



Volume 4, Issue 2, April 2009

reSearch

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

Custodial and parental rights of individuals with disabilities

In this edition of *reSearch* we explore the topic of parental and custodial abilities of individuals with disabilities and their rights under current state and federal policies. *reSearch* was originally created as a vehicle to further explore disability related topics presented by patrons through our information service via phone, mail, email, and our chat-based reference service. In March, NARIC received a chat request for information regarding parental rights and adoption:

Parental rights of adoptive child and removal of rights? (03/09/2009)

Information specialists directed the patron toward information and legal resources related to custody and parental rights of parents with disabilities and their children.

Research on parenting children with disabilities is prevalent. The search string “parents with disabilities” produces over 1,000 results—most have nothing to do with parents who themselves have disabilities, but rather parents whose children have disabilities. Locating information on custodial and parental rights of parents with disabilities proved to be more challenging. Much of the information found was related to specifically to parents who have intellectual or psychiatric disabilities. We chose not to include information on social supports and/or programs geared toward parents with disabilities (i.e. parents with intellectual or mental disability). Rather, we chose to focus on custodial and parental rights (i.e. adoption, child protection, custody, foster care, legislation, etc.).

The research presented in this issue provides a “snapshot” of custodial and parental rights of parents and grandparents with disabilities. Combined search terms included: parents with disabilities, rights of disabled parents, parental rights, custody, disabled parents, and parenting with a disability. A listing of ap-

proximately 70 additional descriptor terms between the NARIC, CIRRIE, ERIC, and PubMed databases can be found at the end of this document. A search of the REHABDATA database resulted in 28 documents published between 1983 and 2008. A search of CIRRIE and ERIC databases resulted in three documents between 1999 and 2005 and five documents between 1981 and 2005, respectively. Finally, a search of the PubMed database resulted in 10 documents between 1994 and 2008. The complete citations are included in this research brief.

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**NIDRR Funded Projects
Related to Custodial and Parental rights of
Individuals with Disabilities**

In addition to document searches, we searched our NIDRR Program Database to locate grantees/projects related to custodial and parental rights of individuals with disabilities. The search resulted in eight NIDRR funded projects — three currently funded and five which have completed their research activities. Project information and their publications are offered as additional resources for our patrons.

A Mixed Methods Study of Parenting, Children, and Recovery in Mothers with Severe Psychiatric Disabilities.

Project Number: H133F080009
Phone: 508/856-8712
Email: joanne.nicholson@umassmed.edu

National Center for Parents with Disabilities and Their Families

Project Number: H133A080034
Phone: 510/848-1112
Email: tlg@lookingglass.org
www.lookingglass.org

Parent-Infant Interaction Project (PIIP)

Project Number: H133G080132
Phone: 503/725-4687
Email: munsonl@pdx.edu

The following projects have completed their research activities:

Adaptive Parenting Equipment: Evaluation, Development, Dissemination, and Marketing.

Project Number: H133G60036
Toll Free: 800/644-2666
Email: tlg@lookingglass.org
www.lookingglass.org

Evaluation of Barriers to Delivery of Rehabilitative Services to Infants and Toddlers in the Custody of the Illinois Department of Children and Family Services.

Project Number: H133F050018
Public Contact Phone: 312/641-2505, ext. 41
Email: bruhn@uiuc.edu

The Parenting Options Project: A Development Project for Parents with Psychiatric Disabilities.

Project Number: H133G70079
Phone: 508/856-8721
Email: joanne.nicholson@umassmed.edu
www.umassmed.edu/pop

Parents with Disabilities and Their Adolescent Children.

Project Number: H133G990130
Toll Free: 800/644-2666
Email: rolkin@lookingglass.org
www.lookingglass.org

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

Project Number: H133B30070
Phone: 785/864-7600
Email: beach@dole.lsi.ukans.edu
www.lsi.ukans.edu/Beach/Beachhp.htm



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

2008

Buckland, K., Callow, E., & Jones, S. (2008). *The disability movement and a new focus on legislative protection for children in families with parental disability.*

NARIC Accession Number: O17447
ABSTRACT: Article addresses the issue of the removal of children from the custody of parents with disabilities. The seven sections present a case for sweeping legislative changes to protect the children in families with parental disability from unnecessary removals and the accompanying trauma. Section I discusses family and dependency laws in general, and the history of parenting with a disability in America. Section II looks at the affected population, data we have collected on the demographics of that group and rates of removal. Section III outlines the identified causes of removals and Section IV examines the effects on children. Section V reviews the state legislation that has been developed specifically to combat the problems in practice and strategy and unintentionally applicable federal legislation. Section VI proposes model elements for fu-

ture remedial legislation if it is to be useful and discusses the possibility for a federal versus state fix. Section VII concludes with a brief examination of developments at the international level.

2007

Flaro, L., Green, P., & Robertson, E. (2007). **Word memory test failure 23 times higher in mild brain injury than in parents seeking custody: The power of external incentives.** *Brain Injury, 21*(4), 373-383.

