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ABSTRACT

This annotated bibliography presents a selective overview of materials on the topic of children with special health needs. Materials are divided into the following topics: (1) early identification and intervention (21 resources); (2) family-centered, community-based, culturally competent care (23 resources); (3) financing services (10 resources); (4) guides to resources (9 resources); (5) legislation, program, and policy issues (12 resources); (6) medical reference books (8 resources); (7) nutrition (8 resources); (8) parenting (21 resources); (9) respite care (8 resources); (10) school issues (4 resources); (11) siblings (4 resources); and (12) transition (15 resources.) Materials include books, periodicals, reports, and videotapes. (CR)

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Children with Special Health Needs
Selections from the NCEMCH Reference Collection
March 1997

This bibliography presents a selective overview of materials on the topic of children with special health needs. The items listed may be obtained from the sources cited.

EARLY IDENTIFICATION AND INTERVENTION

American Academy of Pediatrics, Medical Home Program for Children with Special Needs. ***The medical home and early intervention: Linking services for children with special needs*** Elk Grove Village, IL: American Academy of Pediatrics, 1995. 16 pp.
Contact: National Maternal and Child Health Clearinghouse, 2070 Chain Bridge Road, Suite 450, Vienna, VA 22182-2536. Telephone: (703) 356-1964 / Fax (703) 821-2098 / Email nmchc@circsol.com. Available at no charge. NMCHC inv.code I023.

This handbook serves as a tool for pediatricians, health care professionals, families, and community members in incorporating the medical home concept into the design of coordinated community systems of health care. It discusses the medical home concept and the role of the Early Intervention Program for Infants and Toddlers With Disabilities in providing the statewide system for early intervention services. [Funded by the Maternal and Child Health Bureau]

American Nurses Association Consensus Committee. ***National standards of nursing practice for early intervention services = The wonderful world where everyone is different*** Lexington, KY: College of Nursing, University of Kentucky, 1993. 36 pp.
Contact: National Maternal and Child Health Clearinghouse, 2070 Chain Bridge Road, Suite 450, Vienna, VA 22182-2536. Telephone: (703) 356-1964 / Fax (703) 821-2098 / Email nmchc@circsol.com. Available at no charge. Also available from Gwen Lee, Associate Professor and Director, Division of Parent-child Nursing, College of Nursing, University of Kentucky Chandler Medical Center, Lexington, KY 40536-2322. Telephone: (606) 323-6687. NMCHC inv.code H058.

This manual describes nursing's scope of practice with regard to early intervention and includes standards for nurses providing early intervention services. It provides an overview of Part H of the Individuals with Disabilities Education Act (IDEA) and reviews the relationship between nursing and Part H of IDEA. It covers the purpose and description of standards of nursing practice, guidelines for using the standards, standards of care, standards of professional performance, and specialty practice guidelines. A glossary, references and appendices are also included. The cover shows a drawing of the globe with the legend "The Wonderful World Where Everyone Is Different" inscribed around the perimeter.

Anderson, W., and Takemoto, C. ***Beginning with families: A parents' guide to early intervention*** Fairfax, VA: Parent Educational Advocacy Training Center, 1992. 41 pp.
Contact: Cherie Takemoto, Parent Educational Advocacy Training Center, 10340 Democracy Lane, Suite 206, Fairfax, VA 22030. Telephone: (703) 691-7826 / Fax (703) 691-8148 / Email peatcinc@aol.com. $5 plus $2 shipping and handling.

This guide provides information and direction for parents of infants and young children with disabilities. Early intervention services and suggestions for navigating through the requirements are included along with a glossary of terminology. Forms, records, and charts are provided along with contact telephone numbers for Parent Training and Information Centers in all the states plus Puerto Rico. In addition, there is a list of books and articles in the guide.

Berman, C., and Shaw, E. ***Family-directed child evaluation and assessment under IDEA: Lessons from families and programs*** Chapel Hill, NC: National Early Childhood Technical Assistance System, 1995. 25 pp.
Contact: National Early Childhood Technical Assistance System, 137 East Franklin Street, Suite 500 NationsBank Plaza, Chapel Hill, NC 27599-8040. Telephone: (919) 962-2001 / TDD: (919) 966-4041 / Fax (919) 966-7463 / Email nectasta.nectas@mhs.unc.edu; Web site: http://www.nectas.unc.edu. Price unknown.

This report discusses practices which contribute to quality family-directed child evaluations and assessments for young children who have or are at risk for developing disabling conditions. It defines related terms, and discusses issues related to the family, the process, personnel preparation, and the service system. It includes recommendations for policymakers, references, and resources.

Brown, W., Thurman, S. K., and Pearl, L. F. ***Family-centered early intervention with infants and toddlers: Innovative cross-disciplinary approaches*** Baltimore, MD: Paul H. Brookes Publishing Company, 1993. 340 pp.
Contact: Paul H. Brookes Publishing Company, P.O. Box 10624, Baltimore, MD 21285. Telephone: (800) 638-3775 / (410) 337-9580 / Fax (410) 337-8539. $37.00 plus shipping and handling.

This book provides a thorough explanation of Part H of the Individuals with Disabilities Education Act and insight into the evolution of recommended practices in early intervention. The books begins with a legislative review of the key elements of eligibility, assessment, and evaluation. The other chapters address the details of early intervention: service coordination, curricula, special intervention settings, tracking, training, and quality assurance.

Chandler, P. A. ***A place for me: Including children with special needs in early care and education settings*** Washington, DC: National Association for the Education of Young Children, 1994. 85 pp.
Contact: National Association for the Education of Young Children, 1509 16th Street, N.W., Washington, DC 20036-1426. Telephone: (800) 424-2460 / (202) 232-8777 / Fax (202) 328-1846. Price unknown. ISBN 0-935989-59-5; NAEYC no. 237.

This book reviews ways that child care providers and early educators can integrate children with special health needs into their programs. It provides a general description of these children and explains why they are in the classroom; and it suggests ways for the teachers to examine and modify their past perceptions. The book reviews various procedures to ensure a safe physical environment, and it discusses ways of working with the children with special health needs and with the typical children. Information is provided relating to working with the parents of the children and with other agencies. Resource lists include organizations, suppliers of relevant publications, one bibliography for teachers, and second one listing materials appropriate for children.

Council for Exceptional Children, Division for Early Childhood; National Head Start Association, and Mid South Regional Resource Center. ***New opportunities for collaboration: A policy and implementation resource and training manual for the Head Start regulations for children with disabilities*** Reston, VA: Council for Exceptional Children, 1994. ca. 150 pp.
Contact: Ginger W. Katz, Education Specialist, Council for Exceptional Children, 1920 Association Drive, Reston, VA 22091. Telephone: (703) 620-3660 / Fax (703) 264-9494. $17.25, nonmembers; $12.00, CEC members plus $2.50 shipping and handling. ISBN 0-86586-252-4; Stock no. D5053.

This manual provides state and local education agencies guidance in developing policies to ensure the application of the regulations in the Individuals with Disabilities Education Act (IDEA), Part B to Head Start programs. It includes various sections that can be used for training sessions; these include a section on questions and answers, a fact sheet, and masters for transparencies. It also includes a side-by-side comparison of the Head Start regulations, the IDEA regulations, and the Head Start guidance materials; it contains the text of the Head Start regulations and provides a resource directory.

Danaher, J. ***Preschool special education eligibility classifications and criteria. (Rev.)*** Chapel Hill, NC: National Early Childhood Technical Assistance System, 1995. 12 pp. (NEC*TAS notes; no. 6, rev.)
Contact: NEC*TAS Publications, National Early Childhood Technical Assistance System, 500 NationsBank Plaza, 137 East Franklin Street, Chapel Hill, NC 27514. Telephone: (919) 962-2001 / Fax (919) 966-7463 / Email nectasta.nectas@mhs.unc.edu; Web site: http://www.nectas.unc.edu . $2.50 includes shipping and handling.

This paper discusses the identification of children, three through five years of age, in need of special education and related services. The disability categories currently included in the Individuals with Disabilities Education Act are displayed; and it includes tables that indicate the eligibility criteria state governments have developed for identifying these children.

Heekin, S., and Ward-Newton, J. ***Section 619 profile. (6th ed.)*** Chapel Hill, NC: National Early Childhood Technical Assistance System, 1995. 40 pp.
Contact: National Early Childhood Technical Assistance System, 137 East Franklin Street, Suite 500 NationsBank Plaza, Chapel Hill, NC 27599-8040. Telephone: (919) 962-2001 / TDD: (919) 966-4041 / Fax (919) 966-7463 / Email nectasta.nectas@mhs.unc.edu; Web site: http://www.nectas.unc.edu. Price unknown.

This document gives profiles of state services provided under Section 619 of Part B (the Preschool Grants Program) of the Individuals with Disabilities Education Act (IDEA).

Hunt, M., Cornelius, P., Leventhal, P., Miller, P., Murray, T., and Stoner, G. ***Into our lives: A guidebook to the IFSP process for families raising children with developmental disabilities*** Tallmadge, OH: Family Network, ca. 1990. 44 pp.
Contact: Family Child Learning Center, 90 West Overdale Drive, Tallmadge, OH 44278. Telephone: (216) 633-2055 / Fax (216) 633-2658. Price unknown.

This publication is designed for parents of children with special health needs to help familiarize them with the Individualized Family Service Plan (IFSP). It is based on a program of family support and information called 'Building family strengths' that was developed by a group of mothers of children with disabilities and refined based on participation of parents in Ohio. This manual is designed to help prepare parents for full participation in the formulation of their child's IFSP. It discusses how to solve difficult problems using a specific decision-making model, how to improve communication skills, and how to identify coping strategies.

Hurth, J. L., and Goff, P. E. ***Assuring the family's role on the early intervention team: Explaining rights and safeguards*** Chapel Hill, NC: National Early Childhood Technical Assistance System, 1996. 28 pp.

Contact: NEC*TAS Publications, National Early Childhood Technical Assistance System, 500 NationsBank Plaza, 137 East Franklin Street, Chapel Hill, NC 27514. Telephone: (919) 962-2001 / Fax (919) 966-7463 / Email nectasta.nectas@mhs.unc.edu; Web site: http://www.nectas.unc.edu. $6.00 includes shipping and handling; quantity discounts available.

This booklet provides information on procedural safeguards of the early intervention system that are designed to protect the interests of both the families of young children with special needs and the service providers under the Individuals with Disabilities Education Act (IDEA), part H. Ways to explain procedures for complaint resolution and strategies for establishing opportunities for family input are presented. The booklet contains principles and examples of family-friendly language from materials submitted by early intervention programs across the country. The IDEA regulations on procedural safeguards are included.

Johnson, B. H., McGonigel, M. J., and Kaufman, R. K. (Eds.). ***Guidelines and recommended practices for the individualized family service plan.*** Bethesda, MD: Association for the Care of Children's Health, 1991. 192 pp.
Contact: Association for the Care of Children's Health, 7910 Woodmont Avenue, Suite 300, Bethesda, MD 20814. Telephone: (703) 654-6549. $21.00 non-members, $18.50 members. NMCHC inv. code C019.

This monograph presents an emerging consensus about best practices for comprehensive family-centered early intervention services. The major topics addressed include the philosophy and conceptual framework for the Individualized Family Service Plan (IFSP), including the necessary components of the IFSP as outlined in the Education of the Handicapped Act Amendments of 1986 (P.L. 99-457), the IFSP process, which begins with the first contacts between a family and early intervention services and continues through implementation and evaluation; building positive relationships between professionals and families; practices for identifying family strengths, needs, and resources; guidelines for developing IFSP outcomes, strategies, and activities; key concepts and procedures for implementing and evaluating the IFSP; a summary of the implication of the IFSP for state planners and policymakers, service providers, training programs, and families; and sample IFSPs, forms, procedures, and instruments. [Funded by the Maternal and Child Health Bureau]

Johnson-Martin, N. M., Jens, K. G., Attermeier, S. M., and Hacker, B. J. ***The Carolina curriculum for handicapped infants and toddlers with special needs. (2nd ed.).*** Baltimore, MD: Paul H. Brookes Publishing Company, 1991. 376 pp.
Contact: Paul H. Brookes Publishing Company, P.O. Box 10624, Baltimore, MD 21285. Telephone: (800) 638-3775 / (410) 337-9580 / Fax (410) 337-8539. $40.00.

This curriculum, written for early intervention personnel and other caregivers, offers practical assessment and intervention strategies for infants and toddlers with mild, moderate, severe, or multiple disabilities. The curriculum covers five major domains including cognition, communication, social adaptation, and fine motor and gross motor skills, and allows the user to create a program specifically tailored to the strengths and needs of each child. An assessment log for charting the child's progress is also included.

Meisels, S. J., and Fenichel, E. (Eds.). ***New visions for the developmental assessment of infants and young children.*** Washington, DC: Zero to Three/National Center for Infants, Toddlers and Families, 1996. 411 pp.
Contact: Zero to Three/National Center for Infants, Toddlers and Families, 734 15th Street, N.W., 10th Floor, Washington, DC 20005. Telephone: (800) 899-4301 / (202) 638-1144 / Fax (202) 638-0851. $35.00 plus $4.00 for shipping and handling.

This book presents a comprehensive approach to development assessment done in the context of a child's interactions with parents or caregivers, building on the child's strengths and capabilities. It describes principles of good assessment practices, parents' perspectives, contextual perspectives, new approaches to assessment, and policy perspectives.

Meisels, S. J., and Shonkoff, J. P. (Eds.). ***Handbook of early childhood intervention.*** New York, NY: Cambridge University Press, 1990. 760 pp.
Contact: Cambridge University Press, 40 West 20th Street, New York, NY 10011. Hardcover $59.50, paper $27.95.

This handbook integrates theory, research, and practical experiences in its examination of early childhood intervention. It covers concepts of developmental vulnerability, theoretical bases of early intervention, approaches to assessment, models of service delivery, research perspectives and findings, and policy issues and programmatic directions.

National Early Childhood Technical Assistance System. ***Helping our nation's infants and toddlers with disabilities and their families: A briefing paper on Part H of the Individuals with Disabilities Education Act (IDEA), 1986-1995.*** Chapel Hill, NC: National Early Childhood Technical Assistance System, 1995. 39 pp.
Contact: NEC*TAS Publications, National Early Childhood Technical Assistance System, 500 NationsBank Plaza, 137 East Franklin Street, Chapel Hill, NC 27514. Telephone: (919) 962-2001 / TDD: (919) 966-4041 / Fax (919) 966-7463 / Email nectasta.nectas@mhs.unc.edu; Web site: http://www.nectas.unc.edu. $5.00 includes shipping and handling; bulk discounts available. Also available electronically via: Early Childhood Bulletin Board on SpecialNet: FPGCENTER, or World Wide Web at the NEC*TAS Home Page, http://www.nectas.unc.edu.

This briefing paper addresses four questions regarding Part H of the Individuals with Disabilities Education Act: Why is early intervention significant? What is Part H? What have the states achieved to date? What are the future challenges? Background information is provided and a preliminary assessment is given of current progress in meeting the needs of the infants and toddlers and their families. The paper contains a section for each question; a list of references; and appendices that include U.S. Department of Education contacts, state and local Part H coordinators, and Part H lead organizations. It was prepared as a preliminary report for the Federal Interagency Coordinating Council.

National Information Center for Children and Youth with Disabilities. ***A parent's guide: Accessing programs for infants, toddlers, and preschoolers with disabilities.*** Washington, DC: National Information Center for Children and Youth with Disabilities, 1996. 20 pp.
Contact: National Information Center for Children and Youth with Disabilities, P.O. Box 1492, Washington, DC 20013. Telephone: (800) 695-0285. Available at no charge.

