



Volume 5, Issue 5, September 2010

reSearch

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

Sexuality, Intimacy & Disability

In this edition of *reSearch* we explore sexuality, intimacy, and disability. Individuals with disabilities have the same emotional and physical sexual drives as the people without disabilities. However, issues of sexual intimacy and disability remained un-addressed 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.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 agreaterdate.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 20 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: Sexuality, Intimacy, and Disability (Severe, Significant). A listing of near 100 additional descriptor terms between the NARIC, CIRRIE, ERIC, and the PubMed databases can be found at the end of this document.

A search of the REHABDATA database resulted in 52 documents published between 1991 and 2009. The CIRRIE and ERIC database searches resulted in 6 documents between 1999 and 2007 and 15 documents between 1990 to 2010; respectively. Finally, a search of the PubMed database resulted in 16 documents between 1990 and 2010. The complete citations are included in this research brief.

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Full-text copies of these documents may be available through NARIC's document delivery service. To order any of the documents listed, please note the NARIC Accession Number (starts with a J, O, or R) and call an information specialist at 800/346-2742. You may also order online at www.naric.com/services/requestform.cfm. There is a charge of five cents for copying and shipping with a \$5 minimum on all orders. International shipping fees may apply.

NIDRR Funded Projects Related to Sexuality, Intimacy, and Disability

In addition to document searches, we searched our NIDRR Program Database to locate grantees/projects related to sexuality, intimacy, and disability. The search resulted in 30 NIDRR funded projects — 5 currently funded and 25 which have completed their research activities. Project information and their publications are offered as additional resources for our patrons.

CIL-Based Abuse Education and Safety Planning Program for Women with Disabilities

Project Number: H133G070196
Email: rhughes@ruralinstitute.umt.edu
Phone: 406/243-2898

Developing Strategies to Foster Community Integration and Participation (CIP) for Individuals with Traumatic Brain Injury

Project Number: H133B090023
Email: angelle.sander@memorialhermann.org
Phone: 713/630-0516

Participation, Subjective Well-Being, Health, and Spinal Cord Injury: A 35-Year Longitudinal Study

Project Number: H133G060126
Email: cokerj@musc.edu
Phone: 843/792-7051
www.musc.edu/chp/sciorg

Rehabilitation Research and Training Center for Health and Function Across the Lifespan of Individuals with Intellectual and Developmental Disabilities

Project Number: H133B080009
Phone: 800/996-8845
Email: rrtcamr@uic.edu
www.rrtcadd.org

Rehabilitation Research and Training Center on Health and Wellness in Long Term Disability

Project Number: H133B040034
Email: rrtc@ohsu.edu
Phone: 503/494-8364
www.healthwellness.org

The following projects have completed their research activities:

Health Promotion for Women Aging with Disability

Project Number: H133G000226
Email: rhughes@bcm.tmc.edu
Phone: 713/960-0505
www.bcm.edu/crowd

International Disability Exchanges and Studies (IDEAS) Project 2000

Project Number: H133D40028 (See also H133A990006)
Email: kathy@wid.org
Phone: 510/763-4100
www.wid.org/projects/intl.htm

Meeting the Needs of Women with Disabilities: A Blueprint for Change

Project Number: H133G40077
Email: ann@bpacal.com
Phone: 510/465-7884

Missouri Model Spinal Cord Injury System

Project Number: H133N000012
Email: clarkmj@health.missouri.edu
Phone: 573/882-5711
www.hsc.missouri.edu/~momscis

Model Construct for Community Integration in SCI

Project Number: H133N50024
Email: denmaim@aol.com, ifiedler@post.its.mcw.edu
Phone: 414/259-2109
www.mcw.edu/spinal

Model Spinal Cord Injury System

Project Number: H133N50009
Email: lindsey@uab.edu
Phone: 205/934-3330
main.uab.edu/show.asp?durki=10712

Model Spinal Cord Injury System

Project Number: H133N00027 (See also H133N50021)
Phone: 215/955-6579

National Research and Training Center on Psychiatric Disability

Project Number: H133B50004 (See also H133B000700)
Phone: 312/422-8180, ext. 18
www.psych.uic.edu/uicnrtc

National Resource Center on Community Integration for People with Mental Retardation

Project Number: H133D50037 (See also H133A990001)
Email: thechp@sued.syr.edu
Phone: 315/443-3851
soeweb.syr.edu/thechp/nrc.htm

Northern California Model Spinal Cord Injury System

Project Number: H133N50003 (See also H133N000007)
Email: tbsci@tbi-sci.org
Phone: 408/295-9896, ext. 16
www.tbi-sci.org

Project Shake It Up! Health Promotion and Capacity Building for Persons with Traumatic Spinal Cord Injury and other Neuromuscular Disabilities

Project Number: H133G010094
Email: sarah_everhart@brown.edu
Phone: 401/444-1876

Reducing Risk Factors for Abuse among Low-Income Minority Women with Disabilities

Project Number: H133A60045
Email: mnosek@bcm.tmc.edu
Phone: 713/960-0505
www.bcm.tmc.edu/crowd

Rehabilitation Research and Training Center in Secondary Complications in Spinal Cord Injury

Project Number: H133B30025 (See also H133B980016)
Email: lindsey@sun.rehabm.uab.edu
Phone: 205/934-3283
www.sci.rehabm.uab.edu/docs/rrtchome.htm

Rehabilitation Research and Training Center for Infants, Children, and Youth

Project Number: H133B40019
Email: instihd@tc.umn.edu
Phone: 612/626-2401
www.peds.umn.edu/peds-adol

Rehabilitation Research and Training Center on Independent Living and Disability Policy

Project Number: H133B50005
Email: devva@wid.org jackie@wid.org
Phone: 510/251-4318
www.wid.org/ildp/index.html

Rehabilitation Research and Training Center on Improving Community Integration for Persons with Mental Retardation

Project Number: H133B30072 (See also H133B980047)
Email: lakin001@maroon.tc.umn.edu
Phone: 612/625-6046
www.ici.coled.umn.edu/ici

Research and Training Center on Improving the Functioning of Families Who Have Members with Disabilities

Project Number: H133B80046 (See also H133B30070)
Phone: 913/864-7600

Research and Training Center on Neural Recovery and Functional Enhancement

Project Number: H133B80017
Phone: 215/955-6574

Rehabilitation Research and Training Center on Positive Behavior Support

Project Number: H133B980005
Email: rtrcpbs@fmhi.usf.edu
Phone: 813/974-4612
www.rtrcpbs.org

Rehabilitation Research and Training Center on Secondary Conditions of Spinal Cord Injury: Promoting General Health, Well-Being, and Community Integration through Home-Based, Self-Directed Care

Project Number: H133B980016
Email: rtc@uab.edu
Phone: 205/934-3283
main.uab.edu/show.asp?durki=8762

Research and Training Center on the Social Psychological Development of Children and Youth with Disabilities

Project Number: H133B90012
Email: kohen001@maroon.tc.umn.edu
Phone: 612/626-4032

Special Projects and Demonstrations for Spinal Cord Injuries

Project Number: H133N50014 (See also H133N000024)
Email: tricia.regan@bmc.org
Phone: 617/638-7310
www.bumc.bu.edu/Departments/eMain.asp?DepartmentID=91

The Social Construction of Hopelessness: Chronicity and the Rise of Therapeutic Failure in the Social History of People with Significant Disabilities

Project Number: H133F60028
Email: pferguso@oregon.uoregon.edu
Phone: 541/346-2463

VCU Model Spinal Cord Injury Center

Project Number: H133N000015
Email: wmckinle@hsc.vcu.edu
Phone: 804/828-5401
www.sci.pmr.vcu.edu



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

2009

Corine, G., Dijkstra, P.U., Geertzen, J.H.B., & Van, E. (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, Psychinfo 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.

2008

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.

Wiwanitkit, V. (2008). **Sexuality in Parkinsonism.** *Sexuality & 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

Davis, S., & Taylor, B. (2007). **The extended PLISSIT model for addressing the sexual wellbeing of individuals with an acquired disability or chronic illness.** *Sexuality & 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 & 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.

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

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

2006

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

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 im-

paired. 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 & 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 & 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.

Sakellariou, D. (2006). **If not the disability, then what? Barriers to reclaiming sexuality following spinal cord injury.** *Sexuality & 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 sug-

gested 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.

2005

Sharma, S.C., & Singh, R. (2005). **Sexuality and women with spinal cord injury.** *Sexuality & Disability*, 23(1), 21-33.

NARIC Accession Number: J50017

ABSTRACT: Forty women with spinal cord injury (SCI) were interviewed to assess their issues with sexuality. Questions related social, medical, and sexual activity problems; menstruation and female hygiene; pregnancy and child bearing; and relationships. Results indicated that interest in sex and the importance of sex did not change significantly after SCI. The participants' key concerns were sexual, bladder and bowel dysfunctions, bed sores, pain, spasticity, and satisfaction of partner. Only 30 percent of the women had received information on sexuality since their injury.

2003

Heller, J.A., & Mayers, K.S. (2003). **Sexuality and the late stage Huntington's disease patient.** *Sexuality & Disability*, 21(2), 91-105.

