



How to Find Appropriate Child Care

Finding suitable child care for your son or daughter with a disability can be a challenge—yet the benefits can be significant. The right program can help your child learn from typically developing children, form friendships, and develop a positive self-image, say early childhood experts.

As you begin your search, remember that a good program is designed to meet the individual needs of each child, and its staff should be willing to make modifications if necessary. A good program also will encourage your participation and offer to have its staff communicate regularly with your child’s health and educational providers, say PACER experts.

When considering child care providers, you may want to begin by asking about their:

- License and accreditation
- Experience in caring for children with special needs and any specialized training staff may have taken
- Staff-to-child ratio
- Cost and any financial assistance available
- Process for handling children’s illnesses and medical emergencies
- Discipline policies

Before making a decision, visit each program at different times during the day. Look for such things as:

- A clean, safe environment, inside and out
- Happy, active children
- A variety of toys and learning materials
- Positive interactions among staff and children
- Children with special needs being included in group activities



- Activities and play materials that are adapted for children with special needs
- A suitable place for children to nap
- An outdoor play area that is safe and well supervised

After visiting a few programs and selecting one or two that you think might best meet your child’s needs, check references. Ask other parents who use the center questions such as:

- Is their child happy here?
- Is the caregiver reliable?
- Would they recommend the program?
- Do they feel respected and valued?
- Does the staff understand and respect their culture and family values?

If you like what you hear, ask yourself:

- Would my child be happy here?
- Can the program meet my child’s needs?
- Are the staff’s values similar to mine?

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Equipped with this information, you will be able to make a more confident, informed choice about a child care program. After you've made your selection, you can begin working with the staff to prepare them for your child's arrival.

You can start by completing all necessary paperwork, such as information release forms if you want the staff to be able to communicate with your child's other providers. You also could suggest some reading material about your child's disability or special needs and share any other suggestions that might assist the staff in caring for your child.

If your child has an Individual Family Service Plan (IFSP) or an Individualized Education Program (IEP), it would help to share a copy of the document with the staff. Be sure to let the staff know about any services that your child receives from other agencies that should be coordinated with child care. If necessary, ask the IFSP or IEP team to consult with the child care staff.

You may even want to schedule regular meetings with all the people involved in your child's life. If the child care staff cannot attend IFSP or IEP team meetings, ask them to prepare written comments about your child's progress and any observations that they believe are important for the team to know.

You also may want to discuss the following items with the staff prior to your child's arrival:

- Special equipment, considerations, or accommodations that your child requires
- Your child's personality and temperament
- Favorite toys, games, activities
- Your child's communication style and needs
- Physical or health-related conditions, including medications that your child takes

- Ways the staff can prepare the other children for your child's arrival, such as sharing books about disabilities or preparing responses to potential questions regarding your child's disability

With the staff now ready, consider preparing your child for this new experience. You and your child could, for example, visit the staff and other children a few times before starting the program.

Once your child begins attending child care, good communication between the staff and family can keep things working well. Sending a notebook with daily information back and forth between home and the child care provider works well for many families.

Finding a child care provider who is a good match for your child with disabilities can take time. To avoid making a rushed decision, try to begin looking several months before you need the placement. The results of your effort will be well worth the time invested.

Information in this article was provided by PACER's Early Childhood Project.

Child Care Resources

Whether you are a parent seeking a child care provider, an early childhood teacher, or a child care provider wanting to learn more about including children with special needs, PACER suggests contacting these state-funded organizations.

The Center for Inclusive Child Care provides free child care consultations and resources to parents, licensed professionals, and friends, neighbors, or family members who provide child care. Online services help you:

- Find answers to frequently asked questions
- Submit a question and receive a personal response
- Find a consultant to help answer questions and solve inclusion problems

Visit www.inclusivechildcare.org or call 651-603-6265 to learn more.

The Minnesota Child Care Resource and Referral Network, a statewide network of community agencies, offers a comprehensive, individualized listing of child care options, including the providers' experience with children with special needs. Services include:

- Child care resources and referral services statewide
- Searchable online database of caregivers
- Statewide referral line, 888-291-9811

Visit www.mnchildcare.org or call 888-291-9811 to learn more.

