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# ECI LIBRARY MATTERS

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December 2005

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*Featuring resources on cerebral palsy, cleft palate, cystic fibrosis, fetal alcohol syndrome, Fragile X, sickle cell disease, and spina bifida*

## Cerebral Palsy - Books

**Caring for Children with Cerebral Palsy: A Team Approach.** John P. Dormans, 1998. (203.21 D736 ECI).

This book describes the collaborative approach used to provide care for children with cerebral palsy by a team of pediatricians, orthopedic surgeons, physical and occupational therapists, speech-language pathologists, social workers, and educators. The book offers information on the diagnosis, treatment, and support of these children within the context of team-based caregiving.

**Cerebral Palsy: A Complete Guide for Caregiving.** Freeman Miller and Steven Bachrach, 1995. (203.21 M614 ECI).

This book, which is aimed at family members and health care professionals, addresses the complexities and uncertainties of cerebral palsy while providing information about everything that anyone might ever need to know about the condition.

**Developmental Disabilities in Infancy and Childhood: Volume II: The Spectrum of Developmental Disabilities.** Arnold J. Capute and Pasquale J. Accardo, 1996. (226.5 C255 1996 ECI).

This book covers the continuum of motor disorders and disorders of higher cortical function, cerebral palsy, the spectrum of motor dysfunction, mental retardation, the spectrum of language and communication disorders, the spectrum of disorders of learning and attention, and associated deficits.

**Developmental Visual Dysfunction: Models for Assessment and Management.** Rhoda Priest Erhardt, 1990. (219.1 Er35 ECI).

Three case studies of children with moderate, mild and severe cerebral palsy are presented. This book also provides practical strategies for assessment of children with multiple disabilities. The inclusion of the *Erhardt Developmental Vision Assessment* allows professionals to identify the presence or absence of certain skills so that they may determine appropriate goals in the management of developmental visual impairments.

**Expect the Unexpected: My Dreams and How I Got There.** Larry P. Espling, 1998. (800.1 E77 1998).

Mr. Espling, a man with cerebral palsy, shares his life story. He recounts experiences from his childhood in New Sweden, Maine and his adulthood in Boston, Massachusetts. He also provides readers with cerebral palsy with specific strategies for living life to the fullest extent possible.

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## Cerebral Palsy - Books (continued)

**From Where I Sit: Making My Way with Cerebral Palsy.** Shelley Nixon, 1999. (800.1 N736 1999).

In this autobiography, the young author tells of the obstacles she has overcome to lead her life on her own terms.

**The Question of David: A Disabled Mother's Journey Through Adoption, Family, and Life.** Denise S. Jacobson, 1999.(800.1 J17 1999).

The author, who has cerebral palsy, writes about her life as wife, mother and activist for the rights of individuals with disabilities. This book is about the universal challenge and courage to demand and gain the rights that all human beings deserve.

## Cerebral Palsy - Videos

**Cerebral Palsy: What Every Parent Should Know.** 19 minutes. (203.21 F487 1991).

This video explores the causes, symptoms, and possible interventions for cerebral palsy, including the relationship between physical and cognitive impairments, and the role of medications and physical therapy. Animation illustrates the area of the brain affected by cerebral palsy. Selective posterior rhizotomy surgery is examined.

**A Day at a Time.** 58 minutes. (VC5339).

The film makers follow a family with four children, including a set of twins with cerebral palsy. They show how the love of the family has turned a difficult situation into an affirmation of life. The challenges of parenting children with special needs are documented.

**The Flowering of a Child with Disabilities: Micah's Story.** 58 minutes. (800.1 T245 1998).

This video, produced and filmed by Micah's father, shows the daily activities and adventures of Micah and his family. It also documents how inclusion in an elementary school has helped Micah and his classmates.

**If I Can't Do it.** 57 minutes. (800.1 B782).

This is the story of Arthur Campbell who developed cerebral palsy as a result of a difficult birth. Campbell grew up in poverty in the hills of Kentucky with a dysfunctional family, but in spite of his disability and the environment in which he was reared, he grew up to seek independence and to work as an advocate for people with disabilities. This contains frank, although not explicit, discussion and language.

**King Gimp.** 50 minutes. (800.1 K38 2002).

This is a documentary portrait of an artist with cerebral palsy. The film makers document thirteen years in the life of Dan Keplinger as he graduates, progresses in his education and develops his artistic talents.

