This bibliography combines the bibliographies built by Charles Lund and Liam Ennis as posted on the ASTA Listserv in 2002 and 2003 and updates/adds to them. When the bibliography was provided to ATSA List members recently, quite a few members responded with numerous additional citations and various leads for further information. As a result, the May 2004 bibliography was been revised and expanded considerably twice now, resulting in this, July 2004 version. The literature is vast and this is in no way a complete bibliography. In particular, not included here are numerous studies that provide incidence and epidemiological data.

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Publishers Specializing in Disabilities, Developmental Disabilities, Special Needs


The mission of the Autism Asperger Publishing Company (AAPC) is to "be your first source for practical solutions related to autism, Asperger Syndrome, and other pervasive developmental disorders." The AAPC also publishes a newsletter and sponsors conferences.


The Institute publishes a newsletter and a journal, The New Zealand Journal of Disability Studies. The Institute also publishes various books. All can be reached through the main web page.


Brookes has a variety of "guidebooks, texts, curricula, videos, and tools based on the best research in disabilities, education and child development."

Child Welfare League of America (CWLA)  http://www.cwla.org

CWLA publishes a number of books and informational resources.

Diverse City Press  http://www.diverse-city.com

Publishes much of David Hingsburger's and his colleagues' work.

Free Spirit Publishing  http://www.freespirit.com

"produces award-winning books and learning materials for children, teens, parents, educators, counselors and everyone else who cares about kids."

Future Horizons  http://www.futurehorizons-autism.com

Bills itself as "the leading publisher in the world in autism/Asperger's primarily because [the owner's] son, Alex, was diagnosed with autism."

Learner Managed Designs, Inc.  http://www.lmdusa.com

Offers "the best in health and education resources for those serving infants, toddlers, school-aged children and young adults with special needs and their families. Our resources are developed by nationally recognized professionals who share our concern for kids with special needs. Our award-winning resources are used for in-service training, parent education, staff development and graduate studies."


Has a variety of books, videos, and curriculums. See their materials in Sexuality and Sex Education, Conflict Management, Social and Life Skills, School to Work Skills, and At Risk. Especially good on sexuality issues are the Circles, Life Horizons, and DateSmart curriculums. For conflict management, the Be Cool curriculum is excellent.


"is a leading publisher of nationally standardized test, resource and reference texts, curricular and therapy materials, and professional journals" that includes special education (developmental disabilities, rehabilitation, gifted education), as well as speech, language and hearing; psychology and counseling; early childhood intervention; and occupational and physical therapy. PRO-ED also publishes the following journals: Communication Disorders Quarterly; Focus on Autism and Other Developmental Disabilities; Intervention in School and Clinic; Journal of Emotional and Behavioral Disorders; Journal of Learning Disabilities; Journal of Positive Behavior Interventions; Journal of Special Education; Rehabilitation Counseling Bulletin; Remedial and Special Education; Topics in Early Childhood Special Education; and Word of Mouth. See the web site for details and http://www.ingenta.com for access to tables of contents.

Compiled by Alan Listiak, Ph.D.  Minnesota Dept. of Corrections
Selected Web Sites on Disabilities, Developmental Disabilities, and Special Needs

The American Association on Mental Retardation  http://www.aamr.org

An excellent source for current and past (to 1999) references. Quote from the web page: “The Current Awareness Bulletin (CAB) is a short, quick-reference guide of the latest books, journals and reprints available at the Tighe Resource Centre. We produce the CAB once a month for our clients, staff and other community organizations. The CAB also lists upcoming disability and rehabilitation conferences.”

Center for Effective Collaboration and Practice  http://www.air.org/cecp
The Center is devoted to “improving services for children and youth with emotional and behavioral problems; helping communities creates schools that promote emotional well-being, effective instruction and safe learning; and supporting effective collaboration at a local, state and national level.”

Council for Exceptional Children (CEC)  http://www.cec.sped.org
An international professional organization “dedicated to improving educational outcomes for individuals with exceptionalities, students with disabilities, and/or the gifted.”

The site has a New and Noteworthy section and sections on autism, ADD, and Cerebral Palsy. Written and overseen by Lewis Mehl-Madrona, M.D., Ph.D., the sections on autism, ADD, and Cerebral Palsy each have excellent overviews of the theories and treatments of these disorders, an interactive web forum, and an extensive list of links.

International Association for the Scientific Study of Intellectual Disabilities  http://www.iassid.org

J. P. Das Developmental Disabilities Centre  http://www.ualberta.ca/~jpdasddc/INDEX.html
Has a variety of resources and links. The Centre publishes the Developmental Disabilities Bulletin. Current issue and back issues of the bulletin can be obtained at http://www.ualberta.ca/~jpdasddc/bulletin/index.html.

The International Coalition on Abuse and Disability (ICAD) Listserv
Has about 200 members in 12 countries. To join, send an email message to majordomo@majordomo.srv.ualberta.ca and in the body of the message type “subscribe ICAD” (without the quotation marks). If you have difficulty joining, contact dick.sobsey@ualberta.ca.

Has a list of and links to many resources.

Sopris West  http://www.sopriswest.com
Publishes and distributes books and programs, and provides professional services for the education of children and youth, especially those at risk for school failure.

Woodbine House  http://www.woodbinehouse.com
Publishes a wide range of books and materials for all kinds of disabilities, including The Special Needs Collection, which added 8 titles for Spring 2004.
National Association for the Dually Diagnosed (NADD)  http://www.thenadd.org

At NADD you can access (partially) current and past issues of the NADD Bulletin. To access the full articles in the Bulletin, you have to be a paid-up member of NADD. Another good web site is the Ontario Chapter of the NADD at http://www.dualdiagnosisontario.org.


National Association on Mental Retardation (ARC)  http://www.thearc.org

National Center on Education, Disability and Juvenile Justice (EDJJ)  http://www.edjj.org

“examines the overrepresentation of youth with disabilities at-risk for contact with the courts or already involved in the juvenile delinquency system. We provide professional development and technical assistance, conduct research and disseminate resources in three areas of national significance: prevention of school failure and delinquency, education and special education for detained and committed youth, and transition services for youth returning to schools and communities.” EDJJ also publishes a newsletter, EDJJ Notes. Subscription is free and available on the web page.