Simple Pleasures

Imagine an amazing technology that could help your young child with disabilities learn to communicate, read, and count. Picture an incredible piece of equipment that you wouldn't need to plug in, boot up, or reprogram. Visualize a shelf full of such technology in your home, at the ready to help your child. Now picture the price tag. Hundreds of dollars? Thousands? Try \$15 — or less.

Not all assistive technology is expensive or even electronic. Much of it is at your fingertips at home or at your nearest discount store. Believe it or not, a cookie sheet, a potato chip can, and even a film canister can be used to create tools that can help your child gain important early literacy skills.

Literacy is more than reading. It involves a variety of skills such as being able to manipulate a crayon or pencil, turn pages, position a notebook, and other abilities. That's where some ingenuity with everyday objects can help your young child develop early literacy skills.

Here are some ideas to try:

Get a grip!

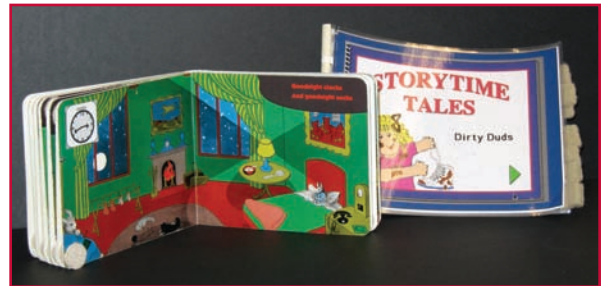
- Polyethylene foam, used to wrap pipe, can be used to make a grip for sidewalk chalk, markers, pencils, crayons, or other implements that can be hard to hold. It also can help children who have sensory issues feel more comfortable writing and drawing.



- A film canister with a slit in the top makes a great crayon holder for children with fine motor skill challenges.

Book 'em!

- Turning pages can be made easier by attaching Velcro tabs to each page. "Page fluffers" — small felt discs that separate pages — make turning easy. These devices work best on board books.



Alpha-you-betcha!

- Buy magnetic letters and use them on the refrigerator, a magnet board, or a cookie sheet.
- Stamp out illiteracy with alphabet stamps — big letters your child can press into ink or paint and stamp onto paper. They come with either big grips or foam grips.

Write on!

- Problems writing or drawing on a flat surface? Make a slant board by securing a potato chip can to the back of a clipboard.

Picture this!

- Children who cannot speak often find picture symbols a useful way to communicate. Put pictures of everyday objects, places, and people on small paper squares, laminate them, and hook them on a keychain your child can carry and use to show others what he or she would like.

For more low-tech, no-tech literacy ideas, call PACER's Simon Technology Center at 952-838-9000.

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Project KITE Promotes Assistive Technology for Home and School

PACER's Project KITE (Kids Included through Technology are Enriched) trains teams of professionals and parents to use assistive technology at school and home. Its goal is to promote inclusion, active participation in learning, and peer interactions for children ages 3 to 8 with disabilities. Learn more at www.pacer.org/kite or call Tenley Pettyjohn at PACER, 952-838-9000.

Service Coordination Helps Families Thrive

With five children under 5, Sara Hayden knows a bit about coordinating things. From mealtimes to naptimes to everything in between, she knows what it takes to keep family life running smoothly. “I have five different kids who need five different styles of parenting,” she says of 5-year-old Mason, 3-year-old Madilynn, and 2-year-old triplets Cody, Averi, and Wyatt.

Some of those coordination skills she learned three years ago, when Madi was born with Down syndrome. “I was 29, and there was no indication from any of the tests during pregnancy that she had Down syndrome,” Sara says. “She sailed under the radar.”

Surprised and not sure where to turn or even what questions to ask, Sara and her husband, Chris, soon learned about something called service coordination. Available at no cost to families who have a child with disabilities from birth to age 3,

this early intervention service offers a single point of contact for accessing a variety of community resources that can help both the child and the family.