NARIC Accession Number: J46294

ABSTRACT: Presents the results of interviews conducted with patients with late-stage Huntington disease (HD) residing in a long-term care facility. The interviews focused on the patients' sexual interests and needs, the patients' perceptions of their intimate and sexual relationships, and their interest in discussing sexuality concerns with staff. Results indicated the need for caregivers to recognize that patients are sexual beings, with sexual needs, fantasies, and wishes. Patients with HD have the potential to develop feelings of attraction, which must be dealt with in a sensitive manner. Suggestions are offered for ways in which caregiving staff can compensate for the patients' sexual losses.

Jans, I., Revell, A., & Vansteenwegen, A. (2003). **Sexual experience of women with physical disability: A comparative study.** *Sexuality & Disability*, 21(4), 283-290.

NARIC Accession Number: J46678

ABSTRACT: Study used a self-administered questionnaire to compare the sexual experiences of women with

and without physical disabilities. Results showed that women with disabilities have more negative attitudes toward sexuality, have less sexual knowledge and experience with intercourse, and are less satisfied with their sexual experience. No differences were found between groups regarding sexual desire and fantasy.

2002

(2002). **Health and wellness for teens living with disabilities: Understanding and becoming sensitive to the issues. Module two: Relationships and sexuality.**

NARIC Accession Number: O15031

ABSTRACT: Presents trainer and student versions of training module designed to introduce issues related to relationships and sexuality for teens with disabilities. Module is designed to increase awareness of the importance of social skills and peer relationships, to recognize barriers that might keep teens from obtaining sexuality information, and to help healthcare providers be more comfortable talking to teens about their social-sexual development.

Wade, H.A. (2002). **Discrimination, sexuality and people with significant disabilities: Issues of access and the right to sexual expression in the United States.** *Disability Studies Quarterly*, 22(4), 9-27.

NARIC Accession Number: J48925

ABSTRACT: Article addresses issues faced by people with significant disabilities with regard to their right to participate in sex education and to engage in sexuality activity and expression. Individuals with significant disabilities are those who have moderate to profound intellectual disabilities and may experience a secondary sensory or physical disability. Author presents the history of legislation, policy, services related to the sexuality of people with disabilities, and discusses issues of competence and consent. Continuing issues include: the lack of access to sexuality education, the need for ongoing intensive support, the system's requirement for competence and consent, minimal support for the individual's interest in sexual expression, and the interests of parents and society to protect people with disabilities from their right to sexual expression. Suggestions for addressing these issues include: instituting policies that support sexuality education for all people with disabilities, providing opportunities for learning and support in real-life settings, placing limits on the states' ability to determine a person's ability to explore their sexual expression, and continuing support of individuals as they develop relationships with others.

2001

Cohen-Schneider, R., Holzapfel, S., & Lemieux, L. (2001). **Aphasia and sexuality.** *Sexuality & Disability, 19*(4), 253-266.

NARIC Accession Number: J43928

ABSTRACT: Describes how stroke changed the sexuality of people with aphasia and their spouses. Materials and methods were developed to interview stroke survivors with moderate and severe aphasia, which refers to difficulty understanding, speaking, reading, or writing. Responses were qualitatively analyzed; themes emerging from the responses are discussed. Subjects indicated that their aphasia limited their ability to initiate sexual activity. The study points to the possibility that aphasia is at least partially responsible for a reduction in sexual activity.

Esmail, S., Esmail, Y., & Munro, B. (2001). **Sexuality and disability: The role of health care professionals in providing options and alternatives for couples.** *Sexuality & Disability, 19*(4), 267-282.

NARIC Accession Number: J43929

ABSTRACT: Article reviews the literature on the impact of disability on a couple's sexual relationship and the treatment strategies used by health care providers. Specific concerns and difficulties related to issues of sexuality are identified. Some common intervention strategies that have been shown to be effective in helping couples affected by disability or illness are described. Discusses the P-LI-SS-IT (Permission, Limited Information, Specific Suggestions, and Intensive Therapy) model which can be used to determine the clients' needs as well as to assess the health care provider's level of comfort and expertise in dealing sexuality issues.

McCabe, M.P., & Taleporos, G. (2001). **Physical disability and sexual esteem.** *Sexuality & Disability, 19*(2), 131-148.

NARIC Accession Number: J43151

ABSTRACT: Study investigated the effects of physical disability on sexual feelings, sexual experiences, and sexual esteem. Thirty-five individuals with physical disabilities participated in focus groups to discuss how the disability affected their sexuality and responded to questions that were specific to sexual esteem. Many participants expressed the belief that they were less desirable than able-bodied persons. Implications for future research are discussed.

Milligan, M.S., & Neufeldt, A.H. (2001). **The myth of asexuality: A survey of social and empirical evi-**

dence. *Sexuality & Disability, 19*(2), 91-109.
NARIC Accession Number: J43148

Abstract: Paper evaluates the social and empirical evidence for the contention that people with disabilities lack the desire, ability, and capacity for sexual relationships. Presents sources of social evidence that support the myth of asexuality including personal narratives of people with disabilities, popular cultural images of disabled persons, and the historical rehabilitation practices. Indirect empirical evidence from a variety of sources including attitude research and investigations of intimate relationships is reviewed.

2000

Cook, J.A. (2000). **Sexuality and people with psychiatric disabilities.** *Sexuality & Disability, 18*(3), 195-206.

NARIC Accession Number: J40944

ABSTRACT: Article on the sexuality of people with psychiatric disabilities. Characteristics of psychiatric disability and of society's attitude toward it that can have an impact on the sexuality of people with psychiatric disabilities are discussed. Other topics include barriers to sexual expression, usage of contraception and safe sex practices, issues for specific groups (women, gays/lesbians, and HIV-positive individuals with psychiatric disabilities), and results of a 1990 survey of 325 individuals with psychiatric disabilities.

Cummins, R.A., Deeks, A.A., & McCabe, M.P. (2000). **Sexuality and quality of life among people with physical disability.** *Sexuality & Disability, 18*(2), 115-123.

NARIC Accession Number: J40239

ABSTRACT: Study examining the association between sexuality and quality of life (QOL) among persons with congenital physical disabilities. Participants were 60 community-dwelling adults (33 men, 27 women), mean age 28. Respondents each completed the Sexual Knowledge, Experience and Needs Scale, which assesses knowledge, experience, positive or negative feelings, and needs in 12 areas of sexuality, and the Comprehensive Quality of Life Scale, which assessed the importance attached to and satisfaction with various aspects of life. Results showed few associations between sexuality and QOL. The strongest association was between feelings regarding sexual intimacy and the importance given to certain life domains. Sexuality was regarded as important to QOL, but was not associated with life satisfaction.

Davies, D. (2000). **Sex and relationship facilitation project for people with disabilities.** *Sexuality & Disability, 18*(3), 187-194.

NARIC Accession Number: J40943

ABSTRACT: Article describing a proposed Sexuality and Relationship Facilitation Project for People with Disabilities. The aim of the project would be to develop the sexuality and relationship skills, self-confidence, and self-esteem of people with disabilities. The article discusses the why, how, where, and when of such a project, that is, reasons such a project is needed, elements envisioned for the project, sources of funding, how the project could be adapted to circumstances in different countries, and things to do to get such a project started. A draft syllabus for facilitator training is included as an appendix.

Fiduccia, B.W. (2000). **Current issues in sexuality and the disability movement.** *Sexuality & Disability, 18*(3), 167-174.

NARIC Accession Number: J40941

ABSTRACT: Article on issues related to sexuality and reproduction of people with disabilities, including the marriage penalty for Social Security benefits, retention of child custody, inadequate sex education, and lack of privacy and sexual freedom for individuals living in institutions.

Gardos, P.S., & Mona, L.R. (2000). **Disabled sexual partners.** In Szuchman & Muscarella (Eds.), *Psychological perspectives on human sexuality* (pp. 309-354). New York: Wiley & Sons.

NARIC Accession Number: J40438

ABSTRACT: Chapter from a book on psychological perspectives on human sexuality, focusing on the sexuality of persons with disabilities. Topics include: historical models of disability; society's influence on the sexuality of people with disabilities; sex education for persons with specific disabilities, including developmental disabilities, blindness, and deafness; the effects of various disabilities on sexual activity including spinal cord injury, multiple sclerosis, diabetes, cancer, cardiac conditions, neuromuscular disorders, arthritis, and brain injury; establishing and maintaining intimate relationships; and pregnancy and parenting with a disability. The chapter also discusses clinical applications of the sexual concerns of persons with disabilities.

Guldin, A. (2000). **Self-claiming sexuality: Mobility impaired people and American culture.** *Sexuality & Disability, 18*(4), 233-238.

NARIC Accession Number: J41275

Abstract: Study examining the manner by which dominant cultural notions of sexuality and disability are, at times, simultaneously challenged and reinforced by participants as they self-claim their own sexualities. Data are from multiple, in-depth interviews with seven participants.

Koller, R. (2000). **Sexuality and adolescents with autism.** *Sexuality & Disability, 18*(2), 125-135.

NARIC Accession Number: J40240

ABSTRACT: Article discussing sex education for youth with autism. Discusses the need for sex education for youth with autism, effective teaching methods and approaches, and challenges in providing sex education, with particular attention to adolescence as a developmental stage, masturbation, and sexual abuse.

