Bibliography

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An Annotated Bibliography on Children with Disabilities

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Children with disabilities is a large area to cover. This bibliography is an attempt to provide an introduction to the field. These entries should be viewed as starting points for further investigation of the various topics. They are divided into the following categories: Education; Ethics; Families; Fiscal Matters; International; Nutrition; Other; Policy (non-fiscal); Prenatal Care; Quality of life; Rights; and Services. Some entries are included in more than one category. The entries are listed alphabetically within each category.

Education

Alderson, Priscilla; Goodey, Christopher. (1999) Autism in special and inclusive schools: "There has to be a point to their being there." Disability and Society, 14(2): 249-61. A discussion based on observations of what type of schools are most suitable for pupils with autism and the meanings of autism and autistic spectrum disorders along with a discussion of current theory and practice.

Annino, Paolo G. (1999) The new IDEA regulations: The next step in improving the quality of special education. Mental and Physical Disability Law Reporter, 23(3): 439-42. A discussion of the Department of Education's regulations implementing the Individual with Disabilities Education Act Amendments of 1997 relating to autism, attention deficit hyperactivity disorder (ADHD), charter schools, native languages, parents, and free appropriate public education.

Biklen, Douglas. (1992) Schooling without Labels: Parents, Educators, and Inclusive Education. Philadelphia: Temple University Press. Using the example of six families whose disabled children play a full role in family life, the author argues that the same effect could be achieved in public school and in the community.

Branson, Jan; Miller, Don; Branson, Kylie. (1988) An Obstacle Race: A Case Study of a Child's Schooling in Australia and England. Disability, Handicap & Society, 3(2): 101-18. The narrative by a disabled person who is a graduate student in education (and her college faculty parents) of the problems confronting her as a child attempting to obtain an education. The

barriers were based upon the prejudices of professionals (especially physicians) who denied her individuality and creativity.

Brody-Hasazi, Susan; Furney, Katharine S.; DeStefano, Lizanne. (1999) Implementing the IDEA transition mandates. Exceptional Children, 65(4): 555-66. Reports on an analysis at nine sites of the implementation of the mandates for transition contained in the Individuals with Disabilities Education Act (IDEA). The finding is that the mandates were critical in establishing and keeping promising practices.

Campbell, N. Jo; Dobson, Judith E.; Bost, Jane M. (1985) Educator Perceptions of Behavior Problems of Mainstreamed Students. Exceptional Children, 51: 298-303. A sample of 39 elementary school teachers, 31 secondary school teachers, seven special education teachers, five school counselors, and 23 school administrators were asked to assess six hypothetical behavior cases and to recommend treatment. The behavior of mentally disabled students was judged to be less serious than that of physically disabled and non-disabled students. The recommended treatment was more authoritarian for non-disabled students than for disabled students. Conclusion is that educators need to develop necessary skills for behavior management in a mainstream environment and to review their attitudes.

Cutler, Barbara Coyne. (1993) You, Your Child and "Special" Education: A Guide to Making the System Work. Baltimore: Brookes Publishing Company. A clear outline of how parents can use the IDEA process to obtain services for their children and how important is the role of the parent.

Gregg, Noel; Scott, Sally; McPeek, Donna; Ferri, Beth. (1999) Definitions and eligibility criteria applied to the adolescent and adult population with learning disabilities across agencies. Learning Disability Quarterly, 22(3): 213-23. An investigation of the definitions and eligibility criteria found in the 50 state and the DC departments of special education and vocational rehabilitation agencies for people with learning disabilities with suggestions for changes.

Guralnick, Michael J. (1998) Effectiveness of early intervention for vulnerable children: A developmental perspective. American Journal on Mental Retardation, 102(4): 319-45. A discussion of an early intervention model which focuses on the child's cognitive development and the effects, both short term and long term.

Harry, Beth; Kalyanpur, Maya. (1994) Cultural underpinnings of special education: Implications for professional interactions with culturally diverse families. Disability and Society, 9(2): 145-65. Discusses the cultural assumptions of special education in the US. A lack of awareness of them leads to cultural dissonance. The medical model assumptions of the law results in misunderstandings between parents and professionals who have different value systems. They disagree over the definition of disability, how much power professionals should have, whether science is objective, styles of parenting, the goals of education goals, the proper concerns of the family and the community, and communication.

Losen, D.J.; Welner, K.G. (2001) Disabling Discrimination in Our Public Schools: Comprehensive Legal Challenges to Inappropriate and Inadequate Special Education Services for

Minority Children. Harvard Civil Rights Civil Liberties Law Review, 36(2): 407-60. The problem of poor special education services for minority children and what can be done.

Oswald, D.P.; Coutinho, M.J.; Best, A.M.; Nguyen, N. (2001) Impact of Sociodemographic Characteristics on the Identification Rates of Minority Students as Having Mental Retardation. Mental Retardation, 39(5): 351-67. Certain characteristics influence the diagnosis of mental retardation in minority students.

Parry, John. (1985) Least Restrictive Alternative: An Overview of the Concept. Mental and Physical Disability Law Reporter, 9: 314-16. A discussion of the different views of the concept of the least restrictive alternative with their legal implications drawing upon relevant court cases.

Patton, James M. (1998) The Disproportionate Representation of African Americans in Special Education: Looking behind the Curtain for Understanding and Solutions. Journal of Special Education, 32(1): 25-31. Considers the question of why African American children are over represented in special education programs and suggests that cultural competency is one reason.

Ramey, Craig T.; Ramey, Sharon Landesman. (1998) Early intervention and early experience. American Psychologist, 53(2): 109-20. A review of the history and the four conceptual frameworks of early intervention.

Ray, Barbara M. (1985) Measuring the Social Position of the Mainstreamed Handicapped Child. Exceptional Children, September: 57-62. A study of 60 mainstreamed disabled children and 624 non-disabled children in grades 3 to 6 indicated that the disabled children were more likely to be identified by their teachers as having problems with social interaction, were more likely to not be chosen in a sociometric instrument by their peers, and equally likely to have positive social interaction in class.

Rubenfeld, Phyllis. (1993) "The More Things Change, the More They Stay the Same": A Call for a New Drive to Integrate Students with Disabilities. Journal of Disability Policy Studies, 1: 117-30. There has been very little real improvement in the education of children with disabilities. Based on the author's personal experience in the 1950s and the experiences of two persons with disabilities in the 1980s, the author shows that there is educational, social, and psychological damage done to academically competent students with disabilities by separating them from their nondisabled peers. Changes which have occurred in special education philosophy and policies must be reflected in teaching practices.

Schwarz, Frederick A.O., Jr.; Schaffer, Frederick P. (1985-86) AIDS in the Classroom. Hofstra Law Review, 14: 163-91. Discusses the District 27 Case which upheld the New York City Board of Education policy of not automatically excluding a child with AIDS from public school. First case in the US to consider the issues in such depth.

Zima, Bonnie T.; Bussing, Regina; Forness, Steven R.; Benjamin, Bernadette. (1997) Sheltered homeless children: Their eligibility and unmet need for special education evaluations. American Journal of Public Health, 87(2): 236-40. A study of whether children living in emergency homeless family shelters in Los Angeles could be eligible for special education evaluations.

