



Family Listening Session Report
2018 Circles of Life Conference

Executive Summary

Family Listening Session 2018

Families need opportunities to share their experiences, daily challenges and successes as they care for their children with disabilities and special health care needs. With that in mind, Family Voices of Wisconsin hosts an annual listening session as part of the Circles of Life Conference. In 2018, the session was held on May 3 at Paper Valley Hotel and Conference Center, Appleton, Wisconsin from 5:00 – 6:30pm.

With close to 200 participants, the session was dynamic and participants were highly engaged. More than at any of our past sessions, a majority of those who shared their experiences were from diverse backgrounds, including many Spanish speaking parents and grandparents. Family Voices invited one of our community consultants, Elsa Diaz Bautista, Director of Alianza Latina, to speak at the beginning of the listening session. Elsa urged families she works with to participate and share their experiences during the session.

At past sessions while many of these families attended, they did not feel comfortable standing up in front of a large group. This year, however, after a few Spanish speaking parents spoke out, others felt more willing to also share their personal stories and challenges. In addition, there were a large number of families from the Milwaukee area who shared their stories and experiences struggling to get what they needed for their child and family.

As with past listening sessions, families shared experiences that were difficult and things that could be better, but we also heard success stories and words of thanks for what children and teens are able to accomplish in their communities and at school when the right supports and resources are available. More than in the past families also shared their sincere appreciation for events like the Circles of Life Conference that brings families together to learn from each other and become more knowledgeable about programs and services. They also shared that as families they need to be a strong and consistent voices for their children and advocate for what their children (and others) need.

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Another difference was that many more teens and youth adults shared their experiences with the group. Several youth who participated in the PROMISE Grant were eager to explain how that program made an impact in their lives and helped to support them, and their family, to find work in their community. After the formal sharing session, several teens spent time sharing their lives, their dreams and their plans for the future with Family Voices staff members.

Multiple parents thanked Family Voices staff for this important opportunity for their children to be part of the listening session and appreciated that their ideas and their voices would be part of the report.



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Listening Session Themes

The following themes were recorded by Family Voices and our partners. These were heard repeated by families throughout the May 3, 2018 Listening Session.

- ◆ Difficulty finding and navigating systems including schools, transportation and other home and community programs.
- ◆ Shortage of direct care workers.
- ◆ Frustration and disappointment with Milwaukee Public Schools and community supports in Milwaukee County.
- ◆ Appreciation for programs and organizations that support families including the Circles of Life Conference and Wisconsin PROMISE.

Report of Findings

Family Listening Session 2018

Introduction

The 2018 Family Listening Session was held on Thursday, May 3, as part of the Circles of Life Conference in Appleton. Approximately 190 parents, family members and providers participated in the session. Close to 40% of the who attended were from traditionally underserved populations. Spanish language interpreters were available during the session for those who needed their questions or comments translated.

Liz Hecht and Barbara Katz, Family Voices Co-Directors, introduced the session by asking several questions and encouraging participants to share their suggestions and lived experiences with the group. Worksheets were available at each table for those who preferred to submit their thoughts and suggestions in writing. This worksheet was also projected on a PowerPoint slide in both English and Spanish during the session. (See the worksheet in Appendix A.)



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What We Did

In planning for this session, Family Voices undertook several strategies to prepare and encourage increased family participation at the listening session.

- ◆ Community connectors from several family groups were contacted before the session and invited to work closely with Family Voices to invite and prepare families who were attending the conference.
- ◆ A worksheet was created, and translated into Spanish, to guide these key contacts as the community connectors talked with families.
(See *Appendix A*)
- ◆ For the Milwaukee ‘Parents University’ group, families met prior to the conference to share their ideas and thoughts.

In addition, during the session introductions, Family Voices staff invited our community connectors to speak and encourage the family members they were connected with to share their experiences and not feel intimidated. We believe this had a very positive impact on what we heard and the diversity of families who came to the microphone to share their stories, frustrations and successes!

Questions for Participants

“Tell us about an experience you had. Is there something that went well or has been hard related to caring for your child with disabilities or special needs? What would you change to make things better for your family?”

“¿Nos dice sobre algo que ha sido difícil para su familia relaciona con su hijo con necesidades especiales? ¿Qué cambiarías para hacer las cosas mejor para su familia?”