**Movin' On.** 24 minutes. (322.1 M869).

This video documents the educational and professional accomplishments of six people with disabilities who have overcome challenges to succeed. The stories are framed by the music of John Mellencamp, Indiana's own star who was a patient at the Riley Hospital for Children. The video profiles people who have cerebral palsy, hearing and visual impairments, spina bifida and post-polio syndrome.

**Normal Hand Development, Birth to 15 Months.** 34 minutes. (VT0080).

Infants with cerebral palsy show differences in motor development when compared to their typically developing peers. This video discusses and shows typical hand motor development. The accompanying assessment tool, *Erhardt Developmental Prehension Assessment*, allows the viewer to follow along.

**Normal Visual Development, Birth to Six Months.** 30 minutes. (VT0106).

Rhoda Erhardt describes what is typical in the visual development of infants up to age six months. She shows infants as they are assessed with lights, movements, sounds, and touch. An assessment instrument (EDVA) accompanies the video. Viewers can refer to the Erhardt book, *Developmental Visual Dysfunction: Models for Assessment & Management*, for additional information.

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## Cerebral Palsy - Videos (continued)

**Same Walk, Different Streets.** 30 minutes. (322.1 J546).

Geri Jewell uses humor to explain cerebral palsy and other disabilities to a live audience. She talks about the ADA, service dogs, and “handicaps” people with disabilities face.

**Triumph Over Odds: The Story of David Ring.** 53 minutes. (780R472).

David Ring was born with cerebral palsy in 1953. After being orphaned at an early age, he was cast about from family to family. Life seemed hopeless to him until events in his life caused him to learn to love himself just the way he was.

## Cerebral Palsy - Children's Books

**Can't You Be Still?** Sarah Yates, 1992. (805.1 Y34c 1992).

This is the story of a little girl with cerebral palsy and her experiences in preschool. Ann doesn't fit in with her classmates until she becomes a heroine through helping others in a swimming pool.

**Nobody Knows!** Sarah Yates, 1994. (805.1 Y34n 1994).

This is the second book in a series about Ann, a little girl of six with cerebral palsy. Ann and her friend Jay, who is disguised as a clown, go to the park to see animals and eat their picnic lunch without asking her Mom's permission.

## Cerebral Palsy - Websites

**United Cerebral Palsy:** <http://www.ucp.org/>

**MedlinePlus:** <http://www.nlm.nih.gov/medlineplus/cerebralpalsy.html>

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## Cleft Palate - Books

**Cleft Palate Speech Management: A Multidisciplinary Approach.** Robert J. Shprintzen and Janusz Bardach, 1995. (201.2 Sh82 ECI).

This book, meant to be used in the clinical setting, discusses what the clinician should do when treating a patient with a communicative impairment related to clefting. Several new concepts are presented, several tried and true procedures are discussed, and some widely accepted procedures are challenged.

**Cleft Palate: Interdisciplinary Issues and Treatment.** Karlind T. Moller and Clark D. Starr, 1993. (201.2 M726c 1993 RHB).

This textbook provides direct instruction and practical knowledge to speech pathologists for helping patients with clefts. Information from multiple disciplines is presented.

**Communicative Disorders Related to Cleft Lip and Palate.** Kenneth R. Bzoch, 1997. (201.2 B863 1997 ECI).

This textbook presents research on the general and diagnostic aspects of cleft palate along with information about early preventive and later rehabilitative speech therapy. Contributors include speech pathologists, surgeons, physicians, dental specialists and scientists.

**A Curriculum for Infants and Toddlers with Cleft Palate: Developing Speech and Language.** Bonnie Brookshire, Donna Fox, and Joan I. Lynch, 1993. (201.2 L987 1993 ECI).

This is a curriculum suggested to be used weekly or biweekly in close cooperation with a child's parents or caregiver. The material is divided into five sections: curriculum, determining entry levels and progress, essentials for interaction, and information for parents.

**Don't Despair Cleft Repair.** Karen S. Lipman and Rick Lipman, 1996. (800.1 L764 1996).

The authors present basic information about cleft lip and palate and photos to document their son's progress through the reconstructive surgery.

**A Parent's Guide to Cleft Lip and Palate.** Karlind T. Moller, Clark D. Starr, and Sylvia A. Johnson, 1990. (201.2 G678 ECI).

