FAMILY LISTENING SESSION

and

COMMUNITY CONVERSATION

Findings Report 2025

Family Voices of Wisconsin

Celebrating 30 Years

2025 Findings Report
Family Listening Session and Community Conversation

Family Voices of Wisconsin (FVW) hosts listening sessions and other opportunities for families of children with disabilities and special health care needs to share their experiences and insights with listeners from across the state. In April and May 2025, FVW hosted two events for Wisconsin families: a virtual listening session on April 30 and a community conversation on May 8 in partnership with the Wisconsin Board for People with Developmental Disabilities (WI BPDD) as part of the Circles of Life Conference.

Twenty-seven families and providers participated in the virtual session. Approximately 115 individuals participated in the in-person community conversation. This included parents, foster/adoptive parents, youth with disabilities and their siblings, providers from county agencies, adult self-advocates, and other professionals.

Agency and Organization Listeners

Representatives from state agencies and organizations whose mission is to serve and support children with disabilities and/or special healthcare needs in Wisconsin were invited to participate. This format gave representatives the opportunity to hear directly from families. This year's invited listeners included:

- Wisconsin Department of Children and Families
- Wisconsin Department of Health Services
    - Bureau of Children's Services
    - Children's Long-Term Support Council
    - Office of Children's Mental Health
- Wisconsin Department of Public Instruction
- Wisconsin Board for People with Developmental Disabilities
- Wisconsin Survival Coalition of Disability Organizations
- Disability Rights Wisconsin

Questions Asked of Participants

1. Tell us about what is going well. What programs or resources have been the most helpful to your family?

2. What has been the most challenging issue or biggest barrier you have experienced as you care for your child with a disability?

3. Tell us about your experiences with education. What is going well at school and what could be better? (virtual session only)

Discussion Themes

We asked participants open-ended questions, and due to the variety of environments and the diverse experiences of those who shared, we have organized their responses into key themes.

Theme 1: Access to Resources and Community

Families shared that resource organizations have a positive impact, though there are still areas where improvements can be made, especially when it comes to resource awareness.

At both sessions, families shared "You don't know what you don't know." Even with all the programs and services currently available, families continue to struggle to find the programs their children need. A few examples include difficulty finding inclusive summer camps and after-school programs for their children. Parents shared that their communities lacked resources for those over age 21, especially in more rural areas of the state.

A parent stated they learned about the Circles of Life Conference from another family but wished they had known about events like this years ago. Nobody at their school, long-term support program, or others had offered them ideas like this conference to connect with other families.

Several families shared their worries about potential cuts to resources and support programs. They reflected that it's a challenge to feel hopeful when they don't know what might happen in the next few months or the next few years.

Despite having concerns, there are several resources making a positive impact for children and their families.

Disability Organizations
State and local disability organizations, including Easterseals, the Down Syndrome Association, ALAS, GiGi's Playhouse and the Fox Valley Autism Society have been instrumental in keeping families connected and engaged in community activities. Opportunities like cooking classes, tutoring and summer camp programs make a real difference for their children. These organizations also offer guidance to families when they are navigating complex systems and support programs.

Family Leadership and Advocacy
Family leadership learning sessions provided by FVW and WI BPDD were described as especially helpful in creating connections, confidence and skill-building as advocates.

Two parents shared that Wisconsin Family Leadership Institute (WiFLI) allowed them to connect with others and supported them in their advocacy efforts. Others spoke very highly of Partners in Policymaking. A parent stated that she appreciates the "momentum of the advocacy community here in Wisconsin." Training and support for adults to become self-advocates was also highlighted, including connections through WI BPDD.

Job Supports
The Division of Vocational Rehabilitation (DVR) services have been important for young adults. Some noted that job-training opportunities have been positive experiences in their children's lives and allowed them to grow and gain more independence. Other parents said they cannot find enough support for their adult child who wants to be employed.

Faith Community
Several individuals shared that their faith community is important to their family's success. This environment has inclusive programming and faith leaders who connect families with supports. A family shared how they enjoyed a church-sponsored inclusive summer camp that welcomed their child with special healthcare needs.

