



**FAMILY LISTENING SESSION REPORT
2022 CIRCLES OF LIFE CONFERENCE**



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Family Voices of Wisconsin

Annual Listening Session Report

Circles of Life Conference

Virtual Group

May 10, 2022

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 systems that support their children and family. Spanish interpreters are also made available to the group.

Due to the continuing uncertainty related to the pandemic, the listening session was held virtually over Zoom on Tuesday, May 10, from 4:00 – 5:15 pm. The session was promoted to all Circles of Life Conference registrants, and email and social media were used to reach families across the state. Conference registration was not required.

Agency/Organization Listeners

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

This year's session included listeners from the Wisconsin Children and Youth with Special Health Care Needs (CYSHCN) Regional Centers, the Wisconsin Department of Health Services (DHS)—Bureau of Children's Services, and the DHS 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, the Survival Coalition, Disability Rights Wisconsin, and the Waisman Center/UCEDD.

Who Participated

Fifty-one individuals participated in this virtual listening session. Most participants were parents or other family members. In addition, agency representatives and other professionals who work with children with special healthcare needs were part of the session. The family members who shared their experiences were diverse. These participants ranged from a parent with a newly diagnosed two-year-old, to parents with young adults, or youth in their teens. Families also represented a variety of communities, including rural areas (25%), suburban (30%), and urban (45%) areas of the state. Several participants were both professionals working with CYSHCN as well as parents, so they had the dual perspective when sharing the challenges and joys in their lives.

WHAT WE ASKED

Participants were asked to respond to the following questions:

- What is the most challenging issue your family is facing?
- What is one thing you would change to improve your child's life?
- Who/what is most helpful for your family on a daily/weekly basis?
- 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 that work directly with Spanish-speaking families who have children with special health care needs and disabilities.

THEMES WE HEARD FROM FAMILIES

Direct Caregiver Shortage

Throughout the listening session, we heard that the lack of direct caregivers was one of the most pressing issues families are currently facing. The pandemic and current economy have exacerbated this problem for many families.

A mom shared, "Providers don't call back and sometimes even the support brokers can't help. We do lots of calling around and chasing." Another parent stated, "Very challenging to find a provider who can do any kind of daily living skills...the likelihood of finding anyone ... I need to find someone to spend time with him. Nobody else can support him during his meltdowns—constantly putting extra pressure on me as a parent. I know I am not alone."

While many families have access to funding to pay for respite, skilled nursing services, or Medicaid Personal Care Services, they are not able to find and retain caregivers. Families told us that finding caregivers during the summer for their children with disabilities is especially difficult this year.

- "I have the funding, but I don't have the providers."
- "A broader support network would make a difference for us."
- "We have respite hours approved but no providers."
- "We are left without a bench to back us up."

A foster mom whose son needs 24/7 nursing care told how she struggles daily to find nurses and often has no coverage during the night. There are added complexities due to the training requirements, so even when she finds a candidate, she ends up losing them because the course they need to take is only offered monthly.

Coordinating Care Needs and Navigating Systems

The challenge of coordinating all the programs and services their children need was another theme we heard from families. Families feel overwhelmed and overworked. They often don't feel they have the support they need to navigate the services, benefits, and programs and wish someone could be by their side to help them.

- “Having to juggle parenting my child the way he needs parenting and working...sometimes I have to spend two hours with him if he's had a meltdown. That burden continues to be on me. I wish I didn't have to choose between my passion and parenting needs.”
- “Just triaging their care is my biggest challenge.”
- “Having to manage everything is overwhelming.”
- “I do have some support from my family, but I do still burn out.”

A parent with a young child stated that coordinating all their services has been harder, “He is connected to the B to 3 Program, but they are only doing a monthly check-in to see if his condition has changed. We could really use more support and help with finding what he needs.”

A mom told us that one of the things that were **most** helpful for her was a hospital-based care coordinator. Someone who assisted with appointments, referrals and communication between her child's many medical providers.

A family member who assists her adult relative stated that navigating adult services and managing coverage through the IRIS program is her biggest challenge. “Transitioning from high school to the adult world and navigating a new system has been hard. There's not a lot of support or guidance. I find it really challenging to navigate that transition.”