Shakespeare, T. (2000). **Disabled sexuality: Towards rights and recognition.** *Sexuality & Disability, 18*(3), 159-166.

NARIC Accession Number: J40940

ABSTRACT: Article on issues of sexuality and its place in disability studies. The author supports a social constructivist model of sexuality, but with reservations. He questions whether people with disabilities should want to be normal and whether more sex is the right goal. He concludes with some suggestions about connecting sexuality to the agenda of the disability movement.

1999

Levi, R., & Westgren, N. (1999). **Sexuality after injury: Interviews with women after traumatic spinal cord injury.** *Sexuality & Disability, 17*(4), 309-319.

NARIC Accession Number: J38544

ABSTRACT: Qualitative study of the sexual experiences of women after spinal cord injury (SCI), including psychological, physical, and social barriers that must be overcome to allow resumption of a sexually active life with a partner. Data are from interviews with eight women ages 20 through 43 with experience of stable heterosexual relationships both before and after SCI. Topics include: (1) expectations, concerns, and outcome of the first sexual contact after injury; (2) communication with partner on sexual matters, before and after injury; and (3) limitations of sexual activity after injury, and compensatory strategies.

Li, A., Odette, F., & Yoshida, K.K. (1999). **Cross-cultural views of disability and sexuality: Experiences of a group of ethno-racial women with physical disabilities.** *Sexuality & Disability, 17*(4), 321-337.
NARIC Accession Number: J38545

ABSTRACT: Qualitative study comparing the experiences and perspectives of women with disabilities from different ethnic/racial groups with regard to sexuality. Data are from grounded theory analysis of focus group interviews with 10 Canadian women from different backgrounds, all with physical disabilities. Issues identified and developed include barriers to learning about sexuality, cultural mores that make it hard to find intimate relationships, lack of community support for having babies with or without marriage, and insensitivity from health care professionals.

McCabe, M.P. (1999). **Sexual knowledge, experience and feelings among people with disability.** *Sexuality & Disability, 17*(2), 157-170.

NARIC Accession Number: J37456

ABSTRACT: Study comparing the sexual knowledge, experience, feelings, and needs of people with intellectual disabilities, physical disabilities, and no disabilities. Participants were 60 people with mild intellectual disability, 60 with physical disability, and 100 from the general population. Participants completed the Sexual Knowledge, Experience, and Needs Scale (SexKen), which evaluates knowledge, experience, feelings, and needs in 12 areas of sexuality. It was found that persons with intellectual disabilities scored lower than those with physical disabilities, and that those with physical disabilities scored lower than the general population.

1998

Davies, H.D., Shea, E.A., Tinklenberg, J.R., & Zeiss, A.M. (1998). **Sexuality and intimacy in Alzheimer's patients and their partners.** *Sexuality & Disability, 16*(3), 193-203.

NARIC Accession Number: J35747

ABSTRACT: Article on means of fostering acceptance by professionals and families of sexuality among older adults with dementia, including means of creating an environment that nurtures sexuality in couples coping with dementia. Topics include: sexual difficulties due to cognitive changes; barriers in addressing sexual issues; assessment of sexual concerns; and intervention for sexual concerns, including training older adults with dementia in sexual permission/prohibition systems.

Wright, L.K. (1998). **Affection and sexuality in the presence of Alzheimer's disease: A longitudinal study.** *Sexuality & Disability, 16*(3), 167-179.

NARIC Accession Number: J35745

ABSTRACT: Longitudinal study of affection and sexuality in two groups of couples, one consisting of couples in which one spouse has Alzheimer's disease and the other spouse is the primary caregiver, and the other group consisting of couples in which both spouses are relatively healthy. It was found that expressions of affection were not significantly different in the two groups prior to illness, but declined significantly for the Alzheimer's disease group 5 years into the illness, while remaining stable for the healthy group. Affection increased significantly after nursing home placement of an ill spouse. Fewer couples with a spouse with Alzheimer's disease were sexually active, although sexual activity also declined over time among healthy couples.

1997

Crabtree, L., & Levy, P. (1997). **Charcot-Marie-Tooth disease: Sex, sexuality and self-esteem.** *Sexuality & Disability, 15*(4), 293-306.

NARIC Accession Number: J34391

ABSTRACT: Article about sexual concerns of individuals with Charcot-Marie-Tooth disease (CMT), also known as hereditary motor and sensory neuropathy (HMSN) or peroneal muscular atrophy. Topics include: CMT and teenage sexuality; CMT and marriage; concerns about the risk that a child may inherit CMT; CMT and adult sexuality; impotence; difficulty in reaching orgasm; masturbation; body image and self esteem; lack of being touched; CMT weakness and sex; incontinence and flatulence; and hygiene.

Ducharme, S.H., & Gill, K.M. (1997). **Sexuality after spinal cord injury: Answers to your questions.** Baltimore: Paul H. Brookes Publishing Co.

NARIC Accession Number: R07599

ABSTRACT: Book providing answers to questions on sexuality for men and women with spinal cord injury. Discusses physical, social, and emotional aspects of sexuality. Topics include sexual anatomy, sexual function, intercourse, fertility, birth control, pregnancy, parenting, body image and self esteem, relationships and marriage, sexual effects of smoking and drugs, and sexually transmitted diseases. Appendices include information resources and listings of Independent Living Centers in the U.S. and Canada.

1996

Cummins, R.A., & McCabe, M.P. (1996). **The sexual knowledge, experience, feelings and needs of people with mild intellectual disability.** *Education & Training in Mental Retardation & Developmental Disabilities, 31*(1), 13-21.

NARIC Accession Number: J30741

ABSTRACT: This study compared the sexual awareness and experience of thirty people with mild mental retardation with those of fifty first year graduate psychology students. Using detailed, identical questionnaires, the authors found that the individuals with mild mental retardation knew less than the students about dating and intimacy, sexual interaction, contraception, pregnancy, abortion and childbirth, sexually transmitted diseases, masturbation, and sexual abuse. There were no differences between the two groups on menstruation or identifying body parts. Individuals with mild mental retardation had less experience than the students in kissing, oral sex, feelings of intimacy, and sexual intercourse, but were more likely to masturbate, have a sexually transmitted disease, or to have been pregnant. Both groups had the same level of experience in contraception, current sexual partners, homosexual experience, dating, and unwanted sexual contact. People with mild mental retardation held more positive feelings about sexual abuse, not using condoms, and having sex with everyone, but held more negative feelings about their level of privacy, getting married and having children, sexual interaction, masturbation, and homosexuality. The authors refer to other studies which support their findings, point to the need for further research, and stress the need for further sex education for people with mild mental retardation.

1995

Bostick, R., & Tan, G. (1995). **Sexual dysfunction and disability: Psychosocial determinants and interventions.** *Physical Therapy, 9*(2), 539-554.

NARIC Accession Number: J31440

ABSTRACT: Article in a special journal issue on sexuality and disability. (See AN #XJ31429-39 for other articles in the issue.) This article addresses psychosocial issues related to disability and sexuality and the treatment of sexual dysfunctions. The first section reviews the literature on the psychological and psychosocial impact of disability on sexuality, including the role of maladaptive cognitive factors, issues in interpersonal relationships, and the impact of the individual's premorbid psychological state. The second section discusses the psychological treatment of specific sexual dysfunctions,

including sexual desire disorder, sexual aversions, female sexual arousal disorder, male erectile disorder, female orgasm disorder, inhibited male orgasm, premature ejaculation, and sexual pain disorder. The final section describes the elements of comprehensive sex education and counseling programs for individuals with disabilities.

Chen, D., & Yarkony, G.M. (1995). **Sexuality in patients with spinal cord injury.** *Physical Therapy, 9*(2), 325-344.

NARIC Accession Number: J31430

ABSTRACT: Article in a special journal issue on sexuality and disability. (See AN #XJ31429 and XJ31431-40 for other articles in the issue.) This article discusses the management of sexual dysfunction in men and women with spinal cord injuries (SCI). The first part addresses male sexual dysfunction. Topics include: 1) problems with erection and ejaculation; 2) semen quality in men with SCI; 3) techniques to restore erections; 4) methods to obtain semen for sperm analysis or artificial insemination; and, 5) counseling men with SCI and sexual dysfunction. The second part addresses female sexual functioning after SCI, including: 1) the role of counseling in the adaptation process; 2) management of problems during pregnancy, labor, and delivery; and 3) the management of spasticity and the safety of specific drugs during pregnancy.

Donohue, J., & Gebhard, P. (1995). **The Kinsey Institute/Indiana University report on sexuality and spinal cord injury.** *Sexuality & Disability, 13*(1), 7-85.

NARIC Accession Number: J29683

ABSTRACT: Report of the Kinsey Institute/Indiana University study on sexuality and spinal cord injury. In depth interviews were conducted with a sample of 140 males and 46 females, aged 18 and older, with spinal cord injuries. The interviews addressed such topics as: demographics, nature of injury, attitudes toward and knowledge about various sexual activities, current mood and emotional status, sexual arousal from various stimuli pre- and post-injury, physiological responses to sexual arousal, masturbation, orgasm in sleep and sexual dreams, petting and foreplay (non-coital heterosexual activity), sexual intercourse (premarital, marital, extramarital), homosexual activity, contraception and fertility, sexual partners, and open ended questions about the positive and negative aspects of spinal cord injury, how sexual partners were obtained, what sexual problems existed and what solutions were attempted, and general advice for other persons with spinal cord injuries. This report describes the study methodology and presents findings in the areas investigated.

