

Advocacy Made the Difference for Molly



Molly Longtin

Molly Longtin loves her job so much that the words bubble out of her mouth when she talks about it. “It’s been such an incredible experience,” she says of her first year as a middle and high school science teacher at Arete Academy, the Midwest’s first school designed for twice-exceptional (2e) learners (students who are gifted and talented, but learn differently due to one or more disabilities). “I get to teach students who are like me!”

It’s been a long road to success and independence for Molly. She has significant progressive hearing loss, complicated by a cleft palate, and is herself a student who struggled in traditional schools. “We always knew Molly was bright, and that she wasn’t learning because she couldn’t hear. She would come home at night and we would have to try to re-teach her everything she didn’t learn in school that day,” said Julie Longtin, Molly’s mom.

“The problems really began in elementary school,” Molly recalled. “It was difficult being the only one in class with hearing aids – the only one who couldn’t hear. It affected my academics and I felt stupid. I couldn’t learn because I didn’t have the same access as everyone else. I had to work significantly harder. I was exhausted and it still wasn’t enough.” In addition to struggling academically, Molly was severely bullied.

The Longtins tried various options in an effort to get Molly the education she was entitled to. One year, Julie homeschooled her daughter and hired a private American Sign Language (ASL) tutor to provide better access to language for the years ahead. Julie and Eric Longtin turned to PACER for help when Molly re-entered public elementary school and was repeatedly denied the services of an ASL interpreter.

PACER’s involvement

When Julie called PACER, she was connected to Deanne Curran, a parent advocate who specializes in working with families of Deaf, DeafBlind, and hard of hearing students. Deanne herself is the parent of two DeafBlind young adults.

“Deanne told us we should request a change in Molly’s IEP [Individualized Education Program],” Julie said. “She was able to get the district to agree to a six-week trial with an ASL interpreter.”

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During the trial, the change in Molly's learning was dramatic. She went from earning D's and F's to A's and B's. "I didn't realize the amount I was missing each day," Molly said. "With the ASL interpreter, it was not like a game of MadLibs anymore. I had the same access as the other students.

"The best way to compare getting an ASL interpreter for those who are not hard of hearing is to compare it to getting glasses," Molly said. "I typically say something along the lines of, 'with my interpreter, it was like getting glasses and realizing that trees aren't just green blobs – they have leaves and texture!'"

The Longtins were thrilled with the difference in Molly. "My husband is a math teacher," Julie said. "He put together all the data, including grades and tests pre- and post-ASL interpreter. It was just so apparent that we thought it was a slam dunk, that the district would approve it." But instead, the district said Molly did not qualify for the change in her IEP – she did not need a sign language ASL interpreter."

PACER referred the Longtins to the Minnesota Disability Law Center, who represented them in a due process hearing. The hearing was decided in their favor, and an ASL interpreter for Molly was added into the IEP.

"I remember hearing from mom, 'Deanne will be on the phone at the IEP meeting... we got a letter or call from Deanne...' whenever Deanne's name came up, I knew she was going to help us fix whatever was going wrong at school," Molly said.

Although the district complied with the ruling and provided Molly with an ASL interpreter, it wasn't always as successful as the Longtins had hoped. One teacher deliberately stood in front of the ASL interpreter so Molly couldn't see her.

"She resented having the ASL interpreter in her classroom," Molly said. And things got worse: "When I was in seventh grade, the school hired an uncertified ASL interpreter, which is illegal," Molly said. Minnesota law requires that classroom ASL interpreters be properly trained and certified.

Bullying intensifies

That was a particularly hard year for Molly – she was saddled with an ASL interpreter for part of the year who didn't meet her needs, and couldn't accurately interpret, and the bullying intensified. The girls who bullied Molly also bullied her friends for their association with Molly. Some friends ended their friendships because they didn't want to endure what Molly experienced every day.

"Molly was bullied so badly about her hearing that she stopped wearing hearing aids to school," Deanne said. "When she did wear them, she grew her hair long to hide them."

Molly recalled that due to the bullying and lack of educational access, "middle school was an isolating and lonely period of time for me." Her vivid memories of the struggles she faced during that time have made her a better and more empathetic teacher. "I know what it's like to be struggling at school each day."

Julie added, "Molly's self-advocacy – with the help of Deanne, Eric, and I – is what ultimately slowed the bullying. Molly had some pivotal teachers and students who gave her a safe space in school, but the administration never made genuine steps to alleviate or prevent the bullying."

Molly learns to self advocate

The *Student Action Plan Against Bullying** resource from PACER's National Bullying Prevention Center helped Molly



Deanne Curran

"Julie Longtin's persistence was incredible. No matter what the setback, she kept moving, looking for a way forward. She was absolutely determined that Molly have the education she was entitled to."

– Deanne Curran



to identify the steps needed to avoid certain situations and identify which staff allowed bullying so she could take steps to protect herself in their classrooms. “The student action plan helped me in talking to teachers,” Molly said. “I would say, ‘I see you’re not following the IEP plan. You’re not doing this right, and I need you to do it.’ That was crucial for me.”

High school was easier for Molly. The student who bullied her no longer attended her school, and Molly’s athletic involvement and the supportive group of friends she found helped her thrive outside of the classroom. In the classroom, with the help of an “awesome” ASL interpreter, academics were not an issue.

After high school, Molly attended Bethel University, where she earned a B.S. in Environmental Science and Biology. “What I learned from developing that student action plan really helped me in college,” Molly said. She used her advocacy skills nearly every semester during her time as an undergraduate, as she was the only student on campus in nearly seven years who utilized an ASL Interpreter.

Today, Molly is a happy and successful adult who advocates for herself and others. She is resilient and has persevered in the face of many challenges.

“I am excited to tell my story,” Molly said. “I haven’t had the opportunity to do that, and I hope it will help others.” ■



Molly Longtin

“PACER was such a huge advocate, and it made such a difference. Deanne taught my mom how to advocate for me, and then my mom taught me how to advocate for myself, and now I teach my students how to advocate.”

– Molly Longtin

*PACER’s Student Action Plan Against Bullying is available online at: PACER.org/publications/bullypdf/BP-25.pdf

Has PACER Helped Your Family?

