



# Early Intervention Clearinghouse

<http://eiclearinghouse.org>

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## You Are Your Child's Best Advocate

It can be difficult to advocate for your child. Depending on your child's needs, you may need to advocate for services, medical issues, and inclusion. You may wonder: How can I be the best advocate for my child?

As an expert on your child, you already are your child's best advocate. You should feel confident in expressing your concerns to professionals. Indeed, you know your child better than anyone else.

Advocacy is often broken down into two types: proactive and reactive. Proactive advocacy occurs when you anticipate needing to advocate for your child to avoid a problem or crisis. For example, you may proactively advocate to receive a handicap parking permit so you can access public and private locations. Reactive advocacy occurs when there is a problem. For example, if a child care agency refuses to enroll your child because of a disability, you may advocate for the child care agency to change its stance.

Regardless of the type of advocacy, we have several tips to help you be a good advocate. Below, we provide those tips on generic advocacy, educational advocacy, and medical advocacy.

Please see **ADVOCATE**, Page 2

# Answering Questions About Your Child's Disabilities

Have you ever felt that people judge you, look at you differently, or comment on your parenting when your child starts screaming in the grocery store because they don't know how to communicate their needs or because the noise is too overwhelming?

Have you ever felt that people always ask questions about your child's disability that you don't know how to answer, or try to say something nice but actually sound amazingly rude?

If you've ever been upset or felt like screaming "Are you serious?", take a deep breath. These moments can be opportunities for you to educate other parents or advocate for yourself.

Here's some advice to get you started:

## 1. "She looks so normal! If you hadn't told me, I wouldn't have known that she is disabled!"

Yes, this comment might make you feel angry and offended. But remember, many people don't know how to use language that puts people first. When they used the word normal, they might think they're trying to be kind by complimenting your child. You can use this as an opportunity to spread disability awareness by saying:

"Every child is different. They learn and do things in a different way. My child has a disability, but it doesn't mean she is different than other children or that there is something wrong with her. It's just like some people have to read with glasses, and some people don't.

"That's why I prefer to use person-first language. Disability is not a problem. Instead of defining a person by their disability or diagnosis, use language to emphasize the person first. For example, a child with a disability. This allows us to focus more on a person's strengths. When you start using 'person first,' I believe it changes the way you view the world."

## ADVOCATE

Continued from Page One

### Generic Advocacy

- Document your advocacy efforts. It is important to have a paper trail detailing the circumstances requiring advocacy and your advocacy efforts. Documentation may include saving e-mails, saving documents to your computer, and keeping paper documents in a safe space.

- Meet other families of children with similar needs. This will help you learn other advocacy tips. Often, other families have experienced similar barriers and reasons for advocacy. There is no reason to reinvent the wheel! Talk to other families to learn successful advocacy strategies.

- Ground your advocacy in what your child needs. It is hard to argue with what your child needs. Remember, this is not about what you want but what your child needs. Your advocacy should always be grounded in "This is what my child needs."

### Educational Advocacy

- Write a parent input statement for the meeting. Educational meetings can be overwhelming. Write your concerns into a parent input statement. Share the statement with the educational professionals. This will help document and voice your concerns.

- Ask for a copy of evaluations and draft service plans before meetings. It can be hard to prepare for a meeting without

having a draft of the evaluation and/or service plan. Ask for a copy of the documents so you can ground your advocacy in these reports.

### Medical Advocacy

- Bring someone to your appointments with you. It can be difficult to ask questions at medical appointments and advocate for your child while attending appointments with your child. Ask someone to go with you to watch your child so you can ask questions of the medical professional.

- Read your insurance coverage. It is critical that you are well-versed about what your insurance will and will not cover. Carefully read materials from your insurance agency to be informed.



## 2. "What is wrong with him? You need to discipline him more." "You must let him do whatever he wants at home."

This is another common hurtful comment. It can make you want to scream, "Stop judging us!" Again, take a deep breath and explain:

"Every child can have a public meltdown once in a while, and it's not necessarily a sign of bad parenting. There's nothing wrong with my child. He is just sensitive to lights and sounds, and I'm trying to find ways to help him calm down."

## 3. "He'll grow out of it." "Is he able to go to school?"

Most parents don't know your life's journey, and they might not know anything about your child's disability. You can share your personal story with them:

"My child will not grow out of her disability. Having a disability doesn't stop my child from going to school, learning, or making friends. I can tell you more about my child's disability if you'd like to know more."

