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# ECI LIBRARY MATTERS

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January 2008

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## **Personal Narratives and Parent Advocacy**

*This month we are featuring personal narratives by parents of children with disabilities or by adults with disabilities. We have also included library resources on parent advocacy.*

*Check out the new additions to the collection on page 8!*

## **Autobiography and Biography - Books**

**Alex: The Fathering of a Premie.** Jeff Stimpson, 2004. (800.1 S859a 2004 ECI).

This is the story of the first years of baby Alex who was born weighing 21 ounces. It is the story of doctors, hospitals, conferences, and all the extreme emotions of parenting a preemie. It is the story as told by Alex's father.

**Another Season: A Coach's Story of Raising an Exceptional Son.** Gene Stallings, 1997. (800.1 S782 1997 RHB).

In this autobiography, the author shares with honesty, perception, and compassion the trials and tribulations of raising his son who has Down syndrome. Stallings offers a glimpse of family life, a few football anecdotes, and some poignant lessons.

**Babyface: A Story of Heart and Bones.** Jeanne McDermott, 2000. (800.1 M134 2000 ECI).

This book is the story of a parent whose son was born with Apert syndrome, a genetic craniofacial condition that results in a towering skull, a sunken face, and fingers webbed so tightly that hands look like mittens. Based on the author's journal, kept during the baby's first year, she combines facts and feelings to illuminate how she and her husband dealt with their family's experience.

**Becoming Citizens: Family Life and the Politics of Disability.** Susan Schwartzenberg, 2005. (350.3 S399b 2005 RHB).

This book tells the story of the role of parents in the disability rights movement. Photographs and narrative explain how a group of thirteen families in Seattle, WA went against conventional wisdom and refused to institutionalize their children with developmental disabilities. The book traces the determination of these families to make meaningful lives for their children. The law passed in Washington state was the precursor to the national law securing educational rights for every person with a disability in America.

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## Autobiography and Biography - Books (continued)

### **Beyond the Wall: Personal Experiences with Autism and Asperger Syndrome.**

Stephen Shore, 2002. (800.1 S559 2002).

In this book, the author provides an unusually interesting, well-written, and insightful autobiographical account of the life of a person with Asperger syndrome.

### **The Child Who Never Grew.** Pearl S. Buck, 1992. (800.1 B922 1992 RHB).

Pearl S. Buck originally published this account in 1950 to share her experiences as the mother of Carol, a child with a developmental disability. It was the first disclosure of its kind by a public figure. This revised edition contains a foreword by James A. Michener who gives a historical perspective and update to the author's original work. The afterward is written by Janice Walsh, Buck's second daughter. Walsh, an occupational therapist, gives an overview of Carol Buck's life and the school where Carol lived from the age of nine until her death in 1992.

### **Count Us In: Growing Up with Down Syndrome.** Jason Kingsley and Mitchell Levitz, 2007. (800.1 K55 2007 RHB).

This book presents conversations between two boys with Down syndrome discussing their life experiences growing up with Down syndrome. They share their innermost thoughts, feelings, hopes, and dreams and reminisce about their lifelong friendship. An afterword has been added that recounts their successes and challenges as adults.

### **Damaged Angels: An Adoptive Mother Discovers the Tragic Toll of Alcohol in Pregnancy.** Bonnie Buxton, 2005. (201.4 B991d 2005 ECI).

Part heartfelt memoir, part practical guide, this book recounts the author's struggles to raise an adopted daughter whom she did not realize has fetal alcohol syndrome. The book offers guidance to parents who have children with fetal alcohol syndrome.

### **Discovering My Autism: Apologia Pro Vita Sua (With Apologies To Cardinal Newman).** Edgar Schneider, 1999. (800.1 S358 1999 RHB).

In the 1970's, Edgar Schneider was diagnosed with schizophrenia. Years later Schneider was given the accurate diagnosis of autism. Schneider shares memories of his childhood and tells of his experiences as well as the satisfaction he has derived from his interest in the arts.

