

FAMILY LISTENING SESSION REPORT
2024 Circles of Life Conference
and Online Session



Family Voices of Wisconsin

2024 Family Listening Session Report

In-Person Session: May 2

Online Session: May 16

SUMMARY



Family Voices of Wisconsin hosts listening sessions annually for families of children with disabilities and special health care needs. At these sessions, participants are asked to share their experiences, challenges and ideas for improving the systems that support their children and family. Spanish-language interpreters are available at these sessions.

In 2024, Family Voices hosted two Listening Sessions for families. The first was held online using Zoom on Thursday evening, May 2. It was promoted statewide and allowed those who were not able to attend the in-person gathering a way to offer their input. The second Listening Session was held as part of the Circles of Life Conference at the Holiday Inn Stevens Point - Convention Center, on Thursday, May 16.

Agency and Organization Listeners

Representatives from state agencies and organizations whose mission is to serve and support children with disabilities in Wisconsin were invited to participate. These sessions gave organization representatives an opportunity to hear feedback directly from families.

This year's sessions included listeners from:

- The Wisconsin Department of Health Services
 - Bureau of Children's Services
 - Council on Children's Long-Term Support
- The Wisconsin Department of Public Instruction
- The Wisconsin Department of Children and Families
- The Wisconsin Board for People with Developmental Disabilities
- Survival Coalition

Participants

Approximately 130 people attended the in-person session as part of the Circles of Life Conference. The online session had 38 participants. The majority of participants were parents of children or youth with special health care needs and/or disabilities, or other family members.

WHAT WE ASKED

Participants were asked to respond to the following questions:

1. What has been the most challenging issue or biggest barrier you have experienced, as you care for your child with a disability?
2. What programs or resources have been the most helpful to your family?
3. If you could change or update a policy or regulation, what would it be and any?
4. As you went through the renewal process for Medicaid and Medicaid waiver programs this year (after pre-COVID rules were put back in place), did you experience any challenges? How did that process go for your family?
5. Family Voices continues to focus on assisting families who have children in the transition years (from children's services to the adult world). Are there areas of the transition to adulthood that you wish you understood better? What topics have been most confusing (legal, financial, health or education)?

These questions were also translated into Spanish and distributed in advance to family groups working directly with Spanish-speaking families who have children with special health care needs and disabilities.

The following sections contain summaries and responses from our family participants to these questions.

BARRIERS AND CHALLENGES

Difficulty Finding Direct Caregivers

Many participants raised that they continue to struggle to find respite providers and other nonfamily caregivers for their children with disabilities or special health care needs. Others mentioned challenges finding caregivers during the summer months, recruiting private duty nurses and hiring personal care workers in addition to the lack of respite providers.

Difficulty Finding Direct Caregivers (continued)

Parents as Paid Caregivers: Several families suggested one way to address this challenge for Wisconsin to consider paying parents who have children with complex needs as caregivers.

“Being in a rural area it's hard to find skilled workers to come into the home. It makes it difficult to find a full-time job as a single parent.”

“It would be a gamechanger for Wisconsin to have a paid parent policy.”

Low pay and other job opportunities that offer better wages and easier work environments were cited as some of the reasons why families cannot find direct care workers. Without respite or other direct caregivers, families cannot focus on the other members of their family, find work-family life balance, or properly care for their own health and wellness. For families whose children need nursing services, the current pay rate makes finding private duty nurses very difficult.

“Finding good, qualified caregivers to come to the home is so difficult!”

“Finding anyone that wants to do respite...and parents not being able to be paid to care for their child. I can't really hold a job.”

“Can we talk about all the hoop jumping between respite vs. childcare vs. camps? There's so much demand on parents to navigate these systems and they just don't make sense for real life with kids.”

Provider Shortages

Families in several areas of the state talked about difficulty finding childcare, dentists, therapists and mental health providers for their children. A parent shared that while their child qualified for, and had funding to cover occupational and physical therapy services, there was so much turnover that their child was not making progress because they had to “start over” every few months. Another parent stated that her teen has autism and mental health needs, and it has been impossible to find a therapist who can address both of his conditions. During our online session, a parent noted that recent facility closures in western Wisconsin have exacerbated these problems.

“It's also really hard to find childcare for kids who have aged out of daycare but can't stay home alone.”

