



### TIPS FROM DADS FOR RAISING CHILDREN WITH DISABILITIES

Surprise. Concern. Confusion. These are among some of the many emotions parents feel when they first learn that their child has a disability, but fathers and mothers may respond differently to such news.

With information, planning, and access to supports and services, families can learn to nurture new hopes and expectations while celebrating growth and accomplishments along the way.

When you have a child with a disability, however, there is sometimes a tendency to focus on needs and services. Parents also need to pay attention to their child's strengths and interests so they can find activities to do together and enjoy time as a family.

In the profiles below, three fathers share their reactions and responses to learning that their child has a developmental delay or disability, and what they have learned in the process.

#### Steve Mattson

Six-year-old Ben Mattson is an active, energetic little boy who loves grilled cheese sandwiches and adores his dog. It was a speech therapist who was providing in-home services for Ben who first suggested that the Mattsons have him evaluated.



“Both my wife and I were first-time parents, and we didn’t really have anything to compare it to,” said Steve, whose son was soon diagnosed with Autism Spectrum Disorder. “Your first reaction is denial. ‘What are you talking about? Not my son!’” he said. “I’m sure every parent goes through that. After that, confusion is probably the best word to describe it.”

Together the couple faced their new reality and set about finding available resources. “My wife, bless her heart, dove into it head first,” Steve said. “She went on the Internet, and she pulled out the phone book and started calling people

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and asking questions. ‘What is available? Where are the resources? How do we do this?’ It was full speed ahead!”

With the help of caring professionals and their newly acquired knowledge, the Mattsons are doing what they can to help Ben be successful, and he is on track to enter elementary school this fall with his peers.

Steve and Jessica have adapted to Ben’s public outbursts and learned how to prevent them by making plans well in advance, avoiding places that are noisy or crowded, and bringing along a bag of Legos to keep Ben occupied.

What else has Steve learned as the dad of a child with a disability? “Patience. Lots and lots of patience,” he said, “and my wife has way more patience than I do.”

### Jon Hartmann

When their third child was born, Jon and Jessica Hartmann already knew instinctively that children develop at their own pace, but it wasn’t long before they began questioning Sam’s behavior.

“There was always this nagging feeling that something was wrong,” Jon said, “but, at the same time, there were all of these people around us — including our family doctor — who told us not to worry, that everything would be fine.”



*“When you first find out that your child has a disability, you are mad, you’re sad, you’re happy, you’re angry. You kind of go through all those different steps.”*

*-Matt Ripley*

When a professional in Minnesota’s early childhood Follow Along program voiced concerns about Sam’s development, the Hartmanns knew their concerns had been right. “That was our ‘Aha!’ moment,” Jon said.

Sam was diagnosed with developmental delays, fine and gross motor skills delays, ADHD, and unspecified learning disabilities. Jon reacted with worry, concern, and questions:

What does this mean? How do we fix it? What can be done? His other reaction was to assume the role of protective husband and father. “I was concerned for Jessica because she was so worried and was quite emotional,” he said. “I had to try to keep myself together at that point and not show too much emotion. It wasn’t necessarily by design. I am not any kind of a traditional, detached, stoic guy, but I don’t like it when my wife becomes emotional. I was trying to remain as calm as I could as we learned more about Sam’s disabilities.”

It was an approach that worked for the Hartmanns. Once the initial shock subsided, Jon and Jessica sought practical solutions and adapted their lifestyle accordingly. When their fourth child was born, Jon became a stay-at-home dad.

Now 6 years old, Sam is small for his age, but he is an active, growing boy who is involved in activities at his church and in the community. What would Jon tell other dads about his experiences? “I would tell them that you can still be immensely proud of your kids,” he said.

### Matt Ripley

Matt Ripley remembers his first reaction upon learning that his newborn son Blake was deaf. “The first thing I asked was, ‘Is my son going to be able to play sports? Is he going to have the same opportunities as other kids?’” Matt said. “There are a lot of team-building activities that take place in athletics that really help you in life. I wanted to know if he was going to have the same opportunities I had.”

Matt was upset, confused, and filled with uncertainty. He wanted answers. Why had this happened? Was it something they had done? “When you first find out that your child has a disability, you are mad, you’re sad, you’re happy, you’re angry. You kind of go through all those different steps,” he said.

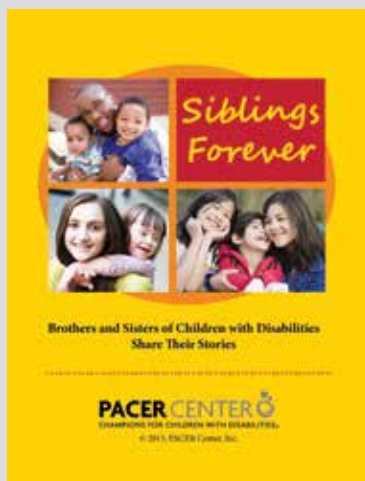
When things settled down Matt reverted to what he knew best — hard work. His wife Kelly left her career to focus on caring for Blake while Matt worked long hours to pay skyrocketing medical bills. Without even thinking about it, Matt had taken on the traditional role of “father as provider” while trying to emotionally support his wife.

