Parents with Intellectual Disability- Resource Guide

Best Practice: Understanding and Supporting Parents with Intellectual Disabilities

Best Practice in Parenting Education: Understanding and Supporting Parents with Learning Difficulties. Mildon, R., Matthews, J., Victorian Parenting Centre, & Dr. Susana Gavidia-Payne, RMIT University. This paper Understanding and Supporting Parents who Have Learning Difficulties addresses issues about how to provide effective support to families where one or both parents have a learning difficulty. This is a growing issue for professionals in health, education and welfare agencies. Unfortunately, the idea that parents with an intellectual disability are incapable of being adequate parents is a widely held view in the community. It is often wrongly assumed that child abuse or neglect is an inevitable consequence of parenting by parents with an intellectual disability. Understanding and Supporting Parents who have Learning Difficulties uses contemporary thinking, the latest research, and our own clinical experience. The paper identifies factors contributing to an over-representation of parents with learning difficulties in the child protection system. It also addresses issues related to the design and implementation of effective supports, specifically discussing clinical strategies that have shown promise in assessment and skills development programs.

http://www.parentingrc.org.au/images/stories/resources/understanding_supporting_parent s_learning_difficulties.pdf

Child Welfare Practice with Parents who have Cognitive Limitations. Children's Services Practice Notes (2004). Chapel Hill, NC. The Jordan Institute for Families. A newsletter issue focusing specifically on parents with intellectual disabilities, including strengths, vulnerabilities, and suggestions for practice. References are provided for those wishing to seek further information. http://www.practicenotes.org/vol9_no2/CSPN_coglims_final_2.pdf

Finding the Right Support? A Review of the Issues and Positive Practice in Supporting Parents with Learning Difficulties and their Children. Tarleton, B., Ward, L., and Howarth, J. May 2006. Baring Foundation http://www.baringfoundation.org.uk/Findingrightsupport.pdf

Good Practice Guidance on Working with Parents with Learning Disability- department for education and skills, Dept. of Health. UK.

http://www.norfolkparents.org.uk/img/files/Good%20Practice%20on%20working%20with%20parents%20with%20a%20learning%20disability%20dh_075118.pdf

Practice Points adapted from the Australian Family and Disability Studies Research Collaboration (2004). Healthy Start is a national capacity building strategy which aims to

improve health and wellbeing outcomes for children whose parents have learning difficulties. Healthy Start is coordinated by the Australian Supported Parenting Consortium and is an initiative by The University of Sydney and the Parenting Research Centre. It provides access to best practice information, summaries of latest research, and evidence-based programs.

http://www.healthystart.net.au/resources/doc_download/30-understanding-and-supporting-parents-with-learning-difficulties

Supporting Parents with Intellectual Disabilities-Practice Points: University of Alberta-

Family and Disability Studies Initiative-

Who are parents with intellectual disabilities?

http://www.fdsa.ualberta.ca/AboutUs/SupportingParentswithIntellectualDisabilities/~/media/Family%20and%20Disability%20Studies%20Initiatives/Documents/who_are_parents_with_LD.pdf

Parenting Capacity Assessments: Some Guiding Principles

http://www.fdsa.ualberta.ca/AboutUs/SupportingParentswithIntellectualDisabilities/~/media/Family%20and%20Disability%20Studies%20Initiatives/Documents/capacity.pdf

Communication with Parents with Learning Disabilities

http://www.fdsa.ualberta.ca/AboutUs/SupportingParentswithIntellectualDisabilities/~/media/Family%20and%20Disability%20Studies%20Initiatives/Documents/communicating.pdf
Facts and Fallacies

http://www.fdsa.ualberta.ca/AboutUs/SupportingParentswithIntellectualDisabilities/~/media /Family%20and%20Disability%20Studies%20Initiatives/Documents/facts_and_fallacies.pdf Parent Education and Training

http://www.fdsa.ualberta.ca/AboutUs/SupportingParentswithIntellectualDisabilities/~/media/Family%20and%20Disability%20Studies%20Initiatives/Documents/Parent_Education_and_Training.pdf

Parent and Family Support

http://www.fdsa.ualberta.ca/AboutUs/SupportingParentswithIntellectualDisabilities/~/media/Family%20and%20Disability%20Studies%20Initiatives/Documents/Parent_and_Family_Support.pdf

Professional Training and Information

Australian Family & Disability Studies Research Collaboration (2008)

Parents with Intellectual Disabilities. The Australian Family and Disability Studies Research Collaboration is part of the Faculty of Health Sciences, University of Sydney. This website contains numerous publications and resources for professionals working with parents with intellectual disabilities. http://sydney.edu.au/health_sciences/afdsrc/parents/index.shtml

Building Foundations - A Curriculum Guide for Supported Parenting

Baltimore, MD: Kennedy Krieger Institute. By Bridget McCusker & Bernadette Irwin, Revised 2013.

*The guide may be used for training new staff, as a review tool for seasoned staff, and to identify points of discussion during staff meetings, staff development and supervision. This curriculum guide focuses on specific teaching strategies that are known to be successful with persons with cognitive limitations. The strategies are presented in the context of parenting skills. While the Growing Tree acknowledges that one size does not fit all and that programs should be tailored to the needs of families, it believes this curriculum guide will provide an excellent resource utilizing best practices for supporting parents who has cognitive limitations.

Part I: Creating a Framework provides the conceptual framework for supporting parents with cognitive limitations. This section contains valuable and essential background information about working with adults with intellectual disabilities.

