Injury Questionnaire of Sexuality (BIQS), the Hospital Anxiety and Depression Scale, the Rosenberg Self-Esteem Scale and an assessment of ADLs. All participants had been assessed on 1 or more occasions, providing a total of 1673 assessments across 1, 2, 3, 5, 10, and 20 years after injury. Analyses revealed that being depressed, older in age, at shorter time post-injury, and less independence in ADLs significantly predicted poorer overall BIQS scores as well as the Sexual Functioning subscale score. Poorer Relationship Quality and Self-esteem scores on the BIQS were predicted by older age at injury and higher levels of depression. Lower Mood score on the BIQS was associated with shorter posttraumatic amnesia duration, younger age, and higher levels of depression. Self-esteem was associated positively with sexuality outcome.

Downing, M.G., Ponsford, J.L., & Stolwyk, R. (2013). **Sexual changes in individuals with traumatic brain injury: A control comparison.** *Journal of Head Trauma Rehabilitation*, 28(3), 171-178.

NARIC Accession Number: J66440

ABSTRACT: Study compared sexuality in individuals with traumatic brain injury (TBI) with that in healthy controls matched for age and gender. The purpose of the study was to characterize those individuals who reported a decrease in sexuality relative to those reporting an increase according to certain demographic and injury variables. A total of 865 participants with predominantly moderate to severe TBI and 142 controls completed the Brain Injury Questionnaire of Sexuality (BIQS), the Hospital Anxiety and Depression Scale, and the Rosenberg

Self-Esteem Scale on one occasion. The results indicated that there was a significant difference between participants with TBI and controls on all the BIQS subscales as well as the total score. Age, depression, anxiety, and self-esteem levels significantly differentiated participants with TBI who reported decreased sexuality from those who reported increased sexuality. Participants with TBI attributed sexual changes to various causes: fatigue, low confidence, pain, decreased mobility, and feeling unattractive.

Gerhardt, P. (2013). *Sexuality instruction and learners with ASD.*

NARIC Accession Number: O19258

Project Number: H133A080027

ABSTRACT: Webcast provides information on sex and sexuality education for individuals with autism spectrum disorder (ASD). Presenter states what the working definition of sexuality is from the World Health Organization (WHO), 1975. He offers information on what research findings (or the lack thereof) are available on individuals with ASD and compares that to the research on individuals with intellectual disabilities. Other topics discussed include puberty and girls, boys, and ASD; reasons to teach sexuality education to individuals with ASD; myths about sexuality; basic guidelines for teaching; and teaching materials. The presenter also stresses the importance of teaching sexuality education to individuals with autism spectrum disorder and the challenges that may emerge. Run time: 55 minutes 54 seconds. NOTE: This video is of a frank sexual nature. Viewer discretion advised.

Hammond, F.M., Hanks, R.A., Maestas, K.L., Millis, S.R., & Sander, A.M. (2013). **Changes in sexual functioning from 6 to 12 months following traumatic brain injury: A prospective TBI model system multicenter study.** *Journal of Head Trauma Rehabilitation*, 28(3), 179-185.

NARIC Accession Number: J66441

Project Number(s): H133A070042, H133A070043, H133A080044, H133A120020, H133B031117, H133B090023

ABSTRACT: Study investigated changes in sexual functioning and satisfaction with sexuality during the first year following moderate to severe traumatic brain injury (TBI). Participants were 182 patients (53

women and 129 men) with moderate to severe TBI who were admitted to 1 of 6 participating TBI Model System centers and followed in the community. The Derogatis Interview for Sexual Functioning-Self-Report (DISF-SR) and the Global Sexual Satisfaction Index (GSSI) were administered at 6 and 12 months after injury. The DISF-SR rates the quality of a person's sexual functioning in 5 areas: sexual cognition/fantasy, sexual arousal, sexual behavior/experience, orgasm, and sexual drive/relationship. The GSSI is a subjective measure of satisfaction with current sexual relationship. Mean T-scores on the DISF-SR Arousal subscale demonstrated marginal improvement over time, with a 2.59-point increase from 6 to 12 months after injury. There were no significant differences over this 6-month period on the remaining DISF-SR subscales, including sexual cognition/fantasy, sexual behavior/experience, and orgasm. There was no significant change in satisfaction with sexual functioning on the GSSI from 6 months (72 percent satisfied) to 12 months (71 percent satisfied). Sexual function and satisfaction appears to be stable in those with moderate to severe TBI from 6 to 12 months after injury, with the exception of minimal improvement in arousal.

Hammond, F.M., Hanks, R.A., Maestas, K.L., Nick, T.G., Pappadis, M.R., Ripley, D.L., & Sander, A.M. (2013). **Predictors of sexual functioning and satisfaction 1 year following traumatic brain injury: A TBI model systems multicenter study.** *Journal of Head Trauma Rehabilitation*, 28(3), 186-194.

NARIC Accession Number: J66442

Project Number(s): H133A070013, H133A070022, H133A070042, H133A070043, H133A080044, H133A080045, H133A120020, H133B031117, H133B090023

ABSTRACT: Study investigated predictors of sexual functioning 1 year following traumatic brain injury (TBI). A total of 255 people with TBI who had been treated at 1 of 6 TBI Model Systems inpatient rehabilitation units and were living in the community participated. Sexual functioning was assessed using the Derogatis Interview for Sexual Functioning-Self-Report and the Global Sexual Satisfaction Index. Predictor variable included age, gender, and injury severity). The following measures were also used as predictors: Functional Independence Measure,

Participation Assessment with Recombined Tools-Objective, and Patient Health Questionnaire-9. Analyses revealed that older age, female gender, and more severe injury were associated with greater sexual dysfunction 1 year following injury. As age increased from 24 to 49 years, the odds of sexual impairment increased more than 3-fold. Females were 2.5 times more likely than males to report sexual impairment. Greater social participation was predictive of better sexual functioning. Dissatisfaction with sexual functioning was predicted by older age and depression. Results suggest that older adults and females appear to be at greater risk for sexual dysfunction after TBI and may benefit from specialized assessment and treatment services. Relationships were identified between social participation and sexual function and between depression and sexual satisfaction that may serve as clinical indicators for further assessment and intervention.

Hoffman, J. (2013). *Love and marriage after spinal cord injury*.

NARIC Accession Number: O19290.

Project Number: H133N110009

ABSTRACT: Panelists in this forum consist of three individuals with spinal cord injury (SCI), and their spouses (married 21, 20, and 1.5 years), who describe how and when their injuries happened and what their level of injury is. The couples share their stories of how they met and became a couple after SCI. They also provide advice to newly injured individuals about starting or getting back into dating, along with tips they've learned along the way on marriage, having children, parenting, household responsibilities, home modifications, caregiving, and stress the importance of communicating with your partner. Run time: 1 hour 13 minutes 59 seconds.

Kapperman, G., & Kelly, S.M. (2013). **Sex education instruction for students who are visually impaired: Recommendations to guide practitioners.** *Journal of Visual Impairment & Blindness*, 107(3), 226-230.

NARIC Accession Number: J66370

ABSTRACT: Article presents a series of recommendations for accommodations and additional teaching and pre-teaching to guide teachers of students with visual impairments in sex education in-

struction for students with visual impairments. The recommendations focus on three specific categories that should be addressed in developing a framework for sex education instruction involving students with visual impairments: content, learning environment, and delivery.

Manucharian, S.R. (2013). **Changes in sexual functioning in persons with limb amputation.** *JPO: Journal of Prosthetics and Orthotics*, 25(4), 177-183.

NARIC Accession Number: J67431

ABSTRACT: Study examined the impact of demographic factors and comorbidities, such as diabetes mellitus, peripheral vascular disease (PVD), and hypertension, on the sexual functioning of individuals with lower-limb amputations. The sexual function of 51 lower-limb amputees and 38 non-amputees of similar age range was measured using the Changes in Sexual Functioning Questionnaire Short Form instrument. The results did not reveal any reduction in sexual functioning solely due to an amputation. Among the comorbidities, the presence of diabetes mellitus in the participants was the only predictor of reduced sexual functioning. This finding was significant only in the amputee group.

Nolan, M. (2013). **Masculinity lost: A systematic review of qualitative research on men with spinal cord injury.** *Spinal Cord (formerly Paraplegia)*, 51(8), 588-595.

NARIC Accession Number: J66929

ABSTRACT: Study systematically reviewed qualitative research that explores the gendered experience of men with spinal cord injury (SCI). A systematic search of databases and hand search of relevant journals were conducted to identify articles providing sufficient depth of information, relevant participant quotes, and phenomenological insight into the gendered experience of men with SCI. Eight papers, representing four separate studies, met the review criteria for relevance and rigor. Three broad, overlapping themes describing the gendered experience of men with SCI were identified: (1) lost masculinity, outlining the impact of SCI on traditional masculine identity; (2) fighting back, describing the battle to regain and reclaim masculinity and integrate disability into a revised identity; and (3) beyond hegemony, refer-

ring to possibilities beyond adherence to traditional masculine scripts. This review demonstrates a lack of explicit focus on men as gendered beings within the available qualitative literature. The findings are consistent with the limited quantitative data, which indicates that grappling with altered gendered identity is a central feature of life for men with SCI. Masculine identity emerges in this review as vulnerable to the impact of SCI, and given the strong links identified between masculinity, rehabilitation and health, as an aspect of experience that warrants more attention than it has received.

Tennille, J., & Wright, E. (2013). *Addressing the intimacy interests of people with mental health conditions: Acknowledging consumer desires, provider discomforts, and system denial.*

NARIC Accession Number: O18915

Project Number: H133B100037

ABSTRACT: This monograph focuses on the intimacy concerns of individuals with mental health conditions. Acknowledging that sexual intimacy is a lifelong priority for all men and women, the monograph reviews current mental health research on the topic, the issues raised by men and women with mental health conditions with regard to the barriers they face in developing satisfactory intimate lives, and the uneasiness of most community mental health practitioners in discussing intimacy and sexuality with the people they serve. Examining issues organized around systems, program providers, and consumers offers a starting point for taking action to create more inclusive practices and policies that foster greater opportunity for sexual expression and spaces for the development of intimate relationships.

2012

Agosti, M., Felzani, G., Franceschini, M., Mazzarella, F., Pagliacci, M.C., & Sale, P. (2012). **Predictors of changes in sentimental and sexual life after traumatic spinal cord injury.** *Archives of Physical Medicine and Rehabilitation*, 93(11), 1930-1936.

NARIC Accession Number: J64920

ABSTRACT: Study investigated changes in and identified predictors of sentimental relationships and sexual life after traumatic spinal cord injury (SCI). A total of 403 subjects with traumatic SCI were interviewed by phone an average of 3.8 years after discharge from 24 centers participating in a previous epidemiologic prospective survey. Satisfaction with sentimental life and satisfaction with sexual life were assessed and correlated with the following independent variables: demographic (age, sex, marital status, vocational status), SCI related (severity, level, bowel/bladder continence), car-driving ability, perceived quality of life (QoL), and impact of sentimental life, social integration, and vocational status on QoL. Satisfaction with sentimental life was reportedly increased or the same as before SCI in 69 percent of the sample, but satisfaction with sexual life increased or stayed the same in only 31 percent. Lesser satisfaction with sexual life was reported by men than women and by married people than singles. Significant predictors of sentimental life were perceived QoL and preserved driving ability. Bladder continence was positively associated with a better satisfaction with sexual life. Bowel continence did not remain a significant predictor of satisfaction with sexual life in multivariate analysis.

Boulet, M., Charvier, K., Cote, I., Courtois, F., Dahan, V., Rodrigue, X., & Vezina, J.G. (2012). **Sexual function and autonomic dysreflexia in men with spinal cord injuries: How should we treat?** *Spinal Cord (formerly Paraplegia)*, 50(12), 869-877.

NARIC Accession Number: J64970

ABSTRACT: Study reviewed the literature on the acute or prophylactic treatment of autonomic dysreflexia (AD) in the context of sexual function in men with spinal cord injury (SCI). Thirty-seven papers on the specific treatment of AD showed that nifedipine, prazosin, captopril and clonidine are candi-

dates in the context of sexual activities. Prazosin, however, has an initial hypotensive effect requiring treatment to begin 12 hours before intercourse, which makes it less ideal for spontaneous sexual activities. Captopril has an initial hypotensive effect and was only studied in acute AD. Its usefulness in prophylaxis remains to be demonstrated. Clonidine has successfully been used clinically for decades, but never studied in randomized control trials. Nifedipine remains the most widely studied and significant treatment of AD whether in acute or prophylactic conditions. Recent concerns suggest increased cardiovascular risks with sublingual nifedipine in non-SCI populations, but negative long-term effects have not been reported in the SCI population.

Cohen-Kettenis, P.T., Ketelaar, M., Roebroek, M.E., Stam, H.J., & Wiegerink, D.J.H.G. (2012). **Personal and environmental factors contributing to participation in romantic relationships and sexual activity of young adults with cerebral palsy.** *Disability and Rehabilitation*, 34(17), 1481-1487.

NARIC Accession Number: J64368

ABSTRACT: Study explored the determinants of romantic relationships and sexual activity in 74 young adults, aged 20 to 25 years, with cerebral palsy (CP), examining personal and environmental factors in addition to demographic and physical characteristics. Associations were analyzed using logistic regression analyses. Results indicated that more females than males with CP were in a current romantic relationship. Self-esteem, sexual esteem, and feelings of competence regarding self-efficacy contributed positively to having current romantic relationships. A negative parenting style contributed negatively. Age and gross motor functioning explained 20 percent of the variance in experience with intercourse. In addition, sexual esteem and taking initiative contributed significantly to intercourse experience. For young adults with CP personal factors (20 to 35 percent explained variances) seem to contribute more than environmental factors (9 to 12 percent explained variances) to current romantic relationships and sexual experiences. The authors advise parents and professionals to focus on self-efficacy, self-esteem and sexual self-esteem in development of young adults with CP.

Couwenhoven, T. (2012). *The boys' guide to growing up: Choices & changes during puberty.*

NARIC Accession Number: R09185

ABSTRACT: This book is designed to help boys with intellectual and developmental disabilities understand what to expect during puberty. Written at a third-grade reading level for boys aged 9 to 16 years with Down syndrome, autism, cerebral palsy, mental retardation, fragile X, or other special needs, it gives practical advice on common concerns such as shaving, what to do about acne, and how to smell nice. More complex and essential topics are covered too, such as how to know when flirting is reciprocated (or not!), how to hide or discourage an erection in public, what information is okay to share with others versus what should remain private, and how to stay safe. The book includes a question-and-answer section, many illustrations to enhance the text, and a note to parents.

Del Castillo, A., Etzbach, C.A., Marini, I., & Wang, X. (2012). **Ethnic, gender, and contact differences in intimacy attitudes toward wheelchair users.** *Rehabilitation Counseling Bulletin (RCB)*, 56(3), 135-145.

NARIC Accession Number: J65697

ABSTRACT: Study examined attitudes of undergraduate students toward having a relationship with someone who uses a wheelchair. A total of 810 primarily Hispanic and Caucasian undergraduate students initially selected one of six opposite-gender head shots and subsequently viewed their selection's whole body photograph in a wheelchair along with reading a short biography. Participants were surveyed regarding their interest in potentially being friends, dating, or marrying a wheelchair user. Chi-square tests of pairwise association, logistical regression, and test of proportional odds revealed significant differences between ethnicity, gender, type of relationship, and having had a prior disability relationship. Sixty-six percent of participants indicated they would have no problem dating or marrying a wheelchair user. Personal traits of intelligence, humor, kindness, and physical appearance were rated most highly. Those unwilling to date or marry their selection perceived the partner would require too much caregiving, social interaction awkwardness, inability to sexually perform, and the partner being sick often.

Findings suggest that counselors can benefit from informing clients about intimacy misconceptions by role-playing and providing clients with insights regarding societal beliefs.

Eide, A.H., Rohleder, P., Schneider, M., & Swartz, L. (2012). **Challenges to providing HIV prevention education to youth with disabilities in South Africa.** *Disability and Rehabilitation, 34*(8), 619-624.

NARIC Accession Number: J63170

ABSTRACT: Study explored the extent to which HIV prevention education is provided to people with disabilities in South Africa, and the challenges faced by educators who provide HIV prevention education to learners with disabilities. A survey questionnaire completed by 34 schools for learners with special education needs in the Western Cape province of South Africa. Additional complimentary data were collected through interviews with a total of 21 members of staff at schools for learners with disabilities. Respondents recognize the importance of providing HIV prevention education for people with disabilities. Staff reported some challenges in providing HIV prevention education: barriers to communication, discomfort about issues of sexuality and disability, disagreements among staff about what is appropriate content for sexual health education, and fears of promoting sexual activity.

Eide, A.H., Ranchod, C., Rohleder, P., Schneider, M., Schur, C., & Swartz, L. (2012). **Gender differences in HIV knowledge and unsafe sexual behaviors among disabled people in South Africa.** *Disability and Rehabilitation, 34*(7), 605-610.

NARIC Accession Number: J63168

ABSTRACT: Study explored gender differences in HIV knowledge and unsafe sexual behaviors among individuals with disabilities in South Africa. Data was collected by means of a survey questionnaire from a total of 285 people with disabilities in three of the nine provinces in South Africa. Data was analyzed using descriptive statistics. Results indicated that there are low levels and uncertainty of knowledge about HIV transmission and HIV prevention, with females tending to have lower levels of knowledge than males. Although the importance of condoms in HIV prevention was recognized, there were relatively high levels of reported unsafe sexual behaviors. Males reported higher number of monogamous and concurrent sexual partnerships and

sex without a condom after alcohol use. The results support the literature that suggests that people with disabilities are at risk for HIV infection, and that both male and female individuals with disability are at risk.

Hammond, F.M., Hanks, R., Maestas, K.L., Pappadis, M.R., Sander, A.M., & Sherer, M. (2012). **Sexual functioning 1 year after traumatic brain injury: Findings from a prospective traumatic brain injury model systems collaborative study.** *Archives of Physical Medicine and Rehabilitation, 93*(8), 1331-1337.

NARIC Accession Number: J64484

Project Number(s): H133A070042, H133A070043, H133A080044, H133B090023, H133P080007

ABSTRACT: Study investigated the incidence and types of sexual difficulties in men and women with traumatic brain injury (TBI) 1 year after injury, as well as their comfort level in discussing problems with health care professionals. Participants were 223 people with TBI (165 men and 58 women) who had been treated at 1 of 6 participating TBI Model Systems inpatient rehabilitation units and were living in the community. Data were collected using the following measures: the Derogatis Interview for Sexual Functioning-self-report (DISF-SR), the Global Sexual Satisfaction Index (GSSI), a structured interview regarding changes in sexual functioning, and questions about comfort level discussing sexuality with health care professionals. Women with TBI scored significantly below the normative sample for all subscales of the DISF-SR, including sexual cognition/fantasy, arousal, sexual behavior/experience, and orgasm. Men scored significantly below the normative sample on all scales except arousal. Women reported greater dysfunction than men for sexual cognition/fantasy and arousal. Twenty-nine percent of participants reported dissatisfaction with sexual functioning on the GSSI, with a greater percentage of men reporting dissatisfaction. Sixty-eight percent of participants indicated that they would spontaneously raise issues of sexual difficulties with health care professionals, while the remainder would either bring it up only if directly asked or would not discuss it at all. Sexual difficulties were present in a substantial portion of community-dwelling people with TBI at 1 year after injury. Educational interventions to increase awareness among people with TBI and rehabilitation professionals are warranted, as well as interventions to improve sexual functioning.

Hastings, R.P., Jahoda, A., & Pownall, J.D. (2012). **Sexuality and sex education of adolescents with intellectual disability: Mothers' attitudes, experiences, and support needs.** *Intellectual and Developmental Disabilities - IDD (formerly Mental Retardation)*, 50(2), 140-154.

NARIC Accession Number: J63523

ABSTRACT: Study compared the attitudes and behaviors of mothers of 30 young people with and 30 without intellectual disability (ID). Both groups placed similar importance on dealing with their children's developing sexuality and were similarly confident in doing so. Mothers of young people with ID held more cautious attitudes about contraception, readiness to learn about sex, and decisions about intimate relationships. Mothers expressed concerns about their children with ID and sexual vulnerability. They had also spoken about fewer sexual topics with their children and began these discussions when their children were older. The findings can be used to help develop more sensitive supports and materials to help families deal with the sexual development of their offspring.

Hattjar, B. (Ed.). (2012). **Sexuality and occupational therapy: Strategies for persons with disabilities.**

NARIC Accession Number: R09333

ABSTRACT: This handbook intends to provide occupational therapy clinicians, educators, and students with a basic level of understanding about how to address, evaluate, and intervene with clients who experience difficulty with sexual activity. Sexual activity is a valued occupation among most people, and many clients who experience an injury or disease would still like to pursue it. Although sexuality is an activity of daily living not often addressed in occupational therapy settings or educational programs, occupational therapy practitioners are ideally suited to address this issue. Reflecting the profession's focus on occupation and its holistic spirit, this book aims to equip practitioners with the knowledge and strategies to discuss the topic with clients, including approaching the topic, understanding the specifics, and referring to an appropriate specialist. The text discusses sexuality in relation to some of the most common diagnoses and conditions affect-

ing occupational therapy clients, including: arthritis, cancer, diabetes, spinal cord injury, cardiac conditions, traumatic brain injury, stroke, mental health and developmental disorders, and adolescents with disabilities.

Hess, M.J., & Hough, S. (2012). **Impact of spinal cord injury on sexuality: Broad-based clinical practice intervention and practical application.** *Journal of Spinal Cord Medicine (JSCM) (formerly Journal of the American Paraplegia Society)*, 35(4), 211-218.

NARIC Accession Number: J64432

ABSTRACT: Article discusses the impact a spinal cord injury (SCI) may have on achieving physical and emotional intimacy, and the potential of rehabilitation to maximize sexual ability and quality of life. SCI is a traumatic, life-altering event that is usually associated with loss of motor and sensory function, as well as sexual impairment. At the time of injury, the individual is faced with devastating loss and an abundance of new information in a setting of extreme stress and challenge. In the acute rehabilitation setting, there is often a considerable void in providing education and resources regarding sexual concerns and needs. There is a positive relationship between sexual education and sexual activity. The impact of inadequate sexual counseling and education as a part of rehabilitation can be deleterious.

Hoffman, J. (2012). **It happened to both of us: Conversations with couples.**

NARIC Accession Number: O18661

Project Number: H133N110009

ABSTRACT: This video presents a panelist of couples that have been through the trauma and adjustment of spinal cord injury (SCI) together who talk about their experiences and what they do to stay together and maintain a healthy and lasting relationship. Topics include: how partners cope, feel, and adjust; how roles and expectations change; how couples survive the stresses and challenges of a life altering event; and how to lead a satisfying life together. Run time: 1 hour 21 minutes 14 seconds.

Kapperman, G., & Kelly, S.M. (2012). **Sexual activity of young adults who are visually impaired and the need for effective sex education.** *Journal of Visual Impairment & Blindness*, 106(9), 519-526.

NARIC Accession Number: J66343

ABSTRACT: Study compared the sexual experiences of transition-age young adults (19 to 23 years) who are visually impaired with those of young adults without disabilities. Data from the National Longitudinal Transition Study-2 (NLTS2), a large nationally representative data set, were considered to measure the sexual activity of young adults with visual impairments. Data from the database of the Centers for Disease Control and Prevention (CDC) were used to measure the sexual activity of young adults without specifically identified disabilities. The CDC survey sample included young adults who were two to three years younger than the participants in the NLTS2 sample. Fifty-seven percent of the young adults with visual impairments reported having sexual intercourse, and 65 percent of the young adults without disabilities reported having sexual intercourse. Likewise, nearly 40 percent of the young adults with visual impairments and approximately 50 percent of those without disabilities reported having had sexual intercourse in the three months before the survey. The use of condoms was also similar (64 percent of those with visual impairments and 54 percent of those without disabilities) even though the use of contraceptives other than condoms varied between the samples. The young adults with visual impairments reported having similar rates of sexual experiences as their sighted counterparts, except two to three years later. The researchers concluded that there is a need to provide effective instruction in sexual health that incorporates meaningful methods and materials that are designed specifically to meet the unique needs of young adults who are visually impaired.

Miller, J. (2012). **Marriage stability after traumatic brain injury.** *Points of Empowerment*, 10, December 2012.

NARIC Accession Number: O18852

Project Number: H133A080060

ABSTRACT: Fact sheet provides information about the effects of traumatic brain injury (TBI) on married life. It discusses potential factors in separation

and divorce, the impact of TBI on the uninjured spouse as well as the injured spouse, sexual satisfaction, and resources for assistance.

Murphy, C. (Ed.). (2012). *TBI News & Views, Winter 2012.*

NARIC Accession Number: O19264

Project Number: H133A070037

ABSTRACT: Semi-annual newsletter provides individuals with traumatic brain injury (TBI) and their families with the latest news in care and research. In this issue: adjusting after brain injury; an interview with Dr. David Scarisbrick about sexuality and TBI; finding employment through the New Jersey Division of Vocational Rehabilitation Services; the Opportunity Project; TBI professionals in research and clinical care; meet the staff: Phlagun Nori and Lauren Henning; and study participants needed.

Parmenter, T., Shuttleworth, R., Stancliffe, R., & Wilson, N.J. (2012). **Masculinity theory in applied research with men and boys with intellectual disability.** *Intellectual and Developmental Disabilities - IDD (formerly Mental Retardation)*, 50(3), 261-272.

NARIC Accession Number: J64313

ABSTRACT: Article summarizes contemporary, mainstream theories of masculinity and suggests ways they may be applied to research on, and to therapeutic interventions with, men and boys with intellectual disability. An example from one research project that explored male sexual health illustrates how using masculinity theory provided greater insight into gendered data. The following five topics are discussed to illustrate how researchers might use theories of masculinity: (1) fathering, (2) male physical expression, (3) sexual expression, (4) men's health, and (5) underweight and obesity. Theories of masculinity offer an additional framework to analyze and conceptualize gendered data; the authors challenge researchers to engage with this body of work.

2011

(2011). *Sexuality and reproductive health in adults with spinal cord injury: What you should know: A guide for people with spinal cord injury.*

NARIC Accession Number: R09128

ABSTRACT: This consumer guide provides information about how spinal cord injury (SCI) affects sexuality and sexual function. Topics include sexuality education, sexual response and enjoyment, female reproductive health and fertility, male fertility, practical considerations for sexual activity, physical health issues, psychological health considerations, lifestyle issues, and relationship issues.

Albiani, J.J., Blackmore, D.E., Hart, S.L., & Mohr, D.C. (2011). **Improvements in partner support predict sexual satisfaction among individuals with multiple sclerosis.** *Rehabilitation Psychology, 56*(2), 117-122.

NARIC Accession Number: J61105

ABSTRACT: Study investigated the extent to which changes in negative and positive partner support predict sexual satisfaction levels over time in individuals with multiple sclerosis (MS). Eighty-one individuals with MS completed measures of sexual dysfunction, sexual satisfaction, partner social support, and depression. Data from baseline and post-treatment follow-up were obtained from a larger randomized clinical trial of telephone-administered psychotherapy for depression in a population with MS. Multiple regression analyses were conducted with change in overall sexual satisfaction from baseline to post-treatment as the outcome variable. After controlling for age, gender, sexual dysfunction, years diagnosed with MS, and depression severity, those with increased positive partner support reported significant improvement in sexual satisfaction over time, as did individuals with decreased negative partner support. Results suggest that both positive and negative partner support have a distinctive role in the outcome of sexual satisfaction for individuals with MS. Understanding the unique role of positive and negative forms of partner support on sexual satisfaction will help lead to future interventions to improve sexual satisfaction among couples.

Arnold, K., Graham, B., Nelis, T., Parker, S., & Sandman, L. (2011). **Promoting sexual citizenship and self-advocacy for people with intellectual and developmental disabilities: The sexuality and disability consortium.** *The Community Psychologist, 44*(1), 8-11.

NARIC Accession Number: J62947

Project Number: H133B080009

ABSTRACT: Article presents a strategy to promote sexual citizenship and self-advocacy for people with intellectual and developmental disabilities (I/DD). The article begins with a discussion of some of the needs and forms of marginalization that exist for people with I/DD in regard to sexual health. The authors then examine the concept of sexual citizenship, highlighting examples and implications for the marginalized experiences of adults with I/DD. Finally, they describe a university-based disability and sexuality consortium working to address sexual citizenship and self-advocacy for adults with I/DD.

Aue, N., & Gowen, L.K. (Eds.). (2011). *Sexual health disparities among disenfranchised youth.*

NARIC Accession Number: O18464

Project Number: H133B090019

ABSTRACT: This book compiles a series of research briefs addressing the sexual health of youth populations known to have sexual disparities. They include: (1) youth in corrections; (2) youth with developmental disabilities; (3) youth in foster care; (4) homeless youth; (5) lesbian, gay, bisexual, transgender, and questioning (LGBTQ) youth; (6) youth with mental health conditions; and (7) youth who have experienced sexual abuse. It was found that many of these groups experience the same negative health outcomes. Three disparities are present in all seven populations: higher rates of pregnancy involvement, sexual abuse, and sexually transmitted infections. Overall, there is a dearth of research on the sexual health outcomes of marginalized youth.

Biering-Sorensen, F., Kreuter, M., Siosteen, A., & Taft, C. (2011). **Women's sexual functioning and sex life after spinal cord injury.** *Spinal Cord (formerly Paraplegia), 49*(1), 154-160.