This brief guide for parents is presented in a question and answer format consisting of the most commonly asked questions about early intervention services for children ages birth through 2 years and special education and related services for children ages 3 through 5 years old. A glossary of terms and references for further information are provided.

Rab, V. Y., and Wood, K. I., with Taylor, J. ***Child care and the ADA: A handbook for inclusive programs*** Baltimore, MD: Paul H. Brookes Publishing Company, 1995. 211 pp.
Contact: Paul H. Brookes Publishing Company, P.O. Box 10624, Baltimore, MD 21285. Telephone: (800) 638-3775 / (410) 337-9580 / Fax (410) 337-8539. $25.00; no shipping and handling charge if prepaid. ISBN 1-55766-185-5.

This book considers the impact of the following federal laws on the operations of child care centers: the Americans with Disabilities Act (ADA), Section 504, and the Individuals with Disabilities Education Act. In the first section of the book, the obligations, rights and responsibilities related to serving children with disabilities are considered in detail. The second section focuses on administrative issues that will address staff concerns and on implementing program and policy changes to assure an inclusive program. The final section considers situations teachers may encounter in the classroom and suggests appropriate solutions. The book includes a glossary and lists of resources and references.

Russell, F. F., Powell, J. A., Jones, J. O., Michael, B., Mills, B. C., Mitchell, A. W., Murphy, L., Perkins, D. J., Rike, R., Sawyer, J., Scott, E. A. G., and Todd, M. ***Early intervention for young children***

and their families affected by maternal substance abuse: Report of a five year project. Memphis, TN: Boling Center for Developmental Disabilities, University of Tennessee, Memphis, 1993. 73 pp.
Contact: Boling Center for Developmental Disabilities, University of Tennessee, Memphis, 711 Jefferson Avenue, Memphis, TN 38105. Price unknown.

This report describes the experiences of a project partially funded by the U.S. Administration for Developmental Disabilities from 1988 to 1993 that served families of infants and young children prenatally affected by maternal substance abuse. Components of the program included referral, assessment and intervention, care coordination, parent/caregiver training, and an interdisciplinary team approach. Sample forms are included.

Shonkoff, J. P., Hauser-Cram, P., Krauss, M. W., and Upshur, C. C. ***Development of infants with disabilities and their families.*** Chicago, IL: University of Chicago Press, 1992. 167 pp. (Monographs of the Society for Research in Child Development; serial no. 230, v. 57, no. 6, 1992)
Contact: University of Chicago Press, 5720 South Woodlawn, Chicago, IL 60637. $7.75.

This book describes an evaluation of early intervention services for 190 developmentally delayed infants and their families. The study identifies subgroups of resilient and vulnerable children and details correlates of successful adaptive behavior. Implications of the study's findings for social policy and developmental theory are discussed.

Urbano, M. T. ***Preschool children with special health needs.*** San Diego, CA: Singular Publishing Group, 1992. 230 pp.
Contact: Singular Publishing Group, 4284 41st Street, San Diego, CA 92105-1197. Telephone: (619) 521-8000. $34.95.

This book is a practical guide written for professionals working in preschool settings, and addresses the continuum from basic primary health care important for all children to the management of complex medical conditions. The major focus is on the process of early identification and practical management of special health care needs of preschoolers.

FAMILY-CENTERED, COMMUNITY-BASED, CULTURALLY COMPETENT CARE

Anderson, M., and Goldberg, P. F. ***Cultural competence in screening and assessment: Implications for services to young children with special needs ages birth through five.*** Minneapolis, MN: PACER Center, National Early Childhood Technical Assistance System, 1991. 26 pp.
Contact: PACER Center, 4826 Chicago Avenue South, Minneapolis, MN 55417. Telephone: (612) 827-2966 / Fax (612) 827-3065. $4.00 includes postage and handling; make check payable to PACER Center.

This report examines issues related to the screening and assessment of infants, toddlers, and preschoolers from families with various cultural and linguistic backgrounds. This publication is intended as a tool to raise awareness about issues of cultural and linguistic diversity and to assist in sharing and creating strategies for developing sensitivity and competence as we respond to the challenges and opportunities of our multicultural society. Part I addresses the main issues of cultural and linguistic competence and provides definitions of key terms. Part II presents interviews with five individuals discussing their experiences and perspectives on cultural competence. Part III offers suggested strategies for ways to ensure cultural competence in screening and assessment. Part IV lists selected additional resources on the topic.

Bishop, K. K., Woll, J., and Arango, P. ***Family/professional collaboration for children with special health needs and their families.*** Burlington, VT: Department of Social Work, University of Vermont, 1993. 48 pp.

Contact: National Maternal and Child Health Clearinghouse, 2070 Chain Bridge Road, Suite 450, Vienna, VA 22182-2536. Telephone: (703) 356-1964 / Fax (703) 821-2098 / Email nmchc@circsol.com. Available at no charge. NMCHC inv.code G017.

This monograph synthesizes the views expressed by professionals, family members, and parents in formal and informal meetings and discussions since 1984 on the subject of family/professional collaboration. The principles of family/professional collaboration include the behaviors, beliefs, attitudes, and values that must be present in a collaborative relationship; the monograph defines these principles based on information provided by families and professionals. Resources and references are included in the publication. [Funded by the Maternal and Child Health Bureau]

Bronheim, S. M., Keefe, M. L., and Morgan, C. C. ***Building blocks of a community-based system of care: The Communities Can Campaign experience*** Washington, DC: Georgetown University Child Development Center, 1993. 91 pp. (Communities can; v. 1)
Contact: Mary Deacon, Georgetown University Child Development Center, 3307 M Street, N.W., Suite 401, Washington, DC 20007-3935. Telephone: (202) 687-8635. $10.00.

This report is the first in a series focused on the details of how individual communities can realize the vision of providing family-centered, community-based, coordinated care for children with special health needs and their families. It describes lessons learned from localities honored in the Communities Can Campaign, which identified communities that have made substantial progress toward realizing this vision. Winning strategies included fostering interagency collaboration, establishing public/private partnerships, identifying nonmonetary resources, promoting active participation by physicians and families in system development, building on existing programs, developing generic systems of care to serve all children, and developing cultural competence. This campaign was implemented as part of the Healthy People 2000 objectives for the nation, and funded by the Maternal and Child Health Bureau, U.S. Department of Health and Human Services, and by the American Academy of Pediatrics.

deFosset, S., Rasbold, R. A., Battigelli, S., Ament, N., and Rooney, R. ***Including young children with disabilities in community settings: A resource packet*** Chapel Hill, NC: National Early Childhood Technical Assistance System, 1996. 84 pp., 5 items.
Contact: NEC*TAS Publications, National Early Childhood Technical Assistance System, 137 East Franklin Street, Suite 500 NationsBank Plaza, 27599-8040. Telephone: (919) 962-2001 / TDD: (919) 966-4041 / Fax (919) 966-7463 / Email nectasta.nectas@mhs.unc.edu; Webs ite: http://www.nectas.unc.edu. $15.00 includes shipping and handling. Limited number available.

This packet of materials presents information for individuals and organizations attempting to implement a program that includes children with special health needs in regular preschool programs. The packet contains: (1) issues papers on serving young children with disabilities in programs with their nondisabled peers; (2) information on provisions of the Americans with Disabilities Act, especially as they relate to child care services; (3) articles on the basis in federal law for inclusive practices; (4) information on additional projects and resources, including those funded under the U.S. Department of Education's Early Education Program for Children with Disabilities; and (5) an annotated bibliography of selected literature published between 1990 and 1996.

Edelman, L., Greenland, B., and Mills, B. L. ***Building parent/professional collaboration: Facilitator's guide*** St. Paul, MN: Pathfinder Resources, Inc., 1992. 61 pp. (Train-the-trainer series)
Contact: Publications Department, Kennedy Krieger Community Resources, 2911 East Biddle Street, Baltimore, MD 21213. Telephone: (410) 550-9700 / Fax (410) 550-9766. $10.00 plus $3.00 shipping and handling; make checks payable to the Kennedy Krieger Institute.

This guide provides step-by-step instructions for leading a training session that explores how to build and strengthen collaborative relationships between families with special needs children and service providers. The guide includes a suggested agenda, handout packet, checklist of materials and equipment, training tips, evaluation form, and resource list. The session is designed for parents and professional service providers. Topics include the benefits and barriers of collaboration; building mutual trust and respect; communicating assertively; solving problems and resolving conflicts; and steps to build relationships. [Funded by the Maternal and Child Health Bureau]

Harvard Family Research Project. ***Raising our future: Families, schools, and communities joining together.*** Cambridge, MA: Harvard Family Research Project, 1995. 540 pp.
Contact: Publications Department, Harvard Family Research Project, Harvard Graduate School of Education, Longfellow Hall, Appian Way, Cambridge, MA 02138-2357. Telephone: (617) 495-9108 / Fax (617) 495-8594. $25.95. ISBN 0-9630627-0-0.

This directory, intended for the use of parents, educators, community leaders, and policy makers, lists 73 school-affiliated family support and education programs for families with children between birth and age six. It provides a national resource guide that characterizes the types of programs being implemented in schools today to serve families with young children. The entries cover topics such as: preschool and early childhood programs with parental involvement, support for children with special health needs and their parents, home visits for parenting support, school- and center-based programs, family literacy and intergenerational skills development, and family resource centers. Introductory chapters provide an overview of family and parent support efforts; individual entries provide contact information and substantial annotations describing the community, the program's goals and philosophy, its history, features, participant profiles, and services, among others.

Hornak, R. T., and Carothers, L. H. ***First years together: A curriculum for use in interventions with high risk infants and their families.*** Raleigh, NC: Project Enlightenment, Wake County Public School System, 1989. 254 pp.
Contact: Project Enlightenment, Wake County Public School System, 501 South Boylan Avenue, Raleigh, NC 27603. Telephone: (919) 755-6935. $20.00 plus 15 percent shipping and handling.

This manual is designed for professionals in child development, nursing, education, psychology, or related fields who work with high-risk infants and their families. It is a step by step plan describing how to provide education and support to families. The key features are: 1) building a partnership between professional and parents; 2) involving parents in the monitoring and assessment of their child's development; 3) helping parents anticipate and nurture approaching developmental milestones in their child; and 4) supporting parents in parent-child interactions, in caregiving and in handling their ongoing emotional reactions resulting from the birth of a high-risk infant.

Ireys, H. T. ***Blueprint for a needs assessment: Contributing to a system of care for children with special needs and their families: A technical resource brief.*** Baltimore, MD: Child and Adolescent Health Policy Center, Johns Hopkins University, 1995. 11 pp. (A technical resource brief)
Contact: National Maternal and Child Health Clearinghouse, 2070 Chain Bridge Road, Suite 450, Vienna, VA 22182-2536. Telephone: (703) 356-1964 / Fax (703) 821-2098 / Email nmchc@circsol.com. Available at no charge. NMCHC inv.code H126.

This report develops specifications for conducting a practical needs assessment of children with special needs and their families. Presented within the overall context of resource constraints, the report discusses six specific steps in planning and conducting a needs assessment, and identifies key decision points and recommendations for each step. [Funded by the Maternal and Child Health Bureau]

Jeppson, E. S., and Thomas, J. ***Essential allies: Families as advisors.*** Bethesda, MD: Institute for Family-Centered Care, [1994]. 76 pp.
Contact: National Maternal and Child Health Clearinghouse, 2070 Chain Bridge Road, Suite 450, Vienna, VA 22182-2536. Telephone: (703) 356-1964 / Fax (703) 821-2098 / Email nmchc@circsol.com. Available at no charge. NMCHC inv.code I012.

This publication was developed to facilitate collaboration and partnerships between health service providers and families. The information and tools presented equip professionals to work more effectively with family members at the program and policy level. The benefits and barriers to family participation in advisory activities are briefly reviewed in the opening sections; the remainder of the publication presents guidelines for promoting family participation. Specific strategies for identifying families to serve in advisory capacities and approaches for supporting and maintaining their involvement are offered. Examples of family/professional collaboration are included throughout the publication. The appendixes contain sample job descriptions, letters, questionnaires, guidelines, and family advisory council bylaws. [Funded by the Maternal and Child Health Bureau]

Katz-Leavy, J. W., Lourie, I. S., Stroul, B. A., and Zeigler-Dendy, C. ***Individualized services in a system of care*** Washington, DC: Child and Adolescent Service Support Program Technical Assistance Center, Georgetown University Child Development Center, 1992. 46 pp.
Contact: Mary Deacon, CASSP Technical Assistance Center, Georgetown University Child Development Center, 2233 Wisconsin Avenue, N.W., Washington, DC 20007. Telephone: (202) 338-1831. $7.00; make check payable to Georgetown University Child Development Center.

This report presents a case study of communities that made substantial progress toward developing comprehensive, coordinated, community-based systems of care for emotionally disturbed children and adolescents and their families. The report includes an overview of the philosophy and process of building individualized services in a system of care, a discussion of the issues involved in operationalizing individualized services, an evaluation of individualized services, and a discussion of the major strengths and challenges of individualized care. It is intended to serve as a resource for other states and communities as they develop local systems of care for troubled children and adolescents and their families.

Kinney, J., Strand, K., Hagerup, M., and Bruner, C. ***Beyond the buzzwords: Key principles in effective frontline practice*** Falls Church, VA: National Center for Service Integration, 1994. 36 pp. (Working paper)
Contact: National Center for Service Integration, Child and Family Policy Center, Fleming Building, Suite 1021, 218 Sixth Avenue, Des Moines, IA 50309-2200. Telephone: (515) 280-9027 / Fax (515) 244-8997. $4.00 includes shipping and handling; prepayment required; make check payable to NCSI.

This report argues that buzzwords such as "community-based "or "family-centered services" are frequently used to capture the good intent of new services but do not result in action steps for delivering the actual services. The authors examine service principles that seem to work well: emphasizing clients' strengths, using a holistic approach, building partnerships, tailoring programs to individuals' needs, using goal setting and monitoring techniques, and defining helpful skills and attitudes commonly shared by service workers. Each principle is supported by research that indicates the efficacy of the principle being considered.

National Center for Youth with Disabilities. ***Children and youth with disabilities in a changing health care environment*** Minneapolis, MN: National Center for Youth with Disabilities, University of Minnesota, 1996. 32 pp. (CYDLINE reviews)
Contact: Project Connect, National Center for Youth with Disabilities, University of Minnesota-Project Connect, Box 721 - UMHC, 420 Delaware Street, S.E., Minneapolis, MN 55455. Telephone: (612) 626-2825 / TDD: (612) 624-3939 / Fax (612) 626-2134 / Email ncyd@gold.tc.umn.edu. $6.50.

This annotated bibliography focuses on health care reform, especially managed care and its impact on the provision of health care services to children and youth with special health needs. Topics include demographics; access to health care services; rural health issues; culture and ethnicity; disability; child/adolescent health; Medicaid; and mental health and disability. [Funded by the Maternal and Child Health Bureau]

Pathfinder Resources. ***Lessons learned in developing systems to improve care and quality of life for children with special health needs and their families: Survey of Special Projects of Regional and National Significance/Maternal and Child Health Improvement Projects (SPRANS/MCHIP)—Final report*** St. Paul, MN: Pathfinder Resources, 1994. 36 pp.

Contact: Pathfinder Resources, 2324 University Avenue West, Suite 105, Saint Paul, MN 55114. Telephone: (612) 647-6905. Single copies available at no charge.