Ethics

Christiansen, John B.; Leigh, Irene W. (2002) Cochlear Implants in Children: Ethics and Choices. Washington, D.C.: Gallaudet University Press. Discusses the ethical implications of implanting cochlear devices in the ears of children before they are old enough to make their own decision.

Davis, Dena S. (1997) Genetic dilemmas and the child's right to an open future. Hastings Center Report, 27:7-15. Discusses the problems which face genetic counselors in relating to parents with disabilities (especially deafness) who are seeking help in having a child who will also have their disability.

Smith, Wesley J. (1998) The deadly ethics of "futile care theory". Weekly Standard, 4:(Nov 30-Dec 7): 32-5. World Wide Web: <www.weeklystandard.com>. Discusses the futile-care theory set forth by bioethicists on the decision to keep a person alive. It says that care, other than for pain relief, should not be given after predefined age, illness, or disability.

Thornton, J.G. (1994) The ethics of prenatal screening and abortion for fetal abnormality: A personal view. Journal of Reproductive and Infant Psychology, 12(3): 155-161. Special Issue: Ethics at the beginning of life. Discusses the ethics of prenatal screening and abortion for fetal abnormality, presents possible safeguards for eugenic screening for disabilities, and market demand for screening.

Families

Alexander, C.J.; Hwang, K.; Sipski, M.L. (2002) Mothers With Spinal Cord Injuries: Impact on Marital, Family, and Children's Adjustment. Archives of Physical Medicine and Rehabilitation, 83(1): 24-30. An analysis of the implications which spinal cord injuries have on the adjustment of the entire family including children.

Altman, Barbara M.; et al. (1999) The case of disability in the family: impact on health care utilization and expenditures for nondisabled members. Milbank Quarterly, 77(1): 39-75. Looks at and discusses expenditure patterns for families with disabled and nondisabled members.

Baker, Kristan; Donelly, Michelle. (2001) The Social Experiences of Children with Disability and the Influence of Environment: A framework for intervention. Disability and Society, 16(1): 71-86.

Banks, Pauline; Cogan, Nicola; Deeley, Susan; Hill, Malcolm; Riddell, Sheila; Tisdall, Kay. (2001) Seeing the Invisible Children and Young People Affected by Disability. Disability and Society, 16(6): 797-814. A literature review and a discussion of alternative conceptual frameworks.

BatChava, Y.; Martin, D. (2002) Sibling Relationships of Deaf Children: The Impact of Child and Family Characteristics. Rehabilitation Psychology, 47(1): 73-91. A study of the characteristics in families and among siblings when there is a deaf family member who is a child.

Biklen, Douglas. (1992) Schooling without Labels: Parents, Educators, and Inclusive Education. Philadelphia: Temple

University Press. Using the example of six families whose disabled children play a full role in family life, the author argues that the same effect could be achieved in public school and in the community.

Blau, David M. (1999) The Effect of Income on Child Development. Review of Economics and Statistics, 81(2): 261-76. The effect of family income on children's cognitive, social, and emotional development is small unless it is a very large and permanent change. Family background characteristics are more important than income.

Case, Stephen. (2001) Learning to Partner, Disabling Conflict: early indications of an improving relationship between parents and professionals with regard to service provision for children with learning disabilities. Disability and Society, 16(6): 837-54. Professionals are beginning to provide information, acknowledge parental expertise, and encourage parental involvement, but much remains to be done.

Cook, P.; Cook, M.; Tran, L.; Tu, W. (1997) Children enabling change: a multicultural, participatory, community-based rehabilitation research project involving Chinese children with disabilities and their families. Child and Youth Care Forum, 26(3): 205-19. With an n=94 of family members caring for a child with a disability and others, negative attitudes toward children with disabilities were found. They were based in cultural beliefs that a child with a disability could not contribute to the family, the use of traditional healers, and little knowledge of support agencies.

Cooke, K.; Lawton, D. (1985) Housing Circumstances and Standards of Families with Disabled Children. Child: Care, Health and Development, 11(2): 71-79. Based upon a national sample, it was found that families with a disabled child are more likely to live in public housing and to be over crowded and less likely to have central heating than families without a disabled child.

Damiani, V.B. (1999) Responsibility and adjustment in siblings of children with disabilities: update and review. Families in Society, 80(1): 34-40. After a review of earlier research on the psychological adjustment of siblings of children with disabilities, the author concludes that it did not establish as a risk factor that the siblings had a higher amount of responsibility for the child with a disability nor the type of responsibility. These factors need to be further researched as does the influence of cultural and religious factors.

Dowling, Monica; Dolan, Linda. (2001) Families with Children with Disabilities - Inequalities and the Social Model. Disability and Society, 16(1): 21-36. It is not just children with disabilities who experience inequality, but the entire family.

Floyd, F.J.; Gallagher, E.M. (1997) Parental stress, care demands, and use of support services for school-age children with disabilities and behavior problems. Family Relations, 46(4): 359-371. A sample (n=231) of mothers and fathers of children labelled mentally retarded, or with chronic illness, or not disabled with behavior problems was drawn. Compared with their teachers, mothers noted fewer behavior problems with children labelled mentally retarded and more with children labelled chronically ill. The existence of behavior problems was more highly associated with stress than was type of disability. Parents of children labelled mentally retarded were the most concerned with future care and single mothers were not more stressed, but they did use more services.

Fujiura, Glenn T.; Yamaki, Kiyoshi; Czechowicz, Susan. (1998) Disability among ethnic and racial minorities in the United States: A summary of economic status and family structure. Journal of Disability Policy Studies, 9(2): 111-30. This investigation of the relationship of disability prevalence, low income status, and family structure among ethnic and racial minorities in the US supported prior reports of the highest rates for disability among Native Americans and the lowest among Asians. In addition there were interactions with age, economic status, and family structure with the highest rates of disability among low income households. The findings show the need for the broader policy discussions of poverty, social risk, and income inequality to include disability policy.

Hand, Jennifer E.; Trewby, Mary; Reid, Pat M. (1994) When a family member has an intellectual handicap. Disability and Society, 9(2): 167-184. With a New Zealand sample of 10 relatives of intellectually disabled persons ages 51 to 71 issues about long term caregiving and public policy issues were analyzed. The authors conclude that families can not cope without help and community participation of the intellectually disabled persons depended on good public resources and programs of inclusion.

Harry, Beth; Kalyanpur, Maya. (1994) Cultural underpinnings of special education: Implications for professional interactions with culturally diverse families. Disability and Society, 9(2): 145-65. Discusses the cultural assumptions of special education in the US. A lack of awareness of them leads to cultural dissonance. The medical model assumptions of the law results in misunderstandings between parents and professionals who have different value systems. They disagree over the definition of disability, how much power professionals should have, whether science is objective, styles of parenting, the goals of education goals, the proper concerns of the family and the community, and communication.

Heller, T.; Hsieh, K.; Rowitz, L. (1997) Maternal and paternal caregiving of persons with mental retardation across the lifespan. Family Relations, 46(4): 407-415. A comparison of the time, the amount of support provided, and the "caregiving burden" for fathers and mothers of both children and adults labelled mentally retarded who lived in the family home and in other settings. Mothers spent more time than and offered more types of support than fathers and felt more of a "caregiving burden". Out of home placement of adults (not children) was associated with less of a burden.