Part II: Strategies provides instructional strategies as well as methods for teaching a particular skill or skills. It provides insight into the unique challenges and joys of being a parent.

Part III: Core Areas and Resources covers ten areas pertinent to parenting and independent living skills: nutrition, health, safety, transportation, childcare, education, money management, time & household management, housing and additional resources.

Training Products Division, Kennedy Kreiger Institute.

http://www.pact.kennedykrieger.org/buildingfoundationforsupportedparenting.htm

<u>"Different Moms"</u> video is a compassionate portrait of three families that shows the challenges parents with intellectual disabilities face when raising their families and the odds they overcome to bring up healthy, happy children. This hour-long documentary portrays three families in very different circumstances. All of the parents face barriers caused by attitudes about their ability to parent, as well as from the lack of services for parents with disabilities. The video comes with a guide for getting involved. Moxie Firecracker Films, 232 3rd Street B402b, Brooklyn, New York 11215. (718) 230-5111

Email: info@moxiefirecracker.com

<u>Parenting with an Intellectual Disability.</u> Parent's stories describing successes and challenges in being a parent with an intellectual disability. Raising Children Network, Australia. (2008) http://raisingchildren.net.au/articles/parenting_with_an_intellectual_disability.html

Strategies and Adaptations in Working with Parents with Intellectual Disabilities

Corbus, K., Hansen, S. & Tuleja, C. (2006). Berkeley, CA: Through the Looking Glass. This succinct module outlines behavioral indicators of intellectual disabilities and strategies for engagement, intervention and adaptive approaches for supporting parents with intellectual disabilities. http://www.lookingglass.org

Supporting Families: When Parents Have Intellectual Disabilities -Cathy Haarstad, MS. The manual offers practical suggestions and resources that will hopefully make it easier for providers to step out of traditional roles and reach out to parents with pervasive and lifelong learning challenges. It is also hoped that the use of these strategies will lead to the development of integrated service delivery. It is believed that appropriate support will allow

families with parents who have intellectual disabilities to thrive and flourish and thus prove the case for continued support. It is also believed that the strategies will benefit many other families, who may not have intellectual disabilities but struggle with parenting.http://www.srcp.org/pdf_versions/supportingfamilies.pdf

Working with Parents who have Cognitive Limitations: Guidance for Teachers, Nurses, and Social Service Providers

This research-based program shows teachers, nurses and social service providers how to:

- Recognize when parents might have cognitive limitations.
- Develop respectful relationships with parents.
- Communicate effectively with parents.
- Maximize beneficial conditions for the parents' children.

This program includes a viewer's guide and three video modules on DVD: Teachers Supporting Student Learning (25 min.), Nurses Supporting Access to Health Care (27 min.), Social Service Providers Supporting Families (27 min.) Links to online resources, printable posters, and a printable visual prescription form are also included in the viewer's guide. https://www.irised.com/products/intellectual_disabilities/working_with_parents_who_havecognitive_limitations#.U1kl4K1OWCg

Assessments and Curriculums

<u>Building Foundations – A Curriculum Guide for Supported Parenting.</u>

Baltimore, MD: Kennedy Krieger Institute. Bridget McCusker & Bernadette Irwin, Revised 2013.

*The guide may be used for training new staff, as a review tool for seasoned staff, and to identify points of discussion during staff meetings, staff development and supervision. This curriculum guide focuses on specific teaching strategies that are known to be successful with persons with cognitive limitations. The strategies are presented in the context of parenting skills. While the Growing Tree acknowledges that one size does not fit all and that programs should be tailored to the needs of families, it believes this curriculum guide will provide an excellent resource utilizing best practices for supporting parents who has cognitive limitations.

Part I: Creating a Framework provides the conceptual framework for supporting parents with cognitive limitations. This section contains valuable and essential background information about working with adults with intellectual disabilities.

Part II: Strategies provides instructional strategies as well as methods for teaching a particular skill or skills. It provides insight into the unique challenges and joys of being a parent.

Part III: Core Areas and Resources covers ten areas pertinent to parenting and independent living skills: nutrition, health, safety, transportation, childcare, education, money management, time & household management, housing and additional resources.

Training Products Division, Kennedy Kreiger Institute.

http://www.pact.kennedykrieger.org/buildingfoundationforsupportedparenting.htm

Enabling Parenting with Support: Effective working with parents with learning disabilities. Deborah Chinn. Pavilion Publishing and Media Ltd, 2012. This training pack will enable managers and trainers to ensure staff have the knowledge and skills to provide parents with learning disabilities the best support available, and that these parents are equipped with the skills they need to protect their children and to give them the best possible start in life. Using a range of effective learning techniques, it aims to directly enhance the skills of staff who work with parents with learning disabilities in a number of key areas including assessment, communication and teaching parenting skills. This pack contains: CD-ROM containing handouts, PowerPoint slides in a ring binder.

http://www.pavpub.com/enabling-parenting-with-support/

<u>Healthy & Safe: What is Healthy & Safe?</u> An Australian Parent Education Kit is a program developed to meet the demand for a home-based education resource tailored to the learning needs of parents with learning difficulties. It is designed to equip parents of young children with the knowledge and skills necessary for managing home dangers, accidents and childhood illness. http://www.healthystart.net.au/index.php/resources/education-a-development/healthy-and-safe-an-australian-parent-education-kit