“It took over 6 months to be seen by the doctor and then we couldn't get the prescription covered or filled for weeks.”

“We had lots of life-and-death safety issues from about ages 5-10. It is also really difficult to find medical and mental health professionals trained in fetal alcohol spectrum disorder (FASD) so we see the one person we can find with training, but her availability is extremely limited.”

Provider Shortages (continued)

Access to dentists who have training to work with children with disabilities is a real problem for families, especially those in rural areas. For some children and adults, they need hospital-based sedation to have dental work done for medical or sensory reasons. It is extremely difficult to find a dentist who is able to admit a child to a hospital to offer these services. A foster parent noted that there are children that have multiple infected teeth or end up losing teeth because of lack of access to proper dental care.

“Kids are having raging infections and going to school like this [untreated] with infections in one tooth moving into multiple teeth. I know of a 13-year-old that had an infection move into her jawbone.”

School and IEP Challenges

Listening session participants stated that they struggle to get the school-based services their child needs to be successful. Families also had the perception that school staff have a lack understanding of the needs of children with disabilities. Some noted that it took a lot of advocacy and persistence to have their child qualify for special education services, develop meaningful IEPs, and make sure their child was receiving the services that were outlined in their child’s IEP.

“What is agreed to in IEP isn't always followed. We continue to fight the system.”

Other participants wanted school staff to offer parents more support.

“Educators need more training and to give support to parents. These communication issues and lack of support are happening everywhere.”

“My dream is for a state advocacy organization for all students with IEPs.”

More than one parent suggested greater teacher and staff training about invisible disabilities would have a big impact on her students’ experiences. Too often their child’s behaviors are identified as behavior needing correcting rather than something connected to their disability. Another parent added, “I wouldn’t be working this hard if it was just bad parenting.”

“The relationship between the parents and staff on the IEP team feels ‘adversarial’. It’s disappointing that it’s this way, but it really has been. I’d love to see more advocacy be available for parents.”

Community Social Support and Interaction

Especially for young adults, parents shared that it is not easy to find ways for their young adult/teen to make community connections. Others worried that when their child finished school, they would be isolated and lack community and social opportunities.

“My son is quick to make friends but then gets bullied from those who he thinks are his friends. It contributes to his feelings of isolation and leads to depression.”

Finding, Navigating and Coordinating Services

Families experienced a variety of challenges finding necessary programs, equipment and services for their children. Some needed help after their child received a diagnosis, and others needed help finding and paying for specific items like specialized shoes. One parent shared that without help, they had a difficult time maintaining balance in their life and had fallen into poverty. Others shared that coordinating all the therapy, programs and school services for their child was often overwhelming.

“The other challenging aspect of caring for our child is the fact that from the time he was a toddler, coordination of his care, managing his medicines, school/IEP planning, everything has been my full-time job. And that’s on top of my actual full-time job.”

“Nobody called me back—We received a diagnosis but didn’t know where to go.”

“Finding resources as a whole [is a challenge]. You don’t know what to look for when you don’t know what is available.”

MOST HELPFUL PROGRAMS AND RESOURCES



Wisconsin has many programs for families who have children with special health care needs and/or disabilities. We wanted to hear which ones they found to be most helpful. They called out the following:

Children’s Long-Term Support (CLTS) Program

Participants in the Listening Sessions told us CLTS made a big difference in their families’ lives. Having funds for respite, programs that improved a child’s social skills, learning independent living skills and improving self-advocacy were vitally important to these families.

“We think CLTS is such a great resource and has been a huge blessing.”

“The CLTS program is beneficial for many families and easy to utilize. The Hudson office is professional, prompt and friendly for both clients and helpers.”

“CLTS for us right now, is funding a case manager through the family partnership program at LSS, and she has been amazing. She is knowledgeable about my child’s diagnosis, and she is a fantastic advocate in trying to support us and connect us with more resources.”

However, several parents noted that it is not clear to them why CLTS is different from county-to-county. A parent stated, “The fact that CLTS approves different things by county. It is a state program, but each county approves different things.”

Wisconsin Wayfinder

Several parents praised Wayfinder as a great support for Wisconsin families.

“Wisconsin Wayfinder [has been a great resource] now that it is live. This will definitely help those who are new to the world of disabilities.”