We would appreciate the opportunity to learn about how PACER has helped your child or family. Whether you worked with a parent advocate, attended a workshop or Symposium, received help from the Simon Technology Center, or a combination of PACER services – please tell us about the positive impact PACER has made in your life. We would love to share your story (with your permission), so the success you experienced can inspire others.

Email us at communications@PACER.org. Thank you in advance!

Back to School: When your child is not receiving the services written in their IEP

One of the most common questions parents have at the beginning of the school year is how to ensure their child receives the services they are entitled to, as documented in their child's Individualized Education Program (IEP). Parents are especially concerned when not all of these services were provided in the previous school year, including extended school year services (ESY) the child was supposed to receive.

"There are a number of reasons why a school district may struggle to provide the services a child is entitled to," commented Vava Guthrie, PACER's director of parent training and advocacy. Two of the most common reasons cited, she said, is that the district may lack the staff or the funding to provide services. "While we understand the challenges schools are facing, when services are not provided, the child is the one who faces the consequences."

Shared goals

Professionals and families share the same goal: improved outcomes for students. To meet that goal, school districts are legally obligated to meet a child's identified needs and provide them with a free appropriate public education (FAPE). According to Sonia Smith, Minnesota's Director of Special Education, who spoke with PACER this past summer, staffing or budget issues are not acceptable reasons for a child not receiving FAPE. "Most often, school districts want the opportunity to work with families to ensure that FAPE is being provided," she said. "If the parent feels the district is not doing enough, the first thing we want to see happen is a conversation between the families and the schools."

Vava agrees that conversations are important, and that parents and school staff should work together to find solutions. She also suggests that parents first put their concerns in writing, especially if they are feeling upset or emotional. "It's natural to get angry when your child is not receiving the education they are entitled to," she said. "When you put your concerns in writing, you can regulate what you say, stay focused on the issue, and look it over before you send."

Sometimes the next step may be an IEP team meeting. In this meeting, parents should be prepared to respond to the school's reasons for not providing services by acknowledging the school's difficulties, while focusing on the child's needs and making it clear that they are not okay with their child not receiving services. "Parents can turn the conversation back to the child by saying, 'Yes, I understand you have (funding, staffing) issues. My child missed 10 hours of instruction, how can that be made up?'"

Parents may need to take the lead in being creative about how to solve the problem. For example, Vava said, if a district is having staffing difficulties, a parent may suggest contracting with an outside provider to access needed services, or ask, "What options do I have when you can't provide services?"

One thing that is critical is making sure that missed services are made up so that a child doesn't fall further behind. In addition to agreeing that services will be provided going forward, a school should work with parents to plan how missed services will be remedied.

It is also important that parents ask for prior written notice (PWN) if a district proposes to deviate from the IEP, which is a legal document. The PWN must be provided prior to the services not being provided. Not providing services that are required is cause for a district to provide the PWN, which must include the services that will be denied to the child and the reason they will not be provided. If a district did not provide the PWN prior to not providing services, they are in violation of the federal Individuals with Disabilities Education Act (IDEA). This is important for a parent to know because the PWN may be an issue in the future; for example, if they cannot reach agreement with the school about services, there are a variety of dispute resolution options available to them.

When you can't reach agreement with the school district

When parents and the school districts are unable to reach an agreement, there is a range of dispute resolution options available to parents of children in special education:

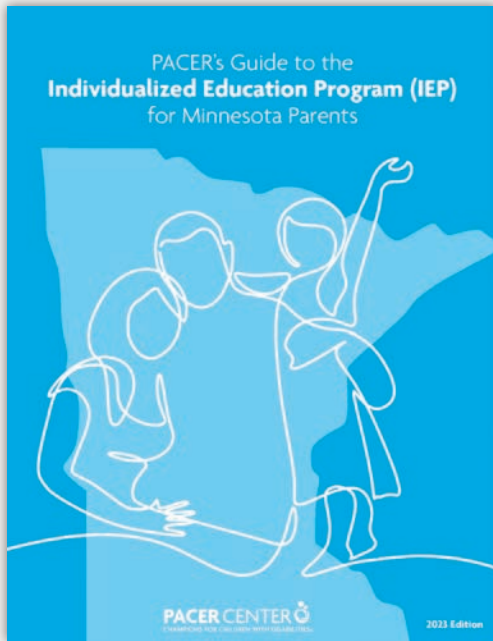
- Conciliation conference
- Facilitated team meeting
- Mediation
- Special education complaint
- Due process complaint and hearing
- Discrimination complaint

For detailed information about these options, including how to request a meeting or file a complaint, who participates in the meeting or hearings, timelines, who makes the decision and how it is rendered, and outcomes, go to [PACER.org/learning-center/dispute-resolution/du-process-options](https://www.pacer.org/learning-center/dispute-resolution/du-process-options).

Parents who have questions or are not certain how to proceed can reach out to a PACER parent advocate at 952.838.9000 or PACER@PACER.org. ■

PACER resources for parents about the IEP and Minnesota dispute resolution options

Contact PACER with questions, for additional pricing, and to order, at:
PACER@PACER.org or 952.838.9000.



PACER's Guide to the Individualized Education Program (IEP) for Minnesota Parents

This robust resource contains information for parents about how they can work with schools to address their child's unique special education needs through understanding the required components of the IEP.

Updated September 2023.

Ordering information:

- One free copy to MN parents
- Free download at PACER.org
- Publication code: PHP-a12



Minnesota Dispute Resolution Options

The first brochure centers on special education meetings where parents and school districts work together to resolve disagreements. The second brochure features the complaint processes available to parents of students with disabilities. Also available in Hmong, Somali, and Spanish.

Updated September 2022.

Ordering information:

- One free copy to MN parents
- Free download at PACER.org
- Publication codes: PHP-a59/PHP-a60

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FOLLOW PACER ON SOCIAL MEDIA!

For up-to-date information on workshops and trainings, events, stories, publications, and more, find us online [@PACERCenter](https://www.facebook.com/PACERCenter).



One important thing for parents to remember is that they are not alone – PACER is here to answer questions and provide information and support.

To reach a PACER advocate, call 952.838.9000, or email PACER@PACER.org. Be sure to allow several days for a response – the beginning of the school year is a busy time for us.

OCTOBER IS

NATIONAL BULLYING PREVENTION MONTH

National Bullying Prevention Month (NBPM), which focuses on preventing childhood bullying and promoting kindness, acceptance, and inclusion, runs throughout October. Unity Day, its signature event, is Wednesday, October 18.