This report presents the results of a telephone survey of SPRANS and MCHIP grant recipients to determine their progress toward implementing the Surgeon General's 1987 action agenda to improve the care and the quality of life for children with special health needs and their families. The report covers grantee activities for the preceding five years, with information on: developing systems of care, preparing parents and care providers, community-based care, coalition building, cultural competence, and managing SPRANS. A related title, "Implementing the Surgeon General's Action Agenda," contains the results of a written survey on the same topic.

Peters, G. ***Rural voices*** Washington, DC: Georgetown University Child Development Center, Center for Child Health and Mental Health Policy, 1993. 50 pp.
Contact: Mary Deacon, Child Development Center, 3307 M Street, N.W., Suite 401, Washington, DC 20007-3935. Telephone: (202) 687-5000 / Fax 202-687-1954. $5.00.

This publication contains a collection of vignettes by families faced with treating children with chronic illnesses and disabling conditions in rural areas. These families' knowledge about treatment, in many cases, has been rudimentary and self-taught through trial and error, repeated trips to emergency rooms, hospitals, or clinics at any time of night or day. The book is intended to raise the consciousness of the medical and social services community in each state and to promote an understanding of the myriad demands and needs of children with special health needs living in rural areas.

Poyadue, F. S. ***Steps to starting a family resource center or a self-help group*** San Jose, CA: National Center on Parent Directed Family Resource Centers, 1993. 150 pp.
Contact: National Center on Parent Directed Family Resource Centers, 535 Race Street, San Jose, CA 95126. Telephone: (408) 288-5010. Price unknown.

This manual contains material designed to assist a beginner individual or small group develop a support group or information network. The subjects covered are: self-help in general, primary steps to getting started, developing secondary components, workshop training programs, and bridging the gap to professionals. Appendices cover many aspects of getting started, organizing, and functioning for a group. The manual contains an index. [Funded by the Maternal and Child Health Bureau]

Rauch, J. B. (Ed.). ***Community-based, family-centered services in a changing health care environment*** Baltimore, MD: School of Social Work, University of Maryland at Baltimore, 1995?. 164 pp.
Contact: Librarian, National Center for Education in Maternal and Child Health, 2000 15th Street North, Suite 701, Arlington, VA 22201-2617. Telephone: (703) 524-7802 / Fax (703) 524-9335 / Email info@ncemch.org; Web site: http://www.ncemch.org. Available for loan. NMCHC inv.code I009.

These proceedings include selected papers from a conference held June 6 and 7, 1994 in Baltimore, Maryland. They discuss the following topics: maternal and child health social work, genetic technology, support groups, partnerships with parents, inter-agency relationships, siblings of children with special health needs, pediatric and maternal HIV/AIDS, culturally competent services for Asian women, evaluation of psychosocial services, grant development, the Americans with Disabilities Act, an Afro-centric model of prevention, integrating policy and practice, and living with budget cuts. [Funded by the Maternal and Child Health Bureau]

Shelton, T. L., and Stepanek, J. S. ***Family-centered care for children needing specialized health and developmental services. (3rd ed.)*** Bethesda, MD: Association for the Care of Children's Health, 1994. 120 pp.
Contact: Association for the Care of Children's Health, 7910 Woodmont Avenue, Suite 300, Bethesda, MD 20814. Telephone: (301) 654-6549 / Fax (301) 986-4553. $10.00 members, $12.00 non-members; plus $3.50 shipping and handling. NMCHC inv.code H054; ISBN 0-937821-87-X.

This book reviews factors that administrators, service providers, educators, policy makers, and professionals need to consider in order to assure the delivery of quality services for children who need specialized health or developmental services. It defines the key elements of family-centered care, provides an historical perspective, and elaborates on basic tenants for service delivery. It considers the following topics: the family as a constant, collaboration between families and professionals, the exchange of complete and unbiased information, acknowledging the diversity of families, coping and support, peer networking, and coordinated services. For each topic, it discusses the philosophy behind the key elements; and it indicates organizations; programs, policies, and practices; and resources that can help make them a reality. The book includes checklists and a bibliography. An earlier version of this book was called "Family-centered Care for Children with Special Health Care Needs." [Sponsored by the Maternal and Child Health Bureau]

Southwest Communication Resources. ***Culturally responsive services for children and families: A training manual for health and education service providers*** Bernalillo, NM: Southwest Communication Resources, 1993. 100 pp.
Contact: Southwest Communication Resources, P.O. Box 788, Bernalillo, NM 87004. Telephone: (505) 867-3396. $35.95 manual; $89.00 manual and videotapes; make check payable to Southwest Communication Resources.

This training manual is intended for the service providers of children with special health needs and their families. It is designed to provide information and activities that stimulate increased awareness of the barriers that cultural differences can present to effective service delivery; facilitate learning of effective methods for preventing cultural differences from becoming barriers and for overcoming barriers that do exist; and facilitate changes that will increase the cultural competency of individuals and organizations who provide health care services to Native American children and their families. The manual includes activity pages, handouts, and visual aids. Although specific information about Native American issues is presented, the activities can be applied to a variety of cultural groups. [Funded by the Maternal and Child Health Bureau]

Southwest Communication Resources. ***Family perspectives: cultural/ethnic issues affecting children with special health care needs—Educational fact packets for health and human service providers*** Bernalillo, NM: Southwest Communication Resources, 1996. 24 pp., 3 items.
Contact: National Maternal and Child Health Clearinghouse, 2070 Chain Bridge Road, Suite 450, Vienna, VA 22182-2536. Telephone: (703) 821-8955 / Fax (703) 821-2098 / Email nmchc@circsol.com. Available at no charge. NMCHC inv.code J049.

This notebook is intended for health care service providers who wanted to know more about the perspectives of families from diverse cultural backgrounds. It provides concise summaries about barriers that inhibit cross-cultural communication and methods for overcoming them. It also contains two additional publications and a products catalog from the publisher. It was compiled as part of the OPUS project (Opportunities for Parents and Professionals to Understand Strategies for Cross-Cultural Communication), a three-year Special Project of Regional and National Significance which aimed to improve services to children with special health care needs by developing a culturally responsive model to improve family-provider communication and collaboration. [Funded in part by the Maternal and Child Health Bureau]

University of Southern Maine, Edmund S. Muskie Institute of Public Affairs, Parents in Partnership Project. ***Every child a treasure*** Portland, ME: Parents in Partnership Project, University of Southern Maine, 1993. 1 videotape (31:00 min.).
Contact: Jayne Marsh, Edmund S. Muskie Institute of Public Affairs, University of Southern Maine, Post Office Square, P. O. Box 15010, Portland, ME 04112. Telephone: (207) 780-5822 / Fax (207) 780-5817 / Email jaynem@usm.maine.edu. $30.00 plus 10 percent shipping and handling. no. V020018.

This videotape presents stories of families of children with special health needs, told with a view toward sensitizing professionals to the emotional realities of the lives of these families. Particular emphasis is given to the effects of both positive and negative interactions with professionals. [Funded by the Maternal and Child Health Bureau]

University of Southern Maine, Edmund S. Muskie Institute of Public Affairs, Child and Family Center. ***Parent-professional communication: Problem versus opportunity–A training manual for parents and professionals in partnership for children with special needs*** Portland, ME: Parents in Partnership Project, University of Southern Maine, 1993. 30 pp., 1 videotape (12:50).
Contact: Jayne Marsh, Edmund S. Muskie Institute of Public Affairs, University of Southern Maine, Post Office Square, P.O. Box 15010, Portland, ME 04112. Telephone: (207) 780-5822 / Fax (207) 780-5817 / Email jaynem@usm.maine.edu. Manual $8.00, videotape $30.00 plus 10 percent shipping and handling. no. V020022.

This manual and videotape offer vignettes and supporting documents toward establishing and maintaining positive parent-professional communication and partnerships. The training topics are: the home visit; the school conference; the health care consultation; and positive relationship building. The manual also contains handouts and a bibliography. [Funded by the Maternal and Child Health Bureau]

View, V. A., and Amos, K. J. ***Living and testing the collaborative process: A case study of community-based services integration—The Promoting Success in Zero to Three Services Project*** Arlington, VA: Zero to Three/National Center for Clinical Infant Programs, 1994. 195 pp., exec. summ. (13 pp.).
Contact: Zero to Three/National Center for Clinical Infant Programs, 734 15th Street, N.W., 10th Floor, Washington, DC 20005. Telephone: (800) 899-4301 / (202) 638-1144 / Fax (202) 638-0851. $14.95 Case study, $4.00 Executive summary, plus $2.50 shipping and handling. NMCHC inv.code H055; Executive Summary H052; ISBN 0-943657-33-4.

This report reviews the history of the Promoting Success in Zero to Three Services Project and considers the implications of that study for maternal and child health care services for developing public policy. The project involved case studies in six communities: Fremont County, Colorado; Lawndale Community in Chicago, Illinois; Scott County, Indiana; Kent County, Rhode Island; Travis County, Texas; and Snohomish County, Washington. The report details the programs that were established in each community. The project itself focused on defining early intervention services for families with young children, developing systems at the local level, accessing data to integrate services, promoting leadership and support for developing systems to provide needed services. The authors include recommendations for national and state policymakers, and for community planners and policymakers. An executive summary contains the main points of the full report. [Funded in part by the Maternal and Child Health Bureau]

West Virginia Committee for Children with Special Needs. ***Enriching the lives of children with special needs*** Morgantown, WV: W. G. Klingberg Center for Child Development, West Virginia University Health Sciences Center, 1993. 17 pp.
Contact: Chet Johnson, M.D., W. G. Klingberg Center for Child Development, West Virginia University Health Sciences Center, P.O. Box 9216, Morgantown, WV 26506. Telephone: (304) 293-7331. Price unknown.

This report was developed by the West Virginia Committee for Children with Special Needs, a concerned group of parents and professionals working to improve services to children with special needs and their families. The major finding of the committee is that when parents and professionals join together and work as a team, the best possible care can then be provided for the child with special needs. The report highlights key issues and makes recommendations in seven areas: public/provider awareness, identification, access, assessment, coordinated services, training, and program evaluation (effectiveness).

FINANCING SERVICES

Alliance of Genetic Support Groups. ***Health insurance resource guide***Chevy Chase, MD: Alliance of Genetic Support Groups, 1992. 83 pp.
Contact: March of Dimes Supply Department, 1275 Mamaroneck Avenue, White Plains, NY 10605. Telephone: (914) 428-7100 / 800-367-6630. $10.00.

This guide is designed to provide a basic understanding of how the health insurance system works, to help families affected by genetic disorders find their way through the world of health insurance. It discusses types of private health policies, plan options, the preexisting condition dilemma, obtaining and keeping health insurance, important provisions to note, prices, strategies for reimbursement, income taxes and medical expenses, government assistance programs, and voluntary associations. Appendices list how to find help in each state, sample letters, checklists, and other resources. [Funded by the Maternal and Child Health Bureau]

Harry, L. L. (Ed.). ***Direct connect*** Solvang, CA: Direct Link for the disABLED, 1993-. quarterly.
Contact: Direct Link for the disABLED, P.O. Box 1036, Solvang, CA 93464. Telephone: (805) 688-1603 / Fax 805-686-5285. Available at no charge; annual donation covers printing and postage.

This newsletter is the quarterly publication of Direct Link for the disABLED, a non-profit organization. It focuses on sources for financing health care for chronically ill and disabled individuals. Articles describe specific funding reference guides and organizations involved in providing services for those with special health needs. Information also is provided on other publications of the organization.

Larson, G., and Kahn, J. A. ***Special needs/special solutions: How to get quality care for a child with special health needs: A guide to health services and how to pay for them*** St. Paul, MN: Lifeline Press, 1991. 88 pp.
Contact: Pathfinder, 2324 University Avenue West, Suite 105, Minneapolis, MN 55414. Telephone: (612) 647-6905 / Fax (612) 647-6908. $7.95 plus $2.00 postage/handling.

This publication is designed to help parents negotiate the health care and payment systems for children with special needs.

Lesko, M., with Martello, M. A., and Naprawa, A. ***What to do when you can't afford health care*** Kensington, MD: Information USA, 1993. 769 pp.
Contact: Information USA, P.O. Box E, Kensington, MD 20895. Telephone: (301) 942-6303. $24.95.

This book provides numerous listings of sources that provide free health care. It lists federal agencies, free publications and videos, sources of free drugs, and how to find out about free clinics and physicians who will treat patients at no charge. Sources for statistics, for identifying clinical trials, and help with health care rights are included.

National Information Center for Children and Youth with Disabilities. ***Paying the medical bills. (Rev. ed.).*** Washington, DC: National Information Center for Children and Youth with Disabilities, 1996. 18 pp.
Contact: National Information Center for Children and Youth with Disabilities, P.O. Box 1492, Washington, DC 20013. Telephone: (800) 695-0285 / (202) 884-8200 / Email nichcy@aed.org. Price unknown.

The information provided in this paper can help the family and/or care providers make a full search of the possible ways to meet medical expenses for children with complex health needs. Included in this paper are a glossary of terms, a list of resource materials and organizations, and lists of state insurance commissioners, and state Medicaid directors.

New England SERVE. ***Ensuring access: Family-centered health care financing systems for children with special health needs*** Boston, MA: New England SERVE, 1991. 27 pp. *Contact:* Alexa Halberg, New England SERVE, 101 Tremont Street, Suite 812, Boston, MA 02108. Telephone: (617) 574-9493. Available at no charge.

Developed by the New England SERVE Regional Task Force on Health Care Financing, this report presents 14 criteria to assess the adequacy of public and private financing systems and outlines new proposals for reform of the financing and delivery of health care for children with special health needs. The report is intended to be used to assess financing proposals at the state or federal level for their appropriateness for children with special health needs and their families; educate parents, providers, policymakers, and the public about the components of a family-centered financing system; and evaluate current health financing systems at the local, state, or federal level. An executive summary of the report was produced in 1992. [Funded by the Maternal and Child Health Bureau]

Peterson, R. A., Jr., with Tenenbaum, D. ***Fighting back: A guide to challenging health insurance denials*** Madison, WI: Center for Public Representation, 1993. 109 pp. *Contact:* Center for Public Representation, 121 South Pinckney Street, Madison, WI 53703. Telephone: (608) 251-4008 / (800)369-0388. $14.95 plus $2.50 postage/handling.

This consumer-oriented book explains the basic principles of health insurance, and outlines strategies and tactics to use when confronted with the denial of a claim or benefit. The rights of an insurance consumer are described, with specific references to Wisconsin law. Information on public benefit programs and legal rights is provided for those with medical debts. The appendices contain sample letters to insurance companies and a list of resources.

Rosenfeld, L. R. ***Your child and health care: A "dollars and sense" guide for families with special needs*** Baltimore, MD: Brookes Publishing Company, 1994. 576 pp. *Contact:* Brookes Publishing Company, P.O. Box 10624, Baltimore, MD 21285-0624. Telephone: (410) 337-9580 / Fax (410) 337-8539. $29.00 if prepaid; add 10 percent shipping and handling if not prepaid.

This book is designed to help with the financial aspects of having a child with special health needs. The suggestions and guidelines assist families in obtaining needed help for their children at costs they can afford. The author offers practical advice on how to limit out-of-pocket expenses; appeal health insurance claims that are denied; select a health insurance plan that fits the family's needs and budget; set up payment plans with doctors, clinics, and hospitals; keep credit in good standing; and approach organizations that have funds designated to help pay for medical care. Appendixes include sample letters to help families in writing to individuals or organizations about their child, resources that provide assistance to families, a glossary, and a bibliography.

