Parent leaders are vital in early childhood education

Parent leadership and advocacy has always played a major role in special education services for children with disabilities. Along with professionals, it was parents who expressed the desire for equal access to education and helped to successfully encourage Congress to pass the Education for All Handicapped Children Act in 1975, which is now the Individuals with Disabilities Education Act (IDEA).

Parent involvement has continued to be an important component of special education law, policy, and services. Parts of IDEA focus on support for parents’ involvement in their children’s education. PACER Center provides assistance to parents in a variety of areas, including parent leadership training.

Parent leaders offer unique perspectives. They bring a sense of reality to ideas and tasks, improving the quality of services and supports, ensuring that programs and policies meet the needs of families, and anticipating the impact that system changes will have on children and families.

Leadership roles vary. Parents may volunteer in their child’s school, serve on a school district or regional advisory committee, or pursue an appointment to a state or federal task force. Parents may also join organizations such as PACER, speak at a school board meeting, or contact their state and federal legislators.

The common ideal among all parent leaders is a motivation to make sure that systems work for families and children with disabilities in a way that respects their values and cultures.

Wanting to know more
Jamie Burden is beginning her journey as a parent leader. She attended PACER’s Early Childhood Family Leadership Summit in April, and is a member of the Williams Syndrome Association (WSA) and her school district’s Special Education Advisory Committee (SEAC). Burden described PACER’s leadership summit as a “great outline for how the system is intended to work.”
was impressed by the positive tone and the opportunity to speak with other parents who are also considering leadership roles.

“I just felt completely clueless, but the PACER workshops and Special Education Advisory Committee have been an immersion for me,” Burden said. “We need to have a voice in the school system and in the community. My involvement is all about educating myself and wanting to be part of that community.”

Burden’s five-year-old daughter Norah was diagnosed with Williams syndrome, a genetic condition, when she was five weeks old. Features of Williams syndrome can include cardiovascular issues, developmental delays, and learning disabilities, among other symptoms.

Norah attends school in an inclusion room in her district’s kinder prep program. She receives occupational therapy, speech therapy, indirect physical therapy through the school’s adaptive physical education department, and special education services.

“I want to be supportive of the school,” Burden said, adding that her involvement is a way to give back. “I’m less afraid to assert myself. I learned that the way to get qualified is to jump in.”

Burden previously attended PACER's Day at the Capitol in March, where she received training on sharing her personal story with elected officials.

“Our story is valued,” Burden said. “You don’t have to know the law to be qualified to speak about your experience.”

Share your story

Sharing her story led Angie Strobel to her current leadership role in the Parent Partner Program through the Region 11 Interagency Early Intervention Committee (IEIC), which serves the seven-county metro area. She was seeking a greater role on the IEIC and so she reached out to parent representative Lisa Keitel, who asked Strobel to talk about her personal experience at a local event.

“There is no better way to have that compassion and experience without having gone through it,” Strobel said. “We can share what we have learned. We’re helping those who come after us.”

Strobel’s son Ray recently turned six years old. From the time he was two and a half, Strobel began noticing “nuances” and “quirks,” though he consistently met his developmental milestones. She talked to her pediatrician, and at age three, Ray was referred to a psychologist, who ultimately dismissed Strobel’s concerns.

“But my ‘mom voice’ wouldn’t be quiet,” Strobel said. Her instincts were proven right when Ray’s complaints about the lights and noise at his childcare provider led to a diagnosis of sensory processing disorder and adjustment disorder, as well as serious motor functioning issues.

In her research, Strobel found Help Me Grow, an interagency initiative of the State of Minnesota, and Danielle Mickelson, then her school district’s Early Childhood Supervisor.

“I knew nothing at the time about services offered by the school district for early intervention,” Strobel said. “But Danielle really listened to me and I felt safe. I could share my fears and concerns.”

Strobel encountered pushback from her childcare provider, who had rarely communicated concerns but was now threatening to expel Ray from the program. That led Strobel to become a parent leader and advocate, and today she talks very freely about her experience — even in the park or at the grocery store.

“The more you talk about it, the more people will be aware,” she said.
Strobel has also attended PACER trainings and workshops, and she is committed to sharing her parent’s perspective with graduates of nursing programs and early educators. Professionally, she works in law enforcement, and would like to implement autism trainings for officers.