PACER's National Bullying Prevention Center (NBPC) developed the nationwide campaign in 2006 to help raise awareness of the issue and encourage community action.

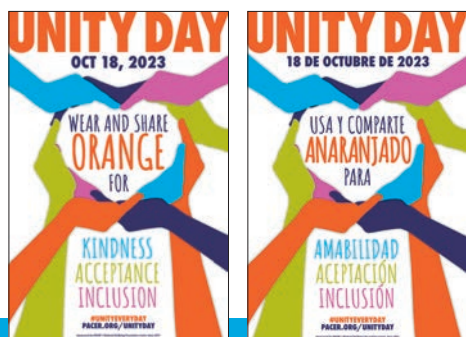
Studies point out that children who are bullied often experience negative effects ranging from poor self-esteem and school performance to long-term physical and mental health issues. Children with disabilities, such as learning or mental health disabilities, autism, and other nonvisible disabilities, are frequently targeted.

"No child of any ability or life situation should ever experience bullying," said Julie Hertzog, director of PACER's NBPC. "Bullying prevention involves the whole community. Families, schools, businesses, and communities can engage in a wide range of bullying prevention activities. October and Unity Day, especially, offer opportunities to take action against bullying," Julie added.

PACER offers many ideas on how to be involved. In addition, individuals and groups have used their own creativity to develop bullying prevention initiatives. The bottom line: taking action to prevent bullying in October or any time of year can help all children have a safer school experience and increase their sense of belonging.

The following are examples of NBPC activities and products available during October and throughout the year:

- **Take a personal pledge** against bullying. Examples of pledges are on the NBPC website.
- **Request PACER's free Unity Day posters.** The colorful 24x36-inch posters can be displayed in schools, businesses, and other public places. They are available in English and Spanish.



- **Wear orange to call attention to National Bullying Prevention Month, especially on Unity Day.** A signature Unity Day t-shirt with a bullying prevention message can be purchased for \$14 (bulk pricing available). Order by Oct. 6 to ensure delivery by Unity Day.



- **Share information about National Bullying Prevention Month.** Mention NBPM on social media and websites; notify community newspapers and other local media outlets; and contact community leaders, such as city council or school board members, with additional information.
- **Encourage a local school or youth organization to become a Champion Against Bullying.** It's as simple as submitting a request form on the NBPC website. Champions are listed with a link to their own website and a summary of their activities or events planned in connection with bullying prevention.
- **Order bullying prevention bookmarks,** designed for two age groups: children or teens. They are sold in sets of 100 for \$20 and can be distributed year-round.
- **Check out the National Bullying Prevention Month Student Activity Kits.** Developed by PACER, the kits include activities to use throughout a four-week period. The activities help students in classrooms or youth organizations explore, plan, celebrate, and reflect on how to prevent bullying. \$10 for the first kit and \$5 for each additional set.
- **Share messages of kindness, acceptance, and inclusion** on Unity Day with #UnityEveryDay.

For ordering and additional information on these and other bullying prevention ideas, visit PACER.org/Bullying. ■



Jireh Mabamba

Jireh's Journey

school in Duluth, Minnesota. The scholarship required that the student's family host an exchange student; when Jireh's family was unable to do this, another family stepped forward in their place. It was, Jireh says, another example of someone reaching out to give him a hand up.

Jireh's host family met him at the airport with blankets and jackets. He saw snow for the first time. And Duluth ended up being his home for years. He met the chancellor of the University of Minnesota-Duluth (UMD) at a Rotary function, and was invited to visit the campus. Jireh was awarded scholarships to attend UMD, where he earned bachelor's degrees in marketing and organizational management. It was at UMD that he first learned about development work.

"The chief development officer at UMD was a Rotarian, too," Jireh said. "I asked her to teach me how to raise funds, and she said yes and created a paid internship for me." Jireh already knew a thing or two about raising money. "While I was at UMD, I started a nonprofit to help homeless people with blankets and food. I had once been homeless myself."

Jireh Mabamba (pronounced G-Ray), who joined PACER this summer as director of development, says that the theme of his life is "gratitude."

"During my whole life, there were always people around me who did not hesitate to give me a hand, to help me when I needed it. My heart is full of gratitude for the kindness of others." He is determined to actively pay it forward.

Beginnings

Jireh's story began in the Democratic Republic of the Congo, where he was born. His father was a community leader and pastor who helped children escape from the rebel armies they were forced to join. "These kids were 12, 13, 14 years old. The rebels would send them in first to be slaughtered. My dad couldn't stand by, he had to do something about it. Our family became a target." Fearing for their safety, Jireh's parents packed their bags, taking only their children and what they could carry.

The family ended up traveling thousands of miles to South Africa. "We were on the streets. We had no place to go, we didn't know anyone, we didn't speak the language."

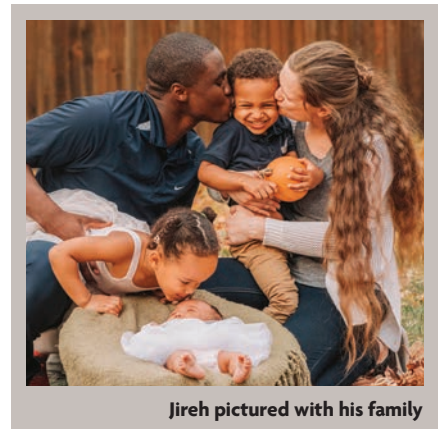
After their initial difficulties, the family settled into life in their adopted country. Jireh's parents found jobs, and he and his siblings enrolled in school. Jireh eventually learned English and went to the immigration office as an interpreter for his parents and other refugees.

When Jireh was in middle school, he won a scholarship to Durban High School, an academically rigorous boarding school in South Africa. "A lot of people saw something in me and helped," Jireh said. "I was the first student from my middle school to be admitted to Durban. It was a huge deal, they were so proud! The principal drove me to the interview."

Duluth

Success at Durban led to Jireh winning a Rotary International exchange scholarship to attend an additional year of high

Jireh and his wife, Kayla, met when both were students at UMD. The couple has been married for six years and has three young children: Vivian is 5, Kyle is 3, and Lillian is a year old. The family, which includes Jireh's parents, lives in Mounds View.