This book provides information about the medical, dental, speech, hearing, and psychological concerns of those with a cleft lip or palate. Methods of treatment are detailed along with the benefits of a team approach to treatment.

## Cleft Palate - Videos

**Face First.** 29 minutes. (800.1 G889).

This video looks at the social isolation four individuals, each with a facial birth defect, felt as children. Their stark anecdotes about the pain of corrective procedures, coupled with the sting of ridicule and rejection, reflect the reality faced by many who are seen as different.

**Giving Your Child a Smile.** 22 minutes. (VC5317).

This video provides parents of a baby with cleft lip and palate with the information needed to make decisions about their child's future. Medical illustrations and computer graphics are interwoven with expert narration to reassure parents that cleft lip and palate are correctable and that medical interventions can help give their child a better life.

**The Special Touch Babies Need: Caring for the Infant with Cleft Lip/Palate.** 16 minutes. (VC7180).

This video is intended for parents of babies born with a cleft lip or cleft palate and health clinicians involved in the care of these infants. It gives practical and crucial information for helping parents adjust to their special needs situation. It also shows the importance of breastfeeding the baby and instructions on providing breastmilk to the baby before and after surgery. Help and information for bottle-feeding are included.

**Syndromes Associated with Multiple Congenital Anomalies.** 116 minutes. (VC7255).

This video presents an overview of congenital disabilities with examples of individuals at different ages. It includes descriptions and examples of 23 syndromes, associations and sequences, including cleft palate, Down syndrome, neurofibromatosis, Marfan's syndrome, and fetal alcohol syndrome.

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## Cleft Palate - Websites

**Cleft Palate Foundation:** <http://www.cleftline.org/welcome/>

**MedlinePlus:** <http://www.nlm.nih.gov/medlineplus/cleftlipandpalate.html>

## Cystic Fibrosis - Books

**Alex: The Life of a Child.** Frank Deford, 1983. (800.1 D362).

This is a biography of an eight year old girl with cystic fibrosis as told by her father.

**Cystic Fibrosis: A Guide for Patient and Family.** David M. Orenstein, 1997. (208.4 O66 1997).

This book presents clear explanations and practical advice on cystic fibrosis and its management.

**An Introduction to Cystic Fibrosis for Patients and Families.** James C. Cunningham and Lynn M. Tausig, 1991. (208.4 C993 ECI).

This book provides a basic understanding of cystic fibrosis (CF), how it is treated, corrects common misconceptions about CF, and identifies sources of information and support for the family.

**Understanding Cystic Fibrosis.** Karen Hopkin, 1998. (208.4 H793 1998 RHB).

This book charts the progress that has been made since the discovery of the CF gene in identifying the mutations that cause CF and in understanding how these genetic anomalies cause a disease whose symptoms can range from mild respiratory distress to life-threatening lung infections.

## Cystic Fibrosis - Videos

**Breathing.** 20 minutes. (208F486).

This program begins by looking at a typical day in the life of a young girl with cystic fibrosis. The structure and function of the lungs are seen through a combination of computer graphics and video. The program also provides an introduction to the lungs and associated topics; causes and symptoms of cystic fibrosis; and genetic diseases and gene therapy.

**Diagnosing and Treating Cystic Fibrosis.** 21 minutes. (VT 1314).

This video examines the presentation, diagnostic testing, treatment, and biochemistry of cystic fibrosis.

**Jeremy Bishop Explains CF.** 17 minutes. (VC6000).

This video dramatizes a day in the life of a 10-year-old boy with cystic fibrosis by chronicling his difficulties with his therapeutic regimen and the concerns his CF raises among his peers. The boy is shown the inside of the body of a child with CF via computer animation. Once he understands why the bodies of persons with CF are different, the boy changes his behavior and becomes more compliant, which resolves many of his problems.

**Living with Cystic Fibrosis.** 25 minutes. (VT 1315).

Patients, healthcare professionals and scientists answer the commonly asked questions about cystic fibrosis and provide an in-depth look at a unique way of life.

## Cystic Fibrosis - Websites

**Cystic Fibrosis Foundation:** <http://www.cff.org/home/>

**MedlinePlus:** <http://www.nlm.nih.gov/medlineplus/cysticfibrosis.html>

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## Fetal Alcohol Syndrome - Books

**The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities.** Ann Streissguth, 1997. (201.4 Str83 ECI).

This book presents a summary of recent findings and recommendations by a team who conducted the largest study ever done on people of all ages with fetal alcohol syndrome and fetal alcohol effects. More than twenty experts from the fields of human services, education, and criminal justice describe their solutions to this disability that targets the brain and has lifelong consequences, including mental health issues, disrupted school experience, inappropriate sexual behavior, substance abuse problems, and homelessness.