Joesch, Jutta M.; Smith, Ken R. (1997) Children's Health and Their Mothers' Risk of Divorce or Separation. Social Biology, 44(3-4): 159-169. Using a sample of the 1988 household survey data on 7246 US children, ages 0-17, and their mothers who were married at one time or still married but separated, the authors find an association between childhood chronic health conditions and the risk of the mother being divorced or separated. Mothers whose children are diagnosed with congenital heart disease, cerebral palsy, or blindness are two to three times more likely to be divorced than are mothers of children with no chronic health conditions. There is also an association between low birth weight and marriage dissolution. Mothers of children who have migraines, a respiratory allergy, a learning disability, asthma, a permanent deformity, or loss of digit/limb have a lower divorce rates.

Jones, Lesley; Atkin, Karl; Ahmad, Waqar I.U. (2001) Supporting Asian Deaf Young People and their Families: The role of professionals and services. Disability and Society, 16(1): 51-70. Providers, by emphasizing oralism and Western values, further disabled young deaf Asian persons and make for an ambivalent relationship between the family and the Deaf community.

Lakin, K. Charlie; Anderson, Lynda; Prouty, Robert. (1998) Decreases continue in out-of-home residential placements of children and youth with mental retardation. Mental Retardation, 36(2): 165-67. Since the SSI program began there has been less out of home placement of children labelled mentally retarded.

Llewellyn, Gwynnyth; Dunn, P.; Fante, M.; Turnbull, L.; Grace, R. (1999) Family factors influencing out-of-home placement decisions. Journal of Intellectual Disability Research, 43(3): 219-33. An analysis of the factors associated with the decision of families to keep their severely disabled children at home or to find placement for them. Although all families said that they wanted to keep their children home, those who sought or had already chosen placement said the reason was family survival or serious other circumstances.

Meyer, Donald (Editor); Pillo, Cary (Illustrator). (1997) Views from our shoes: Growing up with a brother or sister with special needs. Bethesda: Woodbine House. Experiences of siblings of persons with a developmental disability.

Morris, Jenny. (1997) Gone missing? Disabled children living away from their families. Disability and Society, 12(2): 241-58. It is important to examine the experiences of children with disabilities who lived away from home during their youth.

Quinn, P. (1999) Supporting and encouraging father involvement in families of children who have a disability. Child and Adolescent Social Work Journal, 16(6): 439-54. How fathers can and are involved in the care of a child with disabilities.

Sarimski, Klaus. (1998) Children with Apert syndrome: Behavioural problems and family stress. Developmental Medicine and Child Neurology, 40(1): 44-49. A discussion of the problems which parents and children possibly face when the child has Apert syndrome.

Schwartz, Paul. (1985) Parental Rights and the Habilitation Decision for Mentally Retarded Children. Yale Law Journal, 94: 1715-40. Argues that parents, not human service workers, must make the decisions regarding Individual Habilitation Plans (IHP) for children labelled mentally retarded and that current limitations on parents' rights and roles violate the US Constitution. It then sets forth a standard - the requirement of parents' informed consent to the IHP, if the parents wish to be involved - as a way to remedy the current situation.

Seltzer, M.M.; Heller, T. (1997) Families and caregiving across the life course: research advances on the influence of context. Family Relations, 46(4): whole issue. The whole issue of eleven papers is devoted to families and caregiving across the life course focusing on family members who provide care to a child with a disability.

Sensky, Tom. (1985) Family Stigma and Physical Deformity in Children. General Hospital Psychiatry, 7: 385-86. The parents of disabled children share the stigma along with the child. Their attitudes contribute to the child's problems during life transitions. The relevance of the stigma to the child is dependent upon the child's self-concept and social identity.

Stark, S. (2001) Creating Disability in the Home: The role of environmental barriers in the United States. Disability and Society, 16(1): 37-50. Over two dozen different types of barriers were identified in homes which cause and/or make worse disabilities experienced by people including children.

Warfield, Marji Erickson. (1994) A cost-effectiveness analysis of early intervention services in Massachusetts: Implications for policy. Educational Evaluation and Policy Analysis, 16(1): 87-99. An analysis of the cost effectiveness of early intervention services in Massachusetts with a sample of 157 children (aged 1.3 to 26.9 months) in early intervention programs for children with Down syndrome, motor impairment, and developmental delays of uncertain etiology and their families. The children showed varying amounts of improvement in adaptive behavior and child-mother interaction based on severity of disability and age of entry into the early intervention program. Studies such as this one can give policy makers and providers insight into program effectiveness.

Weigel-Garrey, Cindy-J.; Cook, Christine C.; Brotherson, Mary Jane. (1998) Children and privacy: Choice, control, and access in home environments. Journal of Family Issues, 19(1): 43-64. How privacy at home affects the development of self-identity and autonomy in children with disabilities.

Weiss, Meira. (1995) Of Man and Beast: From `Person' to `Non-Person'. Semiotica, 106(1-2): 55-76. Analyzes the concepts of person and nonperson using field observations of parents (n=450) of newly born babies. A subset of the sample (n=350) had babies with physical deformities or otherwise labelled disabled. The author concludes that children are rejected by their parents when they fail to fit the accepted image of a person in the view of the parents.

Weiss, Meira. (1997) Territorial isolation and physical deformity: Israeli parents' reaction to disabled children. Disability and Society, 12(2): 259-71. A study of the attitudes of Israeli parents toward children with deformities.

Fiscal Matters

Altman, Barbara M.; et al. (1999) The case of disability in the family: impact on health care utilization and expenditures for nondisabled members. Milbank Quarterly, 77(1): 39-75. Looks at and discusses expenditure patterns for families with disabled and nondisabled members.

Braddock, David; Hemp, Richard. (1996) Medicaid spending reductions and developmental disabilities. Journal of Disability Policy Studies, 7(1): 1-32. A historical summary of service provision for persons labelled mentally retarded focusing on financing by Medicaid.

Conover, C.J.; Rankin, P.J.; Sloan, F.A. (2001) Effects of Tennessee Medicaid Managed Care on Obstetrical Care and Birth Outcomes. Journal of Health Politics Policy and Law, 26(6): 1291-1324. The effects which Medicaid managed care has on care and outcomes of birth.

Crossley, Mary A. (1995) Medical futility and disability discrimination. Iowa Law Review, 81:179-259. Raises the question of whether limiting medical care when it is futile is discrimination based on a disability and brings in the implications of insurance funding.

Fujiura, G.T.; Roccoforte, J.A.; Braddock, D. (1994) Cost of family care for adults with mental retardation and related developmental disabilities. American Journal on Mental Retardation, 99(3): 250-61. In families with an adult member labelled mentally retarded or with a related developmental disability, the out of pocket costs went up as household income went down. Policy and service delivery implications are reviewed.

Kronebusch, K. (2001) Children's Medicaid Enrollment: The Impacts of Mandates, Welfare Reform, and Policy Delinking. Journal of Health Politics Policy and Law, 26(6): 1223-60. A discussion of how various Medicaid mandates affect the enrollment of children.

Kubik, Jeffrey D. (1999) Incentives for the Identification and Treatment of Children with Disabilities: The Supplemental Security Income Program. Journal of Public Economics, 73(2): 187-215. Analyzes the relationship of Supplemental Security Income (SSI) benefits and the identification of health problems in children by their parents. When SSI eligibility was broadened in 1990 there was alot of health status re-examinations of low income children by their parents. As SSI benefits increase so does the identification of a chronic impairment in the child. The increase in benefits increases the chances that children's disabilities will be detected and treated in low income families.