### **Emergence: Labeled Autistic.** Temple Grandin, 1996. (800.1 G764 1996 ECI).

In this book, the author tells the story of how she emerged from a fear-gripped childhood to become a successful professional and a world leader in her field.

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

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 specific strategies for living life to the fullest extent possible.

### **Extraordinary People with Disabilities.** Deborah Kent, 1996. (800.1 K37 1996 RHB).

This book profiles 53 people throughout history with various physical or mental disabilities and provides additional articles giving historical background on the disability rights movement.

### **Fragile X, Fragile Hope: Finding Joy in Parenting a Child with Special Needs.** Elizabeth Griffin, 2005. (201 G851f 2005 ECI).

This is the story of Zack from the perspective of his mother. Zack has fragile X syndrome and autism. His mother shares her journey of grief and joy.

### **Grief Dancers: A Journey into the Depths of the Soul.** Susan Zimmerman, 1997. (800.1 Z76 1997 ECI).

This book shares the author's soul-searching journey through grief, loss, hope, anger, and despair to a place of unconditional love and acceptance as she describes her experiences with her daughter Katherine who has Rett syndrome.

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## Autobiography and Biography - Books (continued)

**A Healing Family.** Kenzaburo Oe, 1996. (800.1 Oe1 1996 ECI).

The author, a winner of the Nobel Prize for Literature, creates a portrait of his son. His son is a gifted composer of music who has autism.

**Home Bound: Growing up with a Disability in America.** Cass Irvin, 2004. (800.1 I72 2004 RHB).

This is the story of Cass Irvin, an activist in the disability rights movement. She describes her life as a survivor of polio, her struggles, successes, and the importance of getting involved in sociopolitical issues.

**I Witness: History and a Person with a Developmental Disability.** Dave Hingsburger, 1992. (800.1 H663 1992 RHB).

In this book, the author presents the history of people with disabilities through the personal experiences and story of one of his clients, Noreen.

**Laughing Allegra: The Inspiring Story of a Mother's Struggle and Triumph Raising a Daughter with Learning Disabilities.** Anne Ford, 1998. (800.1 F699 2003 RHB).

This is the true story of the great-granddaughter of Henry Ford as told by her mother. This book shows how learning disabilities affect the whole family. Sections are included on how to find help and on sibling relationships.

**Like Sound Through Water: A Mother's Journey through Auditory Processing Disorder.** Karen J. Foli, 2002. (800.1 F665 2002 ECI).

This book is the story of a mother's struggles to get the help her son, who has auditory processing disorder, needs to be able to communicate with the people in his world.

**My Perfect Son Has Cerebral Palsy: A Mother's Guide of Helpful Hints.** Marie A. Kennedy, 2001. (800 K36m 2001 ECI).

This is a mother's story of her life with her son who has cerebral palsy. She writes of the concerns, joys, and sadness of sharing life with her child.

**Nobody Nowhere: The Extraordinary Autobiography of an Autistic.** Donna Williams, 1992. (800.1 W671 1992 RHB).

This book is the account of the author's journey from a childhood as a severely withdrawn and bewildered toddler to a university educated, successful writer.

**Pretending To Be Normal: Living with Asperger's Syndrome.** Liane Holliday Willey, 1999. (800.1 W714p 1999 RHB).

This autobiography presents the world as it is known to a person with Asperger's syndrome. It is an insightful account of the author's life and a glimpse into her daily struggles and challenges.

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

Jacobsen shares the story of how her family was formed. Jacobsen and her husband both have cerebral palsy. They adopted a baby boy who also has cerebral palsy.

**Reflections from a Different Journey: What Adults with Disabilities Wish all Parents Knew.** Stanley D. Klein, 2004. (263.1 R332 2004 ECI).