The National Institutes of Health, National Institute of child Health and Human Development has a Mental Retardation and Developmental Disabilities Branch (MRDD)  http://www.nichd.nih.gov/crmc/mrdd/mrdd.htm

The Pacer Center  http://www.pacer.org

Psychological Software Services  http://www.neuroscience.cnter.com/pss/PSSCogReHab/index.htm

Sells the PSSCogReHab software program. A demo is available for downloading. The blurb on the web page says that PSSCogReHab is used by psychologists, occupational therapists, speech therapists, rehabilitation specialists and special teachers. The software is described as “the most comprehensive and easy-to-use multimedia cognitive rehabilitation software available. The eight software packages in this system include some sixty-four computerized therapy tasks, most of which contain User modifiable parameters that extend the utility of each program to fit nearly any requirement presented by your patient or student. The focus of the individual exercises extends from simple attention and executive skills, through multiple avenues and modalities of visuospatial and memory skills all the way up to, from simple to extremely complex, problem solving skills. This compendium of programs has been twenty + years in the making and is programmed to take advantage of the cutting edge of computer technology. The tasks included, the theoretical backdrop from which the tasks have emanated and the manner and order of presentation have been developed and refined by twenty years of clinical use of these programs in earlier and the current versions with over 1500 patients with compromised brain functioning at a clinical treatment facility, The NeuroScience Center of Indianapolis. These patients include those with traumatic injury, stroke, tumor, neurological disease, learning disability and attention deficit disorders.”

Psychological Software Services is the parent of NeuroPsychOnline  https://www.neuropsychonline.com/enter.htm

According to the webpage, “NeuroPsychOnline is a subscription website providing web based clinical applications for the assessment, diagnosis and treatment of injury, disease or anomaly of the central nervous system. As you will learn from this tour, NeuroPsychOnline (NPO) is unlike most websites in that we actually provide working, interactive programs and applications that run directly in your web browser when you select them. There is no software to purchase and install. Upgrades are automatic since you run from the one and only master every time you select a program. And, once you subscribe as a provider ($50.00 per month), you have unlimited use of the software to assess, diagnose, write clinical reports about and treat an unlimited number of patients.”

QualityMall.org  http://www.qualitymall.org/services/about.asp

“The primary purpose of QualityMall.org is to collect and disseminate information related to or useful in promoting quality of life for persons with developmental disabilities. It is not a retailer or vendor of products or services, but uses the theme of a shopping mall to help connect visitors to the best products and services available. People involved with, experienced with, or simply aware of such services are invited to visit QualityMall.org, shop the many "stores," and make recommendations for new products and services.”

The Special Needs Project (SNP)  http://www.specialneeds.com/store/

Is a source for “good books about disabilities” and includes many materials in Spanish.
TASH http://www.tash.org

An organization for equity, opportunity and inclusion for people with disabilities that publishes a monthly news magazine, TASH Connections, and the journal, Research and Practice for Persons with Severe Disabilities.

Women with Developmental Disabilities http://www.npi.ucla.edu/wdw/

Selected Web Sites for ADD/ADHD and Learning Disabilities

ADD/ADHD Online Newsletter http://www.nlci.com/nutrition
A free monthly publication “for helping children and adults with ADHD.” It has an emphasis on nutrition. Laura J. Stevens, MS, is the publisher. She has a book available through the web site called 12 Effective Ways to Help Your ADD/ADHD Child that addresses “the biological, environmental and nutritional pieces of the puzzle.”

ADD Clinic http://www.the-add-clinic.com/addinfo.htm

The ADHD Owner’s Manual http://www.edutechsbs.com/adhd/
Developed and operated by Neil Alex, MD.

ADHD/Special Needs/Attention Deficit Disorder and Related Learning Style Differences http://adhd.kids.tripod.com
Here are “Resources for Parenting and Teaching Misunderstood Kids Who Thrive ‘Outside the Box!’”

Attention Deficit Disorder Association http://www.add.org

Attention deficit Hyperactivity Disorder Information Library http://www.newideas.net

Attention Research Update http://www.helpforadd.com
David Rabiner, Ph.D. writes and publishes this free newsletter that provides information about recent research on ADHD. Reportedly has over 25,000 subscribers. Sign up at the web page.

The Bible’s Way to Victory over ADHD and Other Childhood Challenges http://christian-parenting.learninginfo.org
A free online book, no author cited, presenting a Christian approach that provides “sound answers on preventing and overcoming behavioral, emotional and learning problems, including ADD, ADHD, ODD, and Conduct Disorder.”

One reviewer said: “This is a book that should be compulsory reading for every parent and would-be parent, for every student, for every pastor, for every medical doctor, for every teacher. There is no one who has anything to do with children and their development who should not read this book... If you care about your child, if you love your child, you will read this book and be informed as to what is happening around you...” — Rev. Brian Darroll, Radio Pulpit.

Children and Adults with Attention Deficit/Hyperactivity Disorder (CHADD) http://www.chadd.org

CHADD is a membership organization that bills itself as “the nation’s leading non-profit organization serving individuals with Attention Deficit/Hyperactivity Disorder (AD/HD). Through collaborative leadership, advocacy, research, education and support, CHADD provides science-based, evidence-based information about AD/HD to parents, educators, professionals, the media and the general public.” The organization has a national resource center, a monthly ask the expert chat, and a bimonthly magazine entitled Attention!

Discussion Forum on Attention Deficit Disorder http://add.about.com/mpboards.htm
Register for free.

Dr. Mac’s Amazing Behavior Management Advice Site http://behavioradvisor.com
A site for educators/teachers. Dr. Tom McIntyre’s introduction says “This site offers THOUSANDS of tips on managing student behavior, and provides step-by-step directions for implementing a great number of standard interventions. It also contains a bulletin board on which you can post your disciplinary concerns and receive suggestions from teachers around the world.” Dr. Mac also has a book for sale.