U.S. Department of Health and Human Services, Social Security Administration. ***Social Security and SSI benefits for children with disabilities*** Washington, DC: U.S. Government Printing Office, 1993. 18 pp. *Contact:* Public Information Distribution Center, Social Security Administration, P.O. Box 17743, Baltimore, MD 21235. Telephone: (800) 772-1213. Available at no charge. SSA pub. No. 05-10026.

This booklet is for parents and caregivers of children with disabilities and adults disabled since childhood. It explains the kinds of Social Security and Supplemental Security Income (SSI) benefits a child with a disability might be eligible for, and explains how disability claims for children are evaluated.

Wells, E., Cole, M., Gresek, C., Mitchell, M., Ohlson, T., and Wachtenheim, M. ***Paying the bills: Tips for families on financing health care for children with special needs.*** Boston, MA: New England SERVE, 1992. 55 pp.
Contact: New England SERVE, 101 Tremont Street, Suite 812, Boston, MA 02108. Telephone: (617) 574-9493. $5.00.

This booklet is written by parents who have children with special needs, who draw on their own experiences and those of other families and professionals in order to share information and strategies for getting payment for children's health care. It encourages parents to ask questions, learn about the health financing system, and be persistent. Topics covered include identifying your child's needs, making private health insurance and public programs work, tackling medical bills, influencing decision makers, documenting the child's special needs, changing decisions, saving money, finding other sources of funding, and connecting with other families. [Funded by the Maternal and Child Health Bureau]

GUIDES TO RESOURCES

Alliance of Genetic Support Groups. ***Directory of national voluntary genetic organizations and related resources. (2nd ed.)*** Chevy Chase, MD: Alliance of Genetic Support Groups, 1995. 178 pp.
Contact: Alliance of Genetic Support Groups, 35 Wisconsin Circle, Suite 440, Chevy Chase, MD 20815. Telephone: (800) 336-GENE / (301) 652-5553 / Fax (301) 654-0171 / Email alliance@capaccess.org. $20.00 plus $2.00 shipping and handling; prepayment required. NMCHC inv.code F075 (1992).

This directory provides a listing and description of mutual support groups concerned with the medical and psychosocial impacts of genetic disorders and birth defects on affected individuals and families. This directory is arranged according to categories of disorders, and contains an organizational index and subject index as well. The directory is based upon the "Guide to Selected National Genetic Voluntary Organizations." In 1996, the directory was made available online at http://medhlp.netusa.net/www/agsg.htm.

American Association of University Affiliated Programs. ***Resource guide to organizations concerned with developmental and related disabilities.*** Silver Spring, MD: American Association of University Affiliated Programs, 1996. 206 pp.
Contact: American Association of University Affiliated Programs, 8630 Fenton Street, Suite 410, Silver Spring, MD 20910. Telephone: (301) 588-8252 / Fax (301) 588-2842. $10.00 includes shipping and handling. NMCHC inv. code D024 (1990 edition), (1989 edition C041), (1984-85 edition A330).

This directory provides information on American Association of University Affiliated Programs member organizations and mental retardation research centers as well as selected government and state agencies and programs and other resources. Member listings include 1-2 pages for each member giving the names and phone numbers of administration staff, discipline coordinators, and coordinators of special projects, educational programs, technical assistance, and research. Federal and state agencies and programs listed include the National Agent Orange Training and Technical Assistance projects, Administration on Developmental Disabilities, National Institute of Child Health and Human Development, Maternal and Child Health Bureau, State Title V Programs, Association of Maternal and Child Health Programs, Special Projects of Regional and National Significance, Office of Special Education and Rehabilitative Services, State Directors of Developmental Disabilities Services, Administration for Children, Youth and Families, and State Child Welfare Programs, and other resources.

Anderson, M. F. ***Hospitalized children and books: A guide for librarians, families, and caregivers. (2nd ed.)*** Metuchen, NJ: MLA/Association Publishers, Scarecrow Press, 1991. 154 pp.

Contact: MLA/Association Publishers, Scarecrow Press, P.O. Box 4167, Metuchen, NJ 08840. Telephone: (800) 537-7107 / (908) 548-8600. $19.95 plus $2.50 shipping and handling.

This book provides information about the operation, programming, and goals of a library in a pediatric setting. The second edition includes guidelines for serving an increasingly large number of preschool-age, technology-dependent, and chronically ill children. Services discussed include story hours, read-aloud times, book carts, bibliotherapy, poetry writing, a family health resource center, and community outreach. Lists of books for children and of books and other resources for adults are included.

Battigelli, S., and Heekin, S. (Eds.). ***EEPCD resources supporting inclusion.*** Chapel Hill, NC: National Early Childhood Technical Assistance System, 1995. 39 pp.
Contact: NEC*TAS Publications, National Early Childhood Technical Assistance System, 500 NationsBank Plaza, 137 East Franklin Street, Chapel Hill, NC 27510. Telephone: (919) 962-2001 / TDD: (919) 966-4041 / Fax (919) 966-7463 / Email nectasta.nectas@mhs.unc.edu; Web site: http://www.nectas.unc.edu. $5.00 includes shipping and handling; discounts available for bulk orders.

This bibliography lists publications and audiovisual materials produced by recipients of grants from the U.S. Department of Education, Office of Special Education Programs, Early Education Program for Children with Disabilities (EEPCD). The grants are used to develop projects which support the inclusion of children with special health needs in community programs and public schools. This bibliography lists field-tested materials developed by these projects which can be used by their advocates; each entry lists the name of the product, its format, a description, the targeted audience, the cost, and source information.

Lawrence, K., Johnson, G., and Stepanek, J. (Eds.). ***Parent resource directory. (5th ed.)*** Washington, DC: National Center for Family-Centered Care, Association for the Care of Children's Health, 1994. 119 pp.
Contact: Association for the Care of Children's Health, 7910 Woodmont Avenue, Suite 300, Bethesda, MD 20814. Telephone: (301) 654-6549. $9.00 members, $12.00 nonmembers, plus $3.50 shipping and handling. NMCHC inv.code H046.

This directory contains entries from families throughout the United States and Canada who have a child with a disability. It is intended to help parents locate others who share their interests, concerns, and experiences, and to help parents and professionals identify one another and form relationships to improve the health care system for children with special needs and their families. Entries are arranged by state, and include information on the child's disabilities and the care facility at which the child receives the majority of his or her care, as well as information on the parents' affiliations, skills, interests, experience, and related employment. The directory also includes a list of Parent Training and Information Centers. [Funded by the Maternal and Child Health Bureau]

Mackenzie, L. ***The complete directory for people with disabilities.*** Lakeville, CT: Grey House Publishing, 1996. 580 pp.
Contact: Grey House Publishing, Pocket Knife Square, Lakeville, CT 06039. Telephone: (203) 435-0868 / Fax (203) 435-0867. $59.95 plus $7.50 shipping and handling.

This directory was designed to provide people with disabilities and the professionals who work with them a comprehensive source of information on the resources, products, and services that are available to people with disabilities and their families. It lists publications and conferences of interest to persons with disabilities, as well as organizations, government agencies, libraries, residential centers, and programs. Products for persons with disabilities, including assistive devices, clothing, and computers are also included.

New Hampshire Emergency Medical Services for Children Project. ***The SKIP resource directory: Special Kids Information Program.*** Hanover, NH: New Hampshire Emergency Medical Services for Children Project, Dartmouth Medical School, 1996. 49 pp.

Contact: New Hampshire Emergency Medical Services for Children Project, Dartmouth Medical School, Hanover, NH 03755. Telephone: (603) 650-1814. Price unknown.

This directory provides listings of publications and service agencies or associations that provide information or services for children with special health needs; it was prepared to help emergency medical services personnel locate information about caring for these children. The directory is arranged by type of disorder or by several general topics. For each disorder or topic, the entries list the names and contact information for national agencies and associations; and state and local agencies; and provides contact information for producers of books, videos, and pamphlets.

U.S. Department of Health and Human Services, Public Health Service, Health Resources and Services Administration, Maternal and Child Health Bureau. ***Abstracts of active projects FY 19__.*** Washington, DC: U.S. Department of Health and Human Services, 1988-. annual.
Contact: Librarian, National Center for Education in Maternal and Child Health, 2000 15th Street North, Suite 701, Arlington, VA 22201-2617. Telephone: (703) 524-7802 / Fax (703) 524-9335 / Email Info@ncemch.org; Website: http://www.ncemch.org. Available for loan. NMCHC inv.code I062 (1995), I061 (1994), H003 (1993), H002 (1992), E056 (1991), D048 (1990), C094 (1989), B320 (1988), A351 (1987).

This annual directory lists currently active grants funded by the Maternal and Child Health Bureau, U.S. Department of Health and Human Services, for special projects of regional and national significance (SPRANS) and other grants in the areas of maternal and child health. [Funded by the Maternal and Child Health Bureau]

Velleman, R. A. ***Meeting the needs of people with disabilities: A guide for librarians, educators, and other service professionals.*** Phoenix, AZ: Oryx Press, 1990. 271 pp.
Contact: Oryx Press, 4041 North Central Avenue, Suite 700, Phoenix, AZ 85012-3397. Telephone: (800) 279-6799 / Fax (800) 279-4663 / Email info@oryxpress.com; Web site: http://www.oryxpress.com. $37.95.

This reference book provides information for and about physically, mentally, emotionally, and developmentally disabled people. Issues addressed include attitudes about disabilities, definitions of common disabilities, benefits under the law, computers and other technology, rehabilitation, special education, the disabled and the public, school and university libraries, rehabilitation library collections, barrier-free design for libraries, and book and periodical resources for core collections on special health needs and rehabilitation. Names and addresses of organizations and agencies are included.

LEGISLATION, PROGRAM, AND POLICY ISSUES

Farrow, F., and Bruner, C. ***Getting to the bottom line: State and community strategies for financing comprehensive community service systems.*** Falls Church, VA: National Center for Service Integration, ca. 1993. 24 pp. (Resource brief; 4)
Contact: National Center for Service Integration, Child and Family Policy Center, Fleming Building, Suite 1021, 218 Sixth Avenue, Des Moines, IA 50309-2200. Telephone: (515) 280-9027 / Fax (515) 244-8997. $4.00 includes shipping and handling; prepayment required; make check payable to NCSI.

This report, based on current experiences of states and communities, examines ways that they can finance integrated services for children and families. The authors consider various concepts that can be used in designing new financing strategies and review the basic principles that underlie these strategies. The report describes various strategies that can be used to promote more comprehensive, locally controlled services that focus on preventive care. Also included are selected financing strategies references.

Maloney, M. H. ***Early childhood law and policy desk book.*** Horsham, PA: LRP Publications, 1993-. annual.

Contact: Teresa, LRP Publications, 747 Dresher Road, Suite 500, P.O. Box 980, Horsham, PA 19044-0980. Telephone: (800) 341-7874 ext. 264 / (215) 784-0860 / Fax (215) 784-9639. $55.00 plus $3.50 postage and handling.

This manual is a review of the judicial and administrative decisions and federal policy rulings affecting early intervention and preschool programs for infants, toddlers, and children with disabilities and their families. The cases and rulings discussed were all originally published in the "Early Childhood Law and Policy Reporter (ECLPR)". The appendices contain a table of cases and documents summarized, the texts of the 20 most significant cases and documents reported in the "ECLPR," and a list of the relevant statues and regulations pertaining to early intervention and preschool services for children with disabilities.

McManus, M., Fox, H., Newacheck, P., McPherson, M., and Roy, B. ***Strengthening partnerships between state programs for children with special health needs and managed care organizations*** Washington, DC: Maternal and Child Health Policy Research Center, 1996. 30 pp.
Contact: Maternal and Child Health Policy Research Center, McManus Policy Center, 2 Wisconsin Circle, Suite 700, Chevy Chase, MD 20815. Telephone: (202) 686-4797 / Fax (202) 686-4791. $15.00 includes shipping and handling; or through MCH NET.

This report contains results of a Maternal and Child Health Bureau survey to ascertain how many states are using managed care systems to provide services to children with special health needs who are also enrolled in Medicaid. The history of the survey is given. Results are given for these: (1) defining and identifying children with special health needs, (2) enrollment assistance and family participation in managed care plans, (3) pediatric provider and service requirements, (4) education and training, (5) quality of care, (6) risk adjusted capitation mechanisms, and (7) innovative services integration projects. For each topic, the report elaborates on the significance of the topic, provides statistics based on the responses, and describes activities within specific states. [Funded by the Maternal and Child Health Bureau]

National Coalition for Family Leadership. ***The ABC's of managed care: Standards and criteria for children with special health care needs*** [Algodones, NM: Family Voices], 1996. 7 pp.
Contact: Polly Arango, Family Voices, P.O. Box 769, Algodones, NM 87001. Telephone: (505) 867-2368 / Fax (505) 867-6517. $1.00 includes shipping and handling.

This report presents information based on a September 1995 meeting at Egg Harbor, Wisconsin. At the meeting, parent leaders discussed the services that managed care systems provide children with special health needs and decided to develop standards of care so the children's needs will be met. The report defines managed care, family-centered care, and children with special health needs; and it outlines principles on these topics: families as the core of the health care system; the significance of family-professional partnerships; the importance of access to equitable care; the need for flexible services; and the provision of comprehensive, coordinated, community-based care. The principles are used to develop standards of care regarding: access, benefits, capacity, decision-making, evaluation and data gathering, and financing. [Funded by the Maternal and Child Health Bureau]

Pope, A. M., and Tarlov, A. R. (Eds.). ***Disability in America: Toward a national agenda for prevention—Full report, summary and recommendations*** Washington, DC: National Academy Press, 1991. 362 pp., summ. (36 pp.).
Contact: National Academy Press, 2101 Constitution Avenue, N.W., Lockbox 285, Washington, DC 20055. Telephone: (800) 624-6242 / Fax (202) 334-2451 / Email Web site: http://www.nap.edu. Summary available in limited quantities; full report $29.95 plus $3.00 shipping and handling from the National Academy Press.

This report provides a follow-up to the Institute of Medicine's report "Injury in America" released in 1985. It describes a comprehensive approach to disability prevention. Included are developmental disability, disabilities caused by injury, chronic disease and aging, and secondary conditions arising from primary disabling conditions. It presents a five-prong strategy (organization and coordination within and between the public and private sectors, surveillance, research, access to medical care, and education) for reducing the incidence and prevalence of disability as well as its personal, social, and economic consequences. The summary provides an overview of the full report.

Rinehart, P. M. (Ed.). ***Health issues for children and youth and their families.*** Minneapolis, MN: Center for Children with Chronic Illness and Disability, 1995-. irregular.
Contact: Center for Children with Chronic Illness and Disability, Box 721 - UMHC, Harvard Street at East River Road, Minneapolis, MN 55455. Telephone: (612) 626-4032 / TDD: (612) 624-3939. Price unknown.