This book is a compilation of essays written by adults with many different disabilities: cerebral palsy, Down syndrome, autism, learning disabilities, deafness, blindness, mental illness, developmental disabilities, spina bifida, muscular dystrophy, attention deficit hyperactivity disorder and more. The authors were asked to write about something they wished their own parents had read or been told while they were growing up.

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## Autobiography and Biography - Books (continued)

**Retarded Isn't Stupid, Mom!** Sandra Z. Kaufman, 1999. (266.5 K21r 1999 ECI).

Nicole is two years old and her family just learned that she has a developmental disability. In this fast-paced, engaging story, Nicole's mother, Sandra Kaufman, frankly reveals the feelings of denial, guilt, frustration, and eventual acceptance that result in a determination to help her child live an independent life. This revised edition issued on the 10th anniversary of the book's original publication, adds a progress report that updates readers on Nicole's adult years. Kaufman reflects on the revolutionary changes in society's attitudes toward people with disabilities since Nicole's birth in 1955.

**Riding the Bus with My Sister: A True Life Journey.** Rachel Simon, 2002. (800.1 S596 2002 RHB).

In this book, the author describes her life as a child growing up in a dysfunctional family with a sister who is developmentally disabled. As an adult she decides to devote a year to understanding her sister. Her life changes as she shares her sister's pastime of riding on city buses.

**Somebody Somewhere: Breaking Free from the World of Autism.** Donna Williams, 1995. (800.1 W672 1995 RHB).

In this book, the second chronicle of her life as a person with autism, the author describes how she was able to break free of her world of hiding and withdrawal.

**Snapshots of Autism: A Family Album.** Jennifer Overton, 2003. (800.1 O96 2003 ECI).

Starting and ending on her son Nicholas' birthday, Jennifer Overton uses key calendar events in the year to illustrate the roller coaster of emotions that accompany life with her son, a child who has autism. She describes the grief involved in parenting a child with autism, but at the same time shares the overall sense of joy in her son's accomplishments through entertaining and insightful vignettes.

**Staring Back: The Disability Experience from the Inside Out.** Kenny Fries, 1997. (800.1 F913 1997 RHB).

This book, an anthology of 38 writers who have a disability, showcases their experiences firsthand through their nonfiction, poetry, fiction, and drama. This book challenges the ignorance and stereotyped misunderstandings about people with disabilities.

**Thinking in Pictures and Other Reports from My Life with Autism.** Temple Grandin, 2006. (800.1 G764 2006 RHB).

In this biography, the author describes in her own words what it is like to live with autism, and to be a person who has broken through many of the neurological impairments associated with autism.

**You Will Dream New Dreams: Inspiring Personal Stories by Parents of Children with Disabilities.** Stanley D. Klein, 2001. (800 K64 2001 ECI).

This book contains the stories of real-life experiences by parents of children with disabilities. Healing, coping, surviving, and even being happy again; these messages of encouragement and hope, from parent to parent, offer a helping hand when it is most needed during tough days or any time true understanding can make all the difference.

## Autobiography and Biography - Audiovisuals

**The Autism Continuum.** 90 min. 1998. (VT1260).

The author, Dr. Temple Grandin, herself an individual with autism, presents an insider's look at autism, its characteristics and how it affects communication, social, and sensory processing. In this witty, inspirational and personal portrait, Dr. Grandin discusses what life with autism is like, her views on medical, educational, and behavioral interventions and how parents can better understand their child who has autism.

**Autism is a World.** 40 min. 2004. (DD0099).

This documentary shows the everyday reality of Sue Rabin, a college student who has autism. Sue did not begin to communicate until she started using a keyboard at age 13. This program takes the viewer on a journey into her mind, her daily world, and her life with autism.

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## Autobiography and Biography - Audiovisuals (continued)

**Best Boy.** 104 min. 1979. (VT1435).

This Academy Award winning documentary, now considered a classic, portrays a family's love and protection of their adult son with a developmental disability and his quest for independence.