Levinson, Arik; Ullman, Frank. (1998) Medicaid Managed Care and Infant Health. Journal of Health Economics, 17(3): 351-68. Outcomes under managed care were not significantly different from outcomes under fee-for-service financing systems. Cost savings from Wisconsin Medicaid managed care were not coming at the expense of the mothers or infants.

McGlynn, Elizabeth A.; Halfon, Neal. (1998) Overview of Issues in Improving Quality of Care for Children. Health Services Research, 33(4, Part 2): 977-1000. The purpose of this article is to put forth seven topics in the area of care for children which need to be researched in order to improve that care. The topics are: (1) children's health; (2) how efficient and effective are present children's health services; (3) how to assess the quality of children's health care; (4) how to improve the quality of care in the delivery systems; (5) how to assess and to improve care at the community level; (6) financial incentives; and (7) how to disseminate the results of this research. Only by focusing on these topics can an effective overall research strategy be formulated in the same way as it has been done for adult health care and its delivery.

Meyers, M.K.; Lukemeyers, A.; Smeeding, T. (1998) The cost of caring: childhood disability and poor families. Social Service Review, 72(2): 209-223. The prevalence and the cost of children with disabilities and chronic health problems in poor families and the increased cost for public programs are important factors for public policy, but the are usually overlooked. Using data from California on welfare families, this article studies these factors and concludes in part that the families face more material hardship and out of pocket costs than non-welfare families.

International

Arias, R. (1994) Groupwork with women who have a child with a developmental disability. Australian Social Work, 47(4): 37-42. Groupwork with a feminist approach is effective and empowering for women who are mothers of a child with a developmental disability. The group allows the women to share experiences and find emotional support and help.

Branson, Jan; Miller, Don; Branson, Kylie. (1988) An Obstacle Race: A Case Study of a Child's Schooling in Australia and England. Disability, Handicap & Society, 3(2): 101-18. The narrative by a disabled person who is a graduate student in education (and her college faculty parents) of the problems confronting her as a child attempting to obtain an education. The barriers were based upon the prejudices of professionals (especially physicians) who denied her individuality and creativity.

Hand, Jennifer E.; Trewby, Mary; Reid, Pat M. (1994) When a family member has an intellectual handicap. Disability and Society, 9(2): 167-184. With a New Zealand sample of 10 relatives of intellectually disabled persons ages 51 to 71 issues about long term caregiving and public policy issues were analyzed. The authors conclude that families can not cope without help and community participation of the intellectually disabled persons depended on good public resources and programs of inclusion.

Mank, David. (1994) The underachievement of supported employment: A call for reinvestment. Journal of Disability Policy Studies, 5(2): 1-24. The problems with supported employment are discussed and recommendations for improvement of supported employment are made.

Neumayer, Robert; Bleasdale, Michael. (1996) Personal lifestyle preferences of people with an intellectual disability. Journal of Intellectual and Developmental Disability, 21(2): 91-114. With a sample of 30 individuals age 20-73 with an intellectual disability in Australia, questions were asked about home, work, leisure, and relationships. There was small concern about sharing a home and about interacting with another person disabled or non-disabled. Work was important, but few received intrinsic benefits from it and most were not satisfied with their work. A third did not know what was available for their leisure time or else they had transportation problems. Service providers need to reevaluate their programs.

Rosenthal, Eric; et al. (1999) Implementing the right to community integration for children with disabilities in Russia: a human rights framework for international action. Health and Human Rights, 4(1):82-113. Gives a strategy to insure the rights of institutionalized children under the Convention on the Rights of the Child.

Zeitzer, Ilene R. (1995) Social Insurance Provisions for Children with Disabilities in Selected Industrialized Countries. Social Security Bulletin, 58(3, Fall): 32-48. A comparison of social insurance provisions for children with disabilities in 18 industrialized countries including Australia, France, Germany, Japan, and the United Kingdom.

Nutrition

Costa, Dora L. (1998) Unequal at Birth: A Long-Term Comparison of Income and Birth Weight. Journal of Economic History, 58(4): 987-1009. Children born at the start of the twentieth century were similar to children born at the end of the twentieth century in terms of birth weight. However, the former had high death rates. Because of past practice, there was insufficient nutrition by ten days of age, but today improved knowledge and practice result in increased weight at ten days.

Secrist-Mertz, Christine; Brotherson, Mary Jane; Oakland, Mary Jane; Litchfield, Ruth. (1997) Helping families meet the nutritional needs of children with disabilities: An integrated model. Children's Health Care, 26(3): 151-68. How nutrition services can help families with children with disabilities.

Variyam, Jayachandran N.; Blaylock, James; Lin, Biing-Hwan; Ralston, Katherine; Smallwood, David. (1999) Mother's Nutrition Knowledge and Children's Dietary Intakes. American Journal of Agricultural Economics, 81(2): 373-84. Analyzes the relationship between the mother's knowledge of nutrition and the food eaten by her children (ages 4-17). Mothers do influence the children's eating, but the influence declines as children age. Concludes that nutrition education should be directed toward the mothers as well as the children.

Other

Ablon, Joan. (1990) Ambiguity and Difference: Families with Dwarf Children. Social Science and Medicine, 30(8): 879-87. The self view and the social perception of dwarfs is different from that of persons with disabilities. Although different, most dwarfs are not physically disabled. There is much ambiguity in the reactions of most people to dwarfs and also in the reactions of parents of dwarf children.

Ali, Zoebia; Fazil, Qulsom; Bywaters, Paul; Wallace, Louise; Singh, Gurnam. (2001) Disability, Ethnicity and Childhood: a critical review of research. Disability and Society, 16(7): 949-68. A literature review of the good and bad experiences which non-white children with disabilities encounter.

Annie E. Casey Foundation. (2002) The Right Start for America's Newborns: A Decade of City and State Trends (1990-1999), <http://www.aecf.org/kidscount/rightstart2002/>. There are still many infants born in the US prematurely with below normal birth weights and unmarried mothers.

Beuf, Ann Hill. (1990) Beauty Is the Beast: Appearance-Impaired Children in America. Philadelphia: University of Pennsylvania Press. Children who are appearance-impaired experience stigmatization. This work is a careful study of the phenomenon.

Burgess, Simon M.; Propper, Carol. (1998) Early Health-Related Behaviours and Their Impact on Later Life Chances: Evidence from the US. Health Economics, 7(5): 381-99. Using a sample of late adolescent males in the US, an analysis was made of the effect of alcohol, drugs, and behavior on their lives ten years later. Consumption of alcohol and soft drugs had no harmful effects, but hard drugs and violent behavior are related to lower productivity by the late twenties which substantially limited their earnings in both level and growth even with a number of background variables included. However, the violent behavior did not effect household formation.

Langer, E.J.; Bashner, R.S.; Chanowitz, B. (1985) Decreasing Prejudice by Increasing Discrimination. Journal of Personality and Social Psychology, 49: 113-20. An experiment in which it was determined that by teaching children to be more aware of disabilities, they were aware that disabilities are function and not people specific. In addition, they were less likely to reject a disabled person.