This book is written at a 4th to 5th grade reading level and can be used with ages 9-15. The blurb says the book “guides youngsters to better understand themselves and the problems their behavior creates. In kid language, “Dr. Mac” describes what BD is (and isn’t), the types and causes of BD, and special school programs for kids with BD. He provides many strategies that kids can use to handle strong feelings and make positive choices. Stories and quotes from real kids labeled as being behavior disordered let readers know they’re not alone; “IDEA! boxes” present activities for practicing these new ways to behave. Kids learn to believe in themselves, take responsibility for their actions, make smarter choices, and enjoy the results of their better behavior. The book includes a glossary and additional resources for kids, parents, and teachers.”

Learning Disability Institute (LDI)  [http://www.ldinstitute.org/index.shtml](http://www.ldinstitute.org/index.shtml)

The LDI "is a national non-profit organization whose mission is to determine and disseminate successful approaches to and provide scholarships for diagnostics, prevention and treatment for persons of all ages with Learning Disabilities." LDI has a certification program and trains Certified Instructors (special education teachers) and Certified Master Trainers (trainers of teachers) in successful approaches for best practices in academic teaching and in the prevention and remediation of most forms of Specific Learning Disabilities.

LDOnLine  [http://www.ldonline.org](http://www.ldonline.org)

LDOnLine bills itself as "the leading web site on learning disabilities for parents, teachers, and other professionals. It publishes a monthly newsletter that has free subscription. Also has numerous articles available and hosts a variety of bulletin boards.

National Center for Learning Disabilities  [http://www.ncld.org](http://www.ncld.org)

National Resource Center on AD/HD  [http://www.help4adhd.org](http://www.help4adhd.org)


Nonverbal Learning Disorders (NDL)  [http://www.nldline.com](http://www.nldline.com)
**Selected Web Sites on Autistic Spectrum Disorders**

**ASAFARI**  [http://ctrf.net/asafari](http://ctrf.net/asafari)

An online gallery of art by children with Asperger’s Syndrome, autism, hyperlexia, PDD, and “cousins.”

**Autism-Asperger’s Digest**  [http://www.autismdigest.com](http://www.autismdigest.com)

A bimonthly magazine that is billed as “the premier source of information for parents and professionals on Autism, Asperger’s and PDD. Featuring original articles and material from sources around the world, each 52 page issue covers the latest people, products, research, news & viewpoints emerging in the autism field.” Subscriptions for US residents cost $49.95 US ($59.95 non-US) for one year or $79.95 ($99.95 non-US) for two years (“It’s like getting 4 issues free). The contents of past issues can be viewed and some past issues can be purchased for $5.

**Autism Network for Dietary Intervention (ANDI)**  [http://members.aol.com/AutismNDI/PAGES/links.htm](http://members.aol.com/AutismNDI/PAGES/links.htm)

Advocates and provides information on diet and vitamins as treatments for ASDs.


See the ARI Publications List for a wide variety of ARI pamphlets, papers, books, and videotapes on subjects related to autistic spectrum disorders. Related pages are the Center for the Study of Autism at [http://www.autism.org](http://www.autism.org) and [http://autism.com](http://autism.com).

**Autism Resources**  [http://www.autism-resources.com/](http://www.autism-resources.com/)

Managed by John Wobus and has a comprehensive book list, advice, and much more on autism and Asperger’s Syndrome.

**Autism Society of America**  [http://www.autism-society.org](http://www.autism-society.org)

Membership is $30 for individuals, $100 for professionals, $500 for agencies — all include a one year subscription to *The Advocate Newsletter*, which is published quarterly.


**Autism Today**  [http://www.autismtoday.com](http://www.autismtoday.com)

Bills its web site as “everything you need to know about autism.” The site can be perused as a guest or as a registered member. Registration is free and comes with a subscription to the bimonthly newsletter, *Autism Today*.

**The Maze: Jypsy’s Autism Links**  [http://www.isn.net/~jypsy/autilink.htm](http://www.isn.net/~jypsy/autilink.htm)

Regarded as one of the largest collections of addresses for autism-related web sites – with a dose of humor.

**National Alliance for Autism Research**  [http://www.naar.org](http://www.naar.org)

**Online Asperger’s Syndrome Information and Support (O.A.S.I.S.)**  [http://www.udel.edu/bkirby/asperger/](http://www.udel.edu/bkirby/asperger/)

Run by Patty Bashe and Barb Kirby who market their book, *The OASIS Guide to Asperger’s Syndrome*, (Crown, 2001) through the web site. Several forums are available here including, the OASIS: Asperger Syndrome Forum and the OASIS: Raising Teens and Young Adults with AS Support Forum, which are open to parents, adult family members, and caregivers. Registration is free. Also available is a list and links to free and purchasable diagnostic rating scales for Asperger’s Syndrome, newsletters, an up-to-date bookstore, and much other information/links.

**Selected National Resources for Information on Autism Spectrum Disorders**  [http://www.iidc.indiana.edu/irca/family/famnatresources.html](http://www.iidc.indiana.edu/irca/family/famnatresources.html)

Complied by Marci Wheeler and Siegal Eli of the Indiana Resource Center for Autism.
Fetal Alcohol Syndrome/Fetal Alcohol Exposure

Web Sites

The Alcohol Related Birth Injury (FAS/FAE) Resource Site  http://www.arbi.org

Fetal Alcohol Syndrome – Everything You Need to Know About Fetal Alcohol Spectrum Disorders  http://www.come-over.to/FAS

National Organization on Fetal Alcohol Syndrome  http://www.nofas.org/main/index2.htm

Has much information and many resources.

FAS Community Resource Center  http://www.come-over.to/FASCRC/

Provides “information about Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Spectrum Disorders (FASD). There are several articles on FAS and sexuality available here.

Fetal Alcohol and Drug Unit at the University of Washington  http://depts.washington.edu/fadu/

A web site filled with resources, research, and publications.

