

SIECUS wishes to thank staff intern Renee Muza and the following sexuality education professionals for their guidance: Donna Bernert, PhD, LSHE; Mary Greenfield, MAT, AASECT; C.J. Turett, MEd; Darrel Lang, EdD; Nancy Nowell, MPA, MEd; Bill Taverner, MA; and Mitchell Tepper, PhD, MPH.

### Websites

<http://www.sexsupport.org> **Susan's Sex Support Site** provides information about anatomy, behavior, civil rights, abuse prevention, gender identity, disability, and relationships in easy to understand, sex positive language with extensive links to other resources.

<http://www.teachingsexualhealth.ca> Canada's **Teaching Sexual Health** site was developed by educators and health professionals to provide parents, teachers, and students with information about sexual health and sexuality education. Includes materials for teaching learners with disabilities.

<http://www.sexualhealth.com> **Sexualhealth.com** provides a wide range of information, support and resources, including an "Ask an Expert" section that provides answers to reader's questions or concerns about disability and sexuality.

[http://www.brainline.org/function\\_pages/results.php#intimaterelationships](http://www.brainline.org/function_pages/results.php#intimaterelationships) The **Brainline.org** web site on prevention and treatment of traumatic brain injury includes a section on issues related to sexuality (look under "Intimate Relationships." Includes articles, videos, and other educational media.

[http://sexuality.about.com/od/sexdisabilityresources/Sex\\_and\\_Disability\\_Resources.htm](http://sexuality.about.com/od/sexdisabilityresources/Sex_and_Disability_Resources.htm) is the page for **About.com's** sexuality and disability resource page, with an exhaustive list of current websites.

### Books for Consumers

#### **A 5 Is Against the Law! Social Boundaries: Straight Up! An Honest Guide for Teens and Young Adults**

*Kari Dunn Buron*

Using a five point scale, this book explains what constitutes appropriate and inappropriate behavior to adolescents with Asperger Syndrome or autism. Chapters include "When a Kiss Becomes a Crime," "Understanding the Grey Areas," and "When Things Seem to Get out of Control."

2007; \$24; *Autism Asperger Publishing Company*

#### **Autism-Asperger's and Sexuality: Puberty and Beyond**

*Jerry Newport and Mary Newport*

Written for adolescents and young adults with autism spectrum disorders, chapters in this book include "When Desire Leads to a Bad Relationship," "The Best Way to Date Someone is to be Yourself," and "Surviving the First Wave of Sexual Interest."

2002; \$20; *Future Horizons*; <http://fhautism.com>

### **Freaks, Geeks, and Asperger's Syndrome: A User Guide to Adolescence**

*Luke Jackson*

Written by a teenager with Asperger Syndrome, the author writes about his life and the challenges he faces on a daily basis. Chapters include "Friendships and Socializing," "The Dating Game," and "Bullying."

2002; \$19.95; Jessica Kingsley Publishers

### **Gay, Lesbian, Bisexual and Transgender People with Developmental Disabilities and Mental Retardation: Stories of the Rainbow Support Group**

*John D. Allen*

This book chronicles the formation of the Rainbow Support Group and provides descriptions of the founding members. Each chapter highlights one member, in which that person describes his or her understanding of what it means to be a sexual minority with a developmental disability.

2003; \$54; Routledge

### **The Girls' Guide to Growing Up: Choices & Changes in the Tween Years**

*Terri Couwenhoven*

This book just for girls with intellectual disabilities is an introduction to the physical and emotional changes they'll encounter during puberty. Written on a third-grade reading level for girls to read by themselves or with a parent. Includes age-appropriate facts, realistic illustrations and photos, icons, and a Q&A.

2011; \$16.95; Woodbine House; <http://woodbinehouse.com>

### **MS and Intimacy: Managing Specific Issues**

*Tanya Radford*

This booklet is for people living with multiple sclerosis (MS) and their partners. It addresses the importance of communication between partners and discusses sexual problems associated with MS for both men and women. Includes a list of other national resources.

2000; Free to clients; National Multiple Sclerosis Society

Only Online at: <http://www.nationalmssociety.org/chapters/DCW/programs--services/information-and-referral/brochures/managing-specific-issues/index.aspx>

### **Sex Education for Parents of Children with Autism Spectrum Disorder**

*Mark Steege and Shannon L. Peck*

This manual is designed to give parents assistance in their efforts to educate their children about their emerging sexuality in explicit yet sensitive ways. It addresses general, common anxieties parents have in terms of discussing sexuality with their children, as well as issues that are specific to children on the autism spectrum.