**Fantastic Antone Succeeds! Experiences in Educating Children with Fetal Alcohol Syndrome.** Judith Kleinfeld and Siobhan Wescott, 1993. (201.4 K673 ECI).

This book presents case studies of children affected by alcohol and three optimistic messages: (1) Existing negative stereotypes of these children may be misleading; (2) Early diagnosis and intervention, together with excellent family care and schooling, make a great difference in these children's success and happiness; (3) Specific educational strategies help children affected by alcohol succeed.

**Fetal Alcohol Syndrome and Fetal Alcohol Effects: Strategies for Professionals.** Diane Malbin, 1993. (201.4 M292 RHB).

This booklet provides information on fetal alcohol syndrome and fetal alcohol effects to help support professionals in their work with clients whose lives have been affected by fetal alcohol exposure.

**Fetal Alcohol Syndrome: A Guide for Families and Communities.** Ann Streissguth, 1997. (201.4 St84 ECI).

A completely preventable disability, Fetal Alcohol Syndrome (FAS) changes the life course of thousands of babies each year. This book, using case studies, photos, illustrations, and validated empirical research, will help physicians, psychologists, social workers, and families of children and adults with FAS work toward an educated community, a supportive network and better futures.

## Fetal Alcohol Syndrome - Videos

**Alcohol and Pregnancy: Fetal Alcohol Syndrome and Fetal Alcohol Effects.** 20 minutes. (201.4 A294 1990).

This video shows how alcohol adversely affects the developing fetus and points out critical periods during pregnancy when the fetus is most vulnerable. Through candid interviews, it presents a realistic look at the daily struggles of the child with fetal alcohol syndrome/fetal alcohol effects (FAS/FAE) and his parents or caregivers. The interviews, featuring a diverse group of children, teenagers, biological parents and foster parents, create a developmental overview of FAS/FAE.

**David with Fetal Alcohol Syndrome.** 45 minutes. (VC7251).

David and his adoptive family describe what is like to grow up and live with the effects of fetal alcohol syndrome. The permanent brain damage he suffered was not diagnosed for the first eighteen years of his life.

**Fetal Alcohol Syndrome and Other Drug Use During Pregnancy.** 19 minutes. (201.4 F487).

This video profiles an eight-year-old Apache boy born with FAS, showing how alcohol ingested by his mother crossed the placenta and entered the bloodstream of the fetus, remaining long after it left the mother's bloodstream. The common characteristics of children with FAS are described in detail. The program also examines the plight of babies born to cocaine-addicted mothers.

**Fetal Alcohol Syndrome: Life Sentence.** 24 minutes. (201.4 F487 1998).

This program examines how early identification and treatment of infants and children with fetal alcohol syndrome, which is the result of permanent organic injury to the brain of the fetus caused by maternal drinking during pregnancy, can help prevent extreme antisocial behavior in adulthood. This program discusses FAS within the context of a recent study that suggests that 20 to 25 percent of all prison inmates may suffer from the condition.

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## Fetal Alcohol Syndrome - Multimedia

### **Fetal Alcohol Syndrome Tutor.** (CD0002).

This is interactive software that assists in the screening and diagnosis of fetal alcohol syndrome using descriptive text, video clips, animations and illustrations.

## Fetal Alcohol Syndrome - Websites

**National Organization on Fetal Alcohol Syndrome:** <http://www.nofas.org/>

**MedlinePlus:** <http://www.nlm.nih.gov/medlineplus/fetalalcoholsyndrome.html>

## Fragile X Syndrome - Books

### **Children with Fragile X Syndrome: A Parents' Guide.** Jayne D. Weber, 2000. (201 W374 2000 ECI).

This guide, essential to families, teachers and other professionals working with children with this developmental disability, presents current information that will help families adjust, understand their child's strengths and weaknesses, and to know where to seek further help and expertise.

### **Genetics and Mental Retardation Syndromes: A New Look at Behavior and Interventions.** Elizabeth M. Dykens, Robert M. Hodapp, Brenda M. Finucane, 2000. (226.1 D996 2000 RHB).