“I guess I wouldn’t know any better,” he said with a laugh. “It is very important to me that my wife can put her full attention to working with our son. I also had to stay strong because my wife was quite emotional and I felt I had to be the rock to a certain degree and keep my feelings under control.”

While friends and family have been supportive, Matt knows it is impossible for others to understand what parents of children with disabilities deal with. “Everyone has struggles in life and I’m not a ‘pity party’ kind of guy,” he said. “I just go about my business. I think you need to keep your head up and stay focused on providing what’s best for your child.”

### **New! Siblings Forever: Brothers and Sisters of Children with Disabilities Share Their Stories**

Having a sibling with a disability presents a unique set of challenges and opportunities for brothers and sisters. By sharing the feelings and experiences of 21 different siblings ages 5 to 47, this new PACER booklet provides a way for families to explore the unique challenges and opportunities siblings may encounter. The booklet includes practical tips for parents on raising siblings of children with disabilities, along with resource and book lists about the sibling relationship that are suitable for all ages. Books are \$8 each or \$6 each for orders of 10 or more. Order online at [PACER.org](http://PACER.org) or call (952) 838-9000 and ask for item AP-44.



## **Tips from one dad to another**

### **1. Be informed and ask questions**

“It is really important to get as much information as possible. The more you know, the better you will be able to support your child and your family,” Matt said. “We didn’t have any idea what to do in our situation. We just kept asking questions.”

### **2. Face reality**

“You get to a point where you have to stop being in denial,” Jon said. “You have to get over yourself a little bit and realize that it is the kids who you are working for. There are always going to be a lot of well-intentioned people in your life who will tell you there’s nothing wrong, but if you listen to them, you can be late in the game of getting your child the help they need.”

### **3. Pursue early intervention**

“If you are wondering about your child’s behavior, you need to get it checked out,” says Steve. “Because of early intervention Ben has come leaps and bounds compared to other kids.”

Jon agrees. “To me not knowing is worse than finding out what the issue is,” he said.

### **4. Have high expectations**

“I think it’s important to not use the disability as an excuse,” Jon said. “If you know someone has a disability, it’s always easier to think that they can’t do something than it is to give them the benefit of the doubt. Kids sometimes need to be pushed.”

### **5. Do everything you can for your child**

“To me the whole goal of fatherhood is to help your kids reach their full potential whatever that may be,” Jon said.

Matt agrees. “I look forward, I don’t look back,” he said. “It is a struggle at times but at the end of the day we want to know that we have given him all of the opportunities that he can possibly have.”

Although the journey is often difficult, Steve believes you can still enjoy the ride. “Every day is a struggle to make Ben’s life better,” he said. “I try every minute of every day to help him, to encourage him, to try and lift him up. Having a child is a gift, it’s a blessing, and you need to embrace it.”

## PACER ANSWERS FREQUENTLY ASKED QUESTIONS

Judy Swett, PACER's early childhood advocate, has answers for your questions on child and family outcomes.

**Q:** My child has a history of running away from me and tends to isolate herself. Because of that, I think she will need a paraprofessional while she is attending preschool. How can I discuss this at our next meeting to plan the IEP (Individualized Education Program)?

**A:** Rather than telling the team that you think she needs a paraprofessional, begin the discussion by talking about her history of running, and then discuss the activities in the preschool classroom for which you think she will need additional adult support. Start with her bus ride to school and then go through the schedule for the classroom until the end of the day. Try to be specific about your concerns and focus on her having meaningful involvement and engagement in classroom activities and social interactions with peers. Bring up your concerns about her safety as well. For instance, if she has a history of running away from you unless you are holding her hand, let the team know about that. You will also want to discuss any needs she may have as far as toileting and dressing. If you and the rest of the team agree on the need for additional supports, the specific requirements for additional adult support can be written in the IEP under the Supplementary Aids and Services. If the rest of the team does not agree with you and the additional support is not included in the proposed IEP, you can use dispute resolution options to address the disagreement. (Call PACER and ask to speak with an early childhood advocate for more information.)

**Q:** I think my son would benefit from a full-day kindergarten program, but my district only offers a half-day program. There is an optional program for the extra half day, but parents have to pay for it. I can't afford the fee. How can I get my district to pay for the extra half day?