HELP: When the Parent Has Disabilities: Early Childhood Developmental Curriculum. (1999). Edited by Stephanie Parks. This unique and pioneering resource offers thousands of activities and training techniques for directly involving parents who are blind, deaf, have physical or learning disabilities, or have cognitive delays. Thousands of activities for parents to support, encourage, and facilitate their child's growth and development. Palo Alto, CA: Vort Corporation. http://www.vort.com/HELP-When-the-Parent-has-Disabilities.html

<u>Learning Curves</u>: The Assessment of Parents with a learning disability: A manual for practitioners. Norfolk Area Child Protection Committee. Norfolk ACPC. 2004 http://www.nscb.norfolk.gov.uk/documents/learningCurves.pdf

Life Skills Progression (LSP): Karen Peifer Ph.D. M.P.H, and Deanna Gomby Ph.D. An Outcome and Intervention Planning instrument for Use with Families at Risk (Paul H. Brookes Publishing Co., 2006) For use with at-risk families of children from birth to 3 years of age. The LSP helps professionals establish baseline client profiles, identify strengths and needs, plan interventions, and monitor outcomes to show that interventions are working. View our recorded webinar: *Improving Home Visiting Practice with the Life Skills Progressionals (LSP)* presented by Linda Wollesen. http://www.amazon.com/Life-Skills-Progression-LSP-Intervention/dp/1557668302

<u>Parent Assessment Manual</u> (PAMS-3.0). Susan McGaw, Pill Creek Publishing LTD. Parent Assessment Manual includes 34 Child & Parent Domains, is a structured, wide-ranging functional & multi-dimensional parenting assessment. PAM is aimed at vulnerable families: children (0-19 years) and their parents. PAM assesses 333 skills (364 incl. sub-skills) focusing on Parenting Knowledge-Skills-Practice for each parent/jointly couple. PAM provides

Child/Parent Profiles & Teaching Programs electronically. PAM is a quick accurate tool for measuring baselines and teaching evaluations. http://www.pillcreekpublishing.com/

Parenting Young Children (PYC) is a comprehensive, home-based parent training and support program for parents with learning difficulties and their young children. PYC was developed in 2003, has been evaluated and widely disseminated across Australia as a part of the Australian national strategy 'Healthy Start'. Healthy Start is a national capacity building strategy which aims to improve health and well-being outcomes for children whose parents have learning difficulties. Catherine Wade, PhD.

http://www.healthystart.net.au/images/resources/05-Education-and-Development/PYC%20Information%20Sheet.pdf

Sunny Side of the Street: Mentor & Parent Handbook

This curriculum is designed to help you assist parents in your community to encourage their children's development by building positive family relationships and establishing healthy home and playtime routines. The program uses music games, videos, cards, pictures, and positive modeling to promote activities that support social, emotional and literacy development for children 3-7 years old. It is an ideal tool for working with at-risk parents, including parents who have intellectual disabilities. Five multi-media modules include: Ready for School, Ready to Play, Ready for Bed, Ready to Get Along, and Ready to Read. https://irised.com/products/k 12/sunny side of the street

The Health and Wellness Program: A Parenting Curriculum for Families at Risk

Alexander J. Tymchuk, Ph.D. (Paul H. Brookes Publishing Co., 2006) Ideal for psychologists, nurses, social workers, home visitors, parent educators, and others who work with families at risk, this complete program gives professionals everything they need to support parents with a wide range of disabilities or learning challenges as they learn about child health and safety. Professionals will get a program manual with background information on parents with disabilities, guidance on establishing a program and assessing parents' skills, overviews of what to teach in parent education programs, and assessment tools with clear instructions and illustrations. To ensure learning, the program includes 18 printable workbook-style handouts to give to parents, each using clear, simple language and realistic colored illustrations to teach critical skills such as

- recognizing symptoms of common child health problems
- taking a child's temperature and pulse
- identifying and eliminating fire, electrical, and cooking hazards
- making good health and safety decisions
- creating a comprehensive home safety plan
- reading medicine labels and following the instructions accurately
- preventing emergencies and learning how to respond if one occurs

Professionals can print an unlimited quantity of the handouts (including the illustrations) from the included CD-ROM, http://forms.brookespublishing.com/store/books/tymchuk-8175/index.htm

The Step-by-Step Parenting Program Maurice Feldman, PhD, C. Psych., BCBA-D. The Step by Step Parenting Program breaks down essential child-care skills for children from birth to about 3 years or age into small steps. A wide-range of parenting skills are covered related to child health, safety, and development, including: newborn care; feeding and nutrition; diapering; bathing; home and sleep safety; first aid; toilet training; parent-child interactions; and positive behavior support. The Step-by-Step Parenting Program© combines the Step-by-Step Child-Care Manual, modelling, roleplaying, and performance feedback to help teach the parents the above skills. The 230-page Step-by-Step Child-Care Manual includes over 60 step-by-step child-care checklists developed with the input of pediatric health care professionals and consumers, and corresponding picture books for about half of these skills. Maurice Feldman, PhD, Psych., BCBA-D, mfeldman@brocku.ca phone: (905) 688-5550 x4894

Working with Families with Children/Parents with Developmental Disabilities- is a training curriculum for child welfare workers and other helping professionals. This training curriculum is part of a more comprehensive training program that focuses on the intersection of intellectual disabilities and child protection issues. This one-day training emphasizes the learning style and needs of parents and offers teaching and intervention strategies. It identifies the strengths and needs of parents with cognitive limitations and how to set goals that are realistic, reasonable and fair. Trainees practice how to break down goals into action steps and learning tasks that allows parents to demonstrate reasonable progress. It utilizes appropriate cognitive behavioral strategies to assist parents in meeting his/her goals. Trainees learn to select the most appropriate strategies and measurement tools to evaluate a parent's success. http://www.developmentaldisability.org/ Sponsored by the Social Work Program at the Metropolitan State College of Denver, Colorado. For information on acquiring this curriculum, contact Virginia Cruz (303/556-4464; VCruz@DevelopmentalDisability.org).