This book presents a comprehensive guide to the genetic and behavior characteristics of nine specific genetic mental retardation syndromes, including Fragile X syndrome, explaining how they affect individuals' behavior.

## Fragile X Syndrome - Video

### **The Fragile X Syndrome Diagnosis and Treatment.** 33 minutes. (201N213).

Fragile X syndrome, a genetic disorder, is the most common form of inherited mental retardation. While this syndrome occurs in all races and ethnic groups, it is more common in males. This video discusses the diagnosis, symptoms, and interventions.

## Fragile X Syndrome - Websites

**National Fragile X Foundation:** <http://www.nfxf.org/html/home.shtml>

**MedlinePlus:** <http://www.nlm.nih.gov/medlineplus/fragilexsyndrome.html>

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## Sickle Cell Disease - Books

**Understanding Sickle Cell Disease.** Miriam Bloom, 1995. (207.22 B623 ECI).

This book was written for people with the disease, their families, carriers of the gene, and those who work with them. It also includes discussion of the symptoms and emotional aspects of the disease.

## Sickle Cell Disease - Videos

**Care for the Child with Sickle Cell Disease.** 13 minutes. (VC5956).

This video discusses the symptoms of sickle cell disease in children and the extra care parents must provide. It emphasizes that these children should be encouraged to lead normal lives and to reach their full potential. It also describes the many programs and types of specialists available to treat this disease.

**The Child with Sickle Cell Disease.** 16 minutes. (VC4921).

This video covers the origins and incidence of the disease. It also discusses four types of sickle cell disease and the differences between them. Information is provided about the symptoms, when to contact a physician, and life-threatening situations.

**Invisible Illness: Living with Sickle Cell Anemia.** 13 minutes. (VC5508).

This video explains the disease of sickle cell anemia and its invisible side effects. It reveals the most common symptom-the intense pain-and how sufferers try to mentally work through it. Explains that the disease often hinders everyday activities, such as going to school. Colorful graphics show how normal blood cells act differently than sickle-shaped blood cells, and what causes the intense pain felt by sufferers.

**Sickle-Cell Anemia.** 16 minutes. (207.22 F487 2000).

This video provides a thorough overview of the sickle-cell phenomenon by presenting the symptoms, treatment, possible complications, screening methods, and the biochemical reasons for the characteristic shape of sickle-cell.

## Sickle Cell Disease - Websites

**Sickle Cell Disease Association of America:** <http://www.sicklecelldisease.org/>

**MedlinePlus:** <http://www.nlm.nih.gov/medlineplus/sicklecellanemia.html>

## Spina Bifida - Books

**Answering your Questions about Spina Bifida.** 1995. (201.1 C437 ECI).

This book, which is a guide from The Spina Bifida Program Department of General Pediatrics, answers commonly asked questions about spina bifida. It also includes information on specific medical and social issues of interest to families of those with spina bifida.

**Children with Spina Bifida: A Parent's Guide.** Marlene Lutkenhoff, 1999. (201.1 L973 1999 ECI).

This book provides parents with information, guidance, and support to meet their child's often intensive needs from birth through childhood.

**Living with Spina Bifida: A Guide for Families and Professionals.** Adrian Sandler, 1997. (201.1 Sa56 ECI).

This guide covers pregnancy, childbirth and each developmental stage of childhood. The key medical, habilitation, and emotional issues of spina bifida during each stage are explained.



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## Spina Bifida - Children's Books

**All Kinds of Friends, Even Green!** Ellen B. Senisi, 2002. (805.1 S477 2002).

Seven-year-old Moses, who has spina bifida and uses a wheelchair, reflects that his neighbor's disabled iguana resembles him because they both have figured out how to get where they want to be in different ways than those around them.

## Spina Bifida - Videos

**In the Middle.** 28 minutes. (557 C437).

This video profiles a child named Ryanna who was born with spina bifida. She is shown engaging in learning activities in a Head Start preschool program, which will eventually ease her transition into elementary school. Her preschool teachers discuss the rewards and difficulties of working with children with disabilities and children without disabilities in the same program. The focus throughout is on Ryanna's abilities, rather than her disabilities.

## Spina Bifida - Websites

**MedlinePlus:** <http://www.nlm.nih.gov/medlineplus/spinabifida.html>

**Spina Bifida Association:** <http://www.sbaa.org>

## Comprehensive Video

**Syndromes Associated with Multiple Congenital Anomalies.** 116 minutes. (VC7255).

This video presents an overview of congenital disabilities with examples of individuals at different ages. It includes descriptions and examples of 23 syndromes, associations and sequences, including cleft palate, Down syndrome, neurofibromatosis, Marfan's syndrome, and fetal alcohol syndrome.