Jireh pictured with his family

Jireh subsequently earned a master's degree at the Twin Cities campus of the University of Minnesota, where Kayla earned her Doctor of Physical Therapy degree. Jireh worked for the University's foundation for nine years in a variety of roles. During his time in the Twin Cities, he has been active in a number of volunteer roles, including mentoring international students, with the Rotary, and as a board member of the American Red Cross Minnesota & Dakotas Region.

Landing at PACER

Last spring, when the Red Cross had an opening for a regional development role, Jireh thought he might apply for the job. He called Tonia Teasley, PACER's executive director, with whom he'd worked briefly when she was at the Red Cross, to ask for advice.

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L to R: Dao Xiong, Jesús Villaseñor, and Hassan Samantar

Parent Language Access Rights

PACER steps up to define the role of interpreters

To ensure that parents' rights to language access are front and center in special education meetings, including dispute resolution meetings, PACER's multicultural advocates, Jesús Villaseñor, Hassan Samantar, and Dao Xiong, developed a new training geared to interpreters who support families of children with disabilities in special education meetings. The training, held this September, outlined the interpreter's role and responsibilities, discussed best practices for effective interpreting in special education meetings, and offered an opportunity for questions and dialogue about difficult situations that interpreters encounter in their work.

When a parent whose first language is not English meets with a school district about their child's special education needs or services, the district is required, under Title VI of the Civil Rights Act of 1964, Executive Order 13166, and the Individuals with Disabilities Education Act (IDEA), to provide a language interpreter. For a number of reasons, this isn't as easy and straightforward as it may sound, according to PACER's multicultural advocates.

Not all interpreters are familiar with the technical terms and alphabet soup of special education language, said Jesús. "It can be difficult for a family if the interpreter does not understand the educational terminology," he noted. As an example, school staff may say, "We are providing FAPE (free appropriate public education)", but the interpreter may not understand what FAPE means, and there may be no comparable meaning in the parent's first language. "If an interpreter doesn't understand the terminology, they may skip over something," Jesús said.

Jesús pointed out that the Minnesota Department of Education advises districts to work with interpreters trained in special education, but not all districts are able to do this. Hassan said that in the majority of special education meetings he attends with parents, the school does not have a trained interpreter available. "More and more often, schools have come to rely on outside companies who offer interpreting services over the phone for a fee, and their interpreters often don't know special education terminology," Hassan noted.

"Interpreting is a demanding job," Jesús said. "It's not easy, and interpreters don't always feel appreciated, but their job is essential for parents in the special education process. Clear and effective communication prevents misconceptions and misunderstandings that lead to serious conflicts."

It is not uncommon for districts who do have interpreters on staff to also employ them as cultural liaisons, and this dual role can be a problem (see "Roles and Responsibilities"). Hassan said, "If an interpreter wears two hats – as an interpreter and a cultural liaison – the line between the two roles may get blurred." For example, families may trust and come to depend on the cultural liaison for providing cultural explanations to school staff. But when the cultural liaison is acting as an interpreter in an IEP meeting, they need to strictly adhere to conveying exactly what is said by both sides, and they cannot speak on behalf of the family. This can be challenging, Hassan said. "In many cases, an interpreter adopts the role of an advocate."

To make things even more muddled, in some districts interpreters are called “parent advocates” although they do not advocate and their role is limited to oral interpretation in meetings between parents and school staff. Additionally, parents may perceive a conflict of interest when the interpreters who participate in special education meetings are school employees who rely on the district for their livelihood. This may be heightened in situations where the parent is in strong disagreement with the district.

Jesús offered the example of a highly educated mother who spent a week preparing for her child’s special education meeting, choosing carefully what she wanted to advocate for on behalf of her child. However, at the meeting, the interpreter ignored or watered down some of what mother wanted. Though the mother is not fluent, she knew enough English to recognize that the interpreter was not accurately communicating her message to the school. Jesús emphasized that other parents with the same level of passion for their children’s success, but far less formal education, face an extra barrier in making their voices heard through an interpreter in special education meetings.

Jesús and Hassan shared a similar perspective about the fact that a comparatively low number of parents whose first language is not English request a Facilitated Team Meeting or a Mediation to resolve a dispute with the district. They observed that while the reasons are complex, there are obvious inequities in parents’ access to these dispute resolution options.

PACER can help

Hassan said that many interpreters are happy to know that PACER’s multicultural advocates are available to support and educate families. “When we tell them how we work with families and what we can offer, they are surprised and grateful. They will take my business cards and distribute them to families and say, ‘Call this guy!’”

In preparation for the interpreter training in September, Jesús, Hassan, and Dao translated the following PACER resources into Spanish, Somali, and Hmong:

- Minnesota Dispute Resolution Options: Special Education Meetings Where Parents and School Districts Work Together to Resolve Disagreements (brochure)
- Minnesota Dispute Resolution Options: Complaint Processes Available to Parents of Students with Disabilities (brochure)
- Checklist for School Staff: Working Effectively with an Interpreter in a Special Education Meeting to Support Parent Participation (tip sheet)
- My Voice Matters (video series)

All of these resources can be accessed online at: [PACER.org/learning-center/dispute-resolution](https://pacer.org/learning-center/dispute-resolution) ■

This project is made possible with funding from the Minnesota Department of Education.

Roles and Responsibilities

Interpreter

The interpreter conveys orally in one language what has been said or written in the other, without adding, editing, or polishing what is said by either side. A skilled interpreter will understand special education terminology and have the ability to use language or words that convey the intended meaning of the speaker or writer (such as interpreting a term or expression that doesn’t have an equivalent in the parent’s native language). They do not offer opinions or advice.

Cultural Liaison

A cultural liaison has a broader role than an interpreter, and is generally employed by the school district. According to the Minnesota Administrative Rules, a cultural liaison is defined as a person who provides information to the IEP team about a student’s race, cultural, socioeconomic, and linguistic background; assists the IEP team in understanding how these factors impact educational progress; and facilitates the parent’s understanding and involvement in the special education process [Minn. R. 3525.0210, subp. 10].

