



# Family Voices of Wisconsin

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**Family Listening Session 2017**

October 30, 2017



[www.familyvoicesofwisconsin.com](http://www.familyvoicesofwisconsin.com)

## Executive Summary

For over a decade, Family Voices of Wisconsin (FVofWI) has hosted a listening session for families who have children and youth with disabilities and/or special health care needs as part of the Circles of Life Conference. In 2017, the session was held on May 4 at the Stevens Point Holiday Inn.

This session was the largest and most dynamic listening session FVofWI has ever facilitated. This was due in part to our focused effort to prepare families in advance of the session that created a *safe space* to share experiences and challenges as families care for their children with special needs. Not only did we hear about things that are difficult and things that could be better, 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 they are given the right supports and resources.



### Themes of the session included:

- Lack of access to information about services and programs that could benefit children at home and in their communities.
- Family stress due to multiple challenges including: affording what their child needs, coordinating care and maintaining a job.
- Lack of training and quality of care provided at school for children/teens with chronic or complex medical needs during the school day.
- Bureaucracy and long wait lists for children's long-term support programs.

# Family Voices of Wisconsin 2017 Family Listening Session

## Report of Findings

### **Introduction:**

The 2017 Family Listening Session was held on Thursday, May 4, as part of the Circles of Life Conference in Stevens Point. Approximately 220 parents/family members and providers participated in this lively session. Close to 40% of those who attended were from traditionally underserved populations. Spanish interpreters were available during the session for those who needed the session translated.

FVofWI staff 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. (worksheet in Appendix A.)



### **New Strategies to Increase Participation:**

In planning for this session, Family Voices undertook several new 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 FVofWI 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.
- In a few cases, families met prior to the conference to share their ideas and thoughts.
- For a group who traveled together to Stevens Point, the community connector facilitated a discussion while they were on the bus to help families think about what they wanted to say during the listening session.

**“I struggle as a parent just holding down a job.”**

**“The information is not available and I’m going broke paying for what he needs!”**

## What We Heard:

During the hour and fifteen minutes available for this session, twenty-five participants shared their experiences and suggestions with the whole group. In addition, six people submitted their comments to Family Voices in writing. From listening and reviewing the comments, the following themes came to light:



1. **Access to services:** Families did not know about them, had a hard time accessing them, and found barriers are put up to get what families need.

2. **Family stress:** Parents stated they find it difficult to maintain a job; the long wait for services added to their stress at home, and there was stress around not being able to pay for what their children with special needs needed for daily living in the community.

3. **Schools not able to safely and competently care for students with medical needs:** Families had examples of teachers not being

trained or able to recognize when a child needed help. If the

child's regular school aide was not present, other staff or substitute

staff had not been trained and parents were not notified about their child's illness in a timely

way. Parents did not feel that appropriate school personnel were given the specific training on

their child's disability or medical condition so there was a lack of understanding.

**"I worry about people who don't advocate."**

4. **Bureaucracy in the Medicaid Program and Children's Long-Term Support Program (CLTS):**

Examples of families not getting the supplies they needed and waiting many months to get equipment fixed or approved were shared.

Long waits and red tape before a child

was enrolled in the CLTS Program was

also reported.

**"We have been waiting for years to find out if my son qualifies for the Waiver—Now they tell me they lost his paperwork."**

Several families from Milwaukee talked about their frustration with the CLTS Program; having to apply and then re-apply when paperwork was lost, as well as being denied and having to appeal the denial. These families did not fully understand, and were not readily told, what services or supports could be covered through the CLTS Program. Families felt that, in general, they were not treated well and there was a perception that the county was not adding children to the CLTS wait list when their children would have qualified for the program.

## What's Going Well?

During the session FVofWI also heard many positive stories from families who are getting the supports and services in their community for their child/children with special needs. Families shared their experiences of asking for additional help in times of crisis and having medical or county staff providing the help they needed in a timely way. Others shared their experiences with their children being included in their school, having positive social opportunities in their community, and finding helpful vocational training and supports. Some families related that their children's schools were good partners and provided necessary services and technology (e.g. augmentative communication devices) that proved to be very helpful.

**"What's good is that I am finding resources that I didn't know were possible. I'm not afraid to ruffle feathers."**

## Next Steps:

FVofWI looks forward to working with the Department of Health Services and the Department of Public Instruction 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.

FVofWI 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.