For sample handouts, go to www.developmentaldisability.org/Hand%20Outs.htm

"A Fair Chance" Developed as part of the above-mentioned curriculum; this video takes you inside the homes and lives of six parents with developmental disabilities. It focuses on what helps them succeed and which factors seem to contribute to the placement of their children. "A Fair Chance" offers a frank discussion of the prejudices faced by parents with development disabilities and the support services they have found effective. To learn more, visit, http://www.developmentaldisability.org/parents_with_disabilities.htm Cost: \$140 (includes shipping and tax). To order, call 303/556-4464.

Parent Support Groups

Designing Support Groups for Parents with Intellectual Disabilities. By Sherrie Hansen & Kathie Corbus (2007). Berkeley, CA: Through the Looking Glass. This 85-page module is designed as a tool for individuals or organizations planning and guiding parent support groups; includes DVD with video clips of actual support group meetings. www.lookingglass.org

Parent Education Programs

Bancroft's Parenting Program helps parents with such challenges build the skills necessary to successfully raise their children and keep their family together. At the same time, the program provides a full range of residential assistance and medical, educational, psychological and employment support services, to ensure parents with disabilities achieve their full potential. In addition, this unique program helps children understand and accept the reality of their family situation, so they too can achieve fulfilling lives. Bancroft's Parenting Program is provided through The Walker Center at Bancroft in suburban Philadelphia. http://www.bancroft.org/autism/adults/parenting-program/#.U3zFEfldU1I

Cultivating Competence: Directory and Resource Guide on Supported Parenting, 2nd Edition (2000). Edited by Dolores Ullmer Liamba. Of special interest to child welfare workers will be the articles "Guiding Principles for Supporting Families Headed by Parents with Cognitive Limitations," "Discovering the Parent's Language of Learning," and a list of suggested readings. Published by the Wisconsin Council on Developmental Disabilities. http://www.wi-bpdd.org/publications/2009/cultivating_competence.pdf

The HOPE Initiative- (Hands on Parenting) utilizes a home-based parent training model to teach parenting skills in the context of the family's daily life. Training includes weekly home visitation, phone support, crisis intervention and materials from the HOPE Parenting Curriculum. Kris Saurini, Director (303) 362-0990. Kris.saurini@thehopeinitiative.org.

PACT- Growing Together is a supported parenting program for mothers and fathers with intellectual disabilities who have children under the age of three. The program is licensed by the Developmental Disabilities Administration and is the only supported parenting program of this type in Maryland. Growing Together is a center-based program with a home-based component. PACT teaches parenting and independent living skills. Promotes developmental growth of children through parent-child activities. Assesses children's developmental progress and secures physical, occupational and speech/language therapy services, if needed. Provides opportunities for socialization and recreational activities. Offers center and home-based services. Provides transportation to and from the program

and offers a curriculum guide, along with training and consultation, to other organizations serving parents with intellectual disabilities. There are no fees for parents to participate. Parents may contact Growing Together directly about enrolling in the program. Other referral sources include, Department of Social Services, Developmental Disabilities Administration, nurses and pediatricians. For more information, contact Bridget McCusker at 410-298-9281 or mccusker@kennedykrieger.org or download the Growing Together leaflet.

Positive Parenting Resource Center focuses on the needs of families headed by parents with cognitive disabilities. Provides education and builds upon the strengths of parents with learning differences to enhance their parenting skills and become recognized as valued, contributing members of their community. The Center provides training, resource materials and consultation to agencies that want to expand their expertise in working with families. Center staff facilitates parent training and support groups designed to teach or refine basic parenting skill. Staff offers home visitation, individualized parent education, case management, and service advocacy. The Positive Parenting Resource Center is a component of the United Arc's Family Support Program which serves families in Franklin and Hampshire Counties and neighboring communities. For more information about the Resource Center, contact Susan Jones at the United Arc, (413)774-5558 or email suejones@unitedarc.org. or http://www.unitedarc/positiveparenting.html.

Programs and Resources for Child Welfare In-Home Services for Parents with Intellectual Disabilities. The National Resource Center for In-Home Services interviewed six exemplary programs for parents with Intellectual Disabilities.

https://www.nrcihs.org/sites/default/files/events/Programs%20and%20Resources%20Parent s%20with%20ID.pdf

Educational Teaching Tools and Resources

CHANGE- is an organization working for the rights of people with learning disabilities. They produce illustrated, easy read books for parents with learning disabilities: My Pregnancy, My Choice; You and Your Baby 0-1; You and Your Little Child 1-5. http://www.changepeople.org/

Cooking Made Easy. A cookbook for people with developmental disabilities who can read. Recipes are broken down into detailed, easy to understand steps. Every recipe is coded from 1-5 according to level of difficulty. Eileen Laird, 1996 eileen@cookingmadeeasy.org

Mencap's "Make it Clear"- A Guide to making easy read information. http://www.dinf.ne.jp/doc/japanese/access/guideline/make_it_clear.pdf

Parenting in Pictures- These step-by-step guides can help you with essential skills for parenting children from babies to teenagers. Topics range from breastfeeding, CPR and bathing to healthy eating, teenage sleep and cyberbullying. You can print the guides and put them up for quick and easy reference when you need

them.http://healthystart.net.au/index.php/for-parents-64489/parenting-in-pictures