Advocate

An advocate speaks on behalf of the parent, and/or assists them in understanding and participating in the special education process. All parents have the right to involve an advocate at any point during the special education process, from evaluation to developing an IEP and placement. If parents have a disagreement with the district, they should request assistance from an advocate who is not employed by the district. PACER parent advocates are knowledgeable and supportive; to contact an advocate, email PACER@PACER.org or call 952-838-9000.

Sara Sagedahl:

Spreading the word about PACER



L to R: Adam, Oliver, Sophie, Evan, and Sara Sagedahl

Sara Sagedahl learned about PACER through a co-worker at General Mills, where she worked in marketing. Sara's son Evan, who had been diagnosed with Down syndrome shortly after birth, was just over a year old. "I was so excited to come across PACER and learn about the different types of things they could help with," Sara said. Her co-worker introduced her to Julie Hertzog, director of PACER's National Bullying Prevention Center, who also has a son with Down syndrome. Julie, in turn introduced Sara to the late Paula Goldberg, PACER's executive director.

Before long, Sara was invited to join PACER's board of directors. "It was easy to say yes to Paula," Sara said. "She was so passionate about PACER's work and the families they support."

That was back in 2014, and Sara has been involved with PACER ever since. "Board service with PACER has been a wonderful experience for me. I've really enjoyed getting to know the board members and there is a great sense of community. Everyone has a connection to disabilities, yet we all have different perspectives and unique experiences. It is very easy and rewarding to work together."

As the parent of a young child with multiple disabilities (Evan, now 11, was diagnosed with autism five years ago), Sara became a kind of ambassador, spreading the word about PACER through Facebook groups for parents of children with disabilities. When Evan was a toddler, Sara was part of a family network group leadership team at General Mills that brought in presenter Judy Swett, a PACER parent advocate and coordinator of the early childhood program. "She was amazing. Parents were awed by how much information she presented. They were so grateful – I heard many say, 'I didn't know about PACER, how much is available to families.' It was eye-opening chatting with them."

In addition to attending workshops, the Sagedahl family found working with PACER advocates "invaluable," Sara said.

"When we were working on Evan's Individualized Education Program (IEP) in the first grade, we had a difficult meeting

with the special ed team at his school," she recalled. "A PACER advocate was able to look at what was in the IEP and help us think about some different things we should consider. When it's early elementary school and a parent is new to special education, you just don't know what to ask for or what services might be available for your child. Having an advocate made an incredible difference. They suggested Evan have a one-on-one paraprofessional, so we pushed for that, and ultimately it was included in his IEP. PACER helped us develop a really good plan for him.

"PACER has been there through all of Evan's transitions," Sara said, including changing schools and during the pandemic. "We always knew we could count on PACER advocates for whatever Evan needed."

Along with Evan, now 11 and in the fifth grade, Sara and her husband Adam are the parents of three. They have two typical children: Sophie is 13, and Oliver is six. Sara now works at Best Buy, focusing on digital and social media marketing. "I've just taken on a new role, content strategy for our Best Buy video content on YouTube. Digital and social are changing and evolving, and that makes me think of unique ways PACER can connect with parents, and how to reach families where they are.

"I'm passionate about helping families connect with PACER. I think back to when I was the parent of a baby with a disability. It was a new world. I was unsure about where to start, how to get help. What a simple call to PACER can do!

"Paula knew so much, and she and the staff did an incredible job building PACER's foundation. It's exciting to think about how Tonia [Teasley, PACER's current executive director] and the staff will take PACER to a new level."

One thing she is certain of: Sara plans to be part of it. Per PACER's bylaws for board service, she will rotate off the board this fall, something she hopes will be temporary. "Our family has benefited so much from our involvement with PACER, and I plan to be active in the long term.

"PACER is very close to my heart." ■

"These meetings can be difficult... when a parent is new to special education, you just don't know what to ask for or what services might be available for your child. Having that PACER advocate made an incredible difference."

– Sara Sagedahl

Mental Health and the IEP:

What parents can do

If a student's mental health issue or behavioral disorder is not documented in the student's Individualized Education Program (IEP), they may not be addressed at school, said Laura Jean, a PACER parent advocacy and training manager. This can occur when mental health is not the primary diagnosis or has not been observed by the school. "There are times when an IEP notes mental health symptoms, such as self-harming behavior that is symptomatic of anxiety, without putting in place any accommodations," Laura said.

While some symptoms may be evident, others are more subtle and go undetected. For example, a student may be passing their classes but not reaching their potential because their needs make it difficult for them to fully focus on schoolwork; or a student may appear fine at school but fall apart when trying to complete assignments at home because they are working hard to hold it together at school.

"It's important that the IEP includes the data necessary so that the student can receive all of the services and accommodations they are entitled to," Laura said. Under the federal Individuals with Disabilities Education Act (IDEA), children with disabilities have the right to a free appropriate public education (FAPE). FAPE is a powerful tool that requires a district to provide special education to meet the child's unique needs, as documented in the IEP. If the IEP team needs more information or updated data related to mental health needs or emotional/behavioral disorders in the IEP, parents can ask for a new functional behavioral assessment (FBA) or whether a new overall evaluation is needed.

"A re-evaluation can capture the information needed so that there can be a formal assessment to address each concern," Laura noted. "It's more than just one observation of the student's behavior or an informal interview; formal tools are needed to determine concrete data because each child's symptoms and needs are different. If the team doesn't have the data documented to support adding the services or accommodations the parent thinks are needed, parents can ask what tools can be used to capture mental health or behavioral issues that are impacting the student."

Laura suggests that parents ask their child regularly how they are doing and what's hard and easy for them, and document this in a journal that can be presented to the IEP team as part of an FBA or evaluation. She also said that an interview with the student could be part of the evaluation. "Kids are honest, and they will respond if they're told, 'we need to know what you're feeling so we can help you feel better.'" Laura and other PACER parent advocates are available to provide support and coach parents through the IEP process.

"A PACER advocate can make suggestions to address parent concerns, talk through issues, and explain available options – not only for resolving the conflict, but concrete suggestions of services and accommodations. Reach out to us – we are here to help," Laura said.

Parent advocates can be reached by calling 952.838.9000 or emailing PACER@PACER.org. ■



Laura Jean

Jireh's Journey continued from page 7

Tonia was glad to let Jireh pick her brain – but the conversation turned into something more when Tonia mentioned that PACER was seeking a development director.