Health Care and Therapy Programs
A parent told us they appreciate the fantastic health care their child received at Froedtert Hospital saying their medical providers, "pay attention to every concern, even the very small issues." Others shared that music therapy, art therapy, ABA and specific therapy providers, like Children's Therapy Network, and ODC made a positive impact on their children's lives. A youth told us alternative therapies and support programs through his providers were beneficial. Several families emphasized that having both Katie Beckett Medicaid and private insurance to cover these services for their children is critical.

Support Groups
Parents and caregivers spoke about online support groups, in-person and virtual conferences, and other social events that offer ways to feel less isolated and provide important opportunities to learn more about programs and resources. Several families wished there were more local support groups. They reported having a hard time finding connections, especially with older children who are no longer in school.

Theme 2: Children's Long-Term Support (CLTS) Program is Valued by Families When It Works Well, but Creates Challenges When It Doesn't

At both sessions, many families talked about the significant positive impact the CLTS program has on supporting their entire family, while others expressed some frustrations.

Families Appreciate the CLTS Program
The CLTS Program has been incredibly important for families. It provides resources, equipment, meaningful support from a support and service coordinator (SSC), and funding for memberships to gyms, museums and other activities to be part of their community.

Access to respite services was mentioned by several family members as being very important. Respite services allow families to step away from the stresses of caregiving, making it critical for mental health and resilience. A parent of twin boys told us the program has been important for her family's well-being so they can enjoy activities. Having a respite provider allows her to get out of the house and decreases her isolation.

Using Comprehensive Community Services (CCS) and CLTS has worked for families in difficult situations. A mom with multiple foster children said without these programs they would never have been able to maintain balance in their lives. Their service coordinator helps them with paperwork and scheduling appointments. Their CCS case manager jumped in when there were crises situations at school. She noted that CCS was able to find therapy services when they could not. When asked what made these programs so helpful, she noted that the case manager[s] trusts them, and mutual trust has been critical. She noted, "They have seen me raw and were able to help me."

A family talked about using CLTS funds to cover some of the extra costs for their child's ketogenic diet, wipes, nighttime diapers and other important supplies. Others mentioned art classes and swimming lessons that have made it possible for their children to be part of their community. The addition of fences to homes increased safety for families, which gave caregivers peace of mind.

Another parent told us that CLTS has been great when it works smoothly, but there are times when there has been a disconnect in communication. "Sometimes I don't get follow up and I have to chase them down." Other families at these sessions echoed with similar experiences.

There May Be Opportunities

One area of concern raised by families is the perception of high turnover rates for SSCs. Parents said their new coordinators did not seem to have a full understanding of the CLTS Program, which put them in the position of training their professionals. The feeling among these families was that SSCs couldn't be a helpful resource to them when they didn't seem to understand the program.

Some families saw their SSCs as resource gatekeepers and felt they were, "putting up roadblocks to access supports." They explained their experiences as perceived intentional barriers created by their SSCs and at times, they felt these barriers were personally directed. For instance, some families talked about having to appeal constant denials, with one sharing that their SSC asked them to retract a recently filed appeal because the agency had reconsidered the item and was now willing to provide it. There were also occasions shared when something inexpensive would have helped their child, but only a disability specific toy or device that was more expensive was able to be approved.

Several families from Milwaukee County were told the program had stopped paying for certain categories of services. One example was covering the cost of transportation. A parent shared in the past they were able to get help paying for rides to a CLTS covered program, but this year her SSC stopped and told her they no longer pay for transportation.

At times, personality differences hindered meaningful interactions between SSCs and families. A parent shared an experience advocating for a different coordinator after having multiple differences with her assigned SSC. She met with the agency to work out the conflicts but did not make any progress. She felt that while program service coordinators were supposed to use the *Deciding Together* model, they did not follow this philosophy.

Sometimes there was a feeling CLTS was adding more frustration than help or support for families. One parent described it as "…giving a feeling of false hope." Another parent shared that her request for childcare support was not approved, and she experienced red tape to get anything approved. "I sometimes want to give up!"

A parent from southwestern Wisconsin told the group, “CLTS has failed my family.” She feels that she has experienced retaliation for her advocacy and has not received the services that her children need.

A parent from southeastern Wisconsin explained that their new SSC has denied coverage for everything she requested. “We have gotten absolutely nothing covered. Everything is denied and even when I appeal, I don’t get anywhere. When we meet, we talk about items and programs that would be helpful for my child, but they don’t seem to understand.”