Parenting Videos - Provides video clips, ranging from 1 to 7 minutes, which cover a variety of parenting skills including dressing a newborn and bottle preparation.

http://healthystart.net.au/index.php/for-parents-64489/parenting-videos

Practical Tools

http://healthystart.net.au/index.php/resources?catid=1:resources&id=32:resources-practical-tools

Parenting Toolkit: Meeting the Needs of People with Learning Difficulties.

http://www.bristol.ac.uk/wtwpn/resources/parenting-toolkit.pdf

Practitioner Resources - These tip sheets provide strategies for providers on ways to "check and understand" the information you are attempting to convey to them. Healthy Start (2005-2006). East Melbourne, VIC. http://healthystart.net.au/resources/basics

Safety Starts at Home: The Essential Childproofing Guide

This video covers such topics as fire safety, choking hazards, crib safety, prevention of falls, drowning prevention, and emergency preparation. It also contains a detailed room by room safety checklist. The video provides a straightforward, visual way to teach and review home safety needs with parents with cognitive disabilities. (Length: 37 minutes). Produced by InJoy Birth & Parenting Education (2003). Available from InJoy. 7107 La Vista Place, Longmont, CO 80503. www.injoyvideos.com

Teachervision Printables - Although designed for teachers, this website contains a number of "printable" handouts that can be used with parents around communicating with school providers, creating homework checklists, and developing behavior rules and consequences. Pearson Education, Inc. (2000-2010).

http://www.teachervision.fen.com/classroom-management/printable/6391.html?detoured=1

You Make the Difference in Helping Your Child Learn. Manolson, A., Ward, B. & Dodington, N. These well-illustrated guidebooks are designed to help parents with limited literacy skills foster their children's self-esteem and language development; accompanying DVD to use with parents; available in Spanish language. The Hanen Centre. (1995Toronto, ON Canada).

Project IMPACT This program provides intensive, in-home services for parents with intellectual and/or significant learning disabilities (ID/LD) who are risk for family disruption due to allegations of child maltreatment. Services are provided three times a week for six months. Program areas include basic child care, home and health safety, child management, and problem-solving skills. All skills are taught in a multimodal intervention format designed to meet a family's particular learning style. Baseline, ongoing, and post intervention data is collected on both parent and home functioning. Trupti Rao, PsyD: trao@wihd.org. Westchester Institute for Human Development. www.wihd.org

Parents with Intellectual Disabilities (PID). The main objective of the project is to support people with learning or intellectual disabilities in all matters relating to a loving relationship, marriage, family, and parenthood. They have the right to raise their children and to live a family life like everyone else. To reach this aim the authors of the project will focus on better preparation of professionals and practitioners working with this target group.

The consortium will provide professionals and practitioners a EUROPEAN FAMILY SET. It is a set of different principles and practices of efficacious support services, empowering interventions and successful parenting education programs from all over Europe. The EUROPEAN FAMILY SET is intended to be used by practitioners in their respective support offers. http://pid-project.eu/about-the-project.php Furthermore a "Family Buddies Online Training" (e-training) should prepare volunteers for supporting and accompanying mothers and fathers with intellectual disabilities and their family in a right way.

http://pidproject.eu/doc/FAMILY %20BUDDIES Online Training Guideline.pdf

Through the Looking Glass (TLG) is a nationally recognized center that has pioneered research, training, and services for families in which a child, parent or grandparent has a disability or medical issue. TLG is a disability community based nonprofit organization. TLG provides direct services, information and referral to a diverse group of parents with disabilities, including parents with intellectual disabilities, their families, and professionals who work with them. There is a link on this website to TLG's Legal Program for Parents with Disabilities that provides information on policy & legislation as well as publications, trainings, & recommended resources. Berkeley, CA 94710-2204(voice): 1-800-644-2666, (TTY): 1-510-848-1005, Fax: 1-510-848-4445. http://lookingglass.org/index.php

Additional Resources

Parents with Intellectual Disabilities. ARC (2011). Washington, D.C.

http://www.thearc.org/page.aspx?pid=3195

What Is The Arc's Position?

The presence of an intellectual and/or developmental disability does not in itself preclude effective parenting; therefore, the rights of parenthood must not be denied individuals soley on the basis of intellectual and/or developmental disabilities. Read the entire Position Statement at http://www.thearc.org/page.aspx?pid=2375.

The Association for Supported Parenting (TASP) – This national organization is "dedicated to enhancing the well-being of at-risk parents with learning difficulties and their children" (parents with intellectual disabilities and borderline intellectual functioning). TASP membership and leadership is drawn from parents with I.D., public and private agency personnel who serve parents with I.D.; university professors who specialize in research and training for and about parents with I.D., and other advocates and supporters. TASP maintains a website with links to important information and websites. They co-sponsor an

international conference with the Connecticut Parents with Cognitive Limitations Workgroup, this year to be held in Mystic, CT, October 1 & 2, with the theme of "Innovative"

Healthy Start Australia

Healthy Start Australia is an Australia-wide initiative to support parents with learning difficulties. Resources on the website include information regarding parents with intellectual disabilities, "real stories" of parents with disabilities, and resources for parents and practitioners. http://www.healthystart.net.au/

The Parenting Research Centre is dedicated to supporting parents. We believe that the most effective way to support parents is through developing resources, programs and policies based on scientific evidence. http://www.parentingrc.org.au/