This newsletter contains articles of interest to families whose children or adolescents have special health needs and to the health professionals and others who provide services to them. The articles focus on topics such as assuring that these children and adolescents have access to health care, data collection, public policy issues related to their health care, helping youth live independently, providing health care to adolescents with special health needs, transition programs, gathering demographic data on this population, and resilience and coping. In 1993 and 1994 the newsletter was published as "Children's Health Issues;" in 1995 and 1996 the title was "Children's and Youth's Health Issues." [Funded in part by the Maternal and Child Health Bureau]

Smith, K. ***Care coordination in state CSHCN agencies: Report of a national survey.*** Los Angeles, CA: Center for Automation and Care Coordination Enhancing Service Systems in Maternal and Child Health (ACCESS-MCH), 1995. ca. 300 pp.
Contact: Kathryn Smith, RN, MN or Laurie Thompson, Center for Automation and Care Coordination Enhancing Service Systems in Maternal and Child Health (ACCESS-MCH), University Affiliated Program, Children's Hospital Los Angeles, P.O. Box 54700, Mail Stop 53, Los Angeles, CA 90054-0700. Telephone: (213) 913-4400 / Fax (213) 913-1003. Available at no charge to Title V agencies; $15.00 for others.

This document gives the results of a nationwide survey of state agencies for children with special health needs that focused on care coordination. It gives information on care coordination definitions, quality guidelines, personnel preparation and training standards, and strategies for evaluating outcomes. It also includes a list of products developed by the states, such as assessment tools, service plans, policies and procedures, performance standards, and other documents. [Funded by the Maternal and Child Health Bureau]

Trohanis, P. L. ***Progress in providing services to young children with special needs and their families: An overview to and update to implementing the Individuals with Disabilities Education Act (IDEA).*** Chapel Hill, NC: National Early Childhood Technical Assistance System, 1995. 20 pp. (NEC*TAS notes; no. 7)
Contact: NEC*TAS Publications, National Early Childhood Technical Assistance System, 500 NationsBank Plaza, 137 East Franklin Street, Chapel Hill, NC 27514. Telephone: (919) 962-2001 / TDD: (919) 966-4041 / Fax (919) 966-7463 / Email nectasta.nectas@mhs.unc.edu / Web site: http://www.nectas.unc.edu. $3.00 includes shipping and handling.

This paper gives and overview and outline of major accomplishments of three federal programs included in the Individuals with Disabilities Education Act (IDEA): Part H, the Program for Infants and Toddlers with Disabilities; Section 619 of Part B, the Preschool Grants Program; and under Part C, the Early Education Program for Children with Disabilities.

U.S. Department of Education, Clearinghouse on Disability Information. ***Pocket guide to federal help for individuals with disabilities.*** Washington, DC: Clearinghouse on Disability Information, U.S. Department of Education, 1989. 26 pp.
Contact: Communication and Information Services, Office of Special Education and Rehabilitative Services, U.S. Department of Education, 330 C Street, S.W., Switzer Building, Room 3129, Washington, DC 20202-2524. Telephone: (202) 205-8241. Available at no charge. E-89-22002.

This publication was written for persons with handicaps, their families, and service providers, and contains information on government-wide benefits and services for which individuals with disabilities may be eligible. It includes sections on developmental disabilities, vocational rehabilitation, education, employment, financial assistance, medical assistance, civil rights, housing, tax benefits, and transportation.

U.S. Department of Education, Office of Special Education and Rehabilitative Services, Clearinghouse on the Handicapped. ***Summary of existing legislation affecting persons with disabilities*** Washington, DC: U.S. Government Printing Office, 1992. 235 pp.
Contact: Communication and Information Services, Office of Special Education and Rehabilitative Services, U.S. Department of Education, 330 C Street, S.W., Switzer Building, Room 3129, Washington, DC 20202-2524. Telephone: (202) 205-8241. Available at no charge. E/OSERS 92-8.

This publication offers a summary of federal laws relevant to people with disabilities, for use by consumers, professionals, providers, advocates, and family members. It provides information on over 60 federal laws, in the areas of education, employment, health, housing, income maintenance, nutrition, rights, social services, transportation, and vocational rehabilitation.

U.S. Department of Health and Human Services, Public Health Service. ***Healthy people 2000: National health promotion and disease prevention objectives.*** Washington, DC: Public Health Service, U.S. Department of Health and Human Services, 1991. 2 v.
Contact: Superintendent of Documents, U.S. Government Printing Office, Washington, DC 20402. Telephone: (202) 512-1800 / Fax (202) 512-2250. $31.00 for the report; $9.00 for the summary (GPO no. 017-001-00474-0, full report; 017-001-00473-1, summary). NMCHC inv. code D089; PHS 91-50212.

This report identifies a national strategy for improving the health of the Nation by addressing the prevention of major chronic illnesses, injuries, and infectious diseases. It provides a discussion of the health needs of different age groups and special populations, the goals for the nation, the priorities for health promotion and disease prevention, and the commitment of shared responsibility. Also provided are the national health promotion and disease prevention objectives for the year 2000. A list of the lead agencies in each priority area is included in the appendices. A summary report is available which contains an overview of Healthy People and summarizes the national health promotion and disease prevention objectives and highlights specific objectives under each topic area.

Wallace, H. M., Biehl, R. F., MacQueen, J. C., and Blackman, J. A. (Eds.). ***Mosby's resource guide to children with disabilities and chronic illness.*** St. Louis, MO: Mosby Year-Book, 1997. 352 pp.
Contact: Order Services Department, Mosby-Year Book, 11830 Westline Industrial Drive, Saint Louis, MO 63146. Telephone: (800) 325-4177 / (314) 872-8370 / Fax (314) 432-1380. $54.95 plus $3.74 shipping and handling. ISBN 0-8151-9051-4; order no. 28151.

This book provides an overview of services for children with special health needs. The essays are organized in six main sections: the first provides an overview of the population, an analysis of the long-term effect of chronic illness on children and their families, and an history of the development of public health programs for them; the second discusses future trends in services and programs; the third focuses on issues affecting their ability to lead normal and productive lives. The fourth section describes the significant services needed by the children and their families, and the scope and objectives of the services; the fifth contains descriptions of common chronic conditions in a standardized format; and the last section reviews the role of various professional disciplines within the interdisciplinary approach to service.

MEDICAL REFERENCE BOOKS

Batshaw, M. L., and Perret, Y. M. ***Children with disabilities: A medical primer. (3rd ed.)*** Baltimore, MD: Paul H. Brookes Publishing Company, 1992. 664 pp.
Contact: Paul H. Brookes Publishing Company, P.O. Box 10624, Baltimore, MD 21285. Telephone: (800) 638-3775 / (410) 337-9580 / Fax (410) 337-8539. $29.00; new edition available July 1997.

Written primarily for a health care audience (special educators, physical therapists, occupational therapists, speech and language pathologists, social workers, child life specialists), this book has found an additional audience in parents and in others who work with families of children with special health needs. Information on a wide range of topics is covered: heredity, birth defects, normal fetal growth and development, labor and delivery, premature birth, nutrition, dental care, brain and nervous system, bones and muscles, and normal and abnormal development. Additional chapters cover specific problems of vision, hearing, speech and language, autism, attention deficit disorder and hyperactivity, learning disabilities, cerebral palsy, and epilepsy. The final chapters discuss how families cope with a child with special needs; ethical dilemmas; and public benefits, legal services, and estate planning for families. Appendices include a glossary, a brief description of certain syndromes, a list of resources, and general lifesaving techniques.

Buyse, M. L. (Ed.). ***Birth defects encyclopedia***Dover, MA: Center for Birth Defects Information Services, 1992. 1892 pp.
Contact: Center for Birth Defects Information Services, Dover Medical Building, 30 Springdale Avenue, Box 1776, Dover, MA 02030. Telephone: (508) 785-2525 / Fax (508) 785-2526. Out of stock, may be reprinted.

This encyclopedia presents structured articles on human anomalies of clinical relevance, written by the leading experts in each topic or birth defect condition. Information includes related disorders that are included or excluded in the condition, major diagnostic criteria, clinical findings, complications, associated findings, etiology, pathogenesis, Mendelian Inheritance in Man number, sex ratio, occurrence, risk of recurrence for patient's child or sibling, age of detectability, gene mapping and linkage, prevention, treatment, prognosis, detection of carrier, special considerations, support groups, and references. Illustrations are included. Updates to the information provided are available from the publisher.

Jablonski, S. ***Jablonski's dictionary of syndromes and eponymic diseases. (2nd.ed.)*** Melbourne, FL: Krieger Publishing Company, 1991. 665 pp.
Contact: Krieger Publishing Company, P.O. Box 9542, Melbourne, FL 32902-9542. Telephone: (407) 724-9542 / (407) 727-7270 / Fax (407) 951-3671. $99.50 plus $4.00 shipping and handling.

This book was developed to provide information to physicians and laymen on the thousands of syndromes and eponymous diseases. Each entry contains a brief description of the syndrome or disease, as well as one or more bibliographic citations from the medical literature. The dictionary is intended to be an on-going project, and periodic updates and supplements will be issued.

Jones, K. L. ***Smith's recognizable patterns of human malformation. (5th ed.)*** Philadelphia, PA: W. B. Saunders Company, 1996. 778 pp.
Contact: Order Department, W. B. Saunders Company, 6277 Sea Harbor Drive, 4th Floor, Orlando, FL 32821-9989. Telephone: (800) 545-2522 / (800) 633-4434. $70.00.

This book focuses on patterns of malformation; specific chapters related to normal and abnormal morphogenesis, genetics and genetic counseling, the psychological adaptation to children with structural anomalies, and clinical approaches to specific anomalies are included. This book is designed for clinical application, as well as to provide a basic text for the education of those interested in human malformation.

McKusick, V. A. ***Mendelian inheritance in man. (12th ed.)***Baltimore, MD: Johns Hopkins University Press, 1997. 2 v. with quarterly updates.
Contact: Johns Hopkins University Press, 701 West 40th Street, Suite 275, Baltimore, MD 21211. Telephone: (410) 516-6960. $200; publication is forthcoming.

This book is a technical reference that consists of catalogs of autosomal dominant, autosomal recessive, and X-linked phenotypes. This reference book contains alphabetical listings of these three subject headings, as well as an author and title index. This information may also be accessed via computer, through OMIM (On-line Mendelian Inheritance in Man), available from The William H. Welch

Medical Library, Johns Hopkins University, 1830 East Monument Street, Third Floor, Baltimore, MD 21205; telephone (301) 955-7058, fax (301) 955-0054.

Taeusch, H. W., Ballard, R. A., and Avery, M. E. ***Schaffer and Avery's diseases of the newborn. (6th ed.).*** Philadelphia, PA: W.B. Saunders Company, 1991. 1,115 pp.
Contact: Order Department, W.B. Saunders Company, 6277 Sea Harbor Drive, 4th Floor, Orlando, FL 32821-9939. Telephone: (800) 5452522 / (800) 633-4434. $130.00.

This textbook cover major influences on fetal growth and development, genetic diseases, stabilization and initial evaluations of the newborn, general principles of care, infections and immunologic defense mechanisms, neuromuscular disorders, the respiratory system, nutrition, disorder of bilirubin metabolism, the hematologic system, nonimmune hydrops fetalis, the renal and genitourinary systems, the metabolic and endrocine and exocrine systems, dermatologic conditions, disorders of the eye, and other neoplasms and miscellaneous conditions.

Thoene, J. G. (Ed.). ***Physicians' guide to rare diseases. (2nd ed.)***Montvale, NJ: Dowden Publishing, 1995. ca. 1200 pp.
Contact: Dowden Publishing Company, 110 Summit Avenue, Montvale, NJ 07645. Telephone: (201) 391-9100 / Fax (201) 391-2778. $69.50.

This work is an adaptation of the National Organization for Rare Disorders' database on Compuserve. Entries on rare disorders are designed to address the concerns of physicians in primary care specialties by providing ready access to information on signs and symptoms for help in differential diagnosis, availability of therapy, and the location of support groups for these patients. It includes a full-color atlas of visual diagnostic signs; a directory of orphan drugs organized by use and providing the name of a key contact person at each research center; and a detailed index of symptoms and signs.

van Dyck, K., and Fineman, R. ***Anticipatory guidance for children with congenital defects*** Salt Lake City, UT: Baby Your Baby Well Child Care Program, Utah Department of Health, 1991. ca. 200 pp.
Contact: Early Intervention Program, Division of Family Health Services, Utah Department of Health, 288 North 1460 West, P.O. Box 16650, Salt Lake City, UT 84116. Telephone: (801) 538-6161. $20.00.

This manual is intended to be used by primary health care providers involved in the ongoing care of infants and children with established birth defects or genetic disease. Its purpose is to familiarize primary care providers with the genetics of specific conditions and to help them differentiate between a straightforward condition, for which they may feel qualified to counsel the family, and more complicated conditions or syndromes for which a formal genetic counseling referral may be appropriate. The manual contains entries for thirty-nine disorders.

NUTRITION

Allen, J. (Ed.). ***Nutrition and children with special health care needs: The state of the union*** ASTPHND Newsletter. (Supplement): 1-20. Winter 1993.
Contact: Association of State and Territorial Public Health Nutrition Directors, 415 Second Avenue, N.E., Suite 200, Washington, DC 20002. Telephone: (202) 546-6963 / Fax (202) 544-9349. Price unknown.

This supplement to the newsletter of the Association of State and Territorial Public Health Nutrition Directors is devoted to descriptions of programs in 19 states which address the nutritional needs of children with special health care needs. In addition, there are regional reports, and a short bibliography.

Arizona Department of Health Services, Office of Nutrition Services, Project Change. ***A guide to feeding young children with special needs.*** Phoenix, AZ: Office of Nutrition Services, Arizona Department of Health Services, 1995. 95 pp.
Contact: Office of Nutrition Services, Arizona Department of Health Services, 1740 West Adams Street, Phoenix, AZ 85007. Telephone: (602) 542-1886 / Email lrider@hs.state.az.us. Available at no charge.

This manual helps parents and child care providers working with children with special health needs gain insight into their nutrition needs and feeding concerns. The guide builds upon a team approach, explores the relationships between nutrition and growth, reviews stages in child development and oral motor skills, and considers issues relating to self-feeding skills and the mealtime experience. The manual reviews special needs and special diets; provides definitions of children with special needs; and includes selected references and a list of national resource organizations. [Funded by the Maternal and Child Health Bureau]

Ekvall, S. W. (Ed.). ***Pediatric nutrition in chronic diseases and developmental disorders: Prevention, assessment, and treatment.*** New York, NY: Oxford University Press, 1993. 541 pp.
Contact: Oxford University Press, 2001 Evans Road, Cary, NC 27513. Telephone: (800) 451-7556. $65.00.

This book for health professionals reviews the current status of research regarding nutrition in chronic diseases and developmental disorders of children and helps translate this research into clinical practice. Each chapter focuses on biochemical and/or clinical abnormalities, techniques in nutrition evaluation or diagnosis (including behavior), nutritional treatment or management, and follow-up procedures. Although directed toward the health care of children, the text provides for all ages information on current issues in preventive nutrition and normal growth. Appendices include Recommended Dietary Allowances, black and white NCHS growth charts for special conditions and the general population, nutrition assessment records, intensive care nursery protocol, quality assurance standards, anthropometric standards, maturation charts, and adult nutrition records and assessment values.

Horsley, J. W., Allen, E. R., and Daniel, P. W. ***Nutrition management of school age children with special needs: A resource manual for school personnel, families, and health professionals = Nutrition management of handicapped and chronically ill school children. (2nd ed.)*** Richmond, VA: Virginia Department of Health and Virginia Department of Education, 1996. 93 pp.
Contact: National Maternal and Child Health Clearinghouse, 2070 Chain Bridge Road, Suite 450, Vienna, VA 22182-2536. Telephone: (703) 356-1964 / Fax (703) 821-2098 / Email nmchc@circsol.com. Available at no charge.