NARIC Accession Number: J60742

ABSTRACT: Study describes women's experiences of sexual functioning and sex life after spinal cord injury (SCI). A total of 963 community-dwelling women treated at spinal cord center in Sweden,

Denmark, Norway, Finland, and Iceland meeting inclusion criteria were mailed the SCI Women Questionnaire. Out of the 532 respondents, 392 reported having had sex after injury and were thus included in the study. The included women had a mean age of 42 years and a mean time since injury of 11 years. Participants reported that the injury caused many changes in their sex life and affected many aspects of their sexuality negatively. Some changes were of a physical nature (for example, decreased, lost, or changed sensation; difficulties to achieve orgasm; bladder or bowel problems; and difficulties to move and position oneself) whereas other changes were of a psychological nature (for example, feeling unattractive or less attractive, having less self-confidence, and difficulties to meet or find a partner). Successful SCI rehabilitation requires a holistic approach, taking into account the patient's physical, psychological, and interpersonal circumstances. Given that many women with SCI remain sexually active but often experience less satisfaction after injury, it is important that rehabilitation efforts address this aspect of the patient's life. The strategies described by the respondents to compensate for loss of genital sensation and cope with physiological impairment during sexual activity may serve to help professionals in developing rehabilitation programs for women with SCI.

Blakeney, P., Meyer, W.J., Robert, R.S., Russell, W., & Thomas, C.R. (2011). **Sexual attitudes and behavior of young adults who were burned as children.** *Burns*, 37(2), 215-221.

NARIC Accession Number: J62904

Project Number: H133A070026, H133G990052

ABSTRACT: Study examined the sexual attitudes and behaviors of adults burned as children. It was hypothesized that survivors with large burn scars would have differences in sexual attitudes and behaviors from their unburned counterparts. Ninety-two young adults, who were burned on 30 percent or more of their total body surface area as children, completed the questionnaires that assessed sources of sexual information, attitudes toward different sexual behaviors, and experience with different sexual behaviors. Sixty-five percent of the females and 52 percent of the males currently had a significant other. Although only 54 percent of women and 60 percent of men felt they were sexually attractive, 83 and 87 percent, respectively, endorsed feeling confident

about sex. Experience with sexual intercourse was common: 90 percent of females and 76 percent of males. Burn severity was not significantly correlated with sexual attitudes and behaviors. In this study, the majority of 92 young adults burned as children described sexual attitudes and behaviors comparable to the general population and the vast majority had significant sexual experience.

Cameron, R.P., Chen, S.S., Cordes, C.C., Fraley, S.S., Klein, L.S., Lemos, L., Mona, L.R., Smith, K., Syme, M.L., & Welsh, E. (2011). **Sexuality among wounded veterans of operation enduring freedom (OEF), operation Iraqi freedom (OIF), and operation new dawn (OND): Implications for rehabilitation psychologists.** *Rehabilitation Psychology*, 56(4), 289-301.

NARIC Accession Number: J62472

ABSTRACT: Article examines the intimate relationships and sexual lives of returning sexual lives of returning Operation Enduring Freedom, Operation Iraqi Freedom, and Operation New Dawn veterans within the context of their personal cultural variables and the diverse experience of military life. Given the nature of military social and cultural contexts, the potential for exposure to combat-related stressors that may lead to posttraumatic stress disorder, and the risk of traumatic brain injury secondary to physical injury, the potential for significant psychological and relational ramifications exists. Culturally competent assessment and evidenced-based treatment approaches offer clinicians initial strategies to begin treatment of sexuality issues within the returning veteran population. These clinical tools are discussed within a positive psychology approach that emphasizes healthy sexuality as a part of overall satisfactory quality of life.

Cyborski, C., Hammond, F.M., Kendall, K.S., Moessner, A.M., Pappadis, M.R., & Sander, A.M. (2011). **Sexual functioning and satisfaction after traumatic brain injury: An educational manual.**

NARIC Accession Number: O18719

Project Number: H133A070043

ABSTRACT: Booklet describes some common changes in sexual functioning that can occur after traumatic brain injury (TBI) and suggest ways to improve sexual functioning and satisfaction.

Gill, C.J., Mazzei, D., Robins, N., Sander, A.M., & Struchen, M.A. (2011). **Exploring experiences of intimacy from the viewpoint of individuals with traumatic brain injury and their partners.** *Journal of Head Trauma Rehabilitation*, 26(1), 59-68.

NARIC Accession Number: J60320

Project Number(s): H133A070043, H133A70015, H133B031117, H133B090023

ABSTRACT: Study explored the experience of intimacy from the viewpoint of people with traumatic brain injury (TBI) and their intimate partners. Open-ended, semi-structured, in-depth interviews were conducted with 18 individuals with TBI and their intimate partners regarding participants' experience of intimacy, factors impacting intimacy, and need for services. Factors that were perceived as helping relationships remain strong included unconditional commitment, spending time together, open communication, a strong pre-injury relationship, bonding through surviving the injury together, social support, family bonds, spirituality, experience with overcoming hardship, and coping skills. Factors that were perceived as barriers to intimacy included injury-related changes, emotional reactions to changes, sexual difficulties, role conflict and strain, family issues, social isolation, and communication issues. The authors conclude that education regarding the impact of TBI on intimacy should be integrated into rehabilitation. Health professionals should be sensitized as to the needs that persons with TBI and their partners have regarding intimacy and how to make appropriate referrals to assist them.

Hastings, R., Jahoda, A., Kerr, L., & Pownall, J.D. (2011). **Sexual understanding and development of young people with intellectual disabilities: Mothers' perspectives of within-family context.** *American Journal on Intellectual and Developmental Disabilities (formerly American Journal on Mental Retardation AJMR)*, 116(3), 205-219.

NARIC Accession Number: J61369

ABSTRACT: Study used interpretive phenomenological analysis to explore how mothers' views concerning the sexuality of young people with intellectual disabilities (ID) in the context of their family life and broader social circumstances. Eight mothers were asked to discuss their experience of supporting similarly aged siblings with and without intel-

lectual disabilities. Themes identified in the interviews were grouped into three general categories: (1) the balance between independence and control, (2) support for their children's emerging sexuality, and (3) discussion of sexual matters and sources of information. There were both similarities and differences in how mothers handled these issues for their child with and without disabilities, and mother's experiences differed widely across these themes. Acknowledgment of their nondisabled child's sexuality was demanded by increasing autonomy, whereas continuing dependence of the child with ID hindered mothers who were addressing this intensely private and sensitive issue with them. The topic of sexuality revealed mothers' fears about their child's ability to cope with the challenges of adulthood.

Hoffman, J. (2011). ***Conversations from the Bedroom: Sex after spinal cord injury.***

NARIC Accession Number: O18472

Project Number: H133N060033

ABSTRACT: This video presents a forum of two men with tetraplegia (quadriplegia) and one woman with paraplegia who talk about their real sexual experiences since injury including the good, the bad, and the funny. Participants answer real life questions that newly injured people have concerns about like: will they ever have sex again or for the first time, how to develop satisfying intimate relationships, and how to navigate sexuality with a spinal cord injury (SCI). Also, a rehabilitation physician answers questions related to medical issues and sexual activity. Run time: 1 hour 14 minutes. Note: This video is of a frank sexual nature. Viewer discretion advised.

Kim, H-S., Oh, H-S., Seo, W., & Song, H-S. (2011). **Effects of a sexual rehabilitation intervention program on stroke patients and their spouses.** *Neurorehabilitation*, 28(2), 143-150.

NARIC Accession Number: J64218

ABSTRACT: Study examined whether a sexual rehabilitation intervention program, designed for stroke patients and their spouses, was effective in terms of sexual knowledge and satisfaction and frequency of sexual activity at 1 month after intervention. The study subjects were conveniently selected from stroke patients admitted to the neurology department at a university hospital located in Incheon,

South Korea. Forty-six subjects (12 couples for the experimental group and 11 couples for the control group) were included. Sexual knowledge, sexual satisfaction, frequency of sexual activity, level of cognitive function, and performance with respect to daily living activities were measured. The results obtained demonstrated that the devised sexual rehabilitation intervention program significantly increased sexual satisfaction and frequency of sexual activity, but that it did not promote sexual knowledge. This study has meaning because the intervention program could be used as a practical guideline for post-stroke sexual rehabilitation. In addition, the findings of this study provide evidence regarding the usefulness of sexual education and counseling on the sexual health of post-stroke patients and their spouses.

Maestas, K., & Sander, A.M. (2011). *La sexualidad después de una lesión cerebral traumática. Información para el consumidor del Sistema Modelo de Lesión Cerebral Traumática.*

NARIC Accession Number: O18940

Project Number: H133A110004

ABSTRACT: Fact sheet describes common sexual problems that can occur after traumatic brain injury (TBI) and suggests ways to help resolve these problems and improve sexual functioning. This document is also available in English (see accession number O18939). Esta publicación también está disponible en inglés (mire al número de acceso O18939).

Maestas, K., & Sander, A.M. (2011). *Sexuality after traumatic brain injury. Traumatic Brain Injury Model System Consumer Information.*

NARIC Accession Number: O18939

Project Number: H133A110004

ABSTRACT: Fact sheet describes common sexual problems that can occur after traumatic brain injury (TBI) and suggests ways to help resolve these problems and improve sexual functioning. This publication is also available in Spanish (see accession number O18940). El artículo es disponible en español (mire al número de acceso O18940).

Parmenter, T.R., Shuttleworth, R.P., Stancliffe, R.J., & Wilson, N.J. (2011). **Gendered service delivery: A masculine and feminine perspective on staff gender.** *Intellectual and Developmental Disabilities - IDD (formerly Mental Retardation)*, 49(5), 341-351.

NARIC Accession Number: J62232

ABSTRACT: Article presents data from a qualitative study conducted to determine what impact staff gender has on the sexual health needs of men and boys with intellectual disability in community group homes. Findings suggest that staff gender is an important consideration when dealing with sexual health matters and can enhance the type and quality of relationships between people with intellectual disability. Paid caregivers are not gender-neutral beings who can provide a standardized form of care and support. Moreover, these data also demonstrate that the gendered relationships, and the meaning of those relationships, between not only paid caregivers but also the clients in their care are indeed diverse and quite complex. Staff gender does matter and does contribute toward different care and support outcomes; some that promote the meaning in one's quality of life, others that may limit that meaning.

2010

(2010). *Sexuality and reproductive health in adults with spinal cord injury: A clinical practice guideline for healthcare professionals.*

NARIC Accession Number: R09129

ABSTRACT: This clinical practice guideline provides addresses a wide range of topics related to sexuality and reproductive health after spinal cord injury (SCI). It includes recommendations that address physical, interpersonal, emotional, and medical concerns. The recommendations express best clinical practice based on research and expert opinion. Topics include: the importance of sexuality and reproduction to the individual; sexual history and assessment, education, maintaining sexual well-being; physical and practical considerations; effect of injury on sexual function, responsiveness, and expression; treatment of dysfunction; effects on fertility; and relationship issues.

Beck, T., & DiGiovanni, L. (2010). **Developmental approach to sexuality and intimacy.** *Topics in Spinal Cord Injury Rehabilitation*, 16(1), 48-54.

NARIC Accession Number: J59994

ABSTRACT: Article offers strategies and tools that healthcare professionals can use to address the sexual concerns of children and adolescents with spinal cord injuries (SCI). A developmental approach is needed when delivering appropriate and accurate sex education to children and adolescents with SCI. Health care professionals are responsible for conveying this information in a positive and comprehensive way to the children and adolescents and/or the parents. The information in this article can be used to help create a developmentally based outline regarding sexuality topics that should be addressed to the children and adolescents.

Bosch, J., Caruso, D.M., Foster, K.N., Jost, J.C., Lesnard, C.R., Pressman, M.S., Rimmer, R.B., & Rutter, C.E. (2010). **Burn care professionals' attitudes and practices regarding discussions of sexuality and intimacy with adult burn survivors.** *Journal of Burn Care and Research (formerly Journal of Burn Care & Rehabilitation)*, 31(4), 579-589.

NARIC Accession Number: J59078

ABSTRACT: Study investigated burn center practices related to sexuality and intimacy concerns of burn survivors and their partners. A 28-item survey was distributed to burn care practitioners attending general sessions at several burn conferences in the United States. Seventy-one (86 percent) of the invited respondents completed the survey, with nursing representing the majority. Mean tenure working in burn care was 10 years. Mean age of respondents was 40.5 years, with 75 percent being female. Nearly half (47 percent) reported that specific staff was not designated to discuss sexuality and intimacy with survivors in their center. Sixty-two percent reported that special training regarding sexuality and intimacy was not available at their burn center. Only 14 percent of respondents indicated that they were "very comfortable" initiating conversation regarding these topics. Fifty-five percent said they were only likely to discuss sexuality and intimacy if the patient/partner initiated the discussion; however, 95 percent agreed that the patient should not have this responsibility. Although findings from only 37 burn

centers are present, the results suggest that issues of sexuality and intimacy are not being effectively addressed in the participating centers. Designated staff to provide education is lacking, and there is limited comfort on the part of health care providers in initiating such conversations. These factors seem to often prevent burn care professionals from adequately addressing burn survivor's sexuality and intimacy needs and establish the need for further development of training and educational materials specific to sexuality, intimacy, and burn injury survival.

Brodwin, M.G., Frederick, P.C. (2010). **Sexuality and societal beliefs regarding persons living with disabilities.** *Journal of Rehabilitation*, 76(4), 37-41.

NARIC Accession Number: J59676

ABSTRACT: Article examines the myths and misconceptions regarding sexuality and people living with disabilities. Stereotypes associated with people with disabilities presume that they are not sexually attractive, are incapable of having sexual desires, and that any kind of sexual expression is inappropriate. Discussion includes the influence of self-esteem, self-concept, and psychological variables; gender identity; cultural patterns and beliefs, interpersonal relationships, and the knowledge and sensitivity of rehabilitation professionals on these incorrect assumptions.

Celso, M., Del Popolo, G., Lombardi, G., Macchiarella, A., & Mencarini, M. (2010). **Sexual rehabilitation in women with spinal cord injury: A critical review of the literature.** *Spinal Cord*, 48(12), 842-849.

NARIC Accession Number: J59833

ABSTRACT: Study presents a critical review of literature on the multiple aspects of sexual rehabilitation in women with spinal cord injury (SCI) from initial recovery to long-term follow-up. Articles on sexuality published from 1993 to 2009 that met the inclusion criteria were selected from PubMed. Research supported by significant statistical analyses reported that females with complete tetraplegia deserved special attention immediately at initial recovery; sexual intercourse is much more difficult for them (as compared with other women with SCI) mainly because of autonomic dysreflexia and

urinary incontinence. There are sparse data on predictable factors favoring sexual rehabilitation such as the age SCI was incurred, the importance of one's sexual orientation, and the SCI etiology. Information after initial discharge is based chiefly on questionnaires, which report that as more time passes since the injury, patients attain more sexual satisfaction compared with recently injured women. Studies on neurological changes after SCI, and their effect on sexual response, are supported by a significant statistical analysis, but with few SCI patients. One topic reported the effect of sildenafil on sexuality, without benefit. No paper offers any detailed analysis on the sexual impact of medical and psychological treatments related to SCI. Literature reports that some co-morbidities are more prevalent in women with SCI compared with able-bodied women but data on sexual functioning are missing. To improve sexual rehabilitation services, evaluation of sexual issues during periodical check-ups is recommended, using validated questionnaires administered by a physician 'guide' who coordinates other professional operators, thus providing personalized programmable interventions.

Cohen-Kettenis, P.T., Gorter, J.W., Roebroek, M.E., Stam, H.J., & Wiegerink, D.J. (2010). **Development of romantic relationships and sexual activity in young adults with cerebral palsy: A longitudinal study.** *Archives of Physical Medicine and Rehabilitation*, 91(9), 1423-1428.

NARIC Accession Number: J59456

ABSTRACT: Study examined the development of romantic relationships and sexual activity in young adults with cerebral palsy (CP) over a 4-year period and investigated whether this development is associated with demographic and physical characteristics. The study also compared the sexual activity of this group with an age-appropriate Dutch reference population. One hundred three young adults (age 16 to 20 years at first assessment) with CP were recruited from 8 rehabilitation centers and departments in the southwestern regions of The Netherlands. Data collected included age, gender, education level, Gross Motor Function Classification System level, sexual interest, romantic relationships, and sexual activity. A significant increase in dating was observed in young adults with CP during the 4-year period; how-

ever, the experience in romantic relationships did not increase largely during this period. Young adults with a lower education level began dating later than those with higher levels. Significantly more women were in current romantic relationships than men. During the 4 years, participants' sexual experience increased significantly for all sexual milestones evaluated. Level of gross motor function was associated significantly with intercourse experience. Compared with an age-appropriate Dutch reference population, young adults with CP participated at a lower level in romantic relationships and sexual activities, but had equal sexual interest at the final assessment.

Darry, K., Esmail, S., Knupp, H., & Walter, A. (2010). **Attitudes and perceptions towards disability and sexuality.** *Disability and Rehabilitation*, 32(14), 1148-1155.

NARIC Accession Number: J59153

ABSTRACT: Study examined current societal perceptions and attitudes towards sexuality and disability and how social stigma differs between individuals living with visible and invisible disabilities. Focus groups were conducted with the following groups: service providers, people with visible disabilities, people with invisible disabilities, and the general public. The focus group participants viewed a short documentary film on sexuality and disability to stimulate discussion midway through the session. Findings suggest that individuals with disabilities are commonly viewed as asexual due to a predominant hetero-normative idea of sex and what is considered natural. A lack of information and education on sexuality and disability was felt to be a major contributing factor towards the stigma attached to disability and sexuality. Stigma can lead individuals to internalize concepts of asexuality and may negatively impact confidence, desire, and ability to find a partner while distorting one's overall sexual self-concept. Societal attitudes and perceptions are driven by education and knowledge, if there is no exposure to sexuality and disability, it follows suit that society would have a narrow understanding of these issues. Further research should focus on how best to educate and inform all members of society.

Ducharme, S., & Johnston, S.L. (2010). **Intimate relationships.** *PN/Paraplegia News*, 64(5), 21-25. NARIC Accession Number: J58664

ABSTRACT: Article reviews some of the approaches used to address erectile dysfunction resulting from spinal cord injury. Research on the use and effectiveness of various treatments are presented, including oral medications (Viagra, Levitra, and Cialis); intracavernosal injections (Alprostadil or prostaglandin E1); intraurethral suppositories; topical agents; vacuum devices, and implants.

Ely, C., Fager, S., Hancox, D., & Stenhjem, P. (Eds.). (2010). **Impact: Feature issue on sexuality and people with intellectual, developmental and other disabilities**, 23(2).

NARIC Accession Number: O17868

Project Number: H133B080005

ABSTRACT: This issue focuses on sexuality in people with intellectual, developmental, and other disabilities. Topics include: self-advocates speak up about sex; what parents of children with intellectual disabilities should know about sexuality; preparing a child for puberty and adolescence; parents talk about sexuality and disability; the role of guardianship in sexual expression for adults with disabilities; resources supporting dating, marriage, and parenting; a sexuality policy that truly supports people with disabilities; sex, disability, and direct support professionals (DSPs); DSPs talk about supporting individuals who are gay, lesbian, bisexual, and transgender; people with disabilities and federal marriage penalties; new ways of thinking about parents with intellectual disabilities; and personal stories, resources, and more.

Esmail, S., & Krupa, C. (2010). **Sexual health education for children with visual impairments: Talking about sex is not enough.** *Journal of Visual Impairment & Blindness*, 104(6), 327-337.

NARIC Accession Number: J59042

ABSTRACT: Study investigated problems that children with visual impairments experience with sexual health education. Data were collected through one-on-one interviews conducted with 8 adults with low vision and a focus group involving 9 adults with low vision. The participants identified themes that affected their knowledge of sexual health and the need for sexual health education. Their stories

revealed that they did not receive the same opportunities as their sighted peers to explore and discover sexuality. The analysis and synthesis of the data revealed three specific categories that need to be addressed when developing an appropriate framework for sexual health education: content, delivery, and environment. Strategies that address sexual health issues for individuals with visual impairments are described.

Finkelstein, M., & Schmitz, M.A. (2010). **Perspectives on post-stroke sexual issues and rehabilitation needs.** *Topics in Stroke Rehabilitation*, 17(3), 204-213.

NARIC Accession Number: J59102

ABSTRACT: Study examined the perspectives and experiences of stroke survivors and partners of stroke survivors regarding sexual issues and perceived rehabilitation needs. Using semi-structured interviews, 15 stroke survivors and 14 partners of stroke survivors provided information about sexual issues experienced after stroke and their perspectives on how to address sexual concerns in a rehabilitation setting. A qualitative thematic analysis was applied to transcribed interviews to identify and describe common themes within the data relevant to the aim of the study. A quantitative analysis was used to determine the frequency of themes by demographic characteristics that were not readily apparent using a qualitative method alone. Seven themes were identified. Two related to the effects of stroke on sexual life: physical/functional changes and relationship changes. Five related to addressing sexual issues in the process of rehabilitation: (1) difficulty in patients and providers talking about sexual matters, (2) little to no discussion of post-stroke sexuality, (3) need for tailoring education to an individual or couple's unique needs, (4) provider rapport and competence, and (5) timing of post-stroke sexual education.

Hoffman, J. (2010). **Communication in dating and relationships after spinal cord injury.**

NARIC Accession Number: O18598

Project Number: H133N060033

ABSTRACT: This video presents a panelist of single, dating, and married individuals with a spinal cord injury (SCI) who share their experiences with pre and post-injury dating and relationships. Participants answer real life questions like: how to

meet new people, get out and date, have long term relationships, breaking the ice and putting down barriers, and how communication plays such an important part in starting and continuing a lasting relationship. The panelists also discuss when and how to start talking about the physical side of SCI, such as bowel, bladder, and sexual function. Run time: 73 minutes.

Kazukaukas, K.A., & Lam, C.S. (2010). **Sexual Behavior in High-Functioning Male Adolescents and Young Adults with Autism Spectrum Disorder.** *Rehabilitation Counseling Bulletin (RCB)*, 54(1), 15-25.

NARIC Accession Number: J59572

ABSTRACT: Study investigated certified rehabilitation counselors' (CRCs) attitudes, knowledge, and comfort in addressing disability and sexuality issues. One hundred ninety-nine CRCs completed a modified version of the Knowledge, Comfort, Approach and Attitudes toward Sexuality Scale to determine the effect of knowledge and attitudes on level of comfort in addressing sexuality issues with consumers. Counseling and education-type comfort and comfort with sexual solicitations or discovering consumers in sexual situations (approach) were assessed separately. Participants demonstrated low discomfort on the education and counseling-related comfort scale and medium discomfort on the approach-related comfort scale, positive attitudes, and average knowledge. Results of regression analyses indicated that 17 percent of the variance on comfort and 19 percent of the variance on approach could be accounted for by CRCs' knowledge and attitude, indicating that these were contributing to CRC comfort levels in addressing sexuality with consumers. Implications include the need for continued research concerning factors affecting CRC comfort in addressing sexuality-related issues with consumers, and the need for increased CRC education and training in sexuality and disability.

Tincani, M., & Travers, J. (2010). **Sexuality education for individuals with autism spectrum disorders: Critical issues and decision making guidelines.** *Education and Training in Autism and Developmental Disabilities (formerly Education and Training in Developmental Disabilities)*, 45(2), 284-293.

NARIC Accession Number: J58684

ABSTRACT: This article presents one position in support of sexuality education for children and adolescents with autism spectrum disorders (ASD). While the topic of sexuality has received increased attention in the fields of mental retardation and developmental disabilities generally, less consideration has focused specifically on the unique needs of individuals with ASD. The nature of human sexuality is discussed to provide a context for the rights of individuals with ASD to learn about their sexuality. Further justification for providing sexuality education in terms of the unique characteristics of this population is offered in conjunction with potential consequences of failing to provide sexuality education. Lastly, information regarding a decision-making process for sexuality education curriculum is presented, including the responsibilities of families and professionals providing sexuality education.

2009

Alexander, M.S., Bodner, D., Brackett, N.L., Elliott, S., Jackson, A., & Sonksen, J. (2009). **From the 2006 NIDRR SCI measures meeting: Measurement of sexual functioning after spinal cord injury: Preferred instruments.** *Journal of Spinal Cord Medicine (JSCM) (formerly Journal of the American Paraplegia Society)*, 32(3), 226-236.

NARIC Accession Number: J56869

Project Number: H133N060021

ABSTRACT: Study reviewed the literature pertaining to measures of sexual and reproductive capabilities to determine the validity of specific instruments for assessing sexuality and fertility following spinal cord injury (SCI). An expert panel selected 4 key areas to study: male sexual function, female sexual function, male reproductive function, and female reproductive function. Based on frequency of use, the group identified 5 measurement tools to assess in detail. They included: (1) the Female Sexual Function

Index (FSFI) to assess female sexual function, (2) vaginal photoplethysmography to measure vaginal pulse amplitude (VPA), (3) the International Index of Erectile Function (IIEF) to assess male sexual function, and the measurement of (4) ejaculatory function and (5) semen quality to assess male reproductive capability. There were no measures identified to assess female reproductive function. For clinical trials aiming to improve sexual function after SCI, the FSFI or the IIEF is currently preferred. Although VPA is an appropriate means to assess female sexual responses, it is only useful for laboratory studies and is too invasive for use in clinical trials. For assessment of male fertility potential, assessment of ejaculatory capacity and semen analysis are recommended.

Arbor, K. (2009). *Sexability*.

NARIC Accession Number: O18744

Project Number: H133N060003

ABSTRACT: This video is a general presentation of techniques that are options for individuals with spinal cord injury (SCI) for enhancing sexual experiences. The information is of a general nature and does not include specific concerns or risks for individuals with SCI. Topics discussed include anatomy, masturbation, communication tips, and sex toys. Questions are also answered. Run time: 62 minutes 25 seconds. NOTE: This video is of a frank sexual nature. Viewer discretion advised.

Berven, N.L., Juergens, M.H., & Smedema, S.M. (2009). **Willingness of graduate students in rehabilitation counseling to discuss sexuality with clients.** *Rehabilitation Counseling Bulletin (ARCA)*, 53(1), 34-43.

NARIC Accession Number: J57204

ABSTRACT: The purpose of this study was to obtain a greater understanding of the willingness of graduate students in rehabilitation counseling to discuss sexuality with clients. Path analysis was used to test a model of factors predicted to influence the willingness of rehabilitation counseling master's students to discuss sexuality with clients. The results suggest that sexuality knowledge, sexuality education, attitudes toward the sexuality of people with disabilities, and comfort with sexuality affect the willingness of rehabilitation counselors to discuss sexuality with clients, with sexuality knowledge and comfort with sexuality having direct effects on willingness.

Understanding the relationships between these variables may facilitate the design of interventions that promote the willingness of rehabilitation counselors to discuss sexuality with clients.

Cameron, R.P., Fraley, S.S., Goldwaser, G., Miller, A.R., Mona, L.R., & Syme, M.L. (2009). **Prescription for pleasure: Exploring sex-positive approaches in women with spinal cord injury.** *Topics in Spinal Cord Injury Rehabilitation*, 15(1), 15-28.

NARIC Accession Number: J56779

ABSTRACT: Article reviews the literature on the sexual experiences and needs of women with spinal cord injury (SCI), focusing on sexual health, sexual behavior and pleasure, and sex-positive therapies. Among the approaches that show promise, disability affirmative therapy, cognitive behavioral therapy, third-wave cognitive-behavioral therapies, feminist sex therapy, and a range of sex therapies, including tantric intervention, are reviewed for their potential application for women with SCI. A clinical example is illustrated to provide mental health professionals with new perspectives about interventions for promoting sexual pleasure among women with SCI.

Dijkstra, P.U., Geertzen, J.H.B., & Van Es, C.G. (2009). **Sexuality and amputation: A systematic literature review.** *Disability and Rehabilitation*, 31(7), 522-527.

NARIC Accession Number: J56881

ABSTRACT: This systematic review of the literature provides an overview of the knowledge of the field of sexuality and patients who have suffered from an amputation of an arm or a leg. A search of 5 publication databases (Pubmed, Cinahl, Embase, Psycinfo and Recall) yielded a total of 11 eligible studies. The studies were characterized by a diversity of study populations, sampling methods, gender and age distributions, assessment methods, and outcomes measures. The use of the terminology regarding sexuality was ambiguous. All studies found an impact of the amputation of a limb on some part of sexual functioning to some degree. Amputees complain that there is little support from professionals. The authors recommend the use of the International Classification of Functioning, Disability and Health terminology to provide a unified and standardized language for describing and measuring outcomes of future research.

Ducharme, S. (2009). **Let's talk about sex – please!** *PN/Paraplegia News*, 63(11), 32-35.

NARIC Accession Number: J57362

ABSTRACT: Article discusses the development and publication of a new clinical practice guideline (CPG) on sexuality and reproductive health that can help healthcare professionals present facts about intimacy and relationships to people living with spinal cord injury (SCI). Based on a 2-year review of the available literature and scientific research, the CPG includes several areas where new research has been reported, including information on the timing of sexual counseling, autonomic dysreflexia, and pregnancy.

Larsen, L. (Ed.). (2009). *Sexually transmitted diseases sourcebook, fourth edition. Health Reference Series.*

NARIC Accession Number: R09018

ABSTRACT: Book provides updated information about sexually transmitted diseases (STDs), their symptoms and treatments, and their occurrence in specific groups, such as women, teens, seniors, and homosexuals. It explains treatment and testing options, statistical data, and current research about STD prevention, clinical trials, vaccines, and other medical news. It discusses methods of preventing the spread of STDs, tips for living with STDs, guidelines for disclosing that one has an STD, and suggestions about talking to other about STDs. The book concludes with a glossary of related terms and a list of resources for further information.

Matevosyan, N.R. (2009). **Reproductive health in women with serious mental illnesses: A review.** *Sexuality and Disability*, 27(2), 109-118.