Parents with Intellectual Disabilities. This website provides resources, a synopsis of some of the key challenges facing parents with intellectual disabilities, as well as list of print references related to the topic. Although the resources listed are primarily for providers working in the UK, the concerns and needs noted are relevant to parents with intellectual disabilities worldwide. St. George's, University of London (2010). http://www.intellectualdisability.info/families/parents-with-intellectual-disabilities

Parents with Intellectual Disabilities (PID). The main objective of the project is to support people with learning or intellectual disabilities in all matters relating to a loving relationship, marriage, family, and parenthood. They have the right to raise their children and to live a family life like everyone else. To reach this aim the authors of the project will focus on better preparation of professionals and practitioners working with this target group. The consortium will provide professionals and practitioners a EUROPEAN FAMILY SET. It is a set of different principles and practices of efficacious support services, empowering interventions and successful parenting education programs from all over Europe. The EUROPEAN FAMILY SET is intended to be used by practitioners in their respective support offers. http://pid-project.eu/about-the-project.php

Furthermore a "Family Buddies Online Training" (e-training) should prepare volunteers for supporting and accompanying mothers and fathers with intellectual disabilities and their family in a right way.

http://pidproject.eu/doc/FAMILY %20BUDDIES Online Training Guideline.pdf

Services for parents with disabilities, Child Welfare Information Gateway—Parents with disabilities face many challenges and can benefit from support and assistance. This page highlights relevant policy and social issues affecting disabled parents as well as the availability of needed treatment and services. http://z.umn.edu/cwinfodis

Through the Looking Glass (TLG) is a nationally recognized center that has pioneered research, training, and services for families in which a child, parent or grandparent has a disability or medical issue. TLG is a disability community based nonprofit organization. TLG provides direct services, information and referral to a diverse group of parents with

disabilities, including parents with intellectual disabilities, their families, and professionals who work with them. There is a link on this website to TLG's Legal Program for Parents with Disabilities that provides information on policy & legislation as well as publications, trainings, & recommended resources. Berkeley, CA 94710-2204(voice): 1-800-644-2666, (TTY): 1-510-848-1005, Fax: 1-510-848-4445. http://lookingglass.org/index.php

Westchester Institute for Human Development. -Resources and Programs for Parents with Intellectual Disabilities - Westchester Institute for Human Development is a leader in addressing major social and health issues affecting people with disabilities and vulnerable children. WIHD addresses major social and health issues by developing and delivering medical, clinical and support services to individuals, their families and caregivers. As one of only 67 University Centers for Excellence in Developmental Disabilities, WIHD creates better futures for these individuals through the creation and dissemination of innovative research, professional leadership education and best practices trainings. - See more at: http://www.wihd.org/page.aspx?pid=660#sthash.sDL34upz.dpu

Newsletters

Workgroups

Parents With Cognitive Limitations and The Connecticut Workgroup

The Connecticut Parents with Cognitive Limitations Work Group (PWCL) was formed in 2002 to address the issue of support of parents with cognitive limitations and their families. Although the number of families headed by a parent with cognitive limitations is uncertain, and identification of these families is one of the group's challenges, it is estimated that at least one third of the families in the current child welfare system are families headed by a parent with cognitive limitations. To address these issues, The Workgroup developed a training on "Identifying and Working with Parents with Cognitive Limitations" which has been offered in many communities throughout the State and additional trainings will continue to be offered each year. In addition to offering a conference for administrators and supervisors, the Workgroup also created an Interview Assessment Guide to assist workers in identifying these families. The Workgroup has drafted recommendations regarding the use of plain language in communicating with all parents (See Plain Language tab under Parents with Cognitive Limitations) and developed training on plain language. For more information, email Wendy Kwalwasser, Ph.D., Co-chair, at wendy.kwalwasser@ct.gov or Barbara Nadeau, Co-chair, MA, OTR/L, CB/ST, barbara.nadeau@quinnipiac.edu For more information about the Connecticut Workgroup and resources compiled by this group: http://www.ct.gov/dcf/cwp/view.asp?a=2570&q=314504

Articles, Assessments, Curriculums and Publications on Parents with Intellectual Disabilities are available at the Connecticut Clearinghouse, 334 Farmington Avenue. Plainville, CT 06062. Tel: 800.232.4424 http://www.ct.gov/dcf/cwp/view.asp?a=2570&q=317456

Webinars

Healthy Start is a national capacity building strategy which aims to improve health and wellbeing outcomes for children whose parents have learning difficulties.

Online knowledge exchange events hosted by **Healthy Start**, with presentations from experts from around the world. http://healthystartonline.net.au/page/webinars

Webinar Title

Overview



Influences in the social worlds of children of mothers with intellectual disability

Susan Collings discusses findings and recommendations from her research examining the lives of children of mothers with intellectual disability.



Insights from Sweden:
Enhanced care and support
during pregnancy and birth
for women with intellectual
disability

Dr Berit Höglund discusses her research findings and recommendations made in two papers published in Acta Obstetricia et Gynecologica Scandinavica, 2012.



Against All Odds: Fathering with an intellectual disability

A compelling story from a mother with an adult son who is a father with an intellectual disability.



Assessment for Parents with Learning Difficulties and their Children

Dr Marjorie Aunos provides examples of approaches to parenting capacity assessment and gives a description of best practice in assessment as applicable to the Australian context.



Preschool for Children of Parents with Learning Difficulties: A Model from Eugene, Oregon Dr Renée K. Van Norman discusses an exciting approach to educating and supporting young children and their families with special learning needs through a wrap-around service delivery model with 60 years of history in the community of Eugene, Oregon.



