



Early Intervention Clearinghouse

<http://eiclearinghouse.org>

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Connections on Your Early Intervention Journey

When you began this early intervention (EI) journey, you probably had many questions about your child, the system of services, which provider to choose, where to get the best information, what the future might look like, and so on. As on some trips, the first connection that you make is with a travel agent, or in this case your EI service coordinator. The service coordinator is part of the Child and Family Connections office and is assigned to your family upon referral. He or she can help answer those questions and find additional resources for you. The service coordinator will help you navigate services from your initial referral to the transition out of EI.

Once your family's travel plan is complete, it is time to set forth. In early intervention, this travel plan is called an individual family service plan (IFSP), which outlines the paths to take and the connections with providers you will make along the way.

The connections you make can help this be a more meaningful and less stressful trip than you had originally thought. You will likely meet other families who are experiencing or have experienced similar paths. These families will have the "tried and true" suggestions or tips to remember as you travel along your route.

The EI families who have been there will help you understand what should be in your "suitcase or toolbox" of information, such as your child's birth and health information as well as information about his or her condition. They also may help you understand how your family's culture and values may affect your interactions with service providers or agencies. It is important to research and investigate all possibilities, including services and treatment options, and add them to your toolbox. This information will help you on this road.

Many families report that connecting with other families has been one of the most empowering actions they have taken. There are parent-to-parent programs available to help connect families. The parent liaison at your local Child & Family Connections Office is a great place to start. He or she can walk with you on this

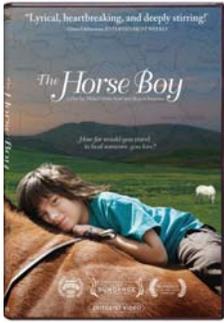
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Off the Shelf at the Clearinghouse



The Horse Boy

An intensely personal yet epic spiritual quest, *The Horse Boy* follows one Texas couple and their autistic son as they trek on horseback through the breathtaking grasslands of Mongolia in an attempt to find healing for him.

Autistic-like: Graham's Story

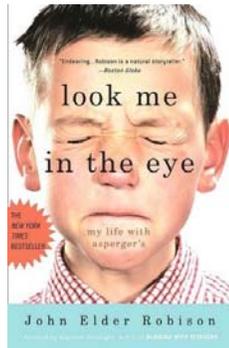
Autistic-like is an intimate family portrait showing one dad's determined quest to find the right therapies, the right doctors, and even the right words to describe his son.

A Mother's Courage: Talking Back to Autism

This inspiring film follows one woman's quest around the world to find a way to unlock her autistic son's mind.

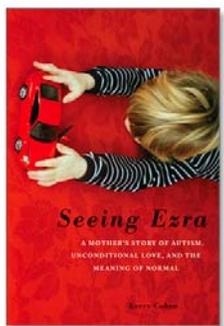
Look Me in the Eye: My Life With Asperger's

In his bestselling memoir, John Elder Robison writes with honesty and dry wit about growing up with Asperger's syndrome at a time when the diagnosis didn't exist.



Be Different: Adventures of a Free-range Aspergian

In his second book, bestselling author John Elder Robison shares more endearing stories about his life, giving peers, families, and teachers a rare window into the Aspergian mind.



Seeing Ezra: A Mother's Story of Autism, Unconditional Love, and the Meaning of Normal

Seeing Ezra is the soulful story of a mother's fierce love for her autistic son and a poignant examination of what it means to be "normal."

A Child's Journey Out of Autism: One Family's Story of Living in Hope and Finding a Cure

In this extraordinary story of one family's struggle with autism, Leeann Whiffen gives voice to the fear of losing a child and the fight to reclaim him.

Emma's Gifts

Following the journey of a little girl with Down Syndrome through the preschool years, *Emma's Gifts* is a film about differences—how they matter and how they don't.

Word From Parent Liaisons

"I have found connecting with other parents is the MOST IMPORTANT thing we can do for ourselves and our children! There is no one else who understands the highs and lows of our daily lives."

—Sharon Pike, *Easter Seals Dupage*

"Always check with your local school district and library for play groups and parent group/classes. Also, park district classes or special recreation classes are a great way to meet families with similar interests."

—Aimee Pfister,

Child and Family Connections No. 4, Geneva, IL

"Remember to take care of yourself, find time for your partner, your other children, and your friends and family. This is not a sprint, but a marathon."

—Cara Long, *Easter Seals Fox Valley Region*

CONNECTIONS

Continued from Page One

journey and help you learn the terminology, maintain a positive outlook, keep in touch with reality, and find additional programs for your child.

It is important to recognize that siblings are also affected by a diagnosis or condition. The world as they know it has shifted. Their routines may have changed; more people are now involved in their day. The age of the sibling will help to determine what they understand. Before age 5, most children cannot express their feelings verbally but will express them through behavior. Elementary children will become aware of differences and may start experiencing conflicting feelings of jealousy, worry, or guilt. They will adapt to the situation better if you talk through these mixed emotions with them. Adolescents may begin to ask detailed questions and may feel embarrassed or resentful of their sibling. There are books and organizations available to help siblings work through their feelings and make connections with others.

You are not alone. There may be forks in the road, but fortunately the roads are paved and well lit by other families that have effectively and successfully traveled this journey and can help guide and support your family. For a list of organizations in your area, please see <http://illinoisparents.crc.uiuc.edu/orgs-lib.html>

Answering Questions About Your Child's Special Needs

At family gatherings or in neighborhood parks, adults often start conversations by asking about your newborn or young child. Easy questions can range from "How old is he?" to "Does he let you sleep through the night yet?" As your child grows, family and friends may ask more intrusive questions about your child if his development is slower than normal or delayed. Do you respond to their questions? If so, how, why, and when?