# What's in Your IFSP?

An Individualized Family Service Plan is developed for every child receiving services through the Illinois early intervention system. Once eligibility is determined, and within 45 days of referral, the IFSP is developed by the early intervention team to support and build upon the strengths of the child's family. The basic components of an IFSP are:



## Child and Family Status

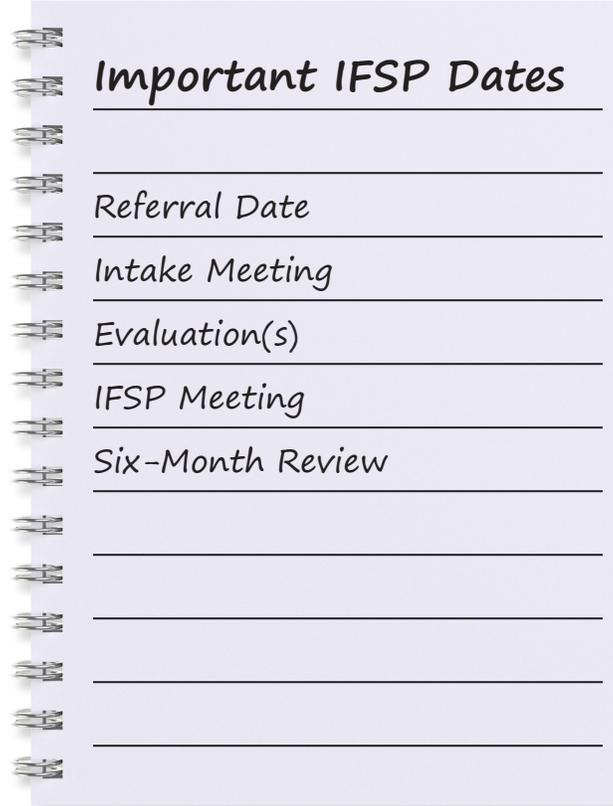
- Present levels of physical, cognitive, communication, social/emotional, and adaptive development based on evaluations, observations, and conversations with your family
- Resources, priorities, and concerns of family members closely involved with your child

## Outcomes Expected

- Measurable changes and benefits that you want for your child and family

## Early Intervention Services

- Those necessary to achieve identified outcomes
- Include "dosage"—method, duration, frequency, and intensity of services
- Must be provided in child's natural environments to the maximum extent possible



## Other Services

- Those provided but not required nor funded by early intervention
- Your service coordinator and/or parent liaison can assist you in finding these services

## Service Coordinator

- Is responsible for implementing services
- Coordinates with other agencies and people

## Transition Plan

- Outlines steps and services to support a smooth transition out of early intervention for any reason or when a child turns 3

- Begins no sooner than nine months before 3rd birthday
- Informs parents of options for services

## Other details

- Beginning date for and duration of services
- Payment information
- Families must consent to services in writing

To learn more about IFSPs in Illinois, please see Section 3 of *The Illinois Early Intervention Program: A Guide for Families*

 For more information, visit the Illinois Early Intervention Clearinghouse at <https://eicclearinghouse.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.



# Stories of Strength, Love, and Hope

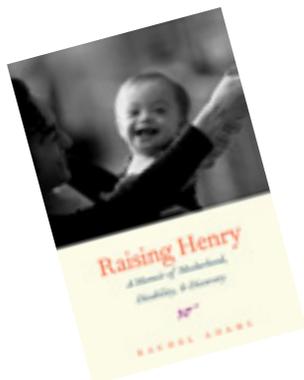
## A Different Beautiful: Discovering and Celebrating Beauty in Places You Never Expected

Courtney Westlake  
Shiloh Run, 2016  
HQ 759.913 .W5276 2016



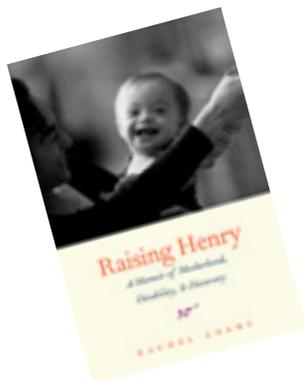
## What Color Is Monday? How Autism Changed One Family for the Better