**The Collector of Bedford Street.** 33 min. 2002. (VT2491).

This video, which was nominated for an Academy Award for Best Documentary Short in 2003, describes the life of Larry Selman, a man who has a developmental disability. Selman lives in Greenwich Village, New York City. He spends much of his time collecting money for national and local charities from his neighbors. Realizing that his aging family members will soon be unable to take care of his financial needs, his neighbors and friends set up a trust fund.

**A Day in the Life of Richard Devylder.** 12 min. 2005. (DD0143).

Filmmakers follow Richard Devylder, California Department of Rehabilitation Deputy Director, through a typical day. Devylder was born without any arms or legs. He is able to live independently by using assistive technology.

**Educating Peter.** 30 minutes, 1993. (VT0507).

The story of Peter, a child with Down syndrome, is presented in this video. This winner of an Academy Award for Best Documentary Short Subject chronicles the frustrations and achievements during the school year of Peter, his family, and fellow students.

**Graduating Peter: Down Syndrome in the Inclusive Classroom.** 75 minutes, 2003. (VT2304).

This documentary video features Peter's educational experiences in sixth grade, eighth grade, and high school as he adds speech therapy and life skills classes and on-the-job training to his academic coursework. Interviews with Peter's parents, teachers, fellow students, aides, and doctors demonstrate the broad-based, ongoing support mobilized to help him fight depression, improve his ability to communicate, and move ahead in building a meaningful life for himself.

**King Gimp.** 50 min. 2002. (VT2489).

This video, winner of an Academy Award for best documentary short, presents the true story of Dan Keplinger who was born with cerebral palsy. Filmed over a thirteen year time span, it chronicles Dan's life from his years in a special school to his college graduation. It describes Dan's discovery of his artistic abilities in painting and drawing that freed his spirit and his ongoing career as a successful painter.

**Raymond's Portrait.** 27 min. 1997. (VT2488).

This video presents the life of 19 year old Raymond Hu, a Chinese brush painter who has Down syndrome. Viewers get to know Raymond through home movies and interviews with both parents, his brother, art teacher and Raymond himself. Raymond's sensitivity and passion for life comes out through his paintings of animals.

**Sound and Fury: A Film about the Communication Wars of the Deaf.** 55 min. 2000. (VT1391).

In this Academy Award nominated documentary, parents who are deaf try to understand why their young daughter wants to have a cochlear implant when she knows sign language very well. The filmmakers explore the conflict over cochlear implants and the nature of deaf identity and culture.

**Sound and Fury: 6 Years Later.** 29 min. 2006. (DD0089).

This DVD is a sequel to the documentary Sound and Fury. The previous film chronicled the Artinian family's struggle concerning whether or not to give their daughter who is deaf a cochlear implant that would enable her to hear. In the end, they decided that they would rather move to Frederick, Maryland to bring their children up in the signing world. This sequel takes a new look at the family as it follows them in the next six years of their life. Eventually, they move back to Long Island to be closer to their extended family where they can get the support they need.

**Triumph over Odds: The Story of David Ring.** 53 min. 1993. (VT2465).

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

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## Advocacy - Books

**Adopting and Advocating for the Special Needs Child: A Guide for Parents and Professionals.** L. Anne Babb, 1997. (271.8 B113 ECI).

This edited volume contains contributions from leading researchers, policy makers, practitioners, and advocates in adoption policy and practice. Topics include adoption advocacy, race and adoption, placement of children who are older and children with disabilities, adoption disruption, adoptive parent recruitment, and policy related to federal adoption subsidy support.

**How to Organize an Effective Parent/Advocacy Group and Move Bureaucracies.** Charlotte Des Jardins, 1993. (102.1 D464).

This book explains how to get the services that a child needs by forming a parent advocacy group. Full of practical advice and step-by-step directions, it includes such information as how to organize a group, how to get other parents involved, how to write a newsletter, how to contact media and government officials, and how to lobby.

