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February 2007



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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.*

*Check out the new additions to the collection on page 9!*

## Working with Families - Books

**NEW! Beyond the Autism Diagnosis: A Professional's Guide to Helping Families.** Marion O'Brien and Julie A. Daggett, 2006. (203.6 O13b 2006 ECI).

This book will help professionals improve the assessment and intervention process, communicate accurately and sensitively, avoid misunderstandings, assist families in choosing and evaluating intervention services and help families manage short- and long-term issues.

**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).

Brothers and sisters speak openly about the challenges and rewards of 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.

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## Working with Families - Books (continued)

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

This book weaves together brief vignettes to help readers experience the essence of caring for an ill child. By being explicit and thorough, the authors tell the pediatric patient, family, and caretakers what to expect when caring for an ill child.

**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.

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

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

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

This book, which contains essays by various experts, 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.

**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 children with physical disabilities. Siblings discuss their feelings of not being understood, of being alone, and of being taken for granted.

**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 the 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 promotes the idea that disability is a natural condition of the human experience.

**Down Syndrome: Birth to Adulthood Giving Families an Edge.** John E. Rynders and J. Margaret Horrobin, 1996. (226.11 R995 1996).

The authors share photographs and real life case studies of families from the EDGE Project at the University of Minnesota to guide parents of children with Down syndrome.

**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.

**The Essential Grandparent: A Guide to Making a Difference.** Lillian Carson, 1996. (271.53 C321 1996 ECI).

In this book, the author describes the joys and dreams of grandparents while dispelling the myths surrounding grandparenting and addressing serious concerns.

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## Working with Families - Books (continued)

**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 accounts of 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.

**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).

The complex role of the father of a disabled child is examined. 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, written for fathers of young children who are blind or visually impaired, 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, 1993. (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 Klombenbug, 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.

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## Working with Families - Books (continued)

**In the Shadow of Illness: Parents and Siblings of the Chronically Ill Child.** Myra Bluebond-Langner, 1996. (271.6 B658i 1996).

This book illuminates the lives of those who live in the shadow of chronic illness, the parents and well siblings of children who have cystic fibrosis (CF). The author discusses the condition and coping strategies, by redefining normal family life to include CF care and reassessing family priorities.

**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, brothers and sisters who are typically developing 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.

**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, 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).

In this book 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 to help others understand the issues faced by these siblings.

**Uncommon Fathers: Reflections on Raising a Child with a Disability.** Donald J. Meyer, 1995. (271.52 M575 ECI). Fathers of children with disabilities share their personal experiences.

**Understanding Families: Approaches to Diversity, Disability and Risk.** Marci J. Hanson and Eleanor W. Lynch, 2004. (271 H249 2004 ECI).

This book, which is written for early interventionists, service providers, and educators, presents the combined research on families and family-centered services with practical information needed to be able to work respectfully with families of every type, especially those whose young children are at risk or have disabilities.

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## Working with Families - Books (continued)

**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).

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

**Wonderful Ways to Love A Grandchild.** Judy Ford, 1997. (271.53 F699 1997 ECI).

This book presents ways grandparents can actively participate in the lives of their grandchildren.

**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 - Children's Books

**NEW! The Best Worst Brother.** Stephanie Stuve-Bodeen and Charlotte Fremaux, 2005. (805.1 S937b 2005 ECI).

Older sister Emma tries to be patient while teaching three-year-old Isaac, who has Down syndrome, how to communicate using sign language. The book includes questions and answers about sign language.

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

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

**NEW! Keisha's Doors / Las Puertas de Keisha.** Marvie Ellis, 2005. (805.1 E47k 2005 ECI).

An older sister can't understand why her little sister, Keisha, won't play with her. The family finds out that Keisha has autism and goes to see a therapist to understand what autism means to them.

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

This book presents the story of growing up, trying to be accepted, and having a sister with Down syndrome which makes life a challenge for Charlie.

**NEW! Oh, Brother!: Growing Up with a Special Needs Sibling.** Natalie Hale and Kate Sternberg, 2004. (805.1 H163 2004 ECI)

An eleven-year-old girl finds ways to handle the unique challenges presented by her thirteen-year-old brother who has special needs by looking for his good qualities and taking the rest in stride.

**Robert Lives With His Grandparents.** Martha W. Hickman, 1995. (805.1 H628 1995 ECI).

In this illustrated children's story, Robert is embarrassed to admit to his classmates that he has lived with his grandparents ever since his parents' divorce.

**NEW! Tacos Anyone?: An Autism Story.** Marvie Ellis, 2005. (805.1 E47t 2005 ECI).

Michael is a four year old boy with autism. His older brother, Thomas, doesn't understand why Michael behaves the way he does. The service provider teaches Thomas how to play with Michael, making sibling time fun again.

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## Working with Families - Videos

### **Being a Kid.** 6 min. (VT1836).

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

### **Extended Family Members.** 30 min. (VT1728).

This video will help 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. (VT1755).