Carrie Cariello  
Riddle Brook, 2013  
WM 203.5 .C1914 2013



## Raising Henry: A Memoir of Motherhood, Disability and Discovery

Rachel Adams  
Yale University Press, 2013  
WS 107.5 .A2111 2013



## Love That Boy: What Two Presidents, Eight Road Trips, and My Son Taught Me About a Parent's Expectations

Ron Fournier  
Harmony Books, 2016  
HQ 759.913 .F821 2016  
Also available as a **CD audiobook**  
and **digital audiobook**



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

Kerry Cohen  
Seal Press, 2011  
WM 203.5 .C6601 2010

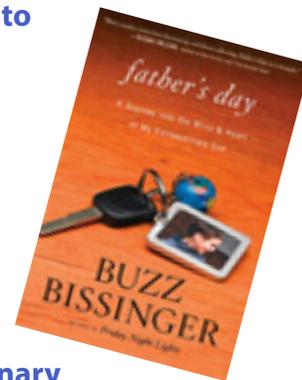


## Beautiful Eyes: A Father Transformed

Paul Austin  
W.W. Norton, 2014  
WS 107 .Au761 2014

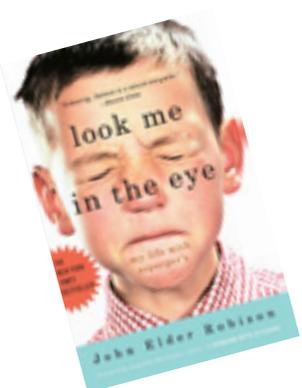
## Father's Day: A Journey Into the Mind and Heart of My Extraordinary Son

Buzz Bissinger  
Houghton Mifflin, 2012  
HQ 759.913 .B57 2012



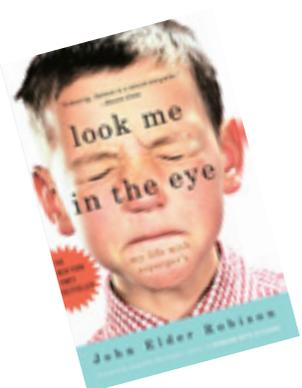
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Ian Brown  
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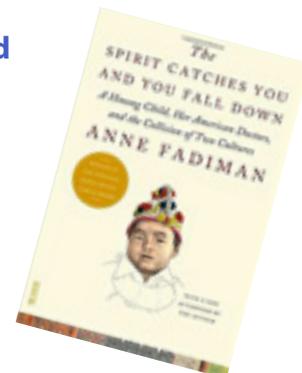
## Look Me in the Eye: My Life With Asperger's

John Elder Robison  
Three Rivers Press, 2008  
WM 203.5 .R5601 2008  
Also available as an **eBook**  
and **digital audiobook**



## The Spirit Catches You and You Fall Down: A Hmong Child, Her American Doctors, and the Collision of Two Cultures

Anne Fadiman  
Farrar, Straus and Giroux,  
2012  
WL 385 .F146s 2012



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# What Is a Parent Liaison?

A parent liaison works with local Child and Family Connections offices to help families with questions. All parent liaisons have experienced raising a child with special needs.

Parent liaisons can support families in a variety of ways. We asked parent liaisons throughout Illinois to share some of the ways they reach out and help families.

- I find different ways to best support each family. Some examples include providing lists of child-friendly activities, connecting families with similar needs, informing families about events in the community, and planning playgroups.

- I explain what our program can and cannot do. I let parents, medical professionals, EI providers, and community partners know what other community resources are available.

- I help families by providing an ear to listen to their concerns and meet them where they are at along their journey.

- I help families with the transition out of early intervention and the first IEP meeting with the local school district.

**I think one of the most valuable things I can do for parents is validate what they are going through.**

**Often there can be frustration over various challenges, and it just gets to feel like too much. I offer a listening ear. Relating to the situation from having been through it myself can be very powerful.**

- I help provide families resources to be the best advocate for their child as they move through the stages of development.

- I answer questions, offer support during challenging times, and provide resources.

- I teach special education advocacy to parents so they can feel empowered to be their child's advocate.

- I help families feel more knowledgeable, empowered, and supported on their journeys.

- I answer a family's questions about having a child with a disability in general and listen to how they try to navigate their life with the changes they are living.

- I provide resources on different topics such as respite, educational advocacy, and disability-related support to provide a good foundation for families as they navigate uncharted waters.

- I think one of the most valuable things I can do for parents is validate what they are going through. Often there can be frustration over various challenges, and it just gets to feel like too much. I offer a listening ear. Relating to the situation from having been through it myself can be very powerful.

Ask your service coordinator to put you in touch with the parent liaison that serves your area.

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