This manual, a product of an interagency project between the Virginia Departments of Health and Education, is a guide for parents and professionals on the management of nutrition problems of school children with special needs. It helps school personnel plan nutrition services for students who have special health needs or are chronically ill. The information included facilitates the management of special diets and the expansion of nutrition education in the school curriculum. It includes information on these topics: common nutrition problems and interventions during the school day; dietary considerations of specific conditions and related factors; and nutrition goals and objectives for the individualized education program. Dietary considerations and sources of information and/or nutrition education materials for the following conditions are discussed: cerebral palsy, cystic fibrosis, diabetes mellitus, Down syndrome, juvenile rheumatoid arthritis, phenylketonuria, seizure disorders, spina bifida, constipation, feeding abnormalities, and tube feeding. Nine case studies are presented. The appendix includes information on lunch menu ideas for special diets, nutritious snacks, textural modifications, arthritis diet and drugs, complications of tube feeding, and PKU diet free foods. [Funded by the Maternal and Child Health Bureau]

New Mexico Health and Environment Department, Public Health Division, C.H.E.W.S. Nutrition Project. ***[C.H.E.W.S. Nutrition Project information package]*** Santa Fe, NM: C.H.E.W.S. Nutrition Project, New Mexico Health and Environment Department, ca. 1989. 3 pamphlets (10 pp.), 6 fact sheets, 2 brochures.
Contact: C.H.E.W.S. Nutrition Project, Public Health Division, MCH Bureau, New Mexico Health and Environment Department, 1190 St. Francis Drive, Room N3078, P.O. Box 968, Santa Fe, NM 87504-0968.

This information package contains items produced by the Children with Handicaps Expanding Statewide Services (C.H.E.W.S.) Nutrition Project. The package includes the 'Community Nutrition Resource Directory,' listing dietitians and nutritionists who have attended a C.H.E.W.S. training; a pamphlet in English and Spanish, 'Hiding Extra Calories=Como Esconder Las Calorias,' providing tips on helping underweight children gain weight through adding extra calories and protein into favorite foods; a brochure in English and Spanish, 'Growing Up Fit=Creciendo Saludable,' promoting good food, healthy eating habits, and exercise for children; English-Spanish fact sheets on constipation, feeding positions, feeding time, and fluids. [Funded by the Maternal and Child Health Bureau]

Pipes, P., and Lucas, B. ***Guidelines for the development and training of community-based feeding teams in Washington State*** Olympia, WA: Office of Children with Special Health Care Needs, Washington State Department of Health, 1994. 26 pp.
Contact: Maria Nardella, Nutrition Consultant, Office of Children with Special Health Care Needs, Division of Community and Family Health, Washington State Department of Health, Airdustrial Park, Building 7, P.O. Box 47880, Olympia, 98504-7880. Telephone: (206) 586-3373 / Fax (206) 586-7868. Single copies available at no charge.

This manual provides guidelines for coordinating activities among community-based nutrition services in Washington State that care for children with special health needs. Since many different services are involved in this process, these guidelines use a team approach to resolve conflicts that result from other service models. The authors provide an overview of the team approach and review the steps involved in establishing and training the community feeding teams. Appendixes include models, training agendas, mission statements, and other materials related to establishing the teams.

Washington State Department of Health, Division of Community and Family Health, Office of Children with Special Health Care Needs. ***Focus groups on nutrition services with parents of children with special health care needs in Washington State*** Olympia, WA: Office of Children with Special Health Care Needs, Washington State Department of Health, 1994. 18 pp.
Contact: Maria Nardella, Nutrition Consultant, Office of Children with Special Health Care Needs, Division of Community and Family Health, Washington State Department of Health, Airdustrial Park, Building 7, P.O. Box 47880, Olympia, WA 98504-7880. Telephone: (206) 586-3373 / Fax (206) 586-7868. Single copies available at no charge.

This report summarizes the results of four focus groups held by the Washington Office of Children with Special Health Care Needs and the Child Development and Mental Retardation Center. These focus groups of parents of children with special health needs were held to assess and improve the state's community-based nutrition services for these children. The report reviews the methodology, summarizes the findings from the focus groups, and includes recommendations for future modifications.

Yadrick, K., and Sneed, J. ***Providing for the special food and nutrition needs of children*** Hattiesburg, MS: Division of Applied Research, National Food Service Management Institute, University of Southern Mississippi, 1993. ca. 70 pp.

PARENTING

Association for the Care of Children's Health. ***Your child with special needs at home and in the community*** Bethesda, MD: Association for the Care of Children's Health, 1991. 29 pp. *Contact:* Association for the Care of Children's Health, 7910 Woodmont Avenue, Suite 300, Bethesda, MD 20814. Telephone: (301) 654-6549. $2.50; bulk rates available.

This booklet offers practical information on family life, managing medical care, school, and finances. Extensive listings of books and organizations are included. This publication was produced as part of the Association for the Care of Children's Health's MCH-funded project to develop a nationwide program to enhance the implementation of a family-centered approach to care for children with special health needs. [Funded by the Maternal and Child Health Bureau]

Bowman, P., et. al. ***From the heart: Stories by mothers of children with special needs*** Portland, ME: Parents in Partnership Project, University of Southern Maine, 1994. 151 pp. *Contact:* Jayne Marsh, Edmund S. Muskie Institute of Public Affairs, Child and Family Center, University of Southern Maine, Post Office Square, P.O. Box 15010, Portland, ME 04112. Telephone: (207) 780-5822 / Fax (207)780-5817 / Email jaynem@usm.maine.edu. $12.00 plus 10 percent shipping and handling. no. B050129.

This book contains stories that chronicle the struggles and successes, happy endings and setbacks, failures and accomplishments that are daily experiences of families raising a child who is different one way or another from what is considered normal. Project Parents in Partnership is designed to assist in the development of a continuum of services to parents of young children with special needs. [Funded by the Maternal and Child Health Bureau]

Callanan, C. R. ***Since Owen: A parent-to-parent guide for care of the disabled child*** Baltimore, MD: Johns Hopkins University Press, 1990. 466 pp. *Contact:* Johns Hopkins University Press, 701 West 40th Street, Suite 275, Baltimore, MD 21211. Telephone: (410) 516-6960. $16.95.

Written by the parent of a severely disabled child, this book will alert parents to the many areas that affect the child with a disability. It covers family planning, birth, being in the hospital, coping with the first few years at home, appropriate education, and life in the adult world. It includes a list of dos and don'ts and a list of resources for further information.

Capper, L. ***That's my child: Strategies for parents of children with disabilities*** Washington, DC: Child and Family Press, 1996. 198 pp. *Contact:* Child Welfare League of America, c/o CSSC, P.O. Box 7816, 300 Raritan Center Parkway, 08818-7816. Telephone: (800) 407-6273 / (908) 225-1900 / Fax (908) 417-0482. $12.95 plus shipping and handling; no shipping and handling if prepaid. ISBN 0-87868-595-2.

The book covers a broad range of information that parents of children with chronic illnesses or disabilities need. It reviews the roles that the parents will need to play including care giver, social worker, advocate, a parent fostering the growth and development of their child, and as a liaison with others. It also includes information on working with health professionals, rights and services guaranteed by federal law, working with school systems to provide special education, child day care, and recreational activities, among other topics. Appendices include definitions of disabilities, lists of organizations, a bibliography, and a glossary.

Children's Hospital, Boston, Project School Care. ***Working toward a balance in our lives: A booklet for families of children with disabilities and special health care needs*** Boston, MA: Project School Care, Children's Hospital, 1992. 90 pp.

Contact: Judith Palfrey, M.D., Director, Project School Care, Children's Hospital, 300 Longwood Avenue, Boston, MA 02115. Telephone: (617) 735-6714 / Fax (617) 735-7940.

This booklet is designed to help parents of children with special health needs deal with their children's experiences in the hospital, at home, and at school. It was developed by a group of parents and staff of Project School Care, a program at Children's Hospital, Boston. Project School Care was established to foster educational opportunities for children with special health needs, particularly those assisted by medical technology. The booklet discusses the hospital experience, common questions after hospitalization, home care, home nursing, respite care, financing health care, equipment, education, vocational training and planning for adulthood, recreation and travel, and record keeping. Appendices include a list of resource organizations, suggested readings, and a glossary. The booklet was supported by grants from the U.S. Maternal and Child Health Bureau and the Charles A. Lindbergh Fund. [Funded by the Maternal and Child Health Bureau]

Cooper, A., and Harpin, V. (Eds.). ***This is our child: How parents experience the medical world*** New York, NY: Oxford University Press, 1991. 152 pp.
Contact: Oxford University Press, 2001 Evans Road, Cary, NC 27513. Telephone: (800) 451-7556 / (919) 677-0977 / Fax (919) 677-1303. $14.95.

This book, written for all health professionals working with children and their families, is a collection of personal accounts by parents and adolescents of their experiences with their child's illness, including premature birth, congenital anomalies and genetic disorders, and of the medical world. Each account is followed by a brief medical explanation. The book is designed to facilitate discussion between parents and professionals and provide support to parents and children who find themselves in similar situations.

Exceptional Parent. ***Exceptional parent: Parenting your child or young adult with a disability*** Oradell, NJ: Psy-Ed Corporation, 1970-. monthly.
Contact: Psy-Ed Corporation, 555 Kinderkamack Road, Oradell, NJ 07649. Telephone: (800) 247-8080 / Email Web site: http://www.familyeducation.com. $28.00 per year.

This magazine contains articles of interest to parents and professionals on such topics as education, advocacy, treatment, and care of children and young adults with special health needs.

Finston, P. ***Parenting plus: Raising children with special health needs*** New York, NY: Viking Penguin Press, 1990. 295 pp.
Contact: Viking Penguin Press, 375 Hudson Street, New York, NY 10014. Telephone: (212) 366-2000. $19.95.

This book gives advice on how to deal with the difficulties of raising children who are handicapped or chronically ill. Its chapters cover learning to identify the problem and live with it, not feeling sorry, teaching children to care for themselves, helping them make friends and deal with enemies, making the professional a partner, helping adolescents develop independence, and staying in the mainstream. It won the 1991 media award from the President's Committee on Employment of People with Disabilities.

Heustis, J., Kressley, K. G., Greer, M., and Klein, S. ***Parent liaison training manual: A resource guide for parent educators working within medical and social work teams*** Indianapolis, IN: Indianapolis Parent Information Network, 1993. ca. 200 pp.
Contact: Librarian, National Center for Education in Maternal and Child Health, 2000 15th Street North, Suite 701, Arlington, VA 22201. Telephone: (703) 524-7802 / Fax (703) 524-9335 / Email info@ncemch.org; Web site: http://www.ncemch.org. Available for loan.

This training manual complements the skills of parent liaisons, parents of children with special health needs who work within a medical and social work team to assist other families to become more effective caregivers for their own children with special health needs. This guide aims to increase the parent liaison's understanding of families and how they cope with special issues; enhance their communication and problem-solving strategies; and clarify their roles and responsibilities. Resources include a bibliography; a glossary of medical, disability and education terms; fact sheets about medical conditions; reprints of some of the additional readings; and resource directories. Each topic area includes case studies, instructional activities, and suggested readings. [Funded by the Maternal and Child Health Bureau]

May, J. ***Circles of care and understanding: Support programs for fathers of children with special needs*** Bethesda, MD: Association for the Care of Children's Health, 1992. 85 pp. *Contact:* Association for the Care of Children's Health, 7910 Woodmont Avenue, Suite 300, Bethesda, MD 20814. Telephone: (301) 654-6549 / Fax (301) 986-4553. NMCHC inv.code F063.

This manual is designed for those who organize and facilitate support groups for fathers of children with special health needs. It provides background information, and discusses getting started, effective leadership and facilitation, organization, and evaluation. Appendices include sample materials and program ideas. [Funded by the Maternal and Child Health Bureau]

May, J. (Ed.). ***National Fathers' Network newsletter*** Bethesda, MD: National Fathers' Network, National Center for Family-Centered Care, Association for the Care of Children's Health, 1993-. *Contact:* National Fathers' Network, National Center for Family-Centered Care, Association for the Care of Children's Health, 7910 Woodmont Avenue, Suite 300, Bethesda, MD 20814. Telephone: (301) 654-6549. Price unknown.

This newsletter contains short articles, responses, ideas, and commentary written by and for fathers of children with special health needs.

MetroHealth Medical Center, Pediatric Service Coordination Program. ***My book: A family care plan*** Cleveland, OH: Pediatric Service Coordination Program, MetroHealth Medical Center, 1991. 75 pp. *Contact:* SKIP of Ohio, P.O. Box 93016, Cleveland, OH 44101-5016. Telephone: (216) 283-6525. $20.00.

This notebook was created to assist in organizing the discharge process for a child with complex needs. It serves as a record of what has been done to prepare a family to care for their child at home, and attempts to promote a philosophy of family-centered care. It includes sections on family concerns, assessment, education, follow-up, emergencies, plans, and home records. [Funded by the Maternal and Child Health Bureau]

Michigan Department of Public Health, Bureau of Child and Family Services, Division of Children's Special Health Care Services, Parent Participation Program, Project: Uptown. ***Packaging wisdom*** Lansing, MI: Project: Uptown, Children's Special Health Care Services, Michigan Department of Public Health, 1995. 32 pp. *Contact:* Sue Middleton, Children's Special Health Care Services, Michigan Community Public Health Agency, P.O. Box 30195, Lansing, MI 48909-7695. Telephone: (517) 335-8959 / Fax (517) 335-9419. Available at no charge. P-974.

This handbook is designed to record in one place all the pertinent and necessary information that a parent will need when an emergency arises. Multiple forms cover all aspects of a child's medical and social history. A glossary of commonly used terms is included. [Funded by the Maternal and Child Health Bureau]

Moffitt, K., Reiss, J., and Nackashi, J. (Eds.). ***Special children, special care*** Tallahassee, FL: Florida Developmental Disabilities Planning Council, ca. 1992. ca. 350 pp. *Contact:* USF Bookstores, 4202 E. Fowler Avenue, Tampa, FL 33620. Telephone: (813) 974-2631. $28.95, make checks payable to USF.

This training and resource manual for families and others who care for children with special health needs is intended to address the challenges and issues facing families as they care for their children at home. Part I, Care Management, includes information related to record keeping, emotional aspects, family affairs, financial assistance, legal issues, and educational needs. The second part, Care Provision, includes skills and techniques needed for using equipment, dispensing medication, meeting daily physical needs, and providing basic home health and first aid techniques. The manual includes forms, checklists and charts for parents to record information on the care of their child. Resource lists and bibliographies are provided at the end of each section.

National Fathers' Network. ***Equal partners: African-American fathers and systems of health care.*** Bellevue, WA: National Fathers' Network, Kindering Center, 1996. 1 videotape (25:50 minutes), 1 guide (ca. 75 pp.).
Contact: National Maternal and Child Health Clearinghouse, 2070 Chain Bridge Road, Suite 450, Vienna, VA 22182-2536. Telephone: (703) 356-1964 / Fax (703) 821-2098 / Email nmchc@circsol.com. Available at no charge. NMCHC inv.code I086.

This videotape is designed to portray the unique challenges African American fathers confront when working with the health care delivery system, to investigate means for health care delivery systems to be inclusive of African American fathers as equal partners, and to portray positive images of African American fathers' involvement in their families. The videotape particularly focuses on fathers whose children have special health needs. The guide provides information about the project, a discussion guide for use with the video, assessment instruments, program suggestions, lists of organizations and materials for further information, and a set of articles. [Funded by the Maternal and Child Health Bureau]

National Pediatric HIV Resource Center. ***You're in charge: Your child's health care.*** Newark, NJ: National Pediatric HIV Resource Center, 1992. 1 videotape (18 minutes).
Contact: Television and Film Production, 1736 Columbia Road, N.W., Suite 110, Washington, DC 20009. Telephone: (202) 797-0818 / Fax (202) 232-2261. Contact source for price information.