Books and Articles


Guidelines and Best Practices/Evidence Based Treatments


**Background:** Practice-based evidence represents the contribution of practitioners who utilize research methodologies to examine the quality of their clinical practice and service provision. **Methods:** The present paper describes the evolution of a routine practice-based evidence system (PBES) via four phases of research and development. The four phases are described, as is their relevance to assessment and intervention with regard to the mental health problems of people with mild intellectual disability. Phase four describes the development of a routine PBES. **Results:** The PBES is capable of profiling the individual mental health needs of service users and examining service effectiveness and quality at an organizational level. **Conclusions:** The PBES is discussed according to its current utility and possible directions for future development. The system is presented as an example of clinical governance that could be utilized by multidisciplinary teams to develop and maintain an organizational culture of quality.


Virginia Commission on Youth (2002). *Collection of Evidence-Based Treatment Modalities for Children and Adolescents with Mental Health Treatment Needs.* Available at [http://coy.state.va.us/Modalities/contents.htm](http://coy.state.va.us/Modalities/contents.htm).

**Legal and Ethical Issues**


### Some Web Sites with Resources on Sexuality and Disability/Developmental Disability

  - Has much information and many national and state level resources at.

- **Addup.org** [http://dev.addup.org/](http://dev.addup.org/)
  - Is the Administration of Developmental Disabilities online resource for communication and collaboration. There are search engines for a resource library, projects and priorities, and products.

- **The Disability Resource Library** [http://www.medicine.uiowa.edu/uhs/drl/index.cfm](http://www.medicine.uiowa.edu/uhs/drl/index.cfm)
  - At the Center for Disabilities and Development, University of Iowa Hospitals and Clinics is an excellent resource. Persons in surrounding states can even borrow materials from the library. You can get research assistance from experienced staff, and booklets, brochures, and hanging files of current information on a wide range of disability-related issues.

- **National Dissemination Center for Children with Disabilities (NICHCY)** [http://www.nichcy.org](http://www.nichcy.org)
  - Gathers the research on “what works” with children and students with disabilities and passes it along through research-focused publications and links to relevant materials, projects and Web sites.

- **Sexual Health.com** [http://www.sexualhealth.com](http://www.sexualhealth.com)
  - Presents many aspects of sexuality as related to disability. There are many links as well as many commentaries on a wide variety of topics.

  - Has a list of “Materials on the Subject of Sexuality.”

### Some Selected Sexuality and Sex Education Guides and Curricula


Heighway, S., & Webster, S. K. (1993). *STARS 2: A Guidebook for Teaching Positive Sexuality and the Prevention*. Madison, WI: Waisman Center UAP, University of Wisconsin–Madison. This publication is now being distributed by Susan Heighway. To request an order form, please contact her at the following: Susan Heighway, P.O. Box 5122, Madison, WI 53705, 608–263–5996 or by e-mail at: heighway@waisman.wisc.edu.

Heighway, S., & Webster, S. K. (1998). *STARS: Skills Training for Assertiveness, Relationship Building and Sexual Awareness* (5th edition, Ed.). Madison, WI: Waisman Center UAP, University of Wisconsin–Madison. This publication is now being distributed by Susan Heighway. To request an order form, please contact her at the following: Susan Heighway, P.O. Box 5122, Madison, WI 53705, 608–263–5996 or by e-mail at: heighway@waisman.wisc.edu.

Horton, Tim, & Frugoli, Tracey, (no date). *Healthy Choices: Creative Ideas for Working with Developmentally Delayed Sex Offenders*. Bloomington, IL: Acme Halo. [Focuses on DD juvenile sex offenders in residential settings.] This workbook can be ordered on the web for $30 plus $3 shipping/handling at [http://www.healthychoices4dd.com/](http://www.healthychoices4dd.com/) or by mail from Healthy Choices, PO Box 933, Bloomington, IL 61702–9033.


http://sexsupport.org/DDresources.html.

The Committee on Sexuality advocates for persons with developmental disabilities “to have opportunities for social relationships and sexual expression. [It does] this by promoting education, counseling and advocacy.” Web page is at http://www.w3ddesign.com/committee/.

The Planned Parenthood of Greater Iowa web page has a comprehensive list of curricula on various topics related to sexuality: http://www.ppgi.org/view_edsvcs.asp?page_id=curriculum.


**Videos**


“Roots and Wings is a video on sexuality education for teenagers with cognitive disabilities. In this video you will meet several teens with special needs and watch caregivers and parents prepare them for adulthood. The strong roots of caregivers, family, and friends help the teenagers develop their wings of independence.” (Quoted from the informational blurb on the order page.)


This book and video set discusses privacy, pleasure and the realities of sharing living spaces with others. The narrator of the video talks about myths and suggests that masturbation can be a way of learning about sex, while the book discusses masturbation from the point of view of both health and pleasure. (from the Diverse City web page).


“For too long others have determined what people with disabilities need to know to stop victimization. This video involved people with disabilities in acting, writing, producing and directing a film aimed at others with disabilities. From discussing disability to teaching boundaries and body parts, people with disabilities take the lead.” (from the Diverse City web page)


“This training package looks at the delicate issue of touch. Those who provide direct care to people with developmental disabilities are often asked to be in private places performing intimate services. From bathing to toileting to dressing, we are
necessarily in close proximity to those we serve. Given this situation, it is imperative that staff be aware of how to provide these services while maintaining appropriate professional boundaries. How do we appropriately express affection toward those we serve? This video suggests new and healthy ways of helping people with disabilities fulfill their deepest needs.

The package includes over 2 hours of lecture on 'touch', 'privacy' and 'boundaries' by renowned trainer Dave Hingsburger and a manual, co-authored by Mary Harber of the Sexual Health Resource Network, which staff can use to participate in the training.” (from the Diverse City web page).


“This book and video set is aimed at teaching women with developmental disabilities about masturbation. It also confronts typical myths about female sexuality. A gentle, positive film that is clear, graphic and dignified. The book includes a step by step photographic essay about masturbation, and the joy of private time.” (from the Diverse City web page)


“In this video, counselors who work with clients with developmental disabilities who have been sexually abused talk about the challenges and rewards of their work. A select group of successful counsellors from the US, England, and Canada provide practical insights and strategies for effective counseling.”