NARIC Accession Number: J60489

Project Number: H133P070001

ABSTRACT: This literature review examined the extent to which a serious mental illness (SMI) interferes with reproductive health (RH). The primary focus is the question of whether or not women with SMI are at high risk for sexually transmitted infections, female cancer, unwanted pregnancies, and sexual dysfunction. Eighty-four original studies published between 1971 and 2008 were identified through database, journal, and Internet searches and

categorized by their focus and sampling techniques. The RH primary outcomes (unwanted pregnancies, abortion, sexually transmitted infections, female cancer, sexual dysfunction) and their determinants (awareness, attitudes, socio-economic status, stigma, psychiatric condition, sexual activity, contraceptive usage, access to RH services) were considered as measurable outcomes. The review revealed little data about the awareness (knowledge, attitudes) in RH among women with SMI. The evidence suggests that women with SMI have more lifetime sex partners, low contraceptive usage, higher rates of unwanted pregnancies, and are at high risk for sexually transmitted infections. The findings highlight the importance of integration of the RH education into the psychosocial rehabilitation programs.

2008

Abramson, C.E., Elliott, S.L., Konnyu, K.J., & McBride, K.E. (2008). **Sexual health outcome measures for individuals with a spinal cord injury: A systematic review.** *Spinal Cord*, 46(5), 320-324.

NARIC Accession Number: J54784

ABSTRACT: Study systematically reviewed the literature evaluating the psychometric properties of sexual health outcome measures used in spinal cord injury (SCI) populations in order to determine the clinical relevance of the tools and suggest recommendations for future tool development. Electronic databases searches were limited to papers published between January 1986 and January 2006. Four outcome measures met the search criteria: (1) the Emotional Quality of the Relationship Scale, (2) the Sexual Activity and Satisfaction Scale, (3) the Sexual Attitude and Information Questionnaire, and (4) the Sexual Interest and Satisfaction Scale. Although these 4 outcome measurement tools have not been used extensively and are becoming outdated, they may still be useful in SCI research and clinical practice.

Aito, S., Cecconi, F., Del Popolo, G., Lombardi, G., & Macchiarella, A. (2008). **Sexual life of males over 50 years of age with spinal-cord lesions of at least 20 years.** *Spinal Cord*, 46(10), 679-683.

NARIC Accession Number: J56076

ABSTRACT: Study assessed the sexuality of 99 male patients over 50 years of age with spinal cord lesions for at least 20 years. Participants were divided into 2 groups: 44 patients under 60 years and 55 patients over 60 years. All patients completed the SF-36 Health Survey questionnaire and answered questions about their sexuality including questions 13 and 14 of the International Index of Erectile Function, concerning overall sexual satisfaction. The younger group reached a median score of over 50 for each domain of the SF-36; however, the differences between the two groups are not statistically relevant. In the younger group, 29 of the 44 individuals (65.9 percent) claimed erectile dysfunction versus 43 of the 55 (78.1 percent) in the older group. The most relevant difference in sexual function between the 2 groups was that 77.2 of the younger group reported having sexual intercourse versus 23.6 percent of the older group. In the older group, 29 (52.7 percent) individuals reported physical intimacy without sexual intercourse. Most aging couples presented a different way of thinking about sex without the need for intercourse. For both groups, overall sexual satisfaction was statistically correlated to the duration of the relationship.

Alexander, A. (2008). **An expressed perspective: The disability of love and sex.** *Exceptional Parent*, 38(5), 81-82.

NARIC Accession Number: J56144

ABSTRACT: The author provides a personal perspective on experiencing love and sex while living with a disability.

Cardenas, D.D., McLaughling, J.F., Topolski, T.D., Walker, W.O., & White, C.J. (2008). **Sexual functioning in adolescents and young adults with spina bifida.** *Archives of Physical Medicine and Rehabilitation*, 89(1), 31-35.

NARIC Accession Number: J53822

ABSTRACT: Questionnaires were mailed to 487 adolescents and young adults, 15 to 35 years old, with spina bifida, to assess their experience with

sex education and sexual functioning. The questionnaires included demographic information, the Perceived Quality of Life Scale, the Medical Outcomes Study 36-Item Short-Form Health Survey, the Satisfaction with Life Scale, questions on bowel and bladder continence, and 11 questions regarding sexuality and pregnancy. Almost all the participants received sex education at school, less at home or by physicians. Twenty-five percent of men and 68 percent of women were informed about reproductive function by their physicians. Participants who reported that they smoked were 10 times more likely to report being sexually active. Women were 2.3 times more likely to be sexually active than men. Hydrocephalus was a significant predictor of sexual activity among women but not men. Participants with urinary incontinence were less likely to be sexually active. Women without hydrocephalus were significantly more satisfied with life than women with hydrocephalus.

Gianotten, W.L., Heijnen, L., Lambers, E.J.H.R., Post, M.W.M., & Willems, M. (2008). **Sexological competence of different rehabilitation disciplines and effects of a discipline-specific sexological training.** *Sexuality and Disability*, 26(1), 3-14.

NARIC Accession Number: J54636

ABSTRACT: Study examined differences in sexological competence among different rehabilitation disciplines and examined the effects of a discipline-specific training program on sexuality. Among the 283 participants were physicians, physical therapists, occupational therapists, psychologists and social workers, and nurses. Goals of the training were to improve knowledge and attitude in order to feel at ease discussing matters of sexuality and to apply the skills of a specific discipline to the sexual concerns of patients. Participants were evaluated at the start and end of the training, and at 3 to 4 months after the end of training using the Knowledge, Comfort, Approach, and Attitudes towards Sexuality Scale. Results indicated that the increases in self-perceived sexological competence in all disciplines that were found following training were maintained at follow-up. Disciplines differed in sexual competence before training and in the increase of sexual competence after training.

Klebine, P. (Ed.). (2008). *Pushin' on*, 26(2).

NARIC Accession Number: O18148

Project Number: H133N060021

ABSTRACT: Newsletter provides information on aspects of spinal cord injury (SCI) for individuals with SCI, their families, and service providers. In this issue: headline news; probiotics and urinary tract infections; research reviews: (1) vardenafil improves ejaculation success rates and self-confidence in men with erectile dysfunction due to SCI and (2) a review of completed, ongoing, and planned clinical trials for acute SCI; political changes ahead for 2009; walking aid devices and robotic technologies; and volunteers needed for SCI-related research.

Spero, D. (2008). **When diabetes affects your sex life.** *Diabetes Self-Management*, 25(3), 82, 85-87.

NARIC Accession Number: J55958

ABSTRACT: Article discusses the potential effects of diabetes on sexual function and what to do about it. Medical treatment options and self-management approaches are presented.

Swango-Wilson, A. (2008). **Caregiver perception of sexual behaviors of individuals with intellectual disabilities.** *Sexuality and Disability*, 26(2), 75-81.

NARIC Accession Number: J56055

ABSTRACT: This descriptive survey study examined the perception of caregivers toward the sexuality of individuals with intellectual disabilities (ID). The Perception of Sexuality scale was used to measure caregiver attitudes toward sexual behaviors of individuals with ID. The survey was sent to 160 caregivers and yielded responses from 87 participants. Inferential statistics was used to determine basic characteristics of the responses. Results indicated that caregivers are uncertain about the appropriateness of sexual behaviors of individuals with ID. Sexual behaviors were rated as more appropriate for the caregiver and their peers than for the individual with ID.

Tarnai, B., & Wolfe, P.S. (2008). **Social stories for sexuality education for persons with autism/pervasive developmental disorder.** *Sexuality and Disability*, 26(1), 29-36.

NARIC Accession Number: J54638

ABSTRACT: Article describes the instructional use of Social Stories for individuals with autism/pervasive developmental disorder. A Social Story is a

short story with specific characteristics that describe a social situation, concept, or social skill using a format that is meaningful to people with autism spectrum disorders. The authors examine features that make Social Stories a promising method of intervention and discuss implications for the utility of Social Stories for sexuality education in particular.

Wiwanitkit, V. (2008). **Sexuality in parkinsonism.** *Sexuality and Disability*, 26(2), 105-108.

NARIC Accession Number: J56057

ABSTRACT: Article focuses on the sexuality of Parkinson's disease. Parkinson's disease has traditionally been considered as a pure motor condition; characterized by tremor, rigidity, bradykinesia and slow postural reflexes. In addition to general physical and psychological abnormalities, sexual dysfunction is common in Parkinson's disease, occurring as a non-motor manifestation of the illness but often compounded by secondary problems relating to physical disability, psychological factors, and medication effects.

2007

Aloni, R., Katz, S., & Keren, O. (2007). **Sex therapy surrogate partners for individuals with very limited functional ability following traumatic brain injury.** *Sexuality and Disability*, 25(3), 125-134.

NARIC Accession Number: J53425

ABSTRACT: Article discusses the use of surrogate sex therapists for people with very limited functional ability (VLFA) following traumatic brain injury (TBI). It includes the rationale of using surrogate therapy with this population as well as some of the professional and ethical issues that such therapy can evoke. It is suggested that surrogate therapy can provide satisfaction and positive experiences to the restricted lives of some of the TBI survivors with VLFA. The use of surrogate therapy is viewed as a part of the integral rehabilitation process aimed at improving the quality of life and the fulfillment of basic human intimacy needs. Surrogate therapy is an activity that can help survivors with TBI monitor and initiate feelings, reactions, and motivation in intimate relationships, as well as provide a certain amount of control over their lives. A case study is presented to illustrate the process of sex therapy with a surrogate partner for a VLFA-TBI survivor.

Anderson, K.D., Borisoff, J.F., Elliott, S.L., Johnson, R.D., & Stiens, S.A. (2007). **The impact of spinal cord injury on sexual function: Concerns of the general population.** *Spinal Cord*, 45(5), 328-337.

NARIC Accession Number: J52645

ABSTRACT: A secure, web-based survey was used to obtain information about sexual issues that are important to people in the general spinal cord injury (SCI) population. A total of 286 subjects completed the survey. The majority of participants stated that SCI altered their sexual sense of self and that improving their sexual function would improve their quality of life. The primary reason for pursuing sexual activity was for intimacy, not fertility. Bladder and bowel concerns during sex were not strong enough to deter the majority of respondents from engaging in sexual activity. However, in the subset of individuals concerned about bladder and/or bowel incontinence during sexual activity, this was a significant issue. In addition, the occurrence of autonomic dysreflexia (AD) during typical bladder or bowel care was a significant variable predicting the occurrence of AD during sexual activity.

Anderson, K.D., Borisoff, J.F., Elliott, S.L., Johnson, R.D., & Stiens, S.A. (2007). **Long-term effects of spinal cord injury on sexual function in men: Implications for neuroplasticity.** *Spinal Cord*, 45(5), 338-348.

NARIC Accession Number: J52646

ABSTRACT: A secure, web-based survey was used to obtain information about sexual function in men with spinal cord injury (SCI). Results indicate that the presence of genital sensation was positively correlated with the ability to feel a buildup or sexual tension in the body during sexual stimulation and that mental arousal translates to the genitals as physical sensation. A positive relationship existed between the occurrence of spasticity during sexual activity and the ability to achieve an erection. Only 48 percent has successfully achieved ejaculation post-injury and the most commonly used methods were hand stimulation, sexual intercourse, and vibrostimulation. Less than half reported having experienced orgasm post-injury and this was influenced by the length of time since SCI and sacral sparing.

Anderson, K.D., Borisoff, J.F., Elliott, S.L., Johnson, R.D., & Stiens, S.A. (2007). **Spinal cord injury influences psychogenic as well as physical components of female sexual ability.** *Spinal Cord*, 45(5), 349-359.

NARIC Accession Number: J52647

ABSTRACT: A secure, web-based survey was used to obtain information concerning both psychological and physical aspects of sexual stimulation and arousal in women with spinal cord injury (SCI). Bladder and/or bowel incontinence during sexual activity were significant concerns reported by participants. Autonomic dysreflexia was interpreted negatively by many and was found to interfere with sexual activity. Most subjects reported difficulty becoming psychologically aroused as well as physically aroused, which were both correlated with feeling that their SCI had altered their sense of self. The most commonly reported sexual stimulation leading to best arousal involved stimulation of the head/neck and torso areas. Most participants reported difficulty with positioning during foreplay and intercourse, vaginal lubrication, and spasticity during intercourse.

Chiodo, A.E., Ho, C.H., Kirshblum, S.C., Priebe, M.M., Scelza, W.M., & Wuermsler, L.A. (2007). **Spinal cord injury medicine. 5. Long-term medical issues and health maintenance.** *Archives of Physical Medicine and Rehabilitation*, 88(3, Supplement 1), S76-S83.

NARIC Accession Number: J72492

Project Number: H133N060032

ABSTRACT: Article discusses long-term care issues in patients with spinal cord injury (SCI), including health maintenance, secondary conditions, women's health, sexual function, pain, and spinal cord regeneration and recovery. The most common secondary medical complications include pressure ulcers, pneumonia, and genitourinary issues. Health care maintenance is important to prevent medical complications, for general health as well as for issues specific to SCI. Women with SCI have gender-specific issues regarding amenorrhea, sexuality, fertility, and menopause. Options exist to assist disabled men with sexuality and fertility complications. Pain is a common complication after SCI. Many new areas of research in the field of SCI are discussed. This self-directed learning module is part of the study guide on SCI medicine in the Self-Directed Physiatric Educational Program for practitioners and trainees in physical medicine and rehabilitation.

Cohen, J.E., Dahlbeck, D.T., & Lease, S.H. (2007). **Body and sexual esteem as mediators of the physical-interpersonal competencies relation.** *Rehabilitation Psychology, 52*(4), 399-408.

NARIC Accession Number: J53593

ABSTRACT: Study examined whether sexual satisfaction, perceived disability severity, and social perceptions of the visible physical disability would predict interpersonal competence in initiating intimate relationships and being assertive in negative situations. The study also examined whether the identified relationships would be mediated by body and sexual esteem. Body esteem refers to the evaluation of the body as positive or negative. Sexual esteem is defined as the positive regard for and confidence in one's capacity to experience sexual satisfaction. For men, sexual satisfaction, social perceptions of the disability, and perceived severity of the disability significantly predicted competence with relationship initiation. Sexual satisfaction and social perceptions of the disability predicted competence with negative assertion. For women, social perceptions of the disability predicted both domains of interpersonal competencies and sexual satisfaction predicted competence with negative assertion. For both men and women, the social perceptions of the disability were either partially mediated or fully mediated by sexual attractiveness to others or body esteem.

Connor, J.P., & Furlong, M. (2007). **The measurement of disability-related stress in wheelchair users.** *Archives of Physical Medicine and Rehabilitation, 88*(10), 1260-1267.

NARIC Accession Number: J53357

ABSTRACT: Article describes the development of the Physical Disability Stress Scale (PDSS) to measure aspects of disability that are most commonly stressful to wheelchair users. The initial common areas of disability-related stress for the PDSS were established through a survey in which participants described the 5 most stressful aspects of having a physical disability. The 5 domains identified were: access, perceptions and attitudes of others, social and sexual relationships, physical health, and adjustment and loss of independence. The PDSS, the General Health Questionnaire-28 (GHQ), and the World Health Organization Quality of Life (WHO-

QOL-BREF) were completed by 119 wheelchair users. Factor analysis of PDSS items revealed 4 main factors: (1) access, representing the aspect of disability-related stress that is associated with limited access and reduced mobility, accounted for 33.7 percent of the variance; (2) physical, which refers to the stress of reduced bodily movements and functional ability, accounted for 8.4 percent of the variance and; (3) social, covering stress that is experienced through social stigma and social interactions with other members of society, accounted for 7.9 percent of the variance; and (4) burden of care, relating to the stress and burden of having and managing numerous health care needs and of relying on others, accounted for 7.2 percent of the variance. Internal consistencies for the 4 factors were within acceptable ranges. Concurrent validity was shown with the PDSS factors predicting 7 percent to 23 percent of the variance in GHQ subscales and total score and 12 to 31 percent of the WHOQOL-BREF subscales. Overall, the findings indicate that the PDSS is a valid measure of disability-related stress.

Couwenhoven, T. (2007). **Teaching children with Down syndrome about their bodies, boundaries, and sexuality: A guide for parents and professionals.**

NARIC Accession Number: R08874

ABSTRACT: Book presents factual information and practical ideas for teaching children with Down syndrome about their bodies, puberty, and sexuality. In an easy-to-read, non-clinical style, the author covers relevant issues and concerns for children of all ages, such as: labeling and explaining private body parts, identifying and expressing emotions, respecting personal space, teaching self-care and hygiene, understanding norms of privacy, understanding gender identity, showing appropriate levels of affection. Chapters also cover issues that affect teenagers and young adults, including: anticipating and understanding puberty, dealing with periods and bras for girls, experiencing erections and wet dreams for boys, relating to the opposite sex, sharing parental values about sexuality, explaining sexual relationships, preventing sexual abuse, and understanding how Down syndrome affects puberty and fertility rates. Each chapter highlights important points with key messages, teaching activities, parental pauses,

and anecdotes. The final chapter covers the special concerns of parents who are now teaching teenaged or adult children about sexuality for the first time. Appendices contain valuable teaching materials and illustrations of body parts and functions.

Davis, S., & Taylor, B. (2007). **The extended PLISSIT model for addressing the sexual well-being of individuals with an acquired disability or chronic illness.** *Sexuality and Disability*, 25(3), 135-139.

NARIC Accession Number: J53426

ABSTRACT: Article discusses the limitations in the way that healthcare practitioners may use Jack Annon's PLISSIT model and proposes the use of the Ex-PLISSIT model in meeting the sexual well-being needs of individuals with an acquired disability or chronic illness. The PLISSIT model comprises 4 levels of intervention: Permission (P), Limited Information (LI), Specific Suggestions (SS), and Intensive Therapy (IT). The Ex-PLISSIT model extends the original model by emphasizing permission-giving at all stages. Key features of this model include explicit permission-giving as a core feature of each of the other stages, the requirement to review all interactions with patients, and the incorporation of reflection as a means of increasing self-awareness by challenging assumptions.

Esmail, S., Gibson, N., & Munro, B. (2007). **Couple's experience with multiple sclerosis in the context of their sexual relationship.** *Sexuality and Disability*, 25(4), 163-177.

NARIC Accession Number: J54026

ABSTRACT: Study examined the impact of multiple sclerosis (MS) on the sexual relationship of six couples in which the female partner was diagnosed with MS after the relationship was established. An in-depth semi-structured interview was conducted with each partner separately. Six main themes emerged from the interviews of the women with MS: (1) communication, (2) patterns of denial and acceptance, (3) the impact of MS on sexual activity, (4) the partner's needs take precedence, (5) impact on established roles, and (6) the importance of a partner's love and support. There were 5 main themes that emerged from the interviews of the male partners: (1) communication, (2) the impact of MS on sexual activity, (3) impact on established roles, (4) the importance of intimacy and closeness, and (5) partner's emotional response to MS is the problem.

Everett, B. (2007). **Ethically managing sexual activity in long-term care.** *Sexuality and Disability*, 25(1), 21-27.

NARIC Accession Number: J52359

ABSTRACT: Article provides long-term care facilities with a framework for developing guidelines for the ethical, legal, and socially responsible management of residents' sexual activity. These institutional guidelines provide criteria for determining how and when providers can intervene in residents' sexual activity.

Gill, K.M., & Hough, S. (2007). **Sexuality training, education and therapy in the healthcare environment: Taboo, avoidance, discomfort or ignorance?** *Sexuality and Disability*, 25(2), 73-76.

NARIC Accession Number: J53201

ABSTRACT: Article addresses the multiple sources of resistance to comprehensive assessment and intervention present in the healthcare environment regarding sexuality issues. The authors examine the diversity of needs and values presented by consumers with disabilities and encourage providers to equip themselves educationally, emotionally, and ethically so they can deliver relevant education, counseling, and therapy services.

Hess, M.J., Hough, S., & Tamaro, E. (2007). **The experience of four individuals with paraplegia enrolled in an outpatient interdisciplinary sexuality program.** *Sexuality and Disability*, 25(4), 189-195.

NARIC Accession Number: J54028

ABSTRACT: Four men with paraplegia were referred to the outpatient spinal cord injury sexuality program at an urban Veterans Affairs Medical Center and seen by an interdisciplinary team comprised of a nurse, physician, and psychologist. The nursing assessment included a focused clinical and sexual history and learning needs assessment and patients were educated regarding safe sexual practices and adaptive equipment options, and provided with individualized medication education on prescribed medications or interventions. The physician history included a review of medical comorbidities that could affect sexual function. The psychological component included an assessment and intervention based on the PLISSIT (Permission, Limited Information, Specific Suggestions, and Intensive Therapy) model. In

general, all patients were very satisfied with their clinic experience. They felt that their questions had been answered and their emotional well-being had been appropriately addressed in a respectful environment and effective process.

Hwang, K., Johnston, M., & Smith, J.K. (2007). **Romantic attachment in individuals with physical disabilities.** *Rehabilitation Psychology*, 52(2), 184-195.

NARIC Accession Number: J52461

Project Number: H133P70011

ABSTRACT: Study examined the relationship between adult romantic attachment style and dyadic adjustment among people with spinal cord injury (SCI) and congenital disabilities (CON). Attachment styles did not differ significantly between participants with SCI and those with CON, and the attachment styles of these 2 groups did not differ significantly from people without disabilities. Dyadic adjustment was predicted by attachment variables and differed between people with SCI and those with CON; people with SCI reported greater total dyadic adjustment. Participants with secure and preoccupied attachment styles reported greater overall adjustment than did those with fearful or dismissing attachment styles. Social integration and mobility both appeared to have a significant positive relationship with dyadic satisfaction.

Kautz, D.D. (2007). **Hope for love: Practical advice for intimacy and sex after stroke.** *Rehabilitation Nursing*, 32(3), 95-103.

NARIC Accession Number: J52575

ABSTRACT: Article briefly reviews the changes in intimacy and sexuality caused by stroke and comorbid diseases and provides practical advice that nurses can give to patients and their partners to help them overcome these problems. Multiple resources are cited to provide additional information for nurses, patients, and family members.

Leibowitz, R.Q., & Stanton, A.L. (2007). **Sexuality after spinal cord injury: A conceptual model based on women's narratives.** *Rehabilitation Psychology*, 52(1), 44-55.

NARIC Accession Number: J52175

Project Number: H133N000012

ABSTRACT: Interviews were conducted with 24 women with spinal cord injury to investigate how women with SCI experience their sexuality. A con-

ceptual model of sexual domains was proposed based on content analysis of the narratives. The proposed domains are: (1) self- versus other focus, (2) genital versus whole-body focus, (3) physical sex versus holistic intimacy, (4) sexuality as a bodily versus mental phenomenon, (5) exuberance versus negativity, and (6) past versus present focus. The domains are defined and illustrated with excerpts from the narratives.

Leutar, Z., & Mihokovic, M. (2007). **Level of knowledge about sexuality of people with mental disabilities.** *Sexuality and Disability*, 25(3), 93-109.

NARIC Accession Number: J53424

ABSTRACT: Study examined the level of knowledge about sexuality among people with mental disabilities. Structured interviews were conducted and a questionnaire on sexuality was administered to 24 people with mental disabilities. Results indicated that the respondents had an insufficient level of knowledge about sexuality. Respondents generally differentiated between male and female sex, but showed an inadequate level of knowledge about basic sexual differences. Low knowledge was shown in the areas of sexual diseases and the ways to protect against them, contraception, pregnancy, and appropriate ways to react in situations of sexual abuse. Differences regarding sex and the level of disability were found. The findings indicate the need for additional education on sexuality for people with disabilities and their parents.

Lyden, M. (2007). **Assessment of sexual consent capacity.** *Sexuality and Disability*, 25(1), 3-20.

NARIC Accession Number: J52358

ABSTRACT: Article discusses the rationale for and ethical and legal issues related to assessing the capacity of a person with cognitive impairment to engage in a sexual relationship. It presents a summary of relevant literature and describes the current assessment practices used by the author. Discussion includes state, national, and international laws, policies, ethical codes relevant to sexual relations between people who have intellectual disabilities. Technical information about a tool for assessing capacity to give consent for sexual relationships is described. Finally, the article proposes a clinical standard for assessing sexual consent capacity along with suggested assessment practices.

Marshak, L.E., & Prezant, F.P. (2007). ***Married with special-needs children: A couples' guide to keeping connected.***

NARIC Accession Number: R08792

ABSTRACT: This book examines the stress that is often placed on a marriage when a couple has a child with a disability. The authors examine many of the underlying stresses and concerns and present a wide range of strategies for handling or preventing common problems such as communication breakdowns, lack of romance and sexual intimacy, conflict over parenting styles and roles, intolerance of different coping and problem-solving strategies, differing expectations of a child, and issues arising in second marriages and blended families. For parents looking for ways to strengthen their marriage, prevent future strife, or resolve or move on from significant relationship difficulties, this guide offers guidance and expertise for taking the next step.

McCabe, M.P., & McDonald, E. (2007). ***Perceptions of relationship and sexual satisfaction among people with multiple sclerosis and their partners.*** *Sexuality and Disability*, 25(4), 179-188.

NARIC Accession Number: J54027

ABSTRACT: Study evaluated the level of relationship satisfaction, sexual satisfaction, and sexual dysfunction among people with multiple sclerosis (MS) and their partners compared to findings among couples in the general population. Semi-structured interviews were conducted with 45 people with MS and their partners and 32 people from the general population and their partners. Overall, the partners of people with MS were more likely than people with MS to feel that MS had a negative impact on the physical and emotional support in their relationship. People with MS also experienced more problems in the relationship and sexual functioning, but not their sexual satisfaction, than people from the general population. The implications of these findings in terms of support programs for people with MS and their partners are discussed.

Solvang, P. (2007). ***The amputee body desired: Beauty destabilized? Disability re-valued?*** *Sexuality and Disability*, 25(2), 51-64.

NARIC Accession Number: J53199

ABSTRACT: Article examines the motives and ob-

jectives of men who seek romantic and sexual relationships with female amputees and the reactions they elicit from women with amputations. Societal views of disability and beauty as related to amputation are addressed.

Sweeney, L. (2007). ***The importance of human sexuality education for students with disabilities.*** *Exceptional Parent*, 37(9), 36, 38-39.

NARIC Accession Number: J53155

ABSTRACT: Article offers advice for parents and educators about how to discuss sex and sexuality with children and adolescents with disabilities.

Walker-Hirsch, L. (Ed.). ***The facts of life . . . and more: Sexuality and intimacy for people with intellectual disabilities.***

NARIC Accession Number: R08911

ABSTRACT: Book provides information to help professionals educate people with intellectual disabilities about sexuality and intimacy. The chapters incorporate special education techniques, vivid case studies, and candid interviews that show how real-life couples with disabilities handle the joys and challenges of their relationships.

2006

Alexander, C.J., Gomez-Marin, O., Sipski, M. (2006). ***Effects of level and degree of spinal cord injury on male orgasm.*** *Spinal Cord*, 44(12), 798-804.

NARIC Accession Number: J51792

Project Number: H133N000017

ABSTRACT: Article describes a laboratory-based analysis of the ability of 45 men with spinal cord injuries (SCI) and 16 able-bodied control subjects to achieve orgasm. Subjects underwent a complete history and physical examination, neurological examination, and administration of the International Index of Erectile Function. Results showed that men with SCI were less likely than controls to achieve orgasm. Men with incomplete SCI were more likely to achieve orgasm than those with complete SCI. A number of men with SCI achieved orgasm without ejaculation. Mean latency to orgasm, blood pressure, and heart rates at orgasm were similar between controls and men with SCI.

Arendt-Nielsen, L., Delmar, C., Laursen, B.S., Olesen, A.S., & Overvad, K. (2006). **Ongoing pain, sexual desire, and frequency of sexual intercourses in females with chronic pain syndromes.** *Sexuality and Disability*, 24(1), 27-37.

NARIC Accession Number: J51715

ABSTRACT: Study assessed the importance of an active sex life, the ability to feel sexual desire, and the frequency of sexual intercourse in women with 4 different chronic pain syndromes: low back pain, fibromyalgia/whiplash, endometriosis, and arthritis. Participants included 40 female pain patients and 41 healthy control subjects. The patients with pain found an active sex life less important than did the healthy control subjects. A total of 23 of the patients (58 percent) experienced no ability to feel sexual desire at all. The pain patients had a significantly lower frequency of sexual intercourse than the control subjects. The findings show reduced sexual activity and desire in females with chronic pain, with no correlation to the origin or intensity of pain.

Balen, R., & Crawshaw, M. (Eds.). (2006). **Sexuality and fertility issues in ill health and disability: From early adolescence to adulthood.**

NARIC Accession Number: R08906

ABSTRACT: Book explores sexuality and fertility issues for youth with a wide range of health conditions and disabilities. Chapters consider the ways in which teenagers and young adults manage their emerging sexuality when there is a chance that their fertility is impaired. Topics include: the experiences of minority ethnic groups, managing relationships, fertility preservation and treatment, legal and ethical issues, and the transition to parenthood.

Bos, H., & Kef, S. (2006). **Is love blind? Sexual behavior and psychological adjustment or adolescents with blindness.** *Sexuality and Disability*, 24(2), 89-100.

NARIC Accession Number: J51160

ABSTRACT: Study examined the sexual knowledge, sexual behavior, and psychological adjustment of adolescents with blindness in the Netherlands. Results of the interviews revealed no problems regarding sexual knowledge or psychological adjustment; however, sexual behavior was more at risk.

Dahlof, L-G., Karlsson, A-K., Siosteen, A., Valtonen, K., & Viikari-Juntura, E. (2006). **Satisfaction with sexual life among persons with traumatic spinal cord injury and meningomyelocele.** *Disability and Rehabilitation*, 28(16), 965-976.

NARIC Accession Number: J51291

ABSTRACT: Study investigated satisfaction with sexual life and self-assessed sufficiency of sexual counseling in men and women with traumatic spinal cord injury (SCI) and meningomyelocele (MMC). One hundred ninety people with traumatic SCI and 41 people with MMC responded to a mail survey on aspects of health and functioning in which satisfaction with sexual life was rated using a numerical scale from 0 (dissatisfied) to 10 (satisfied). The results corroborated findings for previous studies indicating that satisfaction with sexual life is rather low among people with SCI. Inconvenience caused by urinary and fecal incontinence, as well as neuropathic pain, increased sexual dissatisfaction in men with traumatic SCI. Sexual satisfaction declined with increasing age in both groups. Sixty-nine percent of men with traumatic SCI and 56 to 59 percent of subjects in the other subgroups reported that the sexual counseling they had received was sufficient.