2002; \$37; Steege Corporation, San Antonio, TX

### **Sex, Sexuality, and the Autism Spectrum**

*Wendy Lawson and Glenys Jones*

Written by an adult on the autism spectrum from her vantage point as a lesbian, the author explores issues such as sexuality education, relationships, and same sex attractions. Chapters include “Discovering Bisexuality, Homosexuality and Transgender Dispositions,” “Making it Work,” and “Building a Safe Space.”

2005; \$21.95; *Jessica Kingsley Publishers*

### **Sex When You're Sick: Reclaiming Sexual Health after Illness or Injury**

*Anne Katz*

This book considers how illness and injury affect sexuality and offers strategies to overcome sexual difficulties after health challenges. Chapters include “Sexuality in Medical Disease,” “Sexuality Across the Lifespan,” and “Sexuality and Cancer in Both Men and Women.”

2009; *Praeger*; \$43

### **Sexuality: Your Sons and Daughters with Intellectual Disabilities**

*Karin Melberg Schwier and Dave Hingsburger*

Information for parents and caregivers to help them interact with their children—of any age or ability—and to increase their children’s self-esteem, encourage appropriate behavior, empower children to recognize and respond to abuse, and enable them to develop lifelong relationships. Throughout the book, parents share their joys and challenges in raising children with intellectual disabilities, while offering advice and practical strategies.

2000; \$24.95; *Brookes Publishing*

### **Take 3 Steps to Women’s Health! A Workbook for Women with Developmental Disabilities**

*Jacilyn E. Fricks and Lucille Martin Duguay*

A workbook that provides essential health information and takes the mystery out of routine breast and pelvic screenings. Three women of different ages and abilities act as role models to empower others to increase their breast health awareness, to tolerate the clinical breast exam, the GYN exam, and a mammogram. Full color photos and illustrations, along with simple language and workbook activities, reinforce the important health messages.

2010; \$20 *Oak Hill Center for Relationship and Sexuality Education* <http://oakhillcrse.org/index.asp>

### **Taking Care of Myself: A Healthy Hygiene, Puberty and Personal Curriculum for Young People with Autism**

*Mary Wrobel*

This book is written to help parents teach sexual hygiene to children with autism with the goal of fostering good habits that sustain wellness and independence. The book is organized into 7 units: Hygiene, Health, Modesty, Growth and Development, Menstruation, Touching and Personal Safety, and Masturbation.

2003; \$25; *Future Horizons*; <http://fhautism.com>

### **Teaching Children with Down Syndrome About Their Bodies, Boundaries, and Sexuality**

*Terri Couwenhoven*

For parents of children with Down syndrome, this book provides parents with guidance on initiating conversations about sexuality. Topics include respecting personal space, understanding gender identity, showing appropriate levels of affection, and preventing sexual abuse.

2007; \$25; Woodbine House; <http://woodbinehouse.com>

### **Ten Tips for Healthy Relationships: A Workbook for Adults with Developmental Disabilities**

*Jacilyn E. Fricks and Lucille Martin Duguay*

A workbook for adults with developmental disabilities, to assist decision-making about safe relationships. Using simple language, full color pictures, and a variety of concrete scenarios and activities, this manual addresses important topics related to self-esteem, consent, assertiveness, trust, and commitment within different relationship contexts, including friendship and dating. Can be completed independently, under the guidance of a care provider, or within a facilitated group.

2010; \$25 Oak Hill Center for Relationship and Sexuality Education <http://oakhillcrse.org/index.asp>

### **The Ultimate Guide to Sex and Disability: For All of Us Who Live with Disabilities, Chronic Pain, and Illness, 2<sup>nd</sup> Edition**

*Miriam Kaufman, M.D. Cory Silverberg, Fran Odette*

Written for adults, this book provides guidance on creating active, healthy sex lives for people with disabilities. Discusses sex toys, tantric sex, how to talk about sexual issues with physicians, how to approach potential sex partners, and how to build a positive self-image.

