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Working with Families

Families are a key part of the early childhood intervention team. This month we are featuring resources about parenting, grandparenting, sibling relationships, working as a team, and DEC recommended practices.

Working with Families Books

Brothers and Sisters: A Guide for Families of Children with Epilepsy and Just for You! 1992. (203.11 P371 1992 ECI).

The first half of this book, written for parents concerned about the effect one child with epilepsy may have on other children, discusses this issue and provides tools for understanding and assisting siblings. The second half, Just for You!, is for siblings of individuals with epilepsy, and is divided into three sections which children can progress through as they grow and develop.

Brothers and Sisters: A Special Part of Exceptional Families. Thomas H. Powell, 1993. (271.6 P871 ECI).

In this book, the special bond siblings have between each other is shared through personal testimonies from the perspective of the brother or sister. They speak openly about the challenges they face having a sibling with special needs.

Brothers, Sisters, and Special Needs: Information and Activities for Helping Young Siblings of Children with Chronic Illnesses and Developmental Disabilities. Debra J. Lobato, 1990. (271.6 L111 1990 ECI).

This book is designed for professionals and parents to use to help young children, ages 3 to 8, learn more about their own personal strengths, recognize positive characteristics about their sibling with special needs, and learn ways to cope constructively with stressful family events.

Building the Healing Partnership: Parents, Professionals and Children with Chronic Illness. Elaine H. Walizer, 1992. (244.5 L521 ECI).

This book weaves together brief vignette after vignette to help readers experience the essence of caring, over time, for an ill child. By being so explicit and thorough, the authors tell the pediatric patient, family, and caretakers what to expect and give permission to experience and adapt to the full range of feelings possible when caring for a child who is ill.

Circles of Care and Understanding: Support Programs for Fathers of Children with Special Needs. James May, 1992. (271.52 M452 ECI).

This book provides creative avenues for supporting fathers and the children and families they care about.

Working with Families Books (continued)

Collaboration with Parents and Families of Children and Youth with Exceptionalities. Marvin Fine and Richard L. Simpson, 2000. (740 F495 2000 ECI).

This book contains essays by various experts and expresses the importance of educating and empowering parents and families so they can become active partners with the professional community in meeting the needs of their own children.

Collaboration: Putting the Puzzle Pieces Together. Mary Beth Bruder, 1996. (560 B888 1996 ECI).

The purpose of this manual is to highlight the important aspects of the collaborative process for early intervention.

Coping with a Physically Challenged Brother or Sister. Linda L. Ratto, 1992. (271.6 R237c 1992 ECI).

In this book, young people discuss their feelings as siblings of those who are physically disabled. The book also describes the inner pain these siblings feel, their feelings of not being understood, of being alone, and of being taken for granted.

Dad and Me in the Morning. Patricia Lakin, 1994. (805.1 L192 1994 ECI).

A boy who is deaf and his father share a special time as they watch the sunrise at the beach together.

DEC Recommended Practices in Early Intervention/Early Childhood Special Education: A Comprehensive Guide for Practical Application. Susan Sandall, 2005. (325 S213d 2005 ECI).

This book contains all the helpful information found in DEC Recommended Practices, plus real life examples and practical tips for implementation. It includes strategies for program assessment and improvement, useful checklists for parents and administrators, and an annotated list of relevant resources.

Disability Is Natural: Revolutionary Common Sense for Raising Successful Children with Disabilities.

Kathie Snow, 2001. (322 S674 2001 RHB).

This book, which promotes the idea that disability is a natural condition of the human experience, presents a new slant on attitudes about people with disabilities and aims to lead readers to a new set of actions.

The Effects of Mental Retardation, Disability, and Illness on Sibling Relationships. Zolinda Stoneman, 1993. (271.6 St71 ECI).

These articles, authored by different experts, were originally presented at a National Institute of Child Health and Human Development conference addressing topics like out-of-home placement, pediatric HIV, differential treatment, stress, coping mechanisms, and issues critical to sibling relationships. The purpose of this volume is to present research findings concerning siblings and disability and to provide a discussion of conceptual and methodological challenges in this field of study.

Essential Allies: Families as Advisors. Elizabeth Jeppson and Josie Thomas, 1995. (230 J54e 1995 ECI).

This publication was developed to help bridge the gap between providers' past training and experience and new expectations of collaboration and partnership with families.

Families as Advisors: A Training Guide for Collaboration. Elizabeth Jeppson and Josie Thomas, 1995. (230 J54f 1997 ECI).