**A:** In order for the district to agree to pay for the extra half-day program, the IEP team would need to determine



that the additional program was necessary in order for your child to make progress on his IEP goals and in the kindergarten curriculum. Special education is specially designed instruction provided at no cost to parents to meet the unique needs of a child with a disability. This instruction is intended to help a child make progress in the general education curriculum. In the case of a school district which only offers a half-day kindergarten program at no cost to parents, the district is not obligated to pay the cost of the additional half-day.

*Have more questions? Call PACER at (952) 838-9000 and ask to speak with an early childhood advocate.*

### Receive Early Childhood Updates Via Text Message!

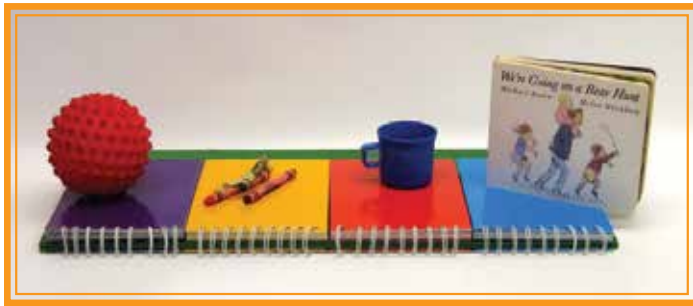
You can now sign up to receive updates via text message! This PACER service provides families and others with specific information from PACER programs, including notice of upcoming workshops, reminders, short tips and ideas, and new PACER resources. Your plan's text messaging rates will apply.

**Text "ECSE" to 51555**

## Do-It-Yourself: Assistive Technology Devices Made at Home

Assistive technology doesn't need to be expensive or sophisticated to make a positive difference in the life of a child with a disability. Sometimes the most effective devices can be built at home by do-it-yourself moms and dads. Here are a few examples worth exploring.

### Object Calendar



Transitions from one activity to the next can be difficult, especially after preferred activities like playtime and story time. When it's time to clean up or start a new activity, help make the transition easier with an object calendar. The object calendar will help your child anticipate what activity comes next. Divide a small shelf or a board into sections using masking tape. You can place objects representing an activity on a shelf or board divided into sections using masking tape. The number of sections depends on how many activities will be in your child's schedule. Find small objects that represent those activities. For example, toy food could represent lunch time, or a doll's pillow could represent nap time. Put the objects in the correct sequence on the appropriate section of the divided shelf. Once the activity has ended, your child can place a dish towel over the object to show that the activity is "all done."

### Access PACER's Archived Early Childhood Webinars Online

PACER's archived early childhood webinars offer a wealth of information on working effectively with professionals, finding funding programs and determining eligibility, and developing outcomes for your young child. Access any of PACER's free early childhood webinars ("Parents as Team Members," "TEFRA/Medical Assistance," and "Families Are Important") at any time by visiting [PACER.org/webinars/archive-listing.asp](http://PACER.org/webinars/archive-listing.asp).

### Communication Key Chain



Electronic communication devices can't always be taken everywhere—like to the pool or to a park—but without a way to communicate, your child may become frustrated and throw a tantrum. This communication key chain will allow your child to share food and activity choices without having a problem. First, create several picture communication symbols, print them out, laminate or place them in a clear key chain, and attach the key chain to your child's belt loop or backpack zipper.

### Adapted Grip



Some crayons, markers, or utensils may be hard for your child to hold. This adaptation can be used in coloring activities and to help make mealtime less messy. Use empty prescription bottles or an old 35 mm film container and remove the bottom of the container with a scissors. Insert the utensil or crayon into the hole and anchor it by placing playdough or modeling clay inside the container.

*These assistive technology ideas were adapted from EZ AT II. Books are available for \$5 each. Call PACER at (952) 838-9000 or (800) 537-2237 to order publication STC-24 or visit [PACER.org/publications/stc.asp](http://PACER.org/publications/stc.asp).*

## HELP YOUR CHILD LEARN TO SHARE



Sharing is not a skill children are born with, and learning to share can be a challenge. After all, who wants to put aside their own needs in order to make someone else happy? Fortunately, you can teach your child how to share and grasp how their sharing helps solve a problem or make someone else happy.

Learning to share takes practice. As an adult, it's up to you to provide your child with many different opportunities to practice sharing and see other children sharing, too. When a child learns how to share, he or she feels more confident and can play with other children more easily. Learning to share also gives children an important set of skills that help build friendships, a solid base to build on as they grow.