NARIC Accession Number: J54237

ABSTRACT: Study examined how external incentives impacted performance on the Word Memory Test (WMT), a measure of effort, by comparing groups with different external incentives. Performance on the WMT was assessed in a group of adults with traumatic brain injury (TBI), tested as part of workers' compensation, disability, or personal injury, who stood to gain financially by appearing impaired on testing. In contrast, parents ordered by the court to undergo a parenting assessment were highly motivated to do their best on the cognitive tests because their goal was to regain custody of their children. Consistent with these assumptions, 98.3 percent of the 118 parents seeking child custody passed the WMT effort test but the pass rate on the WMT was only 60 percent among the 774 adults with mild TBI. The WMT failure rate in the mild TBI group was 23 times higher than in the group of parents seeking custody. WMT failure was twice as frequent in the mild TBI group compared to those with more severe TBI. It is concluded that such differences in failure rates on the WMT test cannot be explained by differences in cognitive skills, but are explained by differences in external incentives.

2006

Callow, E. (2006). **The adoption experience: A guide for prospective parents with disabilities and their advocates.** *National Resource Center for Parents with Disabilities, Through the Looking Glass.*

NARIC Accession Number: O16944

ABSTRACT: This guide is intended to help parents with disabilities understand and protect their rights during the child adoption process. Sections address how to start the process, types of adoptions, special laws

which apply to prospective parents with disabilities, who are involved in the process, basic steps in the adoption process, and special steps prospective adoptive parents with disabilities can take during the home study phase and other key phases in the adoption process.

Callow, E. (2006). **The child protective service/dependency court experience: A guide for parents with disabilities and their advocates.** *National Resource Center for Parents with Disabilities, Through the Looking Glass.*

NARIC Accession Number: O16943

ABSTRACT: This guide is intended to help parents with disabilities understand and protect their rights in a child dependency case. Sections address when a parent's right to their child can be terminated, the steps that lead to termination or parental rights, which parts of the state government are involved in the dependency process, and what special steps parents with disabilities need to take at each phase of the process and what special laws apply to them.

Callow, E. (2006). **The family court experience: A guide for parents with disabilities and their advocates.** *National Resource Center for Parents with Disabilities, Through the Looking Glass.*

NARIC Accession Number: O16940

ABSTRACT: This guide is intended to help parents with disabilities understand and protect their rights in a child custody case. Sections address when and how to request custody, types of custody arrangements, steps involved in securing a custody arrangement through stipulation or judgment, who may be involved in a family law proceeding addressing custody, evaluations, special steps that parents with disabilities may want to take at each phase of the process, and special laws that apply to parents with disabilities.

Callow, E. (2006). **Summaries of legal precedents and law review articles concerning parents with disabilities.** *National Resource Center for Parents with Disabilities, Through the Looking Glass.*

NARIC Accession Number: O16945

ABSTRACT: Document presents a collection of annotations; law review articles, including comments and notes; case law summaries (by state); and federal case summaries involving parents with disabilities.

LaLiberte, T., & Lightfoot, E. (2006). **The inclusion of disability as grounds for termination of parental rights in state codes.** *Policy Research Brief, 17*(2).

NARIC Accession Number: O16652

Available in full-text at www.naric.com/research/rehab/download.cfm?ID=103317.

ABSTRACT: This brief examines state policies regarding termination of parental rights (TPR), focusing on the extent to which states use disability as grounds for termination. An analysis of legal documents revealed that many states include disability inappropriately in their TPR statutes, including using inappropriate terminology to refer to a person's disability, using imprecise definitions of disability, and often focusing on disability rather than behavior. Currently, 36 states have specific grounds for termination for mental illness, 32 have grounds for intellectual or developmental disability, 18 have grounds for emotional disability, and 8 have grounds for physical disability. Of the states that do not include disability-related language in their TPR statutes, they all have general provisions that would allow TPR of parents with disabilities, though such a TPR would focus on the parent's abusive or neglectful behavior rather than disability status.

2005

(2005). **Parenting with a mental illness: Child welfare and custody issues.** *Community Integration Tools.*

NARIC Accession Number: O16022

Available in full-text at <http://www.naric.com/research/rehab/download.cfm?ID=99655>.

ABSTRACT: Fact sheet addresses child custody issues for parents with psychiatric disabilities. It offers advice on how to stay mentally healthy and how to deal with the legal system for parents with mental illness who child has been removed from their custody by the local child welfare agency.

Callow, E. (2005). **Good practice . . . upholding parents' rights.** *Disability, Pregnancy & Parenthood International. National Resource Center for Parents with Disabilities, Through the Looking Glass.*

NARIC Accession Number: O16947

ABSTRACT: Author, who is an attorney, describes how she assists parents with disabilities, advocates, and professionals when they are involved in child custody litigation. She includes information on legal resources for parents in the United States and in the United Kingdom.

Gudenzi, M. (Ed.). (2005). **Parenting with a disability, 11**(2). *National Resource Center for Parents with Disabilities, Through the Looking Glass.*

NARIC Accession Number: O16942

ABSTRACT: Newsletter includes items about the activities of Through the Looking Glass (TLG), an organization that provides research, training, and services for families in which a child, parent, or grandparent has a disability. In this issue: TLG's resources for parents with intellectual disabilities, new training module for occupational therapists, 2005 college scholarships, custody and legal resources, a new book on pregnancy and birth, and systems development in Kansas.

2003

Baer, R.L., Kirshbaum, M., & Taube, D.O. (2003). **Parents with disabilities: Problems in family court practice.** *Journal of the Center for Families, Children and the Courts, 4*, 27-48.