“Find what makes you passionate, find something that really speaks to you,” Strobel said. “Trust your gut, find your niche. It can be a fabulous fit to make a difference in your area and help other children with disabilities.”

**A new career path**

Jessica Mattson spent 10 years in the hospitality management field before transitioning to a stay-at-home mom with her son, Ben.

When Ben was about 18 months old, Mattson began noticing he was not talking and would not interact with other children. Ben was three years old when he was diagnosed with autism spectrum disorder (ASD).

“I didn’t have any awareness of special education at that time,” Mattson said. “I had a concern about the diagnosis, but you come to a realization: How am I going to figure all this out?”

Mattson’s mother, along with her husband, are special education professors, and they recommended PACER. Mattson was selected to attend a leadership and advocacy training in 2010 and continued to participate in the early childhood parent leadership summit in subsequent years.

Five years ago, PACER Executive Director Paula Goldberg asked Mattson to join PACER’s board of directors.

Mattson then connected with Jolene Pearson, a former Interagency Early Intervention Committee coordinator and now an early childhood professor, who brought Mattson onto the local IEIC, where Mattson continues to serve as a parent representative. She is also finishing up her four-year term as a parent representative and co-chair on the governor’s Interagency Coordinating Council (ICC) on Early Childhood Intervention.

“Every day, I was learning to advocate,” Mattson said. “I had a place where I felt my voice was important, and I believe we can make the system better for other families.”

But Mattson wanted to do more, so she created her own special studies master’s degree at St. Cloud State University called Early Childhood Special Education: Community and Family Studies.

An internship at the Minnesota Department of Education later turned into a full-time job. Mattson is now the Parent Aware Coordinator and works in other roles in the Early Learning Division.

Her advice to professionals: “Parents don’t arrive and learn about the systems on their own. It takes intentional leadership to educate and show them where and how they can be involved. I attribute much of my success to the people that took the time to teach me and continue to support me today.”

For parents, Mattson says, “Come as you are and use the gifts you have to be a part of making the system better for all families.”

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**Run Walk Roll AGAINST BULLYING**

Register now for PACER’s Run, Walk, Roll Against Bullying on Saturday, Oct. 1, presented by the Friends of PACER. This fun, family event, which raises awareness and funds for PACER’s National Bullying Prevention Center, will take place at Mt. Normandale Lake Park in Bloomington, Minn. It includes a four-mile run and a two-mile fun walk/roll, followed by presentations, speakers, and live music. Registration is $20 for ages 16 and older, $10 for ages 7 to 15, and children 6 and under are free.

Register online at PACER.org/RWR
Do you have questions about your young child’s early learning? Judy Swett, PACER’s early childhood staff advocate, provides helpful answers.

**Q:** I am interested in serving on my school district’s Special Education Advisory Council (SEAC). How can PACER help me find information on the committee and the work that they are doing?

**A:** You can contact your district’s special education director. If you do not have this information, feel free to contact PACER and we can help you access it. When you contact the special education director, ask for contact information for the current chair and if minutes from previous meetings are available on the district’s website. You can find additional information regarding SEACs on PACER’s website at PACER.org/leadership.

**Q:** I am interested in learning how to contact my state and federal legislators, and how I can tell my story or comment on a piece of legislation. Where can I find this information?

**A:** You can find contact information for your local leaders, and state and federal legislators at www.usa.gov/elected-officials. If you want to learn how to tell your story, you can find information on PACER’s website at PACER.org/leadership/handouts/ParentStory.asp.

**Q:** I would like to take on a leadership role, but I am not sure that I have enough knowledge about special education beyond what I have learned about how to advocate for my own child. How can PACER help me learn more?

**A:** To begin, you may want to attend some additional workshops at PACER in order to get a solid foundation of special education law and policies in Minnesota. The PACESETTER and the PACER workshop e-blast both have information about upcoming workshops, all of which are free to families. If you are not currently subscribed, go to PACER.org/newsletters, click on the publication you wish to receive and then click the subscribe button.