A foster and adoptive parent praised the CLTS program for being extremely helpful to her family. She added however, that it is getting complicated as their foster child begins the transition to adulthood and they struggle to determine the appropriateness of guardianship.

It was suggested that SSCs statewide may benefit from increased education on the CLTS Program and its offerings, with an emphasis on the importance of avoiding ‘dead ends’ (i.e. “They just said ‘no’ and we went on to talk about other things…”) and exploring meaningful ways to form positive professional-family relationships.

Theme 3: Caring for the Whole Family

Families explained to us the stark realities of full-time caregiving—that caring for their child with a disability or complex need brings stress, isolation and financial worries, which are not easily solved.

Need for Paid Family Caregivers
The temporary flexibility during COVID allowed one mother to be paid for providing direct care to her child with a disability, which “was a blessing.” This support made it possible for her to move into her own home. Since that policy ended, she has faced financial hardship. She also noted that while they qualify for SNAP, the benefits do not last through the month.

A parent of a medically fragile child also expressed her frustration with not being able to be financially compensated. They cannot find nurses or other direct caregivers who are knowledgeable and competent to care for her child, so she can’t work outside the home.

Self-Care
Several parents explained that the lack of respite or other outside caregivers meant that they did not have time to care for themselves or focus on their other children. Without help and support, several parents felt burned out, as well as physically and emotionally exhausted.

Isolation and Feelings of Exclusion
Several parents shared that having a child who behaves and looks differently than others creates lasting barriers to being part of the community. Parents remembered that when their child was younger they could not go to a restaurant or public place without people staring and making them feel excluded. School was the only place that felt comfortable. Others told us it was difficult to participate in faith community activities or other public or community events, which increased feelings of isolation.

Financial Stress
Trying to provide financially for her family has been one mother's biggest challenge. An in-home daycare provider could not care for her child, and like many other single parents, she struggles. She told us she was a teacher and wanted to continue to work, but she had no choice but to quit and care for her child. "My plan was to be a teacher and work fulltime, but we are doing the best we can with what we have."

Theme 4: Lack of Providers

When there is a shortage of providers, it has an impact on the entire family unit. Very often, out of necessity, parents step out of the workplace and into these roles, but there are profound impacts on employment, added financial stress, and changes to relationships.

Daycare Programs and Supports for Children with Disabilities
A parent with a younger child said for their family, finding daycare willing to accept their child has been extremely difficult. They explained CLTS won't pay for full-time care, so she is not able to hold down a full-time job and feels stuck. Another parent shared that her child was dismissed from five daycare centers. They could not find a place that was equipped and skilled to care for their child's needs. A parent shared that they bring their 7-year-old to work with them in the afternoons because they cannot find childcare, so they have no choice but to either leave work or take their child with them.

Difficulty Finding Respite Workers
Wisconsin families know how difficult it is to find a respite provider and because of this, most respite programs now rely on families to find their own providers. This is hard at best and sometimes is not possible. Other families noted how burdensome it is to find male caregivers, or caregivers who were available when families needed them on weekends, evenings or for extended hours during the summer months.

Private Duty Nursing
Finding private duty nurses is problematic for families, even when their child qualifies for these Medicaid services. For some parents who have a child with complex medical needs, it was difficult to trust another caregiver and that left them unable to get the time away from caregiving duties they needed, which added to their stress. Another parent commented that they don't have extended family in the area to help them. Their impression was that programs assume these extended family members can assist with a child who has a disability, but without grandparents or other family nearby, they have only their SSC to find nursing support.

Mental Health Providers and Services
Several families commented on the challenges they experience finding services for children and adults with mental health needs, especially in rural areas of the state. They worry about interactions with law enforcement and a lack of understanding when access to mental health services is so limited.

Theme 5: Contracted Medicaid Services

Families value trouble-free access to services in the Medicaid program. When families find the use of these benefits doesn't go according to plan, it can cause a major disruption to their lives.

Non-Emergency Medical Transportation
A family told us they have been able to work with MTM to receive gas mileage reimbursement. She said that when it works, it's great, but there have been obstacles, including one time when MTM's helpline was not working. She shared that she kept trying and was eventually able to receive mileage reimbursement for longer trips to medical appointments for her child.

Several other families expressed both positive and negative experiences with MTM. "When it works, it works," but when you depend on it and your ride does not show up or is over an hour late, it can be frustrating. When you wait months to see a medical provider, having the ride not show up is devastating. Those in rural areas noted that rides are often not available at all.