NARIC Accession Number: J52969

ABSTRACT: Article examines the barriers that parents with disabilities face in child custody cases. Examples are provided of biased assumptions in the judicial approaches to four broad classes of disability: physical, sensory, cognitive, and psychiatric. Absent or poorly articulated statutory and professional guidelines for conducting child custody evaluations, the relative unavailability of legal services, attitudinal and accessibility barriers, and lack of disability awareness, knowledge, and skill in family courts are described as evidence of a legal structure that has not addressed bias against parents with disabilities. Suggestions are made for improving the functioning of family court to provide realistic, positive options and accommodations for parents with disabilities and their children.

Cameron, N., & Swain, P.A. (2003). **Good enough parenting: Parental disability and child protection.** *Disability & Society, 18*(2), 165-177.

NARIC Accession Number: J45396

ABSTRACT: Presents findings from research examining court practices in Australia regarding child protection matters involving parents with disabilities. Results indicated that parents with a disability often had no representation in courts. Concerns were more likely to be raised regarding neglect, or sexual or emotional abuse, when parental disability was noted. Formal court interventions only infrequently made recommendations regarding support, training, and advice such parents needed in order to retain care of their children.

2000

Llewellyn, G., & McConnell, D. (2000). **Disability and discrimination in statutory child protection proceedings.** *Disability & Society, 15*(6), 883-895.

NARIC Accession Number: J40853

ABSTRACT: Article on discrimination faced by parents with mental retardation in statutory child protection proceedings. The authors briefly review the literature on rates of child removal and circumstances in which removal is predetermined. Political and social conditions underlying discrimination are discussed, including outmoded and stereotypic beliefs about persons with mental retardation; an expectation that families should be autonomous and independent, so that parents who are themselves dependent should not be heads of families; an emphasis on individual responsibility, leading to false attribution of parenting difficulties to the disability rather than to poverty and social factors; and a focus on individual rights, leading to an adversarial conflict between parental rights and the rights of children.

1997

Haight-Liotta, S., & Strong, M.F. (1997). **When a mother has a disability: Dealing with disability in the AFDC and CPS systems.** *Meeting the needs of women with disabilities: A blueprint for change.*

NARIC Accession Number: O12287

ABSTRACT: Booklet designed for social workers in Aid to Families with Dependent Children (AFDC) and Child Protective Services (CPS) programs who are working with mothers who have disabilities. Topics include a brief introduction to mothers with disabilities and typical discrimination faced by the population; work-welfare requirements as they relate to women who have disabilities; social service requirements under the Americans with Disabilities Act; disability-specific considerations; and strategies for improving social service program provisions to mothers with disabilities. An appendix includes bibliographies and resources.

Kelley, S.D.M., Sikka, A., & Venkatesan, S. (1997). **A review of research on parental disability: Implications for research and counseling practice.** *Rehabilitation Counseling Bulletin, 41*(2), 105-121.

NARIC Accession Number: J34518

ABSTRACT: Reviews parental disability literature published since 1980 and explores factors associated with processes and outcomes of parenting by persons with physical, cognitive, or sensory disabilities. Consists of two major sections. The first considers conceptual problems associated with defining and understanding how chronic illness or disability influences parental role functioning and families. The second section presents findings from empirical studies dealing with physical, cognitive, or sensory disabilities in parents. Concludes with a discussion of the implications for research and counseling practice with this population.

1996

Estrada, M. (1996). **California adoption agencies: How do they assess parents with disabilities?**

NARIC Accession Number: O12660

ABSTRACT: Paper on adoption agency views regarding adoption of children by persons with physical disabilities. Data are from 31 responses to a survey of executive directors of California adoption agencies, and from analysis of the agencies' written policies. Participants were asked about the number and frequency of adoption placements with parents with disabilities, the presence and frequency of disability training, and

agency characteristics, and regression analyses were performed to assess the relationships between these variables. It was found that the variables correlating most significantly with placement of children with disabled parents were adoption fees, disability training, agency expectations of parents with disabilities, and prior placement of children with parents with disabilities.

Herman, A. (1996). **Bringing up Donald: Challenges and solutions for parents with disabilities.** *New Mobility*, 7(36).

NARIC Accession Number: J32768

ABSTRACT: Describes the various challenges parents with disabilities can face while raising non-disabled children. Focuses on a family in which both parents are wheelchair dependent for mobility. Provides information on adaptations and coping mechanisms they used from the time of their child's birth through his teens. Lists U.S. and Canadian resources for parenting.

1994

Culbert, J.P., Sonenklar, N.A., & Urbach, J.R. (1994). **Risk factors and assessment in children of brain-injured parents.** *Journal of Neuropsychiatry & Clinical Neurosciences*, 6(3), 289-295.

NARIC Accession Number: J28736

ABSTRACT: Discusses the impact of parental head injury on children and examines issues in assessing children's reactions and choosing appropriate interventions. The first section outlines the specific types of psychosocial difficulties that may be experienced by the family following a head trauma in a family member. The second section reviews the impact of other parental psychiatric and neurologic disorders on children. The third section discusses the impact of parental brain injury on children, including the mediators of children's risk after parental brain injury, typical responses by children to specific symptoms of a brain injured parent, and suggested interventions. The third section outlines areas to investigate when screening for problems in children and when screening for general family dysfunction. Two case examples are used throughout the article to illustrate these assessment and intervention issues.