De Jong, M.D.T., Roelvink, L., & Siebelink, E.M. (2006). **Sexuality and people with intellectual disabilities: Assessment of knowledge, attitudes, experiences, and needs.** *Mental Retardation*, 44(4), 283-294.

NARIC Accession Number: J51049

ABSTRACT: Structured interviews were conducted with 76 people with intellectual disabilities to investigate their sexual knowledge, attitudes, experience, and needs. During the interviews, observational data were gathered to check the validity of the interview questionnaire. Results confirmed that sexuality and romantic relationships are important issues in the lives of people with intellectual disabilities. Males generally reported more sexual needs than did females. Correlations were found between sexual knowledge and attitudes and between attitudes and experience or needs, suggesting that general behavioral models may be used to explore the topic of sexuality among people with intellectual disabilities. The observation data collected during the interviews confirmed that the questions were generally understandable for the respondents.

Ducharme, S. (2006). **Sexuality and SCI: Autonomic dysreflexia.** *PN/Paraplegia News*, 60(11), 17-18.

NARIC Accession Number: J51726

ABSTRACT: Article examines what is known and not known about the dangers of autonomic dysreflexia (AD) in men with spinal cord injury who use vibrostimulation. AD is a condition in which drastic blood pressure changes occur. Vibrostimulation involves the placement of a strong vibrator on the frenulum of the penis to facilitate ejaculation. In a recent study of vibrostimulation, 65 percent of the men experienced AD at the time of ejaculation. However, the long-term risks associated with frequent episodes of AD are unknown. Monitoring and limiting the use of vibrostimulation is recommended.

Forsythe, E.; & Horsewell, J.E. (2006). **Sexual rehabilitation of women with a spinal cord injury.** *Spinal Cord*, 44(4), 234-241.

NARIC Accession Number: J50727

ABSTRACT: Article reviews literature examining the various neurological, physical, and psychosocial issues that may affect the successful sexual rehabilitation of women with spinal cord injury (SCI). Articles from the United Kingdom, Denmark, and Sweden are reviewed and qualitative results from discussions with women with SCI in Denmark and Sweden are presented. Neurophysiological studies of sexual response in women following SCI are divided into those that evaluate sexual arousal and those that assess the ability to achieve orgasm. Physical consequences of SCI such as urinary and bowel, incontinence, spasticity, vaginal lubrication, and autonomic dysreflexia appear to have the most impact on sexual activity. More recent studies have acknowledged that psychosocial factors such as age and partnership status may also influence sexual rehabilitation. Discussions with women with SCI on their reactions to information and counseling offered during rehabilitation revealed an overwhelming need for the exchange of information and experience with other women with SCI, and a desire for opportunities after initial rehabilitation.

Hieronimus, L., & Maguire, L. (2006). **Sexual wellness.** *Diabetes Self-Management*, 23(2), 19-22.

NARIC Accession Number: J50585

ABSTRACT: Article discusses the impact that diabetes can have on sexual desire and function. Sexual dysfunction disorders are divided into 4 categories: desire disorders, arousal disorders, orgasm disorders, and pain disorders. Physical health issues commonly associated with diabetes that can contribute to sexual problems include high blood glucose levels, impaired circulation, and nerve damage. Advice is offered on preventing diabetes complications and getting help for sexual difficulties.

Klebine, P. (Ed.). (2006). **Pushin' on**, 24(1), 1-8.

NARIC Accession Number: O16600

Project Number: H133N000016

ABSTRACT: Newsletter provides information on aspects of spinal cord injury (SCI) for individuals with SCI, their families, and service providers. In this issue: relationship issues, treatment options for erectile dysfunction, financial resources, research on the effects of SCI on female sexual response, announcements, and Internet resources.

Sakellariou, D. (2006). **If not the disability, then what? Barriers to reclaiming sexuality following spinal cord injury.** *Sexuality and Disability*, 24(2), 101-111.

NARIC Accession Number: J51161

ABSTRACT: Article discusses barriers that may compromise the sexuality of men with spinal cord injury. Study participants felt that several barriers compromised their right to a satisfying sex life, including certain social beliefs and attitudes, lack of employment, inappropriate personal assistance, and inaccessibility. It is suggested that changes in education as well as the removal of physical barriers may positively influence societal attitudes and make sexuality more "accessible" to people with disabilities.

Tarnai, B. (2006). **Review of effective interventions for socially inappropriate masturbation in persons with cognitive disabilities.** *Sexuality and Disability*, 24(3), 151-168.

NARIC Accession Number: J51671

ABSTRACT: Literature review analyzes and summarizes the effects of interventions to reduce socially inappropriate masturbation in people with cognitive disabilities. The study reviews definitions of socially inappropriate autoerotic behavior, investigates factors contributing to displaying inappropriate masturbation, identifies the type of interventions that are effective for different types of cognitive disabilities, and examines the evolution of document intervention from the late 1960s to the early 2000s. The evidence suggests that advances toward more humane, supportive, and self-regulative interventions are more likely to help people with milder cognitive disabilities. Ethical and legal questions of different treatment approaches are discussed.

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Documents from the International Research Collection available through REHABDATA are listed below:

2010

Kalyva, E. (2010). **Teachers' perspectives of the sexuality of children with autism spectrum disorders.** *Research in Autism Spectrum Disorders*, 4(3), 433-437.

NARIC Accession Number: I121529

Romans, S. (2010). **Sexuality in women with schizophrenia.** *Current Women's Health Reviews*, 6(1), 3-11.

NARIC Accession Number: I115903

2009

Bengner, T., Molleken, D., Richter-Appelt, H., & Stodieck, S. (2009). **Sexual quality of life in epilepsy: correlations with sex hormone blood levels.** *Epilepsy and Behavior*, 14(1), 226-31.

NARIC Accession Number: I106862

Broglin, D. (2009). **[Sexual disorders in epileptic patients]. Troubles sexuels chez les patients épileptiques.** *Epilepsies*, 21(4), 380-391.

NARIC Accession Number: I118760

Chan, K.S., Lau, D.Y.K., Ng, G.S.M., & Yau, M.K.S. (2009). **Exploring sexuality and sexual concerns of adult persons with intellectual disability in a cultural context.** *British Journal of Developmental Disabilities*, 55(2), 97-108.

NARIC Accession Number: I115210

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

NARIC Accession Number: I111031

Duvdevany, I., Mazor, D., & Moin, V. (2009). **Sexual identity, body image, and life satisfaction among women with and without physical disability.** *Sexuality and Disability*, 27(2), 83-95.

NARIC Accession Number: I120587

Garrett, A., Martins, F., & Teixeira, Z. (2009). **[Sexual activity: After spinal cord injury - Therapeutics helps]. A activdade sexual: Apos lesao medular - Meios terapeuticos.** *Acta Medica Portuguesa*, 22(6), 821-826.

NARIC Accession Number: I117746

Kayser, K., & Scott, J.L. (2009). **A review of couple-based interventions for enhancing women's sexual adjustment and body image after cancer.** *Cancer Journal*, 15(1), 48-56.

NARIC Accession Number: I112468

Radomski, D., & Tederko, P. (2009). **[Sexual health of persons with spine injuries complicated by neurological disorders]. Zdrowie seksualne osob po urazie kregoslupa powiklanym zaburzeniami neurologicznymi.** *Seksuologia Polska*, 7(2), 65-72.

NARIC Accession Number: I119706

2008

Charvier, K., Courtois, F., Leriche, A., & Vezina, J.G. (2008). **Perceived physiological and orgasmic sensations at ejaculation in spinal cord injured men.** *Journal of Sexual Medicine*, 5(10), 2419-30.

NARIC Accession Number: I113116



Documents from the Education Resource Information Center (ERIC) search at www.eric.ed.gov are listed below:

2016

Haya, I., Lázaro-Visa, S., & Rojas, S. (2016). **“My great hope in life is to have a house, a family and a daughter”:** Relationships and sexuality in intellectually disabled people. *British Journal of Learning Disabilities*, 44(1), 56-62.

ERIC Number: EJ1088125

ABSTRACT: This study starts from the premise that we are sexual beings, and therefore, sexuality is part of our lives and defines us as human beings. This is also true with regard to intellectually disabled people. Within the framework of broader qualitative research carried out in Spain, some partial results of an ongoing study aimed at finding out what a group of adults see as important in different areas of their lives are presented here. Through the personal narratives of 16 intellectually disabled people, this paper explores some of their ideas and demands about sexuality and their sexual lives. Most of the people interviewed expressed their desire to have a partner and to live as a couple. There is no doubt that many intellectually disabled people have greater control over their lives and the decisions that affect them, but as they tell us, the presence of old ideas can hinder them from securing their fundamental rights.

Himle, M.B., Holmes, L.G., & Strassberg, D.S. (2016). **Parental romantic expectations and parent-child sexuality communication in autism spectrum disorder.** *Autism: The International Journal of Research and Practice*, 20(6), 687-699.

ERIC Number: EJ1106099

ABSTRACT: This study examined the relationship between core symptoms of autism spectrum disorder, parental romantic expectations, and parental provision of sexuality and relationship education in an online sample of 190 parents of youth 12-18 years of age with a parent-reported diagnosis of autism spectrum disorder. Regression analyses were conducted separately for youth with autism spectrum disorder + parent-reported average or above IQ and youth with autism spectrum disorder + parent-reported

below average IQ. For youth with autism spectrum disorder + parent-reported average or above IQ, autism spectrum disorder severity predicted parental romantic expectations, but not parental provision of sexuality and relationship education. For youth with autism spectrum disorder + parent-reported below average IQ, parental romantic expectations mediated the relationship between autism spectrum disorder severity and parent provision of sexuality and relationship education. This supports the importance of carefully considering intellectual functioning in autism spectrum disorder sexuality research and suggests that acknowledging and addressing parent expectations may be important for parent-focused sexuality and relationship education interventions.

2015

Azzopardi-Lane, C., & Callus, A-M. (2015). **Constructing sexual identities: People with intellectual disability talking about sexuality.** *British Journal of Learning Disabilities*, 43(1), 32-37.

ERIC Number: EJ1049659

ABSTRACT: This paper presented research undertaken in collaboration with a self-advocacy group using inclusive research methods and puts forward the views of people with intellectual disability on the topics of sexuality and relationships. The paper presents the perceptions of sexuality of the people with intellectual disability and how these are influenced by social and cultural norms. Using Judith Butler's concept of performativity, the analysis of the findings shows how some people with intellectual disability accept the sexual norms that are ascribed to them, while others resist them. The paper also shows how the inclusive research process itself enabled the people with intellectual disability who took part to articulate their acceptance or resistance of these norms.

de Reus, L., Hanass-Hancock, J., Henken, S., & van Brakel, W. (2015). **Challenges in providing HIV and sexuality education to learners with disabilities in South Africa: The voice of educators.** *Sex Education: Sexuality, Society, and Learning*, 15(4), 333-347.

ERIC Number: EJ1068315

ABSTRACT: People with disabilities are at increased risk of exposure to HIV, yet they lack access to HIV prevention, treatment care and support

including sexuality education. Lack of knowledge, skills and confidence of educators teaching sexuality education to learners with disabilities is related to this increased vulnerability. This study identifies possible challenges educators of learners with disabilities face when teaching sexuality and HIV education. Five focus groups were conducted in three purposely selected types of special schools representing four impairment groups in KwaZulu-Natal, South Africa. Educators recognise that teaching about sexuality is part of the South African Life Orientation curriculum and understand its importance to learners. However, they identified a number of challenges to such work, including barriers in communication and language, cultural values and expectations, learners' knowledge and behaviour, handling of sexual abuse cases and the teachers' own life experiences. Educators feel a lack of support from parents, departments of education, fellow educators and members of the community. They report the need for training and adapted HIV and sexuality education tools and resources to accommodate learners with disabilities. This training needs to provide knowledge on disability and HIV, offer guidance on disability-appropriate communication strategies, deal with sexual abuse and include educational tools for the classroom.

Elia, J.P., & Tokunaga, J. (2015). **Sexuality education: Implications for health, equity, and social justice in the United States.** *Health Education*, 115(1), 105-120.

ERIC Number: EJ1054053

ABSTRACT: Purpose: The purpose of this paper is to examine how school-based sexuality education has had a long and troubled history of exclusionary pedagogical practices that have negatively affected such populations as lesbian, gay, bisexual, trans, queer (LGBTQ) individuals, people of color, and the disabled. The social ecological model is introduced as a way of offering sexuality educators and school administrators a way of thinking more broadly about how to achieve sexual health through sexuality education efforts inside and outside of the school environment. Design/methodology/approach: This paper uses critical analysis of current and historical school-based sexuality education methods and curricula used in the USA. Authors use both academic journals and their own expertise/experience teaching sexuality education in the USA to analyze and

critique the sources of sexuality education information and curricula used in schools. Findings: Historically, sexuality education in school settings in the USA has been biased and has generally not offered an educational experience fostering sexual health for all students. There are now welcome signs of reform and movement toward a more inclusive and progressive approach, but there is still some way to go. Sexuality education programs in schools need to be further and fundamentally reformed to do more to foster sexual health particularly for LG-BTQ individuals, students of color, and people with disabilities. Practical implications: This paper offers sexuality educators a way of addressing structural issues within the sexuality education curriculum to better serve all students to increase the quality of their sexual health. Integrating critical pedagogy and anti-oppressive education can increase students' sexual health along physical, social, emotional, intellectual, and spiritual dimensions. Originality/value: This paper provides historical analysis along with the identification of structural difficulties in the sexuality education curriculum and proposes both critical pedagogy and anti-oppressive education as ways of addressing sex and relationships education.

2014

Adams, R.H., Linton, K.F., & Williams, L.R. (2014). **School social workers' needs in supporting adolescents with disabilities toward dating and sexual health: A qualitative study.** *Children & Schools, 36*(2), 79-90.

ERIC Number: EJ1034345

ABSTRACT: School social workers approach their direct practice from ecological systems and justice-oriented perspectives. As such, they may hold a critical role in providing needed sexual health and dating education and services to adolescents with disabilities. Thirteen high school social workers who work closely with adolescents with disabilities were interviewed to identify their needs and challenges in supporting such adolescents toward dating and sexual health. Mesosystemic challenges at the school level evidenced three themes: (1) the desire for school-based comprehensive sexual education for all adolescents, (2) a multitiered and ancillary approach to educating adolescents with disabilities

about dating and sexual health, and (3) increased time (that is, via additional funding) to provide social work services to adolescents with disabilities. Exosystemic needs and challenges were reflected in discussions about community resources that social workers deemed integral to their work with adolescents with disabilities. Finally, dialogue reflective of macrosystemic needs and challenges included environmental factors that adolescents with disabilities brought with them to school and that affected social workers' intervention efforts. Consistent with social workers' dialogue, recommendations for social work education, policy reform, and programs for adolescents with disabilities are presented.

Hilberink, S.R., Van der Stege, H.A., Van Staa, A-L., & Visser, A.P. (2014). **Motivational factors in discussing sexual health with young people with chronic conditions or disabilities.** *Sex Education: Sexuality, Society, and Learning, 14*(6), 635-651.

ERIC Number: EJ1041841

ABSTRACT: The objective of this study was to identify determinants of professionals' intention to use the new board game SeCZ TaLK to facilitate sexual health discussions with young people with chronic health conditions and disabilities, and to gauge whether intention led to actual use. A cross-sectional web-based survey of 336 professionals before they received the game sought to measure their intention to use SeCZ TaLK, their attitudes towards discussing sexuality, social professional environment, self-efficacy, opinion on the feasibility of using the game and experience discussing sexuality. Actual use of SeCZ TaLK was assessed at follow-up (N = 105). Professionals with higher self-efficacy and more experience in discussing sexual health were more likely to intend to use the game. At follow-up, intention to use explained 21% of the variance in actual use. SeCZ TaLK fits easily into the daily practice of professionals working in assisted-living and day-care facilities; other professionals experienced greater difficulty integrating the game into their practice. Despite this, SeCZ TaLK was also used across a wide range of settings including in psycho-educational groups, group consultations in hospitals and group therapy in rehabilitation centres. Professionals appreciated the board game SeCZ TaLK, but actual use depended on their own motivation and skills and compatibility with work routines.

Jahoda, A., & Pownall, J. (2014). **Sexual understanding, sources of information and social networks; the reports of young people with intellectual disabilities and their non-disabled peers.** *Journal of Intellectual Disability Research*, 58(5), 430-441.

ERIC Number: EJ1022901

ABSTRACT: Background: Sexual development plays a vital part in young people's emotional adjustment. Method: This study compared the sexual understanding of 30 adolescents with mild intellectual disabilities (ID) and 30 non-disabled adolescents, along with their reports of where they obtained sexual information, and the nature of their social networks and support. Results: As expected, the non-disabled young people had superior levels of knowledge. However, an interaction was found between group and gender. The non-disabled young women had a better grasp of sexual matters than men, whereas the opposite was the case for those with ID. The non-disabled young people reported more formal and informal sources of sexual information and described larger social networks than those with ID. Conclusions: These findings highlight the need to tackle the barriers to sexual knowledge faced by young people with ID, and the need to take account of the broader social context of their lives when doing so. This includes the attitudes to the developing sexuality of young women with ID in particular.

Murray, C., Rushbrooke, E., & Townsend, S. (2014). **The experiences of intimate relationships by people with intellectual disabilities: A qualitative study.** *Journal of Applied Research in Intellectual Disabilities*, 27(6), 531-541.

ERIC Number: EJ1042646

ABSTRACT: Background: People with intellectual disabilities face attitudinal and service barriers when attempting to form intimate relationships. To date, their experiences and views are under-represented in the existing evidence base. Method: The aim of this study was to carry out an interpretative phenomenological analysis exploring the experience of intimate relationships for nine adults with intellectual disabilities. Results: Four main themes were identified: desiring relationships; expressing sexuality; having relationships; and who has control? Together these themes demonstrated that intimate relationships were desired and important to all participants, fulfilling a variety of their needs. In

addition, participants faced a number of challenges related to intimate relationships. Conclusion: The findings raise questions about how best to support people with intellectual disabilities with sexuality and intimate relationships. Implications for caregivers and services are discussed.

2013

Bernert, D.J., & Ogletree, R.J. (2013). **Women with intellectual disabilities talk about their perceptions of sex.** *Journal of Intellectual Disability Research*, 57(3), 240-249.

ERIC Number: EJ1013326

ABSTRACT: Background: Sexuality is learned through sexual socialisation that women with intellectual disabilities (IDs) understand and express. Rules of sexual engagement for these women can include barriers for their socialisation, intimate partner selection, and sexual expression. These rules can become more limiting when coupled with rules of femininity that encourage sexual restraint for women. Methods: This ethnography explored how women with IDs perceived their sexuality and how sexuality functioned in their lives. Sources of data included 48 multiple and in-depth interviews and observations with 14 women. This article specifically describes how the women constructed "sex" and how they described experiencing sex as two of their multiple expressions of sexuality in this study. Results: Most of the women had very limited and exclusively heterosexual sexual experiences, and the majority of women reported practicing abstinence. Criteria they identified for sex included having protected sex, marital and monogamous sex for the purpose of procreation or parenting, and having feelings for a sexual partner. Most held negative perceptions of sex they attributed to fear of the first act, fear of experiencing negative consequences, physiological concerns about the act, and perceived or actual lack of pleasure. Conclusions: Although the women displayed some sense of self-determinism in their sexual behaviour, negative perceptions of sex resulted in self-imposed abstinence predicated by fear of intercourse, intimacy, or outcome. Central to their sexuality education then is increasing self-efficacy perceptions and performance of safer sex practices to prevent negative sexual consequence. Sexuality education from a positive perspective that enhances their sexual self-determinism and encourages sexual health is recommended.

Borges, C., Elkington, K.S., Hackler, D., Latack, J.A., McKinnon, K., Wainberg, M.L., Walsh, T.A., & Wright, E.R. (2013). **Perceived mental illness stigma, intimate relationships, and sexual risk behavior in youth with mental illness.** *Journal of Adolescent Research*, 28(3), 378-404.

ERIC Number: EJ1010610

ABSTRACT: The current study examines the role of mental illness-related stigma on romantic or sexual relationships and sexual behavior among youth with mental illness (MI), including youths' experiences of stigma, the internalization of these experiences, and the behavior associated with managing stigma within romantic and sexual relationships. We conducted in-depth interviews with "N" = 20 youth with mental illness (MI) (55 percent male, 16-24 years, 75 percent Latino) from 4 psychiatric outpatient clinics in New York City. We conducted a thematic analysis to investigate shared experiences of MI stigma and its impact on youth's sexual or romantic relationships and associated behaviors. Our analysis revealed four main themes: (1) societal perceptions of those with MI as partners (societal stigma); (2) individual experiences of stigma within relationships (individual level); (3) internalized stigma of self as a partner (social-psychological processes); and (4) managing a stigmatized identity, of which some of the behaviors directly placed them at increased risk for HIV. We found that just under half of the sample ("n" = 9/20) endorsed all themes, including engaging in HIV/STI sexual risk behaviors as a method to manage a stigmatized identity, which suggests that MI stigma and sexual risk may be linked. We discuss differences by gender and diagnosis. Findings provide new information for providers and researchers to address on the role of stigma experiences in the romantic and sexual behavior of youth in psychiatric treatment. Implications for stigma and HIV/STI prevention interventions are discussed.

Byers, E.S., Nichols, S., Reilly, G., & Voyer, S.D. (2013). **Sexual well-being of a community sample of high-functioning adults on the autism spectrum who have been in a romantic relationship.** *Autism: The International Journal of Research and Practice*, 17(4), 418-433.

ERIC Number: EJ1015040

ABSTRACT: This study explored factors (gender,

age, relationship status, symptomatology) associated with the sexual well-being of 141 (56 men and 85 women) adults with high-functioning autism and Asperger syndrome (HFA/AS) living in the community. Participants completed an online survey consisting of a measure of autistic symptoms as well as measures of dyadic and solitary sexual well-being. Canonical correlation analyses showed that participants who were currently in a romantic relationship reported more frequent dyadic affectionate and genital activity and greater sexual assertiveness and sexual satisfaction, pointing to the importance of context in an active sex life. After controlling for the first variate, men and individuals with less autism symptomatology, particularly in the social and communication domains, generally reported significantly greater dyadic sexual well-being, including greater sexual satisfaction, assertiveness, arousability, and desire and lower sexual anxiety and fewer sexual problems. Men also reported better solitary sexual well-being, including more sexual thoughts, more sexual desire, and more frequent solitary sexual activity; however, they had lower sexual knowledge. These results highlight the importance for research and sexuality education with individuals with HFA/AS to conceptualize sexual well-being as a multidimensional construct consisting of both dyadic and solitary aspects.

Curfs, L.M.G., Kok, G., Schaafsma, D., & Stofelen, J.M.T. (2013). **Exploring the development of existing sex education programmes for people with intellectual disabilities: An intervention mapping approach.** *Journal of Applied Research in Intellectual Disabilities*, 26(2), 157-166.

ERIC Number: EJ1009636

ABSTRACT: Background: People with intellectual disabilities face barriers that affect their sexual health. Sex education programmes have been developed by professionals working in the field of intellectual disabilities with the aim to overcome these barriers. The aim of this study was to explore the development of these programmes. Methods: Sex education programmes geared to people with intellectual disabilities were examined in the context of the Intervention Mapping protocol. Data were obtained via interviews with the programme developers. Results: All programmes lack specific

programme outcomes, do not have a theoretical basis, did not involve members of relevant groups in the development process and lack systematic evaluation. Conclusions: Based on our findings and the literature, we conclude that these programmes are unlikely to be effective. Future programmes should be developed using a more systematic and theory- and evidence-based approach.

Daghustani, W.H., & Huwaidi, M.A. (2013). **Sexual behavior in male adolescents with autism and its relation to social-sexual skills in the Kingdom of Saudi Arabia.** *International Journal of Special Education*, 28(2), 114-122.

ERIC Number: EJ1023316

ABSTRACT: The present study aimed to identify common sexual behavior among adolescents with autism, where parents and teachers of sixty-one male adolescents from twelve to twenty-one years of age were recruited from three cities in the Kingdom of Saudi Arabia. They were asked to respond to a sexual behavior questionnaire, and a social-sexual skills questionnaire. Only teachers were asked to respond to a screening questionnaire for Asperger syndrome and other high functioning autism spectrum disorders to determine the functional level of the adolescents with autism in the sample. This resulted in thirty-two adolescents selected from the main sample; fifteen of them with high functioning autism, and seventeen with low functioning autism. Overall, both parents and teachers reported inappropriate sexual behavior expressed by the adolescents with autism. The results also showed significant correlations between both the social-sexual skills and reported sexual behaviors in all subtests and total scores. The high functioning adolescents with autism displayed significantly less inappropriate sexual behavior and significantly more social-sexual skills when compared to adolescents with low functioning autism.

Fitzgerald, C., & Withers, P. (2013). **"I don't know what a proper woman means": What women with intellectual disabilities think about sex, sexuality, and themselves.** *British Journal of Learning Disabilities*, 41(1), 5-12.

ERIC Number: EJ1010706

ABSTRACT: There is very little literature concerning how women with intellectual disabilities con-

ceptualise their sexuality or develop a sexual identity. Semi-structured interview schedules were used to guide interviews with 10 women with intellectual disabilities. Thematic analysis was used to analyse the interview transcripts. Many of the women could not conceptualise themselves as sexual beings, and they tended to regard sex as a dirty and inappropriate activity for them. They generally believed that other people prohibited them from engaging in sexual activity. The women often considered themselves to be of little value, and the majority had no clear sense of identity. It is incumbent upon services to and the means to empower women with intellectual disabilities to acknowledge, welcome and take control of their own sexuality.

Jones, C. (2013). **Paying for sex: The many obstacles in the way of men with learning disabilities using prostitutes.** *British Journal of Learning Disabilities*, 41(2), 121-127.

ERIC Number: EJ1010648

ABSTRACT: We live in an increasingly sexualised society, and the buying and selling of sex is a feature of this society. The laws about prostitution are complex, but the act of selling or buying sex is in itself not illegal. The author has extensive clinical experience of hearing the stories of men with learning disabilities who do use commercial sex workers and often come to harm in the process. There are other sex workers who have considerable experience of serving people with disabilities, and to date have generally served people with physical disabilities. Section 39 of the Sexual Offences Act makes it a serious crime for care workers to assist people with learning disabilities to engage with sex workers. It is argued that this is contrary to the spirit of Equal Opportunities for people with learning disabilities and against the move towards personal budgets and the freedom to spend them. This law should be reformed. Prostitution is inherently exploitative of women and reinforces the dominant message that women's bodies exist for men's pleasure. This is not a helpful message for men and women with learning disabilities. However, the opinion of this author is that people with learning disabilities should not be expected to shoulder by default any moral responsibility for changing social attitudes. The extra obstacles in the way of accessing sex workers amount to discrimination, and this is wrong.

Pebdani, R.N. (2013). **Rehabilitation counselor knowledge, comfort, approach, and attitude toward sex and disability.** *Rehabilitation Research, Policy, and Education*, 27(1), 32-42.

ERIC Number: EJ1018437

ABSTRACT: This study examined the effect of rehabilitation counseling students' age, sex, disability status, geographic location, marital status, religion, sexual orientation, and level of sexuality training on knowledge, comfort, approach, and attitudes toward the sexuality of people with disabilities. Participants were 312 rehabilitation counseling master's students in Council on Rehabilitation Education (CORE) accredited programs all over the United States. Multivariate analysis of variance (MANOVA) analyses demonstrated that Knowledge scores were affected by intensity of training. Other subscale scores indicated that rehabilitation counseling students had generally negative attitudes toward sex and disability and low levels of comfort with approaches from clients. Results demonstrate the importance of rehabilitation counselor educators incorporating the topic of sex and disability in training programs so that graduating students have the knowledge and comfort necessary to discuss sex with their clients with disabilities.

2012

Berglund, M., Bostrom, M.L., & Brunnberg, E. (2012). **Sexual force at sexual debut. Swedish adolescents with disabilities at higher risk than adolescents without disabilities.** *Child Abuse & Neglect: The International Journal*, 36(4), 285-295.

ERIC Number: EJ966781

ABSTRACT: The aims of this study are first to compare the incidence of force on the first occasion of sexual intercourse reported by participants with disabilities to that of students without disabilities; second to determine whether there are significant differences in mental health, substance abuse, and school performance as reported by participants forced into their sexual debut as opposed to those who were not forced, analysed by gender; and finally to identify the significant variables that predict girls reporting force at sexual debut as opposed to girls not reporting force, as well as to identify simi-

lar variables within the male group. There were no data on sexual abuse prior to the first occasion of full sexual intercourse. Method: This cross-sectional study is based on 2 surveys: Life and Health--Young People 2005 and 2007. All 17/18-year-old adolescents in upper-secondary schools in a county in Sweden were asked the same questions both years. A total of 2,254 students completed the survey in 2005 and 2,641 in 2007. Results: The main finding is that force at sexual debut (intercourse) is more common among adolescents with a disability (4.0%) than those not reporting any disability (1.6%), and is most common among those reporting multiple disabilities (10.4%). This was found both for girls and boys, even if the rates for girls were several times higher. Other findings are that girls and boys reporting force at sexual debut (disability and non-disability groups taken together) reported different profiles. For girls, their country of origin and who they live with are significant. This background data is not significant for boys. Boys report a strong psychosomatic reaction. Conclusion: Culture-, functionality-, and gender-sensitive studies of adolescents' reactions to sexual abuse are needed to help determine relevant and effective interventions.

Bernert, D.J., Ding, K., Hoban, M.T. (2012). **Sexual and substance use behaviors of college students with disabilities.** *American Journal of Health Behavior*, 36(4), 459-471.