This videotape is designed to help parents of children with chronic illness to become informed and proactive consumers of medical and social services. It features health care professionals describing their roles, parents sharing experiences about learning to cope with chronic illness, and demonstrations of successful partnerships between service providers and parents. [Funded by the Maternal and Child Health Bureau]

Nurses' Association of the American College of Obstetricians and Gynecologists. ***Questions to ask when your baby needs special care: Your role as a parent.*** Washington, DC: Nurses' Association of the American College of Obstetricians and Gynecologists, 1991. 13 pp.
Contact: Association of Women's Health, Obstetric, and Neonatal Nurses, 700 14th Street, N.W., Suite 600, Washington, DC 20024-2188. Telephone: (800) 673-8499 / (202) 662-1600 / Fax (202) 737-0575. Minimum order 50 pamphlets, $25.00.

This pamphlet is designed to help parents whose newborn has problems requiring special care in the hospital's nursery. It is intended to help the parents understand their feelings and take an active role in their baby's care.

Pueschel, S. M., Scola, P. S., Weidenman, L. E., and Bernier, J. C. ***Special child: A source book for parents of children with developmental disabilities. (2nd ed.)*** Baltimore, MD: Paul H. Brookes Publishing Company, 1995. 436 pp.
Contact: Paul H. Brookes Publishing Company, P.O. Box 10624, Baltimore, MD 21285. Telephone: (800) 638-3775 / (410) 337-9580 / Fax (410) 337-8539. $26.00. ISBN 1-55766-167-7.

Written for parents of children with developmental disabilities, this book is designed as a general resource for helping parents manage the complex issues involved in caring for their child. It points out how to recognize developmental problems and how to obtain an evaluation that may lead to a specific diagnosis. It discusses the effects a disability can have on family life. It suggests ways to choose a health specialist and describes the parent-professional partnership that is important for enhancing a child's care. Several sections highlight a number of specific tests and procedures, medications, treatments, and operations commonly performed. Other sections focus on educational and legal issues and on learning about and utilizing community resources. The book concludes with a list of resource organizations and a suggested reading list.

Turnbull, A. P., Patterson, J. M., Behr, S. K., Murphy, D. L., Marquis, J. G., and Blue-Banning, M. J. (Eds.). ***Cognitive coping, families, and disability.*** Baltimore, MD: Paul H. Brookes Publishing Company, 1993. 321 pp.
Contact: Paul H. Brookes Publishing Company, P.O. Box 10624, Baltimore, MD 21285. Telephone: (800) 638-3775 / (410) 337-9580 / Fax (410) 337-8539. $28.00.

Based on the findings of a participatory research conference sponsored by the Beach Center on Families and Disability and the Center for Children with Chronic Illness and Disability at the University of Minnesota, this book examines cognitive coping as a set of strategies that encourages individuals and families to successfully confront the daily challenges of disability. Empirical, theoretical, clinical, and consumer perspectives on disability and cognitive coping are revealed in discussions of family adjustment and adaptation to stress; empirical findings on coping strategies; conceptual and definitional issues; determinants of individual coping and coping style; and methodological issues and barriers.

University of Southern Maine, Edmund S. Muskie Institute of Public Affairs, Parents in Partnership Project. ***Parenting a child with special needs: Interviews with parents.*** Portland, ME: Parents in Partnership Project, University of Southern Maine, 1993. 3 videotapes (20:52, 24:43,27:31 min.), 1 booklet (20 pp.).
Contact: Jayne Marsh, Edmund S. Muskie Institute of Public Affairs, Child and Family Center, University of Southern Maine, Post Office Square, P.O. Box 15010, Portland, ME 04112. Telephone: (207) 780-5822 / Fax (207) 780-5817 / Email jaynem@usm.maine.edu. $30.00 plus 10 percent shipping and handling. nos. V020019, V020020, V020021.

These three videotapes cover distinct topics facing parents with a child with special needs. The topics are: Learning a diagnosis for the first time; Coping with a child with special needs; and Fathering a child with special needs. Along with each tape is a guide which gives a brief background to the subjects and suggests questions for leading a discussion. The parents describe the impact of the news on themselves and their families, the nature of the social support they received in the process, and how they would like to be treated in the parent-professional partnership. [Funded by the Maternal and Child Health Bureau]

Wolszon, M., Peet, L., Jones, D., Goldberg, P., and Goldberg, M. ***Celebrating family strengths: A handbook for families.*** Minneapolis, MN: PACER Center, 1993. 22 pp.
Contact: PACER Center, 4826 Chicago Avenue South, Minneapolis, MN 55417. Telephone: (612) 827-2966 / Fax (612) 827-3065. $2.50; includes postage and handling; make checks payable to the PACER Center.

This booklet is designed to help parents, particularly those having children with special health needs, learn how to focus on their children's and their family's strengths. It suggests ways for families to recognize and appreciate their own strengths, stories and traditions. It also expresses the need for good communication, positive messages, and recognizing responsibilities and when to ask for help.

RESPITE CARE

ARCH National Resource Center for Crisis Nurseries and Respite Care Services. ***National directory of crisis nurseries and respite care federal demonstration projects.*** Chapel Hill, NC: ARCH National Resource Center for Crisis Nurseries and Respite Care Services, 1996. 390 pp.
Contact: ARCH National Resource Center for Crisis Nurseries and Respite Care Services, Chapel Hill Training-Outreach Project, 800 Eastowne Drive, Suite 105, Chapel Hill, NC 27514. Telephone: (800) 473-1727 / (919) 490-5577. $25.00 plus $4.50 shipping and handling.

This directory lists projects funded under the Temporary Child Care for Children with Disabilities and Crisis Nurseries Act of 1986. This act provided grants to states to assist private and public agencies in developing temporary care services for children with disabilities, or chronic or terminal illnesses, and for children who have experienced or who are at risk of abuse or neglect. Information is provided on the funded state agency, including grants they made, state interagency efforts, and training; and on service providers, including the program's major goal, program description, program service area, budgets, local interagency collaboration activities, and evaluation.

Bolender, D. (Ed.). ***Conquering dilemmas and creating options: Equality of access to child care in Iowa for families with children with special needs: A proceedings report*** Iowa City, IA: Parent Partnership Program, Iowa Child Health Specialty Clinics, University of Iowa Hospitals and Clinics, 1993. 77 pp.
Contact: Mobile and Regional Child Health Specialty Clinics, University of Iowa Hospitals and Clinics, 100 Hospital School, Iowa City, IA 52242. Telephone: (319) 356-1469 / Fax (319) 356-3715. Price unknown.

This publication reports on two family forums, 'Conquering the day care dilemma for children with special needs' held in October 1991 and 'Respite: Creating child care options in Iowa' held in October 1992. These statewide forums were for families, daycare and respite child care providers, child advocates, resource and referral program staff, child care organizations, AEA and school staff, health care providers, human services staff, state agency staff, and government officials. In addition to summarizing the presentations, this book presents recommendations made by participants during breakout sessions.

Gallagher, J. J. ***Respite care*** Chapel Hill, NC: Early Childhood Research Institute on Service Utilization, 1995. 3 pp. (Raising issues)
Contact: Early Childhood Research Institute on Service Utilization, Frank Porter Graham Child Development Center, University of North Carolina at Chapel Hill, 300 NationsBank Plaza, Chapel Hill, NC 27514. Telephone: (919) 962-7369 / Fax (919) 962-7328. Available at no charge.

This short report suggests strategies respite care programs can take to calm unwarranted fears of parents receiving respite care services for their children with special health needs concerning possible mistreatment or abuse of their child by the respite caretaker.

Huntington, G. S., Garner-McGraw J., and Langmeyer, D. ***Results of descriptive study of crisis nursery and respite care programs***Chapel Hill, NC: Frank Porter Graham Child Development Center, University of North Carolina at Chapel Hill, 1992. 34 pp.
Contact: Frank Porter Graham Child Development Center, University of North Carolina at Chapel Hill, 500 NationsBank Plaza, Chapel Hill, NC 27514. Price unknown.

This report describes the results of two surveys of respite care and crisis nursery programs across the country. The surveys covered grantees of the U.S. Children's Bureau for the period 1988-1990. The report describes funding, eligibility criteria, services offered, and staffing. The survey instruments are included.

National Information Center for Children and Youth with Disabilities. ***Respite care*** Washington, DC: National Information Center for Children and Youth with Disabilities, 1996. 7 pp. (Briefing paper)
Contact: National Information Center for Children and Youth with Disabilities, P.O. Box 1492, Washington, DC 20013. Telephone: (800) 695-0285 / (202) 884-8200. Price unknown.

This paper discusses the emergence and diversity of respite care services, with emphasis on benefits of respite care for families of children with disabilities or special health needs. Tips and advice for parents who are seeking care are also presented. This paper concludes with a listing of readings and organizations that can provide parents and others with additional information on the subject of respite care. It updates an article from the NICHCY News Digest from 1989 that was available in print and on audiocassette.

New York State Department of Health. ***Time out for families: Pediatric respite care***Albany, NY: New York State Department of Health, 1991. 1 videotape (20 minutes, 1/2 inch).
Contact: Barry R. Sherman, Ph. D., Bureau of Child and Adolescent Health, New York State Department of Health, 208 Corning Tower, Empire State Plaza, Albany, NY 12237-0618. Telephone: (518) 474-6781. $25.00; direct purchase requests to Mr. John Cahill, (518) 474-5370.

This videotape is designed for three purposes: to illustrate the need for home-based respite care for families of chronically ill children; to describe a successful model of home based respite care in New York City which utilizes nurses and paraprofessionals as caregivers; and to demonstrate the benefits accrued to families as well as the cost effectiveness of home-based respite care. The film depicts specific activities associated with the hands-on provision of home-based respite care to three families with chronically ill children. Testimonies of the providers and participating parents are included along with footage of the children. The videotape is directed at providers, families, and advocates. [Funded by the Maternal and Child Health Bureau]

Reiss, J., Nackashi, J., and Siderits, P. ***Standards for pediatric medical respite care in Florida*** Gainesville, FL: Institute for Child Health Policy, 1990. 23 pp.
Contact: John G. Reiss, Ph.D., Institute for Child Health Policy, 5700 S.W. 34th Street, Suite 323, Gainesville, FL 32608. Telephone: (904) 392-5904 / Fax (904) 392-8822 / Email ICHP@qm.server.ufl.edu. Web site: http://www.ichp.ufl.edu. Price unknown.

This document presents standards for programs in Florida providing respite care to the families of children with complex medical problems (defined as individuals, ages 0 to 21, who have chronic diseases or conditions that generally require continuous 24-hour a day medical, nursing, and health supervision). The authors warn that these standards are not to be applied to programs providing respite care to the families of children with other types of special needs. These standards of care include a definition of terms, guidelines for personnel, facility requirements, criteria for enrollment, referral and enrollment procedures, and guidelines for in service training, quality assurance, and administration.

Salisbury, C., and Intagliata, J. ***Respite care: Support for persons with developmental disabilities and their families*** Baltimore, MD: Paul H. Brookes Publishing Company, 1986. 336 pp.
Contact: Paul H. Brookes Publishing Company, P.O. Box 10624, Baltimore, MD 21285. Telephone: (800) 638-3775 / (410) 337-9580 / Fax (410) 337-8539. $25.00.

This book is for families who require respite care for a member with a disability. It provides many answers to the most important questions about respite care and is divided into three major sections: rationale and need for respite services; issues and models for delivering respite services; and evaluating respite services.

SCHOOL ISSUES

Children's National Medical Center, Adolescent Employment Readiness Center. ***Children with special health care needs and the school system: Who should know what?*** Washington, DC: Adolescent Employment Readiness Center, Children's National Medical Center, [1995?]. 1 p.
Contact: Vincent Schuyler, Program Coordinator, Adolescent Employment Readiness Center, Children's National Medical Center, 111 Michigan Avenue, N.W., Suite 1300, Washington, DC 20010-2970. Telephone: (202) 884-3203 / Fax (202) 884-3385. Available at no charge.

This fact sheet provides a checklist of school personnel and disclosure information that a parent or student with chronic health conditions may need to make known to the appropriate school official. [Funded by the Maternal and Child Health Bureau]

David and Lucile Packard Foundation, Center for the Future of Children. ***Special education for students with disabilities*** Los Altos, CA: Center for the Future of Children, David and Lucile Packard Foundation, 1996. 173 pp., exec. summ. (7 pp.). (The future of children; v. 6, no. 1, Spring 1996)

Contact: Circulation Department, Center for the Future of Children, David and Lucille Packard Foundation, 300 Second Street, Suite 102, Los Altos, CA 94022. Telephone: (415) 948-3696 / Email Web site: http://www.futureofchildren.org. Available at no charge.

This report discusses the following topics related to special education for students with disabilities: key issues, legislative and litigation history of special education, identification and assessment of students, learning disabilities, placement as the critical factor in the effectiveness of special education, transition from high school to work or college, financing special education, statistics, and selected federal programs serving children with disabilities.

National Information Center for Children and Youth with Disabilities. ***Planning for inclusion*** NICHCY News Digest. 5(1): 1-31. July 1995.
Contact: National Information Center for Children and Youth with Disabilities, P.O. Box 1492, Washington, DC 20013. Telephone: (800) 695-0285 / Email nichcy@capcon.net. Available at no charge.

This special issue of the "NICHCY News Digest" gives a brief look at the range of issues related to including children with disabilities in regular school settings, then provides an annotated listing of resources available on the subject.

Richey, P., and Taylor, J. ***Partners in education: Partnership training program—Team leader manual/workshop guide. (Rev. ed.)*** Atlanta, GA: Arthritis Foundation, American Juvenile Arthritis Organization, 1991, 1995r. ca. 100 pp.
Contact: Arthritis Foundation, American Juvenile Arthritis Organization, 1314 Spring Street, N.W., Atlanta, GA 30309. Telephone: (404) 872-7100, ext. 6251 / Fax (404) 872-0057. Price unknown.

These training materials include course outlines and overhead transparency masters for use in training sessions with health care providers and parents of children with juvenile rheumatoid arthritis. This set of materials is designed to demonstrate how to become advocates for the children for appropriate care in educational systems. The introduction emphasizes the purpose and objectives and lists materials needed for the course. The outlines provide lists of materials and highlight the goals for each of nine training activities. This set of materials is one of four in the Partnership Training Program; the other sets cover the core curriculum, partners in care coordination, and partners in family support; this set also includes the relevant sections of the core curriculum. [Funded by the Maternal and Child Health Bureau]

SIBLINGS

Harris, S. L. ***Siblings of children with autism: A guide for families*** Bethesda, MD: Woodbine House, 1994. 127 pp.
Contact: Woodbine House, 6510 Bells Mill Road, Bethesda, MD 20817. Telephone: (800) 843-7323 / (301) 897-3570 / Fax (301) 897-5838. $12.95. ISBN 0-933149-71-9.

This book provides a guide for parents who have children with autism that will help them teach the child's siblings about the condition. It suggests ways to assure that siblings also get the attention they need. The book indicates methods parents can use to meet the special needs of all their children; it offers suggestions for explaining autism to children, getting children to share their thoughts and feelings, and helping them learn to play. It also covers techniques parents can use to find time for their family, their work, and themselves.