Purchase price is $60 for NADD members, $75 for non–members. Order at [http://www.thenadd.org/cgi-bin/store/store.cgi?&shop=city&cart=68289350x24423&session=40d533695f670346&L=enq&P=CT98-826V](http://www.thenadd.org/cgi-bin/store/store.cgi?&shop=city&cart=68289350x24423&session=40d533695f670346&L=enq&P=CT98-826V).

NADD has a number of videotapes for sale in social and sexual issues, as well as other categories. Enter the NADD Store at [http://www.thenadd.org/content/products/home.shtml](http://www.thenadd.org/content/products/home.shtml).

Two Training Videos are available from YAI National Institute for People with Disabilities. *Group Counseling Tapes (#700A and B)*

Using the Interactive-Behavioral Model Dr. Dan Tomasulo teaches staff how to conduct peer support group counseling sessions, identify factors which enable staff to access how participants are benefiting from peer-supported group counseling, and use specialized role-playing techniques. Tape #1 describes his techniques using examples from an actual group. Tape #2 shows a complete group counseling session with a group of adults who have developmental disabilities.


McCann, Scott, Lucas, Irene Semer (1999). *All of Us: Talking Together; Sex Education for People with Developmental Disabilities*. Video recording in English and Spanish. Sherborn, MA:

From the advertising blurb: This videotape “addresses the critical need for sex education for developmentally disabled young people by providing step-by-step information and direction. Parents, their young adult sons and daughters with developmental disabilities, and educators demonstrate practical models. A detailed sex education segment includes reproductive anatomy, pregnancy, contraception, and disease prevention. Social skills are considered along with the desire for friendship, companionship, romance and relationships. Public and private behavior is also covered as well as sexual abuse reporting.”

Available from Program Development Associates, P.O. Box 2038, Syracuse, NY. Phone: 800–543–2119. Purchase price is $99.95. Web site: [http://www.disabilitytraining.com](http://www.disabilitytraining.com). A number of other videos available in several topical categories are available from these folks.

Sexuality and Sex Education


Abstract: This paper arose as a consequence of joint working between therapists of two different disciplines – clinical psychology and speech and language therapy – on a case involving a young woman who required an assessment of her sexual knowledge and attitudes. It explains how the recent development of a method of communication for those with a severe communication disorder (Talking Mats) has meant that it has become possible to work with those who have a severe learning disability and poor communication. In the past, clients with both severe learning disability with poor communication may have been excluded from traditional and cognitive therapy, which was dependent to a large extent on verbal communication. This paper, therefore, is of value in extending the range of methods for assessment and intervention that may be used by a range of disciplines with people showing severe learning disabilities and severe communication disorder.


Research and practice in sexuality and learning disability has directly and indirectly highlighted the pathological sexual behaviour of men with learning disabilities, particularly their abuse and exploitation of women with learning disabilities, and relatively high HIV risk sexual behaviour with men without learning disabilities. It is consequently argued that there has been a relative neglect of their wider sexuality and sexual needs. This paper reconstructs this wider agenda, drawing on empirical evidence and theoretical interpretations of need from research and sex education in support of the observations made. In identifying a range of key issues for sexuality work with men with learning disabilities and arguing that they require greater recognition and attention, the paper also provides directional pointers for informing such work and for responding more widely.


Kempton, W., Hanson, G., & Adams, B. (1978). *Sexuality and the mentally handicapped (Slide presentations and teacher’s guide)*. Santa Monica, CA: Stanfield Film Associates.


Abstract: This study reports on the development and assessment of the psychometric properties of three measures to assess sexual knowledge, experience, feelings, and needs. The first was designed to assess the Sexual Knowledge, Experience, Feelings, and Needs of people with mild intellectual disabilities (SexKen-ID). The two parallel measures were designed to assess the same areas of sexuality among people with physical disabilities (SexKen-PD) and among the general population (SexKen-GP). The areas of sexuality included in the scales were Friendship, Dating and Intimacy, Marriage, Body Part Identification, Sex and Sex Education, Menstruation, Sexual Interaction, Contraception, Pregnancy, Abortion and Childbirth, Sexually Transmitted Diseases, Masturbation, and Homosexuality. Generation of the items in these scales is described in Studies 1–3. Study 4 describes the evaluation of the psychometric properties of the scales. Sixty-six people with intellectual disabilities, 54 people with physical disabilities, and 100 people from the general population completed the scales. Test-retest reliabilities were also calculated with 30 people with intellectual disabilities, 30 people with physical disabilities, and 30 people from the general population. These data demonstrate the good psychometric properties of the scales and so their suitability for assessing the sexual knowledge, experience, feelings, and needs of people with disability.


Bibliographies


A Selected Bibliography on Sexuality and People with Disabilities is available from the Center for Disability Information and Referral at the Indiana Institute on Disability and Community. Get it at this web page: http://www.iidc.indiana.edu/cedir/sexualitybib.html. Bibliographies on a variety of topics are also available.


The Samuel Gridley Howe Library at Brandeis University has posted a bibliography of Sexual Offenses/Inappropriate Sexual Behavior of People with Mental Handicaps at http://www.brandeis.edu/lemberg/SCHL/Subpages/Collections/bibs/Sex%20Offences.PDF.


Literature Reviews


A systematic review of research on offenders with intellectual disability (ID) was conducted. In the present study, the first of a two-part presentation of the findings, the authors outline the methodology of the review and present data on the prevalence of offending by adults with ID. The review highlights the methodological problems of the research and the low level of rigour in many of the studies. The organization of the penal and ‘care’ systems are seen to have a huge impact on research findings. In addition, studies which adopt an IQ-based concept of ID show low rates of offending, whilst those which use wider definitions (e.g. attendance at special school) show higher ones. There is also preliminary evidence for believing that the prevalence of arson and sexual offences may be higher relative to other kinds of crimes for people with ID than for other offenders.