When Jireh looked into PACER, he found another connection: the family he lived with in Duluth had used PACER's services. "My host brother had a disability, and my host mom used to drive him to PACER from Duluth to try assistive technology from the lending library. She was very excited about PACER."

The more Jireh learned, the more he knew that PACER was the right place for him. He is always up for a challenge, and is finding that in his new role. "For many years, PACER was led by a founder, Paula Goldberg, and many donors had a

great relationship with her. I am trying to reconnect them with PACER and continue with Paula's legacy. This is an opportunity to try new ways, and to also attract new partners and donors who believe in PACER's work."

He is especially excited by the opportunity to introduce families to all that PACER has to offer. "We can share more services and ways to help, rather than limiting families to what they initially came to PACER for. We can help them holistically."

Jireh sees his position as "a calling: a way to give back. I want to be a champion for kids with disabilities and their families.

"This is my chance to use my skills and experience to help the families who walk through PACER's doors." ■



EX.I.T.E. Camp Celebrates 20 Years

One might expect to see a few changes in a program after two decades, and PACER's annual EX.I.T.E. (Exploring Interests in Technology and Engineering) Camp is no exception. What hasn't changed is the enthusiasm of campers, the dedication of partners and presenters, and the inspiration the two groups bring to each other.

"A big part of camp is the camper seeing themselves represented by adults in the field," said Kayla Devorak, PACER's EX.I.T.E. coordinator. "That has remained constant." Looking back as EX.I.T.E. Camp celebrated its 20th year, three trends stand out to Kayla.

Partners and presenters

2003 – The first EX.I.T.E. Camp was a partnership between IBM and PACER. Heidi Kraemer, an IBM employee and PACER supporter, guided the collaboration. IBM had sponsored nearly 50 EX.I.T.E. Camps around the world to encourage the interest of girls in science and technology. PACER's camp was the first for girls with disabilities.

2023 – This year's camp had six partners, including founding partner IBM. Others were Medtronic, Wold Architects & Engineers, Best Buy, 3M, and Greenberg Traurig, LLP. Additional presenters came from The Works Museum, the Minnesota Zoo, and MnDOT.

The camp is popular. PACER was so inundated with applications, that it had to stop accepting them three months prior.

Camp focus

2003 – The camp included activities from varied science and technology areas, but computer technology predominated. IBM had donated equipment so that campers had liberal access to the latest computers.

2023 – EX.I.T.E. Camp still provides campers with state-of-the-art equipment, but now the camp includes broader STEM (science, technology, engineering, and math) activities.

"STEM isn't just about computers," said Kayla. "We show a wide variety of careers and activities that campers can pursue." For example, this year Medtronic featured biomedical engineering demonstrations; Wold introduced designs for

schools, emphasizing accommodations for people with disabilities; and Greenberg Traurig introduced the correlation between technology and intellectual property.

Cultural changes

2003 – EX.I.T.E. Camp was described as being for middle school girls with disabilities.

2023 – This year's camp, and those of the last couple years, have become "gender expansive," said Kayla. They included campers who use "them/they" pronouns, as well as those who consider themselves female.

"We encouraged presenters to incorporate gender expansion in their presentations," said Devorak. "We looked at how to meet the campers where they are. We wanted them to feel that they belonged."

Ann Motl: 20 years and counting

2003 – Ann Motl of Staples, Minn., grew up on a dairy farm and stayed with family in the metro area so she could attend EX.I.T.E. Camp. Ann, who has a muscular disability, already had an interest in science and technology, "but seeing professionals with disabilities and working with them was really important for me," she said.

2023 – Ann Motl is a litigation

attorney with Greenberg Traurig LLP, an international law firm. She has a mechanical engineering degree from the University of St. Thomas and a law degree from the University of Minnesota. Since her time as a camper, Ann has volunteered at EX.I.T.E. Camp. This year, she came as a professional representing Greenberg Traurig and ran an activity on inventions and intellectual property.

"I wanted to get back into involvement with PACER and share my career path," she said. "EX.I.T.E. Camp made a difference for me — meeting people with disabilities, because I really didn't have the chance before."



Ann Motl

Transition Planning Takes Time

The idea that their child with a disability will “transition” from special education services to adult services may seem far in the future for many families. Nevertheless, change will come, and it is helpful for families to prepare. The following general timeline offers an introduction to transition planning:

Young children

Parents of a young child can begin to address the transition process informally by offering their child varied experiences such as visiting a nature center, watching sports events, reading stories about people in their jobs, or doing art projects. Observing what interests the child and encouraging what they enjoy doing often gives direction to the formal transition process and future occupation and life skills.

Preteen years

Before a student enters middle or high school, families can help them become comfortable with explaining their disability or requesting accommodations. It is also a time for youth to practice decision-making, managing money and health care, and increasing community participation. Parents can also begin thinking about future opportunities for postsecondary education or employment and begin introducing the discussion of transition services at Individualized Education Program (IEP) meetings.

Starting in grade 9

Minnesota law requires IEP teams to address a student’s transition needs no later than 9th grade. Students’ input in the process is critical as their hopes and interests guide what transition services are needed. The IEP team will include goals in the transition areas of employment, postsecondary education or training, and independent living or life skills. Parents should ask their team if their child would be eligible for Pre-Employment Transition Services, a program of Vocational Rehabilitation Services that can support students’ employment goals.

High school (grades 10 - 12)

The IEP team will continue looking at the three transition areas throughout the high school years and may design increasingly specific goals as the student advances through the grades. For example, there may be a goal to learn about supported employment, technical training sites, or college campuses. If college-bound, the high school student may need to take tests, such as the ACT or college entrance exams, before applying to the schools. If the student will use VRS, state, or county services after special education, high school years are the time to determine which supports are needed and complete any necessary applications.