2007; \$19; Cleis Press

### **Unwritten Rules of Social Relationships: Decoding Social Mysteries through the Unique Perspectives of Autism.**

*Dr. Temple Grandin and Sean Barron*

Written for anyone who has ever struggled through a social encounter, this guide to social relationships was written by two individuals with autism. Chapters include "How the Autistic Way of Thinking Affects Social Understanding," and "Rule #1: Rules Are Not Absolute: They are Situation Based and People Based."

2005; \$25; Future Horizons; <http://fhautism.com>

### **Venus on Wheels: Two Decades of Dialogue on Disability, Biography, and Being Female in America**

*Gelya Frank*

A cultural biography of Diane DeVries, a woman without arms or legs who has rejected her doctors' recommendations for prostheses. An anthropological analysis of DeVries' sexual autonomy and her participation in the 1970s women's and disability rights movements. Chapters include "My Introduction to Diane," and "the Crisis of Representation: Why it is Time for Cultural Biography."

2000; \$26.95; University of California Press

## **Books for Professionals**

### **Asperger's Syndrome and Sexuality: From Adolescence through Adulthood**

*Isabelle Henault*

This guide to understanding sexuality and its expression among individuals with Asperger Syndrome includes chapters titled “Asperger’s Syndrome and Sexual Development,” “Sexual Diversity and Gender Identity,” and “Inappropriate Sexual Behaviors: Comprehension and Intervention.”

2006; \$27; *Jessica Kingsley Publications*

### **Assessment and Treatment of Sex Offenders with Intellectual Disabilities: A Handbook**

*Leam A. Craig, William R. Lindsay and Kevin D. Browne*

In this book, the editors analyze and summarize recent literature that discusses the treatment and management of sex offenders with developmental and intellectual disabilities. Chapters include “Attachment Problems and Sex Offending,” “Assessment of Sexual Addiction,” “Internet Sex Offenders,” and “Advances in the Treatment of Adult Incarcerated Sex Offenders.”

2010; \$56; *Wiley-Blackwell*

### **Crip Theory: Cultural Signs of Queerness and Disability**

Robert McRuer

This book analyzes the ways in which queer theory and disability theory intersect. Chapters include “Compulsory Able-Bodiedness and Queer/Disabled Existence” and “Coming Out Crip: Malibu is Burning.”

2006; \$24; *New York University Press*

### **Doing What Comes Naturally? Dispelling Myths and Fallacies about Sexuality and People with Developmental Disabilities**

*Orieda Horn Anderson and Jennifer Luvert*

This book addresses sexual activity, sexual relationships, and sexuality education for professionals who work with individuals with developmental disabilities. The authors discuss signs that indicate sexual abuse, how to properly address behavior problems, and counseling techniques.

2000; \$19.95; *High Tide Press*

### **Educators Who Integrate Students with Disabilities** (book chapter)

*Donna Bernert, PhD*

In Bernert’s chapter from *Partners in Prevention* (the American School Health Association’s guide to whole-school approaches), professionals learn about strategies for the inclusion of adolescent students with disabilities into general education sexuality education. Pages 213-23.

2006; \$49.95 plus shipping for *Partners in Prevention: Whole School Approaches to Prevent Adolescent Pregnancy and Sexually Transmitted Infections*; American School Health Association

### **Ethical Dilemmas: Sexuality and Developmental Disability**

*Dorothy Griffiths, Debbie Richards, Paul Federoff, and Shelley L. Watson*

In this book, the authors address ethical issues relating to sexuality and developmental disabilities including consent to sexual relationships, sterilization and birth control, sexual offenses and more. Chapters include “Parents with Intellectual Disabilities: Impediments and Support,” “Inappropriate Sexual Behavior: Inherent or Taught?” and “Sexual Rights and Individuals Who Have Developmental Disabilities.”

2002; \$35; *National Association for the Dually Diagnosed*

### **A Guide to Consent**

*Robert Dinerstein, Stanley Herr, and Joan O’Sullivan, Editors*

This guide explores the legal aspects of self-determination among people with mental retardation. Topics include adult guardianship, consent to sexual activity, capacity in courts, and consent to legal representation. Still widely regarded as a reliable reference work in the field.