**NEW! It's a New IDEA!: The Manual for Parents and Students About Special Education Services in Texas.** 2007. (566 A244 2007).

This manual is designed to help parents become familiar with the requirements of the IDEA so that they may act as an equal partner in planning their child's education. Parents will learn, by using this manual and by working with school staff, how to plan an educational program that will lead to an ordinary life for the child and family. This brochure is also available in Spanish as **Esta es una nueva idea?** (556 A244s 2007 ECI).

**Learning Disabilities-A To Z: A Parent's Complete Guide to Learning Disabilities from Preschool to Adulthood.** Connie Smith and Lisa Strick, 1997. (228 S644 1997 RHB).

This book contains information and encouragement for parents to assist them to become effective advocates for their child by helping them through the maze of challenges to find the help they need.

**Stand for Children: A Parent's Guide to Child Advocacy.** 1996. (102 C439 ECI).

This booklet will help the reader learn how to speak for and act on behalf of children through child advocacy.

**Wrightslaw: Special Education Law.** Peter W. D. Wright, 2004. (104.21 W954 2004 RHB).

In this book, the authors take some of the confusion out of special education law as they teach the reader how to advocate for a child with a disability so they will be fully informed when they need to attend an IEP meeting, mediation, or a due process session.

## Advocacy - Audiovisuals

**Advocacy Is Not a Four-letter Word.** 33 min. 1997. (VT1005).

Two Austin-based leaders of the national disability movement, Bob Kafka and Stephanie Thomas, look at self advocacy, community advocacy, and public policy advocacy with narrator Tim Harrington. They discuss why and how individuals can become involved in the struggle for disability rights.

**Brief Encounters of the Right Kind.** 47 min. 1997. (VT008).

This video offers practical and humorous advice on the do's and don'ts of lobbying. Three seasoned Washington lobbyists show how professionals, families, and consumers can use their own expert knowledge to influence public policy. This program is designed to provide advocates for human services with effective ways of making themselves heard by legislators and other government staff.

**Telling Your Family Story: Parents as Presenters.** 28 min. 1994. (VT0574).

Parents of children with special needs are often called upon to talk about their children, their children's needs, and their families. This video and guide offer suggestions on how parents can increase their effectiveness as speakers and therefore as advocates.

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## Advocacy - Audiovisuals (continued)

**Testifying with Impact.** 41 min. 1994. (VT0575).

Witnesses testify to give information with the objective of helping to formulate opinion. Poorly prepared and delivered testimony can be worse than none. This video explains what factors make testimony effective and tells how to give effective testimony.

**KIT**

**Parent Leadership Development: Building Strong Voices for Children.** 2002. (KT0054).

These materials are designed to be used in a multiple day retreat or workshop setting to encourage and train parents of young children with disabilities to become leaders in the early intervention system.

## Advocacy - Selected Websites

**Advocacy Inc.**'s mission is to advocate for, protect and advance the legal, human and service rights of people with disabilities. See <http://www.advocacyinc.org/>

**The Arc of Texas** is a volunteer organization in Texas committed to creating opportunities for people with intellectual and developmental disabilities. The Arc supports families, advances public policies, provides training programs, and builds a statewide network of advocates. See <http://www.thearcoftexas.org/>

**Community Parent Resource Centers** serve families of children and young adults from birth to age 22 with all disabilities: physical, cognitive, emotional, and learning. They help families obtain education and services; help resolve problems between families and schools or other agencies; and connect families to additional community resources. See <http://www.tea.state.tx.us/special.ed/explansaf/cprc.html>

**Family Village** is a community on the Internet that integrates information, resources, and communication opportunities for persons with cognitive and other disabilities, for their families, and for those that provide services and support. See <http://www.familyvillage.wisc.edu/>

**Texas Parent to Parent** provides support and information for families of children with disabilities, chronic illness and other special needs: <http://www.txp2p.org/>

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## New Additions - Books

**An Activity-Based Approach to Developing Young Children's Social Emotional Competence.** Jane Squires, 2007. (540 S774a 2006 ECI)

This book walks readers through the five-step intervention process called Activity-Based Intervention: Social Emotional. It explains how to screen the child for behaviors of concern and evaluating the family environment. It performs a more detailed assessment of child and caregiver competence. It works with parents on goal development and embeds intervention activities into everyday routines. It shows how to conduct an evaluation of the program.