Powell, T. H., and Ogle, P. A. ***Brothers and sisters: A special part of exceptional families*** Baltimore, MD: Paul H. Brookes Publishing Company, 1985.
Contact: Paul H. Brookes Publishing Company, P.O. Box 10624, Baltimore, MD 21285. Telephone: (800) 638-3775 / (410) 337-9580 / Fax (410) 337-8539. Price unknown.

This book offers advice to parents and professionals on techniques and services that can help non-disabled siblings better understand their unique feelings and circumstances.

University of Connecticut, A. J. Pappanikou Center on Special Education and Rehabilitation, Sibling Information Network. ***Children's literature for sisters and brothers of children with special needs*** South Windsor, CT: A. J. Pappanikou Center on Special Education and Rehabilitation, University of Connecticut, 1993. 20 pp.
Contact: A.J. Pappanikou Center on Special Education and Rehabilitation, University of Connecticut, 1776 Ellington Road, South Windsor, CT 06074. Telephone: (203) 648-1205. Price unknown.

This annotated bibliography covers material appropriate for the siblings of children with special health needs. Sections include general topics, autism, cerebral palsy, emotional disturbance, epilepsy, hearing impairments, learning disabilities, mental retardation, physical disabilities, and visual impairments. A list of bibliographies of children's material on the subject is also provided. The suggested grade level for potential readers of each item is noted.

University of Connecticut, A. J. Pappanikou Center on Special Education and Rehabilitation, Sibling Information Network. ***Sibling information network newsletter*** South Windsor, CT: A.J. Pappanikou Center on Special Education and Rehabilitation, University of Connecticut, 1992-. quarterly.
Contact: Lisa Glidden, A.J. Pappanikou Center on Special Education and Rehabilitation, University of Connecticut, 1776 Ellington Road, South Windsor, CT 06074. Telephone: (203) 648-1205. $7.00, individuals; $15.00, organizations.

This quarterly newsletter contains manuscripts; announcements and information for, about, and by siblings of persons with disabilities, and other issues related to families of persons with disabilities.

TRANSITION

Krajicek, M., and Tompkins, R. (Eds.). ***The medically fragile infant*** Austin, TX: PRO-ED, 1993. 162 pp.
Contact: PRO-ED, 8700 Shoal Creek Boulevard, Austin, TX 78757-6897. Telephone: (512) 451-3246 / (512) 451-8542. $34.00.

This collection of papers reviews, for the medical community, current thinking on the care of medically fragile infants, defined as low birthweight and/or premature infants, infants who have sustained birth asphyxia, and infants with established diagnoses that are associated with a risk for developmental difficulties. The topics discussed include the neonatal intensive care unit (NICU) and early transitional care; ethical implications, family-centered care; the transition from hospital to home; chronic lung disease; continuity of care; developmental intervention at home; and enhancing family and child quality of life. There is a guide to community resources and a bibliography.

Massachusetts Department of Public Health, Bureau of Parent, Child and Adolescent Health. ***Transition from hospital to home care for children with complex medical needs: Standards and indicators for family/health care team collaboration*** Jamaica Plain, MA: Bureau of Parent, Child and Adolescent Health, Massachusetts Department of Public Health, 1993. 17 pp.
Contact: Debbie Allen, Director, Greater Boston Regional Health Office, Massachusetts Department of Public Health, 180 Morton Street, 3rd Floor, Jamaica Plain, MA 02130. Telephone: (617) 727-6941. Price unknown.

This publication provides a guide for parents, continuing care professionals, hospital and home health care teams, and other community supports to assist in providing a safe, smooth transition of the child with complex medical needs from the hospital to his or her home. It contains a set of standards and indicators that identify and describe the important phases in a child's transition from hospital to home. The essential phases discussed in this manual are first an assessment of the need for home health care; second, development of the plan to be carried out in the home; and third, implementation and evaluation of that plan.

Meck, N. E., Fowler, S., Ashworth, J. K., Bishop, M. M., Rasmussen, L. B., Thomas, M. K., O'Brien, A., and Claflin, K. S. ***A manual for using the NICU individualized transition planner: A structured process to facilitate the transition from NICU to home*** Kansas City, KS: Child Development Unit, University of Kansas Medical Center, 1993. 51 pp.
Contact: Nancy Meck, Children's Rehabilitation Unit / Kansas University Affiliated Program, The University of Kansas Medical Center, 3901 Rainbow Boulevard, Kansas City, KS 66160-7340. Telephone: (913) 588-5900. Price unknown.

This procedural manual is for parents and professionals who may be involved with the transition of a newborn from the NICU to the home and who are concerned with making this transition as smooth as possible. The manual includes worksheets along with examples of other cases; references, and a guide to using the planner. Also included is a brochure briefly describing the planner.

Ohio Department of Health, Division of Maternal and Child Health, Bureau of Early Intervention. ***Transition from hospital to home*** Columbus, OH: Bureau of Early Intervention, Ohio Department of Health, 1992. 6 pp.
Contact: Bureau of Early Intervention, Ohio Department of Health, 264 North High Street, Columbus, OH 43266. Telephone: (614) 466-3543. Price unknown.

This brochure, designed for families of infants and toddlers with special health needs, provides an overview of the transition process that occurs when their child is discharged from the hospital. It defines the term transition, describes the components of a smooth transition, explains how discharge planning is a part of the process, and lists what the written discharge plan should include. The brochure also provides an area for parents to write in their child's discharge plan and the names of the family's health care resource people.

Carlin, E. B. (Ed.). ***Transitions in care for young adults with special health needs: Proceedings of a regional conference*** Seattle, WA: Department of Pediatrics, Child Development and Mental Retardation Center, University of Washington, 1992. 119 pp.
Contact: Center on Human Development and Disability, University of Washington, Box 357920, Seattle, WA 98195-7920. Telephone: (206) 543-7701 / Fax (206) 543-5771 / Email chdd@u.washington.edu. Price unknown. NMCHC inv. code F100.

This publication summarizes the proceedings of a regional conference on transitions in care for young adults with special health needs. The purpose of this conference was to involve families, community providers, youth, and staff of the University of Washington's Adolescent Young Adult Transition Program in discussing the transition of those with special health needs from pediatric to adult health care, and to further promote transitional health care as a national issue. The proceedings include presentations by parents, educators, pediatric and adult providers of care, public health professionals, and client advocacy groups. A list of resources and conference participants is provided. [Funded by the Maternal and Child Health Bureau]

Garwick, A. E., and Millar, H. E. C. ***Promoting resilience in youth with chronic conditions and their families*** [Rockville, MD]: Maternal and Child Health Bureau, U.S. Department of Health and Human Services, 1996. 28 pp.
Contact: National Maternal and Child Health Clearinghouse, 2070 Chain Bridge Road, Suite 450, Vienna, VA 22182-2536. Telephone: (703) 356-1964 / Fax (703) 821-2098 / Email nmchc@circsol.com. Available at no charge. NMCHC inv.code I039.

This monograph addresses the impact that chronic illness and disability have on adolescents and their families and presents strategies health professionals can use to help them as they develop and gain independence. It considers how adolescents and their families are affected by these conditions; it reviews the principles of family-centered care and ways to adapt them for adolescents, and it also discusses the role of family assessment and promoting healthy family functioning. [Funded by the Maternal and Child Health Bureau]

Gilmer, D., and McElroy, M. ***Student outcomes: Studying the effectiveness of transition in Maine.*** Orono, ME: Center for Community Inclusion University Affiliated Program, University of Maine, 1993. 77 pp.
Contact: Center for Community Inclusion, University Affiliated Program, University of Maine, 5703 Alumni Hall, Orono, ME 04469-5703. Telephone: (207) 581-1084 / TDD: (207) 581-3328 / Fax (207) 581-1231. $10.00, payable to University of Maine; prepayment required.

This final report presents the major activities undertaken during a year-long student transition project, funded by the Committee on Transition in the state of Maine. The purpose of the project was to develop a follow-up and follow-along survey instrument and data management system that would enhance the capacity of local school districts in Maine to follow their own graduates in order to assess their efforts to prepare youth with disabilities for adult life and to stimulate program review and appropriate modifications. The project's findings and recommendations are examined. Copies of the phone and mail versions of the student outcomes survey are included in an appendix.

Kriegsman, K. H., Zaslow, E. L., and D'Zmura-Rechsteiner, J. ***Taking charge: Teenagers talk about life and physical difficulties.*** Rockville, MD: Woodbine House, 1992. 164 pp.
Contact: Woodbine House, 6510 Bells Mill Road, Bethesda, MD 20817. Telephone: (800) 843-7323 / (301) 897-3570 / Fax (301) 897-5838. $14.95 plus $3.50 postage and handling.

This book, written for adolescents, examines the lives of adolescents with disabilities in an easy-to-read format based on a series of interviews with young people with a variety of health problems. Its three sections examine who the adolescents are, how they relate to others, and how they can get where they want to go. Topics include coping with emotions, dating, sexuality, marriage, dealing with stares and comments of others, family and friends, independence, dependence, expectations, and assertiveness. Appendices discuss disability laws, physical accessibility, technological developments, volunteers for medical engineering, and taking charge of your body.

National Center for Youth with Disabilities. ***Transition from child to adult health care services: A national survey.*** Minneapolis, MN: National Center for Youth with Disabilities, 1996. 16 pp. (Connections)
Contact: Shari Morrison, National Center for Youth with Disabilities, University of Minnesota, Box 721 - UMHC, 420 Delaware Street, S.E., Minneapolis, MN 55455. Telephone: (612) 626-2825 / TDD: (612) 624-3939 / Fax (612) 627-4487 / Email ncyd@gold.tc.umn.edu. Available at no charge.

This report presents the results of a survey of transition services available to children and adolescents with chronic conditions or disabilities as they move from the pediatric to the adult health care system. It reviews the benefits and recent history of transition services, describes the background and methodology of the study, and provides the results of the survey. The report contains information on the professional services available; profiles available programs; and considers program planning and development, staff training, and program financing. [Funded by the Maternal and Child Health Bureau]

National Center for Youth with Disabilities. ***Transition from pediatric to adult health care for youth with disabilities and chronic illnesses.*** Minneapolis, MN: National Center for Youth with Disabilities, University of Minnesota, 1996. 26 pp. (CYDLINE reviews)
Contact: National Center for Youth with Disabilities, University of Minnesota, Box 721 - UMHC, 420 Delaware Street, S.E., Minneapolis, MN 55455. Telephone: (612) 626-2825 / TDD: (612) 624-3939 / Fax (612) 627-4487 / Email ncyd@gold.tc.umn.edu. $3.50.

This annotated bibliography provides abstracts of materials on transition issues for youth with disabilities; the information presented is for use by health care providers and planners. Topics include U.S. demographic and health services utilization data, empirical research on health outcomes, commentary and program descriptions, and health care in the United Kingdom. The bibliography also lists transition programs, with brief abstracts describing their services and available training and educational materials. The third edition of this bibliography was produced in 1991 with the same title. [Funded by the Maternal and Child Health Bureau]

National Center for Youth with Disabilities. ***Transition planning for the 21st century: A call to action*** Minneapolis, MN: National Center for Youth with Disabilities, University of Minnesota, 1995. 24 pp.
Contact: National Center for Youth with Disabilities, University of Minnesota, Box 721 - UMHC, 420 Delaware Street, S.E., Minneapolis, MN 55455. Telephone: (612) 626-2825 / TDD: (612) 624-3939 / Fax (612) 627-4487 / Email ncyd@gold.tc.umn.edu. Limited quantities available at no charge; also available from the ERIC Document Reproduction Service, 7420 Fullerton Road, Suite 110, Springfield, VA 22153-2852, telephone (800) 443-ERIC.

These proceedings summarize the work of two conferences: Transition Planning for the 21st Century (May 19, 1995) and Smoothing the Course of Transition for Adolescents with Chronic Illness and Disability (June 2, 1992). The proceedings review the purpose of the conferences, summarize the sessions, present recommendations, and list the participants. The two conferences focused on developing a vision and planning for interagency services to assure that adolescents with chronic illnesses and disabilities obtain the help they need to transition to adulthood. One of the conferences included a panel of adolescents who contributed to the formulation of the recommendations. [Funded by the Maternal and Child Health Bureau]

National Information Center for Children and Youth with Disabilities. ***Transition services in the IEP*** Washington, DC: National Information Center for Children and Youth with Disabilities, 1993. 27 pp. (NICHCY transition summary)
Contact: National Information Center for Children and Youth with Disabilities, P.O. Box 1492, Washington, DC 20013. Telephone: (800) 695-0285. Available at no charge.

This edition of the "NICHCY Transition Summary" examines the requirements of the Individuals with Disabilities Education Act regarding transition services for youth with disabilities and describes the specific areas to be addressed during transition planning. The first half of the newsletter takes a look at how transition services are defined within federal law. The second half examines recommended transition components to be included in the Individualized Educational Program (IEP) and assessment issues surrounding transition planning in the IEP.

Roberts, N., Schoeller, K., Shapland, C., Goldberg, P., and Goldberg, M. ***Living your own life: A handbook for teenagers by young people and adults with chronic illness or disabilities*** Minneapolis, MN: PACER Center, 1993. 92 pp.
Contact: PACER Center, 4826 Chicago Avenue South, Minneapolis, MN 55417. Telephone: (612) 827-2966 / Fax (612) 827-3065. $8.00, make checks payable to the Pacer Center.

This handbook provides adolescents and young adults who have chronic conditions or disabilities information on how they can make the transition to independent living; it shares the personal narratives of those who have special health needs. Topics covered include learning self assurance, dealing with feelings about health and medicine, making plans based upon an honest assessment of the special health condition, using communication skills, advocating for civil rights, responding to the need for love and affection, and pursuing opportunities in education and employment. Appendices list federal, state, and local resources that can provide assistance to adolescents, young adults, and their families. [Funded by the Maternal and Child Health Bureau]

Shapland, C., Schoeller, K., Goldberg, P., and Goldberg, M. ***Speak up for health: A handbook for parents—Preparing adolescents with chronic illness or disabilities for independence in health care*** Minneapolis, MN: Pacer Center, 1993. 95 pp.
Contact: Pacer Center, 4826 Chicago Avenue South, Minneapolis, MN 55417. Telephone: (612) 827-2966 / Fax (612) 827-3065. $10.00 each; 10 or more copies for $8.00 each; available at no charge to parents of children with disabilities in Minnesota.

This handbook for parents focuses on adolescents with special health needs as they plan the transition to adult-based health services and an independent life. The manual, written by parents and adults with chronic illness or disabilities, emphasizes the importance of preparing for independence in health care. The authors share experiences and insights gained through their struggles with transition issues. Each chapter is followed by a list of helpful hints to assist parents in guiding their adolescents to become as independent as possible in managing their health care. [Funded by the Maternal and Child Health Bureau]

Stafford, E. (Ed.). ***Independence with support: A training manual to prepare paraprofessionals in placement, job coaching and case management techniques: Draft*** Jonesboro, AR: Focus, Inc., n.d. 72 pp.
Contact: Focus, Inc., 2917 King Street, Suite C, Jonesboro, AR 72401. Telephone: (501) 935-2750.

This manual is designed to assist in training paraprofessional personnel in supportive work with adults with developmental disabilities, with the objective of assisting these adults to work in the private sector, and to enjoy the dignity and fulfillment of employment and independent community living. The manual covers training in the 3 main areas of support services, job development and placement, job coaching, and case management. The training manual is presented in a workbook format.