ERIC Number: EJ994467

ABSTRACTS: Objectives: To identify the substance use and the sexual behaviors of college students with disabilities. Methods: A secondary data analysis was conducted of the spring 2009 administration of the ACHA-NCHA II. Results: College students with disabilities tended to be 24 or more years old; of an ethnic minority; and bisexual, gay, or lesbian. They consistently reported engaging in both substance use and sexual risk behaviors more than those of students without disabilities. Conclusions: Substance use and sexuality programs on college campuses should be physically, socially, and intellectually accessible for students with disabilities while considering their multiple identities. Efforts should be made to recruit or target these students for such programming.

Gavidia-Payne, S., & Meaney-Tavares, R. (2012). **Staff characteristics and attitudes towards the sexuality of people with intellectual disability.** *Journal of Intellectual & Developmental Disability*, 37(3), 269-273.

ERIC Number: EJ975740

ABSTRACT: Background: The identification of individual staff characteristics that have a relationship with specific attitudes of staff caring for people with intellectual disability (ID) may enable targeted training and better support. Method: Sixty-six participants from services for people with ID in metropolitan Melbourne, Australia, completed a survey, including the Attitudes to Sexuality Questionnaire (Individuals with an Intellectual Disability; Cuskelly & Gilmore, 2007). Results: Staff attitudes towards the sexuality of people with ID were quite positive. Age, program agency position, and training uptake were all associated with positive staff attitudes. Conclusion: Targeted training programs in sexuality can benefit direct care workers in general, and older staff more specifically. Emphasis is warranted in the area of training for managing male sexual behaviours.

Gore, N., McCarthy, M., & Young, R. (2012). **Staff attitudes towards sexuality in relation to gender of people with intellectual disability: A qualitative study.** *Journal of Intellectual & Developmental Disability*, 37(4), 343-347.

ERIC Number: EJ985991

ABSTRACT: Background: Research has found staff attitudes regarding the sexuality of people with intellectual disability (ID) to be negative but influenced by several factors. The current study aimed to examine whether gender of people with ID affects such attitudes. Method: Semistructured interviews were completed with 10 staff members and analysed using thematic analysis. Results: Results indicated 3 themes: Women are perceived as sexually innocent, men as more sexually motivated, and motivations for sexual relationships are perceived to differ between men and women with ID. Conclusion: The study indicates unfavourable attitudes towards sexuality in individuals with ID that correlate with traditional, restricted gender stereotypes. The identification of these themes highlights the importance of considering gender when supporting the sexuality of people with ID.

Turner, G.W. (2012). *The social-sexual voice of adults with mild intellectual disabilities: A qualitative case study.* ProQuest LLC, Ph.D. Dissertation, Widener University.

ERIC Number: ED548869

ABSTRACT: The purpose of this qualitative case study was to explore how adults with mild intellectual disabilities live out their social-sexual lives. Adults with intellectual disabilities (ID) are often assumed to be asexual or incapable of having sexual lives, resulting in a paucity of research-based knowledge. Research and educational efforts with this population have focused largely on basic sexuality education and abuse prevention, defaulting to safety over the possibilities of human connectedness. This case study, informed by heuristic inquiry and guided by an emancipatory research paradigm, was an investigation of self-reported views, values, and desires of five adults with mild intellectual disabilities regarding relationships, romance, and sexuality. Data sources included observations and a series of interviews, which gave participants the chance to give voice to their social-sexual experiences. Data were analyzed utilizing both deductive and inductive coding along with narrative analysis. Results indicated that adults with ID value a life filled with relational passion and connectedness. They desire rich, pleasure-driven social-sexual experiences beyond the typical abuse prevention focus of disability services. Case studies of the five participants are based on their individual perceptions and experiences. Cross-case findings are presented in these eleven areas: 1. Sexual Attitude, 2. Sexual Self-advocacy, 3. Sexual Self-identity, 4. Sexual Experience, 5. Sex Education, 6. Sexual Script, 7. Sexual Vocabulary, 8. Sexual/Relationship Support, 9. Sensuality, 10. Intimacy, and 11. Reproduction. This study offers a more psychologically and socially-aware perspective in an effort to dispel mainstream society's stereotypical portrayal of disability and sexuality. [The dissertation citations contained here are published with the permission of ProQuest LLC. Further reproduction is prohibited without permission. Copies of dissertations may be obtained by Telephone (800) 1-800-521-0600.]

2011

Chan, R., Feist, A., Flores-Torres, L., & Marini, I. (2011). **Student attitudes toward intimacy with persons who are wheelchair users.** *Rehabilitation Research, Policy, and Education*, 25(1-2), 15-26.

ERIC Number: EJ947308

ABSTRACT: The present study explored whether students would be attracted to having an intimate relationship with a wheelchair user if participants were able to first see a head shot photo and later read a short biography of the person. Four hundred and eight undergraduate students were surveyed regarding their interest in potentially being friends, dating or marrying a wheelchair user. Sixty-six percent indicated they would have no problem dating and/or marrying a wheelchair user. A MANOVA revealed significant differences between gender, type of relationship, and experience with a prior disability relationship. Personal characteristics of intelligence, humor and appearance rated most highly. Those unwilling to date and/or marry their selection cited that the partner would be too much work, interaction would be awkward, and the partner would be sick often. Educators may benefit from training counselors about misconceptions regarding sexuality, whereas counselors can role play and provide clients with insights regarding societal beliefs.

Duguay, L. (2011). **Sexuality: Still a taboo subject?** *Exceptional Parent*, 41(2), 16-17.

ERIC Number: EJ916467

ABSTRACT: In spite of the fact that we are all bombarded with sexual messages every day, the subject of relationship and sexuality education for students with intellectual and developmental disabilities continues to be a taboo one. Generally speaking, the author has found it is not the parents of those young people who are reluctant to have the discussion, since they are usually well aware of their child's adolescent struggle. Rather, it is often on a professional level that there is fear expressed about opening a Pandora's Box. In this article, the author talks about this important issue. She argues that there must be a more proactive way to prepare young people with intellectual and developmental disabilities for healthy adult relationships, rather than providing this edu-

cation and counseling after they had already placed themselves or others in harm's way. She stresses that educators consider for a moment how students with intellectual and developmental disabilities receive relationship and sexuality education where they live. She describes the most important skill educators can teach students with intellectual and developmental disabilities about relationships and sexuality.

Minch, L.M. (2011). **Let's talk about sex: Recommendations for educating adolescents with developmental disabilities.** *ProQuest LLC, Psy.D. Dissertation, John F. Kennedy University.*

ERIC Number: ED552434

ABSTRACTS: Individuals with developmental disabilities are vulnerable to sexual abuse, and are often denied access to sexuality education. Public schools have vague curricula regarding sexuality education for general education students, curricula to which adolescents with developmental disabilities do not have access. The current study sought to determine attitudes of public high school special education teachers regarding teaching sexuality education and the obstacles they encounter when attempting to teach sexuality education to their students. A comprehensive survey method utilizing quantitative and qualitative questions gathered information from public high school special education teachers regarding what sexuality information was taught, what barriers prevented special educators from delivering sexuality education, and educator opinions regarding teaching sexuality education. Descriptive percentages and content analyses were used to analyze and report the data. Thirty-three surveys completed nationwide were used for the current study. It was found that the majority of high school special education teachers agreed that each component of sexuality education should be taught to students, however educators felt uncomfortable teaching some topics. It was also found that inadequate curriculum, materials, and resources were reported as major barriers to teaching sexuality education. Consistent with previous research, public high school special educators agree that students with developmental disabilities should be taught sexuality education in public high schools. Participants agreed that each major component of sexuality education should be taught, but various content areas (e.g. marriage and love)

should be left to parents and community leaders. Also consistent with previous research, public high school special educators reported inadequate curriculum, materials, and resources to be major barriers impeding their ability to teach sexuality education to their students. [The dissertation citations contained here are published with the permission of ProQuest LLC. Further reproduction is prohibited without permission. Copies of dissertations may be obtained by Telephone (800) 1-800-521-0600.]

2010

Chambers, B., & Gilmore, L. (2010). **Intellectual disability and sexuality: Attitudes of disability support staff and leisure industry employees.** *Journal of Intellectual & Developmental Disability*, 35(1), 22-28.

ERIC Number: EJ961826

ABSTRACT: Background: The attitudes of support staff and others in the community towards the sexuality of individuals with an intellectual disability (ID) have the potential to influence opportunities for normalised life experiences in the area of sexuality. Method: A sample of 169 disability support staff and 50 employees from leisure and service industries completed the "Attitudes to Sexuality Questionnaires (Individuals with an Intellectual Disability" [ASQ-ID], and "Individuals from the General Population" [ASQ-GP]). Results: Support staff and leisure workers reported generally positive attitudes towards the sexuality of individuals with an ID, but men were seen as having less self-control than women. Support staff were more cautious in their views about parenting, and both groups considered a lower level of sexual freedom to be desirable for women with an ID compared to women who are developing typically. Conclusions: Attitudes of both groups are generally quite positive in relation to ID and sexuality.

2009

Carley, S.N., Evans, D.S., Healy, E., & McGuire, B.E. (2009). **Sexuality and personal relationships for people with an intellectual disability. Part I: Service-user perspectives.** *Journal of Intellectual Disability Research*, 53(11), 905-912.

ERIC Number: EJ858896

ABSTRACT: Background: Despite a recent ideo-

logical shift towards the recognition of sexual autonomy for people with an intellectual disability (ID), there are continuing social and cultural barriers to sexual expression. Part I of the current two-part study assessed the sexual knowledge, experiences and aspirations of service users through focus groups and also examined their perceptions of impediments to achieving sexual autonomy. Method: Thirty-two participants (20 male, 12 female) attending an ID service participated in focus groups delineated by gender and age group (13-17 years; 18-30 years; 31+ years). Results: Analysis of the focus groups showed that service users, especially those over the age of 18 years, had an understanding of their sexual rights but also identified a number of social and cultural barriers that they felt prevent them from achieving sexual autonomy. Those under the age of 18 years had only rudimentary knowledge of sexuality issues, for example pregnancy and sexual anatomy, but aspired to relationships and marriage similar to those over the age of 18 years. Family and staff attitudes appeared to be very influential in the views of respondents. All service users had received some form of sex education, although the benefits of such education appeared most enduring for those over 18 years. Conclusion: Service users had an understanding of their sexual rights and the social and environmental barriers that prevent them from fulfilling their rights. The provision of sex education training and promotion of positive attitudes towards appropriate sexual expression is critical to the realization of sexual autonomy for people with an ID.

Carley, S.N., Evans, D.S., Healy, E., & McGuire, B.E. (2009). **Sexuality and personal relationships for people with an intellectual disability. Part II: Staff and family carer perspectives.** *Journal of Intellectual Disability Research*, 53(11), 913-921.

ERIC Number: EJ858897

ABSTRACT: Background: Recent ideological shifts in service provision promote appropriate sexual expression for people with an intellectual disability (ID), although there is little evidence that such advances in ideology are matched by current service provision. Part II of the current two-part study assessed the attitudes of staff and family carers to the sexuality of people with an ID. Method: A questionnaire survey which included case scenarios was car-

ried out with family (n = 155) and staff carers (n = 153) of people with an ID in the west of Ireland. Results: In general, staff carers were more inclined than family carers to openly discuss issues of sexuality with service users, and to suggest environmental, rather than service-user characteristics, as impediments to such discussions. Attitudinal differences emerged with significant differences between staff and family carers and between younger and older carers. Staff carers were more likely to support service-user engagement in intimate and non-intimate relationships whereas the majority of family carers (80%) showed a preference for low levels of intimacy in service-user relationships. Conclusion: When compared with the attitudes of family carers towards the sexuality of people with ID, the attitudes of staff carers more closely match those promoted by ideological developments. However, differences in attitudes between carer groups may lead to inconsistent approaches to the management of sexuality. As a consequence, we conclude that there is continued need to provide staff and family carers with opportunities for dialogue and an ongoing need for training in the area of sexuality. [For Part I, see EJ858896.]

Denny, G., Penhollow, T.M., & Young, M. (2009). **Predictors of quality of life, sexual intercourse, and sexual satisfaction among active older adults.** *American Journal of Health Education*, 40(1), 14-22.

ERIC Number: EJ833251

ABSTRACT: Background: Relatively little is known about the sexual behaviors of older people, and the relationship between quality of life and sexuality has not been fully explored. Purpose: The purpose of this study was to investigate the impact of sociological, cultural, and psychological factors to further explain variance beyond biological changes that influence participation in sexual intercourse, sexual satisfaction, and overall quality of life. Methods: Data were collected using a mixed-mode approach to optimize participant response and coverage. Residents of a large active retirement community served as the study participants. Results: Logistic regression identified a set of biopsychosocial variables which significantly distinguished between those who participate and do not participate

in sexual intercourse. Multiple regression procedures identified sets of variables that significantly predicted sexual satisfaction and quality of life. Discussion: Overall findings add to the existing body of literature on aging, sexual health, and quality of life. Translation to Health Education Practice: Health professionals should develop interventions that provide education about sexuality to enhance sexual satisfaction and quality of life among community dwelling older adults.

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(8), 727-734.

ERIC Number: EJ848072

ABSTRACT: Aim: 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. Method: The study adopted a single subject design using multiple baseline method with four adults with a moderate intellectual disability. The intervention consisted of individually tailored sex education adapted from "Living Your Life" (Bustard 2003). Treatment was offered to each participant twice weekly for a 10-week period on a one-to-one basis. The Sexual Consent and Education Assessment (SCEA, Kennedy 1993) was used for measurement purposes. The SCEA K-Scale (knowledge) and the S-Scale (safety practices) were administered weekly throughout the baseline, treatment and post-treatment phases of the study. Staff concerns were also assessed using the SCEA Inappropriate Sexual Behaviour Scale. Results: All four participants improved their decision-making capacity in all targeted areas as measured by improvements in K-Scale and S-Scale scores. Staff concerns were not increased as indicated by results on the Inappropriate Sexual Behaviour Scale. Six-month follow-up data for three of the participants showed maintenance of scores on the S-Scale and some decay in scores on the K-Scale from post-intervention performance. Conclusion: The results demonstrate that tailored sexuality education can improve capacity to make sexuality-related decisions.

Fullwood, H., Harader, D.L., & Hawthorne, M. (2009). **Sexuality among adolescents with moderate disabilities: Promoting positive sexual development.** *Prevention Researcher, 16*(4), 17-20.

ERIC Number: EJ866790

ABSTRACT: Adolescents with moderate disabilities are not being given vital information regarding their sexuality and ways to behave responsibly with their peers. This article examines the laws that govern the education of all persons with disabilities, how societal norms and attitudes have contributed to this lack of sexuality knowledge, how these adolescents are often victims of inappropriate sexual beliefs and attitudes, and how professionals can work effectively with these youth to promote positive sexual attitudes and behaviors.

Hall, I., & Yacoub, E. (2009). **The sexual lives of men with mild learning disability: A qualitative study.** *British Journal of Learning Disabilities, 37*(1), 5-11.

ERIC Number: EJ828608

ABSTRACT: We aimed to explore in detail the sexual lives and behaviour of men with mild learning disabilities living both in community and in secure hospital settings. We wanted to generate hypotheses about them and identify potential unmet needs. We used a narrative interview that focused on areas such as relationships, sex education, contraception and the attitudes of others towards the participants' sexual lives and orientation. We used the constant comparative method to analyse transcribed interviews. Several clients reported engaging in unsafe practices despite being aware of the risks. Participants generally felt that services had shifted from a paternalistic to a more supportive approach towards their sexual lives and orientation. Experiences with other men were commonly reported. Several participants reported being pressurised into sex as adults. In our sample, sexual knowledge did not lead to safe sexual practices. The good rapport with services reported by the participants may be utilised to provide further education and empowerment to improve the safety of sexual practices in this group. Other ways of improved service delivery are suggested.

Hollomotz, A. (2009). **"May we please have sex tonight?" People with learning difficulties pursuing privacy in residential group settings.** *British Journal of Learning Disabilities, 37*(2), 91-97.

ERIC Number: EJ840688

ABSTRACT: Many residential group settings for people with learning difficulties do not provide individuals with the private space in which they can explore their sexual relationships in a safe and dignified manner. Lack of agreed private spaces seriously infringes the individual's human rights. Many people with learning difficulties who lack privacy have no other option but to escape to isolated public or semi-private spaces to be sexually active. This places individuals at risk. It is suggested that self-advocacy driven policy guidance must be developed which must require residential services to review their practice to ensure that they accommodate residents' need for privacy, whilst supporting them to lead safe sexual relationships.

Kazukauskas, K.A., & Lam, C.S. (2009). **Importance of addressing sexuality in certified rehabilitation counselor practice.** *Rehabilitation Education, 23*(2), 127-140.

ERIC Number: EJ932744

ABSTRACT: This study investigated Certified Rehabilitation Counselors' (CRCs) beliefs about the importance of addressing sexuality issues during rehabilitation. A modified version of the Family Life Sex Education Goals Questionnaire (FLSEGQ) was completed by 199 CRCs to determine which issues CRCs believe are most important to address. Six sexuality-related factors were identified: Counseling and Education; Contraception, Pregnancy and STDs; Sexual Development and the Body; Family Inclusion; Traditional Values and; Contemporary Values. Analysis of means revealed that CRCs believe all sexuality-related issues to be important to address during rehabilitation, but that Counseling and Education and Contraception, Pregnancy and STDs are the most critical. Sexuality-related goal planning was found to be the most important item overall. Results suggest that additional training in disability and sexuality issues is needed. Implications for future research are reviewed.

Redelman, M.J. (2009). **Sexual difficulties for persons with multiple sclerosis in New South Wales, Australia.** *International Journal of Rehabilitation Research*, 32(4), 337-347.

ERIC Number: EJ885883

ABSTRACT: This 1992 study was conducted to ascertain the incidence of sexual difficulties in individuals diagnosed with multiple sclerosis (MS) living in New South Wales, Australia. New South Wales is a state lying roughly 29-36 [degrees] south of the equator. This is currently the largest study conducted. The anonymous questionnaire completed by 283 respondents included questions on sexual difficulties, relationship satisfaction and the ability to communicate about and seek help for the sexual difficulties. In this study, 30 percent of respondents claimed to have sexual difficulties attributable to MS. Sexual difficulties were experienced by 51 percent of female and 74 percent of male respondents. For females, the most frequently occurring sexual symptoms were difficulty with achieving orgasm, lowered libido, dissatisfaction with sexual performance, dissatisfaction with frequency of intercourse, arousal difficulties and decreased vaginal lubrication. For males, by far the most common problem was decreased frequency of intercourse, followed by dissatisfaction with sexual performance, masturbation difficulties, difficulty with achieving vaginal orgasms, erectile dysfunctions, retarded ejaculation and premature ejaculation. Overall, females rated their sexual difficulties as 10th in order of importance of disabilities from MS and males ranked sexual difficulties as fourth in importance. For both males and females, sexual disability increased with age, relationship unhappiness and disease disability. Communicating about sexual difficulties was an issue for both males and females. Fifty five percent of males and 39 percent of females had been able to talk about their sexual difficulties and of these, only 29 percent of males and 36 percent of females had been able to access help for their sexual difficulty. Educational level did not predict ability to talk about, or ability to access help. There was a very low satisfaction rate for the sexual help received. The study highlights areas of need for the MS population.

Tissot, C. (2009). **Establishing a sexual identity: Case studies of learners with autism and learning difficulties.** *Autism: The International Journal of Research and Practice*, 13(6), 551-566.

ERIC Number: EJ863768

ABSTRACT: The physical and emotional changes that occur in adolescence are part of the process of sexual maturity. These changes occur irrespective of ability and are often aligned with psychological and social factors. When the nature of a disability has an inherent limitation in social awareness, as is the case for individuals with autism, the achievement of personal sexual identity can become much more complex. Challenges in supporting individuals in this respect can be caused by the sensitive aspects of inappropriate behaviour, the abstract nature of teaching the topic, and the general reluctance on the part of parents and staff to discuss sexuality in individuals with disabilities. This article explores how a residential school addressed this gap. It provides details of how this need was met for seven students and the process undertaken to involve staff, parents and other stakeholders to establish ongoing support.

2008

Brown, R.D., Pirtle, T. (2008). **Beliefs of professional and family caregivers about the sexuality of individuals with intellectual disabilities: Examining beliefs using a Q-methodology approach.** *Sex Education: Sexuality, Society, and Learning*, 8(1), 59-75.

ERIC Number: EJ810959

ABSTRACT: This investigation described the perceptions of involved adults concerning the sexuality of individuals with intellectual disabilities. Participants completed a Q-sort with a concourse of 36 items. Analysis produced four different belief systems: advocates, supporters, regulators, and humanists. These belief systems describe the respondents' views on sex education, birth control methods, and sexual participation concerning individuals with intellectual disabilities. The representative respondents of the advocates can be described as strong supporters of human rights for the individual with intellectual disabilities. The typical respondent for the supporters can be described as an ardent supporter of sex education for the individual with intellectual dis-

abilities. The regulators were similar to the supporters by showing strong favoritism toward educating individuals with intellectual disabilities concerning sex. However, in contrast the regulators also supported extensive birth control measures. Finally, the humanists can be described as being the strongest supporters of human rights for the individual with intellectual disabilities.

2007

Abbott, D., & Howarth, J. (2007). **Still off-limits? Staff views on supporting gay, lesbian, and bisexual people with intellectual disabilities to develop sexual and intimate relationships?** *Journal of Applied Research in Intellectual Disabilities*, 20(2), 116-126.

ERIC Number: EJ835572

ABSTRACT: Background: In the UK and elsewhere, there is a growing policy and legislative imperative to ensure that people with intellectual disabilities are supported to develop relationships, including sexual ones. However, gay, lesbian and bisexual people with intellectual disabilities may have additional needs or face particular barriers in this area of their lives. They may require particular kinds of support from the staff who work with them. But how able, or willing, are staff in services to address these issues? Method: As part of empirical, qualitative research, the authors carried out interviews with 71 staff in 20 intellectual disability services across the UK about their views and experiences of working with people with intellectual disabilities who were, or may have been, gay, lesbian or bisexual. Results: The majority of staff interviewed said that they did not feel confident working in this area. A number of barriers to doing the work were identified including a lack of policy and training as well as the prejudice of staff and parents/carers. Conclusions: The reticence of staff to engage with these issues needs addressing especially in the light of the emerging human rights of people with intellectual disabilities to develop sexual and intimate relationships.

Bazzo, G., Ferrari, L., Minnes, P., Nota, L., & Sore-si, S. (2007). **Attitudes of social service providers towards the sexuality of individuals with intellectual disability.** *Journal of Applied Research in Intellectual Disabilities*, 20(2), 110-115.

ERIC Number: EJ835571

ABSTRACT: Background: The sexual lives of peo-

ple with intellectual disability is made complex by the involvement and influence of social service providers, whose beliefs and values have a great impact on the support they provide. We hypothesized that social service providers' role, educational level and service in which they worked could affect attitudes towards the sexual behaviour of individuals with intellectual disability. Materials and methods: The current study describes attitudes of social service providers towards the sexuality of individuals with disability measured by 20 items of Sexuality and Mental Retardation Attitudes Inventory (SMRAI). This instrument was devised by Brantlinger ["Mental Retardation" (1983) Vol. 21, pp. 17-22] to assess the attitudes of the staff employed by organizations that supplied services to individuals with intellectual disability. Specifically, analysis of variance (type of service x professional role x education) was performed on participants' scores. Results: Results suggested that the social service providers participating in this research study tended to have moderately liberal attitudes. Educational level and role carried out did not produce differences in their attitudes. A significant difference emerged between those who operated in different services. It was especially the staff of the outpatient treatment services who revealed the most liberal and positive attitudes towards the sexuality of individuals with intellectual disability. Conclusions: The data reported in the present study seem to underline some differences between the data collected from the Italian and the Anglo-Saxon social service providers. Failure to record influences associated with the role carried out and previous training could be related to the different contextual differences. Results suggest that particular attention should be paid to the training of those who hold managerial posts in Italian residential services.

Colson, K., Deboutte, D., Hellemans, H., Verbraeken, C., & Vermeiren, R. (2007). **Sexual behavior in high-functioning male adolescents and young adults with autism spectrum disorder.** *Journal of Autism and Developmental Disorders*, 37(2), 260-269.

ERIC Number: EJ758381

ABSTRACT: Group home caregivers of 24 institutionalized, male, high-functioning adolescents and young adults with Autism Spectrum Disorder, were interviewed with the Interview Sexuality Autism. Most subjects were reported to express sexual interest and to display some kind of sexual behav-

ior. Knowledge of socio-sexual skills existed, but practical use was moderate. Masturbation was common. Many subjects were seeking physical contact with others. Half of the sample had experienced a relationship, while three were reported to have had sexual intercourse. The number of bisexual orientations appeared high. Ritual-sexual use of objects and sensory fascinations with a sexual connotation were sometimes present. A paraphilia was present in two subjects. About one third of the group needed intervention regarding sexual development or behavior.

Grieve, A., Lindsay, W.R., & McLaren, S. (2007). **An evaluation of research and training resources for the sex education of people with moderate to severe learning disabilities.** *British Journal of Learning Disabilities*, 35(1), 30-37.

ERIC Number: EJ751768

ABSTRACT: The purpose of this article is to review the literature on issues surrounding the sexuality of people with moderate to severe learning disability (SLD), and evaluate available assessment and training methods. This research arose from an increasing number of referrals for clinical intervention in the training and education of appropriate social and sexual behaviour in people with moderate to SLD. What became apparent was the lack of suitable materials and assessments, which is significant as a large number of persons with SLD have problems with language, and so require tools and programmes which have enhanced levels of pictorial support. This research was necessary as people with SLD are vulnerable and have been open to emotional and sexual abuse ["Ment Handicap Res" 16 (1993) 193]. Also, the present study was also required to help keep clients safe and reduce their vulnerability. It has been proposed that this should be achieved through providing educative input. An extensive review of the literature revealed that the research on sexuality in SLD was limited. Furthermore, where research had been conducted, poor methodology or validation issues were common, and materials appeared overly complicated for clients with moderate to SLD. Further research into the development and validation of assessment tools and training programmes which increase appropriate sexual behaviours is urgently required. [Abstract modified to meet ERIC guidelines.]

Murphy, G.H., & O'Callaghan, A.C. (2007). **Sexual Relationships in Adults with Intellectual Disabilities: Understanding the Law.** *Journal of Intellectual Disability Research*, 51(3), 197-206.

ERIC Number: EJ751523

ABSTRACT: Introduction: Adults with intellectual disabilities (IDs) are known to be very vulnerable to sexual abuse. This may result partly from their lack of sexual knowledge and their powerless position in society. It could also be exacerbated by an ignorance of the law. This study investigates their understanding of the law relating to sexuality. Method: Understanding of the law regarding sexual relationships, consent and abuse was assessed in 60 adults with IDs (mean age 37.6 years) and 60 young people aged 16-18 years (deemed in law capable of consenting to a sexual relationship). Questions were wide ranging, including general laws around sexuality and abuse, as well as the law relating to sexual relationships and ID. Results: There were significant differences between the two groups: adults with IDs 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 IDs (e.g. whether they could have sexual relationships, whether they were allowed to marry, what protection they should expect from the law). Young people without disabilities showed a better understanding, both for general laws and for those relating specifically to adults with IDs. Conclusions: These findings show that there is a need to educate people with IDs about the laws relating to sexuality. It is important for people to understand the law and, given the high rates of sexual abuse perpetrated against people with ID, it is essential for them to benefit from the protection the law affords. The new law in England (Sexual Offences Act 2003) post-dated this study. It will be interesting to see whether the new legislation is easier for people with and without disabilities to understand.



Documents from the National Library of Medicine PubMed search at www.pubmed.com are listed below:

2016

Church, P., Gambino, S., Heller, M.K., Kaufman, M., Lindsay, S., & McPherson, A.C. (2016). **Sexuality and relationships in young people with spina bifida and their partners.** *The Journal of Adolescent Health*, 59(2), 182-8.

PMID: 27222355

ABSTRACT: **PURPOSE:** Research focusing on sexuality in those living with disabilities, such as spina bifida (SB), has not specifically addressed adolescents and has been largely quantitative in design. Our study qualitatively explored how young people with SB think about and discuss sexuality with their sexual and romantic partners in the context of their disability. **METHODS:** Participants aged 16-25 years were recruited using purposive sampling from a large urban pediatric rehabilitation center in Toronto, Canada, as well as through a large Spina Bifida and Hydrocephalus Association. Semistructured interviews were conducted in person or by telephone. Inductive coding and descriptive thematic analysis were conducted on verbatim transcripts. **RESULTS:** There were mixed views on the importance of disclosing their condition to partners. While some participants strongly believed that their disability was important to share with partners, others worried that potential partners would focus on the disability rather than the person. Participants reported challenges about the timing of disclosure, lack of confidence in their abilities to express their sexual needs, and fears of rejection. After disclosure, however, participants often experienced increased confidence in themselves and their relationships. Participants identified a lack of SB-specific sexual education and a desire to learn more from their health care providers. **CONCLUSIONS:** The findings underscore the importance of empowering young people to become more confident talking about their disability, especially in the context of sexual and romantic relationships. Being able to discuss their abilities, needs and desires could potentially facilitate the development of healthy relationships during their transition to adulthood.

Cross, E.M., Lincoln, S., Meredith, S., Murphy, C., & Rintell, D. (2016). **Sex education and intellectual disability: Practices and insight from pediatric genetic counselors.** *Journal of Genetic Counseling*, 25(3), 552-60.