Culler, K.H., Jasch, C., & Scanlan, S. (1994). **Child care and parenting issues for the young stroke survivor.** *Topics in Stroke Rehabilitation*, 1(1), 48-64.

NARIC Accession Number: J28615

ABSTRACT: Article in a special journal issue on the young stroke survivor. (See ANs J28611-J28619 for individual articles in the issue.) This article examines child care and parenting issues for the young stroke survivor. Topics include: 1) the role of health care professionals in promoting involvement of the young stroke survivor in the parenting role, 2) assessment tools that can identify areas of focus for the health professional and parent, 3) adaptive techniques and equipment for maximizing abilities and promoting safe performance of child care tasks, and 4) product and literature resources that can be used by the health care professional or parent to facilitate effective parenting and child care task performance.

Matava, M. (1994). **The implications of parenting standards in child protection: A paradox in disability policy.** *Policy Studies Journal*, 22(1), 146-151.

NARIC Accession Number: J28808

ABSTRACT: Paper discussing a paradox in ADA policy-the rights of a child to be protected from sexual and physical abuse, and neglect, and the rights of a parent with disabilities to raise their child. The article considers three scenarios: parents who are fully able to care for their children but are denied that right through stereotypical assumptions of disabilities; parents who are mentally capable of child-rearing but lack personal assistance for the physical requirements of child care; and parents with mental disabilities who without support could be at risk for child neglect. The impact of the ADA and various state laws upon these situations are considered.

1993

Blackford, K.A. (1993). **Erasing mothers with disabilities through Canadian family-related policy.** *Disability, Handicap & Society*, 8(3), 281-294.

NARIC Accession Number: J25681

ABSTRACT: Examines family policy in Canada as it pertains to mothers with disabilities. Equality rights for Canadian citizens are established in the Charter of Rights and Freedoms (1982). Section 15 of the Charter defines equality as accommodation of difference and a fair share of society's resources for groups who have been historically disadvantaged. While these principles should mean that women with disabilities will have appropriate parenting and family supports available, disablist policies, insufficient funding, and bureaucratic practices continue to discriminate against mothers with disabilities. The author argues that where mothers with disabilities have experienced such discrimination, they are denied their rights and entitlements as Canadian citizens.

Bland, R., Grey, C., & Smith, N.J. (1993). **Handicapped parents with non-handicapped dependents.** *International Journal of Rehabilitation Research*, 16(2), 157-159.

NARIC Accession Number: J24996

ABSTRACT: Study exploring the extent and focus of research concerned with the handicaps experienced by parents with disabilities and their non-disabled dependents. A literature search was conducted using family, psychological, sociological, rehabilitation, and social work databases covering Europe, North America, and Australia. A total of 93 references were found over a 15-year publication period extending back to 1975. Twenty publications addressed general disabilities, 27 addressed specific physical disabilities, and 46 addressed mental disabilities. The main topics were effects of the parental disability on the child's behavior; child development, including communication; impact on family life in general; issues of parental behavior and capabilities; and therapeutic or service approaches to specific disabilities or behaviors. The majority of publications related to the area of mental disability and were concerned with the effects of parental disability on the child's development. Few publications focused on the handicaps facing parents with disabilities and their effects on the parenting role as experienced by the parent.

Booth, T., & Booth, W. (1993). **Accentuate the positive: A personal profile of a parent with learning difficulties.** *Disability, Handicap & Society*, 8(4), 377-392.

NARIC Accession Number: J26022

ABSTRACT: Qualitative study exploring the experience of child-rearing and parenthood by parents with learning difficulties. The purpose was to demonstrate why parental competence can be assessed only in the context of the individuals' life history. The study involved in-depth interviews with 20 parents or sets of parents. This article presents a summary description of these families followed by a detailed analysis of the personal profile of one parent. Two perspectives, one focusing on deficiency and the other on capacity, are applied in the analysis to illustrate how these contrasting views each lead to a different appreciation of the individual and can bias the opinions and response of social services professionals.

Lash, M. (1993). **When a parent has a brain injury: Sons and daughters speak out.** *Massachusetts Head Injury Association*.

NARIC Accession Number: R06795

ABSTRACT: This book describes the experiences of sons and daughters who have a parent with a brain injury: (1) experiences at the hospital (the injury, the coma, reasons to visit); (2) conspiracy of silence (whether the parent would live or die and whether the child could handle the situation); (3) how parents changed (changes in behavior, physical changes, and what independence is); (4) life at home (coming home to change, siblings, teaching parents, and new alliances); (5) the reactions of and explanations to friends (who knows what, fitting in at school, and reactions); and (6) moving on; An appendix includes a message for professionals, recommending that they use the guide to gain insights into the emotions and reactions of sons and daughters. Resources are attached.

White, G.W., & White, N.L. (1993). **The adoptive process: Challenges and opportunities for people with disabilities.** *Sexuality & Disability*, 11(3), 211-219.

