

**FAMILY LISTENING SESSION REPORT
2019 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:
Stevens Point
May 2, 2019

INTRODUCTION

Every year, as part of the Circles of Life Conference, Family Voices of Wisconsin hosts a listening session for families who have children with disabilities and special health care needs and the providers who support them. This annual event provides an opportunity for parents and other family members to share their experiences, daily challenges and successes as they care for their children with disabilities and special health care needs.

This year, in collaboration with the Department of Health Services (DHS), Family Voices asked participants questions that are part of the Maternal and Child Health (MCH) Five Year Needs Assessment as the framework for the event. The responses will help inform the Maternal and Child Health Program as they plan for future programs and services for Wisconsin children and families and complete their next five-year federal block grant application.

Family Voices staff began the session by encouraging families to share their stories and experiences because DHS values hearing directly from families. Close to 30% of the funding from the MCH block grant goes to Children and Youth with Special Health Care Needs (CYSHCN) programs in Wisconsin so the experiences of families are critically important as the department plans its upcoming work.



THE MCH NEEDS ASSESSMENT

Federal Title V legislation requires each state to conduct a state-wide, comprehensive needs assessment every five years. The needs assessment process is a useful tool for strategic planning, strategic decision-making, and resource allocation. It also provides a way for Title V programs to benchmark where they are and assess progress over a five-year period. (AMCHP, [amchp.org/AboutTitleV/Resources/Pages/NeedsAssessmentResources.aspx](https://www.amchp.org/AboutTitleV/Resources/Pages/NeedsAssessmentResources.aspx))

Working collaboratively with DHS staff, Family Voices staff selected four questions from the community assessment from the MAPP Assessment Tool¹, with minor modifications, to pose to listening session participants. This included the addition of the word “family” to questions that asked about “community.” Each question was translated into Spanish and the questions were sent to our partner community consultants in advance of the listening session.

QUESTIONS FOR PARTICIPANTS

1. What is the most important or urgent issue your family/ community is facing right now?
2. What does “living your best life” mean to you?
3. If you could change one thing about your family’s experience, community or neighborhood, what would you change to make it better?
4. What are some good things about your community that make life better for people who are part of it, especially for your family?

¹The MAPP (Mobilizing for Action through Planning and Partnership) Assessment Tool, is a strategic planning resource from the National Association of County and City Health Officials (NACCHO), <https://www.naccho.org/programs/public-health-infrastructure/performance-improvement/community-health-assessment/mapp>

OUR LISTENERS

Family Voices invited representatives from multiple agencies and organizations to attend our listening session. These agencies have programs that impact families as they care for their children with special needs. As such, Family Voices wanted their staff members to be present to hear directly from parents, grandparents, youth and the providers who work with families.

The following agencies and organizations participated:

- The Department of Health Services (DHS) including:
 - Bureau of Children’s Services,
 - Birth-to-Three Program,
 - Katie Beckett Program,
 - Medicaid Program,
 - Children and Youth with Special Health Care Needs Program, and
 - CYSHCN Regional Center directors.
- The Department of Public Instruction and their Wisconsin Statewide Parent Educator Initiative (WSPEI),
- The executive director of the Board for People with Developmental Disabilities,
- The executive director of Disability Rights Wisconsin,
- The Waisman Center, University Center for Excellence in Developmental Disabilities (UCEDD) staff,
- Members of the Survival Coalition of Wisconsin Disability Organizations, and
- Members of the Department of Health Services’ Children’s Long-Term Support Council, advising the DHS Secretary.



OUR PARTICIPANTS

Approximately 160 families, providers and state, county and other agency staff members attended the listening session. A total of 23 participants shared their ideas and suggestions during the session. Participants were engaged and supportive of one another as they shared their lived experiences.

As with past years, we heard from a diverse group of families, youth and providers. Spanish interpreters were available to assist Spanish speaking families. During the session several Spanish speaking parents and grandparents contributed to the conversation and provided valuable insights.

WHAT WE HEARD

Question 1: What is the most important or urgent issue your family/community is facing right now?

Theme: Isolation

Several parents responded that the issue they struggle with the most is isolation. This can be a problem in both rural and urban environments and lack of transportation contributes to the sense of isolation. A parent from Milwaukee commented that her child also experiences isolation in their community and there seems to be less funding available now for programs that support inclusion. Family members specifically said:

- “My kids have been watching from the sidelines for years.”
- “People don’t realize how a disability can affect you every day.”
- “Her world became her family and that is it. She felt so alone.”
- “In Milwaukee, they cut funding for after-school programs. Now we keep them in the house and that brings more isolation. They should be out in the community.”

One parent shared that she has used social media (a Facebook page) to connect with others and this has helped her feel less isolated. She stated, “I have to find my bridge to other families because as a parent of a child with a chronic illness I feel so isolated.”

Theme: Transportation

Families talked about lack of reliable transportation which impacted their ability to get to medical appointments (or made them late) and contributed to their child and family's feeling of isolation. A parent told us that the transportation company (MTM) did not have enough drivers so they were often late or didn't show up so her child missed many therapy appointments.

Another parent shared that, "We have to rely on family. There is no easy way to get out in our (rural) area."

Theme: Lack of Access to Behavioral Health Providers

Families struggle to find mental health and behavioral health providers, including therapists. This is especially acute in rural areas and most of northern Wisconsin. Families have to travel long distances, or their children go without regular treatment or programming due to the lack of behavioral health providers. It also takes months to start the process of getting an evaluation and it usually requires a great deal of travel to find a provider.

Theme: Lack of School Services and Quality Special Education

Several families shared their frustration with the lack of special education teachers and/or poor quality of special education programs at Milwaukee Public Schools (MPS). For them, MPS and the lack of good educational supports and services was the most urgent issue they face.