Ghusn, H. (1995). **Sexuality in institutionalized patients.** *Physical Therapy*, 9(2), 475-486. NARIC Accession Number: J31438

ABSTRACT: Article in a special journal issue on sexuality and disability. (See AN #XJ31429-37 and XJ31439-40 for other articles in the issue.) This article discusses the sexuality of institutionalized elderly persons. Topics include: 1) sexual activities and interests of elderly nursing home residents; 2) attitudes of nursing home residents and nursing home staff toward sexual activity among residents; 3) factors influencing sexual activity among institutionalized elderly, including vascular factors, endocrine factors, neural changes, chronic diseases, pharmacologic factors, psychological factors, partner availability, and environmental factors; 4) risks and benefits of sexual activity in nursing homes; and, 5) therapeutic strategies to enhance the expression of sexuality in institutional settings.

Grabois, M., & Smith, K.G. (1995). **Chronic pain and sexuality.** *Physical Therapy*, 9(2), 443-450. NARIC Accession Number: J31435

ABSTRACT: Article in a special journal issue on sexuality and disability. (See AN #XJ31429-34 and XJ31436-40 for other articles in the issue.) This article addresses issues concerning sexuality and chronic pain. The first section discusses factors influencing sexuality in patients with chronic pain, including the effects of medical treatments for chronic pain and psychological problems associated with pain. The second section examines the impact of chronic pain on the marital relationship and sexual activity. The third section discusses the comorbidity of psychosexual disorders and a history of sexual abuse in patients with chronic pain. The final section discusses the assessment and management of sexual dysfunction in chronic pain patients.

Grana, E.A. (1995). **Sexuality issues in Multiple Sclerosis.** *Physical Therapy*, 9(2), 377-385. NARIC Accession Number: J31433

ABSTRACT: Article in a special journal issue on sexuality and disability. (See AN #XJ31429-32 and XJ31434-40 for other articles in the issue.) This article addresses sexual dysfunction in multiple sclerosis (MS). The first section reviews the scope and nature of the problem, including male and female genital dysfunction, other physiologic dysfunctions affecting sexuality, and psychosocial dysfunctions. The second section describes the assessment of sexual functioning in MS patients. The third section outlines therapeutic interventions for some of the most common physical problems affecting sexual function in MS, including bladder problems, fatigue, impotence, and weakness or spasticity. The final section discusses counseling issues for women

Lefebvre, K.A., & Monga, T.N. (1995). **Sexuality: An overview.** *Physical Therapy*, 9(2), 299-311. NARIC Accession Number: J31429

ABSTRACT: Article in a special journal issue on sexuality and disability. (See AN #XJ31430-40 for other articles in the issue.) This article introduces the series with an overview of topics related to sexuality and disability. These include: 1) terminology used in the study of sexuality; 2) changing views toward sex and sexuality; 3) definitions of impairment, disability, and handicap; 4) the impact of impairment, disability, and handicap on sexuality; 5) sexual infantilization and deprivation; 6) the role of society in the sexual development of persons with disabilities; 7) personal relationships and disability; 8) cultural influences on sexual attitudes and behavior; 9) sexual exploitation of persons with disabilities; 10) political issues concerning sexual and reproductive freedom; and, 11) future research directions.

Lim, P.A.C. (1995). **Sexuality in patients with musculoskeletal diseases.** *Physical Therapy*, 9(2), 401-415.

NARIC Accession Number: J31434

ABSTRACT: Article in a special journal issue on sexuality and disability. (See AN #XJ31429-33 and XJ31435-40 for other articles in the issue.) This article addresses sexual problems in persons with arthritis and other musculoskeletal disorders. The first part discusses sexuality and arthritis, including: 1) the effects of pain, physical limitations, fatigue, medications, and genital lesions on sexuality; 2) psychosocial problems such as depression, anxiety, loss of self esteem, inability to perform expected roles, restricted opportunities for sexual encounters, and physical separation from the sexual partner; 3) sexuality and juvenile rheumatoid arthritis; and, 4) management strategies, including education and counseling, medications, physiotherapeutic modalities, exercise, alternative positions and techniques, and surgery. The remaining sections address problems with sexuality in amputees, individuals with scoliosis, and individuals with pelvic fractures.

Monga, T.N., (Ed.). (1995). **Sexuality and disability.** Philadelphia: Hanley & Belfus, Inc.

NARIC Accession Number: R06854

ABSTRACT: Discusses issues on sexuality for individuals with disabilities: (1) an overview of sexuality, (2) the physiology of sexual function, (3) sexuality in individuals with spinal cord injury, (4) sexuality and sexual adjustment related to stroke, (5) traumatic brain injury and sexuality, (6) sexuality issues in multiple sclerosis, (7) coronary heart disease and sexuality, (8) sexuality in individuals with musculoskeletal diseases, (9) sexual-

ity in individuals with cancer, (10) chronic pain and sexuality, (11) sexuality in childhood disability, (12) the effects of aging and chronic illness on sexual function, (13) sexuality on institutionalized individuals, (14) sexual abuse of women with physical disabilities, (15) fertility and pregnancy (women), (16) evaluation and management of impotence (males), and (17) sexual dysfunction and disability (psychosocial determinants and interventions).

Monga, T.N., & Ostermann, H.J. (1995). **Sexuality and sexual adjustment in stroke patients.** *Physical Therapy, 9*(2), 345-359.

NARIC Accession Number: J31431

ABSTRACT: Article in a special journal issue on sexuality and disability. (See AN #XJ31429-30 and XJ31432-40 for other articles in the issue.) This article discusses sexuality and sexual adjustment in stroke patients. The first part reviews the effects of stroke on the physical and psychosocial aspects of sexuality, including: 1) the effects on libido, coital frequency, arousal, ejaculation and orgasm, enjoyment and satisfaction with sexual activity; 2) sexual problems in aphasic patients; 3) long term effects on sexuality; 4) factors affecting sexuality in stroke patients, including the sidedness of lesion, alcohol use, medications, fear of another stroke, fear of rejection or failure, autonomic dysfunction, altered self image, coping skills, and role changes; and 5) hypersexuality after stroke. The second part describes the assessment and management of sexual problems in stroke patients.

1994

Brown, R.C., Gardos, P.S., & Mona, L.R. (1994). **Sexual self views of women with disabilities: The relationship among age-of-onset, nature of disability and sexual self-esteem.** *Sexuality & Disability, 12*(4), 261-277.

NARIC Accession Number: J29171

ABSTRACT: Study examining relationships between age-of-onset and disability nature, and the sexual self-esteem of 43 women who have visible mobility impairments. A literature review of issues associated with disabilities, sexuality, and self concept is presented. Participants were then administered a demographics questionnaire, the Barthel Index, the Sexuality Scale, and the Rosenberg Self-Esteem Scale. Results showed that: the higher the functional status, the higher the positive level of sexual self-esteem; as the age-of-onset of disability increases, sexual self-esteem ratings decreased; 40 percent of participants masturbated weekly, 40 percent monthly, 16 percent yearly, and 4 percent not at

all. No relationships between masturbation, sexual activity

Cole, S.S., & Cole, T.M. (1994). **Sexuality, disability, and reproductive issues through the lifespan.** *Sexuality & Disability, 11*(3), 189-205.

NARIC Accession Number: J26162

ABSTRACT: The article presents a history of sexuality and reproductive issues for individuals with disabilities. Such issues can be considered from the points of view of sexuality and developmental disabilities, sexuality and acquired disabilities, reproduction, and the aging process. Section one of the article focuses on developmental issues, looking at (1) gender, (2) privacy, (3) language and communication skills, (4) touch, (5) self-exploration, (6) adolescence, (7) perfection/body image, (8) social opportunities, and (9) medical issues. Section two discusses issues concerning acquired disabilities, examining both stable (e.g. spinal cord injuries) and progressive (e.g. multiple sclerosis) disabilities. Section three looks at general medical care, noting individuals with acquired disabilities often avoid general medical care. It is very important that they receive information on sexually transmitted diseases and on sexual options. Section four discusses specific reproductive issues and options, noting the importance of examining issues like family planning. Section five looks at aging, which can also result in physical disabilities that may affect sexuality.

Majerovitz, S.D., & Revenson, T.A. (1994). **Sexuality and rheumatic disease.** *Arthritis Care & Research, 7*(1), 29-34.

NARIC Accession Number: J27644

ABSTRACT: Describes a study that investigated the relationship between functional disability and sexual satisfaction in individuals with rheumatic disease and their spouses, comparing levels of sexual satisfaction to those of healthy comparison couples. Study involved 113 couples involving one spouse with rheumatic disease and 37 healthy comparison couples. Subjects completed mailed questionnaires that assessed sexual dissatisfaction, illness severity, and functional disability. Data analysis indicated that couples with rheumatic disease did not experience more sexual dissatisfaction than did healthy comparison couples. Greater arthritis pain related to greater sexual dissatisfaction for spouses than those with arthritis. The negative impact of rheumatic disease on sexuality was greatest when disability was severe, affecting both members of the couple. Gender was a key factor in explaining sexual satisfaction, with women consistently reporting greater sexual dissatisfaction than men.