NARIC Accession Number: J26164

ABSTRACT: Adoption offers one option for individuals with disabilities to increase their family size. Many people with physical disabilities face barriers when trying to conceive on their own, so adoption is a good alternative. The article examines the adoption process for people with disabilities, looking at why individuals with disabilities might want to adopt and what channels they would have to go through. The adoption process includes the orientation meeting and a home study. International adoption requires that individuals meet both local and foreign adoption requirements. Types of adoption include public agencies, private agencies, independent adoption, interstate placement of children, open adoptions, and unidentified (closed) adoptions. Not all adoption agencies provide equivalent services, so individuals must consider what they are looking for and what the agency accepts. Because the availability of Caucasian infants has diminished severely over the past several years, people are tending to adopt infants from other countries. However, there are many harder-to-place children in the United States available for adoption. They include children with special needs, sibling groups, older children, and children of minority or mixed race.

1990

Accardo, P.J., & Whitman, B.Y. (1990). **When a parent is mentally retarded.** *Paul H. Brookes Publishing Company*, Baltimore, MD, www.brookespublishing.com.

NARIC Accession Number: R05535

ABSTRACT: This publication addresses the issue of the quality of care of children in the homes of parents with mental disabilities and the conflict of the right of persons with mental disabilities to procreate and society's right to see that the basic needs of children are met. The book presents and discusses the topics of mentally retarded parents in the community, agency surveys and needs assessment questionnaires in epidemiological probes, genetics and mental retardation, parenting skills training for adults with mental retardation and other educational interventions, problems and diagnoses of children of parents with mental retardation, the pediatrician's role, the right to marry for per-

sons with mental retardation, parental rights of persons with mental retardation, and ethical issues in parenting by persons with mental retardation and developmental disabilities.

1985

(1985). **Physically disabled parents' rights.** *Mental and Physical Disability Law Reporter*, 9(6), 435-436.

NARIC Accession Number: J07316

ABSTRACT: Describes two court decisions involving the parental rights of mothers with physical disabilities. The first mother, who was permanently disabled with multiple sclerosis and in a wheelchair, was awarded parental rights after an appeals court reversed an original decision, despite her inability to care for her child physically. In the second case, an appeals court affirmed a lower court decision that took away custody of a child from his mother, who was subject to uncontrolled petit mal seizures and was emotionally unstable and immature.

1983

Johnson, P.L. (1983). **Groups for parents with developmental disabilities.**

NARIC Accession Number: O08979

ABSTRACT: A listing and description of group activities for developmentally disabled parents. Five activities are fully described; they address: child development, self-esteem enhancement, meal planning and budgeting, stress management, and child discipline. Step-by-step instructions are given for performing the activities, as are experiences of the authors in using them. The author discusses the experiences he encountered in adapting and using these activities, which he calls a mixed bag of success and failure, in terms of research implications on instructional methodologies as they concern the teaching of abstract concepts, the entangling issues of foster care, court assignments, and parenting, and the problems attendant to conducting such activities in concert with welfare functions.



**Documents from the Center
for International
Rehabilitation Research
Information and Exchange**

(CIRRIE) search at cirrie.buffalo.edu are listed below:

2005

Czerederecka, A. (2005). **Cognitive processes of parents fighting for custody and parental alienation syndrome observed in their children.** *Z Zagadnien Nauk Sadowych*, 61(-), 19-29. (Article in Polish).

ABSTRACT: In process (CIRRIE abstract)

2003

Andritzky, W. (2003). **Child psychiatric documentation in child visitation and custody disputes—results of a survey.** *Praxis der Kinderpsychologie und Kinderpsychiatrie*, 52(10), 794-811. (Article in German).

PMID #: 14699788 (Linked to PubMed abstract from CIRRIE)

ABSTRACT: In the last decade, increasing divorce rates, a joint custodial concept, and a deficient legal situation of non-married fathers have been involuntarily provoking cases of a parent with child custody alienating that child in order to exclude the other parent from visitations and educational participation. Medical certificates are frequently of fateful importance in child custody litigation. In an mail survey conducted in six German cities, N = 133 child psychiatrists were asked about the frequency in which they issue such certificates, what certificates contained, what recommendations were made, and where possible the reasons why the other parent was not included in the diagnostic process. According to the results 74.4 percent of those surveyed were asked to issue such medical certificates at least once in the year prior to the survey; 42 percent of the psychiatrists stating that the other parent never or only sometimes participated. The symptoms most frequently certified were behavioral disorders (46 percent), aggression (34 percent), problems in school/

ADD (28 percent), anxiety (26 percent), bed-wetting (23 percent), depression (21 percent), and psychosomatic reactions (20 percent). Outlining the characteristics of alienated children and of alienating parents, of “natural” and of “induced” stress-symptoms in children after parental separation; the article provides physicians and institutions of the health system with support to prevent medical certificates being abused in child custody litigation. Some fundamental guidelines are presented as to what aspects and should be explored and which persons referred to before certificates are issued to parents, social workers or judges of family law courts.

1999

Pixa, K.U. (1999). **Follow-up study on parenting with intellectual disability in Germany.** *Journal of Intellectual & Developmental Disability*, 24(1), 75-93.

ERIC #: EJ583823 (ERIC abstract from CIRRIE)
ABSTRACT: Five cases of parenthood of persons with intellectual disability were reinvestigated about two years after a previous German study. Problem-centered interviews were conducted with mothers or fathers with an intellectual disability and with the caretakers. Results show developmental disability in two of six children and, in some cases, psychological disorders.