**"If you're told no by one person or agency don't accept it. Go to the next. Self-advocacy is so important!"**

## Contact Us:

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



## FAMILY LISTENING SESSION

### *Here Is What I Want to Say*

We believe that families have a great deal of experience, wisdom and expertise and have ideas that can help improve supports and services for children with disabilities. We would love to hear your experiences and suggestions.

**Tell us about an experience you had, 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?**

## Appendix B – Notes from the Listening Session

- Parent from Waukesha: My son was very sensitive to light, he also had many other issues and required 24/7 care. Thinking back, I would have gone back and advocated more and said that this is not normal and we needed more answers. One day-to-day issue we deal with as we care for our son is incontinence supplies. We can get diapers, but not enough liners so by the end of the month we run out and either have to double up on diapers (which is a waste) or have to buy more liners out-of-pocket. Another issue has been our mobile suction machine—The battery died and it took five months to get a new \$700 machine instead of a \$100 battery. It was an older machine, but they're still selling it. We thought it was a waste of MA resources but could not get them to pay for only the battery.
- Parent from Marshfield: First, I would make things more uniform from county to county. For example, respite providers. Second, my son had his DDB (disability determination) starting in 2014, but we had to reapply. Trying to find the building, which was completely NOT accessible, was so hard. The system is set up for families to fail. Now my son has to go through another DDB even though he already has one because he will be going into the adult system. Third—A young lady in my community asked me to tell you all that she's very independent but her wheelchair battery will die and it takes her months and months to get it fixed. While she waits, her ability to be independent goes away.
- I have a great job that I love. The one issue that I have is the Children's Long-Term waiver. He had six months to wait because they were revising. They said that it would be two years, it's now been two and a half years and they told us they lost his application. I worry about people who don't advocate. I got a call that his application was denied, but how could it be denied if they lost the paperwork.
- Kenosha/ Racine Family Advocate: Young males are having a hard time getting the services in their IEP. I work with families who kids who have to transition from high school to college.
- My son has Sickle Cell I have trouble getting teachers to accommodate kids with special needs and understand what Sickle Cell [is]. I have a great job as a family advocate.
- I am a parent. What's good is that we are still a family unit, in our own home. I struggle as a parent just holding down a job. There's not understanding or flexibility. I get phone calls up to 3 times a day from school. I can't keep my job if I have to leave every day.
- I am a parent of a 15-year old with lots of disabilities. What's good is that I am finding resources that I didn't know were possible. I'm not afraid to ruffle feathers. We just got accepted to the PROMISE program, and we just finished the YIPPE program. Did not know about planning and transition from the school over the next four years. Learning and speaking at dinners at Parents Place in Waukesha. When you put a face to these people and they know who you are, you can get more funding. What's negative—As school struggles, they want to label my child as defiant.

- What's working—I've surrounded myself with people who are positive. If an IEP is individualized, then so should the programs in the school. Anybody who comes into contact with children needs to be trained because it will end stigmas. School districts should do professional development for each disability so all staff understand the disabilities and the differences.
- I get various services for my daughter that are very effective. Children's Hospital staff came over to do an in-service on meds. They trained all staff who work with her on having meds at regular times and now all staff knows.
- Parent from Milwaukee: The FMLA laws have protected me. The information was not readily available to me. I have a good job, but last year my income was \$10,000 because of my son's health. I have so many expenses that insurance does not cover. My son's shoes can cost \$500 – They're not telling me that these resources are available. The information is not available (on programs or funds available) so I'm going broke. We paid out of our pocket for his braces but now we can't afford his shoes so he can't use them.
- I am from Eau Claire and have a son with special needs. He's getting along socially and I'm thankful for the programs that I've found. We found out he has apraxia. He's out socially and it's benefitting him.
- Parent from Milwaukee: I would like to see staff better trained on health care issues at our local schools. My son suffered from a seizure yesterday at school. School (his regular ed teacher) said he didn't want to do anything, he was tired and he just wanted to lie down. We brought him to the hospital with a 105-degree fever. There was no aide at school yesterday (no subs available) and nobody was trained on seizures.
- I have a daughter (age 17). This is my first time at this conference. The bad thing is that there is not a lot of information that is out there and so many parents don't know about resources. I'm very thankful for Delores [Salis, community activist]. I feel like we have been robbed because she could have been involved so many years ago in a lot of programs, but we did not know about them until recently.
- Parent from Appleton: I am thankful for our school district that knew that my son needed a voice and got augmentative technology. It is a challenge for educators but I would like to see more school staff come to this conference since it is such a wonderful opportunity.
- My daughter passed away last Oct. 26. I thank God for Ms. Delores [Salis]. There's a lot of stuff I didn't know I could get for my granddaughter.
- I am a working mom. I'm glad that they've fixed certain diagnosis like autism spectrum. My granddaughter has Long-Term Support waiver and that's been very, very helpful. They come to my house in Brown County. This (conference) is where you get educated. If this is your first time here, don't make it your last. You meet other parents like yourself to keep building. My son is 28. He is not working. Since there was no spectrum for my son, my son used the judicial system to help him. There are not enough proactive services. As soon as the train hits the wall and people struggle, what can we do?