1993

Lamin, J., Shortridge, J., & Steele-Clapp, L. (1993). **Sexuality and disability: A SIECUS annotated bibliography of available print materials.** *Sexuality & Disability, 11*(2), 159-179.

NARIC Accession Number: J25144

ABSTRACT: Annotated bibliography of print materials on sexuality and disability. The bibliography is organized into the following categories of publications: books and booklets, publications for parents, publications for professionals, curricula and related training materials, and journals and newsletters. Listings of bibliographic databases and resource organizations also are provided.

1991

Alexander, C.J., & Sipski, M.L. (1991). **Female sexuality following spinal cord injury.** *SCI Psychosocial Process, Special Edition, 4*(2), 49-52.

NARIC Accession Number: J21402

ABSTRACT: Summarizes available research on female sexuality following spinal cord injury (SCI), noting the paucity of available research. The article focuses on the following topics: (1) sexuality and sex acts (studies conclude that women can lead active and satisfying sexual lives following SCI); (2) sexual physiology; (3) orgasm (women with SCI have been reported to experience orgasm, but physiological events associated with it in that population are uncertain); (4) gynecological and obstetric concerns (menstruation, birth control, pregnancy, labor, and breast feeding); and (5) conclusion (women with SCI experience sexual dysfunction, but there is not enough research on sexuality, sex acts, and sexual physiology).

Bixler, E., Corey, R., Garman, C., Hulse, C., Jacoby, K., Kettl, P., Rowley, F., Sredy, M., Tyson, K., & Zarefoss, S. (1991). **Female sexuality after spinal cord injury.** *Sexuality & Disability, 9*(4), 287-295.

NARIC Accession Number: J21999

ABSTRACT: Researchers sent questionnaires to 74 women with spinal cord injuries (SCI) to determine their perceptions of sexuality and sexual behavior following SCI. A total of 37 percent responded, and results indicated the following: 52 percent could achieve orgasm after injury, but half who experienced it considered it different after the injury; biggest perceived change after SCI was perceived attractiveness of body; women rated bodies as only half as attractive after SCI as before SCI; women rated sex as being 26 percent less important to them after SCI, but also felt 23 percent less satisfied with their sexual lives; and women did not

expand their repertoire of sexual behavior after injury, but continued to express themselves sexually as always. The paper suggests all members of rehabilitation teams need to be comfortable handling issues of sexuality with clients.



Documents from the Center for International Rehabilitation Research Information and Exchange (CIRRIE-2) search at cirrie.buffalo.edu are listed below:

2007

Cuskelly, M., & Gilmore, L. (2007). **Attitudes to sexuality questionnaire (individuals with an intellectual disability): Scale development and community norms.** *Journal of Intellectual & Developmental Disability, 32*(3), 214-21.

ABSTRACT: BACKGROUND: Attitudes to the sexual expression of adults with an intellectual disability (ID) are one reflection of the inclusiveness of a community. Our capacity to measure attitudes towards this important aspect of adult life is limited by the lack of an appropriate instrument. The aim of this study was to continue the development of a recently published questionnaire and to establish normative data. METHOD: The Attitudes to Sexuality Questionnaire (Individuals with an Intellectual Disability) (ASQ-ID: Cuskelly & Bryde, 2004) was modified slightly and questions about hypothesized stereotypical views of sexuality were added. A community sample of 261 adults completed this modified questionnaire, as well as a shorter version of the questionnaire about attitudes to sexual expression in typically developing adults. RESULTS: Factor analysis revealed one general factor associated with sexual rights, plus three other factors related to parenting, non-reproductive sexual behavior, and self-control. There were few differences in attitudes towards male and female sexuality, and attitudes were only slightly less positive for individuals with an ID than for those without a disability. Views about parenting by people with an ID were more cautious than for other aspects of sexuality. CONCLUSIONS: The present study established the factor structure of an instrument for measuring attitudes towards the sexual expression of adults with an ID and provided normative data. Community attitudes towards

the sexual rights of adults with an ID are generally quite positive. (PUBMED Abstract)

2006

Sakellariou, D., & Simo, A.S. (2006). **Sexuality and disability: A case of occupational injustice.** *British Journal of Occupational Therapy*, 69(2), 69-76.

ABSTRACT: The aim of this study was to explore the reasons for the reported unsatisfying sexual life and to reframe it in terms of occupational injustice and the denial of participation in meaningful occupation. In-depth interviews were conducted with six males with spinal cord injury. The participants found that societal beliefs and attitudes had an impact on their participation in sexuality-related occupations and this resulted in them experiencing occupational injustice. The study concluded that occupational therapists should consider occupational justice as one of the purposes of the profession and include issues of sexuality in their programs. (CIRRIE Abstract)

2005

Black, K. (2005). **Disability and sexuality: Holistic care for adolescents.** *Paediatric Nursing*, 17(5), 34-7.

No abstract is available.

2004

Bryde, R., & Cuskelly, M. (2004). **Attitudes towards the sexuality of adults with an intellectual disability: Parents, support staff, and a community sample.** *Journal of Intellectual & Developmental Disability*, 29(3), 255-64.

No abstract is available.

2002

Block, P. (2002). **Sexuality, parenthood, and cognitive disability in Brazil.** *Sexuality & Disability*, 20(1), 7-28.

ABSTRACT: This paper discusses the methods that were used to control the sexuality and fertility of Brazilian women with cognitive disabilities throughout the twentieth century. The emergence of eugenic sterilization, institutionalization, and other repressive measures of social control from cultural notions of gender, race, class, sexuality, and disability are also discussed. The eugenics practices and the vulnerability of women with cognitive disabilities in the United States and Europe

are discussed followed by the historical treatment of Brazilian women with cognitive disabilities. In the end, the most recent cultural perceptions and practices related to the sexuality and fertility of Brazilian women with cognitive disabilities are discussed. (CIRRIE Abstract)

1999

Berman, H., Enright, R., Gilpin, M., & Harris, D., et al. (1999). **Sexuality and the adolescent with a physical disability: Understandings and misunderstandings.** *Issues in Comprehensive Pediatric Nursing*, 22(4), 183-96.

ABSTRACT: The purpose of this descriptive study was to examine the areas of sexual knowledge, sexual behavior, and beliefs about sexuality among adolescents with congenital physical disabilities. The sample consisted of 15 males and 14 females, ranging in age from 12 to 22 years. The Sexual Knowledge Interview Schedule was administered to all participants during face-to-face interviews. In addition, the participants were asked questions regarding their ability to engage in intimate relationships and their future childbearing potential. Overall, the findings suggested that these adolescents are uninformed or misinformed about general sexual knowledge, have many misconceptions about sexuality and their disability, and depend on health care professionals and parents for sex education. Implications of this research are discussed. (PubMed Abstract)



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

2010

Coyle, K., Guerin, S., Lockhart, K., & Shanahan, S. (2010). **Expanding the test of counterfeit deviance: Are sexual knowledge, experience, and needs a factor in the sexualized challenging behavior of adults with intellectual disability?** *Research in Developmental Disabilities: A Multidisciplinary Journal*, 31(1), 117-130.

ERIC #: EJ863819

ABSTRACT: It is posited within the literature that the sexualized challenging behavior of adults with intellectual disability may be influenced by low levels of sexual knowledge, lack of sexual experience and unmet sexual

needs. In this study, individuals with sexualized challenging behavior were identified and matched for gender, age and ability level with individuals recruited to the non-sexualized and no challenging behavior groups. All (n = 24) were interviewed using the Socio-Sexual Knowledge and Attitudes Tool-Revised and the Sexual Knowledge, Experience and Needs Scale for Intellectual Disability to assess their sexual knowledge, experience and needs. Adaptive behavior was measured as a covariate. In the current study, contrary to expectations in the wider literature, the sexualized challenging behavior group showed significantly higher levels of sexual knowledge in several areas when adaptive behavior was controlled. Their needs in relation to dating and intimacy were also significantly higher but no differences were found between groups in relation to sexual experience. The implications of these findings for service provision are outlined along with the considerations of directions for future research.

Rogers, C. (2010). **But it's not all about the sex: Mothering, normalization, & young learning disabled people.** *Disability & Society*, 25(1), 63-74.
ERIC #: EJ882904

ABSTRACT: This paper is about mothering young learning disabled people, their sexualized and relationship lives and normalization—not through the lens of the disabled person, but via a mothers perspective and theoretical discussion. As a mother who has a learning disabled daughter, a feminist and an academic my own mothering experience, my Ph.D. research and social theory are woven throughout this paper with the intention of opening up debate about sex, intimacy and normalization, and how these impact upon young learning disabled people. I suggest that the relationship between sex, reproduction, intimacy and intellectual impairment and a project to decipher what it means to be human in all its dirty glory are also part of the discourse that needs to be discussed experientially and theoretically. So much so that the messy world within which we all live can be variously and differently constructed.

2009

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 #: EJ828608

ABSTRACT: We aimed to explore in detail the sexual lives and behavior of men with mild learning disabilities living both in community and in secure hospital settings. We wanted to generate hypotheses about them and iden-

tify 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 analyze 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 pressurized 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 utilized to provide further education and empowerment to improve the safety of sexual practices in this group. Other ways of improved service delivery are suggested.