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

2009

Llewellyn, G., & Mayes, R. (2009). **What happens to parents with intellectual disability following removal of their child in child protection proceedings?** *Journal of Intellectual & Developmental Disability*, 34(1), 92-95.

ERIC #: EJ830037

ABSTRACT: It is unlikely that every parent with intellectual disability comes under the scrutiny of the care and protection system. That many do is evident in the

figures from a number of countries that report between 30 and 40 percent of the children of parents with intellectual disability are removed from their parents' care and placed in protective custody, in foster care, or in a residential setting. Recent developments, particularly in the United Kingdom and Australia, in seeking permanent placement for children away from their parents earlier rather than later means that many of these children will not be reunited with their parents. As long as the prevalent attitude of current and future parental incompetence continues to exist, having a child taken away—permanently—remains a real possibility for many parents with intellectual disability. In this article, the authors highlight their concern about this situation, as well as their concern that little is known about the potentially devastating outcomes for these parents when their children are taken away by the State.

2007

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

ERIC #: EJ764992

ABSTRACT: Background: As a sequel to a report by the Health Council of the Netherlands on contraception in persons with intellectual disabilities (IDs), a fierce debate about parenthood by such persons occurred, in which a lack of knowledge about parenting competences became clear. Therefore, the Ministry of Health commissioned a study investigating examples of "successful parenthood" by persons with IDs. Methods: In conformity with the literature and with legal categories, we defined "successful parenthood" as "good enough parenthood", meaning no indications for child abuse and/or neglect, no dealings with child protection agencies and no legal custody. We combined a nationwide quantitative questionnaire study with a qualitative interview study. Questionnaires were sent to all institutions involved in caring for persons with ID, interviews were held with "good enough" parents and their professional caregivers, selected on the basis of returned questionnaires. Results: Parenthood occurs in around 1.5 percent of persons with ID in the Netherlands and is mostly restricted to those with mild handicaps. In total, 51 percent of the cases were regarded, by caregivers, as not-good-enough parenthood, 33

percent were clearly good enough and 16 percent were doubtful. Predicting factors included the ability and the willingness to follow advice, the quality of the social network and the acceptance of parenting in the community. However, there is not one decisive predicting factor; particularly, the predictive value of the IQ alone is small. Conclusions: A general policy of discouragement of parenthood, as advocated by the Dutch Ministry, is not supported by our results; moreover, it would probably be impossible and have negative effects on social acceptance of parents with ID. The overall conclusion from the study therefore is that some kind of balancing model, in which positive and negative factors are weighed, may be useful to and need for support.

1998

Anderson, L., Lakin, C., & Mandeville, H., (Eds.). (1998). **Supporting parents who have cognitive limitations.** *Impact*, 11(1).

ERIC #: ED418555

Available in full text at: www.eric.ed.gov/ERICWebPortal/contentdelivery/servlet/ERICServlet?accno=ED418555

ABSTRACT: This feature issue focuses on strategies to support parents who have cognitive limitations to be successful in raising their children. Articles include: (1) "Encounters with Entropy: Marge's Journey from System to System" (John Franz and Pat Miles) that tells a fictional story of a mother with disabilities to illustrate the tendency of human service systems to operate independently of one another, to stay locked into rigidly structured responses, and to avoid collaborative responses; (2) "Helping Parents Be Parents" (Howard Mandeville and Polly Snodgrass); (3) "Mothers with Developmental Disabilities: Common Issues and Needs" (Bette Keltner); (4) "Parents with Cognitive Limitations: What Do We Know about Providing Support?" (Lynda Anderson and K. Charlie Lakin); (5) "Perpetuating the Sprit of Kako'o" (Stacy Kong); (6) "Supporting Parenting Rights: Arc Hennepin" (Lori Gildersleeve); (7) "Two Decades of Parent Support: Reuben Lindh Parenting Program" (Audrey Kvist); (8) "Supporting Fathers with Cognitive Limitations" (Mark D. Simpson and others); (9) "Parents with Cognitive Limitations: Challenging Myths, Changing Perceptions" (Alexander J. Tymchuk); (10) "Supporting Parents and Children during Termination of Parental Rights"

(Deborah Muenzer-Doy and Lynda Anderson); (11) "Strengthening Families of Older Children" (Gwynnyth Llewellyn); (12) "The Adult Children of Parents with Learning Difficulties" (Tim Booth and Wendy Booth); (13) "Welfare Reform and Parents with Disabilities" (Caroline Hoffman and Howard Mandeville); (14) "System Abuse and the Power of Advocacy" (Tim Booth and Wendy Booth); and (15) "How Small Initiatives Make a Difference" (Rick Brooks). The issue closes with a list of supported parenting resources.

1990

Llewellyn, G. (1990). **People with intellectual disability as parents: Perspectives from the professional literature.** *Australia & New Zealand Journal of Developmental Disabilities, 16*(4), 369-80. ERIC #: EJ441223

ABSTRACT: This article reviews the literature on parenthood by people with intellectual disability including parenting after deinstitutionalization, parenting for those already identified as needing assistance, parenting in comparison with other parents, outcomes for children of intellectually disabled parents, and parent experiences before the courts. The heterogeneity of parenting experiences for this population is noted.