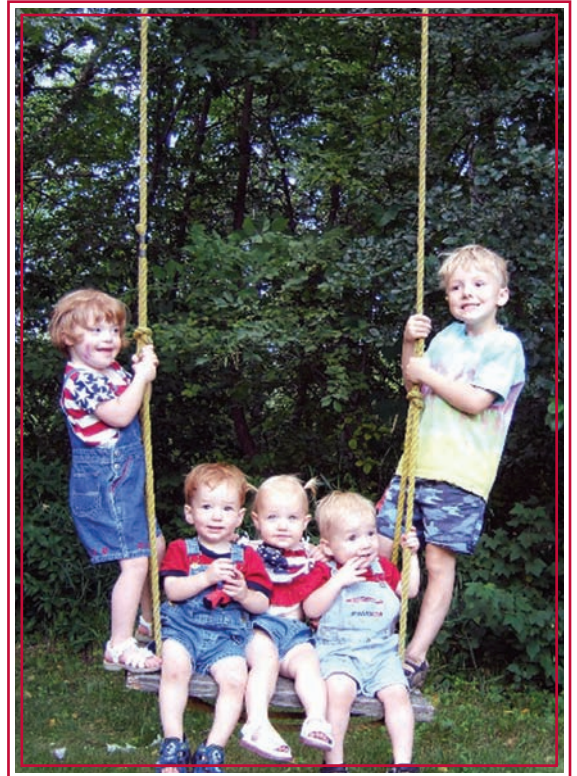
“Within two weeks of coming home from the hospital, we received a call from a service coordinator,” Sara recalls. “She said that she and the school district’s special education teacher would make a home visit to assess Madi and see what her needs would be.”

The Haydens were delighted. “When you’re new at this, you don’t know what you need. The service coordinator guides you through the process of finding the resources that can help,” Sara says.

Denny McBain understands exactly what Sara means. As a service coordinator with the Early Childhood Information and Referral of Ramsey County, he works with families like the Haydens and knows how beneficial service coordination can be.

“Coming into a new experience like having a child with a disability, it’s hard to know what questions to ask or resources to look for,” Denny says. “Service coordinators have the expertise to know what’s appropriate, needed, and available. For example, there are eligibility requirements for some programs that would not be available for all children.

“Service coordination is not intended to be direct service to the child,” he adds. It’s not the nursing



With five children under 5, the Hayden household is in full swing with Madi, Wyatt, Averi, Cody, and Mason.

care, occupational therapy, physical therapy, mental health services, or social support itself. Rather, it’s about pointing families to the school districts, counties, private providers, hospitals, clinics, doctors, and others who can help them meet their needs.

“We help the parent learn how to be a stronger advocate and search out the resource information, service options, and family supports they need,” Denny says. After all, he adds, “families know their kids the best.”

Service coordination includes a wide range of assistance, including:

- finding the best medical services or facility for a child
- making referrals for such things as public health nursing or developmental disability programs



Service coordinator Denny McBain

- assisting families with Social Security applications
- connecting families with other parents who have similar issues
- facilitating Individual Family Service Plan (IFSP) meetings

“Not all service options are appropriate for all families,” Denny adds, noting that it’s fine to call the service provider when things aren’t going well. “We want families to let us know what is working and what is not working. We want to focus on what they need.”

For the Haydens, help came in many ways. “Our service coordinator, Julie, helped us make doctor appointments for Madi and came with us when the doctor did the developmental assessment. She was there to communicate what was going on. She even took notes for me. The help was so practical,” Sara says.

Service coordination also helped the Haydens find speech and physical therapists for Madi and helped them sign up for various family support grants and programs. Julie managed the paperwork when the team developed Madi’s IFSP.

When Sara was pregnant with the triplets and on bed rest for 20 weeks, Julie even arranged for Madi’s therapists to come to the house. “She made sure the whole family was taken care of,” Sara says.

Service coordination provided the Haydens with another major benefit: It taught them how various systems work—from IFSP teams to Social Security to waiting lists for certain programs and services. Since service coordination ends on a child’s third birthday, having that knowledge would be an im-

portant asset in the future. “Julie played such a big role in getting me ready to take over,” Sara says.