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 #: 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.

2007

Anoemuah, O.A., Delano, G.E., Idowu, G.F., Ladipo, O.A., & Olaleye, A.O. (2007). **Sexual behaviors and reproductive health knowledge among in-school young people with disabilities in Ibadan, Nigeria.** *Health Education, 107*(2), 208-218.

ERIC #: EJ802234

ABSTRACT: Purpose: The paper seeks to explore sexual behaviors and reproductive health knowledge among in-school young people with disabilities (PWD) in Ibadan, Nigeria. Design/methodology/approach: In the paper a structured questionnaire was administered to 103 randomly selected PWD, aged ten to 25, from four integrated secondary schools in Ibadan. The data were collected through face-to-face interview. Five categories of disability included were hearing and speech, sight, speech, intellectual, and physical disabilities. Findings: The paper finds that 57 percent of the sample were females and 43 percent were males. Of the 36 (35 percent) respondents who were sexually active, 17 did not give a definite reason for their sexual initiation, nine were influenced by peers, five were "experimenting" with sex, four were raped, while one person began sexual activity for monetary gains. A total of 17 percent of the respondents had either procured abortion or been involved in the procurement of abortion for a sexual partner. In total 28 percent of the sample reported ever being raped. In total, 43 percent had been fondled, kissed, or caressed, against their wishes. Knowledge of contraceptives was reported by 40 percent. A total of 23 percent had never used condoms, while 6 percent were consistent condom users. Half of the respondents had heard about HIV/AIDS, 9 percent had tested for HIV, while 16 percent reported previous episodes of sexually transmitted infections. In total, 70 percent did not know where they could access reproductive health services. Originality/approach: The paper shows that there is an urgent need to develop specific programs for young people with disabilities, especially for those in schools, to address knowledge and behavior issues regarding reproductive health and HIV/AIDS.

2006

Miodrag, N., Richards, D., & Watson, S.L. (2006). **Sexuality and developmental disability: Obstacles to healthy sexuality throughout the lifespan.** *Developmental Disabilities Bulletin, 4*(1-2), 137-155.

ERIC #: EJ815715

Available in full-text at <http://www.eric.ed.gov/ERICWebPortal/contentdelivery/servlet/ERICServlet?accno=EJ815715>.

ABSTRACT: This paper presents a lifespan perspective of sexuality issues for individuals with developmental disabilities. Individuals with developmental disabilities are human beings who have historically been denied the right to express their sexuality or engage in sexual relationships due to misconceptions or negative attitudes. Using a hypothetical case to illustrate the challenges experienced by individuals with disabilities, human rights violations and the need for education and appropriate sexual information are highlighted. Issues such as eugenics, vulnerability to abuse, self-esteem, and individual differences are also discussed. Recommendations for practice are provided.

Wentzell, E. (2006). **Bad bedfellows: Disability sex rights & Viagra.** *Bulletin of Science, Technology & Society, 26*(5), 370-377.

ERIC #: EJ742442

ABSTRACT: The disability rights movement grounds material critiques of the treatment of people with disabilities in a social constructionist perspective, locating disability in the social rather than physical realm, and demedicalizing the concept of disability. However, this conceptualization is threatened by the medicalization of non-normative erections as the biomedical pathology erectile dysfunction (ED). Although use of medical treatments for ED can have positive outcomes for individuals, the medical community's tendency to include sexual difference in the rubric of disability threatens to remedicalize that category. Furthermore, medicalized conceptions of ED often serve to refocus sexuality around phallogentric, normative sex acts and gender roles, undoing the deconstructive work of disability sex studies. Finally, although aging Western populations targeted for ED treatment represent potentially expanded bases for disability movement activism, the pathologizing of nonnormative sexuality may have the power to instead focus this group on individualistic use of medical interventions geared toward "normalcy."

2004

Butler, J., Galea, J., Iacono, T., & Leighton, D. (2004). **The assessment of sexual knowledge in people with intellectual disability.** *Journal of Intellectual & Developmental Disability*, 29(4), 350-365.

ERIC #: EJ681097

ABSTRACT: The aims of this study were to evaluate components of a new tool, the Assessment of Sexual Knowledge (ASK), and to use it to assess the sexual knowledge of adults with intellectual disability. The ASK consists of a Knowledge Section, an Attitudes Section, a Quick Knowledge Quiz and a Problematic Socio-Sexual Behaviors Checklist. A sample of 96 adults with intellectual disability participated in the study. The Knowledge Section was administered twice (with a one to two week interval between testing) to examine its test-retest reliability. Inter-rater reliability was determined by having a second scorer for approximately a third of participants. The Quick Knowledge Quiz (QKQ) was also administered to examine its relationship with the Knowledge Section. The results of this study suggest that the ASK is a tool that is reliable across examiners and will also elicit responses that are stable over time. The relationship between the Knowledge Section and the QKQ indicated that the QKQ is a predictor of knowledge scores in the ASK. In terms of people with intellectual disability's knowledge, the results demonstrated their poor overall knowledge of sexuality, particularly in the areas of sexually transmitted infections, sexual health, safer sex practices, legal issues and contraception.

2002

Christian, L.A., Dotson, L.A., & Stinson, J. (2002). **Overcoming barriers to the sexual expression of women with developmental disabilities.** *Journal of the Association for Persons with Severe Handicaps (JASH)*, 27(1), 18-26.

ERIC #: EJ650486

ABSTRACT: This article discusses barriers to sexual fulfillment faced by women with developmental disabilities, including: access to gynecological healthcare, limited choices regarding reproductive issues, lack of sex education, and prevailing negative stereotypes that affect the way women are viewed by others and the way they view themselves. Recommendations are provided.

Hingsburger, D., & Tough, S. (2002). **Healthy sexuality: Attitudes, systems, and policies.** *Journal of*

the Association for Persons with Severe Handicaps (JASH), 27(1), 8-17.

ERIC #: EJ650485

ABSTRACT: This article discusses attributes of healthy human service systems and the importance of strong sexual self-advocacy by people with disabilities. It outlines how negative attitudes can have traumatizing effects on people with disabilities and argues that by developing positive attitudes a new era of healthy sexual development can begin.

2000

Garwood, M., & McCabe, M.P. (2000). **Impact of sex education programs on sexual knowledge and feelings of men with a mild intellectual disability.** *Education and Training in Mental Retardation & Developmental Disabilities*, 35(3), 269-83.

ERIC #: EJ614649

ABSTRACT: After participating in 6 to 10 sex education sessions, six adolescent and adult men with mild mental retardation showed minimal increases in their knowledge of friendship, contraception, pregnancy, sexual interaction, and social skills. Following sex education, negative feelings developed about marriage, having children, and being present during childbirth.

1998

Konstantareas, M.M., & Lunsky, Y. (1998). **The attitudes of individuals with autism and mental retardation towards sexuality.** *Education & Training in Mental Retardation & Developmental Disabilities*, 33(1), 24-33.

ERIC #: EJ577360

ABSTRACT: A study compared sociosexual attitudes of 31 adults with developmental disability, 15 with autism, and 16 with mental retardation, and 25 typical Canadians and 28 Americans. Most differences were contributed by the individuals with mental retardation who endorsed significantly fewer than 50 percent of sexual activities presented.

1996

Irwin, M.M. (1996). **Sexuality & people with disabilities.**

ERIC #: ED460455

ABSTRACT: This paper discusses issues included with obtaining educational information on sexuality pertinent to the needs of people with disabilities. First, the importance of providing correct information about sexuality

to individuals with disabilities for their mental and physical health is stressed. Specific areas briefly discussed are health-related issues (both general and disability-specific), appropriate and inappropriate sexual behavior, reproduction and pregnancy, and sexuality rights. Suggestions for libraries that serve people with disabilities are also offered, including suggested acquisitions and ways to provide accurate and accessible information. A list of resources includes 11 organizational resources and 18 print materials.

1995

McCabe, M.P., & Szollos, A.A. (1995). **The sexuality of people with mild intellectual disability: Perceptions of clients and caregivers.** *Australia & New Zealand Journal of Developmental Disabilities, 20*(3), 205-22.

ERIC #: EJ513556


ABSTRACT: The sexuality of 25 individuals with mild intellectual disability was assessed based on interviews that addressed their knowledge, experience, feelings, and needs. Compared to 39 college students and 10 care staff, subjects demonstrated a lower level of sex knowledge, less interactive sexual experience, equal frequencies of same-sex experiences, and higher levels of sexual abuse.

1990

Farrow, J. (1990). **Sexuality counseling with clients who have spinal cord injuries.** *Rehabilitation Counseling Bulletin, 33*(3), 251-59.

ERIC #: EJ412770

ABSTRACT: Examines effects of spinal cord injury on sexuality. Discusses areas of sexual concern. Provides suggestions for treating clients with spinal cord injuries experiencing sexual difficulties. Concludes that major goal in working with clients with spinal cord injuries who have sexual difficulties should be the facilitation of a creative and successful adjustment to the disability.

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

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 recognizing 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.

Darry, K., Esmail, S., Knupp, H., & Walter, A. (2010). **Attitudes and perceptions towards disability and sexuality.** *Disability & Rehabilitation, 32*(14), 1148-55.

