

**FAMILY LISTENING SESSION REPORT
2021 CIRCLES OF LIFE CONFERENCE**



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

familyvoiceswi.org

Family Voices of Wisconsin

Annual Listening Session Report

Circles of Life Conference

Virtual Group

May 5, 2021

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, their challenges and their ideas for improving systems and programs that support their children and family. Spanish interpreters are also made available to the group.

Due to the pandemic, the listening session was held virtually over Zoom on Wednesday, May 5, from 4:00 – 5:15 pm. The session was promoted to all, roughly 600, Circles of Life Conference registrants. Email and social media was used to reach the larger community in the month before the event. To get input from the largest group possible, conference registration was not required to participate in the listening session.

Agency/Organization Listeners

Representatives from agencies and organizations whose mission is to serve and support children with disabilities in Wisconsin were invited to listen. This session provided a prime opportunity for these organization representatives to get feedback **directly from families**.

This year's listeners included:

- Wisconsin Children and Youth with Special Health Care Needs (CYSHCN) Regional Centers
- Wisconsin Department of Health Services—Bureau of Children's Services
- Wisconsin Department of Public Instruction
- Wisconsin Board for People with Developmental Disabilities
- Survival Coalition
- Disability Rights Wisconsin
- Wisconsin Department of Health Services' Children's Long-Term Support Council

Who Attended

Seventy-six individuals participated in this virtual listening session. Most participants were family members or primary caregivers. Other participants included organizational representatives, providers and professionals who work with children with special health care needs.

THEMES

Throughout the listening session, the message from families was the profound impact the pandemic has had on families who have children with behavioral and emotional, or mental health challenges. The lack of services due to the pandemic shutdown was challenging in all aspects of life for these families. Their children were left without programming, and families were left without supports and services.

Families who have children with complex medical conditions also experienced increased stress. Quarantining at home to reduce COVID exposure, and lack of direct caregivers, left family members to fill this void leaving many feeling isolated and overwhelmed.

Families also talked about the overall lack of options for their children who experienced a mental health crisis. Most parents chose not to call law enforcement. However, there are no good choices for residential mental health or crisis mental health services in most areas of the state. For their children's and family's safety, parents truly struggled with the lack of available options when their child experienced a crisis.

Finally, many families shared that navigating supports and finding what they need is confusing. The feeling was that no one was there to show them the way, help them find resources they need or understand the benefits of programs.

LISTENING SESSION FINDINGS

Following is a summary including quotes from participants in the May 5, 2021, Family Listening Session.

Impact of COVID and Move to Virtual Learning

The lack of school staff support and the pivot from in-person school and community programming to entirely virtual learning did not work well. Families experienced increased behaviors and anxiety from their children, which elevated stress for the entire family. Even as many schools reopened in the spring, families communicated that community-based programs and supports were still not available in many cases due to COVID restrictions, limited openings or lack of available staff.

- *“I just want to emphasize that families are under-funded and under-served if their child has a behavioral issue. We hit a wall when we are trying to find caregivers or services for these families.”*

Feeling Alone

The pandemic increased the isolation many families were already experiencing. Having fewer outside direct caregivers and no school or community programming, brought about by the pandemic, added to the isolation. As of May 2021, many families continued to feel isolated, especially those who have children with more complex medical conditions or disabilities.

Lack of Access to Services

Families who have children with behavioral issues have a hard time finding services.

A parent reported that her child's school staff and teachers treat these children's behaviors as "disobedience" rather than a result of their disability.

- *"We need teachers who understand our child's behaviors."*

Frustration with Getting Supports in Crisis

One parent explained that her county denied covering the cost of crisis intervention, and residential options were denied. The family in crisis needed coverage for their child to be at the Central Wisconsin Center but continued to have this option dismissed due to the high cost of care and red tape.

- *"Programs shut down during the pandemic that support kids who need school-based behavioral help...and they are not yet up and running. Kids in crisis in school still need those supports, but now they are not being served. It's causing even more stress on families."*
- *"When in crisis, the options are minimal for many of us. Calling the police or arranging to put a child in foster care **should not be the only available options.**"*
- *"My child had to be put into foster care so we could get the help she needed."*

Mental Health Providers Who Understand Children with Intellectual Disabilities

- *"We cannot find a mental health professional who understands my child's FASD."*
- *"We need therapists who can treat both intellectual/developmental disabilities and mental health care needs."*
- One parent stated that she worked hard within Milwaukee Public Schools to bring mindfulness and mental health services for kids with behavioral issues. There is a good curriculum for this.

Vast Differences Between Systems for Children and Adults

The supports are more difficult to find, and families are given less support and direct care as they look to fulfill their adult children's needs.

- *"Transition to adult programs has caused me to grieve for the children's programs. Talking to another parent has helped."*

Need for Emotional Support for Parents

Families lack their own emotional supports while caring for their children, especially parents who have children with medical complexity.

- *"There are so few other parents who are going through what I go through. I am so isolated and spend so much time at the hospital."*

Help Navigating Supports and Understanding Benefits

- *“My son received a ForwardHealth card through the Katie Beckett program, but no other information other than the card. I am looking forward to the Circles breakout session, which will give me the information that I need.”*
- *“I think overall there is a lot of information out there but **no real central location** to help with all the information.”*
- *“It would be helpful to have one place to call for support.”*
- *“It is especially difficult at the beginning of a diagnosis. My son was diagnosed this fall with autism. It would be helpful to have one place to call. I got Forward Health Card but didn’t know how to use it. It is overwhelming at the beginning.”*

Supports, Programs and Providers in Rural Areas

- Families expressed frustration that they live closer to medical centers or therapy in another state (in Minnesota or Iowa). Because Medicaid or other insurance would not cover out-of-state providers, they needed to travel long distances to get what their child needed.
- Lack of in-home care, both respite and personal care, is challenging to find in rural areas.

It was acknowledged that finding a support provider along their family’s journey helped them get the support they needed, but that the system still has many cracks.

FINAL THOUGHTS

The family members at this year’s session expressed gratitude for the opportunity to voice their concerns to this broad audience of listeners. The only regret was not being together to share dinner and conversation! Another parent shared the immense value of the Circles of Life Conference as well as how the system has worked to care for her children and foster children.

- *“The system works. There are downfalls, but it ends up working—lots of hiccups. What helps is seeing these faces year after year. There are people here who will walk through this life with you. There is a lot of support out there.”*

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 influence changes to make services work better for Wisconsin families who have children with disabilities and special health care needs.

If you have questions about the Listening Session or this report, please contact Barbara Katz, Co-Director, Family Voices of Wisconsin at barb@fvofwi.org.