This companion volume to "Essential Allies" and "Words of Advice" completes the series by presenting a set of integrated training activities to encourage discussion and promote creative thinking about new partnerships with families.

Families, Physicians, and Children with Special Health Needs: Collaborative Medical Education Models.

Rosalyn Darling and Margo I. Peter, 1994. (238.2 D249 ECI).

This book provides models that embody the principles and practices characterizing a family-centered system of community-based health care for families and children.

Families Speak Out: International Perspectives on Families' Experiences of Disability. Helle Mittler, 1995. (271 M537 ECI).

The core of this book is a collection of quotations from the experiences of families of persons with a mental disability, coming from a variety of cultures, religions and social groups from all the major regions of the world.

Working with Families Books (continued)

Family-Based Practices. Eva Horn, Michaelene Ostrosky, and Hazel Jones, 2004. (325 H813 2004 ECI).

The articles in this monograph discuss values, beliefs, and practices found in the DEC Recommended Practices by describing specific strategies that will assist practitioners to collaborate with families in achieving the various components of the recommended practices.

Family-Centered Assessment and Intervention in Pediatric Rehabilitation. Mary Law, 1998. (520 L415 1998 ECI).

This book contains several articles written by different specialists all dealing with assessment and intervention in pediatric rehabilitation by a family-centered provider. The articles are written both from the parents' and the providers' point of view.

Fathers of Children with Special Needs: New Horizons. James May, 1991. (271.52 M451 ECI).

This book presents the complex role of being the father of a child with a disability. Many fathers share their experiences in this book.

Fathers: A Common Ground. Paul Schmitt and Fernanda Armenta-Schmitt, 1999. (271.52 S355 1999 ECI).

This book is for fathers of young children who are blind or visually impaired. It emphasizes how important the father is to his family and the impact fathers have on the growth and adaptation of the family.

Getting Men Involved: Strategies for Early Childhood Programs. James A. Levine, Dennis T. Murphy, and Sherrill Wilson. (271.52 L579 ECI).

This book is designed to offer the reader a systematic way of thinking about and approaching male involvement in early childhood programs.

Grandparenting with Love And Logic: Practical Solutions to Today's Grandparenting Challenges. Jim Fay, Foster W. Cline, and Carol Von Klombenburg, 1994. (271.53 F282 1994 ECI).

Sensible, practical solutions based on the Love and Logic philosophy are offered in this book to overcome a variety of challenges that grandparents may face with their grandchildren and adult children.

Grandparents As Parents: A Survival Guide for Raising a Second Family. Sylvie de Toledo and Deborah Edler Brown, 1995. (271.53 T649 1995 ECI).

This guide for grandparents who are raising their grandchildren can also be utilized by those who serve them, such as social service personnel, family therapists, legal professionals, and other groups who work cross-generationally with families to help them stay whole.

Interdisciplinary Teams. Eva Horn and Hazel Jones, 2005. (325 H813i 2005 ECI).

This book describes specific strategies that will assist practitioners to collaborate with families in achieving the various components of the DEC Recommended Practices for early childhood special education.

It Isn't Fair! Siblings of Children with Disabilities. Stanley D. Klein, 1993. (271.6 K674 ECI).

In this book, typically developing brothers and sisters share their feelings and experiences of the various stages when they had to deal with caretaking, frustration, powerlessness, jealousy, guilt, and concern about their sibling with special needs.

Living with a Brother or Sister with Special Needs: A Book for Sibs. Donald J. Meyer, 1985. (271.6 M576 1985 ECI).

This comprehensive book is written just for brothers and sisters. It deals with sensitive topics in a realistic way by utilizing the experiences of many siblings with whom the authors have worked. Throughout this well-researched book, the authors present vignettes and quotes from siblings who discuss their concerns and needs.

Meeting the Challenge of Disability or Chronic Illness: A Family Guide. Lori A. Goldfarb, Mary Jane Brotherson, and Jean Ann Summers, 1986. (215 G566 ECI).

This book explores the sensitive subject of family stress brought on by chronic, disabling illness and offers realistic hope and encouragement to families who face these daily challenges.

Working with Families Books (continued)

My Sister Annie. Bill Dodds, 1993. (805.2 D661 ECI).

Growing up, trying to be accepted, and having a sister with Down syndrome make life a challenge for young Charlie.

Raising Our Children's Children. Deborah Doucette-Dudman, 1996. (271.53 D728 1996 ECI).

This book discusses the challenges, hardships, and rewards faced by grandparents parenting their grandchildren with stories from families who have had these experiences.