PMID #: 20131952

ABSTRACT: PURPOSE: To describe current societal perceptions and attitudes towards sexuality and disability and how social stigma differs between individuals living with visible and invisible disabilities. METHOD: A qualitative approach was used to explore attitudes and perceptions towards sexuality and disability. 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 'Sexability' a documentary film on sexuality and disability to stimulate discussion midway through the session. RESULTS: Findings suggest that individuals with disabilities are commonly viewed as asexual due to a predominant heteronormative 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 factors towards the stigma attached to disability and sexuality. CONCLUSIONS: 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.

2008

Conod, L., & Servais, L. (2008). **Sexual life in subjects with intellectual disability.** *Salud Pública de México*, 50(Suppl 2), s230-8.

PMID #: 18470352

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 expectancy towards sexuality and which medical and educative support that 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.

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

Article is in Portuguese.

PMID #: 18813533

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.

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.

2005

Bonelli, R.M., Hofmann, P., Kapfhammer, H.P., Niederwieser, G., & Schmidt, E.Z. (2005). **Sexuality in multiple sclerosis.** *Journal of Neural Transmission*, 112(9), 1201-11.

PMID #: 15750683

ABSTRACT: Sexuality and partnership have an important influence on the quality of life of every person and also on people with chronic disorders such as multiple sclerosis. The findings in literature show high evidence that people with multiple sclerosis experience high levels of sexual dysfunction, most of them with hypoactive sexual behavior often associated with dissatisfaction in relationship, and also the partners seem to show lower sexual and partnership satisfaction. The most common problems in women are lack of sexual interest and decreased libido, often with problems in orgasmic capacity, while men report erectile dysfunction and also lack of sexual interest. The impact of the level of disability and duration of the illness remains unclear. Positive familial support can often help the patient in coping with the illness; nonetheless, problems with changing roles and multiple-sclerosis-minimizing can improve the need of contacts to outstanding persons.

Murphy, N. (2005). **Sexuality in children and adolescents with disabilities.** *Developmental Medicine & Child Neurology*, 47(9), 640-4.

PMID #: 16138674

ABSTRACT: This review presents a discussion of the sexual development of children and adolescents with disabilities, described in the framework of body structure and function, individual activities, and societal perspectives presented in the World Health Organization's International Classification of Functioning, Disability and Health. Issues of sexual development, gynecological care and contraception, sexual functioning, societal barriers, sexual victimization, and sexuality education are presented. Overall, adolescents with disabilities seem to be participating in sexual relationships without ad-

equated knowledge and skills to keep them healthy, safe, and satisfied. Although their sexual development may be hindered both by functional limitations and by intentional or unintentional societal barriers, the formal and informal opportunities for teenagers with disabilities to develop into sexually expressive and fulfilled persons do exist. Health care providers are urged to increase their awareness of this unmet need and to implement strategies that promote the physical, emotional, social, and psychosexual independence of children, teenagers, and young adults with disabilities.

2004

Ide, M. (2004). **Sexuality in persons with limb amputation: A meaningful discussion of re-integration.** *Disability & Rehabilitation*, 26(14-15), 939-43.

PMID #: 15497925

ABSTRACT: PURPOSE: Rehabilitation professionals do not appear to be sufficiently prepared to deal with the sexual issues of people with a physical disability, although they have recognized the value of discussing them during the rehabilitation process. This commentary argues that the sexuality of people with a disability should be evaluated from the two viewpoints of sexual function and sexual concern. With regard to people with a limb amputation, their sexual life has not attracted researchers' or clinicians' interest because their sexual function is usually preserved, is the same as that of able-bodied persons, and there is a perception that assistance is not required. Indeed, the number of published studies on the sexuality of this population is apparently fewer than the number of studies on the sexuality of persons with central nervous system impairment. CONCLUSION: Investigation of the body image of people with a limb amputation and recognition of their needs are considered to be necessary for further discussion of this theme. Discussion of sexuality with some realistic statistical figures should also have great value in assisting with the re-integration of people with a limb amputation.

2003

McCabe, M.P., & Taleporos, G. (2003). **Sexual esteem, sexual satisfaction, and sexual behavior among people with physical disability.** *Archives of Sexual Behavior*, 32(4), 359-69.

PMID #: 12856897

ABSTRACT: This study investigated the association between the severity and duration of physical disability and sexual esteem, sexual depression, sexual satisfaction, and the frequency of sexual behavior. A total of 1,196 participants completed the study. There were 748 participants (367 males, 381 females) who had a physical disability and 448 participants (171 males, 277 females) who were able-bodied. The age range of participants was 18-69 years, with a mean age of 36.39 years, and a standard deviation equal to 10.41. The results demonstrated that people with more severe physical impairments experienced significantly lower levels of sexual esteem and sexual satisfaction and significantly higher levels of sexual depression than people who had mild impairments or who did not report having a physical impairment. The study also found that people with more severe physical disabilities engaged in mutual sexual activity significantly less frequently. Women with physical disabilities had significantly more positive feelings about their sexuality and significantly more frequent mutual sexual experiences than their male counterparts. For people with physical disabilities, the frequency of oral sex and nude cuddling were significant predictors of sexual satisfaction in men, while the frequency of deep kissing predicted sexual satisfaction in women. Furthermore, the viewing of erotica was significantly related to sexual dissatisfaction in men. Finally, it was found that people who had experienced their physical impairment for a longer period of time reported significantly more positive feelings about their sexuality. Implications of these findings are discussed and suggestions are made for future research.

Sundquist, K.J., & Yee, L.A. (2003). **Older women's sexuality.** *The Medical Journal of Australia*, 178(12), 640-2.

PMID #: 12797854

ABSTRACT: In consultations with older women, doctors should ask about sexual problems. A holistic approach is needed to examine the many different factors that can affect sexuality. Hormonal changes associated with ageing have an impact on women's sexuality. Doctors need to have a clear idea of the place of hormonal treatment for different sexual problems. Physical changes associated with ageing, including illness and disability, may interfere with sexual expression. Diseases of the endocrine, vascular and nervous systems will most commonly affect sexual function. A broad range of psy-

chosocial factors associated with ageing may influence sexuality.

2002

Bryen, D.N., Klingbeil, F., Neufeld, J.A., Silverman, B., & Thomas, A. (2002). **Adolescent sexuality and disability.** *Physical Medicine & Rehabilitation Clinics of North America*, 13(4), 857-73.

PMID #: 12465564

ABSTRACT: Regardless of what our beliefs about sex and disability may be, as health care providers we can promote the health and well being of our patients with disabilities in several ways. First and perhaps foremost, physical and programmatic barriers to accessing general health care including routine gynecologic care must be dramatically reduced. The promise of Title III of the Americans with Disabilities Act must be aggressively extended to our health care system to ensure equal access to routine health care for all. Second, knowledge of community resources that can support the healthy development and exercise of responsible and satisfying sexuality is critical. For example, health care providers should know about adaptive and assistive technologies as well as the use of personal care assistants to support the healthy although sometimes non-typical expression of one's sexuality. Centers for Independent Living are community resources that are often underutilized by the medical profession. These centers — run by and for people with disabilities — are likely resources and allies for providing education, role models, and peer mentoring around relationships, intimacy, sexuality, sexual expression, and parenting with a disability. Finally, sex education is a must and should include the following: Basic facts of life, reproduction, and sexual intercourse; Human growth and development Human reproduction and anatomy Self-pleasuring/masturbation and the use of sexual aids Intimacy and privacy Pregnancy and child birth Contraception and abortion Family life and parenthood Sexual response and consensual sex Sexual orientation Sexual abuse HIV/AIDS and other sexually transmitted diseases. The question should not be whether sex education is provided to persons with disabilities, but rather how it is most effectively provided. Health sex education must include the development of effective communication skills, decision-making skills, assertiveness, and the ability to say "no." It must also include ways to create satisfying relationships.

2000

Low, W.Y., & Zubir, T.N. (2000). **Sexual issues of the disabled: Implications for public health education.** *Asia-Pacific Journal of Public Health*, 12(Suppl), S78-83.

PMID #: 11338746

ABSTRACT: Sexuality of persons with spinal cord injury has received increased attention especially in the Western countries. However, in the local context, studies pertaining to the sexuality of the disabled are almost nil. This paper utilized a qualitative approach in assessing sexual knowledge, attitudes and practices of persons with spinal cord injury. Eight focus group discussions consisting of 28 adult spinal cord injured persons were carried out. The results showed that the frequency of sexual activity decreased following injury. The disabled themselves have a negative self-concept and a low self-esteem and this affects their attitudes towards sexuality and their sexual behavior. Health care professionals tend to neglect this issue perhaps due to their insensitivity to the sexual needs for the disabled or a lack of understanding and expertise in this area. A need for sexual information related to their disability is warranted in the areas of reproduction, contraception and their ability/disability in achieving an erection or ejaculation. This study indicated a need for more comprehensive research in this neglected area of sexual issues of persons with disabilities. Public health education and counseling is deemed necessary for the disabled themselves so as to accommodate their sexual lives to their physical capabilities and desires; moreover, attitudes and misconceptions of the public need to be corrected. Above all, there is a need for education and training for health care professionals in the area of sexual rehabilitation, which is currently non-existent in the country. Perhaps, it is timely to incorporate sexual rehabilitation as part of a holistic medical rehabilitation of the disabled.