PACER has developed an Individual Effectiveness Plan for Parent Leaders in Advisory Positions that is available at PACER.org/leadership/handouts/IEPparentleaders.asp. This publication can be downloaded as a document for you to complete.

PACER also has many publications that are free to parents in Minnesota. You can also access and download many handouts that discuss various issues in special education. These are available at PACER.org/publications. You can also request that they be mailed to you.

Contact Judy Swett, PACER’s early childhood coordinator, for some additional information on how you might find out about various leadership opportunities. Call (952) 838-9000 or email jswett@PACER.org.

*Have more questions? Call PACER at (952) 838-9000 and ask to speak with an early childhood advocate. If you do not have access to a computer, call PACER and ask for copies of information to be mailed to you.*
Minnesota offers many ways for children with disabilities and their families to enjoy summer activities together in a safe and welcoming way. A few ideas are listed below. Additionally, PACER Center provides information on how the Americans with Disabilities Act (ADA) impacts accessibility to social and recreational activities for persons with disabilities at PACER.org/publications/adaqa/summer.asp.

**Take the lead**

If you need help finding a program for your child, call and ask for more information. You can also ask about volunteering to start a new program. Here are some examples:

- **Parks and Recreation**: Many cities and communities offer summer activities, including adaptive recreation leagues. You can also contact your local Parks and Recreation department to find out which playgrounds feature accessible play equipment.

- **Neighborhood libraries**: Most neighborhood libraries have a summer reading program and story hour. Ask the library to order new age-appropriate books, particularly those that feature characters with disabilities.

- **Fire stations**: Call your local fire department and arrange a tour or find out when it will be hosting its annual open house.

**Reel Movies for Real Needs**

Marcus Theatres Reel Movies for Real Needs is a specially designed program to serve families with special needs, such as autism, who seldom attend select first-run movies. This program creates a welcoming and comfortable environment — lower sound, lights up — where families with children who need accommodations will be able to share the experience of seeing family friendly films at a theatre. More information and a schedule of films is at marcustheatres.com/marcus-specials/sensory-specific-films/reel-movies-for-real-needs.

**Free Sensory Flicks, Mall of America, Bloomington**

Sensory-friendly films are shown on Saturdays at 10 a.m. to offer families of children with autism an opportunity to enjoy an outing in a safe and accepting environment. Audience members are welcome to dance, sing, and move around in response to the film. Visit theatresmoa.com/event/free-sensory-friendly-films.

**Navigating MSP Airport**

Those who have family members with special needs avoid flying because they are unsure how they will respond. In an effort to ease the anxiety associated with an airport visit and flying, the Metropolitan Airports Commission (MAC), Fraser and the Autism Society of Minnesota (AuSM) have teamed up to create the Navigating MSP Airport program, which includes events designed for individuals with special needs that guide families through the steps of an airport visit, from walking in the door to finding their seat on a plane. For information, contact Shelly Lopez at (612) 726-5239 or Shelly.Lopez@mspmac.org.

**Minnesota Children’s Museum, St. Paul**

The Minnesota Children’s Museum is dedicated to providing children with a fun, hands-on and stimulating environment to explore and discover. Admission is free on third Saturdays and special membership options are available.

**Minnesota History Center, St. Paul**

This interactive museum, with both permanent and changing exhibits, hosts concerts, lectures, family days and other special events throughout the year.
THE BENEFITS OF SCREEN TIME FOR YOUNG CHILDREN

Before the increased use of computers, smart phones, and tablet devices, screen time was defined as passively sitting in front of a television. Today, newer technologies are evolving and advances happen quickly. There is anecdotal evidence showing that screen time can have a positive impact for all children. However, it should always support positive parent-child relationships.

Apps reinforce learning

For some children with disabilities, technology can give them a voice in the form of an augmentative and alternative communication (AAC) system and open new doors of possibility. For others, it can provide resources that help children anticipate what is coming next and what is expected of them.

Additionally, there are countless applications that enhance and reinforce learning, social skills, play, and language and communication.

Technology can be motivating

Digital, interactive media — such as applications or devices — can be highly motivating. It can boost skill development when used in appropriate amounts and with appropriate supervision.