PMID: 26581379

ABSTRACT: Intellectual disability (ID) with or without other anomalies is a common referral for genetic counseling. Sessions may include discussions of reproductive implications and other issues related to sex education. Patients with ID regularly meet barriers when trying to obtain sex education due to the misperceptions of others as being either asexual or that such education would promote inappropriate sexual behavior. In this pilot study, we surveyed genetic counselors to explore their experiences with being asked to provide sex education counseling and their comfort in doing so for patients with ID ages 9-17. Results were analyzed from 38 respondents. Caregivers and patients most frequently requested information on puberty, sex abuse prevention, and reproductive health. Genetic counselors were most comfortable when they could provide sex education counseling within the context of a particular condition or constellation of features. They were least comfortable when they lacked familiarity with the patient, caregiver, or the family's culture. The most frequently cited barriers that prevented genetic counselors from providing sex education counseling were lack of time, lack of training, the patient's ID being too profound, and a belief that genetic counselors should not be responsible for providing sex education counseling. While many respondents reported that providing sex education counseling is not considered within the scope of a genetic counselor's practice, they also noted that patients' families initiate discussions for which counselors should be prepared. Respondents indicated that resource guides specifically designed for use by genetic counselors would be beneficial to their practice. Genetic counselors have the opportunity to embrace the role of advocate and broach the issue of sexual health with caregivers and patients by directing them toward educational resources, if not providing sex education directly to effectively serve the needs of patients and caregivers.

Ghori, S.J., Shameem, M., & Shandra, C.L. (2016). **Disability and the context of boys' first sexual intercourse.** *The Journal of Adolescent Health, 58*(3), 302-9.

PMID: 26706851

ABSTRACT: PURPOSE: The context in which first sexual intercourse takes place has lasting implications for subsequent sexual behavior. This study examines how adolescent disability associates with boys' age of sexual debut, relationship at first sexual intercourse, degree of discussion about birth control before first sexual intercourse, and contraceptive use at first sexual intercourse. **METHODS:** Data were used from the National Longitudinal Survey of Youth 1997, a nationally representative survey collected annually in the United States. Multinomial logistic regression of a base sample of 2,737 boys examines the likelihood of (1) sexual debut at ages 12-14, 15-17, or =18 years; (2) first intercourse with a stranger, casual acquaintance, dating partner, in a committed relationship, or in an undefined relationship; (3) level of discussion about birth control; (4) contraception; and (5) condom use among those who contracept. **RESULTS:** Compared to boys without disability, those with learning or emotional conditions are more likely-and those with sensory conditions are less likely-to report very early sexual debut. Boys with chronic illness are both more likely to have sex in a committed relationship and in an undefined relationship and also more likely to contracept at first intercourse. Boys with learning or emotional conditions are more likely to discuss birth control but less likely to use condoms if they do contracept. **CONCLUSIONS:** Boys with and without disabilities-and boys with different types of disabilities-vary significantly in multiple aspects of their first sexual experiences. It is pertinent that sexual health interventions are tailored to address this diversity.

McGrath, M., & Sakellariou, D. (2016). **Why has so little progress been made in the practice of occupational therapy in relation to sexuality?** *The American Journal of Occupational Therapy, 70*(1), 7001360010p1-5.

PMID: 26709437

ABSTRACT: Despite recognition of the rights of disabled people to sexuality, occupational therapists

continue to not address sexuality in practice. This failure can be understood as a consequence of social discourses relating to sexuality and disability and a professional discourse that values certain occupations over others. Given the importance of sexuality to the human experience and the evidence of the link between the opportunity for sexual expression and well-being, occupational therapists need to change their practice in relation to sexuality and disability. One method of achieving this change may be to adopt a rights-based approach to sexuality and disability. This article presents the possibilities offered by such an approach, discusses implications for occupational therapy practitioners, and proposes suggestions for future actions to ensure that the rights of disabled people to sexuality are embedded in occupational therapy practice.

Rohleder, P. (2016). **Disability and HIV in Africa: Breaking the barriers to sexual health care.** *Journal of Health Psychology, doi: 10.1177/1359105316628738.*

PMID: 26893296

ABSTRACT: Three decades into the HIV pandemic, the issues affecting people with disabilities remain less known. Increasing attention has been given to this overlooked population when it comes to HIV prevention, treatment and care. This is related to the significant unmet sexual and reproductive healthcare needs facing people with disabilities worldwide. This article discusses the barriers to sexual health for people with disabilities in Africa and presents an argument about how mainstream HIV prevention work and research do not adequately attend to the sorts of systemic barriers that exclude people with disabilities, which a more targeted and critical approach could.

2015

Agrawal, K., Boller, F., & Romano, A. (2015). **Sexual function after strokes.** *Handbook of Clinical Neurology, 130*, 289-95.

PMID: 26003250

ABSTRACT: Strokes are the second leading cause of death and the third leading cause of disability worldwide. Thanks in part to better and more available diagnosis, treatment, and rehabilitation, the vast

majority of stroke patients tend to survive strokes, particularly in the industrialized world. Motor disability and cognitive changes such as aphasia and visuospatial disorders are most often considered among the major contributors to stroke burden. This chapter discusses disorders of sexual functions as another frequent sequel of strokes. Strokes generally induce hyposexuality, but in some instances they may be followed by hypersexuality. There is some evidence suggesting that lesions of either hemisphere affect sexual activities, but for different reasons: aphasia and depression after left-hemisphere lesions, a deficit in arousal and perhaps visuospatial disorders after right-hemisphere lesions. Psychologic, psychosocial, and physical factors, as well as medications, play an important role. A better understanding of the psychosocial and physiologic mechanisms underlying sexual functioning can provide insight into improving sexual activity and therefore quality of life in patients affected by strokes and other brain lesions.

Alegre, J., Aliste, L., Blazquez, A., García-Quintana, A., & Ruiz, E. (2015). **The effect of fatigue and fibromyalgia on sexual dysfunction in women with chronic fatigue syndrome.** *Journal of Sex & Marital Therapy, 41*(1), 1-10.

PMID: 24274008

ABSTRACT: Sexual dysfunction in patients with chronic fatigue syndrome is attracting growing interest but, to date, few studies have analyzed it. For this reason, the authors evaluated sexual dysfunction in women with chronic fatigue syndrome (using the Golombok Rust Inventory of Sexual Satisfaction) and explore correlations with fatigue and other symptoms. Sexual dysfunction was greater in patients with chronic fatigue syndrome (n = 615) with a higher number of cognitive, neurological, and neurovegetative symptoms, concomitant fibromyalgia, Sjögren's syndrome, or myofascial pain syndrome, and more intense fatigue (p < .05).

Azarbayejani, A., Salehi, M., Shafiei, K., Shayegh, B., & Ziaei, T. (2015). **Self-esteem, general and sexual self-concepts in blind people.** *Journal of Research in Medical Sciences, 20*(10), 930-6.

PMID: 26929756

Available in full-text at http://www.jmsjournal.net/temp/JResMedSci2010930-5701045_155010.pdf.

ABSTRACT: BACKGROUND: People with visual

disability have lower self-esteem and social skills than sighted people. This study was designed to describe self-esteem and general and sexual self-concepts in blind people. **MATERIALS AND METHODS:** This was a cross-sectional study, conducted in the Isfahan University of Medical Sciences in 2013-2014. In this study, 138 visually impaired people participated from Isfahan Province Welfare Organization and were interviewed for measuring of self-esteem and self-concept using Eysenck self-esteem and Rogers' self-concept questionnaires. The correlation between above two variables was measured using Statistical Package for the Social Sciences (SPSS) software by Pearson correlation test. **RESULTS:** Mean [\pm standard deviation (SD)] age of patients was 30.9 ± 8 years. The mean (\pm SD) of general self-concept score was 11 ± 5.83 . The mean (\pm SD) of self-esteem score was 16.62 ± 2.85 . Pearson correlation results showed a significant positive correlation between self-esteem and general self-concept ($r = 0.19$, $P = 0.025$). The mean of sexual self-concept scores in five subscales (sexual anxiety, sexual self-efficacy, sexual self-esteem, sexual fear, and sexual depression) were correspondingly 11 ± 4.41 , 19.53 ± 4.53 , 12.96 ± 4.19 , 13.48 ± 1.76 , and 5.38 ± 2.36 . Self-esteem and self-concept had significant positive correlation with sexual anxiety ($r = 0.49$; $P < 0.001$) ($r = -.23$; $P < 0.001$) and sexual fear ($r = 0.25$; $P = 0.003$) ($r = 0.18$; $P = 0.02$) and negative correlation with sexual self-efficacy ($r = -0.26$; $P = 0.002$) ($r = -0.28$; $P = 0.001$) and sexual-esteem ($r = -0.34$; $P < 0.001$) ($r = -0.34$; $P < 0.001$). **CONCLUSION:** Self-esteem and self-concept had significant correlation with sexual anxiety and sexual fear; and negative correlation with sexual self-efficacy and sexual-esteem.

Barnett, J.P., & Maticka-Tyndale, E. (2015). **Qualitative exploration of sexual experiences among adults on the autism spectrum: Implications for sex education.** *Perspectives on Sexual and Reproductive Health, 47*(4), 171-9. PMID: 26418175

ABSTRACT: CONTEXT: The increasing prevalence of autism since the 1990s has led to growing demand for sex education that meets the needs of persons on the autism spectrum. Yet there is a dearth of research documenting the firsthand ex-

periences and perspectives of autistic individuals. **METHODS:** A thematic analysis was conducted of in-depth, Internet-facilitated interviews with 24 adults on the autism spectrum who were recruited from Internet community spaces between November 2012 and May 2013. Inclusion criteria were self-identification as a person on the autism spectrum, being a U.S. resident, being aged 18 or older, and having the ability to communicate orally or through writing. **RESULTS:** Participants were aged 18-61 and were living in the community at the time of interview, most with limited extrafamilial support. They were less likely than the general population to be heterosexual or gender-conforming and were more likely to have experienced romantic or sexual debut after age 18. Participants' most common concerns were courtship difficulties and sensory dysregulation in the context of partnered sexuality. These concerns were exacerbated by inadequate and inappropriate sex education experiences. Participants addressed challenges by using sensory barriers (e.g., latex gloves); planning when and how to have sex; negotiating alternatives to sexual scripts predicated on nondisabled experience; and practicing explicit and intentional communication. **CONCLUSIONS:** Individuals on the autism spectrum would benefit from sex education that normalizes differences (e.g., in identities and experiences of sexuality), is offered throughout young adulthood, addresses disability-relevant sensory and communication needs, and includes practicing neurotypical sociosexual norms.

Boston, P., Rajagopal, M.R., & Sunilkumar, M.M. (2015). **Sexual functioning in men living with a spinal cord injury: A narrative literature review.** *Indian Journal of Palliative Care*, 21(3), 274-81.

PMID: 26600694

Available in full-text at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4617033>.

ABSTRACT: **BACKGROUND:** Sexual dysfunction is a major concern for Indian men living with a spinal cord injury. **OBJECTIVES:** To examine the literature related to sexuality traumatic cord injury and its impact on sexual functioning. **MATERIALS AND METHODS:** Databases using Cumulative Index to Nursing and Allied Health Literature (CINAHL) 2000-2012, Medline 1989-2012, Applied Social Sciences Index and Abstracts (ASSIA) 1989-

2012 and Google Scholar were the search engines used for literature review. **RESULTS:** The search yielded a total of 457 articles and only 75 of them were found relevant. The minimum number of articles required to meet the inclusion criteria for this review was 25-30 articles. Out of the 75 articles, 33 were considered relevant or related to the topic of sexual functioning, spinal cord injury, and paraplegia. Six areas were identified: Sexual stigmatization, physiological barriers to sexual satisfaction, clinical aspects of sexual functioning, biomedical approaches to sexual dysfunction, partner satisfaction, and lack of accessibility to sexual education. **CONCLUSION:** Spinal cord injury and sexual functioning affects a large segment of the male Indian population, yet most current research focuses on quantitative measurement with the emphasis on ejaculatory dysfunction, orgasm impairment, incontinence, and other physiological dysfunction. Further research is needed to address the subjective accounts of patients themselves with respect to the emotional and social impact of sexual disability. This would help to identify the best possible outcomes for both treatment and rehabilitation.

Briken, P., Krueger, R., Schöttle, D., & Turner, D. (2015). **Sexual behavior and its correlates after traumatic brain injury.** *Current Opinion in Psychiatry*, 28(2), 180-7.

PMID: 25602251

ABSTRACT: **PURPOSE OF REVIEW:** Traumatic brain injury (TBI) is one of the leading causes of permanent disability in young adults and is frequently accompanied by changes in sexual behaviors. Satisfying sexuality is an important factor for overall quality of life in people with disabilities. The purpose of this article is to review the studies evaluating the assessment, correlates and management of sexuality following TBI. **RECENT FINDINGS:** The Brain Injury Questionnaire of Sexuality is the first validated questionnaire specifically developed for adults with TBI. A considerable amount of individuals with TBI show inappropriate sexual behaviors and sexual dysfunctions. Whereas inappropriate sexual behaviors are related to younger age, less social participation and more severe injuries, sexual dysfunctions show an association with higher fatigue, higher depression scores, less self-esteem and female sex. Healthcare

professionals have suggested that because of discomfort at the individual or institutional level, sexual problems are often not sufficiently addressed and have suggested that a specialist should treat sexual problems. **SUMMARY:** Although some important correlates of sexual problems could be identified, methodological differences across studies limit their comparability. Furthermore, there is an absence of evidence-based treatment strategies for addressing sexual problems. Therapeutic efforts should take into account the identified correlates of sexual problems following TBI.

Chou, Y.C., Lu, Z.Y., & Pu, C.Y. (2015). **Attitudes toward male and female sexuality among men and women with intellectual disabilities.** *Women & Health, 55*(6), 663-78.

PMID: 26020162

ABSTRACT: Studies comparing the sexual attitudes of men and women with intellectual disabilities (ID) have been limited. A mixed-methods approach was employed to explore attitudes toward sexuality among men and women with ID in Taiwan and to ascertain the disparities between attitudes among men and women with ID. First, fifty-six men and forty-four women with mild and moderate ID completed a face-to-face interview survey. After this, focus groups were conducted for men and women with ID. Results indicated that women with ID were more likely to have negative attitudes toward parenting and non-reproductive sexual behavior than their male counterparts. Qualitative data indicated that men and women with ID had different sexual attitudes and experiences and were subject to different expectations from people around them. Both men and women with ID had very limited opportunities to develop romantic relationships and a healthy sexual identity. Sexual rights awareness and practice should be matters of concern for this group of adults and women with ID in particular.

Enow, H., Nagalingam, P., Singh, R., & Thalitaya, M.D. (2015). **Need for a comprehensive sex and relationship education programme for adults with learning disability.** *Psychiatry Danubina, 27*(Suppl 1), S465-7.

PMID: 26417818

ABSTRACT: INTRODUCTION: Most people with learning disabilities (PWLD) have little understand-

ing of the concept of sex and relationship. PWLD are vulnerable and more likely to be victims of sexual offending. Currently, the only formal access to sex and relationship education that PWLD have is in special need schools. **BACKGROUND:** The right to express their sexuality is frequently restricted or denied by restricted policies, negative attitudes and lack of awareness of their needs. **AIMS:** To provide a Comprehensive Sex and Relationship Education programme for PWLD. **METHODOLOGY:** These group/individual sessions will led by a sexuality support worker with experience in working with PWLD. They will be supported by members of the multidisciplinary team including, psychiatrist, psychologist, occupational therapists etc. **CONCLUSION:** Providing sex and relationship education PWLD would help them achieve a fulfilling and rewarding sexual experience and make them less vulnerable to sexual abuse. There should be greater emphasis to be placed on sex and relationship education in PWLD; preferably by qualified professionals.

Rowen, T.S., Stein, S., & Tepper, M. (2015). **Sexual health care for people with physical disabilities.** *The Journal of Sexual Medicine, 12*(3), 584-9. PMID: 25739683

ABSTRACT: BACKGROUND: People with physical disabilities make up a large and heterogeneous population, many with specific sexual health needs that differ from the general population. **METHODS:** To conduct a review of current definitions and statuses relating to the sexual well-being of people with physical disabilities. Medical, social, and behavioral literature was searched and included to address the specific sexual health needs and disparities in this population. **RESULTS:** People with physical disabilities encompass a broad population, including those with concomitant mental and cognitive impairments. People with physical disabilities have significant sexual and reproductive health disparities when compared with the general population and higher rates of sexual distress. There are specific sexual health concerns for men and women with physical disabilities and approach to their care needs to be interdisciplinary. **CONCLUSIONS:** Sexual health needs for people with physical disabilities should be a priority for healthcare providers. Continued education is essential to ensure disparities and health needs are addressed and treated.

Sankhla, D., & Theodore, K. (2015). **British attitudes towards sexuality in men and women with intellectual disabilities: A comparison between white westerners and south Asians.** *Sexuality and Disability*, 33(4), 429-445.

PMID: 26594077

Available in full-text at https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4643113/pdf/11195_2015_Article_9423.pdf.

ABSTRACT: Although sexuality is a fundamental aspect of human existence, public attitudes towards the sexuality of people with intellectual disabilities may vary. In particular, different ethnic communities may have different perspectives. These differing perspectives may impact on the opportunities and support available for people with intellectual disabilities to express sexuality within 'normalized' life experiences. Despite the South Asian population being one of the largest minority ethnic groups residing within the UK, few studies have aimed to understand how South Asian attitudes towards the sexuality of people with intellectual disabilities may differ from White Western perspectives. This study used an online questionnaire to investigate public attitudes towards the sexuality of people with intellectual disabilities within a UK sample (n = 331). Attitudes between people from White Western (n = 184) and South Asian backgrounds (n = 147) were compared with the use of five scales measuring attitudes towards sexuality. Whilst overall attitudes appeared to be generally positive, South Asian participants were found to have significantly more negative attitudes towards the sexual control and sexual rights of people with intellectual disabilities compared to White Westerners. These differences remained significant even after factors known to influence such attitudes were taken into consideration. These findings implicate the need to develop culturally sensitive interventions to improve knowledge and awareness of sexual needs of people with intellectual disabilities. This paper discusses these implications further, the limitations of the present study and suggested directions for future research.

2014

Akpinar, Z., Gumus, H., & Yilmaz, H. (2014). **Effects of multiple sclerosis on female sexuality: A controlled study.** *The Journal of Sexual Medicine*, 11(2), 481-6.

PMID: 24299569

ABSTRACT: AIM: The aim of this study was to investigate the effects of multiple sclerosis (MS) on female sexuality. METHODS: Present study included 142 females (70 MS patients, 72 healthy controls). MS patients were evaluated by Expanded Disability Status Scale (EDSS) for functional status, by Beck Depression Inventory (BDI) for severity of depression, by Visual Analog Scale (VAS) for severity of pain, and by Female Sexual Function Inventory (FSFI) for sexual function. MAIN OUTCOME MEASURES: FSFI, BDI, EDSS, and VAS were the main outcome measures. RESULTS: The number of weekly sexual intercourse, total FSFI, and FSFI subscale scores were lower in MS women compared with controls. FSFI total and FSFI subscale scores were statistically significantly lower in MS women with BDI score = 17 compared with those with BDI score <17. A negative correlation was found between total FSFI score and BDI, EDSS, VAS, age, and duration of complaint, but a positive correlation was found with education level in MS women. CONCLUSIONS: Sexual functions are negatively affected in MS women. Sexual functions in MS women seem to be associated with enhanced disability, pain, duration of the disease, and degree of concomitant depression. Therefore, women with MS should also be evaluated in terms of sexual function during routine follow-ups.

Biering-Sørensen, F., Biering-Sørensen, I., Hansen, R.B., Liebach, A., Lind, M., Seitzberg, A., & von Linstow, M.E. (2014). **Spina bifida and sexuality.** *Journal of Rehabilitation Medicine*, 46(9), 891-7.

PMID: 25148270

Available in full-text at <http://www.medicaljournals.se/jrm/content/download.php?doi=10.2340/16501977-1863>.

ABSTRACT: OBJECTIVE: To evaluate sexual function amongst adult individuals with spina bifida and to register their subjective satisfaction with their sexual life and relationships. SETTING: Department for Spinal Cord Injuries, East Denmark.

STUDY DESIGN AND METHODS: Cohort study. Medical record information, neurological examination, personal interview, Functional Independence Measure (FIMTM), Medical Outcome Study Short Form 36 (SF-36) on quality of life, and questions on sexual function and related topics. Study cohort: Fifty-three participants (27 women, 26 men) with spina bifida (mean age 27.1, range 18-35) years. Response rate 74 percent. **RESULTS:** Fifty-one percent of subjects regarded their sexual life as a failure or dysfunctional. However, 45 percent reported being satisfied with their sexual life. Participants with partners were more satisfied with their sexual life than those without partners. Faecal, but not urinary, incontinence was associated with poorer sexual function and less satisfaction. Forty-nine percent of subjects indicated that the sexual education they received at puberty was useful; however, 32 percent lacked knowledge about their sexual functioning with regard to their disability. **CONCLUSION:** There is a need for further sexual education and counselling for adults with spina bifida in order to improve their sexuality and quality of life.

Bramanti, P., Calabrò, R.S., Conti-Nibali, V., De Luca, R., Leo, A., & Reitano, S. (2014). **Sexual dysfunction in male patients with multiple sclerosis: A need for counseling!** *The International Journal of Neuroscience*, 124(8), 547-57.

PMID: 24219384

ABSTRACT: Sexuality and sexual health are significant factors in determining the quality of life (QoL). Multiple sclerosis (MS) is one of the most serious causes of neurological disability in young adults, therefore it can considerably reduce sexuality. Physical and cognitive symptoms of MS as well as mental and psycho-social issues can directly affect sexual life and body representation, causing reduced libido and self-esteem. Male patients with MS frequently develop sexual dysfunction (SD) as a result of their neurological impairment: in fact physical, psychological and neuropsychological changes indirectly interfere in the sexual response. Thus, MS physicians' greater concern on SD has led to the enhancement of diagnostic and therapeutic diagnoses on neurogenic SD. Given the increasing number of people coping with MS, a more effective focus on MS-related problems, including SD, is absolutely essential to provide

the patients and their partner with the necessary information to achieve a better sexual health and consequently improve their QoL. This review aims to investigate the epidemiology and pathophysiology of SD in male patients, provide an insight into multidisciplinary diagnostic and therapeutic approaches, and focus on the need of proper counseling.

Chapple, A., Prinjha, S., & Salisbury, H. (2014). **How users of indwelling urinary catheters talk about sex and sexuality: A qualitative study.** *The British Journal of General Practice*, 64(623), e364-71.

PMID: 24868074

Available in full-text at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4032019/pdf/bjgpjun2014-64-623-e364.pdf>.

ABSTRACT: BACKGROUND: An indwelling urinary catheter can solve the problem of incontinence and may be life-saving in individuals with retention, but it can cause problems such as infection and may have a negative impact on body image, sex, and sexuality. **AIM:** To explore the individual's perceptions of how a long-term urinary catheter can affect body image, sex, and sexuality; and to help GPs to discuss the subject in consultations. **DESIGN AND SETTING:** Qualitative study of a diverse sample of individuals living with a long-term urinary catheter. Interviews took place all over the UK, usually in the individuals' homes. **METHOD:** Narrative interviews were audio recorded, transcribed, and analysed thematically, using the constant comparative method. **RESULTS:** Some individuals said that sex was not an important part of their lives because of old age, illness, or the catheter. Others talked about how their catheter and their disability affected their sexual self-esteem, feelings of masculinity or femininity, and how the catheter caused pain, discomfort, or unexpected symptoms during sex. Many noted the lack of information on the subject and also said that health professionals were reluctant to talk about sex. For a minority a catheter was not a major problem in relation to sex. **CONCLUSION:** Some individuals using a urinary catheter would benefit from information on how to have a sexual relationship with a catheter in place and a chance to discuss the subject with their doctors. GPs need to be aware that sex may matter to a person with a catheter and how illness, disability, and a catheter may affect sexuality.

Chappell, P. (2014). **How Zulu-speaking youth with physical and visual disabilities understand love and relationships in constructing their sexual identities.** *Culture, Health, & Sexuality*, 16(9), 1156-68.

PMID: 25036419

ABSTRACT: Popular socio-medical discourses surrounding the sexuality of disabled people have tended to subjugate young people with disabilities as de-gendered and asexual. As a result, very little attention has been given to how young people with disabilities in the African context construct their sexual identities. Based on findings from a participatory research study conducted amongst Zulu-speaking youth with physical and visual disabilities in Kwa-Zulu-Natal, this paper argues that young people with disabilities are similar to other non-disabled youth in the way they construct their sexual identities. Using a post-structural framework, it outlines how the young participants construct discursive truths surrounding disability, culture and gender through their discussions of love and relationships. In this context, it is argued that the sexual identities' of young people with physical and visual disabilities actually emerges within the intersectionality of identity discourses.

Fernandes, A.K., & Fernandes, E.K. (2014). **The demands of human dignity: Sexuality in the young person with intellectual disabilities.** *The Linacre Quarterly*, 81(4), 343-62.

PMID: 25473132

Available in full-text at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4240058/pdf/lnq-81-343.pdf>.

ABSTRACT: The topic of sexuality among the disabled is often ignored within Catholic seminaries; within pediatrics, it is treated as a "problem" where the best solution is contraception or sterilization. In this article, the authors argue for an approach to sexuality in disabled youth that is grounded in the inherent dignity of the person, borne out of Christ's own humanity. Because sexuality is a part of the human person in his or her totality, it cannot be ignored or obscured; on the other hand, it cannot also be the overriding "problem" which defines them. Rather, by friendship, love, and covenantal solidarity with the disabled person, we can begin to set an example for them and for society that there are goods to be

strived for beyond the physical. The demands of dignity require practical changes in seminary and medical education and practice.

Lew-Starowicz, M., & Rola, R. (2014). **Sexual dysfunctions and sexual quality of life in men with multiple sclerosis.** *The Journal of Sexual Medicine*, 11(5), 1294-301.

PMID: 24612517

ABSTRACT: **INTRODUCTION:** Multiple sclerosis (MS) is one of the most frequent diseases of the central nervous system and usually occurs at the age when people would be expected to be in the prime of their sexual lives. Clinicians working in this field commonly concentrate on the classical neurological deficits and often overlook symptoms that seriously affect the quality of life, such as sexual dysfunction (SD). Sexual functioning of MS patients remains poorly understood. **AIM:** The aim of this study was to assess the prevalence of SDs, their relationship with demographic factors, and sexual quality of life in men with multiple sclerosis (MS). **METHODS:** Sixty-seven patients from the National Multiple Sclerosis Center were interviewed, completed the questionnaires, and underwent neurological assessment. **MAIN OUTCOME MEASURES:** Primary outcome measures included the International Index of Erectile Function (IIEF), the Sexual Quality of Life Questionnaire (SQoL), and the Expanded Disability Status Scale (EDSS). **RESULTS:** The most common complaints were erectile dysfunction (52.9 percent), decreased sexual desire (26.8 percent), and difficulties in reaching orgasm (23.1 percent) or ejaculation (17.9 percent). The severity of SD had a clear impact on sexual quality of life, especially in the domains of erectile function and intercourse satisfaction. However, neither IIEF nor SQoL scores were correlated with age, time since onset of MS symptoms, or EDSS scores. Only 6 percent of the patients had ever discussed their concerns with a medical professional or undergone sexual therapy. **CONCLUSIONS:** SD is highly prevalent but commonly overlooked in MS patients and has a significant impact on their sexual quality of life. The data support a multifactorial etiology of SD in MS. More focus on SD and use of appropriate screening tools in clinical practice with MS patients are recommended.

Murray, C., Rushbrooke, E., & Townsend, S. (2014). **The experiences of intimate relationships by people with intellectual disabilities: A qualitative study.** *Journal of Applied Research in Intellectual Disabilities: JARID*, 27(6), 531-41.

PMID: 24478268

ABSTRACT: **BACKGROUND:** People with intellectual disabilities face attitudinal and service barriers when attempting to form intimate relationships. To date, their experiences and views are under-represented in the existing evidence base. **METHOD:** The aim of this study was to carry out an interpretative phenomenological analysis exploring the experience of intimate relationships for nine adults with intellectual disabilities. **RESULTS:** Four main themes were identified: desiring relationships; expressing sexuality; having relationships; and who has control? Together these themes demonstrated that intimate relationships were desired and important to all participants, fulfilling a variety of their needs. In addition, participants faced a number of challenges related to intimate relationships. **CONCLUSION:** The findings raise questions about how best to support people with intellectual disabilities with sexuality and intimate relationships. Implications for caregivers and services are discussed.

Sevène, A. (2014). **[Sexual function, physical handicap].** *La Presse Médicale*, 43(10 Pt 1), 1116-9. [Article in French].

PMID: 25087114

ABSTRACT: While the right to a sexual life for disabled people is not contested, their sexuality cannot be summed up in a debate for or against sexual assistance. In a similar way, sexual function can only be understood in light of all the difficulties related to disability. Medical progress can improve sexual function and solve many problems in order to facilitate access to procreation. However, these are not well known and are reserved to specialized teams. Many disabled persons are totally autonomous in their sexuality, but for some who require medical assistance, it is necessary to support them in a process of creation where therapeutic interventions consist of facilitating or stimulating the patient's own resources.

Tristano, A.G. (2014). **Impact of rheumatoid arthritis on sexual function.** *World Journal of Orthopedics*, 5(2), 107-11.

PMID: 24829873

Available in full-text at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4017303/pdf/WJO-5-107.pdf>.

ABSTRACT: Sexuality is a complex aspect of the human being's life and is more than just the sexual act. Normal sexual functioning consists of sexual activity with transition through the phases from arousal to relaxation with no problems, and with a feeling of pleasure, fulfillment and satisfaction. Rheumatic diseases may affect all aspects of life including sexual functioning. The reasons for disturbing sexual functioning are multifactorial and comprise disease-related factors as well as therapy. Rheumatoid arthritis (RA) is a chronic inflammatory autoimmune disease characterized by progressive joint destruction resulting from chronic synovial inflammation. It leads to various degrees of disability, and ultimately has a profound impact on the social, economic, psychological, and sexual aspects of the patient's life. This is a systemic review about the impact of RA on sexual functioning.