1997

(1997). **Talking about sex and disability: Communication and counseling needs.** *AIDS Action*, 35, 4.

PMID #: 12320859

ABSTRACT: PIP: Caregivers, families, and health workers tend to focus upon disabled person's physical needs and ignore sexual and emotional health. It can be especially difficult for a person with impaired speech or a learning difficulty to talk about their concerns. A good listener and counselor is someone who can make people feel relaxed and safe; use clear, simple language; avoid being judgmental; and have a good basic knowledge of

sex, contraception, HIV, and STDs. Disabled people, health workers, teachers, and caregivers all have important roles to play in discussing such issues. Growing up, life changes, and counseling and support are discussed. Disabled developing adolescents have sexual desires just like the nondisabled. It is not helpful to attempt to deny such individuals knowledge about sex and sexuality. People who become disabled as adults through illness or injury may experience low self-esteem and a sense of failure over the loss of being able to work or continue a sexual relationship.

Bianchi, T.L. (1997). **Aspects of sexuality after burn injury: Outcomes in men.** *Journal of Burn Care & Rehabilitation*, 18(2), 183-6; discussion 182.

PMID #: 9095431

ABSTRACT: A review of the literature provided documentation of a vital link between sexuality and one's adjustment to an acquired disability, such as disfiguring burns. Descriptive correlational research was used to study: (1) the relationship between severity of burn injury and sexual-esteem, sexual-depression, and sexual-preoccupation in burn-injured men, ages 19 to 39 years, and (2) the relationship between selected socio-demographic variables (age, marital status, educational level, ethnicity, length of time since burn injury, and length of time since discharge from the burn unit) and sexual-esteem, sexual-depression, and sexual-preoccupation. The convenience sample consisted of 40 male burn survivors treated and discharged from a burn unit in the southeastern United States within the past 11 years. Statistically significant direct relationships were demonstrated between sexual-preoccupation and sexual-esteem, whereas inverse relationships were demonstrated between age and sexual-preoccupation and also between sexual-esteem and sexual-depression. No relationship was demonstrated between severity of burn and sexual-esteem, sexual-depression, and sexual-preoccupation.

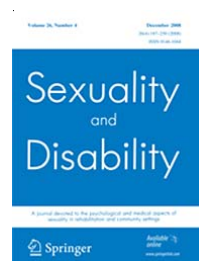
1990

Cromer, B.A., Enrile, B., Fitzpatrick, M., Gerhardstein, M.J., Judis, J., & McCoy, K. (1990). **Knowledge, attitudes, and behavior related to sexuality in adolescents with chronic disability.** *Developmental Medicine & Child Neurology*, 32(7), 602-10.

PMID #: 2143989

ABSTRACT: This study explored the level of knowledge, attitudes and activity related to sexuality in a group of adolescents and young adults with myelomeningocele, a group of matched controls and a group of adolescents with cystic fibrosis. Slightly more than half of

the study sample was female, the mean age was 17.2 years, and their backgrounds were mainly middle-class. 28 per cent of the myelodysplastic group reported previous sexual activity, compared with 60 percent of the control group and 43 per cent of the group with cystic fibrosis. Most of the disabled adolescents expressed a desire to marry and have children, but fewer than 20 per cent had sought information regarding their sexual or reproductive function from their physician. Among those sexually active, 60 percent of the controls and 67 per cent of those with cystic fibrosis had used contraception, compared with 16 per cent of the myelodysplastic group. The authors conclude that sex education and screening for contraceptive need is indicated for adolescents with chronic disabilities.



While researching the NARIC REHABDATA database on sexuality, intimacy, and disability one publication stood out as an authoritative, scholarly resource addressing the psychological and medical aspects of sexuality in the field of rehabilitation—*Sexuality & Disability*. The NARIC REHABDATA database listings resulted in over 30 citations referencing documents published in the journal of *Sexuality & Disability*. An international forum of peer-reviewed and original interdisciplinary scholarly papers, *Sexuality & Disability* includes research articles, review articles, case studies, clinical practice reports, survey data reports, and book and film reviews associated with sexuality related to a wide range of disabilities and conditions. This publication contributes to the knowledgebase and advancement of issues related to sexuality and disability in the rehabilitation, medical, academic, and community settings.

Editorial submissions should be submitted, in English, to the Editor's Office via the journal's web-based online manuscript submission and peer-review system at sedi.edmgr.com. Sigmund Hough, PhD, ABPP the Editor of *Sexuality & Disability* can be reached by phone at 617/323-7700, x 36443 or by email at sigmund_hough@hms.harvard.edu. *Sexuality & Disability* is published quarterly for the months of March, June, September, and December. The latest edition is available for purchase at www.springerlink.com/content/k41466644147.



Quick Looks

Online Resources Related to Sexuality, Intimacy, & 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

Family Village: Sexuality and Disabilities

www.familyvillage.wisc.edu/general/sexuality.htm

“Intimacy and Sexuality in MS”

A brochure from the National Multiple Sclerosis Society (NMSS)

www.nationalmssociety.org/download.aspx?id=152

National Sexuality Resource Center

Phone: 415/817-4525

Email: nsrcinfo@sfsu.edu

Sex & Disability:

nsrc.sfsu.edu/issues/sex-and-disability

nsrc.sfsu.edu

National Spinal Cord Injury Association (NSCIA) Resource Center—Sexuality

spinalcord.org/resources/index.php?link=S&list=88

Sexual Health and Disability Alliance (SHADA) in the UK

Email: Trust@Outsiders.org.uk

Sex & Disability Information/Resources:

www.shada.org.uk/?q=node/7

www.shada.org.uk

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Sexual Health and Fertility after Brain and Spinal Cord Injury

Resources and information from the from [ICORD \(International Collaboration On Repair Discoveries\)](#) and [Vancouver Hospital & Health Sciences Centre \(VHHSC\)](#) in Vancouver, British Columbia, Canada.
www.scisexualhealth.com/sandd.html

Sexual Health Information Related to Parkinson Disease

From the National Parkinson Foundation
www.parkinson.org/Parkinson-s-Disease/Living-Well/Sexual-Health

Sexual Health Information Page –

From [Paralysis Resource Center](#)
www.christopherreeve.org/site/c.mtKZKgMWKwG/b.4453429/k.8982/Sexual_Health.htm

Sexuality and Disability Information and Resources from Disaboom.com

www.disaboom.com/sexuality-and-disability

Sexuality and Intellectual Disability

From the American Association of Intellectual and Developmental Disabilities (AAIDD)
www.aidd.org/content_198.cfm

“Recovery after Stroke: Redefining Sexuality”

Stroke Fact Sheet from the National Stroke Association
www.stroke.org/site/DocServer/NSAFactSheet_Sexuality.pdf?docID=999

































































“Relationships Intimacy & Sexuality in MS”

From the Multiple Sclerosis International Federation (MSIF)
www.msif.org/en/about_ms/ms_by_topic/relationships_intimacy_sexuality/index.html

Video: Mount Sinai Spinal Cord Injury Health and Wellness Series

Chapter 3: *The True Nature of Intimacy*
Chapter 4: *Female Panel on Intimacy and Sexuality*
Chapter 5: *Man Panel on Intimacy and Sexuality*
spinalcord.org/news.php?dep=47&page=277









Search Terms for Sexuality, Intimacy & Disability

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|--|--|
|  Adjustment |  Motor Impairments |
|  Adolescents |  Normalization |
|  Aging/Elderly |  Occupational/Physical Therapy |
|  Alzheimer's Disease |  Paraplegia |
|  Amputation |  Parkinson Disease |
|  Aphasia |  Physical Disabilities/Severe/Significant |
|  Attitudes/Health Personnel/Negative |  Pregnancy |
|  Autism |  Psychiatric Disabilities |
|  Behavior |  Psychomotor Disorders |
|  Body Image |  Psychosexual Development |
|  Burns Injury |  Quality of Life |
|  Cerebral Palsy |  Reproductive Health |
|  Charcot-Marie-Tooth disease |  Self Advocacy |
|  Children with Disabilities |  Severe Disabilities |
|  Chronic Disease |  Sex Education |
|  Cognition |  Sex Factors/Stereotypes |
|  Contraception |  Sexual/Behavior/Dysfunction/
Gender Disorders |
|  Counseling |  Sexuality |
|  Cultural Diversity |  Sexually Transmitted Diseases (STDs) |
|  Cystic Fibrosis |  Social Adjustment/Attitudes/Bias/Influences/
Theories |
|  Dating (Social) |  Socialization |
|  Decision Making |  Spinal Cord Injuries (SCI) |
|  Developmental Disabilities |  Stereotyping |
|  Disabilities |  Stroke |
|  Disability Discrimination/Studies |  Taboo |
|  Discrimination |  Trends |
|  Diseases |  Visual Impairment/Blindness |
|  Gender Differences |  Young Adults |
|  Health/Attitudes/Holistic/Knowledge/
Practice/Promotion | |
|  Huntington's Disease | |
|  Intellectual Disabilities | |
|  Interpersonal Communication/Relationships | |
|  Intervention | |
|  Intimacy | |
|  Knowledge Level | |
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