



FAMILY LISTENING SESSION REPORT
2023 Circles of Life Conference
& Virtual Session



Each family has a voice. Together, our voices will be heard.

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Family Voices of Wisconsin

2023 Annual Listening Session Report

In-Person Session: May 11

Virtual Session: June 6

SUMMARY

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

In 2023, Family Voices hosted two sessions. The first session was part of the Circles of Life conference at the Wilderness Resort, Wisconsin Dells, on Thursday, May 11. The second session was held virtually, using Zoom, on Tuesday evening, June 6. The virtual session allowed those who were not able to attend the conference to provide their input.

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 listen. 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
 - CYSHCN Program
 - Council on Children's Long-Term Supports
- The Wisconsin Department of Public Instruction
- The Wisconsin Department of Children and Families
- The Wisconsin Board for People with Developmental Disabilities
- Survival Coalition
- Disability Rights Wisconsin

Who Participated

Approximately 175 people took part at the in-person session as part of the Circles of Life Conference. The virtual session had 43 participants. Most attendees were parents or other family members.

WHAT WE ASKED

Participants were asked to respond to the following questions:

- Are you concerned about the Medicaid rule changes because of the “unwinding” due to the end of the public health emergency?
- What is the most challenging issue your family is facing?
- What is one thing you would change to improve your child’s life?
- What’s made the biggest difference for your child and family?

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.

THEMES WE HEARD FROM FAMILIES

Concerns Related to Medicaid Unwinding

Families shared several concerns but also talked about ways the public health emergency flexibilities positively impacted their family’s life. A parent stated that the increase in Foodshare during the pandemic made a real difference in her life, and she worried about the move back to pre-pandemic benefits. A foster mom shared that telehealth and the increased use and Medicaid coverage for telehealth (phone or video) visits were important for her child. She was hopeful that medical providers will continue to offer telehealth visits. During the virtual session, one mom shared that not having to go through an annual Badgercare/Medicaid review was helpful for their family. They are self-employed, and not having to complete this paperwork made their life less stressful. Another parent told us that many families in her area are panicking that they will be found ineligible for Medicaid and lose coverage. She reported that they are receiving letters from DHS and fear that they might miss something and lose coverage.

Concerns Related to Medicaid Unwinding (continued)

Families noted that during the pandemic, they had increased coverage under the Children's Long-Term Support Program (CLTS) for respite services, memberships to the zoo, the YMCA, and other community activities and programs that benefited their child and families. Membership to some of these community activities has been denied due to the unwinding. A mother noted that these outings increased her child's vocabulary and additionally had a positive impact on his behavior. In recent months, a Milwaukee area parent also shared that her family's CLTS respite hours were cut when there was no change in the family's need for respite.

Challenges Facing Wisconsin Families

When asked about the most difficult or challenging areas facing families as they care for their child(ren) with disabilities or special health care needs, we heard a wide variety of responses.

• Access to Dental Care

Families from rural and urban areas of the state shared that finding a dentist and having dental care covered was a real challenge. A parent from Iowa County told the group that she was having difficulty finding a dentist for her kids. She has been unable to find a provider who understands children with special needs, and the only dentists with openings do not take their insurance. A Spanish-speaking mom also shared that she cannot find a dentist for her 18-year-old child with autism. Her child needs oral surgery, and no dental providers in Milwaukee take Medicaid or have openings, so she feels stuck.

• Lack of Direct Care Workers

Several families explained that the lack of respite and other direct-care workers has negatively impacted their lives. One parent noted that the low wages for this work and other opportunities, like fast-food restaurants paying \$15 or more, means that families looking for direct-care providers cannot compete. A mom who works with other families across the state told the group that many families are in crisis because they can't find help and need to quit their jobs or cut back on hours to care for their children. A parent shared that her daughter's lack of reliable direct caregivers has led to a loss of trust and has had a real emotional impact on her daughter, who enjoys time with caregivers after school.

A parent and provider in the La Crosse area stated that many of their community services are negatively impacted. They can't find drivers or support workers for many of their home and community programs. This means that children and adults with disabilities cannot return to in-person services or attend events and activities in the community. Another parent noted that even when families find direct care workers, they don't stick around very long, so families must start over and re-train new people repeatedly. For some, this turnover increases their stress and fatigue.