Focus first on positive topics

- Point out what she does well: "She loves to coo and make happy sounds."
- Introduce what you admire and love about your baby: "He has the brightest eyes."
- Note progress in your child's development: "She's sleeping longer at night."

Welcome efforts to include your child

- Identify ways your child can participate. Can he watch the activity or can he join in? If he joins, are there different ways or expectations for participating?
- Acknowledge that your child may need support: "He likes to go down the slide with help, but isn't ready to slide alone. We can take turns if I can help."

Decide what information you want to share

- Not all questions are necessary or appropriate. It's OK to set boundaries around information and decline to answer personal questions.
- If you agree to discuss your child's special needs, then find a time and place when you can talk without interruptions and with privacy. You also may want to include information about early intervention services if the listener shows genuine interest.
- When your child is behaving differently, remember that all children experience challenges and respond in ways that are in fact "childish." You may want to ask the inquiring adult if their child was ever "shy," "awkward," "silly," or "mad." Most will have had similar experiences whether their child has special needs or not.

 For more information about helping your child with special needs, see the Illinois Early Intervention Clearinghouse Web site at <http://eiclearinghouse.org>.

Any opinions, findings, conclusions, or recommendations expressed in this publication are those of the author(s) and do not necessarily reflect the views of the Illinois Department of Human Services, Bureau of Early Intervention.



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Resources for Parenting a Child with Special Needs

Books

Optimistic Parenting: Hope and Help for You and Your Challenging Child. Vincent Mark Durand. Paul H. Brookes, 2011. (Call # WS 350.6 .D948 2011)

Optimistic Parenting is a guidebook for parents and caregivers to help reduce children's challenging behaviors, with a variety of practical tools and strategies on effective behavior management.

Supportive Parenting: Becoming an Advocate for Your Child with Special Needs. Jan Starr Campito. Jessica Kingsley, 2007. (Call # WS 107.5 .R5 C196 2007)

Jan Campito shares her story of becoming a parent of a special needs child and realizing her need to take on the active role of leader and advocate to get her children the help they need.

A Cup of Comfort for Parents of Children with Special Needs: Stories That Celebrate the Differences in Our Extraordinary Kids. Colleen Sell (Ed.). Adams Media, 2009. (Call # WS 105.5 .F2 C974 2009)

This touching and heartfelt book is a collection of 50 stories of parents who have gone from struggling with their child's diagnosis to embracing their child's differences and small achievements.

Videos

A New I.D.E.A. for Special Education: Understanding the System and the New Law: A Guide for Parents, a Tool for Educators. 50-minute DVD. Edvantage Media, 2005. (Call # LB 4031 .N532dvd 2005)

This video explains to parents all about the Individuals with Disabilities Education Act (I.D.E.A.), the law governing special education. It covers the referral and evaluation processes as well as the creation of an individualized education program (IEP).

A Place of Our Own. Early Childhood Solutions: Special Needs. 97-minute DVD. PBS Home Video, 2008. (Call # LB 1132 .P53 2008)

This video provides parents and child care providers with information to help young children develop social, emotional, and cognitive skills in preparation for entering kindergarten.

Websites

[Parenting Special Needs Magazine](http://parentingspecialneeds.org)

<http://parentingspecialneeds.org>

Parenting Special Needs is an online magazine that provides both information and inspiration to parents of children with special needs of all ages and stages of life.

[One Place for Special Needs](http://oneplaceforspecialneeds.com)

<http://oneplaceforspecialneeds.com>

This website, started by the mother of two special needs children, is an information network that allows the disability



community to share resources and make connections in their neighborhoods.

Articles

Parent-Provider-Community Partnerships: Optimizing Outcomes for Children with Disabilities.

Nancy A. Murphy and Paul S. Carbone. (2011). *Pediatrics*, 128(4), 795–802.

The authors of this article explore the challenges of developing effective community-based systems of care for children with disabilities and make suggestions that pediatricians and policy-makers develop better partnerships with the families and other health care providers to best help the children.

“We’re Tired, Not Sad”: Benefits and Burdens of Mothering a Child with a Disability.

Sara Eleanor Green. (2006). *Social Science and Medicine*, 64(1), 150–163.

This study chooses to look at how mothers and caregivers of children with special needs really feel about their socially perceived burdens and the benefits of their caregiving role.

Illinois Early Intervention Clearinghouse

Early Childhood and Parenting Collaborative
University of Illinois at Urbana-Champaign
Children's Research Center
51 Gerty Drive
Champaign, IL 61820-7469

Illinois Calendar

February 18, 2015
Webinar

*Early Identification of ASD:
Why It Matters and How to Support Families*
Contact: Lucy Gimble, (866) 509-3867
lgimble@illinoiseittraining.org
<http://eitp.education.illinois.edu/>

February 25, 2015
Webinar

Supporting Receptive Language Skills in Infants and Toddlers
Contact: Lucy Gimble, (866) 509-3867
lgimble@illinoiseittraining.org

March 18, 2015
Webinar

*Is It a Language Delay? Language Disorder? Language Difference?
Intervention or Not?*
Contact: Lucy Gimble, (866) 509-3867
lgimble@illinoiseittraining.org

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