Susan's Story

Susan Arthur, a mother with learning difficulties, shares her experiences with child removal, and her work in advocacy for people with learning difficulties.



Building Service System Capacity

Dr Robyn Mildon provides an overview of current thinking in the use and application of evidence-based practices to support parents with learning difficulties and their children.



Antenatal and postnatal support: Women with Individual Needs (WIN) Clinic Cherise Smith discusses the Women with Individual Needs (WIN) Clinic at the Royal Women's Hospital in Melbourne has provided antenatal and postnatal care for women with an intellectual disability or learning difficulties since 2003.

Healthy Start Videos



Strengthening Every Family

The Strengthening Every Family video was made by the Parenting Research Centre and the Office of ... Healthy Start Administrator Feb 22, 201376 views



We Are A Family

Article 23 of the UNCRPD as well as Article 7 of CROC enshrines the rights of parents with disabilities...Healthy Start Administrator Jan 16, 2013



Building Adult Capabilities to Improve Child Outcomes: A Theory of Change

This 5-minute video depicts a theory of change from the Frontiers of Innovation community for Olivia Clayton Jun 14, 2013



Insight: What's Best For The Child

A difficult conversation about how an intellectual disability may affect a parent's capacity to... Olivia Clayton Jun 19, 2013

Online Courses

Parenting with a Developmental Disability

Parenting with a Developmental Disability is an online unit of study that can be undertaken within the graduate program in developmental disability at the **University of Sydney**, **Australia**. This unit introduces students to the challenges and achievements typically found in the lives of parents with developmental disability and their children. Students critically examine 'popular' narratives about parents with a developmental disability and become familiar with the literature on parenting with a developmental disability, including evidence-based parent education and family support strategies. Students also learn to identify service gaps and opportunities in their own local areas to promote the health and wellbeing of families headed by a parent with a developmental disability.

The online unit of study runs for one semester. It includes weekly readings and online discussions with other students and teaching staff as well as two assessments during the semester. The extra time commitment for practitioners is offset by the knowledge gained, which will help practitioners and agencies to deliver more cost-effective services to parents with learning difficulties. For more information: Email Roger Stancliffe phone +61 2 9351 9984

Conferences



The Association for Successful Parenting (TASP) 2014 International Conference

The Association for Successful Parenting (TASP), Co-Sponsor with The United Arc, presents: 2014 International Conference

Thursday, June 5th, 2014 8:30 am - 4:00 pm

The Clarion Hotel and Conference Center

1 Atwood Drive, Northampton, MA
Clarion Hotel is offering discount hotel room rate
(\$106.00 per the night of June 4th and 5th)
Call 413-586-1211
View our flyer HERE
Register HERE
Email Sue Jones

International Organizations

- The Centre for Disability Studies (Iceland): http://fotlunarfraedi.hi.is/en/english
- DisabilityCare Australia: http://www.disabilitycareaustralia.gov.au/
- Donald Beasley Institute (New Zealand): http://donaldbeasley.org.nz/
- Family and Disability Studies Initiative, University of Alberta (Canada) http://www.fdsa.ualberta.ca/
- Healthy Start (Australia): http://www.healthystart.net.au/
- Norah Fry Research Centre (UK): http://www.bristol.ac.uk/norahfry/
- Parent's Project Intellectual Disability Rights Service (Australia): http://www.idrs.org.au/

National Organizations

- American Association on Intellectual and Developmental Disabilities: http://www.aaidd.org/
- The Arc: http://www.thearc.org/
- The Association for Successful Parenting: http://www.achancetoparent.net/
- The Legal Program of the National Center for Parents with Disabilities: http://pwd-legalprogram.org/
- National Council on Disability: http://www.ncd.gov/
- National Alliance on Mental Illness (NAMI): http://www.nami.org/
- Through the Looking Glass: http://www.lookingglass.org/

Research

Booth T. and Booth W. (1998). **Growing Up With Parents Who Have Learning Difficulties**. Florence, Kentucky, Routledge Press.

Callow, E. (2005). The Family Court Experience: A Guide for Parents with Disabilities and their Advocates. Berkeley, CA: Through the Looking Glass. www.lookingglass.org

Callow, E. (2009, November). **Maintaining Families When Parents Have Disabilities. Child Law Practice**, 28(9), 133-138. http://www.childlawpractice.org

Child Welfare Process and Outcomes- Parental cognitive impairment and child maltreatment in Canada

http://www.fdsa.ualberta.ca/CurrentResearch/~/media/Family%20and%20Disability%20Studies %20Initiatives/Documents/Child Welfare Process and Outcomes.pdf

Context-Contingent Decision-Making in Child Protection Practice. International Journal of Social Welfare, 15, 230-239.

CW360 - The Intersection of Child Welfare and Disability: Focus on Parents. This issue of provides information about serving parents with disabilities in child welfare systems.

University of Minnesota. Center for Advanced Studies in Child Welfare. (Fall, 2013) http://cascw.umn.edu/wp-content/uploads/2013/12/Fall2013_CW360_WEB.pdf

Feldman, M.A. (1998). **Parents with Intellectual Disabilities: Implications and Interventions.** In Lutzker, J. (Ed.), *Handbook of Child Abuse Research and Treatment*. NY: Plenum Press. Parents with Intellectual Disabilities. Past, Present and Futures. The 1st International cross-disciplinary book to explore and understand the lives of parents with intellectual disabilities, their children, and the systems and services they encounter. http://www.amazon.com/Parents-Intellectual-Disabilities-Present-Futures/dp/0470772948

Feldman, M.A. (2002). **Parents with Intellectual Disabilities and Their Children: Impediments and Supports.** In D. Griffiths & P. Federoff (Eds.) *Ethical Dilemmas: Sexuality and developmental disability*. NY: NADD Press, p.255.