PACER’s Simon Technology Center provides guidance for early childhood educators on the use of technology in ways that support young children’s cognitive, social, emotional, physical, and linguistic development.

Balance is key

Face-to-face interaction between parents and children is very important. All children should have many opportunities to play and explore when tablet or smart phone screens are turned off.

Finding a way to balance the use of technology may be challenging for some families. Below are a few tips to try:

- Create rules and structure around technology use. Have technology-free areas and limit technology use to certain times of day. (An exception to this would be for children who use technology as their method of communication or to reduce anxiety.)
- Model responsible technology use by following the same rules! If your children aren’t allowed to use technology during dinner, make sure you put your devices away, too.
- Maximize the time you already use technology to connect with other parents online, or follow blogs of parents or professionals using similar technology. Search Facebook or Pinterest for activities to enjoy with your kids when the screen turns off.

Technology is one tool

Mobile devices contain features that provide children and adults a wealth of educational and engaging material to which they may not otherwise have had access due to physical, behavioral, or social limitations.

These devices can do things as complex as providing a way to communicate and as simple as being a conversation starter between children. Technology is a tool, and like any tool its effectiveness and value is determined by how it is used.

Contact PACER’s Simon Technology Center to request a consultation for your child or to join the Lending Library, which lets families borrow some of the newest educational and disability-specific software and devices. For information, call (952) 838-9000 or visit PACER.org/stc.
RESOURCES TO SUPPORT YOUR CHILD’S DEVELOPMENT

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.

Help Me Grow | helpmegrowmn.org

Some young children need extra help to learn and grow. Help Me Grow is a resource where parents can view developmental milestones, learn if there are concerns, and take the lead in seeking additional support or in referring their child for a comprehensive, confidential screening or evaluation at no cost. Eligible Minnesota children from birth to age 5 can receive services in their home, child care setting, or school. These services are free regardless of income or immigrant status. An interagency initiative of the State of Minnesota, Help Me Grow is a partner with organizations and agencies statewide, including Minnesota Department of Education, Minnesota Department of Health, and Minnesota Department of Human Services.

16 Gestures By 16 Months | firstwordsproject.com/about-16by16

FIRST WORDS® Project, from the Florida State University Autism Institute in the College of Medicine, has developed a series of online lookbooks that illustrate the important social communication skills that children should reach by the age of 16 months. The first lookbook, “16 Gestures by 16 Months,” was released in 2015. Four additional lookbooks will be released later this year.

Good communication development starts in the first year of life and extends far beyond simply learning how to talk. Communication development has its roots in social interaction with parents and other adults during everyday activities.

Though this project was developed by the Autism Institute, it can be a helpful resource for all families.

Technical Assistance Center on Social Emotional Intervention | challengingbehavior.fmhi.usf.edu/communities/families.htm

The Technical Assistance Center on Social Emotional Intervention for Young Children (TACSEI) contains the research that shows which practices improve the social-emotional outcomes for young children with, or at risk for, delays or disabilities. This website is devoted to families and offers practical, everyday tips on how to deal with social-emotional development and challenging behaviors.

Center on Technology and Disability | ctdinstitute.org/library/early-childhood

Center on Technology and Disability (CTD) is funded by the U.S. Department of Education’s Office of Special Education Programs (OSEP). The Center is designed to increase the capacity of families and providers to advocate for, acquire, and implement effective assistive and instructional technology (AT/IT) practices, devices, and services. PACER Center is a partner in this project.

PACER Center | 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 website has numerous resources, publications, and links to organizations and programs that serve families of young children with disabilities, both in Minnesota and nationwide.
You’re invited! Simon Technology Center’s Family Fun Day is Sept. 17

From high-tech gadgets to technology that supports everything from play to learning to employment, there will be plenty to explore and try at the Simon Technology Center Family Fun Day and Tech Expo. Come to PACER Center on Saturday, Sept. 17 from 10 a.m. to 2 p.m. to explore the possibilities of assistive technology and enjoy interacting with a variety of devices for children, teens, and adults. Attend mini sessions to see iPad app demonstrations, get creative with accessible art and do-it-yourself technology, learn about PACER’s resources, and more.

The event is free but advance registration is required. Register online at PACER.org/stc or call (952) 838-9000.