## Comprehensive Website

The **March of Dimes** provides web pages on many conditions of interest in this issue of the newsletter: <http://www.marchofdimes.com/pnhec/4439.asp>

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Early Childhood Report - November 2005

# Early CHILDHOOD Report

Children With Special Needs & Their Families

Volume 16, Issue 11 November 2005

In This Issue	
<b>INSTRUCTION</b> Learn how teaming can increase inclusive opportunities without reducing intervention or having providers give up their expertise.	<b>PAGE 3</b>
<b>BEHAVIOR</b> You can quell behavior problems by acclimating kids to procedures; address sleep problems for kids with ADHD before medication.	<b>PAGE 5</b>
<b>HEADSTART</b> Read about federal efforts to increase program partnerships with college students; find out what funding cuts advocates say you should expect.	<b>PAGE 8</b>
<b>STUDIES</b> Protect young children from allergy problems; consider mental stimulation to improve IQ scores and reading in children with stunted growth.	<b>PAGE 9</b>
<b>ACCESSIBILITY</b> Make your playgrounds inclusive and compliant; read a recent OCR ruling on playground accommodations.	<b>PAGE 10</b>
<b>YOU BE THE JUDGE</b> See if a district should provide transportation for a student with a specific learning disability. .... 2	
<b>LAWSUITS &amp; RULINGS</b> Parents can sue mayor, city council over inaccessible schools; "struggle" to control disruptive student doesn't violate 504; New Mexico's literacy screening is assessment; student's performance means no special education evaluation. .... 11-12	

## LRE, IEP language in new IDEA could impact early childhood programs

**CONFERENCE NEWS**  
Learn what the feds say about proposed Part C regs and how you can nominate someone for a special award. **Page 4**

## Study: Prevent 'impairment' misdiagnoses in young English-language learners

**INSIDE**  
Find a checklist to help you consider ELL placements when assessing your special education referrals. **Page 6**

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**Exchange - November/December 2005**

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## Feature Articles

---

- 6 Is Education Separate From Care? by Gwen Morgan
- 11 The Changing World of Toys and Toy Play by David Elkind
- 14 NAEYC Accreditation Self-Study: A Unique Opportunity to Reinvent Your Program by Alison Pepper
- 24 Design for Competence: How Competent Can I Be? by Jim Greenman
- 26 Rapid Parental Notification for Child Care Providers by Corey S. Duber
- 32 Child Care Fees Rising S - I - O - W - I - Y by Roger Neugebauer
- 34 Putting Your Best Foot Forward – *Practical tips for effective correspondence* by Donna Rafanello  
NAEYC Exhibit Tour and Conference Guide — center pull-out section
- 53 Decoding Technology – *Parent Communication Tools* by Tim Walker and Chip Donohue
- 58 Would You Like to Get Along With Difficult People? Pick a Number by Karen Talley
- 68 Cover Story – Global Leaders for Young Children: Stepping Forward to Advocate for Early Childhood by Joan Lombardi
- 71 Everyday Exercises for Healthy Caregivers by Theresa M. Sull
- 81 Lessons from Katrina by Kay Albrecht

## Beginnings Workshop

---

- 37 Child Care in Unique Environments
- 38 Strengthening Families in Special Environments by Wayna Buch
- 41 Reaching the Most Vulnerable Children by Elizabeth Ruethling
- 45 Working With Homeless Young Children and Families by Karin Elliott and Sarah Fujiwara
- 49 The Pikler Institute: A Unique Approach to Caring for Children by Janet Gonzalez-Mena, Elsa Chahin, and Laura Briley

Training Suggestions by Kay Albrecht

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Infant Mental Health - November/December 2005

VOLUME 26 • NUMBER 6 • NOV-DEC 2005

# INFANT MENTAL HEALTH JOURNAL

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## SPECIAL SECTION

*Angels in the Nursery*

## INTRODUCTION

*Revisiting "Ghosts" and Finding "Angels"*

JOY D. OSOFSKY • 503

## ARTICLE

*Angels in the Nursery: The Intergenerational Transmission of Benevolent Parental Influences*