1999; \$27.95; *American Association on Intellectual and Developmental Disabilities*

### **Impact Newsletter: Feature Issue on Sexuality and People with Intellectual, Developmental and Other Disabilities**

*University of Minnesota Institute on Community Integration*

This special issue of *Impact* features several articles by experts in sexuality education and disability advocacy, addressing a range of issues. Contributors explore the right and opportunity for people with intellectual, developmental, and other disabilities to understand and express sexuality as an essential dimension of human life.

2010; Spring/Summer, v23, n2; <http://ici.umn.edu/products/impact/232/232.pdf>

### **Learning Disabilities, Sex, and the Law, 2<sup>nd</sup> Edition**

*Claire Fanstone and Sarah Andrews*

Formatted in Q-&-A style, this publication provides guidance around issues relating to sexuality, disability, and laws in England and Wales but may be useful for comparisons with other nations’ legal provisions. Topics addressed include prostitution, sexual abuse, abortion, and contraception.

2009; \$24; *Family Planning Association of London*

### **Sexuality and Disability, 4<sup>th</sup> Edition**

*Maddie Blackburn*

A handbook which explores the sexual needs and knowledge of 100 young adults with spina bifida and hydrocephalus. It examines issues of disabled persons and the law (mainly the British and Welsh system), sexual and relationship experience of the sample population, sexual abuse and violation, and the availability of sexuality education.

2002; \$57; *Butterworth-Heinemann*

### **Sexual Difficulties After Traumatic Brain Injury and Ways to Deal With It**

*Ronit Aloni and Shlomo Katz*

This book focuses on improving the social and intimacy skills of Traumatic Brain Injury (TBI) survivors so that they may return to society and establish relationships in which they will be able to function sexually. The book is designed for professionals in the fields of rehabilitation and physical medicine, as well as counselors and psychologists.

2003; \$34.95; *Charles C. Thomas Publishers*

### **Sexuality and Fertility Issues in Ill Health and Disability: From Early Adolescence to Adulthood**

*Rachel Balen and Marilyn Crawshaw*

A collection of essays by various health professionals and patients about the range of experiences encompassing sexuality and disability. Essays include "Sexuality and Growing up HIV Positive: Lessons from Practice," "Unintended Catharsis through Intended Art," and "The Sting in the Tail: Teenagers Coping with Sperm Banking Following Cancer Diagnosis."

2006; \$48; *Jessica Kingsley Publishers*

### **The SSKAAT-R: Socio-Sexual Knowledge and Attitudes Assessment Tool – Revised**

*Dorothy Griffiths, Ph. D. and Yona Lunsky, Ph. D.*

A tool for psychologists to assess sexual knowledge of persons with intellectual disabilities. Covers topics such as anatomy, menstruation and menopause, masturbation, pregnancy and parenting, contraception, STDs, privacy, and healthy boundaries. Kit available.

2003; Price available by quote; *Stoelting Co.* <https://www.stoeltingco.com>

### **The VISCAT: A Tool for Measuring Sexual Consent Capacity in People with Developmental Disabilities.**

*William J. Taverner, MA and Dr. Christopher DeMarco*

The Verbal Informed Sexual Consent Assessment Tool (VISCAT) is a diagnostic tool to assist professionals with preparing education, counseling, and support plans for individuals with disabilities.

\$30 plus shipping; Contact Bill Taverner at [taverner@ptd.net](mailto:taverner@ptd.net) to order

## Curricula/Teaching Resources

### **Breast Health for Women with Intellectual Disabilities**

*Lucille Martin Duguay*

A curriculum for caregivers with everything they need to teach the practical steps to breast health, including self-examination, clinical exams and mammograms for women of all ages and different abilities. Includes a manual, slides, worksheets and laminated flashcards.

2007; \$69 *Oak Hill Center for Relationship and Sexuality Education* <http://oakhillcrse.org/index.asp>

### **Circles Curriculum**

*Leslie Walker-Hirsch IM.Ed., FAAIDD and additional co-creators*

For students with mild to moderate cognitive impairment, the Circles Video Modeling Curriculum teaches relationship boundaries and relationship-specific behaviors, using a simple multi-layer circle diagram to demonstrate the different relationship levels students will encounter in daily life.

Accompanied by 16 DVDs with material that dramatizes real-life challenges, and guides interpersonal teaching and learning.