Marks, Deborah. (1997) Models of disability. Disability and Rehabilitation: An International Multidisciplinary Journal, 19(3): 85-91. A critical analysis of the medical model of disability which locates the disability in the person. Instead a social model which locates disability within its social context should be used. It challenges many assumptions about "normality" and points toward change through modifying policy, culture, and institutional practices.

Skar, Lisa; Tam, Maare (2001) My Assistant and I: disabled children's and adolescents' roles and relationships to their assistants. Disability and Society, 16(7): 917-32. How children with mobility disabilities relate to their personal assistants.

Policy (non-fiscal)

Fujiura, G.T.; Roccoforte, J.A.; Braddock, D. (1994) Cost of family care for adults with mental retardation and related developmental disabilities. American Journal on Mental Retardation, 99(3): 250-61. In families with an adult member labelled mentally retarded or with a related developmental disability, the out of pocket costs went up as household income went down. Policy and service delivery implications are reviewed.

Fujiura, Glenn T.; Yamaki, Kiyoshi; Czechowicz, Susan. (1998) Disability among ethnic and racial minorities in the United States: A summary of economic status and family structure. Journal of Disability Policy Studies, 9(2): 111-30. This investigation of the relationship of disability prevalence, low income status, and family structure among ethnic and racial minorities in the US supported prior reports of the highest rates for disability among Native Americans and the lowest among Asians. In addition there were interactions with age, economic status, and family structure with the highest rates of disability among low income households. The findings show the need for the broader policy discussions of poverty, social risk, and income inequality to include disability policy.

Lund, Nelson. (1985) Infanticide, Physicians, and the Law: The `Baby Doe' Amendments to the Child Abuse Prevention and Treatment Act. American Journal of Law & Medicine, 11: 1-29. Infanticide has reappeared in Western civilization in the neonatal intensive care unit where infants who are labelled mentally retarded, who have spina bifida, and/or who are born premature are allowed to die. The questions are who will decide on non-treatment and what will be the criteria. The author discusses the background and the likelihood for success of the new legislation. [Note: pre-ADA]

Matava, Marie. (1994) The Implications of Parenting Standards in Child Protection - A Paradox in Disability Policy. Policy Studies Journal, 22(1): 146-151. Child protection workers discount the parenting abilities of persons with disabilities many of whom can successfully parent. However, parents with disabilities can neglect their children as can parents without disabilities. The ADA and state laws place child protection workers in an ambiguous position in regard to parents with disabilities.

Meyers, M.K.; Lukemeyers, A.; Smeeding, T. (1998) The cost of caring: childhood disability and poor families. Social Service Review, 72(2): 209-223. The prevalence and the cost of children with disabilities and chronic health problems in poor families and the increased cost for public programs are important factors for public policy, but the are usually overlooked. Using data from California on welfare families, this article studies these factors and concludes in part that the families face more material hardship and out of pocket costs than non-welfare families.

Prenatal Care

Blumberg, Lisa. (1987) Why Fetal Rights Must Be Opposed. Social Policy, Fall: 40-41. The position of person advocating for "Fetal Rights" is that if a baby is born with a disability, then someone is to blame: the mother. Pregnancy would become a time of terror. Some "Fetal Rights" proponents say that society can not allow "defective children" to be born which is actually a fetal quality control position and eugenics.

Clarke, Leslie L. et al. (1999) The Role of Medical Problems and Behavioral Risks in Explaining Patterns of Prenatal Care Use among High-Risk Women. Health Services Research, 34(1, Part 1): 145-70. Using a sample of 25,000 high risk deliveries, the likelihood of "adequate-plus" prenatal care (as related to three other categories of prenatal care) increased if the mother had a medical condition.

Thornton, J.G. (1994) The ethics of prenatal screening and abortion for fetal abnormality: A personal view. Journal of Reproductive and Infant Psychology, 12(3): 155-161. Special Issue: Ethics at the beginning of life. Discusses the ethics of prenatal screening and abortion for fetal abnormality, presents possible safeguards for eugenic screening for disabilities, and market demand for screening.

Quality of life

Benedict, Mary I.; White, Roger B.; Wulff, Louise M.; Hall, Belinda J. (1990) Reported Maltreatment in Children with Multiple Disabilities. Child Abuse and Neglect, 14(2): 207-17. The authors investigated the contention that disabled children were at greater risk of neglect or abuse. The sample, consisting of children evaluated at the Kennedy Institute between 1973 and

1984, numbered 500 of whom almost all were labelled mentally retarded, 82% had cerebral palsy, and some had vision or hearing impairments. The patterns of abuse were similar to that of the general population.

Cambridge, Paul. (1999) The first hit: A case study of the physical abuse of people with learning disabilities and challenging behaviours in a residential service. Disability and Society, 14(3): 285-308. A discussion of the frequent physical abuse of people with learning disabilities and challenging behaviours who live in residential institutions and in general. Suggestions are put forth as to how to recognize when the abuse occurs, how to report it, and how to implement procedures to prevent it.

Cook, P.; Cook, M.; Tran, L.; Tu, W. (1997) Children enabling change: a multicultural, participatory, community-based rehabilitation research project involving Chinese children with disabilities and their families. Child and Youth Care Forum, 26(3): 205-19. With an n=94 of family members caring for a child with a disability and others, negative attitudes toward children with disabilities were found. They were based in cultural beliefs that a child with a disability could not contribute to the family, the use of traditional healers, and little knowledge of support agencies.

Cooke, K.; Lawton, D. (1985) Housing Circumstances and Standards of Families with Disabled Children. Child: Care, Health and Development, 11(2): 71-79. Based upon a national sample, it was found that families with a disabled child are more likely to live in public housing and to be over crowded and less likely to have central heating than families without a disabled child.

DuPlessis, Helen M.; Inkelas, Moira; Halfon, Neal. (1998) Assessing the Performance of Community Systems for Children. Health Services Research, 33(4, Part 2): 1111-42. How to measure the quality of community systems for children and the important characteristics of them. A research agenda is presented including indicators for evaluation and performance norms.

Freeberg, Ernest. (2001) The Education of Laura Bridgman. Cambridge: Harvard University Press. A half century before Helen Keller, deaf and blind Bridgman was taught by Samuel Gridley Howe to communicate. Freeberg uses her story to discuss what it means to be human.

Homer, Charles J.; Kleinman, Lawrence C.; Goldmann, Donald A. (1998) Improving the Quality of Care for Children in Health Systems. Health Services Research, 33(4, Part 2): 1091-1109. An analysis of the progress of quality improvement in health care for children and what is needed to further improve it.

Lewis, Darrell R.; Johnson, David R.; Mangen, Troy. (1998) Evaluating the multidimensional nature of supported employment. Journal of Applied Research in Intellectual Disabilities, 11(2): 95-115. An examination of how effective and efficient supported employment is for people with disabilities.

Lyon, Jeff. (1985) Playing God in the Nursery. New York: W.W. Norton & Company. A very disturbing book which presents a biased view of the Baby Doe case and then details the financial and emotional burdens of raising a disabled child. He goes on to describe the life of disabled persons as being nothing else but suffering and pain. On the surface his presentation appears reasonable and leads to the position of withholding medical care to disabled infants as a solution to the "disability problem."