MOST HELPFUL PROGRAMS AND RESOURCES (continued)

Wisconsin Birth to 3 Program

Families agreed that their experience with their county's Birth to 3 Program has been very positive.

IRIS

A parent who has an adult child told us that the IRIS program and the resources it provides have been most important to their family. They are able to advocate and get what they need for their adult child.

Family Voices of Wisconsin

One parent who has participated in family leadership training and the Circle of Life Conference shared that the work and support of Family Voices has been the most helpful resource for her.

Other Parents

Multiple participants told us that connecting with other parents has been the biggest help, especially during difficult times.

“The most helpful thing for us is just getting connected with other parents to be able to share resources and gain the wisdom from their personal experiences.”

Local Special-Needs Facebook Group

A mom explained that this group allows, “Sharing with other parents struggles so that we can potentially help others.”

Parent to Parent of Wisconsin

This organization connects a support parent with another parent and it has made a real difference to families.

Home Schooling and Online Schooling

Several parents expressed that they have moved from public school to home schooling their child, including some who began during the pandemic. For their child, being able to home school, and receive support in other areas has been life-changing for their whole family.

In-Home Therapy Programs

A parent from a rural county stated that having therapists come to their home, rather than requiring her to bring the child to a clinic or therapist's office, has been helpful. It is a more comfortable environment for her child and the therapy has allowed her child to make real progress.

CESA's and WSPEI

A parent noted that the programs and support their CESA and WSPEI provide make a real difference.

“Meeting others through these programs has helped us navigate the systems. I don't think I could have done this on my own without the trainings for parents in those programs.”

POLICY OR REGULATION YOU WOULD CHANGE



When asked which policies, rules or regulations Listening Session participants would change to make a real difference in their lives, they shared a large variety of suggestions:

Seclusion and Restraint Reporting

A parent shared her account of her child's experience with repeated abuse at school. This parent suggested that the Department of Public Instruction should have a systematized or standardized form for reporting incidents, including seclusion and restraint.

Parents as Paid Caregivers

Several participants felt the rules around caregiving should be updated to allow parents with younger children to be paid for caregiving, especially for those who have children with more complex behavioral or medical needs. They said they cannot find other qualified caregivers, which means they cannot work outside the home or have had to scale back on their hours at work.

The SSI \$2,000 Asset Limit

Several participants spoke about the SSI Asset Limit. They suggested the need for it to be updated regularly to reflect the cost of living so families and individuals can save money while maintaining eligibility for SSI.

Admitting Procedures for Mental Health Services

A parent shared the experience of her suicidal child not be admitted to Winnebago [Mental Health Institute] because of the 10-minute evaluation process used. Even though over a dozen professionals recommended residential treatment, it showed that he did not meet the level of need for their services.

Special Education and Gifted and Talented Programs

A participant felt that these programs should work together to support students those who would benefit from both programs, but most districts are not able to coordinate these services between programs.

Law Enforcement Training

People with mental health challenges struggle to get the services they need and end up in encounters with police.

“We need more universal training so that those with mental health conditions don't end up in the justice system.”

Wage Policies for Direct Caregivers

Families expressed they continue to struggle to find direct caregivers without an increase in wages. One suggestion was the requirement for benefits or tax exemptions to make these positions more desirable.

POLICY OR REGULATION YOU WOULD CHANGE (continued)

Private Duty Nurses (PDN)

Families indicated that those whose children need in-home nursing services struggle to find and maintain staff due to current regulations and reimbursement under Medicaid. One participant also felt that the rules for what qualifies as eight-hours of nursing services does not make sense. The example cited was tube feeding run time, which does not count, only the time it takes to connect and disconnect counts toward hours.

Supported Employment and Adult Programs

A parent of a transition-aged child with complex medical needs and challenging behaviors learned many programs supporting adults with disabilities are able to restrict who they accept as clients because of ‘disqualifiers.’ These programs, it was felt, need to be more open to supporting a wider variety of people.

Training School-Connected Staff

A participant shared his account of a school bus driver verbally abusing their child. He felt better training for school district and community support staff who work with children who have special needs would have helped because the abuse caused serious emotional distress for his child.

Learning Materials in Other Languages

A parent struggles to find documents and special education materials in their family’s primary language.

Listening to Families

One parent had an ongoing feeling of not being ‘heard’ by academic staff.