Difficulty Accessing Program Benefits

Several parents shared that while they appreciated the Children's Long-Term Support Program and their child's service coordinator, they felt frustrated that what they really needed was hard to get. CLTS requirements and red tape made them feel that they were getting the run-around. Another parent shared that the number of hoops they have to go through to get a service or item covered meant they didn't utilize the CLTS program. Therefore, her family receives minimal support.

- “We are not using the benefits of the program to the level we should because we need a letter from the doctor for everything. After all the other paperwork I am dealing with, it's just too much.”
- “What my son needs is a service dog, but I am being told that our county has never done that and we won't be approved.”
- “I am struggling to get support for CLTS to pay for our small town programs – our county needs W9 forms to pay for any of the programs we need.”
- Another mom shared that they find, “...too many hoops and not enough concrete supports.” Sometimes she feels like the program implies, “I didn't know what was best for my child.”

Lack of Services and Programs

Families told us that finding the right programs to help their child make progress was difficult to find. Especially for those living outside of urban areas, families experience difficulties finding programs for children with autism, or therapies that would benefit their child. The lack of direct providers also impacts access to programs and services for families. Several families shared that summer is an especially hard time to find programs for their child.

- “We have only one place within an hour’s drive, and they don’t have the staff to take him this summer – that is our biggest struggle.”
- “The distance that I have to travel to find resources (there are no programs in our area).”

Need for School Flexibility and Better School Services

Several parents shared that what made the most difference over the last year, especially in light of continuing concerns related to the pandemic, was their child’s school and flexibility. Several families did not send their children back to full-time school and found that was extremely helpful. Others stated that the pandemic and re-entry back to in-person school have been difficult for their kids.

- “I am so glad that school was able to accommodate our needs (for a reduced school day) this past year. It has been helpful to develop his communication skills—keeping that going is the hardest part for us so we don’t lose our jobs.”
- A mom told us, “Our boys need more time for transition, re-teaching, explaining why certain things are perceived a certain way.”

When asked, what is one thing you would change to improve your child’s life, a dad from central Wisconsin stated, “A school atmosphere that actually meets their needs, designed for them and not trying to fit them into an environment, which for our son, is abstract and honestly stressful. (We need) therapists who can come into the home and help with functional skills and behavior.”

A parent whose child just started with their school system told us, “I worry. I’d like to have more support for him at school. Having more individual support for him at school is my dream.”

SOME GOOD NEWS!

While the last two years have been a real challenge for many families, participants had a lot to share about what has been going well and what has been most helpful for their child and family. Families shared that the following have been helpful:

- Being able to use telehealth during the pandemic
- Having the Children’s Long-Term Support Program pay for programs and services like social skills programs and equine therapy
- School therapists and autism treatment programs
- Early intervention services
- The school district’s willingness to be flexible during the pandemic

These all made a big difference in their child’s life and were “game changers” for families.

- Our autism therapy service provider “has been life-changing for us to navigate home life and school.”
- “Our school district is great. They are willing to take the input from the professionals and make changes.”
- “Telehealth has been a godsend. It means not having to transition out of the house and that has been so important and helpful.”
- “Getting him connected right away was so helpful. Having that intensive therapy available to us was a game changer.”

RECOMMENDATIONS & INNOVATIVE IDEAS FROM FAMILIES

As part of the listening session, families are encouraged to also share their ideas to make programs and services work better for all families. The following ideas were shared:

1. When one child is on Children’s Long-Term Support Waiver, can there be some prioritization for another child from that same family? It makes sense that if there is the same service coordinator, why should that family have to wait so long for their second child to be served?
2. What if CLTS or the Birth to 3 Program helped families pay for childcare assistance—not just covering the additional costs, but paying for high-quality childcare? For many, this is the least restrictive environment and would benefit that child.
3. As your child grows, ask for a re-evaluation or reassessment. A dad shared, “Sometimes a fresh look by someone who is impartial (besides school staff) can be important and can help be more realistic about what your child will be able to do.”
4. Continue to allow CLTS to provide funding to families for daily living and respite. There was flexibility during the pandemic to allow parents to get paid and IRIS allows parents to get paid to provide personal care services. For many families who are experiencing hardship finding non-family caregivers, allowing CLTS to pay families could make a big difference.

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.

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