- My granddaughter had a bad seizure. I said, “Let’s get her mom more help” and I was able to get her more help within a few weeks. I am grateful for that.
- Father from Milwaukee: I was at an event a month ago that Delores [Salis] was at. A man talked about completion certificates instead of diplomas. My brother got a CC, but I got diploma. He went to school longer so he (and others with IEPs) should not only get a diploma they should get college credits. It’s comforting to know that there are other people out there in the same situation.
- Parent with a 20 year old daughter: Concordia College started a new program to help students learn job skills and interviewing skills. It was very expensive and we could not afford it. I talked with “Think College” about helping my daughter. Parents might now know that IDEA funding can help pay for college. IRIS would take care of living. Your kid could go to college!
- Mom from Madison area: I recently found out if your child is on Katie Beckett your child is eligible for in-home care. They’ll help feed and position your child. Look for companies that specialize in personal-care services to assess your child’s level of care. You can get personal care hours, but some children ages four to six may get denied, so keep asking and learn more about this amazing benefit.
- Mom who has son with CP and an older son with epilepsy: I’m so blessed to have been through these programs. The bottom line is advocacy. There are so many programs. Start at your county level. I thought that wait lists didn’t work. For wait lists to work you have to get on them. Sign up! Eventually you will get somewhere. Also, if you’re told no by one person or agency don’t accept it. Go to the next. Self-advocacy is so important. IEPs are a legal document and they are so important. You can get overloaded with stories on the Internet, but use what you can learn online and advocate for what your child needs.
- A participant asked, “Are any legislators invited to be here at this listening session?” I think that our legislators should meet us and put a face to what’s going on in their own area.
- It would be nice to have law enforcement or some people from those agencies.
- Parent stated, one issue for me is finding care givers for my son, and also paying a living wage to keep them.
- I want to let all parents who have 16- or 17-year old children that there is an awesome new program in Wisconsin called PROMISE. Look for it—ust know that you have to enroll them no later than three months before their seventeenth birthday.

## Notes from Written Comments

1.

- Keep my job – school doesn't care
- Health Care – being able to find correct medication. Doctors – doctors relocating or dying
- Getting correct services – CLTS
- Guidance for Parents – who have children with disabilities
- Parents don't feel like they are a partner at their child's IEP
- Schools don't follow through with IEP goals and services

2.

### **Positive:**

- Finding resources our family does qualify for and implementing them.
- Not afraid to ruffle feathers
- Finding resources someone might not know about; getting that information and using it myself or passing it on
- Standing up for my beliefs of what works for my child and our family
- Learning and then speaking at dinners – putting a face to the disability aspect and what people are funding
- Doing projects for Parents Place

### **Negative:**

- When people don't want to listen—frustration and anger sets in when people don't take you seriously, want to push you or disregard your concerns
- IEP meetings and the whole process is very long. We don't have information for parents
- We are not getting advocates in to hear families.

3.

- Access services at school – get more help for my son, working with schools and families together
- Teachers are not prepared to work with children with special health care needs. For example, providing them meds, not knowing the condition of the child, not communicating with parents when there is a problem or issue related to a health emergency.
- Very concerned about how regular teacher handled health emergency
- Disconnection between health system with school system and Milwaukee county services

4.

- More access to help with paying for medication for families who don't qualify for other services.

5.

- DPI complaint [formal] process is a barrier for families by nature. Writing a letter and compiling the necessary paperwork is very difficult for many people.
- Schools need to implement parent advocates so that families can feel empowered to express their concerns and have help preparing for IEP meetings and attend when parents ask for that.
- Many families are never connected with CLTS because they never heard about it. More outreach and collaboration from counties to schools to get information to parents.
- Get people on the ground to distribute information face to face to families and to empower them to be advocates.