“I know what works for my child, but when I tell them, they don’t listen. If we had a clear, open form of communication between families and schools where we can talk to each other openly and honestly, I think that would be helpful, if we all knew what was holding each other back.”

Mental Health Training for School Staff

“I would ensure teachers—and everyone in the district—have training on mental health first aid. It’s important for them to recognize when kids are struggling, all kids, not just our kids with disabilities.”

Multiple Children on CLTS

It was shared that the way families are told they need to use respite for multiple children isn’t practical.

“One person took five months to get approved as a respite provider. They had to complete a separate form for each child, working all through the same agency. We’ve been sent to a broker, but we have still had no respite providers come forward.”

Parents Need Support

Families recognize the difficulty of getting care for their child, but aren’t able to get the help they need for themselves. One parent shared their feeling of not being supported as a parent to a child with special health care needs and felt the recognition that supporting the parent was missing.

“For the mental health aspect, there’s nothing out there for parents. If we have to check our kids in, the parents need help too.”

POLICY OR REGULATION YOU WOULD CHANGE (continued)

Institutional Respite Process

Difficulty accessing institutional respite was shared by one parent. Before her son could get institutional respite, she was required to have multiple in-home respite providers, who would not return to their home because they were overwhelmed. Their access to institutional respite was limited and the cycle began again. Her son was aware these provider changes and this parent felt the process negatively impacted the child's mental health.

"I don't know how many times I've almost lost my job because I can't get to work and it's had an effect on me with the stress of keeping all these balls in the air. Calling the police out of safety happened often, due to not having appropriate respite."

MEDICAID UNWINDING



We wanted to know if the move from COVID to post-COVID rules had an impact families' lives. Our Listening Session participants responded this way:

An adult self-advocate stated that COVID continues to impact her organization, programs and activities they plan for adults and families. There is still a hesitation to come to in-person activities. It also continues to impact her, and others' mental health.

One family was caught in a systems-transition during their redetermination time, and ultimately had to do the review process twice.

"We had to submit the proof all over again...it's been a disaster with no access and no county office. It would be nice to still have an office in our area that we can stop at instead of calling the consortium for everything."

The need to complete Medicaid renewal paperwork has been stressful for some families and individuals.

"Personally, it was a bit bumpy, but not terrible. Our CLTS worker was new during COVID, so she just wasn't very familiar with the 'regular' rules and procedures."

"Being able to use telehealth/telemedicine was very helpful during the pandemic and we are now being asked to return to in-person provider visits. There was progress in increasing access, and forcing people to go back to in-person is a barrier."

TRANSITION TO ADULTHOOD



The transition to adulthood is a big change for families. We wanted to know which topics, if any, are confusing or they wanted to understand better. Participants told us the following:

Transition IEPs

A parent wants to know more and better understand the process for her child's transition IEP. She also needs to learn more about how that might translate to college/post-secondary education.

Transition Process

There was a comment that the school needs to help families understand what will happen during a student's transition process. "I don't really know anything about transition planning for adulthood. My son is 15 but I suspect that time will fly by!"

Friendships and Social Connections

Several parents worried about how their young adults would make social connections with others after high school.

"There is one thing I wondered about. Are there any groups for kids to get together and socialize in a supported yet unstructured environment? I have found some resources but not a lot to help with fostering friendships."

"My son just started a college program, and it became very apparent that he still didn't have the social skills he needed."

"Still trying to understand guardianship or Supported Decision-Making. I had to seek out information on my own, the school IEP in this area is very weak. We have to know a lot of things while there is still a lot of unknowns."

Supported Decision-Making

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HOW WE USE WHAT WE HEAR



Family Voices uses these Family Listening Sessions to inform our work, including working toward public policy and systems change. We share our findings with state agencies, including the Department of Health Services, the Department of Public Instruction and the Department of Children and Families, to bring the voice of families to systems and programs. Family Voices strives to influence change that makes services work better for Wisconsin families who have children with disabilities and/or special health care needs.

For information or questions about this Listening Session Report contact **Danielle Tolzmann**, Co-Director, Family Voices of Wisconsin at Danielle@fvofwi.org.

This report, along with past Family Listening Session Reports are available on the Family Voices of Wisconsin website at familyvoiceswi.org/resource-library.