Redefining Family Support: Innovations in Public-Private Partnerships. George H. S. Singer, Laurie E. Powers, and Ardis L. Olson, 1996. (102 S617 1996 ECI).

This book, written by leading researchers and advocates working with people with disabilities, outlines creative and versatile programs and funding options for addressing the diverse needs of families.

Siblings of Children with Autism: A Guide for Families. Sandra L. Harris and Beth A. Glasberg, 2003. (203.6 H316 2003 ECI).

This second edition presents an in-depth description of what it's like to grow up as a sibling of a child with autism. This book helps parents see autism through the eyes of their other children, how to explain autism to the siblings, and how to help siblings share their feelings.

Sibshops: Workshops for Siblings of Children with Special Needs. Donald J. Meyer and Patricia F. Vadasy, 1994. (271.6 M575 1994 ECI).

This manual details how to set up and hold a "Sibshop" where brothers and sisters of children with special needs are provided an opportunity to meet other siblings in a relaxed, recreational setting to share their feelings and to learn about themselves and others in similar situations.

Sisters, Brothers, and Disability: A Family Album. Lydia Gans, 1997. (271.6 G158 ECI).

This book depicts twenty-six families raising children with special needs with an emphasis on the interactions with other siblings. Many photos are included.

Special Siblings: Growing Up with Someone with a Disability. Mary McHugh, 2003. (271.6 M151 2003 ECI).

The author, who grew up with a brother who has cerebral palsy and mental retardation, shares her lifetime of memories and reflections, relevant research, and interviews with hundreds of other siblings and experts. This book helps others understand the issues faced by these siblings.

Straight from the Siblings: Another Look at the Rainbow. Gloria Murray, 1982. (271.6 M961 1982 ECI).

In this book, a group of thirty-four children share their experiences of having brothers and sisters who are terminally ill. Reading about these experiences will help other siblings understand that they are not the only ones who have these problems and will help them discover ways to handle their emotions.

Uncommon Fathers: Reflections on Raising a Child with a Disability. Donald J. Meyer, 1995. (271.52 M575 ECI).

This book presents fathers of children with disabilities sharing their personal experiences.

Views From Our Shoes: Growing Up with a Brother or Sister with Special Needs. Donald J. Meyer, 1997. (271.6 M612 1997 ECI).

This book contains essays from 45 children ranging in age from four to eighteen who are the siblings of children with a variety of special needs. It presents their personal stories which introduce young siblings to others like themselves and allow them to compare experiences.

When Snow Turns to Rain: One Family's Struggle to Solve the Riddle of Autism. Craig B. Schulze, 1993. (800.1 Sch85 1993 ECI).

This book is a father's moving account of his family's experience with autism, his son's perplexing disability. The author tells his personal struggle to accept and understand the reality of his son's disability, and his determination to help his son through treatment and educational programs.

Working with Families Books (continued)

Words of Advice: A Guidebook for Families Serving as Advisors. Josie Thomas and Elizabeth Jeppson, 1997. (230 J54w 1997 ECI).

This workbook is for the person who has never served in an advisory role. It offers guidance for thinking through the benefits and demands of advisory roles for consumers, presents some fundamental principles for being a successful advisor, and suggests practical tips for dealing with the common challenges that families encounter in these new roles.

Working with Families Videos

Being a Kid. 6 min. (320.64 J59).

This video illustrates the trend toward providing intervention for young children in everyday activities and places, known as "natural environments." The video shows a therapist and family working collaboratively to integrate functional goals into everyday routines, and includes comments by both the therapist and parent.

Extended Family Members. 30 min. (271Z32).

This video helps parents and extended family understand the impact a child with a disability has on them; the needs of the extended family in dealing with the immediate family and the child with a developmental disability; how to support an extended family member in dealing with his/her role; and what outside resources are available to extended family members.

Fathers. 30 min. (271.52 Z29).

Becoming a father is a dramatic transition for many men. It requires a significant change in lifestyle, affecting relationships at home, at work, and with friends. For most men, the transition is eased by the joy of having a child. When parents learn that their transition into parenthood will be complicated by the birth of a child who has a developmental disability, their reactions may differ greatly. This video helps parents understand the dynamics of the father's role, the needs of fathers of a child with a disability, and the availability of outside resources.

Good Grief. 40 min. (285K416).

This video focuses on the grieving process associated with parenting a child with disabilities. Ken Moses, a psychologist and the father of a child with a disability, explores how the process helps parents make changes necessary to live with their child and how real life is quite different from what was anticipated.

Having a Disabled Brother or Sister. 30 min. (271.6 Z31).