2013

Atkinson, J.P., Smith, C.A., Ward, K.M., & Windsor, R. (2013). **A friendships and dating program for adults with intellectual and developmental disabilities: A formative evaluation.** *Intellectual and Developmental Disabilities*, 51(1), 22-32.

PMID: 23360406

Available in full-text at <http://aaidjournals.org/doi/pdf/10.1352/1934-9556-51.01.022>.

ABSTRACT: Meaningful relationships with others are often elusive for people with intellectual and developmental disabilities, but no less desired for their full inclusion and participation in society. It is well documented that people with disabilities are victims of interpersonal violence at higher rates than peers without disabilities. This article presents a formative evaluation of the Friendships and Dating Program (FDP). The FDP was designed to teach the social skills needed to develop healthy, meaningful relationships and to prevent violence in dating and partnered relationships. Thirty-one adults were

recruited by 5 community agencies in Alaska to participate. The results showed the size of the participants' social networks increased and the number of incidents of interpersonal violence was reduced for participants who completed the FDP, and outcomes were maintained 10 weeks later.

Bernert, D.J., & Ogletree, R.J. (2013). **Women with intellectual disabilities talk about their perceptions of sex.** *Journal of Intellectual Disability Research*, 57(3), 240-9.

PMID: 23379861

ABSTRACT: **BACKGROUND:** Sexuality is learned through sexual socialisation that women with intellectual disabilities (IDs) understand and express. Rules of sexual engagement for these women can include barriers for their socialisation, intimate partner selection, and sexual expression. These rules can become more limiting when coupled with rules of femininity that encourage sexual restraint for women. **METHODS:** This ethnography explored how women with IDs perceived their sexuality and how sexuality functioned in their lives. Sources of data included 48 multiple and in-depth interviews and observations with 14 women. This article specifically describes how the women constructed 'sex' and how they described experiencing sex as two of their multiple expressions of sexuality in this study. **RESULTS:** Most of the women had very limited and exclusively heterosexual sexual experiences, and the majority of women reported practicing abstinence. Criteria they identified for sex included having protected sex, marital and monogamous sex for the purpose of procreation or parenting, and having feelings for a sexual partner. Most held negative perceptions of sex they attributed to fear of the first act, fear of experiencing negative consequences, physiological concerns about the act, and perceived or actual lack of pleasure. **CONCLUSIONS:** Although the women displayed some sense of self-determinism in their sexual behaviour, negative perceptions of sex resulted in self-imposed abstinence predicated by fear of intercourse, intimacy, or outcome. Central to their sexuality education then is increasing self-efficacy perceptions and performance of safer sex practices to prevent negative sexual consequence. Sexuality education from a positive perspective that enhances their sexual self-determinism and encourages sexual health is recommended.

Bowden, K., McKenzie, K., Quayle, E., & Sullivan, F. (2013). **'Touching people in relationships': A qualitative study of close relationships for people with an intellectual disability.** *Journal of Clinical Nursing*, 22(23-24), 3456-66.

PMID: 24118608

ABSTRACT: **AIMS AND OBJECTIVES:** To explore the experiences and perceptions of close and sexual relationships of people with an intellectual disability. **BACKGROUND:** Positive interpersonal relationships are beneficial for people with an intellectual disability, acting as a protective barrier against, social stigma and negative outcomes such as physical and mental health problems. The social networks of people with an intellectual disability are, however, often more restricted than those of the general population. There has been very little research exploring the views and experiences of people with an intellectual disability about social and sexual relationships. **DESIGN:** Exploratory study using a qualitative research design. **METHODS:** Semi-structured interviews were conducted with 10 (6 male, 4 female) participants. Data were analysed using interpretive phenomenological analysis. **RESULTS:** 'Touching other people in relationships' was identified as a superordinate theme. The theme was represented by five subthemes: 'Is wrong'; 'Unsafe to talk about'; 'Suggesting is safe'; 'No freedom or fun'; and 'Being touched'. The findings presented are drawn from a larger qualitative study. **CONCLUSIONS:** The findings highlight the importance of touch and sexual behaviours in the close relationships of participants. Negative perceptions were observed to surround sexual behaviours. Rules and restrictions regarding physical contact were also described. **RELEVANCE TO CLINICAL PRACTICE:** Disseminating these findings may increase awareness of the importance of physical contact in the close relationships of people with an intellectual disability and promote positive support arrangements.

Dekker, R., Dijkstra, P.U., Enzlin, P., Geertzen, J.H., Verschuren, J.E., & Zhdanova, M.A. (2013). **Let's talk about sex: Lower limb amputation, sexual functioning and sexual well-being: A qualitative study of the partner's perspective.** *Journal of Clinical Nursing*, 22(23-24), 3557-67.

PMID: 24580794

ABSTRACT: **AIMS AND OBJECTIVES:** To describe the impact of patients' lower limb amputations

on their partners' sexual functioning and well-being. **BACKGROUND:** Annually, about 3300 major lower limb amputations are performed in the Netherlands. An amputation may induce limitations in performing marital activities, including expression of sexual feelings between partners. However, up until now, little attention has been paid towards this aspect in both research and clinical practice. The lack of studies on sexual activities and lower limb amputation is even more apparent with respect to partners of patients with such an amputation. Previous studies have shown, however, that the presence of a disease or disability may have a large impact not only on the patient's but also on the partner's sexual activities. **DESIGN:** Qualitative thematic analysis. **METHODS:** Semi-structured interviews. The questions used in the interview were inspired by a generic framework about chronic disease and sexual functioning and well-being. In total, 16 partners of patients with a lower limb amputation who were at least 18 years old were recruited in different rehabilitation centres. **RESULTS:** Seven major themes (i.e. importance of sexuality, thoughts about sexuality before the amputation, changes in sexual functioning and sexual well-being, amputation as the main cause of these changes, acceptance of the amputation, role confusion and communication about sexuality) were derived from the interviews. Minor changes in sexual functioning and sexual well-being were reported by the participants. Problems participants did encounter were solved by the couples themselves. For some participants, their sexual well-being improved after the amputation. **CONCLUSION AND RELEVANCE TO CLINICAL PRACTICE:** Participants in our study reported minor changes in their sexual well-being. Most of them indicated that communication about the changes expected and how to cope with these would have been helpful. It is therefore important that professionals address sexuality during the rehabilitation process with patients and partners.

Kijak, R. (2013). **The sexuality of adults with intellectual disability in Poland.** *Sex and Disability*, 31(2), 109-123.

PMID: 23704799

Available in full-text at https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3659277/pdf/11195_2013_Article_9294.pdf.

ABSTRACT: Sexuality is one of the most important aspects of human life that relates to sex, one's identification, sexual role, sexual preferences, eroticism, pleasure and intimacy. It fulfils such functions as procreative, hedonistic and relationship-building as well as constitutes an integral part of human's personality. The sexuality of people with intellectual disability is a special case - both from medical, pedagogical, psychological and ethical point of view. Little available research shows that it may become a significant factor that modifies their psychological and sexual functioning. The basic poll involved altogether 133 people with mild intellectual disability. The work was carried out in 11 schools and special institutions of three provinces in Poland: kujawsko - pomorskie, wielkopolskie and dolnoslaskie (provinces of Kujawy and Pomerania, Great Poland and Lower Silesia) The respondents qualified to take part in the poll constituted a very uniform group - homogenous as regards their age of 18-25 as well as IQ level that was average for the people with higher degree of intellectual disability (HDID). Their age was of importance as in that life period one can observe the formation of first partner relationships with the clear aim of establishing a family. It is accompanied by a quick development of sexual desire and taking up various forms of sexual activity. People with intellectual disability don't form a homogenous group as regards their psychological and sexual development. In this group, one can observe both different forms of clinical mental handicap which definitely affects the whole process of sexual development. The sexual development is delayed by an average period of 3 years. The people with intellectual disability take up mostly autoerotic behaviour whereas partner relationships within that group are more seldom. The phenomenon of sexuality of people with higher degree of intellectual disability is an issue that needs further constant analysis. The research has also made it possible to detect what kind of sexual behaviour people with intellectual disability undertake and the value of sexuality for such people. The article deals also with some important dilemmas connected with sexual education and what factors trigger off incorrect sexual reaction including their lack in the above mentioned group.

McKenzie, J.A. (2013). **Disabled people in rural South Africa talk about sexuality.** *Culture, Health & Sexuality*, 15(3), 372-86.

PMID: 23227824

ABSTRACT: Disability is emerging as a human rights issue of public concern, rather than an individual tragedy requiring medical attention. The issue of sexuality remains relatively neglected in this agenda, particularly as regards the exploration of the complexities of sexuality encountered by disabled people themselves. This paper focuses on the experiences of sexuality of disabled people and parents of disabled children in settings of poverty in the Eastern Cape Province of South Africa. Three individual interviews and two focus groups were conducted with disabled adults and parents of disabled children. Thematic analysis of the interviews identified three principal themes (1) sexuality development in the family of origin, (2) sexuality in the community and (3) adult sexuality and creating families. Each of these larger themes encompasses various sub-themes that are discussed in the findings. The paper concludes that while sexuality is a very difficult aspect of life for a disabled person due to myths and discrimination against disabled people, it is also an important arena for affirmation and establishing self-worth. It is therefore critical to consider the development of a healthy sexuality amongst disabled people and the promotion of their sexual rights.

Parchomiuk, M. (2013). **Model of intellectual disability and the relationship of attitudes towards the sexuality of persons with an intellectual disability.** *Sexuality and Disability*, 31(2), 125-139.

PMID: 23704800

Available in full-text at https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3659271/pdf/11195_2012_Article_9285.pdf.

ABSTRACT: The following article discusses the relationship between the model of intellectual disability and the attitudes towards sexuality of people with disabilities. This correlation has been verified during the author's own research conducted on students of several medical faculties such as nursing, public health, emergency medical services and physiotherapy. Tools of the author's design have been used in the research. Likert-type scale "Per-

spective of intellectual disability" has been used to determine the model of disability seen from the medical (individual) or social perspective. To examine the attitudes towards sexuality two tools of the author's own design have been used: a Likert-type scale "The essence of sexuality in persons with an intellectual disability" which has been used to analyze the cognitive aspect of the attitudes, and a semantic differential with notions concerning physical and psychosocial aspects of sexuality including the affective-evaluative aspect. As expected, significant correlations have been found between the model and the attitudes both in the cognitive and the affective-evaluative aspect. Higher scores for the individual model correlated with: (a) lower scores for most aspects of sexuality of people with intellectual disability, (b) perceiving them as asexual, (c) biological determinism in the sexual sphere. The social model concurred with positive values given to sexuality of people with intellectual disability and its normalization in the sphere of its determinants and symptoms.

2012

Bertholon, D.R., Combe, B., Kobelt, G., Maugars, Y., Mimoun, S., Perdriger, A., Texier-Richard, B., & Woronoff, A.S. (2012). **Rheumatoid arthritis and sexuality: A patient survey in France.** *BMC Musculoskeletal Disorders*, 13, 170.

PMID: 22963081

Available in full-text at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3493389/pdf/1471-2474-13-170.pdf>.

ABSTRACT: BACKGROUND: The objective of this study was to evaluate the impact of rheumatoid arthritis (RA) on patients' sexuality and identify disease and other factors such as fatigue that most influence sexual relationships. METHODS: A specific pretested questionnaire was sent to all members of a French patient association (ANDAR). Questions related to demographics, disease status, quality of life (utility, EQ-5D), pain, psychological status (mood), fatigue and emotional and sexual relationships. To isolate the impact of RA, an attempt was made to include a matched sample from the general population. RESULTS: The analysis included 1271 patients, but only 70 controls agreed to participate and comparisons should therefore be considered with caution.

The two groups were similar in terms of age, gender distribution, living conditions and diseases other than RA. However, patients scored worse for global health, mood, fatigue, had a lower utility (0.55 versus 0.65). Controls were more active sexually (69 percent versus 63 percent), in particular women (71 percent versus 60 percent). Age, gender, living alone, physical function and mood were significant predictors for being sexually active for patients; for controls, age and overall quality of life (utility) were significant predictors. **CONCLUSIONS:** While it is known that RA has a negative impact on patients' sexuality, there have been few attempts to quantify the problem. Our study highlights the negative impact of RA on patients' sexuality, and triggers the question how to include this aspect into care.

Flanagan, P., Higgins, A., McDonnell, S., Nolan, M., Sharek, D., Sheerin, B., Slaicuinaite, S., & Walsh, H. (2012). **Mixed methods evaluation of an interdisciplinary sexuality education programme for staff working with people who have an acquired physical disability.** *Journal of Advanced Nursing*, 68(11), 2559-69.

PMID: 22348747

ABSTRACT: **AIM:** To report a study evaluating the effectiveness of a 1-day interdisciplinary sexuality education programme for staff working with people with acquired physical disability. **BACKGROUND:** Changes associated with an acquired physical disability can diminish a person's self-esteem, sense of attractiveness, relationships, and sexual functioning. Research suggests that people are dissatisfied with the quality of information and support around sexuality during their rehabilitation. **DESIGN:** A mixed methods design was used, involving pretest and posttest questionnaires and interviews. **METHODS:** Questionnaire data were analysed using descriptive statistics and paired samples t-tests to evaluate the effects of the programme on knowledge, skills, and comfort. Interview data were analyzed thematically, with particular emphasis on participants' opinions about the application of the course within practice. Participants were working in the area of acquired disability and rehabilitation, and were drawn from a number of disciplines. Data was collected between 2008 and 2009. **RESULTS:** Comparison of the pre- and post-measures, based on paired samples t-tests,

showed that the programme statistically significantly increased participants' knowledge, skills, and comfort. Participants felt positive and enthusiastic about the programme and reported numerous incidents where they were more willing to raise issues for discussion and create a supportive listening space for patients to talk about their concerns around sexuality. **CONCLUSION:** Providing healthcare practitioners with a 1-day programme leads to positive changes in knowledge, skills, and comfort towards sexuality. Sexuality education may be an ideal topic for bringing practitioners together within an interdisciplinary education context.

Gore, N., McCarthy, M., & Young, R. (2012). **Staff attitudes towards sexuality in relation to gender of people with intellectual disability: A qualitative study.** *Journal of Intellectual & Developmental Disability*, 37(4), 343-7.

PMID: 22852868

ABSTRACT: **BACKGROUND:** Research has found staff attitudes regarding the sexuality of people with intellectual disability (ID) to be negative but influenced by several factors. The current study aimed to examine whether gender of people with ID affects such attitudes. **METHOD:** Semistructured interviews were completed with 10 staff members and analysed using thematic analysis. **RESULTS:** Results indicated 3 themes: Women are perceived as sexually innocent, men as more sexually motivated, and motivations for sexual relationships are perceived to differ between men and women with ID. **CONCLUSION:** The study indicates unfavourable attitudes towards sexuality in individuals with ID that correlate with traditional, restricted gender stereotypes. The identification of these themes highlights the importance of considering gender when supporting the sexuality of people with ID.

Gavidia-Payne, S., & Meaney-Tavares, R. (2012). **Staff characteristics and attitudes towards the sexuality of people with intellectual disability.** *Journal of Intellectual & Developmental Disability*, 37(3), 269-73.

PMID: 22838968

ABSTRACT: **BACKGROUND:** The identification of individual staff characteristics that have a relationship with specific attitudes of staff caring for

people with intellectual disability (ID) may enable targeted training and better support. **METHOD:** Sixty-six participants from services for people with ID in metropolitan Melbourne, Australia, completed a survey, including the Attitudes to Sexuality Questionnaire (Individuals with an Intellectual Disability; Cuskelly & Gilmore, 2007). **RESULTS:** Staff attitudes towards the sexuality of people with ID were quite positive. Age, program agency position, and training uptake were all associated with positive staff attitudes. **CONCLUSION:** Targeted training programs in sexuality can benefit direct care workers in general, and older staff more specifically. Emphasis is warranted in the area of training for managing male sexual behaviours.

Hardoff, D. (2012). **Sexuality in young people with physical disabilities: Theory and practice.** *Georgian Medical News*, 210, 23-6. [Article in English, Georgian].

PMID: 23045416

ABSTRACT: Sexuality and sexual function are important to persons with disabilities just as they are to their able-bodied counterparts, but knowledge about sexual and reproductive health (SRH) among persons with disabilities is frequently inadequate. Adolescents and young adults with physical disabilities are less active socially, and have difficulties in developing intimate relationships. Thus, despite greater needs for SRH education and service delivery than persons without disabilities, dedicated services regarding sexuality and physical disabilities are scantily reported. Together with a literature survey on sexuality and disability in adolescents, a unique comprehensive SRH service for young people with physical disabilities is described in this review. Despite being interdisciplinary, the utilization of the service was limited due to difficulties in transportation to the clinic and in finding escort for aid in accessibility to public transportation. Health authorities should provide the resources for the development of accessible comprehensive multidisciplinary SRH services dedicated to young people with disabilities, and thus fulfill the United Nations General Assembly declaration on the rights of persons with disabilities.

2011

Bayley, A.A., & McGuire, B.E. (2011). **Relationships, sexuality, and decision-making capacity in people with an intellectual disability.** *Current Opinion in Psychiatry*, 24(5), 398-402.

PMID: 21778882

ABSTRACT: PURPOSE OF REVIEW: The current review attempts to summarize the current status of our knowledge and clinical practice in the complex and challenging area of relationships and sexuality for people with an intellectual disability. **RECENT FINDINGS:** Although there has been an ideological shift within services for people with an intellectual disability towards person-centredness and inclusivity, this change has not manifested in an obvious way at the practice level in the area of relationships and sexual expression. Recent surveys of caregivers and service providers do show a greater awareness of the fact that sexuality is a central part of personal identity, yet generally restrictive or prohibitive attitudes prevail at both individual and organizational levels. These attitudes appear to reflect a fear of possible legal sanction as well as ethical and moral conflicts. The views and experiences of people with an intellectual disability generally confirm this impression that, whereas some small changes have taken place, the prevailing experience is of restriction. Whereas there is now an abundance of sexuality and relationship educational programmes available, they require more rigorous and systematic evaluation both in terms of their effectiveness for enhancing knowledge and, more importantly, for examining the impact of that education on behaviour and capacity to make sexuality-related decisions, which we know to be a fluid ability. **SUMMARY:** There is a need for greater education of caregivers and a need for discussion of the complex issues regarding relationships and sexuality at a societal and policy level. The development of self-advocacy in disability services provides a vehicle to operationalize the changing service ideologies in a way that provides greater opportunities for enriching relationship experiences whilst also preventing undue risk of harm. However, successful self-advocacy requires organizational support, and this remains the greatest challenge for service providers.

Bennett, B., FolCan study group, Friedlander, M., Goldstein, D., Juraskova, I., Lloyd, A.R., Mok, K., & Webber, K. (2011). **If I am in the mood, I enjoy it: An exploration of cancer-related fatigue and sexual functioning in women with breast cancer.**

The Oncologist, 16(9), 1333-44.

PMID: 21835897

Available in full-text at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3228173/pdf/onc1333.pdf>.

ABSTRACT: **BACKGROUND:** We recently reported that cancer-related fatigue (CRF) after adjuvant breast cancer therapy was prevalent and disabling, but largely self-limiting within 12 months. The current paper describes sexual functioning (SF) and its relationship to CRF, mood disorder, and quality of life (QOL) over the first year after completion of adjuvant therapy. **METHODS:** Women were recruited after surgery, but prior to commencing adjuvant treatment, for early-stage breast cancer. Self-reported validated questionnaires assessed SF, CRF, mood, menopausal symptoms, disability, and QOL at baseline, completion of therapy, and at 6 months and 12 months after treatment. **RESULTS:** Of the 218 participants, 92 (42 percent) completed the SF measure (mean age, 50 years). They were significantly younger, more likely to be partnered, and less likely to be postmenopausal than nonresponders. At baseline, 40 percent reported problems with sexual interest and 60 percent reported problems with physical sexual function. SF scores declined across all domains at the end of treatment, then improved but remained below baseline at 12 months, with a significant temporal effect in the physical SF subscale and a trend for overall satisfaction. There were significant correlations between the SF and QOL domains (physical and emotional health, social functioning, and general health) as well as overall QOL. The presence of mood disorder, but not fatigue, demographic, or treatment variables, independently predicted worse overall sexual satisfaction. **CONCLUSIONS:** Sexual dysfunction is common after breast cancer therapy and impacts QOL. Interventions should include identification and treatment of concomitant mood disorder.

Bramanti, P., Calabrò, R.S., & Gervasi, G. (2011). **Male sexual disorders following stroke: An overview.** *The International Journal of Neuroscience*, 121(11), 598-604.

PMID: 21790509

ABSTRACT: Stroke is one of the leading causes of death and disability throughout the world. Although physical and cognitive impairments after stroke have been well studied, little information is known about one of the crucial aspect of the quality of life of stroke patients, namely, sexual functioning and satisfaction. Post-stroke sexual dysfunctions seem to be very common since in men affected by stroke, a decline in libido and poor or tailed erection and ejaculation are frequently observed. Sexual disorders after stroke are thought to be due to multiple etiologies, including both organic (i.e., lesion localization, premorbid medical conditions, and medications) and psychosocial (i.e., fear of recurrences, loss of self-esteem, role changes, anxiety, and depression). Thus, exploration in sexual dysfunctions and sexual counseling by trained professionals should be a part of stroke rehabilitation. The aim of this review is to evaluate the burden of stroke on sexual function taking into account the complex interaction between neurological, psychological, and relational factors.

Di Nucci, E. (2011). **Sexual rights and disability.** *Journal of Medical Ethics*, 37(3), 158-61.

PMID: 21059634

ABSTRACT: This paper argues against Appel's recent proposal-in this journal-that there is a fundamental human right to sexual pleasure, and that therefore the sexual pleasure of severely disabled people should be publicly funded-by thereby partially legalising prostitution. An alternative is proposed that does not need to pose a new positive human right; does not need public funding; does not need the legalisation of prostitution; and that would offer a better experience to the severely disabled: charitable non-profit organisations whose members would voluntarily and freely provide sexual pleasure to the severely disabled.

Eastgate, G. (2011). **Sex and intellectual disability: Dealing with sexual health issues.** *Australian Family Physician, 40*(4), 188-91.

PMID: 21597526

ABSTRACT: **BACKGROUND:** Sexual health is a vital but often neglected aspect of healthcare for people with intellectual disability. It may initially be difficult for the general practitioner to raise sexuality issues with patients with intellectual disability, but there is potential for simple interventions that offer great benefit. **OBJECTIVE:** This article describes ways in which the GP may be able to assist people with an intellectual disability with their sexual health needs. **DISCUSSION:** It is important to engage the person with intellectual disability directly, preferably alone. A person with intellectual disability is likely to have the same range of sexual and relationship needs as other adults. However, there may be multiple barriers to forming healthy, equal sexual relationships. Sexual abuse is widespread. Reporting abuse may be difficult for a person with limited verbal skills, and prevention and support services are limited. The GP is well placed to offer sexual health services such as information, contraception and cervical and sexually transmissible infection screening, and to discourage inappropriate treatments such as sterilisation for social rather than medical reasons, and androgen suppression.

El Miedany, Y., & Palmer, D. (2011). **Sexual dysfunction in rheumatoid arthritis: A hot but sensitive issue.** *British Journal of Nursing, 20*(17), 1134-7.

PMID: 22067584

ABSTRACT: Rheumatoid arthritis (RA) has considerable personal impact for sufferers and their families. Those with RA suffer from pain, restricted joint movements, and fatigue, and can have problems with self-esteem and body image. It is also possible that medication causes sexual problems. Research on the subject is limited, and shows a divergent picture. Assessment for sexual dysfunction in clinical practice might be another hurdle, as patients and health professionals are reluctant to discuss this issue face to face. The aim of the work carried out and described in this article was to study the possibility of implementing sexual dysfunction assessment into standard rheumatology clinical practice. Results re-

vealed that the multidimensional patient-reported outcome measures questionnaire offered the opportunity to assess the disease activity parameters, functional disability, quality of life, sexual dysfunction, and self-helplessness in one format. The patients appeared willing to complete questionnaires and this may be an acceptable tool for assessment. Improving patient education, as well as nurse-patient communication, through discussions about available options may minimize patients' feelings of isolation in addressing the problem and could help compensate for negative effects resulting from the disease.

Gill, C.J., Mazzei, D.K., Robins, N., Sander, A.M., & Struchen, M.A. (2011). **Exploring experiences of intimacy from the viewpoint of individuals with traumatic brain injury and their partners.** *The Journal of Head Trauma Rehabilitation, 26*(1), 56-68.

PMID: 21209563

ABSTRACT: **OBJECTIVE:** To explore qualitatively the experience of intimacy from the viewpoint of persons with traumatic brain injury (TBI) and their intimate partners. **DESIGN:** Qualitative interview study. **SETTING:** Outpatient community. **PARTICIPANTS:** Eighteen persons with TBI and their intimate partners at a mean length of 4.78 years post-injury. **MAIN MEASURES:** Open-ended, semistructured, in-depth interviews regarding participants' experience of intimacy, factors impacting intimacy, and need for services. **RESULTS:** Factors that were perceived as helping relationships remain strong included unconditional commitment, spending time together, open communication, a strong preinjury relationship, bonding through surviving the injury together, social support, family bonds, spirituality, experience with overcoming hardship, and coping skills. Factors that were perceived as barriers to intimacy included injury-related changes, emotional reactions to changes, sexual difficulties, role conflict and strain, family issues, social isolation, and communication issues. **CONCLUSIONS AND IMPLICATIONS:** Education regarding the impact of TBI on intimacy should be integrated into rehabilitation. Health professionals should be sensitized as to the needs that persons with TBI and their partners have regarding intimacy and how to make appropriate referrals to assist them.

Julia, P.E., & Othman, A.S. (2011). **Barriers to sexual activity: Counselling spinal cord injured women in Malaysia.** *Spinal Cord*, 49(7), 791-4. PMID: 21321578

Available in full-text at <http://www.nature.com/sc/journal/v49/n7/pdf/sc20114a.pdf>.

ABSTRACT: **STUDY DESIGN:** This study is a cross-sectional, face-to-face interview. **OBJECTIVES:** To examine the sexual activity in a sample of Malaysian women with traumatic spinal cord injuries (SCIs), identify the physical and psychological barriers to it, and explore their experiences with sexual counseling and rehabilitation. **SETTING:** This study was conducted at the Spinal Rehabilitation Unit of a teaching hospital. **METHODS:** All women who attended scheduled check-ups, over 1 year, and who met the inclusion criteria (age above 18 years, spinal injury of traumatic etiology, living in the community and having completed the rehabilitation) were consecutively included in a face-to-face interview using a self-constructed questionnaire. Sociodemographic and disability-related variables, barriers to sexual activity/satisfaction and experiences of sexual rehabilitation services were obtained. **RESULTS:** During the study period, 33/36 subjects were recruited. Although 67 percent indicated interest in sexual activity, only 24 percent was sexually active. The frequency of sexual activity declined after the injury, from 4.6 times per month to 1.5 times per month. Feeling unattractive, unable to satisfy the partner and less confident about sexual ability were top three psychological barriers to sexual activity, and the top three physical barriers were impaired genital sensation, positioning and vaginal lubrication. In all, 50 percent received some sexual information during rehabilitation. Rehabilitation professionals were expected to initiate sexual counseling by 62.5 percent of subjects. **CONCLUSION:** The effect of SCIs on sexual function is tremendous. Sexual counseling services must be improved and take into account the impact of psychological factors.

Kijak, R.J. (2011). **A desire for love: Considerations on sexuality and sexual education of people with intellectual disability in Poland.** *Sexuality and Disability*, 29(1), 65-74. PMID: 21423325

Available in full-text at https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3034884/pdf/11195_2010_Article_9184.pdf.

ABSTRACT: This article is intended to attract public attention to the fact that people with intellectual disability, despite their delayed sexual development, still remain sexual beings, which is connected with many individual and social consequences. The empirical data collected in this work provides knowledge about biological and psychological conditioning of sexual development of individuals with intellectual disability. However, the problem of sexuality for this population should be further analyzed. One should also think about the possibility of supporting the psychological and sexual development of people with more severe intellectual disability.

2010

Appel, J.M. (2010). **Sex rights for the disabled?** *Journal of Medical Ethics*, 36(3), 152-4. PMID: 20211994

ABSTRACT: The public discourse surrounding sex and severe disability over the past 40 years has largely focused on protecting vulnerable populations from abuse. However, health professionals and activists are increasingly recognising the inherent sexuality of disabled persons and attempting to find ways to accommodate their intimacy needs. This essay explores several ethical issues arising from such efforts.

Chandler, B.J., Gray, W.K., Hand, A., & Walker, R.W. (2010). **Sexual and relationship dysfunction in people with Parkinson's disease.** *Parkinsonism & Related Disorders*, 16(3), 172-6. PMID: 19892579

ABSTRACT: **OBJECTIVES:** To quantify the extent of self-reported sexual and relationship problems in people with Parkinson's disease (PD). **METHODS:** A cross-sectional correlation design was used. All people with idiopathic PD, according to the UK Brain Bank criteria, who were known to the Northumbria Healthcare NHS Trust PD service, were asked to participate. Those who consented were assessed by a research nurse during a six month period using a series of rating scales, including the Unified Parkinson's Disease Rating Scale (UPDRS),

the PD Questionnaire-39, the Mini Mental State Examination (MMSE), the Szasz sexual functioning scale and, for those in long-term relationships, the Golombok Rust Inventory of Marital State. RESULTS: Concern over sexual function was reported in 22 (25 percent) of the 88 participants in the study. Males ($p = 0.001$) and younger people with PD ($p = 0.001$) were significantly more likely to report problems with sexual function. Gender ($p = 0.007$) and UPDRS score ($p = 0.045$) were significant independent predictors of relationship problems. Males with PD and those with increasing functional problems (UPDRS score) were more likely to report problems in their relationship. Disease duration and levels of anxiety and depression (Hospital Anxiety and Depression scale) were not associated with sexual or relationship problems. CONCLUSIONS: Sexual and relationship dysfunction was a problem for many people in this study, but these problems were unlikely to be volunteered unless specifically enquired about. Problems were apparent across all age groups and genders.