Incontinence Products
It was a struggle for one parent to get the right products from J and B Medical. They explained that it took over two months to have her child's products sent out, and that they received the wrong products numerous times. She called the company many times and did not get any resolution. It was only after she left a long message on their website comments section reflecting on their service that she received a call back and shipped the correct products. Others explained there were often delays with their shipments or occasions when different products were sent, which were known to not meet their children's needs.

Theme 6: Systems Navigation Support

A general feeling of, 'you don't know what you don't know,' was expressed by several families. They wished they were informed earlier about programs like Katie Beckett Medicaid and what it covers, as well as other local programs that their children could have benefited from. Others noted the difficulty finding someone to help them navigate new programs and systems, as well as advocate for their family, which is critically important.

An example of the difficulty navigating systems was shared by one family who talked about their experience trying to purchase durable medical equipment. They mentioned a recurring experience where CLTS wouldn't cover an item without a Medicaid denial, but the provider would not submit the paperwork to get a denial because they knew they wouldn't get paid for the item. The family finally paid out of pocket because it was something their child needed, and they felt trapped without a solution.

A professional commented that accessing Health Check Other Services (HCOS) is an ongoing problem. They noted that too many pharmacies still don't know what it is or how to bill using HCOS.

Theme 7: School Experiences

Meaningful engagement and care at school continues to be important to families, with not all experiences being positive. Some shared experiences of not being heard or considered part of their child's learning team, while others dealt with perceptions of rules, plans or standards not being followed.

Schools Make Positive Impacts
Families and professionals shared that their children's school has had significant positive impacts. Inclusive programs, strong and empowered support staff, and qualified special education professionals have helped their children learn and grow. A few parents told us their children's educators used notebooks to communicate daily, which increased school-to-home communication. Another parent liked the school's new sensory rooms for each grade. Another said having access to physical, occupational and speech therapy services at school made a positive difference in her child's development and independence.

Parents Want Partnership
There was also the perception among some families that their children's school team did not follow the IEP, or that the needed services or therapies included in the IEP were not being provided. Several parents explained that their children experienced seclusion, but they were not told until much later. Another parent noted that her teen-age son's school used seclusion and restraint multiple times. A family shared that their request for alternative placement was ignored, and they had to fight for years before it was finally implemented.

A feeling of discouragement was shared among families that claimed to have tried to partner with their schools and districts but were unable to make connections. A dad explained that they tried to work through the DPI complaint procedure, but they felt "unheard through the whole process." Another family shared, "The school dismissed any of the strategies that we use at home which helps her through her day." One mom indicated that she homeschooled her child because the local public school was unable to handle their complex medical needs. She feels many schools are not a good fit for children with complex needs. "Not having consistent support at school has been the biggest barrier."

The parent of a 4-year-old who is non-verbal and will need to use augmentative communication worried that the school her child may go to next year will not be prepared or have the resources to support him. She has visited 4 different schools, and none of the school staff she met with indicated they had experience or therapists who would be ready to support her child.

The family of a student attending Sybil Hoppe in Green Bay shared that their child receives great services from that school. The mother found that public schools [in her area] have "so many issues" they cannot adequately provide the services that her children need.

Transition in Education
Frustration was expressed by a parent whose children attend school in Wisconsin Dells district. She feels that her district does not offer a transition program, instead they graduate every student and in most cases, do not provide additional transition services, even though her teen needed this programming.

The Need for Advocacy

A parent whose child has complex medical needs stated that she needs to advocate for her child every single day. She is frustrated that her child is not getting necessary services. She shared that she is very concerned about the future, especially with the potential changes at the federal level. She spoke to the group, “We need to all push for proper funding for schools.”

How We Use What We Hear

FVW uses the stories and experiences shared by families to inform our work toward program and system improvements. We share these findings with state agencies, including the Department of Health Services, the Department of Public Instruction and the Department of Children and Families, to elevate the voice of families as we work collaboratively to make improvements for Wisconsin families who have children with disabilities and special health care needs.

Please contact Danielle Tolzmann, Family Voices of Wisconsin Executive Director, at danielle@fvofwi.org for further information or questions about these sessions, or this report.

This document along with reports from our past listening sessions are published on the FVW website at familyvoiceswi.org/resource-library.