In the present study, the second part of a review of offending by adults with intellectual disability (ID), data on predisposing factors are presented and there is a discussion of the overall conclusions. The available data are shown to be problematic in a number of respects: there is no offence-specific data; and a number of dimensions are under-explored, specifically race, class and subjective accounts of offenders. Age and gender were the most highly correlated factors, as they are with offenders generally; however, there does appear to be evidence that the average age of offenders with ID is higher than for other offenders. The present authors note with concern the inattention to mainstream criminological research, and a tendency to downplay the extent to which an ‘offender’ is the outcome of complex and multifarious social processes. The authors also argue that the literature is dominated by unsubstantiated assumptions regarding the direction which policy and practice should take.


David Hingsburger and Colleagues


“This three hour lecture describes a means of increasing meaning and purpose in the life of people with developmental disabilities. Self esteem is never far behind. Recorded live, Dave is at his best mixing old stories and new. Inspiration that informs. A remarkable achievement.” (from the Diverse City web page)


In his second I book, Mr. Hingsburger examines issues concerning self-concept and people with developmental disabilities, with a strong message of "fitting-in" without "giving-in." This very readable book suggests that the reader's everyday actions and interactions can give a powerful message of ability and strength rather than the devastating message of dependence and disability.

This highly acclaimed book dissects and explores the assumptions and myths, all too often embraced by both professionals and general society, that mistakenly define, reduce and disregard the sexuality of individuals labeled as developmentally disabled.  This fascinating and well-written book addresses attitudinal and practical issues and does not confine the definition of sexuality as simply the issues of body parts and genital contact.  Through clear and poignant examples, this book examines the challenges and issues faced by individuals who are disabled and offers both parents and professionals suggestions on what can be done to make a difference.


Dave writes about the importance of understanding behaviour messages from people with developmental disabilities in a straight forward yet humorous fashion.  *Behaviour Self* gives insight to parents and staff with new ways on how to get the message right!


A forty page book written for direct care providers. Power Tools challenges the reader to constantly evaluate their use of power when serving people who have disabilities. It is at turns comfortable and at turns reassuring. Written with warmth and humour, it's a must read for all direct care staff.


Assessment and Treatment – Inappropriate Sexual Behavior, Sex Offenders and Nonsex Offenders


The present authors conducted a study of the occurrence of victimization and the perpetration of sexual abuse among 43 inpatients with intellectual disability aged between 9 and 21 years who were admitted to a child and adolescent psychiatric in-patient department over a period of 5 years. A retrospective case-note review was employed that explored the nature and severity of abuse in relation to the age, gender and level of disability. The prevalence of abuse or abusive behaviour, i.e. 14% of 300 admissions, did not change over time. In 13 out of the 43 cases, the issue of sexual abuse was identified after admission. Victimization alone occurred in 21 cases, perpetration alone in six cases, and both victimization and perpetration in 16 cases. Fifty per cent of the victims had been abused by a member of their close or extended family. Most cases (62%) were adolescents. There was only one instance of a victim being abused by a female. However, there were five girls who were perpetrators, all of whom had previously been victims. By contrast, 11 out of the 17 male perpetrators had been victims. Despite difficulties of disclosure, it was possible to establish that severely disabled patients had suffered sexual abuse. The present data support theories which (1) recognize gender differences in sexual abuse patterns and (2) have a developmental perspective, incorporating the influence of adolescence.


Background: Intellectually disabled offenders (IDO) are a poorly served and under-recognized group, who are likely to require long-term specialist treatments and interventions. Method: This prospective study investigated the characteristics and factors that influence outcome in this group, with particular reference to therapeutic interventions. Sixty-one individuals were identified from contact with either (1) specialist health and social services for people with intellectual disability (ID) or (2) nonspecialist services in the criminal justice or (forensic) mental health/social service systems. The participants were assessed at baseline and after a mean of 10 months in order to compare recidivism rates and the impact of therapeutic interventions. Results: The findings suggest that IDO start offending at an early age, that they frequently have a history of multiple offences, and that sex offending and arson are over-represented offence types. Those participants recruited from nonspecialist ID services had significantly higher IQs and were less likely to have had contact with community social and health support agencies. Despite the high rates of psychopathology, there was little evidence for efficacy of therapeutic interventions, which, where offered, appeared to be of a nonspecific nature. At second interview, approximately half of the sample had re-offended.


BACKGROUND: A number of authors note that distorted cognitions may play a significant role in sex offending behaviour in both the people with intellectual disability (ID) and general populations. However, no scales have been specifically developed for use with individuals with ID. To date, there is no valid, reliable, self-report questionnaire that assesses cognitive factors in these individuals. This paper aims to develop a valid, reliable self-report questionnaire to assess antisocial attitudes consistent with sex offending behaviour in individuals who have mild ID. METHODS: Seventeen male individuals with ID who had sexually offended were compared with two non-sex offender groups: 19 males with and 36 males without ID. The Questionnaire on Attitudes Consistent with Sex Offending (QACSO) measure was used to establish sexual attitudes in the three groups. The reliability and validity of the QACSO was examined. RESULTS: The groups were compared and results demonstrated that the QACSO is a promising tool in terms of providing an internally consistent, reliable and valid indicator of cognitive distortions/attitudes held by sex offenders with ID. CONCLUSIONS: The limitations, suggestions for modification, potential uses of the questionnaire and directions for further research are proposed.


The present study addressed two issues using a sample of child and adolescent victims and perpetrators of sexual abuse: (1) the extent of post-traumatic stress disorder (PTSD) in the sample; and (2) the possible distinction between perpetrators whose motivations were sexually impulsive, and those who were controlling and abuse-reactive. Retrospective case material from 43 cases (21 victims only, and 22 perpetrators, of whom 16 were also victims) provided the data. Post-traumatic symptomatology was not common. Only one case of PTSD was found. Perpetrators could be distinguished by whether they had suffered sexual abuse alone, sexual and physical abuse, or neither. The proposed distinction between perpetrators received support. Sexual abuse directed at younger victims was associated with earlier experience of multiple forms of abuse. The present data does not support the view that post-traumatic symptoms following victimization are a mediator of sexual abuse perpetration. It is argued that an elaboration of the Williams & New developmental model of perpetration better fits the data.