Erickson-Davis, C., Paraschos, A.J., Parashos, S.A., Varpness, S.C., & Wielinski, C.L. (2010). **Sexual and relationship satisfaction among persons with young-onset Parkinson's disease.** *The Journal of Sexual Medicine*, 7(4 Pt 1), 1438-44.

PMID: 19656271

ABSTRACT: INTRODUCTION: Parkinson's disease (PD) presents unique personal and social challenges, particularly for those with onset before the age of 50 years. AIM: The aim of this article is to evaluate sexual and non-sexual aspects of relationship satisfaction among persons with young-onset PD and their partners. MAIN OUTCOME MEASURES: The main outcome measures were Index of Sexual Satisfaction (ISS) and Golombok-Rust Inventory of Marital State (GRIMS). METHODS: Persons with PD (PWP) and partners who attended the 2005 National Parkinson Foundation Young Onset Network Conference were asked to complete a survey. Each survey included demographics, a clinical history questionnaire, the Beck Depression Inventory (BDI), ISS, and GRIMS. RESULTS: Sixty PWP (63 percent men, 85 percent in a relationship) responded to the survey. Median age was 50 years (range 29-62), with a median age at symptom on-

set of 43 years (range 17-55). ISS scores indicated clinically significant sexual dissatisfaction in 37 percent. Relationship dissatisfaction measured by the GRIMS was scored as "poor" or worse in 57 percent. Depressive symptomatology was severe in 19 percent and mild in 33 percent. Sexual dissatisfaction (ISS) correlated with relationship dissatisfaction (GRIMS) (correlation coefficient [CC] = 0.58, $P < 0.001$). Relationship dissatisfaction (GRIMS) correlated with depressive symptomatology (BDI) (CC = 0.38, $P = 0.007$). No correlations were found with any demographic or disease characteristics. Thirty-two couples (both the PWP and their partner) completed the surveys. Sexual and relationship dissatisfaction among PWP paralleled that of their partner (ISS: CC = 0.48, $P = 0.005$; GRIMS: CC = 0.61, $P < 0.001$). Depressive symptomatology of the PWP correlated with their partners' relationship dissatisfaction (CC = 0.46, $P = 0.010$). CONCLUSIONS: In this study, sexual and relationship dissatisfaction were prevalent among young-onset PD patients. PD patients were similar to their partners in their level of sexual and relationship dissatisfaction. The degree of dissatisfaction did not correlate with demographics or self-reported disease characteristics. Self-reported depressive symptomatology among PD patients was adversely associated with both their and their partner's relationship satisfaction.

Wiwanitkit, V. (2010). **Management of sexuality problem in quadriplegia: A brief summary.** *Acta Neurologica Taiwanica*, 19(3), 164-7.

PMID: 20824545

ABSTRACT: Quadriplegia is a serious group of spinal disability. Cases with quadriplegia usually present unsatisfactory sexual life. In male, the main problem is the ability to reach orgasm deficient. In female, pregnancy problem should be noted. Management of sexuality problem in quadriplegia is of interest. In this article, the author will briefly review on this topic.

2009

Areskoug-Josefsson, K., Oberg, U. (2009). **A literature review of the sexual health of women with rheumatoid arthritis.** *Musculoskeletal Care*, 7(4), 219-26.

PMID: 19242923

ABSTRACT: Sexual health problems are common for women with Rheumatoid Arthritis, RA. Sexual health is covered in the International Classification of Functioning, Disability and Health (ICF) by two different fields: sexual function and intimate relationships, which are included in the ICF core sets for RA. Most patients with RA are female, and there are differences concerning sexual health between women and men with RA. The aim of this study was to explore the literature concerning the effects of RA on the sexual health of female patients, and also recommend solutions to improve the sexual health of women with RA. Sexual health problems can occur before, during and after sexual activities, and can affect women's sexual health in different perspectives. The investigated areas concerning female RA-patients and sexual are general sexual problems, sexual satisfaction, sexual desire, sexual performance, and sexual functioning. RA affects sexual health as a result of pain, reduced joint mobility, fatigue, depression, and body image alterations. The investigated material provides few solutions to sexual health problems of female RA-patients. The most commonly mentioned solution is increased information and communication between health professionals and patients. Some of the studies recommend physiotherapy. Further research is needed to understand which types of intervention can help women with RA to improve their sexual health.

Cardoso, F.L., Mendes, A.K., & Savall, A.C. (2009). **Self-awareness of the male sexual response after spinal cord injury.** *International Journal of Rehabilitation Research*, 32(4), 294-300.

PMID: 19011580

ABSTRACT: The aim of this study was to assess the impact of spinal cord injury on men's sexual motivation, through the sexual desire self-assessment, and the sexual arousal and orgasm physiological responses. This research consisted of a descriptive, nonprobabilistic and comparative study, designed to

outline the target population characteristics to compare the studied variables. Forty spinal cord injured male patients and a control group composed of 50 able-bodied male individuals filled in a questionnaire that assessed sexual behaviour, functioning and satisfaction. Comparing the control group with the injured group in the post-injury period, there was no significant difference in the sexual desire; however, in relation to sexual arousal and the orgasm intensity, there was a significant difference. The same results were found when comparing the injured participants' preinjury and post-injury period reports. It was clear that the injury significantly reduced sexual arousal among quadriplegic participants and orgasm intensity among both quadriplegic and paraplegic men. The spinal cord injury had a significant impact on sexual arousal and orgasm physiological response, although the sexual desire perception was not significantly altered, indicating that spinal cord injury affects these men's sexual behaviour in terms of sexual performance and body sensitivity.

Castro-Borrero, W., Fletcher, S.G., Frohman, E.M., Lemack, G.E., Remington, G., & Treadaway, K. (2009). **Sexual dysfunction in patients with multiple sclerosis: A multidisciplinary approach to evaluation and management.** *Nature Clinical Practice Urology*, 6(2), 96-107.

PMID: 19198623

ABSTRACT: Multiple sclerosis (MS) is the most common cause of progressive neurological disability in young adults. In addition to spasticity, tremors, weakness, sensory disturbances, depression, cognitive problems, and bladder or bowel dysfunction, sexual dysfunction (SD) is also a prevalent and destructive manifestation of the disease that severely affects quality of life. Evaluation of this disorder requires insight into the primary (changes that directly affect libido, sexual response and orgasm due to direct damage to the nervous system), secondary (complaints which are related to the physical disability of MS, such as fatigue, muscle rigidity, weakness and spasms), and tertiary (emotional, social and cultural aspects of MS) components of MS-associated SD. Given the complexity and multifactorial nature of SD, a multidisciplinary approach is necessary when treating patients with MS. The aim of this Review is to provide a holistic approach to the evaluation

and management of SD in patients with MS, incorporating the latest data from the fields of urology, neurology, nursing, social work, and psychology. What is currently known regarding the evaluation and management of SD in patients with MS will be presented from the perspective of these specialties.

Redelman, M.J. (2009). **Sexual difficulties for persons with multiple sclerosis in New South Wales, Australia.** *International Journal of Rehabilitation Research*, 32(4), 337-47.

PMID: 19440157

ABSTRACT: This 1992 study was conducted to ascertain the incidence of sexual difficulties in individuals diagnosed with multiple sclerosis (MS) living in New South Wales, Australia. New South Wales is a state lying roughly 29-36 degrees south of the equator. This is currently the largest study conducted. The anonymous questionnaire completed by 283 respondents included questions on sexual difficulties, relationship satisfaction and the ability to communicate about and seek help for the sexual difficulties. In this study, 30 percent of respondents claimed to have sexual difficulties attributable to MS. Sexual difficulties were experienced by 51 percent of female and 74 percent of male respondents. For females, the most frequently occurring sexual symptoms were difficulty with achieving orgasm, lowered libido, dissatisfaction with sexual performance, dissatisfaction with frequency of intercourse, arousal difficulties and decreased vaginal lubrication. For males, by far the most common problem was decreased frequency of intercourse, followed by dissatisfaction with sexual performance, masturbation difficulties, difficulty with achieving vaginal orgasms, erectile dysfunctions, retarded ejaculation and premature ejaculation. Overall, females rated their sexual difficulties as 10th in order of importance of disabilities from MS and males ranked sexual difficulties as fourth in importance. For both males and females, sexual disability increased with age, relationship unhappiness and disease disability. Communicating about sexual difficulties was an issue for both males and females. Fifty five percent of males and 39 percent of females had been able to talk about their sexual difficulties and of these, only 29 percent of males and 36 percent of females had been able to access help for their

sexual difficulty. Educational level did not predict ability to talk about, or ability to access help. There was a very low satisfaction rate for the sexual help received. The study highlights areas of need for the MS population.

Tissot, C. (2009). **Establishing a sexual identity. Case studies of learners with autism and learning difficulties.** *Autism*, 13(6), 551-66.

PMID: 19933763

ABSTRACT: The physical and emotional changes that occur in adolescence are part of the process of sexual maturity. These changes occur irrespective of ability and are often aligned with psychological and social factors. When the nature of a disability has an inherent limitation in social awareness, as is the case for individuals with autism, the achievement of personal sexual identity can become much more complex. Challenges in supporting individuals in this respect can be caused by the sensitive aspects of inappropriate behaviour, the abstract nature of teaching the topic, and the general reluctance on the part of parents and staff to discuss sexuality in individuals with disabilities. This article explores how a residential school addressed this gap. It provides details of how this need was met for seven students and the process undertaken to involve staff, parents and other stakeholders to establish ongoing support.

2008

Akil, E., Tamam, B., Tamam, L., Tamam, Y., & Yasan, A. (2008). **Post-stroke sexual functioning in first stroke patients.** *European Journal of Neurology*, 15(7), 660-6.

PMID: 18484994

ABSTRACT: BACKGROUND AND PURPOSE: Although physical problems after stroke have been well studied, there is little information on one of the crucial aspects of the quality of life of those patients, namely sexual functioning and satisfaction. The aim of this study was to assess the impact of stroke on sexual functioning in a stable cohort of Turkish stroke patients with mild or no disability and to assess the relationship between post-stroke sexuality and a number of socio-demographic, clinical and laboratory variables. **METHODS:** The sexual functioning of 103 Turkish stroke patients

with no disability or mild disability was assessed in two consecutive interviews along with clinical and sociodemographic features. NIH stroke, Glasgow coma, Barthel, and Rankin scales were also applied to assess neurologic status and disability. RESULTS: Most of the patients were male (61 percent) and illiterate (70 percent). There was a significant difference between the baseline and post-stroke frequency of sexual activity of the patients. The differences between baseline and post-stroke vaginal lubrication, orgasms and satisfaction were all statistically significant. This latter difference was significant for both genders. Frequency of coitus both prior to and after the stroke was significantly different between males and females. Erection and ejaculation of the males was significantly affected by the stroke, and lubrication and orgasm was affected in the females. Interestingly, fear of recurrent stroke did not differ between genders. DISCUSSION AND CONCLUSION: Our study has shown that Turkish stroke survivors have sexual health needs during the rehabilitation process, though this has not been addressed previously. Sexual health needs seem to be affected by cultural factors and biases.

Conod, L., & Servais, L. (2008). **Sexual life in subjects with intellectual disability.** *Salud Pública de México*, 50(Suppl 2), 230-8.

PMID: 18470352

Available in full-text at <http://www.scielosp.org/pdf/spm/v50s2/a17v50s2.pdf>.

ABSTRACT: During the last decades, the expectancies towards sexual life of people with intellectual disability have been more and more recognized by researchers, clinicians, caregivers and parents. These expectancies, that largely depend on socio-cultural and personal factors, such as the level of disability, must be supported in order to help people with intellectual disability to reach the best quality of life as possible. Therefore, it is important to identify every patients and residents personal expectancies towards sexuality and which medical and educative support he/she needs according to his/her disability and co-morbidity. The aim of the present paper is to review the different research works conducted in this area.

Eastgate, G. (2008). **Sexual health for people with intellectual disability.** *Salud Pública de México*, 50(Suppl 2), s255-9.

PMID: 18470354

Available in full-text at <http://www.scielosp.org/pdf/spm/v50s2/a19v50s2.pdf>.

ABSTRACT: People with intellectual disability experience the same range of sexual needs and desires as other people. However, they experience many difficulties meeting their needs. They may be discouraged from relieving sexual tension by masturbating. They face a high risk of sexual abuse. They are likely not to be offered the full range of choices for contraception and sexual health screening. Poor education and social isolation may increase their risk of committing sexual offences. However, with appropriate education and good social support, people with intellectual disability are capable of safe, constructive sexual expression and healthy relationships. Providing such support is an essential part of supporting people with intellectual disability.

Hall, D.M., & Tice, C.J. (2008). **Sexuality education and adolescents with developmental disabilities: Assessment, policy, and advocacy.** *Journal of Social Work in Disability & Rehabilitation*, 7(1), 47-62.

PMID: 19042301

ABSTRACT: People with disabilities are sexual beings who, like all of us, benefit from sexuality education that examines relationship skills and knowledge, attitudes, behaviors, and values that promote healthy sexuality within those relationships. This article provides an overview of landmark policies relevant to persons with disabilities, defines the strengths perspective in the context of curriculum development, and describes a survey built on this perspective that evaluates sexuality education curricula on the strengths rather than the deficits of people.

Greydanus, D.E., & Omar, H.A. (2008). **Sexuality issues and gynecologic care of adolescents with developmental disabilities.** *Pediatric Clinics of North America*, 55(6), 1315-35, viii.

PMID: 19041460

ABSTRACT: All human beings are sexual from birth to death and all children and adolescents with or without disability or chronic illness must incor-

porate appropriate sexuality concepts into their processes of development from childhood to adolescence. This article considers sexuality issues and reproductive care of adolescents with developmental disabilities. Potential consequences of disability on sexuality are reviewed, including sexual abuse and sexual dysfunction. Comprehensive sexuality education is vital for normal growth and development of all youth including those with developmental disabilities.

Katz, G., & Lazcano-Ponce, E. (2008). **Sexuality in subjects with intellectual disability: An educational intervention proposal for parents and counselors in developing countries.** *Salud Pública de México*, 50(Suppl 2), s239-54.

PMID: 18470353

Available in full-text at <http://www.scielosp.org/pdf/spm/v50s2/a18v50s2.pdf>.

ABSTRACT: In developing countries, the study of intellectual disability has enormous knowledge gaps, especially in the areas of intervention, utilization of services and legislation. This article provides information not only for aiding in the potential development of sexuality in individuals with intellectual disability, but also for fostering their social integration. In Mexico and the region, in order to develop educational interventions for promoting sexual health, it is necessary to consider the following priorities: a) mental health professionals should have the knowledge or receive training for carrying out a sexual education and counseling program; b) educational interventions for subjects with intellectual disability should be adapted for the different stages of life (childhood, adolescence and adulthood); c) during childhood, educational intervention should emphasize the concept of public and private conducts; d) in adolescence, intervention should consider the actual mental age and not the chronological age of the subjects receiving intervention; e) the expression of sexuality in the adult with intellectual disability depends on the early incorporation of factors for promoting social inclusion; f) for educational interventions to be successful, it is fundamental that sexual educators and counselors, in addition to working with the clients, also work with their parents and other close family members; g) intervention programs should establish development objectives for developing in persons with intellectual disability a positive attitude towards sexuality and the improvement in self-esteem; h) in subjects

with intellectual disability, their linguistic comprehension level should be taken into consideration and techniques for open discussion and non-inductive education should be used; i) social integration programs should address the needs of developing countries and their individuals, since it is not feasible to import external programs due to differences in infrastructure and the absence of public policies for promoting development; j) full sexuality in subjects with intellectual disability should be fostered in a comprehensive manner within an independent living program; k) in Mexico and the region, public policies should be instituted for administering independent living programs for people with intellectual disability and should lead to social, familial and economic power for the purpose of being productive. Thus, people with mental deficiency in developing countries can aspire to being integrated into social and work life and to appropriately expressing their sexuality.

Monteiro, L.M., Moreira, M.C., & Soares, A.H. (2008). **[Disabled adolescents: Sexuality and stigma].** *Ciência & Saúde Coletiva*, 13(1), 185-94. [Article in Portuguese].

PMID: 18813533

Available in full-text (Portuguese) at <http://www.scielo.br/pdf/csc/v13n1/22.pdf>.

ABSTRACT: This paper is designed to extend discussions of disability and sexuality, highlighting the expectations, beliefs, desires and experiences of young people with physical disability and presenting the partial findings of the doctoral research project entitled "You laugh because I am different, I laugh because you are all the same: dimensions of the quality of life in adolescents with spina bifida", which discusses the quality of life in two cultures: Brazilian and American. The perception and interest of the participants, and their need to discuss problems related to their sexuality and its implications for their families, friends and healthcare services spurred investigations of this topic in greater depth, indicating the need to address concepts of sexuality on broader bases. The discourse of these youngsters stresses four aspects related to the experience of sexuality: (1) Sexuality and care; (2) Sexuality, body image and discredited characteristics; (3) Sexuality of people with special needs from the standpoint of violence, and finally; (4) Sexuality and questions about medical information.

2007

Balami, J., Robertson, D. (2007). **Parkinson's disease and sexuality.** *British Journal of Hospital Medicine*, 68(12), 644-7.

PMID: 18186397

ABSTRACT: Sexual dysfunction rarely threatens physical health but can take a heavy psychological toll. Sexual dysfunction is common in Parkinson's disease, occurring as a non-motor manifestation of the illness but often compounded by secondary problems relating to physical disability, psychological factors and medication effects.

Bianchi-Demicheli, F., Lövblad, K.O., Ortigue, S., Sekoranj, L., Sztajzel, R., & Temperli, P. (2007). **[Male sexual function after stroke].** *Revue Médicale Suisse*, 3(104), 805-8. [Article in French]

PMID: 17503716

ABSTRACT: Stroke represents the third leading cause of death, ranking behind heart disease and cancer and it is the major cause of worldwide long-term disability after the age of 65. Stroke has an important psychological and emotional impact on the patient and his environment. Some trials show the substantial lowering of libido, of the frequency of sexual intercourse, the presence of erectile dysfunction and reduced sexual satisfaction. After stroke it is important to evaluate the relational and sexual aspects of the patient and his sexual partner. A specialized consultation should be proposed when necessary to optimise the patient's post-stroke rehabilitation.

Clark, L.I., & O'Toole, M.S. (2007). **Intellectual impairment and sexual health: Information needs.** *British Journal of Nursing*, 16(3), 154-6.

PMID: 17363881

ABSTRACT: Inclusion into the wider community for people with learning disabilities and intellectual impairment has been problematic for many people and in some cases the result has been an exacerbation of mental health problems or a reduction in adaptive functioning. Research has found that people who have chronic mental illness or intellectual impairment are a sexually active group although they might not always be perceived as such. Therefore, there are questions that may be raised over an identified lack of sexual health promotion and practices surrounding safe sex. This short article will examine particular barriers to sexual health care for

this patient group in the areas of consent (to sexual acts, screening and treatment), communication and health promotion in this field. Implications for future practice are discussed.

2006

Cohen-Kettenis, P.T., Donkervoort, M., Roebroek, M.E., Stam, H.J., & Wiegerink, D.J. (2006). **Social and sexual relationships of adolescents and young adults with cerebral palsy: A review.** *Clinical Rehabilitation*, 20(12), 1023-31.

PMID: 17148513

ABSTRACT: OBJECTIVE: To investigate possible barriers to successful social and sexual relationships in adolescents and young adults of normal intelligence with cerebral palsy. DESIGN: A literature review based on a PubMed and PsycINFO search for the period 1990-2003. Included were studies focusing on one or more of the outcome parameters (i.e. social, intimate and sexual relationships) or on associated factors that described relationships with the outcome parameters. RESULTS: Fourteen papers were selected. Two studies investigated exclusively people with cerebral palsy whereas 12 concerned people with a congenital disability and/or physical disabilities, including people with cerebral palsy. All studies addressed adolescents or adults of normal intelligence. A. Social and sexual relationships: In social relationships adolescents and young adults with cerebral palsy were less active than their age mates, and dating was often delayed and less frequent. Adolescents with congenital disabilities indicated that sexuality is an important aspect of their lives, but they experienced difficulties developing a sexual relationship. B. Associated factors: Psychological maladjustment, insufficient self-efficacy and low sexual self-esteem may impair the development of social and sexual relationships. Overprotection in raising children with cerebral palsy and the negative attitudes of other people may have a negative influence on the self-efficacy of people with cerebral palsy. CONCLUSION: The reviewed studies suggest many factors that may influence the development of social and sexual relationships in adolescents and young adults with cerebral palsy. However, evidence was found only for the personal factors self-efficacy and sexual self-esteem and their interrelationships with the parents' way of raising their children and successful experiences in social situations.



Quick Looks

Online Resources Related to Sex, Sexuality & Disability

Individuals with disabilities have the same emotional and physical sexual drives as the people without disabilities. The following are various resources related to sex, sexuality, and disability:

American Association on Health and Disability (AAHD)

Phone: 301/545-6140

Email: contact@aahd.us.

www.aahd.us.

“Body Image, Relationships and Sexuality after Amputation”

Amputee Coalition of America (ACA) Easy Read Publication in *First Steps*, 4, 2005.

www.amputee-coalition.org/easyread/first_step_2005/altered_states-ez.pdf.

Center for Research & Education on Gender and Sexuality

Phone: 415/817-4512

Email: cregs@sfsu.edu.

Resources: cregs.sfsu.edu/cregs-publications.
cregs.sfsu.edu.

Disability Sexuality: Information on Sex & Disabled Sexual Issues from Disabled World

www.disabled-world.com/disability/sexuality.

“Intimacy and Sexuality in MS”

A brochure from the National Multiple Sclerosis Society (NMSS)

www.nationalmssociety.org/NationalMSSociety/media/MSNationalFiles/Brochures/Brochure-Intimacy-and-Sexuality.pdf.

Intimacy/Sexuality and Parkinson’s Disease Resources from the National Parkinson Foundation

Resources: www.parkinson.org/pd-library?keys=&tid=42&tid_1=All.

Intimacy & PD: www.parkinson.org/sites/default/files/Intimacy%20and%20PD.pdf.

“Relationships Intimacy & Sexuality in MS” from the Multiple Sclerosis International Federation (MSIF)

www.msif.org/wp-content/uploads/2014/09/MS-in-focus-6-Intimacy-and-sexuality-English.pdf.

Sex and Sexuality Information Resources from the National Stroke Association

www.stroke.org/we-can-help/stroke-survivors/living-stroke/lifestyle/relationships/sex-and-sexuality?docID=999.

Sexual Health and Disability Alliance (SHADA) in the UK

Email: Trust@Outsiders.org.uk.

Sex & Disability: shada.org.uk/wp2/?page_id=16.

www.shada.org.uk.

Sexual Health Information Page – From Paralysis Resource Center

www.christopherreeve.org/living-with-paralysis/health/sexual-health.

Sexuality & Disability Consortium (SDC)

SDC promotes people with disabilities to have healthy sexuality and relationships of their choosing through research and education.

Resources: ahs.uic.edu/dhd/sdc/resources.
ahs.uic.edu/dhd/sdc.

Sexuality and Intellectual Disability

aaid.org/search-results?indexCatalogue=sitesearch&searchQuery=Sexuality&wordsMode=0#.WI9nH_InaOZ.

Sexuality and Disability

This website is geared toward women with disabilities who may have questions about their bodies, mechanics and dynamics of having sex, and the complexities of being in an intimate relationship/or having children.

www.sexualityanddisability.org/#content.

Sexuality and Disability: A SpringLink publication

Sexuality and Disability is an international forum for the publication of peer-reviewed original interdisciplinary scholarly papers that address the psychological and medical aspects of sexuality in relation to rehabilitation.

link.springer.com/journal/11195.

Sexuality Education for Students with Disabilities from the Center for Parent Information and Resources

This resources includes factsheets and information on commercial products.

www.parentcenterhub.org/repository/sexed.

Sexuality Information and Education Council of the United States (CIECUS)

Publications: www.siecus.org/index.cfm?fuseaction=Page.ViewPage&pageId=634.

(Log-in is required but FREE)

www.siecus.org.

United Spinal Association Spinal Cord Resource Center (USASCRC)

Phone: 800/404-2898

Email: info@unitedspinal.org.

Living Your Life: Sexuality Following Spinal Cord Injury: www.unitedspinal.org/pdf/SexualityFollowingSCIBooklet.pdf.

www.spinalcord.org.

Search Terms for Sex, Sexuality, & Disability

- | | |
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| <ul style="list-style-type: none"> 📖 Accessibility 📖 Access to Education 📖 Access to Health Care 📖 Accessibility (for Disabled) 📖 Accommodation 📖 Acquired Immunodeficiency Syndrome (AIDS) 📖 Adjustment 📖 Adolescents 📖 Adults 📖 Advocacy 📖 African Americans 📖 Aging 📖 American Sign Language 📖 Amputations 📖 Anatomy 📖 Asperger Syndrome 📖 Assistive Technology 📖 At Risk Persons 📖 Attitudes Toward Disabilities 📖 Attitudes/Change/Measures 📖 Audiovisual Materials 📖 Autism 📖 Barriers 📖 Behavior 📖 Blind 📖 Body/Image/Functions 📖 Brain Injuries 📖 Burns 📖 Cancer 📖 Caregiver(s)/Attitudes/Role 📖 Case Studies 📖 Cerebral Palsy 📖 Children 📖 Chronic Fatigue Syndrome 📖 Chronic Illness 📖 Civil Rights 📖 Client Satisfaction 📖 Client-Counselor Relations 📖 Clinical Management 📖 College Students 📖 Communication Skills 📖 Comprehensive School Health Education 📖 Consumers | <ul style="list-style-type: none"> 📖 Contraception 📖 Counseling Techniques 📖 Counselor Attitudes/Education/Role/Training 📖 Cultural Difference/Diversity/Influences 📖 Curriculum 📖 Daily Living 📖 Dating (Social) 📖 Deaf 📖 Decision Making 📖 Developmental disabilities 📖 Disability/Management 📖 Diseases 📖 Divorce 📖 Education 📖 Emotions 📖 Empowerment 📖 Epilepsy 📖 Ethics 📖 Evaluation/Methods 📖 Experience 📖 Family Attitudes/Life 📖 Focus Groups 📖 Foreign Countries 📖 Friendship 📖 Gender/Differences 📖 Group Homes 📖 Health Behavior/Care/Education/Programs Promotion 📖 Hearing Impairments 📖 Homosexuality 📖 Humanism 📖 Immune System Disorders 📖 Independent Living 📖 Information Resources 📖 Instructional Materials/Methods 📖 Intellectual Disabilities 📖 Interdisciplinary Activities 📖 International/Rehabilitation/Research 📖 Interpersonal/Attraction/Communication Relationships 📖 Intervention 📖 Intimacy 📖 Learning Disabilities |
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Continued on next page ...

Search Terms for Sex, Sexuality, & Disability continued....

- 📖 Legal Responsibility
- 📖 Legislation
- 📖 Limbs
- 📖 Literature Reviews
- 📖 Long Term Care
- 📖 Low Vision
- 📖 Marital Satisfaction
- 📖 Marriage
- 📖 Measures
- 📖 Mental Health
- 📖 Minority Groups
- 📖 Misconceptions
- 📖 Modeling
- 📖 Multiple Sclerosis
- 📖 Needs Assessment
- 📖 Neurological Disorders/Impairments
- 📖 Occupational Therapy
- 📖 Outcomes
- 📖 Pain
- 📖 Paraplegia
- 📖 Parent Attitudes/Influence/Participation
- 📖 Patient Education
- 📖 Peer Counseling
- 📖 People with Disabilities
- 📖 Personal Narratives
- 📖 Physical Characteristics
- 📖 Physical Disabilities
- 📖 Physiology
- 📖 Pregnancy
- 📖 Prevalence
- 📖 Prevention
- 📖 Privacy
- 📖 Professional Training
- 📖 Program Development/Effectiveness
Evaluation/Implementation
- 📖 Prosthetics
- 📖 Psychiatric Disabilities
- 📖 Qualitative Analysis/Research
- 📖 Quality of Life
- 📖 Rehabilitation/Counseling/Research/Services
- 📖 Reproductive Health
- 📖 Role Playing
- 📖 Safety
- 📖 Satisfaction
- 📖 Schizophrenia
- 📖 Secondary Conditions
- 📖 Self-Advocacy
- 📖 Self-Concept
- 📖 Service Delivery/Integration
- 📖 Severe Disabilities
- 📖 Sex Education
- 📖 Sexual Abuse
- 📖 Sexual Identity/Orientation
- 📖 Sexuality
- 📖 Sexually Transmitted Diseases/Infections
- 📖 Significant Others
- 📖 Social Attitudes/Behavior/Bias/Influences
Services
- 📖 Social Life/Networks/Skills
- 📖 Socialization
- 📖 Special Education
- 📖 Spinal Cord Injuries
- 📖 Spouses
- 📖 Stereotypes
- 📖 Stress
- 📖 Stroke
- 📖 Students
- 📖 Substance Abuse
- 📖 Teacher Attitudes/Collaboration
- 📖 Teaching/Methods
- 📖 Training
- 📖 Values
- 📖 Visual Impairments
- 📖 Well-Being
- 📖 Wheelchairs
- 📖 Young Adults
- 📖 Youth

About reSearch:

reSearch is an information product from the National Rehabilitation Information Center (NARIC). Each issue is based on real-world queries received by our information specialists from researchers, educators, and rehabilitation professionals around the world.

We search several sources both in-house and online, to fill these requests including:

 REHABDATA and the NIDILRR Program database

 Education Resources Information Center

 National Clearinghouse of Rehabilitation Training Materials

 Campbell and Cochrane Collaborations

 PubMed and other National Library of Medicine databases

 Agency for Health Care Policy and Research databases

 and other reputable, scholarly information resources.

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