Grateful for all the help she has received, Sara has found a way to give something back—even in the midst of raising five young children. “Julie connected me with other parents of kids with disabilities,” Sara says, noting that such a connection was invaluable. Consequently, she has spent the past two years serving on the Family Support Committee, part of Washington County’s Interagency Early Intervention Committee (IEIC). IEICs coordinate interagency collaboration and develop local programs to ensure that a system of services exists to meet the needs of children with disabilities and their families.

Along with others on the committee, Sara plans activities for families of young children with disabilities. Coffees, play dates, swimming night at the Y, resource fairs, sign language classes, and more build a network of support and resources.

“I love it,” says Sara, this year’s chairperson. “I just want to help the moms and dads meet other parents who understand what it’s like to have a child with a disability. It’s such a vulnerable time. The ones who are having a harder time, they just need that support,” she says.

For other families of young children with disabilities, Sara has one message: “Use your service coordinator. Call ’em, call ’em, call ’em. That’s what they’re there for. They have an abundance of resources and knowledge we as parents don’t have. Don’t be afraid to reach out.”

How to Access Early Intervention Services—Including Service Coordination

If you live in Minnesota and have a child from birth to age 3 who has disabilities or developmental delays, you may qualify for a variety of early intervention services, including service coordination. These services are available statewide, but they may be accessed differently from one community to the next.

In most cases, the process begins with a referral to your school district’s birth-to-3 assessment team. You can call the school district directly yourself, or someone else can call for you. Often, the referral is made by a relative or the child’s doctor, public health nurse, child care provider, child protection worker, foster parent, clinic, or hospital.

After a referral is made, an early intervention professional will call you and ask if you are interested in being connected with an assessment team to determine if your child may be eligible for services through that school district.

If so, he or she will conduct a preliminary telephone interview to find out about your child’s development and health. That information will then be given to the school district to decide if someone should come to your home to further assess your child and determine if he or she qualifies for services.

The state is required to offer early intervention services, but families have the option of accepting or declining any or all of them.

If your child is already receiving early intervention services, you have a service coordinator. His or her name and contact information are listed on the Individual Family Service Plan (IFSP).

Questions? Call PACER’s Early Childhood staff at 952-838-9000.

I Wish I Knew Then What I Know Now

If you could fast forward into the future, would you want to know now some of the insight that you'll gain over the years as you raise your young child with a disability? Would you like to have the perspective of time and experience today?

There's no magic time-travel machine that can give you that view, of course. The next best thing, however, might be insights from parents who have been through the early years of raising a child with a disability.

Three of PACER's parent advocates who now have teens and young adults with disabilities share their views about the challenges they faced when their children were small. Here's what they wish they'd known then.



**Barb Ziemke,
mother of an
18-year-old
son with a
developmental
disability**

I wish I had ...

... **taken more time to enjoy the satisfying moments of being a parent.** As I look back at photos, I think "he was doing pretty well as a 2-year-old." Focusing on learning about my son's disability sometimes didn't allow me to just enjoy his 2-year-old-ness.

... **lightened up a little and not taken everything so seriously.** Some of the things I thought were so urgent at the time weren't as urgent as I thought.

... **looked at things more holistically and devoted more effort to building informal social supports with the family and community.** It's the people you have relationships with who will provide support for your child in the long run.

... **had higher expectations of my son,** especially around responsibilities, chores, and contributing to family life. I let him off the hook too much because things were more challenging for him or because I didn't have the time and energy to supervise him.

... **trusted other people more with my son and taken more risks** to assume that others would know what to do with him in a social situation. I felt like I had to be there to take care of him. People would have figured things out. I assumed family wouldn't want to be "burdened," but I think many of them would have enjoyed it and risen to the occasion. I didn't give them enough chances to do that.

... **done less apologizing for my son's differences and the extra challenges** that they brought to the situation. It's nothing to be apologetic about because someone is different. I wish I'd seen disability as a natural part of life and expected that others would, too.

Curtis Wenzel, father of a 14-year- old son with autism spectrum disorder



I wish I had ...

... **realized that the real experts on our son were myself and my wife.** Doctors,

teachers, and others might have good intentions and expertise, but ultimately, we are the ones who have to make the decisions and who have the responsibility for raising our child.