Mank, David. (1994) The underachievement of supported employment: A call for reinvestment. Journal of Disability Policy Studies, 5(2): 1-24. The problems with supported employment are discussed and recommendations for improvement of supported employment are made.

Neumayer, Robert; Bleasdale, Michael. (1996) Personal lifestyle preferences of people with an intellectual disability. Journal of Intellectual and Developmental Disability, 21(2): 91-114. With a sample of 30 individuals age 20-73 with an intellectual disability in Australia, questions were asked about home, work, leisure, and relationships. There was small concern about sharing a home and about interacting with another person disabled or non-disabled. Work was important, but few received intrinsic benefits from it and most were not satisfied with their work. A third did not know what was available for their leisure time or else they had transportation problems. Service providers need to reevaluate their programs.

Parish, Thomas S.; Morgan, Hope G. (1985) Ascriptions by Handicapped and Nonhandicapped Children to Themselves, Normal Children, and Handicapped Children. Journal of Genetic Psychology, 146: 279-80. A comparison of 24 disabled children (physical disabled, learning disabled, or emotionally disturbed) and 143 non-disabled children in grades four to seven using the Personal Attribute Inventory for Children showed a significantly different perception in only six out of 48 cases suggesting that the children all share the same views.

Powell, T. Hennessy; Hecimovic, Anton. (1985) Baby Doe and the Search for a Quality Life. Exceptional Children, January: 15-23. Discussion of the dimensions of the quality of life of severely disabled infants and how it can be improved. Improvements in service delivery which improve the quality of life must be made known to service providers, policy makers, and the public.

Smith, Wesley J. (1998) The deadly ethics of "futile care theory". Weekly Standard, 4:(Nov 30-Dec 7): 32-5. World Wide Web: <www.weeklystandard.com>. Discusses the futile-care theory set forth by bioethicists on the decision to keep a person alive. It says that care, other than for pain relief, should not be given after predefined age, illness, or disability.

Szilagyi, Peter G.; Schor, Edward L. (1998) The Health of Children. Health Services Research, 33(4, Part 2): 1001-39. The purpose of this article is to analyze the concept of children's health care and how to measure it. Research opportunities exist, but existing definitions present measurement problems.

Weiss, Meira. (1995) Of Man and Beast: From `Person' to `Non-Person'. Semiotica, 106(1-2): 55-76. Analyzes the concepts of person and nonperson using field observations of parents (n=450) of newly born babies. A subset of the sample (n=350) had babies with physical deformities or otherwise labelled disabled. The author concludes that children are rejected by their parents when they fail to fit the accepted image of a person in the view of the parents.

Rights

Blumberg, Lisa. (1987) Why Fetal Rights Must Be Opposed. Social Policy, Fall: 40-41. The position of person advocating for "Fetal Rights" is that if a baby is born with a disability, then someone is to blame: the mother. Pregnancy would become a time of terror. Some "Fetal Rights" proponents say that society can not allow "defective children" to be born which is actually a fetal quality control position and eugenics.

Bopp, James, Jr. (1985) Protection of Disabled Newborns: Are There Constitutional Limitations? Issues in Law & Medicine, 1(3): 173-200. Discussion of what constitutional limitations exist in the decisions to treat or not to treat disabled newborns including things such as the determination of the child's future quality of life and the parents' rights.

Davis, Dena S. (1997) Genetic dilemmas and the child's right to an open future. Hastings Center Report, 27:7-15. Discusses the problems which face genetic counselors in relating to parents with disabilities (especially deafness) who are seeking help in having a child who will also have their disability.

Crossley, Mary A. (1995) Medical futility and disability discrimination. Iowa Law Review, 81:179-259. Raises the question of whether limiting medical care when it is futile is discrimination based on a disability and brings in the implications of insurance funding.

Goldstein, Marc B. (1991) Examining the Impact of a State Law Prohibiting Discrimination Against Group Homes for People with Developmental Disabilities. Journal of Disability Policy Studies, 2(2): 19-30. A 1979 Connecticut law forbade zoning discrimination again small group homes for developmentally disabled persons. This article studies the impact of the law by comparing the establishment of homes for developmentally disabled individuals and for emotionally disturbed children. More facilities of both types were established and in higher socio-economic census tracts and further away from urban centers. However, there was no clear differential for homes for developmentally disabled persons so the changes can not be attributed to the law.

Jaudes, P.K.; Diamond, L.J. (1985) The Handicapped Child and Child Abuse. Child Abuse & Neglect, 9: 341-47. A study of 37 children with cerebral palsy who had been abused plus a literature review led to the conclusion that the system which is intended to protect the disabled child often fails. The abused disabled child usually is not provided the opportunity to reach his/her developmental potential. Pediatricians must be aware of the possibility of abuse, be an advocate for the abused disabled child, and coordinate the needed services provided to the child.

Losen, D.J.; Welner, K.G. (2001) Disabling Discrimination in Our Public Schools: Comprehensive Legal Challenges to Inappropriate and Inadequate Special Education Services for Minority Children. Harvard Civil Rights Civil Liberties Law Review, 36(2): 407-60. The problem of poor special education services for minority children and what can be done.

Lund, Nelson. (1985) Infanticide, Physicians, and the Law: The `Baby Doe' Amendments to the Child Abuse Prevention and Treatment Act. American Journal of Law & Medicine, 11: 1-29. Infanticide has reappeared in Western civilization in the neonatal intensive care unit where infants who are labelled mentally retarded, who have spina bifida, and/or who are born premature are allowed to die. The questions are who will decide on non-treatment and what will be the criteria. The author discusses the background and the likelihood for success of the new legislation. [Note: pre-ADA]

Lyon, Jeff. (1985) Playing God in the Nursery. New York: W.W. Norton & Company. A very disturbing book which presents a biased view of the Baby Doe case and then details the financial and emotional burdens of raising a disabled child. He goes on to describe the life of disabled persons as being nothing else but suffering and pain. On the surface his presentation appears reasonable and leads to the position of withholding medical care to disabled infants as a solution to the "disability problem."

Matava, Marie. (1994) The Implications of Parenting Standards in Child Protection - A Paradox in Disability Policy. Policy Studies Journal, 22(1): 146-151. Child protection workers discount the parenting abilities of persons with disabilities many of whom can successfully parent. However, parents with disabilities can neglect their children as can parents without disabilities. The ADA and state laws place child protection workers in an ambiguous position in regard to parents with disabilities.

Olkin, Rhoda. (1997) The human rights of children with disabilities. Women and Therapy, 20(2): 29-42. Discusses the rights of children with disabilities in the framework of parenting and no role models.

Orentlicher, David. (1996) Destructuring disability: rationing of health care and unfair discrimination against the sick. Harvard Civil Rights Civil Liberties Law Review, 31:49-87. Discusses the question of whether the Americans with Disabilities Act forbids rationing health care based on type of patient or type of service.

Pardeck, John T. (1997) The Americans with Disabilities Act and child care programs. Early Child Development and Care, 138: 29-39. Overview of day care centers in the context of the ADA and children with disabilities.