Pomerantz, P. (et. al.). (1990). **A case study: Service delivery and parents with disabilities.** *Child Welfare, 69*(1), 65-73. ERIC #: EJ404277


ABSTRACT: Describes a home-based intervention program that provided time-intensive, supervised, paraprofessional services to a family in which parents and infant had serious disabilities. Programmatic needs and delivery of services to disabled parents and families are discussed.

1981

McTate, G.A., & Rosenberg, S.A. (1981). **Intellectually handicapped mothers: Problems and prospects. Working papers in developmental disabilities. (Draft).** ERIC #: ED235657

ABSTRACT: Issues in working with mentally retarded parents are considered. Experiences of the Intensive Services to Families at Risk Project (ISFAR), an effort to prevent the need for foster care by improving

the quality of care for abused and neglected children in their own families, are recounted. Among problems facing retarded parents is a tendency to overgeneralize instructions, difficulty in adjusting parenting styles to changes in child's development, and lack of such vital resources as transportation for medical services or clothing. ISFAR services addressed child care knowledge, parent child interaction, resource deficits, and family supports. In addition, parents were helped to interact with various human service agencies. Activity groups were used to improve parenting abilities, and individual sessions were devoted to unique needs. Benefits of the program are traced, and the need for an array of services is stressed, including skill training, home visiting, and casework designed to reduce resource and social problems.

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

2008

Buchbinder, E., Duvdevany, I., & Yaacov, I. (2008). **Accepting disability: The parenting experience of fathers with spinal cord injury (SCI).** *Qualitative Health Research, 18*(8), 1021-33.

PMID #: 18650559

ABSTRACT: This qualitative study describes and analyzes the perceptions and experiences of fathers with spinal cord injury (SCI) regarding their relationship with their children, in the context of social attitudes toward parenting by persons with SCI. The study was conducted within the phenomenological-constructivist paradigm. The sample included 12 males with SCI. All participants were paraplegic Type D1-D12; 2 have incomplete injury to D11 and D12. Data were collected through in-depth semi-structured interviews designed to understand participants' meanings. Interviews included a brief questionnaire containing socio-demographic items and an interview guide based on the research topics. The model addresses how fathers with SCI cope with negative social attitudes toward their parenting and their actions to facilitate their children's acceptance of and adjustment to the father's disability.

2006

Siegrist, D., & Thibault, P. (2006). **Maternity and handicap, legislative aspects.** *Soins. Pédiatrie, puériculture*, 229, 18-21. (Article in French). PMID #: 16700496

ABSTRACT: *No abstract is available.*

2003

Bishop, S.J. (2003). **Parents with disabilities involved in dependency cases.** *Child Abuse & Neglect*, 27(3), 233-4.

PMID #: 12654322

ABSTRACT: *No abstract is available.*

Ferronato, L., Llewellyn, G., & McConnell, D. (2003). **Prevalence and outcomes for parents with disabilities and their children in an Australian court sample.** *Child Abuse & Neglect*, 27(3), 233-4.

PMID #: 12654323

ABSTRACT: OBJECTIVE: The purpose of this study was to obtain sound prevalence and outcomes data on parents with disabilities and their children in statutory child protection proceedings. METHOD: The court files of all care and protection matters initiated by the statutory child protection authority and finalized in a 9-month period (n=285) at two Children's Courts in NSW, Australia were reviewed. RESULTS: Parents with disabilities featured in almost one-third of the cases (29.5 percent). Parental psychiatric disability was most prevalent at 21.8 percent followed by parental intellectual disability (mental retardation) at 8.8 percent. Significant associations were found between parental disability and court outcome with a disproportionately large number of children of parents with intellectual disability being made wards of the state. CONCLUSIONS: The findings demonstrate that parents with disabilities are significantly over-represented in statutory child protection proceedings and that the outcomes of these proceedings vary according to disability type.

FSS/PACE Program, Community Mental Health Center for Mid-Eastern Iowa. (2003). **Helping parents with serious mental illness retain custody of their children.** *Psychiatric Services*, 54(11), 1526-8.

PMID #: 14600313

Available in full-text at ps.psychiatryonline.org/cgi/content/full/54/11/1526.

ABSTRACT: *No abstract is available.*

2002

(2002). **Can people with disabilities be parents?** *American Psychologist*, 57(11), 988-9; discussion 989-90.

PMID #: 12564213

ABSTRACT: *No abstract is available.*

Walton, M.K. (2002). **Advocacy and leadership when parental rights and child welfare collide: The role of the advanced practice nurse.** *Journal of Pediatric Nursing*, 17(1), 49-58.

PMID #: 11891494

ABSTRACT: This article describes the experience of an advanced practice nurse in a challenging clinical situation. A mother with mental illness and mental retardation seeks to retain parental rights and care for her newborn with cystic fibrosis. The nurse provides leadership to the hospital team and serves as an advocate throughout legal proceedings. A systematic, nonjudgmental, and empathic approach to gathering information, working with the family, welfare, and legal representatives is described. Enacting a complex and court-mandated homecare education regimen to the disabled mother is discussed. Preparation to testify in a termination of parental rights proceeding is outlined and a summary description of the testimony provided. Copyright 2002, Elsevier Science (USA).