Abstract. Individuals who display dangerous behavior towards others have historically been under-treated and under-researched. This paper discusses three published case studies wherein adult males were effectively treated for severe aggression towards others, the environment, and, in two cases, self-injury. All were diagnosed as having mental retardation and two also had a psychiatric diagnosis. All had experienced years of failed attempts to control their aggression through large pharmacological interventions and restricting their freedom of movement via restrictive environments. The use of comprehensive multifaceted behavioral programs involving punishment resulted in dramatic and long lasting reductions in aggression, the elimination or great reduction of drug use, and major lifestyle improvements. The conceptual, clinical, political, legal, philosophical, and ethical considerations that arose during the development and implementation of the programs are discussed as well as scientific issues related to achieving long term maintenance. An early published case study (Martin & Foxx, [1973]) is discussed first because it illustrates how an informal functional analysis was used to design a very simple and effective non-punishment treatment program for a woman who displayed dangerous aggression. Copyright © 2003 John Wiley & Sons, Ltd.


Hingsburger, David – see the separate category for Mr. Hingsburger.


**OBJECTIVES:** To review patterns of physical and sexual abuse in cohorts of sexual offenders and nonsexual offenders with intellectual disability. **METHOD:** Forty-six sexual offenders were compared with 48 male nonsexual offenders in relation to their...
experiences of sexual and physical abuse in childhood. Comprehensive assessments were taken over a period of at least one year, and were conducted independently by a range of professionals. RESULTS: Thirty-eight percent of the sexual offenders and 12.7% of the nonsexual offenders had experienced sexual abuse, while 13% of the sexual offenders and 33% of the nonsexual offenders had experienced physical abuse. CONCLUSIONS: Sexual abuse seems a significant variable in the history of sexual offenders, while physical abuse seems a significant variable in the history of nonsexual offenders. The results support the view that the “cycle of abuse” is neither inevitable nor an adequate explanation of future offending.


BACKGROUND: It has been suggested that sexual offending by people with intellectual disability (ID) results from a pattern of impulsive behaviour that is consistent with psychosocial disadvantage, rather than sexual deviancy. This study aimed to explore this hypothesis by assessing levels of impulsiveness in sexual offenders, non-sexual offenders and non-offenders with mild ID. METHOD: Impulsiveness was assessed using a modified version of the Barratt Impulsiveness Scale (11th edition). Total impulsivity scores were compared between sexual offenders, non-sexual offenders and non-offenders, all with mild ID. RESULTS: There was a significant difference in the levels of impulsiveness between sexual offenders and non-sexual offenders with ID (t=2.83, P<0.01). The sexual offenders were less impulsive than non-sexual offenders. CONCLUSIONS: This study did not support the hypothesis that sexual offending by people with ID is better explained by impulsive behaviour rather than sexual deviancy. It supports recent findings that among the general population, sexual offenders are less impulsive than controls and violent offenders.


Background This report describes a group intervention for men with an intellectual disability who have sexually offended or abused others. The group was in response to referrals to a psychology department. The majority of these individuals had not been subject to legal proceedings. Methods A number of assessments were conducted prior to the group, immediately after the group and at 3– and 6-month follow-up. Results Attitudes consistent with offending reduced after participation for most participants, however, these tended to revert to pre-group levels over time. Locus of control became more external after the group treatment, this was contrary to expectations and results obtained with interventions for individuals without an intellectual disability. Knowledge tended to increase after the group, however, problems with the questionnaire used made interpretation of the results difficult. No further incidents of sexual abuse have been recorded by any of the five group members who completed the group, since the start of the group (a period of 1 year to date). Conclusions This group should be seen as a pilot project. However, further therapeutic work is indicated as is theoretical and questionnaire development.


**BACKGROUND:** Sexual aggression by men with intellectual disability (ID) is a serious problem requiring attention from the relevant agencies. Training for staff working with this problem is often not given sufficient attention and is rarely evaluated. In the present study, an introductory workshop for direct care staff that aimed to increase knowledge and improve attitudes towards work with this client group was evaluated. **METHOD:** Sixty-six staff working in inpatient and community settings completed a 2.5-day workshop. Before training began, the participants completed a survey questionnaire concerning their experiences of work with this client group. An assessment of their knowledge and attitudes was carried out prior to and at the end of training in order to evaluate any changes. The participants also rated the effectiveness of the workshop and their level of satisfaction with the training at the end of the workshop. **RESULTS:** The participants’ knowledge and attitudes improved significantly following the workshop. Staff with greater experience over time and those who had worked with fewer sex offender clients responded to different aspects of the training. The participants’ ratings indicated that they were highly satisfied with the training and found it to be effective. **CONCLUSIONS:** Brief workshop training is acceptable to and can be effective in improving the knowledge, attitudes and confidence of direct care staff working with sex offenders with ID. However, because the results are based on participant self-report, caution should be exercised concerning their external validity.


Assessment and Treatment - Non-offenders


Although children with developmental disabilities have a heightened risk for sexual abuse compared to those without disabilities, little is known about effects of sexual abuse on this population. Some researchers suggest that the effects are similar, and victims appear to share the same range of variability as people without disabilities. Others suggest that the effects may be complicated by limited coping resources and disability-related issues. Documented effects of sexual abuse on individuals with developmental disabilities was discussed. Clinical findings among a group of 43 children with and 43 children without developmental disabilities referred for treatment of child sexual abuse were also presented.


Abstract: “The Wheel of Wellness incorporates 16 characteristics of healthy people, depicted using four concentric circles and 12 spokes, identified through medical and psychosocial research as important components of wellness throughout the life span. This approach is solidly within the foundations of human development that are historically at the core of counselor education and practice in schools, colleges, and many agencies related to employment and rehabilitation. As both an enhancing and remedial intervention, counselors can assist clients in the process of assessing their wellness in components of the Wheel of Wellness and in developing wellness plans to facilitate positive growth and change across the life span. Additional
research is needed to determine the most effective strategies for change to enhance wellness in each component of the model. Furthermore, although we know that the various dimensions of wellness interact and overlap, the extent to which some areas of the model are more closely related to, and thus more likely to have an impact on, other areas of the model has not been determined..."