Feldman, M.A. (2004). **Self-Directed Learning of Child-Care skills by Parents with Intellectual Disabilities.** *Infants and Young Children, 17(1), 17-31.*

Feldman, M. & Aunos, M. (2010). Comprehensive, Competence-Based Parenting Assessment for Parents with Learning Difficulties and Their Children. Kingston, NY: NADD Press. This book provides a comprehensive methodology for a research-based parenting assessment process which deals forthrightly with the challenge of balancing children's rights to safety and nurture with the rights of their parents.

Feldman, M. (1994). **Parenting Education for Parents with Intellectual Disabilities: A Review of Outcome Studies.** Research in Developmental Disabilities, 15(4), 299-332.

Feldman, M. & Case, L. (1999). **Teaching child-care and safety skills to parents with intellectual disabilities through self-learning**. Journal of Intellectual & Developmental Disability, 24(1,) 27-44.

Glazemakers, I. & Deboutte, D. (2012) **Modifying the 'Positive Parenting Program" for parents with intellectual disabilities**. Journal of Intellectual Disability Research, doi: 10.1111/j.1365-2788.2012.01566x

Green, N. & Cruz, V. (2000). **Challenges Facing Parents with Developmental Disabilities.** Denver, Colorado: Metropolitan State College of Denver. Online: http://www.developmentaldisability.org/ChallengesFacingParents.htm

Guide for Creating Legislative Change: Disability Status in Termination of Parental Rights and Other Child Custody Statutes, University of Minnesota—http://z.umn.edu/legchg

Heinz, L.C., & Grant, P.R. (2003). A Process Evaluation of a Parenting Group for Parents with Intellectual Disabilities. The Scientific World Journal [electronic resource], 5, 50-57. McConnell, D., Llewellyn, G., and Ferronato, L. (2006).

Inclusive support for parents with a learning disability' (Mencap 2011) http://www.mencap.org.uk/sites/default/files/documents/2011-03/making%20the%20difference.pdf

Intellectual Disability and Mental Health: A Training Manual in Dual Diagnosis, S. McGilvery & D. Sweetland. Available from http://www.dmid.org/

Llewellyn, G., McConnell, D., Russo, D., Mayes, R. & Honey, A. (2002). **Home-Based Programmes for Parents with Intellectual Disabilities: Lessons from Practice.** *Journal of Applied Research in Intellectual Disabilities*, 15, 341.

Lightfoot, E. & LaLiberte, T. (2006). **The Inclusion of Disability as Grounds for Termination of Parental Rights in State Codes**. *Policy Research Brief,* 17(2).

National Abandoned Infants Assistance Resource Center (2005, Fall). The Intersection of Developmental Disabilities, Substance Abuse and Parenthood: Challenge and Response. The Source – Newsletter of The National Abandoned Infants Assistance Resource Center, 14(2), 1-7.

North Carolina Division of Social Services & Family and Children's Resource Program (2004, January). Child Welfare Practice with Parents Who Have Cognitive Limitations. Children's Services Practice Notes for North Carolina's Child Welfare Social Workers, 9(2), 1-25. (This issue of the N.C. newsletter consists of 8 articles on various topics related to serving parents with I.D.) Retrieved February 24, 2013 from http://www.practicenotes.org/vol9_no2.htm

Pixa-Kettner, U. (1999). **Follow-up Study on Parenting with Intellectual Disability in Germany.** *Journal of Intellectual and Developmental Disability*, 24(1), 75-93.

Rocking the Cradle: Ensuring the rights of parents with disabilities and their children.

National Council on Disability. (2012). Washington, DC: Author. Retrieved September 30, 2012 from (This exhaustive policy document addresses all disabilities & focuses on specific child welfare topics in chapters 5, 6, 7 & 8. http://www.ncd.gov/publications/2012/Sep272012/

Special Issue: Parenting by People with Intellectual Disability. Journal of Applied Research in Intellectual Disabilities. July 2008 Volume 21, Issue 4. Pages 293–387. John Wiley & Sons Ltd

Tarleton, B. & Ward, L. (2007). **Parenting with Support: The Views and Experiences of Parents with Intellectual Disabilities.** Journal of Policy and Practice in Intellectual Disabilities, 4(3), 194-202.

Tymchuk, A. (1998). **The Importance of Matching Educational Interventions to Parent Needs in Child Maltreatment.** In Lutzker, J. (Ed.), Handbook of Child Abuse Research and Treatment. NY: Plenum Press.

United Nations Convention on the Rights of Persons with Disabilities. http://z.umn.edu/crpd

Willems, D.L., de Vries, J.N., Isarin, J., & Reinders, J.S. (2007). **Parenting by Persons with Intellectual Disability: An Explorative Study in the Netherlands.** *Journal of Intellectual Disability Research*, 51(7), 537-544.

*** Additional Articles, Assessments, Curriculums and Publications on Parents with Intellectual Disabilities are available at the Connecticut Clearinghouse, 334 Farmington Avenue. Plainville, CT 06062. Tel: 800.232.4424 http://www.ct.gov/dcf/cwp/view.asp?a=2570&q=317456