Physically Disabled Parents' Rights. (1985) Mental and Physical Disability Law Reporter, 9: 435-36. Discusses the rights which disabled persons who are parents have in regard to keeping their children as found in two cases. In both instances the parent was a mother. In Michigan Department of Social Services v. McDuel, 369 NW 2d 912 (1985), the Michigan Court of Appeals reversed a lower court decision terminating the parental rights of a mother with multiple sclerosis with scathing remarks about the lower judge's misunderstanding of disability. In the other case, In re Green, 480 NE 2d 492 (1984), the Ohio Court of Appeals upheld the awarding of custody to a county agency of children of a mother who had uncontrolled petit mal seizures.

Rhoden, Nancy K.; Arras, John D. (1985) Withholding Treatment from Baby Doe: From Discrimination to Child Abuse. Milbank Memorial Fund Quarterly/Health and Society, 63: 18-51. Discussion of when withholding treatment becomes child abuse. Concludes that moving from a simplistic medical model way to answer the question of whether to withhold treatment to examining the question of the child's best interest is not much progress, but it is better than nothing. [Note: pre-ADA]

Rosenthal, Eric; et al. (1999) Implementing the right to community integration for children with disabilities in Russia: a human rights framework for international action. Health and Human Rights, 4(1):82-113. Gives a strategy to insure the rights of institutionalized children under the Convention on the Rights of the Child.

Schwartz, Paul. (1985) Parental Rights and the Habilitation Decision for Mentally Retarded Children. Yale Law Journal, 94: 1715-40. Argues that parents, not human service workers, must make the decisions regarding Individual Habilitation Plans (IHP) for children labelled mentally retarded and that current limitations on parents' rights and roles violate the US Constitution. It then sets forth a standard - the requirement of parents' informed consent to the IHP, if the parents wish to be involved - as a way to remedy the current situation.

Schwarz, Frederick A.O., Jr.; Schaffer, Frederick P. (1985-86) AIDS in the Classroom. Hofstra Law Review, 14: 163-91. Discusses the District 27 Case which upheld the New York City Board of Education policy of not automatically excluding a child with AIDS from public school. First case in the US to consider the issues in such depth.

Smith, Wesley J. (1998) The deadly ethics of "futile care theory". Weekly Standard, 4:(Nov 30-Dec 7): 32-5. World Wide Web: <www.weeklystandard.com>. Discusses the futile-care theory set forth by bioethicists on the decision to keep a person alive. It says that care, other than for pain relief, should not be given after predefined age, illness, or disability.

Services

Ammerman, R.T. (1998) Physical abuse and childhood disability: Risk and treatment factors. Journal of Aggression, Maltreatment & Trauma, 1(1): 207-24. A review of the literature.

Arias, R. (1994) Groupwork with women who have a child with a developmental disability. Australian Social Work, 47(4): 37-42. Groupwork with a feminist approach is effective and empowering for women who are mothers of a child with a developmental disability. The group allows the women to share experiences and find emotional support and help.

Aron, Laudan Y.; Loprest, Pamela J.; Steuerle, C. Eugene. (1996) Serving Children with Disabilities: A Systematic Look at the Programs. Washington, D.C.: Urban Institute Press. The authors give a set of principles to guide the development of programs for children with disabilities. They also offer issues which need to be resolve and give the details of existing programs.

Braddock, David; Hemp, Richard. (1996) Medicaid spending reductions and developmental disabilities. Journal of Disability Policy Studies, 7(1): 1-32. A historical summary of service provision for persons labelled mentally retarded focusing on financing by Medicaid.

Cutler, Barbara Coyne. (1993) You, Your Child and "Special" Education: A Guide to Making the System Work. Baltimore: Brookes Publishing Company. A clear outline of how parents can use the IDEA process to obtain services for their children and how important is the role of the parent.

DuPlessis, Helen M.; Inkelas, Moira; Halfon, Neal. (1998) Assessing the Performance of Community Systems for Children.

Health Services Research, 33(4, Part 2): 1111-42. How to measure the quality of community systems for children and the important characteristics of them. A research agenda is presented including indicators for evaluation and performance norms.

Floyd, F.J.; Gallagher, E.M. (1997) Parental stress, care demands, and use of support services for school-age children with disabilities and behavior problems. Family Relations, 46(4): 359-371. A sample (n=231) of mothers and fathers of children labelled mentally retarded, or with chronic illness, or not disabled with behavior problems was drawn. Compared with their teachers, mothers noted fewer behavior problems with children labelled mentally retarded and more with children labelled chronically ill. The existence of behavior problems was more highly associated with stress than was type of disability. Parents of children labelled mentally retarded were the most concerned with future care and single mothers were not more stressed, but they did use more services.

Fujiura, G.T.; Roccoforte, J.A.; Braddock, D. (1994) Cost of family care for adults with mental retardation and related developmental disabilities. American Journal on Mental Retardation, 99(3): 250-61. In families with an adult member labelled mentally retarded or with a related developmental disability, the out of pocket costs went up as household income went down. Policy and service delivery implications are reviewed.

Glasberg, B.A.; Harris, S.L. (1997) Grandparents and parents assess the development of their child with autism. Child and Family Behavior Therapy, 19(2): 17-27. Compares the assessment of parents and grandparents of a child with autism.

Goldson, Edward. (1998) Children with Disabilities and Child Maltreatment. Child Abuse and Neglect, 22(7): 663-67. Children with disabilities face increased abuse and maltreatment. Some suggestions for prevention are presented.

Guralnick, Michael J. (1998) Effectiveness of early intervention for vulnerable children: A developmental perspective. American Journal on Mental Retardation, 102(4): 319-45. A discussion of an early intervention model which focuses on the child's cognitive development and the effects, both short term and long term.

Hand, Jennifer E.; Trewby, Mary; Reid, Pat M. (1994) When a family member has an intellectual handicap. Disability and Society, 9(2): 167-184. With a New Zealand sample of 10 relatives of intellectually disabled persons ages 51 to 71 issues about long term caregiving and public policy issues were analyzed. The authors conclude that families can not cope without help and community participation of the intellectually disabled persons depended on good public resources and programs of inclusion.

Jaudes, P.K.; Diamond, L.J. (1985) The Handicapped Child and Child Abuse. Child Abuse & Neglect, 9: 341-47. A study of 37 children with cerebral palsy who had been abused plus a literature review led to the conclusion that the system which is intended to protect the disabled child often fails. The abused disabled child usually is not provided the opportunity to reach his/her developmental potential. Pediatricians must be aware of the possibility of abuse, be an advocate for the abused disabled child, and coordinate the needed services provided to the child.

Levinson, Arik; Ullman, Frank. (1998) Medicaid Managed Care and Infant Health. Journal of Health Economics, 17(3): 351-68.

Outcomes under managed care were not significantly different from outcomes under fee-for-service financing systems. Cost savings from Wisconsin Medicaid managed care were not coming at the expense of the mothers or infants.

Lewis, Darrell R.; Johnson, David R.; Mangen, Troy. (1998) Evaluating the multidimensional nature of supported employment. Journal of Applied Research in Intellectual Disabilities, 11(2): 95-115. An examination of how effective and efficient supported employment is for people with disabilities.

Malcolm, Koressa Kutsick. (1998) Developmental assessment: Evaluation of infants and preschoolers. In Vance, H. Booney et al. (Eds), Psychological assessment of children: Best practices for school and clinical settings, 2nd ed. (pp. 325-354). New York: John Wiley & Sons, Inc., pages 325-54. Refutes the contention that some children can not be tested and gives a framework for doing so.