**From Early Intervention to Preschool Programs and School-Age Services: A Parent's Guide to Transitioning Young Children with Special Needs.** Padmaja Sarathy, 2006. (556.8 S243f 2006 ECI)

This family-focused guide provides a road map of the events a parent can expect in the transition process from early childhood education to preschool and beyond. It is designed to empower families to ask the right questions and seek the most relevant information from the professionals to help parents make effective transition-related decisions for young children with special needs.

**The Out-Of-Sync Child: Recognizing and Coping with Sensory Processing Disorder.** Carol Stock Kranowitz, 2005. (219 K862 2005 ECI)

Oversensitivity to touch, taste, smell, sound; problems with motor coordination; unusually high or low activity level -- these may be symptoms of sensory integration dysfunction. SI dysfunction is a common, but frequently misdiagnosed, problem in which messages from the senses are not correctly processed by the central nervous system. This guide, aimed at parents and other laypeople, offers easily understood information on the disorder and a treatment approach for children who need help.

**Together We Succeed: Building a Better System for Transitioning Preschoolers with Disabilities.** Padmaja Sarathy, 2005. (556.8 S243 2005 ECI)

This practical guide presents a collaborative planning process with a multi-pronged approach to address the challenges of multiple transitions that occur in the preschool years. It provides creative ideas and strategies for developing and implementing a best-practice system to achieve smooth transitions from one service delivery model to another for preschool children with special needs and their families. This edition has been updated to reflect the changes in the 2004 IDEA law.

**Two Homes.** Claire Masurel and Kady MacDonald Denton, 2001. (805.1 M424t 2001 ECI)

A young boy named Alex enjoys the homes of both of his parents who live apart but love Alex very much.

## New Additions - Audiovisuals

**Substance Exposure and Promoting Attachment.** 79 min. 2007. (CA0006)

Mary Susan Rudisill, clinical psychologist, presents information in this audio CD about prenatal substance exposure and the early absence of consistent, loving caregivers. The first part of the session explores the interrelationship of biological and environmental risk factors as they affect attachment and development in substance-exposed children. Part two presents a comprehensive view of this multi-deficit model and innovative intervention options.



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Early Childhood Report - December 2007

# Early CHILDHOOD Report

Children With Special Needs & Their Families

VOLUME 18, ISSUE 12

DECEMBER 2007

## LEGAL SPOTLIGHT

### You Be the Judge

Does IEP's focus on nonverbal communication deny this child FAPE? **Page 2**

### Washington Watch

Learn about the recently passed Head Start reauthorization; find out about a new universal prekindergarten bill introduced by Rep. Dennis Kucinich, D-Ohio; read how you can nominate a colleague for a national award. **Page 3**

### Decisions & Guidance

Read the latest judicial rulings, an OSEP letter, and SEA decisions. **Pages 10-12**

### Part C Primer

Proposed IDEA Part C Section 303.320(e)(1) requires a child's evaluation, assessment, and initial IFSP meeting to occur within 45 days from the date the public agency obtained parental consent for the evaluation. This is meant to increase the time available to agencies for completing these actions. **See page 4 for more on the proposed regulations.**

## COVER STORY

### Devise creative fundraising tactics to supplement federal funding shortfalls

Part C coordinators and providers in nearly every state are struggling to serve an increasing number of young children with special needs. This is particularly burdensome in light of funding shortages. Most recently, the Education Department's *Letter to Perry*, 48 IDELR 162 (ED 2007) demonstrated the rigidity of funding allocations under IDEA Part C. So what can your program do to survive?