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What We Learned

The following responses from families have been organized into theme groups

Difficulty navigating systems:

- ◆ Families find it difficult learning where to get resources, how to navigate from Birth-3 to school system, and who to talk to when they are new to Wisconsin. There is no one road map to guide them.
- ◆ Families voiced their frustration with getting what we need from the school system.
 - ◆ We moved from North Carolina because we heard the services were so good in Wisconsin, but the supports did not transfer well. We had an IEP in place, but we can't get communication services my son needs.
 - ◆ I work in the field and still I don't know how to navigate it. The system is bogged-down and no one is returning calls.
- ◆ Birth to Three Program has been very helpful but sometimes their model doesn't work. Having a vision consultant only able to come quarterly doesn't work—It's so infrequent that my child is afraid of a stranger (the therapist) each time.



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Difficulty navigating systems (cont'd):

- ◆ Parents find the Medicaid transportation systems (MTM) frustrating and time consuming.
 - ◆ Getting reimbursed for driving your own vehicle can be hard to work through and the process is not easy.
 - ◆ The vendor (MTM) doesn't know my county.
 - ◆ Now they have a debit system and I am penalized with postage.
- ◆ Working with CLTS and other programs to get the services we need is hard for us. We experience long waits, paperwork hassles and denials.
 - ◆ We waited for over three years for approval of a GPS system. When pressed, the CLTS staff said they lost our paperwork.
 - ◆ We already have a training approved in our plan but CLTS says they need to approve the curriculum and it's taking months and months to get it approved.
 - ◆ I know there are programs out there, but I don't know how to find them. I have heard about programs so my child could get an iPad for communication, but I don't know where to find it and I don't have anyone who can help us.

Shortage of direct care workers:

- ◆ Even when programs and supports are available to help pay for in-home care, the lack of workers and low wages make finding quality, qualified workers very difficult.
 - ◆ I can't find workers who really want to get to know us and my child.
 - ◆ There is so much turn over because of the low wages—It's hard always having to start over and train new workers so often.

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Frustration with Milwaukee Public Schools and community supports in Milwaukee County:

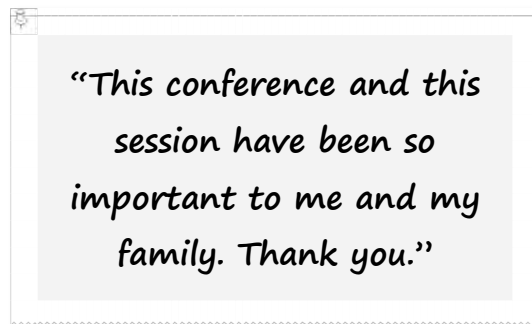
- ◆ Students are not getting the services they need. IEPs are not being followed. Red tape and long waits to get the therapy, equipment, services and supports students need to succeed.
- ◆ I just want the services my son needs (at his Milwaukee school). I do not speak English and translation services within the school district are insufficient.
- ◆ Schools in Milwaukee are providing less and less to our kids; they are taking away services when our kids need them most. We had OT, PT, help with communication and now these services are gone.
- ◆ CLTS in Milwaukee County is confusing and not easy to navigate. They don't cover the things we need in a timely way and many families are frustrated and have to speak up over and over again or they don't get what their child needs.
- ◆ We did not know about resources after high school like employment, DVR and other resources. We were not given the information in a way that we could understand.
- ◆ We had to rely on what other families told us because the school system didn't help us with transition out of high school.
- ◆ Having my son be part of the graduation ceremony was so important, but school made it almost impossible – they didn't tell me about the deadlines, give us the information we needed, or help us through the process. We almost missed this important event for my son.

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Appreciation for programs and organizations that support families:

- ◆ Families find that family-run programs, opportunities like the Circles of Life Conference and learning from other families “who have lived it” is critical in helping them find the supports they need for their children.
 - ◆ Alianza has been critically important for families to find what they need and to connect with others in their community.
 - ◆ We are so thankful for the Circles of Life Conference and what it does for families—It helped me connect with other parents from my area.
- ◆ The PROMISE program has been important to youth and their families and supported them during high school. The one on one counselors and support they provide was important and life changing.
 - ◆ They [the PROMISE Program] embraced us as a family and helped us in our transition.
 - ◆ I am in the PROMISE Program and I have made so many friends. They have helped me find my voice—It was like having another mom, but they didn’t tell me what to do!



“This conference and this session have been so important to me and my family. Thank you.”

Report of Findings

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Next Steps

Family Voices 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 Information

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.

To learn more about Family Voices of Wisconsin please visit our website: familyvoiceswi.org.





Family Listening Session

Families have a lot of experience, wisdom, ideas and expertise that can help improve the supports and services for children with disabilities. We want to hear your family's story!

Tell us about an experience you had. Is there something that went well or has been hard related to caring for your child with disabilities or special needs? What would you change to make things better for your family?

What I Want to Say...

A large rectangular area defined by a dotted border, intended for writing responses.