Siblings of individuals with disabilities often have a hard time getting the attention they want because of the family's focus on the child with a disability. This video will help the sibling understand how life may be different because of having a sibling with a disability; feelings about that sibling; how to cope with difficult situations; and resources that will provide additional support and information.

Perilous Passage: New Zealand Fathers Talk About Their Children with Disabilities. 27 min. (VT0234).

The stories of five New Zealand fathers presented in this program are of very ordinary men, forced by circumstances, to view their lives as fathers in new and extraordinary ways. Each wanted to share with others their experiences of new lives centered around fearless advocacy for their children.

Nuestros Abuelos Enriquecimiento Familiar. 30 min. (271.53 F819).

This video, hosted in Spanish by Don Francisco, provides ideas for making the most out of the grandparent relationship.

Promoting Family Collaboration. 24 min. (200.8 F487pf 1998).

This program presents how doctors and staff can actively encourage parents' participation in the care of their hospitalized child, recognize the parent as the child's advocate, and answer the parents' concerns about their child's situation.

Working with Families Videos (continued)

Siblings. 30 min. (271.6 Z29).

This video introduces the viewer to parents and siblings of children with developmental disabilities. It helps parents understand the dynamics of a family that has a child who is developmentally disabled; the needs of siblings of a child with developmental disabilities; how to support a sibling in dealing with the realities of the disability; and what outside resources are available to parents and siblings.

Skills for Special Sibs: Living with Your Handicapped Brother or Sister. 13 min. (VT0235).

The impact of the presence of a child with a disability on other siblings is the focus of this video and the accompanying manuals. Research indicates that the siblings of children with chronic conditions may be at high risk for emotional and behavioral problems. These materials were designed to help teachers, parents, and professionals attend to the "neglected" brother or sister.

Special Kids, Special Dads: Fathers of Children with Disabilities. 23 min. (271.52 M419).

Three families share their experiences raising children with disabilities. The couples talk about their personal relationships with each other and their frustrations trying to cope daily with their lives.

Surrounded with Love: Grandparents Raising Grandchildren. 22 min. (271.53 B742).

In this video about grandparents raising their own grandchildren, three grandmothers share their personal story of how and why they are raising their grandchildren.

To Be a Father. 29 min. (271.52 R758).

This video, hosted by Ray Romano, presents information about the importance of being a father, and what fathers can do to help promote and participate in their young children's healthy development.

What About Me? Brothers and Sisters of Children with Disabilities (closed captioned). 30 min. (VT0237).

What are some of the thoughts, issues, and feelings you have when you live with a brother or sister who is disabled? This video looks at two young teens with siblings with a disability, and at the adjustments that they have had to make.

Working with Families Web Sites

Parenting in general:

MedlinePlus - Parenting: This website gathers links to reliable, full-text information about current issues in parenting: <http://www.nlm.nih.gov/medlineplus/parenting.html>

Parenting children with special needs:

Children's Disabilities Information: This website by parents of a child with special needs compiles information and advice from other parents and professionals who work with children with special needs: <http://www.childrensdisabilities.info/>

Texas Parent to Parent: This website was created by parents for families of children with disabilities, chronic illnesses, and other special needs throughout Texas. <http://www.main.org/txp2p/index.html>

For or about fathers:

Fathers Network: This is a website to celebrate and support fathers who have children with special health care needs or developmental disabilities: <http://www.fathersnetwork.org/>

LDOnline: At this website, you will find a short article that describes how to maximize involvement of fathers with their children with disabilities: http://www.ldonline.org/ld_indepth/teaching_techniques/father_involvement.html

For grandparents:

Grandspace: This website is for grandparents and "special others" caring for children. They state their mission is hoping to provide a safe and accepting environment where caregivers can join together and give each other the support and comfort they need. What they lend is a caring, knowing, and sympathetic ear because they have been there or are there. <http://www.grandspace.com/>

AARP grandparents site: Current advice on parenting, health tips, taking care of oneself and more is given for grandparents, especially those who are now caring for their grandchildren. One page provides simple descriptions of common disabilities. <http://www.aarp.org/families/grandparents/>

Parent Advocacy Coalition for Educational Rights: Grandparent-to-Grandparent. This website is specifically for grandparents who have grandchildren with disabilities. Although based in Minnesota, there are links to national organizations. <http://www.pacer.org/parent/grand.htm>

For siblings:

Family Village Library: This website has gathered together many links to great information for siblings of children with disabilities. For example, it includes a link to a special listserv just for siblings and much more. http://www.familyvillage.wisc.edu/general/frc_sibl.htm

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