• **Children’s Long-Term Support Program**

A parent from Eau Claire shared that many families in her county continue to wait for CLTS services. This discourages and negatively impacts families whose children qualify for CLTS but must continue waiting a year or more before the county can assist them. Another parent shared that she has a child enrolled in the CLTS Program but frequently receives denials. While she knows what is helpful for her child, the family’s service coordinator told them it these items are recreational and would not be covered.

• **Transition for Adults with Mental Health Needs**

A parent shared that she recently transitioned from children’s services to adult support with her young adult son, which was a real challenge. Because her child has mental health needs, there are few programs or services to support her child and family. She feels she is on her own to navigate the adult mental health world.

• **School Services and IEPs**

Families struggle to get the services their children need during the school day. Several parents of children with autism shared that coordinating providers is complex, and school staff are unwilling to have outside providers come into the school. Another parent stated that her child’s school district does not understand that a child may get good grades but still may need an IEP. These children have sensory needs that schools needs to address, “Our children need to be given a break during the school day!” Another parent, whose child now attends an alternative school, shared that there is a lack of alternative school programs for children who need them. Her child’s school was unwilling to consider having him attend another school, and he struggled for years until they agreed to pay for a school transfer. Her son is now thriving.

Other Challenges

A parent whose adult child has been living in a group home explained that severe conflicts of interest have led to the abuse and neglect of her son. With limited options in her community, finding another residential setting for her child has been difficult. A parent also shared that she has been a foster parent for many years, and noticed that there is a lack of foster parents. The low rates and difficulties of foster children from different counties make fostering children with special needs even more difficult.

IDEAS TO IMPROVE A CHILD'S LIFE

When families were asked what would make a real difference in improving their child's life, they had specific ideas.

- “We need mental health providers who understand various mental health needs, including providers who work with children with mental health and developmental disabilities.”
- “Schools need to partner with ABA providers.” In most cases, families are not allowed to have their ABA therapists come into the schools or coordinate services during the school day. A parent from Milwaukee County also noted that her child's IEP did not allow for continued ABA therapy, negatively impacting his progress. Also seen as a need is better coordination between a child's IEP team and outside providers.
- “Resources need to be available in every county, not just some. There should be more consistency, so children and families across the state can access the same resources. We need more integrated programming and activities in rural areas as well as urban.”
- “We must change how society defines safety and danger for people with disabilities.” A parent shared that at school, her son was put in environments where he was not safe. She further expressed that safety is not only for vulnerable females.

PROGRAMS AND SERVICES THAT MAKE A DIFFERENCE

Finally, listening session participants were asked to share what made the most significant difference in their lives. They told us the following:

- **Disability Rights Wisconsin**

One parent shared, “We have walked through so many storms with them.”

• **A Child's Teacher**

A dad explained, “My child’s teacher allowed my child to be himself. He went from being afraid of students to being a part of the class.” A sibling shared that teacher training has made an enormous impact. “How fun and understanding the teacher is. My brother can be aggressive, but his teacher looked past that. They accept his affection when he shows it.” Another parent mentioned how creative and innovative his child’s special education teacher was and how he understood that his behavior was communication. A parent from La Crosse also complimented her child’s school and special education teacher, who ensured there was daily communication between school and home, and let the parent know if something was off.

• **Many Resources Are Available to Support Families**

A parent noted that Wisconsin has many great resources for children with special health care needs. One example a father shared was the Miracle League, a baseball program for youth with special needs. His son truly enjoys participating and looks forward to these weekly games all year. Another example was the Partners in Policymaking sessions, sponsored by the Board for People with Developmental Disabilities. The parent took part in this program a few years ago and thought it was truly life-changing.

• **The Children's Long-Term Support Program**

A mom of a young child shared, “We are connected with the CLTS Program, and they connected us with Vision Forward for services for our son.” She noted that CLTS has been very beneficial for her family.

HOW WE USE WHAT WE HEAR

Family Voices uses the stories and ideas shared by families to inform our work, including working toward public policy and systems change. We report our findings to state agencies, including the Department of Health Services and the Department of Public Instruction, to bring the voice of families to systems and programs, and work to influence change to make services work better for Wisconsin families who have children with disabilities and special health care needs.

CONTACT

Please contact Barbara Katz, Director, Family Voices of Wisconsin at barb@fvofwi.org for further information or questions about these Listening Sessions or this report.