Matava, Marie. (1994) The Implications of Parenting Standards in Child Protection - A Paradox in Disability Policy. Policy Studies Journal, 22(1): 146-151. Child protection workers discount the parenting abilities of persons with disabilities many of whom can successfully parent. However, parents with disabilities can neglect their children as can parents without disabilities. The ADA and state laws place child protection workers in an ambiguous position in regard to parents with disabilities.

McGlynn, Elizabeth A.; Halfon, Neal. (1998) Overview of Issues in Improving Quality of Care for Children. Health Services Research, 33(4, Part 2): 977-1000. The purpose of this article is to put forth seven topics in the area of care for children which need to be researched in order to improve that care. The topics are: (1) children's health; (2) how efficient and effective are present children's health services; (3) how to assess the quality of children's health care; (4) how to improve the quality of care in the delivery systems; (5) how to assess and to improve care at the community level; (6) financial incentives; and (7) how to disseminate the results of this research. Only by focusing on these topics can an effective overall research strategy be formulated in the same way as it has been done for adult health care and its delivery.

Nabors, Laura. (1997) Social Interactions among Preschool Children in Inclusive Child Care Centers. Applied Developmental Science, 1(4): 162-67. An investigation of the factors influencing cooperative play between preschool children with disabilities and their non-disabled peers in inclusive child care centers.

Orentlicher, David. (1996) Destructuring disability: rationing of health care and unfair discrimination against the sick. Harvard Civil Rights Civil Liberties Law Review, 31:49-87. Discusses the question of whether the Americans with Disabilities Act forbids rationing health care based on type of patient or type of service.

Pardeck, John T. (1997) The Americans with Disabilities Act and child care programs. Early Child Development and Care, 138: 29-39. Overview of day care centers in the context of the ADA and children with disabilities.

Patterson, Joan M. (1997) Meeting the Needs of Native American Families and Their Children with Chronic Health

Conditions. Families, Systems and Health, 15(3): 237-41. The introduction to a special issue on the unique health care needs of Native American children and their families.

Powell, T. Hennessy; Hecimovic, Anton. (1985) Baby Doe and the Search for a Quality Life. Exceptional Children, January: 15-23. Discussion of the dimensions of the quality of life of severely disabled infants and how it can be improved. Improvements in service delivery which improve the quality of life must be made known to service providers, policy makers, and the public.

Ramey, Craig T.; Ramey, Sharon Landesman. (1998) Early intervention and early experience. American Psychologist, 53(2): 109-20. A review of the history and the four conceptual frameworks of early intervention.

Rhoden, Nancy K.; Arras, John D. (1985) Withholding Treatment from Baby Doe: From Discrimination to Child Abuse. Milbank Memorial Fund Quarterly/Health and Society, 63: 18-51. Discussion of when withholding treatment becomes child abuse. Concludes that moving from a simplistic medical model way to answer the question of whether to withhold treatment to examining the question of the child's best interest is not much progress, but it is better than nothing. [Note: pre-ADA]

Roblin, Douglas W., et al. (2000) Variation in the Use of Alternative Levels of Hospital Care for Newborns in a Managed Care Organization. Health Services Research, 34(7): 1535-53. Data was gathered on admission into a neonatal intensive care unit (NICU) and length of stay from four Kaiser Permanente hospitals. Likelihood of admission and length of stay were not associated with HMO membership (Kaiser Permanente) or affiliation of the neonatologists (Kaiser Permanente or not). The best explanation was the difference in practice policy regarding the management of newborns who were sick.

Sarangi, S.; Clarke, A. (2002) Constructing an account by contrast in counselling for childhood genetic testing. Social Science and Medicine, 54(2): 295-308. Impact of various approaches to genetic testing in children.

Schwartz, Paul. (1985) Parental Rights and the Habilitation Decision for Mentally Retarded Children. Yale Law Journal, 94: 1715-40. Argues that parents, not human service workers, must make the decisions regarding Individual Habilitation Plans (IHP) for children labelled mentally retarded and that current limitations on parents' rights and roles violate the US Constitution. It then sets forth a standard - the requirement of parents' informed consent to the IHP, if the parents wish to be involved - as a way to remedy the current situation.

Shah, Robina. (1997) Improving services to Asian families and children with disabilities. Child: Care, Health and Development, 23(1): 41-46. How to provide services to Asian families with children with disabilities.

Smith, Diane C. (1998) Assistive technology: Funding options and strategies. Mental and Physical Disability Law Reporter, 22(1): 115-23. A review of possible funding sources for assistive technology devices.

Streissguth, Ann Pytkowicz. (1997) Fetal alcohol syndrome: A guide for families and communities. Baltimore: Paul H. Brookes Publishing Co. Information about issues concerning the fetal alcohol syndrome (FAS) and fetal alcohol effects (FAE).

Tharinger, Deborah; Horton, Connie B.; Millea, Susan. (1990) Sexual Abuse and Exploitation of Children and Adults with Mental Retardation and Other Handicaps. Child Abuse & Neglect, 14(3): 301-12. A discussion of the problem that persons labelled mentally retarded are especially vulnerable to sexual abuse and need intervention services. Besides their dependence and lack of power and sexual knowledge, these persons with disabilities are not well understood. Professionals must become better educated about mental retardation and the legal rights involved.

Ward, M.J.; Zambone, A.M. (1992) The U.S. Federal Data-Collection Process for Children and Youths Who are Deaf-Blind. Journal of Visual Impairment & Blindness, 86(10): 429-34. It is difficult to obtain accurate statistics about deaf-blind children and youths because the definition of deaf-blindness varies from state to state. A child "can be considered 'deaf-blind' in one state, 'multihandicapped' in another, and 'mentally retarded' in still another."

Warfield, Marji Erickson. (1994) A cost-effectiveness analysis of early intervention services in Massachusetts: Implications for policy. Educational Evaluation and Policy Analysis, 16(1): 87-99. An analysis of the cost effectiveness of early intervention services in Massachusetts with a sample of 157 children (aged 1.3 to 26.9 months) in early intervention programs for children with Down syndrome, motor impairment, and developmental delays of uncertain etiology and their families. The children showed varying amounts of improvement in adaptive behavior and child-mother interaction based on severity of disability and age of entry into the early intervention program. Studies such as this one can give policy makers and providers insight into program effectiveness.

Wolfensberger, Wolf. (1995) Of "Normalization," Lifestyles, the Special Olympics, Deinstitutionalization, Mainstreaming, Integration, and Cabbages and Kings. Mental Retardation, 33(2): 128-31. Refutes the ideas which lead to segregating persons labelled mentally retarded and states that the Special Olympics does not exemplify a "normal" lifestyle and that fruitful interaction between children with disabilities and children without disabilities can and does occur.

Zanandrea, Maria. (1998) Play, social interaction, and motor development: Practical activities for preschoolers with visual impairments. Journal of Visual Impairment and Blindness, 92(3): 176-88. Instructions for ten activities for use with preschool children who have visual disabilities.

This bibliography contains items from David Pfeiffer, An Annotated Bibliography on Children and Disabilities, Disability Studies Quarterly, 13(4, Fall 1993): 58-64, and from David Pfeiffer, An Annotated Bibliography on Children and Disabilities, an unpublished manuscript, 1997. The items are used with permission.

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