### Try This at Home

- Read books about sharing with your child. As the story unfolds, talk about how the characters might feel — a variety of emotions from frustrated and sad to happy and joyful.
- Point it out to your child when you see other children sharing: “Look Amanda, those girls are sharing their snack.”
- Make sure your child knows when you notice that he or she is sharing. “Thank you for sharing your crayons with me. I feel happy when you share.” Or, “When I came to pick you up from school, I noticed that you were sharing toys with Anthony. What a good friend you are!”
- Plan ahead if you anticipate a situation where sharing

might be a concern. “Avery is coming over to our house today for a play date. I know how special your doll is to you. Why don't we put your doll in a special place that is just for you, and then you and Avery can share all of the other toys.”

- Find opportunities to teach your child how to share. “Oh no! For desert tonight we only have three cookies left for you, Joey, me, and Daddy. I wonder what we can do?”

### Practice at School

Children are regularly taught how to share in school through stories, role-playing, and the use of puppets. One way teachers help children learn how to share is by pointing out how a friend looks and feels when a child does or doesn't share.

Teachers also encourage children to begin solving problems by themselves. “I see you have five cars and Ryan has none. I wonder what we can do?” Or, “I wonder which car Ryan can use?” Most importantly, teachers congratulate children when they solve sharing problems and recognize how proud they must feel after they share.

### The Bottom Line

Sharing is a skill your child will use throughout his or her life to get along with others during activities and to build friendships. Children who learn how to share are better able to understand the feelings of others, can negotiate difficult situations with confidence, and can feel secure in their ability to solve problems by themselves.



## HELP YOUR YOUNG CHILD GROW WITH THESE RESOURCES



These resources can provide you with information and support to help your child grow in important ways — and in the three outcome areas outlined by the U.S. Department of Education: building positive social relationships, acquiring and using knowledge and skills, and taking action to meet their needs. For more information on early childhood resources, call PACER at (952) 838-9000 and ask to speak with a parent advocate.

### **CDC National Center on Birth Defects and Disabilities | [cdc.gov/ncbddd/actearly/milestones/index.html](http://cdc.gov/ncbddd/actearly/milestones/index.html)**

The CDC provides bulleted information on developmental milestones for children ages 3 months to 5 years, and provides developmental warning signs for each age group. The site also offers interactive tools for users to specify certain ages, select areas of development, and examine expected changes in milestones over time. Visit [cdc.gov/ncbddd/actearly/downloads.html](http://cdc.gov/ncbddd/actearly/downloads.html) to view information and download materials on the “Learn the Signs. Act Early” campaign for parents and health care professionals.

### **TACSEI Families Community | [challengingbehavior.org/communities/families.htm](http://challengingbehavior.org/communities/families.htm)**

The Technical Assistance Center on Social Emotional Intervention (TACSEI) offers information and select resources that have been compiled specifically with the needs of families in mind. Just as a community changes and grows over time, this website evolves as new interactive elements and resources are created and added.

### **Minnesota Parents Know | [parentsknow.state.mn.us](http://parentsknow.state.mn.us)**

This state program offers trusted parenting information and resources to help your child grow, develop, and learn from birth through high school. Hosted by the Minnesota Department of Education, the website provides up-to-date, research-based information, strategies to support children’s learning, expert tips, an interactive early childhood and child care search, connections to Minnesota services and resources, and videos.

### **Help Me Grow | [parentsknow.state.mn.us/parentsknow/Newborn/HelpMeGrow\\_SpecialNeeds/](http://parentsknow.state.mn.us/parentsknow/Newborn/HelpMeGrow_SpecialNeeds/)**

If you have concerns about your child’s growth or development you can contact Help Me Grow and make a referral to Early Intervention or Early Childhood Preschool Special Education. Minnesota’s Early Intervention Services for eligible infants and toddlers are designed to meet the unique developmental needs of each child and their family. Preschool Special Education Services for eligible children ages 3 to 5 provide special instruction and related services. There is no cost to families.

### **Kidsmart: Guide to early learning and technology for home and school | [kidsmartearlylearning.org/](http://kidsmartearlylearning.org/)**

Whether you are just becoming comfortable with technology or have been using it for years, Kidsmart will help you understand what’s possible when it comes to young children and computer time.

### **PACER Center | [PACER.org/ec](http://PACER.org/ec)**

PACER’s Early Childhood Family Information and Resources Project offers individual assistance, workshops, and print and web-based resources for families of children from birth to age 5. The project webpage has numerous resources, publications, and links to organizations and programs that serve families of young children with disabilities, both in Minnesota and nationwide.

*For more information on early childhood resources, call PACER at (952) 838-9000 and ask to speak with a parent advocate.*

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(Alternate format is available upon request.)



## CELEBRATE YOUR CHILD ON PACER'S WALL OF CHAMPIONS!

Celebrate your young champions (birth to age 5) by submitting their photos to PACER's "Wall of Champions" on PACER's Facebook page. The photos will be posted with first names only. E-mail photos to Judy Swett, Early Childhood Coordinator, at [jswett@PACER.org](mailto:jswett@PACER.org).