*Curriculum package \$1,999; James Stanfield Co.; [www.stanfield.com](http://www.stanfield.com)*

### **Developmental Disabilities and Sexuality Curriculum: Sexuality Education for Adults with Developmental Disabilities**

*Katherine McLaughlin, Karen Topper, and Jessica Lindert*

Includes an instructor manual, 20-lesson curriculum, and pre/post test kit. The curriculum is cognitively accessible for a variety of learner and comes with scripts, handouts, detailed pictures, and teaching tools.

*2009; \$250; Planned Parenthood of Northern New England and Green Mountain Self-Advocates*

### **The Facts of Life and More: Sexuality and Intimacy for People with Intellectual Disabilities.**

*Leslie Walker-Hirsch*

A book with four sections: the first addresses sexuality education and special education; the second explores the cultural phenomenology of sexuality and disability; the third assesses potential risks associated with sexual activity; and the fourth section discusses treatment issues.

*2007; \$30; Paul H. Brookes Publishing Co.*

### **F.L.A.S.H. Special Education: A Curriculum in Family Life and Sexual Health for Middle & High School Students with Special Needs**

*Jane Stangle, et al.*

A curriculum designed by the Seattle Public Health Department's Family Planning Program. For ages 11-21 in self-contained classes. Consists of twenty-eight lesson plans. Topics include Private & Public Relationships, Communication, Exploitation, Understanding the Body, Reproduction, HIV/AIDS & Other STDs. Available on-line or can be purchased in hard-copy format.

*2006; \$60; Seattle-King County, Washington State*

<http://www.kingcounty.gov/healthservices/health/personal/famplan/educators/SpecialEducation.aspx>

### **Intimate Relationships and Sexual Health: A Curriculum for Teaching Adolescents/Adults with High-Functioning Autism Spectrum Disorders and Other Social Challenges**

*Catherine Davies and Melissa Dubies*

This curriculum provides frank, up-to-date resources on sexuality tailored to the unique characteristics of high-functioning adolescents and adults on the spectrum. Based on experience teaching sexual health to individuals with autism spectrum disorders, the authors cover 'all you ever wanted to know but were afraid to ask/teach', focusing on unique learning styles inherent in autism. Accompanied by a CD of electronic resources.

*2011; \$28; AAPC Publishing*



### **Introduction to Sexuality Education for Individuals Who Are Deaf-Blind and Significantly Developmentally Delayed**

*Kate Moss and Robbie Blaha*

Written for parents and professionals, this text offers information and instructional guidance for delivering sex education to deaf-blind students who also have cognitive disabilities. Issues of self-expression related to gender identity, modesty, and appropriate touch are discussed. Specific instruction is included for teaching about menstruation, masturbation, hygiene, health, and sexual abuse.

2001; *Western Oregon University Teaching Research Institute (Monmouth, OR)*

Only On-line at: <http://nationaldb.org/documents/products/sex-ed.pdf>

### **Learn About Life Curriculum: Sexuality and Social Skills**

An illustrated program for students with low or no reading skills, this curriculum includes a teacher's guide with six chapters, 40 lessons, and a Student Resources Packet, featuring six laminated, full-color booklets. The program covers issues such as puberty, dating, STDs, and pregnancy.

2003; \$69; *Attainment Company*

### **Mike's Crush DVD and Curriculum**

*Nancy Nowell, MPA, MEd*

A curriculum and DVD for learners age 15-21. Teaches safe relationship skills to youth with autism, Asperger Syndrome and other intellectual disabilities. Videos show the "right" and "wrong" way to start friendships and other intimate relationships. Designed to keep youth safe from sexual abuse or contact with the criminal justice system because of a misunderstanding or lack of knowledge.

2011; \$159; *Social Signals LLC, Wayne, PA*; <https://socialsignals.com>

### **Positive Choices: A Program on Healthy Relationships, Sexuality, and Safe Boundaries for Secondary Students with Intellectual and Developmental Disabilities**

*Lucille Martin Duguay*

A curriculum to increase learners' critical judgment about relationships and sexuality. Piloted in Greater Hartford, CT, with guidance from an advisory board of self-advocates, parents, educators, clinicians, and administrators. Contains 31 instructional units based on Connecticut State Department of Education Comprehensive School Health Standards. Over 220 scenarios for discussion, role-play and skill rehearsal, plus rubrics, tests, student manuals, and a CD-ROM.

2009; \$850 *Oak Hill Center for Relationship and Sexuality Education* <http://oakhillcrse.org/index.asp>

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