The key is to develop a fundraising foundation, use transportation more efficiently, and consolidate staff responsibilities, say early childhood experts. **Full story, page 4.**

### Regs update

OSEP doesn't expect to release the final IDEA Part C regulations until late next summer. Find out about some of the comments and what Part C personnel hope to see reflected in the final regulations. **Page 4**

## HIGHLIGHTS

### Tackle discipline problems early to increase success

Find out why a special education director recommends implementing buildingwide positive behavior support programs to address young children's challenging behaviors. **Page 5**

### Help parents navigate child find process

Learn how Head Start programs and other early childhood education providers can usher parents through the referral and evaluation process to ensure their children have the opportunity to receive special education services in a timely manner. **Page 6**

### Let peers coach children with hearing impairments

See why children who can hear can contribute to the speech, language and social-emotional development of children with hearing impairments. **Page 7**

### Eye on Autism: Assess children's social skills

Discover ways to evaluate the progress children with autism make in participating in social interactions. **Page 8**

### Link goals, early learning standards to prepare children

Consider how you can connect early childhood achievement standards to your curriculum to best prepare children with special needs for school. Also, learn ways you can collect data to determine staff fidelity and student progress. **Page 9**

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Exceptional Parent - December 2007

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PHOTO CREDIT: HOWARD ROBINSON

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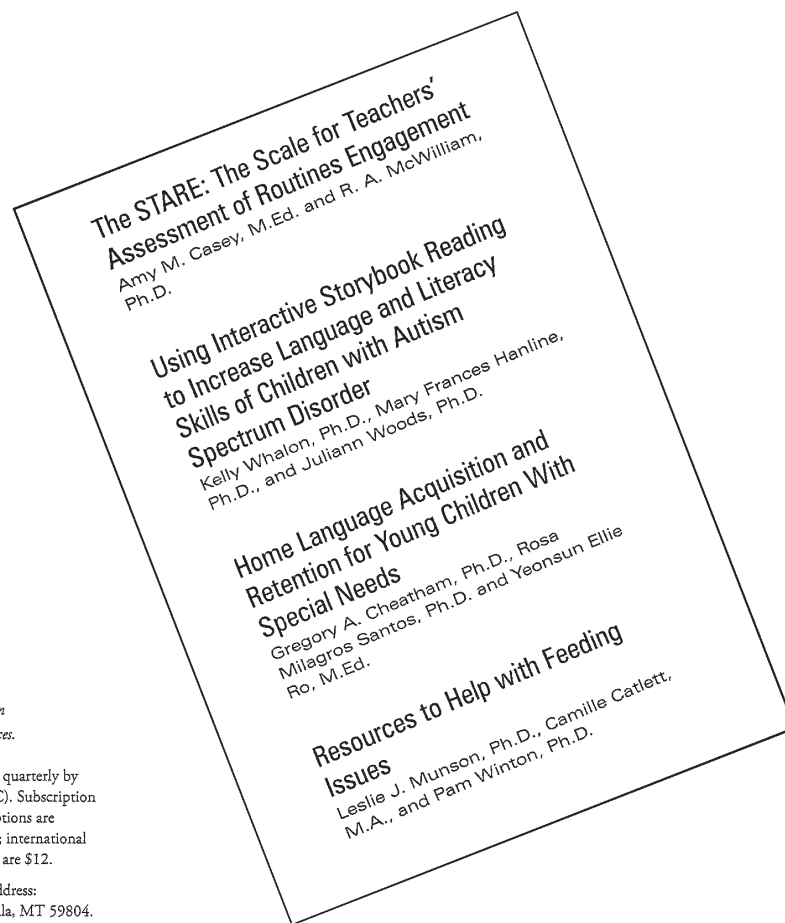
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