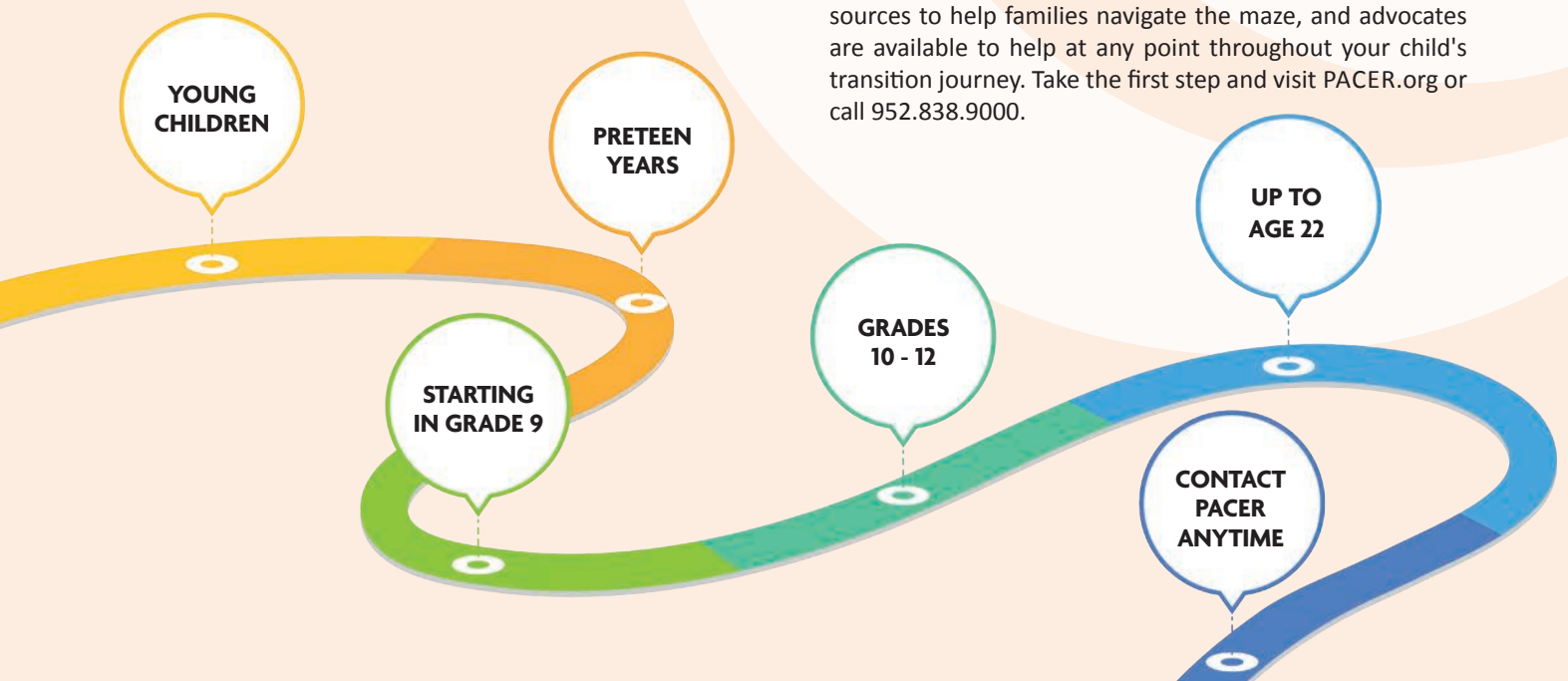
When a person reaches the age of majority at 18, they are considered an adult. All rights, including educational rights, transfer from parent to child, even if the child is a high school student living with their family. The student assumes the parental rights on the IEP team. They can invite the parents to the IEP meeting and to support them in decision-making, but the school is no longer required to invite the parents, unless the parents are the adult child’s legal guardians.

Continuing special education to age 22

If a student remains in special education past their senior year of high school, the IEP team will continue assessing progress in the three transition areas until the student’s 22nd birthday. Families can continue investigating services that may be applicable for an adult with disabilities. Families can also begin to research housing options, as well as managing a home.

Contact PACER

Transition planning can be complex. PACER has many resources to help families navigate the maze, and advocates are available to help at any point throughout your child’s transition journey. Take the first step and visit PACER.org or call 952.838.9000.



Upcoming Workshops & Events



Workshops
& Activities



Annual
Events

WORKSHOPS FOR PARENTS & PROFESSIONALS

SEPTEMBER

Beyond Keyboards: Alternative Tools for Controlling Your Computer

Tues., Sept. 26 • 1 – 2 p.m. • Virtual

Explore different ways to control computers and mobile devices. Demos will range from alternative keyboards and mice to voice control and switch access.

Understanding Special Education Series

Part 1: IDEA – The Big Picture

Tues., Sept. 26 • 6:30 – 7:30 p.m. • Virtual

Participants will gain an overall understanding of special education, the steps in the special education process, and how to request an educational evaluation.

Working Towards Positive Educational Outcomes: Mental Health and Special Education

Wed., Sept. 27 • Noon – 1 p.m. • Virtual

This introductory workshop will provide parents and others with information on the special education process, ideas for interventions and supports to address a child's mental health needs in school, and strategies for positive collaboration and navigating disagreements with the IEP team. *This workshop is funded in part by a grant from the Minnesota Department of Education.*

Assistive Technology to Support Elementary Academics

Wed., Sept. 27 • 2 – 3 p.m. • Virtual

Learn about a variety of low- and high-tech assistive technology tools to help elementary-aged students with reading, writing, and math.

Gearing Up for Graduation and Beyond

Thurs., Sept. 28, 6:30 – 7:45 p.m. • Virtual

Are you a parent or caregiver of a middle or high school student, and unsure about graduation requirements and available resources? Participants of this workshop will learn what questions to ask school staff and tasks to complete with your student. Attendees will receive a set of Graduation Tip Cards.

OCTOBER

Understanding Special Education Series

Part 2: The Individualized Education Program (IEP)

Tues., Oct. 3 • 6:30 – 7:30 p.m. • Virtual

Learn how a child is found eligible for special education, next steps after a finding of eligibility, the required parts of the IEP, and important parent action items after a child receives an IEP.

Understanding Special Education Series

Part 3: What's Next

Tues., Oct. 10 • 6:30 – 7:30 p.m. • Virtual

Parents will learn how to voice concerns or disagreements as an equal member of their child's IEP team, the processes available to resolve conflicts, and additional ways to be involved in special education.

Supplemental Security Income: Qualifying for Benefits

Thurs., Oct. 12 • 7 – 8:30 p.m. • Duluth

Participants will learn basic information on applying for Supplemental Security Income (SSI) for young adults age 18 and over including SSI's eligibility criteria and how to submit a successful application.