"An outstanding reference that covers: 1) characteristics of a therapeutic environment for preventing and treating challenging behavior, 2) setting the occasion for effective implementation of behavior support plans: essential components and staff training procedures, 3) monitoring and evaluating staff proficiency in implementing behavior support plans, and 4) increasing, maintaining, and improving staff proficiency in carrying out behavior support plans." (quoted from Hairston, 2003, p. 55)


"This validated training curriculum has been designed for supervisors and direct support staff. It has all the materials you would need to train supervisors and direct care support staff on how to cope with challenging behavior before it occurs. There is a Supervisory edition (approximate costs $395.00) and a Direct Support edition (approximate costs $295.00). The books have been broken down into 26 modules covering all the necessary areas to assist families and staff to assist people with developmental disabilities lead more independent lives." (quoted from Hairston, 2003, p. 56)


The approach known as "transdisciplinary, whole person assessment and treatment" is described in step-by-step detail by the co-founder of The Community Circle in Denver, Colorado.


Abstract: This literature review examines the use of school-based positive behavior support (PBS), an alternative to traditional disciplinary practices that includes databased decision making and team collaboration. The article first examines the role of archival data in planning intervention priorities and then examines and evaluates efficacy research focusing on the three types of PBS: school-wide (universal), specific setting, and individual student levels. Overall findings of this review were positive across all types of PBS, validating implementation of these research-based practices. This review concludes with a discussion of directions for future research and implications for practice.


From the description on the AAPC web site: “This book is a groundbreaking, personal look at the sexual challenges of those diagnosed with autism or Asperger’s Syndrome. Authors Jerry and Mary Newport were both diagnosed with Asperger's Syndrome as adults. They spent much of their lives trying to be "normal" and never quite fitting in. They beat the odds by becoming one of the few married autistic couples that have not only found love, but kept it alive. Here they share their firsthand knowledge of the challenges of sex and help guide young autistic adults and their caregivers through this sometimes bewildering but fascinating topic.”


Abstract: “One of the most controversial issues in behaviour management has been the urge of rewards to motivate and teach students to follow classroom rules and routines and to complete academic assignments. This article presents and compares current research practices surrounding the use of rewards. A motivational model emerges from several research studies and meta-analyses, providing teachers with an opportunity to view the use of extrinsic rewards in the context of special needs learners to build intrinsic motivation. The authors also discuss teacher use of praise as the focal point to multiple rewards and students' need for equity.”

**Functional Behavior Assessment and Behavioral Intervention Plans**


Center for Effective Collaboration and Practice and Old Dominion University (no date). *Functional Assessment and Behavioral Intervention Plans, Parts I and II*. A two video tape set that covers the definitions and origins of functional behavioral assessment, what is involved in conduction a functional behavioral assessment, the criteria for determining when one is needed, and in-depth discussion of and instruction on how to conduct one. Available from the Center for Effective Collaboration and Practice, 1000 Thomas Jefferson Street NW, Suite 400, Washington, DC 20007. Phone 1–888–457–1551, email center@air.org. Purchase price is $15 (includes S&H). See the web site at [http://www.air.org/cecp/fba/qablequinn.htm#1](http://www.air.org/cecp/fba/qablequinn.htm#1).

Compiled by Alan Listiak, Ph.D. Minnesota Dept. of Corrections


Dr. Miller has a web page with discussion, forms and instructions on multimodal functional behavioral assessment at [http://mfba.net/index.html](http://mfba.net/index.html).


**Medications**


Parker, Harvey C. (no date). Medication chart to treat Attention Deficit Disorders. Available at http://www.ldonline.org/ld_indepth/add_adhd/add_medication_chart.html.


### Staff Issues


Previous studies have focused on staff attitudes to sexuality rather than their experience of dealing with sexual incidents. A self-completion questionnaire was devised in which seven scenarios were proposed relating to client sexuality (e.g. public masturbation and accusation of sexual abuse). Staff noted whether or not they had encountered this type of incident, and if so, how confident they felt (or would feel) in dealing with it, and whether or not they would enlist the help of colleagues. Questionnaires were sent to all statutory, voluntary and private service providers (including schools) within one community health and social services trust area in Northern Ireland, and 150 staff responded. Around two-thirds of staff reported having dealt with at least one of the seven incidents listed. Staff with previous experience of the incident listed, felt that they could deal with it more confidently in future, as did staff working in residential services rather than day services. The latter group of staff were more likely to enlist the help of colleagues than were residential staff. Nearly 50% of staff identified more training and clear policy guidelines as the two means of increasing their confidence in dealing with issues of client sexuality. These results highlight the need for staff training that spans agencies and results in common approaches to client sexuality. Suggestions for further research are noted.


The present study describes the development of a questionnaire, and the subsequent collection of data, to gather information on the demands and supports which influence stress (as measured by anxiety and depression scales) in direct care staff who work with people with intellectual disability. The results from the questionnaire were also used to explore the relationships...
between the factors derived from the questionnaire and to consider how these may be influential in building organizational models. The questionnaire was specifically constructed to measure the demands and supports experienced by direct care staff. The participants included 216 staff working in community residential services for people with intellectual disability. These individuals included staff working for two British health trusts and similar staff working for one local authority. The questionnaire consisted of 33 demands items and 23 supports items. Separate factor analyses were conducted on the demands and supports scales. Analyses of the reliability and validity of the resulting factors were conducted. Stepwise multiple regressions were conducted to further explore the relationship of factors with the measures of anxiety and depression. Four factors were extracted from the demands scale and three factors from the support scale. There was some concern over levels of reliability and validity for individual factors; however, the reliability of the main scales appeared to be satisfactory. All but one support factor correlated significantly with levels of anxiety and depression. The factors explained a modest amount of the variance in the regressions. While there are some concerns about the psychometric properties of the questionnaire, it is argued that the scales and factors can be used to confirm and further understanding of the relationship between groups of demands, supports and stress in staff. The usefulness of the questionnaire as a means of diagnosing specific sources of demand and support is considered. It is suggested that the questionnaire could form the basis for assessment and subsequent intervention in houses where staff are reporting relatively high levels of anxiety and depression.