... **known that my son was okay, that having a disability didn't mean he would have a terrible life.** Some days you see the happiness that he has and the richness of his life, other times you see the limited aspects because you are dealing with a problem. I now understand that whatever he experiences, he is experiencing what it is to be a human being. I really am convinced all human creatures basically have that, no matter what challenges they face.

... **discovered earlier there was a specific process for receiving resources** through the education system and elsewhere to assist us.

... **known it was okay to be mad at my kid with a disability** and not feel guilty for having a normal human response to what can be really challenging behavior.

... **understood how much you have to be confident and straightforward about what your kid's needs are** without becoming a nervous Nelly or shrill, and how you need to learn to work cooperatively with people.

... **known it's better to learn how to forgive people** who act as though the disability is your fault than to bank that flame and keep an ember going. You have to forgive people for their lack of knowledge.

... **figured out earlier that the disability was something he was going to have to live with, that I wouldn't be able to "fix" him.** I've realized this is who he is—and there's a lot that's positive about it. I find my son with high-functioning autism tends to be honest, loyal, and has a great amount of information available at his fingertips. Because of his literalism, he has unique perspectives.

Renelle Nelson, mother of a 26-year-old son with developmental delays and mental health needs



I wish I had...

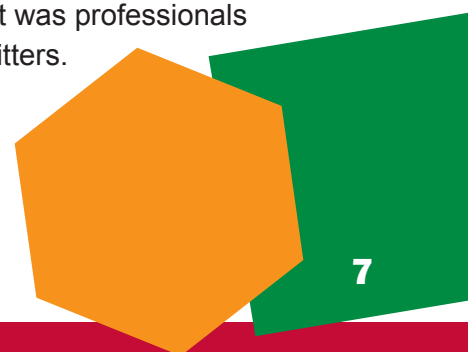
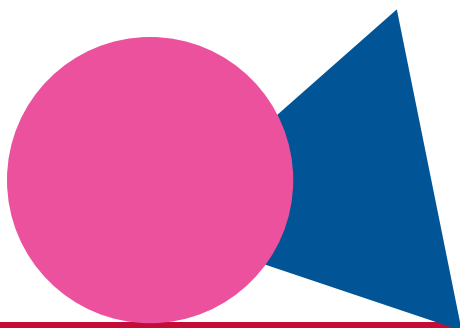
... **picked my battles.** When you have a child with many needs, you spend a lot of time focusing on that to the detriment of others. It takes on a life of its own. If you can keep it in perspective and figure out how to prioritize what is essential, everyone is better off for it.

... **asked my family, "What do you think you can handle? What is most helpful to you, and what can we do to make it happen?"** I didn't do that, but I wish I had planned family meetings and received everyone's input.

... **networked with other parents more.** You are so into the situation of your own little world. Networking would have given me a broader perspective, pulled me out of the little hole I was in, given me more opportunity for informal support—which I needed but didn't realize I needed.

... **put as much priority on setting aside time for myself** as being the glue in the family.

... **worked harder to develop a cadre of caregivers for my son.** I was a proud parent and thought I could handle it all. In hindsight, I think my son and I would have benefited more from having a more comprehensive system of care around him, whether it was professionals or a network of babysitters.



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(Alternate format is available upon request.)

TECHNOLOGY

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More Great Literacy Ideas from PACER

Toys: Universal Tools for Learning, Communication, and Inclusion for Children with Disabilities

Playing with toys helps build the foundation for reading, writing, and other important skills. Learn how to select toys appropriate for your child and find many suggested playthings. Free for parents; \$3 for professionals.

EZ AT: Assistive Technology Activities for Children Ages 3-8 with Disabilities

PACER's latest guide includes nearly 50 activities for use at home or school. \$10.

Let's Talk Activity Cards

Let's Talk activity cards provide an enjoyable, easy way to use everyday moments and places to help improve your child's vocabulary and speaking skills — the first steps in learning to read. Designed for children ages 2 to 6, the illustrated, easy-to-read cards include simple directions. One set is free to Minnesota parents of young children with disabilities. Additional sets are \$4. Ten or more sets, \$2.50 each.



To order any of the above materials, call PACER at 952-838-9000 or 800-537-2237 (toll free), or visit www.pacer.org.