2000

Kerr, S. (2000). **The application of the Americans with Disabilities Act to the termination of the parental rights of individuals with mental disabilities.** *Journal of Contemporary Health Law & Policy*, 16(2), 387-426.

PMID #: 10921234

ABSTRACT: *No abstract is available.*

1999

(1999). **Two courts say ADA doesn't apply in parental rights cases.** *AIDS Policy & Law*, 14(18), 4-5.

PMID #: 11367029

ABSTRACT: AIDS: State courts in Connecticut and Ohio have ruled that the Americans with Disabilities Act (ADA) cannot be used as a defense against ef-

forts by State child welfare agencies to gain custody of neglected or abused children. The ADA prohibits an individual from being denied access to services, programs, or activities of a public entity, but the courts ruled that the ADA did not apply to parental termination cases. The Connecticut and Ohio rulings both held that parents cannot use the ADA to prevent their children from being removed after they have been abused. The cases involved the States' obligations to preserve the family, but the courts ruled the question of whether welfare officials did their best to accommodate parents was irrelevant. A chart displays how the ADA applies to termination hearings in 12 States.

1994

Blum, E.T. (1994). **When terminating parental rights is not enough: A new look at compulsory sterilization.** *Georgia Law Review*, 28(4), 977-1017.

PMID #: 11653343

ABSTRACT: *No abstract is available.*



New Community
Integration Tool from
the UPenn Collaborative
on Community Integration!

Preventing Custody Loss: Suggestions for Parents with Psychiatric Disabilities

The best way to prevent custody loss is to have a plan that helps you improve your parenting skills while managing your psychiatric disability. This CI Tool includes suggestions on how to create a plan to protect the best interests of the child and to demonstrate your maturity as a parent.

Available for free at:

www.upennrrtc.org/var/tool/file/206-Suggestions%20to%20Prevent%20Custody%20Loss%20-%20FINAL.pdf



Quick Looks

Adoption.com – Disabled Parents

adopting.adoption.com/child/disabled-persons-can-adopt.html

Disabled Parents Network (DPN) UK

www.disabledparentsnetwork.org.uk/cgi-bin/site/site.cgi

Family Village – Parents with Disabilities

www.familyvillage.wisc.edu/general/parents/wdis.html

i-Village Message Board: Parents with a Disability

messageboards.ivillage.com/iv-ppdisability

National Center for Parents with Disabilities and their Families – NIDRR Grantee Through the Looking Glass (TLG)

Parents with Disabilities –

lookingglass.org/parents

National Parent-to-Parent Network –

lookingglass.org/parents/ppn.php

Training, Presentations, and Workshops –

lookingglass.org/training

Publications: lookingglass.org/shop

TLG Newsletter—Parenting with a Disability:

www.lookingglass.org/newsletter

Parenting with a Disability Network (PDN) (Canada)

www.cilt.ca/parenting.aspx

Parents with Disabilities Online

www.disabledparents.net

Parents with Disabilities Project

www.uclid.org:8080/uclid/public/uclid-service-details.tdf?ServiceRequest>StatusCode=3&ServiceID=347

Yahoo Discussion Group: Disabled Adoptive Parents (DAP) –

groups.yahoo.com/group/disabledadoptiveparents









Search Terms for Custodial and Parental Rights of Individuals with Disabilities

- | | |
|--|---|
|  ADA |  Government |
|  Adjustment |  Independent Living |
|  Adoption |  Intellectual Disabilities |
|  Advocacy |  International Rehabilitation |
|  Agency Cooperation |  Interpersonal Relationships |
|  Assistive Devices/Technology |  Intervention |
|  Attitudes toward Disabilities |  Judicial Role |
|  Attitudinal Barriers |  Learning Disabilities |
|  Behavior |  Legal Concerns/Services |
|  Blind |  Legislation |
|  Brain Injuries |  Literature Reviews |
|  Caregivers |  Mental Health/Illness/Retardation |
|  Case Management |  Parental Rights |
|  Case studies |  Parent Attitudes/Education |
|  Child Abuse/Care/Development/Rearing/
Welfare |  Parent-Child Relationship |
|  Child Custody/Legislation |  Parenting/Skills |
|  Child of Impaired Parents |  Parenting with a Disability |
|  Children |  Parents with Disabilities |
|  Civil Rights/Legislation |  Peer Counseling |
|  Cognitive Disabilities |  Physical Disabilities |
|  Community Living/Resources |  Policy |
|  Court Cases/Litigation |  Program Development |
|  Custody |  Psychiatric Disabilities |
|  Daily Living |  Public Policy |
|  Deaf |  Reproduction |
|  Developmental Disabilities |  Rights of Parents with a Disability |
|  Disabilities |  Sensory Impairments |
|  Disability Studies |  Social Networks/Services/Support |
|  Disabled Parents |  Social Work |
|  Evaluation/Techniques |  Spinal Cord Injuries (SCI) |
|  Families |  Statistics |
|  Family Life/Programs |  Sterilization/Involuntary |
|  Foster Care |  Training Materials |
|  Goal Setting |  Trends |
| |  Visual Impairments |
| |  Welfare |

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-  Agency for Health Care Policy and Research databases
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