ALICIA F. LIEBERMAN, ELENA PADRÓN, PATRICIA VAN HORN, AND WILLIAM W. HARRIS • 504

## COMMENTARIES

*A Matter of Context: Who Says There Can't Be Friendly Ghosts?*

MARTIN J. DRELL • 521

*Ghosts and Angels: How Can We Find Them in the Nursery and Beyond?*

JOY D. OSOFSKY • 525

*The Pediatrician as Ghostbuster: Angels Voices and Kisses*

BARRY ZUCKERMAN AND PAMELA ZUCKERMAN • 529

## ARTICLES

*Expectant Adolescent Couples' Relations and Subsequent Parenting Behavior*

PAUL FLORSHEIM AND ALLISON SMITH • 533

*Mother Expectation of Bother and Infant Attachment Behaviors as Predictors of Mother and Child Communication at 24 Months in Children of Methadone-Maintained Women*

GEOFF GOODMAN, SYDNEY L. HANS, AND VICTOR J. BERNSTEIN • 549

*Interactions Between Anxious Mothers and Their Infants: An Integration of Theory and Research Findings*

MARSHA KAITZ AND HILLA MAYTAL • 570

AUTHOR INDEX TO VOLUME 26 • 601

VOLUME CONTENTS • I

If you would like to receive copies of articles, please contact the library staff at (512) 458-7260, toll-free: 1-888-963-7111 ext. 7260, fax: (512) 458-7474, e-mail: avlibrary@dshs.state.tx.us.

**Journal of Early Intervention - Fall 2005**

## ***Journal of Early Intervention***

***Volume 28, Number 1***

***Fall 2005***

### **FEATURE ARTICLE**

- 1** Validity and Reliability of a Curriculum-Based Assessment Approach to Determine Eligibility for Part C Services

*Marisa G. Macy, Diane D. Bricker, & Jane K. Squires*

### **INVITED COMMENTARIES**

- 17** The Authentic Alternative for Assessment in Early Intervention: An Emerging Evidence-Based Practice

*Stephen J. Bagnato*

- 23** Using Curriculum-Based Assessment to Determine Eligibility: Time for a Paradigm Shift?

*Mary McLean*

- 28** Intervention-Driven Assessment Practices in Early Childhood/Early Intervention: Measuring what is Possible Rather than what is Present

*Amanda M. VanDerHeyden*

### **REGULAR ARTICLES**

- 34** Treatment Effects on Speech Intelligibility and Length of Utterance in Children with Specific Language and Intelligibility Impairments

*Paul Yoder, Stephen Camarata, & Elizabeth Gardner*

- 50** Building Preschool Accountability Systems: Guidelines Resulting from a National Study

*Beth Rous, Tony LoBianco, Cara Lin Moffett, & Iolene Lund*

### **INNOVATIVE PRACTICES**

- 65** Promoting Inclusion by Improving Child Care Quality in Inner-City Programs

*Philippa Campbell, Suzanne Milbourne, Christine Silverman, & Natalie Feller*

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**Topics in Early Childhood Special Education - Fall 2005**

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Topics in Early Childhood Special Education



# Contents

25:3  
Fall 2005

Future Topics .....	130
Stigma and Discrimination: Perspectives from Mexican and Puerto Rican Mothers of Children with Special Needs .....	131
Patricia Alvarez McHatton and Vivian Correa	
Language Impairment, Parent-Child Shared Reading, and Phonological Awareness: A Feasibility Study .....	143
Laura M. Justice, Joan Kaderavek, Ryan Bowles, and Kevin Grimm	
A Descriptive Analysis of Positive Behavioral Intervention Research With Young Children With Challenging Behavior .....	157
Maureen A. Conroy, Glen Dunlap, Shelley Clarke, and Peter J. Alter	
A Model of Clinical Supervision for Preservice Professionals in Early Intervention and Early Childhood Special Education .....	167
Jantina R. Clifford, Marisa G. Macy, Linda D. Albi, Diane D. Bricker, and Naomi L. Rahn	
Establishing Outcomes for Service Coordination: A Step Toward Evidence-Based Practice .....	177
Mary Beth Bruder, Gloria L. Harbin, Kathleen Whitbread, Michael Conn-Powers, Richard Roberts, Carl J. Dunst, Melissa Van Buren, Cindy Mazzarella, and Glenn Gabbard	
Editorial Policy .....	189
Conference Calendar .....	192