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. (VT1798).

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 a child and how real life is quite different from what was anticipated.

### **Having a Disabled Brother or Sister.** 30 min. (VT1817).

Siblings of children with a disability 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.

### **Nuestros Abuelos Enriquecimiento Familiar.** 30 min. (VT1757).

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

### **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.

### **Promoting Family Collaboration.** 24 min. (VT1175).

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.

### **Siblings.** 30 min. (VT1760).

This video introduces the viewer to parents and siblings of children with developmental disabilities. It will help parents understand the dynamics of a family that has a developmentally disabled child; 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.

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## Working with Families - Videos (continued)

**Special Kids, Special Dads: Fathers of Children with Disabilities.** 23 min. (VT1753).

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. ( VT1756).

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. (DD0029).

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.** 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 who are disabled, and at the adjustments that they have had to make.

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## Working with Families - Selected Websites

### *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.txp2p.org/>

### *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/article/5935>

### *For grandparents:*

**Grandsplace:** 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.grandsplace.org/>

**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. <http://www.aarp.org/families/grandparents/>

One section provides advice for dealing with grandchildren with special needs and includes simple descriptions of common disabilities. See [http://www.aarp.org/families/grandparents/focus\\_child/a2004-12-20-grandparents-special-needs.html](http://www.aarp.org/families/grandparents/focus_child/a2004-12-20-grandparents-special-needs.html)

**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](http://www.familyvillage.wisc.edu/general/frc_sibl.htm)



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## New Additions - Videos

**Just Being Kids.** 50 min. 2001 (DD0077-New in DVD)

This DVD demonstrates how effective supports and services for infants and toddlers with special needs can be when provided in the home. Each of the six stories in this program demonstrates best practices as a therapist or early childhood specialist works collaboratively with a family to achieve meaningful goals for their child in everyday routines, activities, and places.

**Relationship Based Intervention.** 180 min. 2006 (DD0069)

This three part presentation is designed for anyone who works with young children with autism spectrum disorders (ASD). The information presented by Rebecca Klaw is based on her own experience in the field as well as the work of Dr. Stanley Greenspan, Dr. Richard Solomon and Susan Sonders. She also incorporates current research into her training program. Clinical techniques are illustrated with interesting and informative video clips. This item consists of 2 DVDs and 1 CD-ROM.

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Early Childhood Report - January 2007

# Early CHILDHOOD Report

Children With Special Needs & Their Families

VOLUME 18, ISSUE 1

JANUARY 2007

## LEGAL SPOTLIGHT

### YOU BE THE JUDGE

Do injuries at hands of schoolmates entitle this child with autism to compensatory ed? **Page 2**

## WASHINGTON WATCH

Learn about a new autism law allotting more than \$900 million toward research; see what's in store for Head Start reauthorization; and find out how you can nominate a colleague for a national award. **Page 3**

## JUDICIAL DECISION

Find out why parent's removal as classroom aide stems from growing hostility. **Page 10**

### Decisions & Guidance

Learn why preschoolers' eligibility for services shows teacher's referrals were OK; see why district's plan for diabetes training moots 504 claim for related services; determine how North Carolina's 60-day limitations period blocks parents' challenge; find out why extensive ABA is inappropriate for gifted kindergartner with autism; and read why district fails in evaluation process by not addressing written expression. **Pages 10-12**

## COVER STORY

### Gear up for landmark changes in proposed IDEA Part C regulations

The **Education Department** had planned to send the proposed IDEA Part C regulations to the **Office of Management and Budget** by the end of 2006, but OMB Deputy Press Secretary **Andrea Wuebker** said the regulations have yet to be received. The delay has only stoked the anticipation of early childhood experts for the release of the amendments, which are the first to IDEA Part C since 1993. Experts have a laundry list of items they would like to see clarified in the regulations, including language on Part C to Part B transitions and evaluation and service delivery for maltreated children. **See full coverage, pages 4-5.**

### Great expectations

See what policy makers plan to address in the proposed IDEA Part C regulations, including mediation and Part C to Part B transition. **Pages 4-5.**

## HIGHLIGHTS

### See how to improve the motor skills of kids with autism

Find out ways to improve the motor skills and overall sensory processing abilities of young children with autism so they can fully participate in learning activities with their peers. Also learn why you should ask parents about observations at home. **Page 6**

### Learn why you should consider parents' cultural values

See why you should take into account parents' cultural beliefs before discussing the special education of young children with special needs. **Page 7**

### Determine how to boost timely IEP implementation

Learn why your district should strive to implement young children's IEPs as quickly as possible to ensure they don't miss out on any interventions. **Page 8**

### Find out why you should connect service providers

Discover how you can bring diverse service providers together to serve infants with multiple disabilities more efficiently. Also learn how you can enlist parents' help in developing a communication bridge. **Page 9**

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Infant Mental Health Journal - January/February 2007

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# INFANT MENTAL HEALTH JOURNAL

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