- A parent stated, "Year after year they (MPS) has been cutting back on services for our kids. We have been fighting this battle for so many years and it's getting worse."
- "Milwaukee needs more after-school programs for our kids. They used to provide bus passes so they could go to a museum or to other places, but they cut that program."
- A parent shared that she is paying for tutors to supplement school services that are sorely lacking. She has tried to transfer out of the district but has been on a waiting list for four years. Her child is falling farther and farther behind.
- A parent from central Wisconsin explained that she reluctantly sent her daughter to the Wisconsin School for the Deaf because the local school could not provide the support her child needed. They could not handle her behaviors when she became frustrated and violent. She does not like that her daughter is so far from home.

Theme: Employment

Two family members talked about the lack of community supports to help youth with disabilities work with employers in their community which resulted in underemployment or unemployment for those with special needs or sensory issues.

A parent shared that her family cannot find employment experiences for a child with behavioral health needs due to lack of community supports. Another parent shared that they can't find help working with employers that understand sensory issues, "without work supports, he can't keep a job in our community." Other families stated:

- "We are not set up as a society to deal with these individuals. There are *Help Wanted* signs up all over, but no support to help our kids get jobs or stay employed in Milwaukee."
- "The county wants them out in the community, but they are cutting these important programs."

Theme: Home Care Provider Shortage

Families talked about not being able to find help at home. Hiring is difficult and time consuming. Their low wages make it even harder to find personal care and respite providers. This also leads to more isolation. Families in both rural and urban areas experience this problem. A parent stated:

- "We need more access to in home care. The minimum wages make it impossible to hire someone. It's a joke."

A grandparent added, "We need a living wage for personal care workers."

Question 2: What does "living your best life" mean to you?

Families and youth shared their vision for their child and family's best life.

Potential: A parent stated that her child's best life would be if he could live up to his best potential. He does not know he has a disability and, "I wish we could expand that to make a more supportive community for him and others to live in."

Personal: A young adult said, "getting married and working with friends!"

Communication: Two parents told us that having their children be able to use assistive technology at school and in the community would make a big difference

- “To have my son, who is non-verbal, use his communication system and not be so isolated.”
- “MPS no longer provides any speech therapy for my son. For him, getting that help so he could communicate, would make such a difference.”
- “They dropped the ball on therapy and helping her. MPS did not do well by my daughter.”

Employment: Several parents described having necessary supports and services in place so their children can work is helping to build their children’s best life.

- A parent described that her daughter is in school, has all kinds of goals and wants to be an advocate and work in the juvenile justice system.
- Another parent shared that her son has an internship at Children’s Hospital of Wisconsin and is graduating.

“You have to make the best life for yourself...For some parents, the Circles of Life Conference is an opportunity to help get to their best life.”

—A grandparent & participant

Question 3: If you could change one thing about your family’s experience, community or neighborhood, what would you change to make it better?

Families shared the following:

Full Inclusion in Early Childhood Education

- “Let’s focus on the youngest children and find ways to make a difference for them.”

School Funding: Improving the school system and fully implementing and funding recommendations made for children at school.

- “When the doctor makes a recommendation, the school should fully implement that recommendation.”
- Educators are frustrated because they are expected to do more with less. We need to organize volunteers so they can help all kids in schools.”
- “Start a “best buddies” program at more high schools.”
- “Let’s end the achievement gap in schools.”

Living Wage: Provide a living wage for home care workers. This will help us find workers!

Change or Reform My Community:

- “Make the medical community more respected in the school community and then the recommendations made by medical providers would be implemented in schools.”
- “Have more support for all. This includes more support groups, inclusion in community activities and most importantly, don’t give up on our children.”
- “We need to educate families so they can educate the community about kids with disabilities.” *(translated from Spanish)*

Emergency Respite Program:

- “Sometimes I just wish there was a place to go if I needed a break, a place that could help when you need it.”

Question 4: What are some good things about your community that make life better for people who are part of it, especially for your family?

The listening session concluded with Family Voices staff asking participants to share some good things about their communities. Families mentioned the following:

- “Community-Based Organizations like ALAS.”
- “When case workers reach out to families regarding conferences and learning experiences like Circles of Life Conference so families can be empowered.”
- “Our case manager helped us go to this conference, the Self-Determination Conference and that has made such a difference for my family.”

- “There are so many programs out there so educate yourself and take the opportunity to go to these events.”
- “Special Olympics—It’s a great social program and good physically for our kids.”
- “There are many inclusive programs in our communities.”
- “Opportunities like Parents in Partnership (PIP) and other ways to educate ourselves.”
- “The Junior Achievement Program.”

NEXT STEPS

Family Voices of Wisconsin looks forward to working with the Department of Health Services and other decision makers to address these and other challenges that families face as they care for their children with disabilities and special health care needs. We remain committed to providing a “family voice” in public policy and systems change.

We will continue to develop and disseminate materials to help families understand and navigate services for children and youth with special health care needs. We will also continue to find ways to train and support families to advocate for what their children need and help develop family leaders who are able to participate at the local, regional and statewide level to improve systems of support.

CONTACT US

Please contact Family Voices of Wisconsin Co-Directors, Liz Hecht (Liz@fvofwi.org) or Barbara Katz (Barb@fvofwi.org or 608.220.9598), if you have questions about this report or would like to discuss next steps.

Family Voices of Wisconsin is a statewide network of families who have children and youth with special health care needs or disabilities and those who work on their behalf. We are committed to strong partnerships between families and providers to improve the systems of supports and services for children. To learn more about Family Voices of Wisconsin please visit our website at familyvoiceswi.org.