Understanding Pre-Employment Transition Services (Pre-ETS) and Supplemental Security Income (SSI)

Tues., Oct. 17 • 6:30 – 8:30 p.m. • Moorhead

Learn basic information on Pre-ETS and applying for SSI for young adults. Participants will learn about the importance of early work experience for future success and how SSI benefits can help.

School Avoidance in Youth with Mental Health Needs

Wed., Oct. 18 • Noon – 1 p.m. • Virtual

Learn positive interventions for youth who struggle with school avoidance, anxiety, and challenging behaviors, and the role of special education.

Understanding Pre-Employment Transition Services (Pre-ETS) and Supplemental Security Income (SSI)

Wed., Oct. 18 • 6:30 – 8:30 p.m. • Grand Rapids

Learn basic information on Pre-ETS and applying for SSI for young adults. Participants will learn about the importance of early work experience for future success and how SSI benefits can help.

Task and Time Management Tools for K-12 Students

Wed., Oct. 25 • 2:30 – 3:30 p.m. • Virtual

Task and time management can help keep students on track with school. This workshop will explore a variety of tools and strategies to support these skills for K-12 students.

NOVEMBER

Life Planning Series

Part 1: Special/Supplemental Needs Trusts and ABLÉ Accounts

Mon., Nov. 6 • 7 – 8:30 p.m. • Virtual

This workshop will focus on power of attorney, health care directives, maintaining eligibility for government benefits, special and supplemental needs trusts, and ABLÉ Accounts. Presented by Roger Strege, CES™, President of Special Needs Planners, Financial Planner, Certified Estate, and Trust Specialist.

Intro to Assistive Technology (AT): An Overview of Low- to High-Tech Tools

Wed., Nov. 8 • 2 – 3:30 p.m. • Virtual

This workshop will explore AT to support the needs of people with disabilities. Staff will discuss categories of AT, choosing tools to use, and the services of the Simon Technology Center.

Life Planning Series

Part 2: Supported Decision Making and Guardianship

Mon., Nov. 13 • 7 – 8:30 p.m. • Virtual

This workshop will address the consideration and purpose of supported decision-making and guardianship, with a focus on the details of the legal procedures and a discussion about both short and long-term planning. Presented by Joseph P. Kukla, esq., Thiel, Anderson, Kukla & Gunderson, PLLP.

Creating an Evaluation Plan for Your Child with Mental Health Needs

Wed., Nov. 15 • Noon – 1 p.m. • Virtual

Participants will actively work through the planning process with a sample evaluation plan to learn how the plan is created and the role of parents and the special education team.

Assistive Technology for Reading

Wed., Nov. 15 • 1 – 2 p.m. • Virtual

Learn about assistive technology to help with all stages of reading. Apps and tools will be shared to help with learning the basics, minimizing the effects of dyslexia, helping with vision impairments, and more.

DECEMBER

Assistive Technology (AT) for Writing

Wed., Dec. 6 • 1 – 2 p.m. • Virtual

Learn about AT to help with a range of writing skill levels. See apps for drafting to revising along with the basics of writing and various digital and voice options.

Finding Balance: Navigating the Maze of School Stress

Wed., Dec. 13 • 1 – 2 p.m. • Virtual

School can be stressful for many reasons, but stress can be reduced with assistive technology (AT) tools and supports. This workshop focuses on tips, tools, and AT supports that can help decrease school-based stress and anxiety.

ACTIVITIES FOR TEENS

STEAM Rollers Fall Series

Part 1: Sat., Sept. 16 • 10:30 a.m. – 12:30 p.m. • PACER

Part 2: Sat., Sept. 23 • 10:30 a.m. – 12:30 p.m. • PACER

A science, technology, engineering, arts, and math (STEAM) tabletop role-playing group for middle to high school students. Up to six participants will immerse in a challenge while taking on the persona of a STEAM professional to solve a related problem.

Tech for Teens Club: Makerspace Experience

Sat., Sept. 23 • 1 – 2 p.m. • PACER

We want your feedback! Join PACER's Tech for Teens staff on a tour of the new PACER makerspace. Get a first look at the exciting tools and equipment and help staff plan for 2024.

ANNUAL EVENTS

Simon Technology Center Open House & Tech Expo

Sat., Oct. 7, 2023 • 10 a.m. – 2 p.m. • PACER

Learn about assistive technology (AT) and grab a complimentary bite to eat from Viking's Table food truck. Browse our AT lending library, new accessible makerspace, and meet our AT specialists.

Unity Day

Wed., Oct. 18, 2023 • All day • Anywhere

Anyone, anywhere can participate and show support for bullying prevention by wearing ORANGE! For additional ideas to get involved, visit PACER.org/bullying.

Advocacy for Systems Change: Leadership Training for Parents of Children with Disabilities

February 2024 (date coming soon) • Virtual

This training is designed for participants who have children in special education and want to learn leadership and educational advocacy skills. Learn about the history of special education parent leadership in Minnesota, build capacity to advocate for improved supports and services, discover advocacy opportunities at the district and state level, and develop a leadership action plan.

PACER's Day at the Minnesota State Capitol

March 2024 (date coming soon) • State Capitol Building

Parents of students with disabilities have important information and experiences to share with policy makers that impact systems change and improve outcomes for students in Minnesota. Attend a brief presentation by PACER and stay to share your story with your legislators. Details at PACER.org/capitol as they become available.

Save the date!

PACER's Annual Benefit

April 27, 2024

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PACER's Simon Technology Center

OPEN HOUSE & TECH EXPO

Sat., Oct. 7, 2023

10 AM - 2 PM

PACER Center



Scan for info &
to register or
visit [PACER.org](https://www.pacer.org)

Join us for an immersive experience at the Simon Technology Center's Open House & Tech Expo. This event is a fantastic opportunity to explore the world of assistive technology (AT) while enjoying complimentary, delicious food from the Vikings Table food truck!

EVENT HIGHLIGHTS

- Browse PACER's AT lending library with more than 1,700 items, devices, apps, and software
- Explore PACER's new accessible makerspace
- Meet AT specialists to learn about solutions that can help students with all types of disabilities
- Stop outside and enjoy complimentary food from Viking's Table food truck, a program by the Minnesota Vikings Foundation and Xcel Energy
- Stay for a quick visit or dive deep into the world of AT

WE'LL SEE YOU ON OCTOBER 7!