

LISTENING SESSION 2011

Family Voices of Wisconsin held its 6th annual parent listening session on April 28 as part of the 2011 Circles of Life Conference at the Hyatt Regency Hotel, Milwaukee. Liz Hecht, Co-Director, introduced Family Voices, and the listeners from many organizations including the Birth to 3 Interagency Coordinating Council, the Survival Coalition, the Board for People with Developmental Disabilities, the Council on Children's Long Term Support Needs, the Department of Health Services and Family Voices of Wisconsin.

Liz asked the group:

When thinking about accessing health care and community supports for your child, what challenges are you facing, what's working well for your family and what suggestions do you have to improve the systems of supports?

Responses:

- **Budget Proposals and Loss of Medicaid Coverage:** A father of a young adult (Christopher) with developmental disabilities stated, "I have private insurance and Medicaid which helps pay for our co-pays, deductibles and other expenses not covered by my private insurance. I worry that the budget proposals will take his Medicaid card away. Having Medicaid is so important to us and we really need that coverage to afford his care."

(The Department of Health Services representative stated that Medicaid is a coordinated benefit and is very cost effective for the state when private insurance is combined with Medicaid. She is not aware of any proposals to take MA away but it could change in terms of requiring families to pay higher deductibles and co-pays.)

- **Medicaid/Hospice/LTC Support:** A parent stated that better coordination is needed between Medicaid, hospice and long term care supports and eligibility determinations for each. These are time consuming and why should families have to go through the eligibility process multiple times. Why can't programs share this information?
- **Better Care Needed in the ER:** A mother stated, "I am a foster parent to several medically fragile children and young adults and I have seen so many problems with the coordination of care in Milwaukee. I have had some really bad experiences at the hospital. Before they would treat my child in the emergency room they wanted to know his diagnosis. My child was having a seizure and I had to beg the attending physicians to treat him. The comments I got were that he was "well past his expiration date" - before the medical team treated him they left the room and were discussing whether to treat him or let him go. I encourage you all to speak up - in my case I dropped a bed pan and another physician came in and had a different attitude and treated the seizure (although we had been waiting several minutes).

- **Families Voices/Opinions Are Important and Needed:** I want to tell all of you here tonight that when you get surveys or get a request to give feedback DO IT. People really will listen and really do read what you write. I even received calls back from Dennis Smith and Kitty Rhoades asking what I meant about certain comments and asked for more information about my concerns.
- **Medical Residents Need Education on Family Centered Care:** We need to educate medical residents and nursing students ... they don't listen to families and they need all of you to educate them! My experience is that doctors are OK but it's the residents who don't listen and don't understand that they need to listen to and communicate with families when they are caring for our kids.
- **Medicaid and Durable Medical Equipment/Supplies:** My comment is that we need to change how we get durable medical equipment - in my case we go through J& B Medical Supply for our diapers and we receive too many each month. We end up with lots of extra and it's hard to stop the shipments. On the other hand, we are only able to receive 1 G-tube per month and we keep trying to work with the vendor to get more since that is not enough. It would be so nice to only have to call one place each month to get the supplies we need instead of having to work with multiple suppliers who all have their own rules and time lines for re-ordering. We also work with 2 pharmacies who have different rules on the supply of medication we can receive at one time so I end up running around a lot to get what I need.
- **J&B Medical Supply:** We are having a big problem with the diapers that we can get for my daughter from J&B Medical Supply. At first they would only send us a very low quality diaper - we had problems with the absorbency and she had skin irritation, leakage and other problems and accidents. Finally they did send us a better product but recently they told us Medicaid would no longer pay for that type of diaper so we were left with the terrible, low quality kind again. They offered to send liners to put inside the diapers but this ends up costing MA and the taxpayers more money since we are using many more diapers and also liners - why can't we go back to using the type of diaper we used in the past (Activestyle) that worked for my daughter and is probably cheaper (because we use fewer diapers and don't need an extra liner).
- Another comment related to J&B Medical Supply - why are we paying an out of state company to supply poor quality products when we could work with a provider in-state.
- **Waiting Lists for Transition Services:** I am a mother of a son who will be transitioning into the adult long term support system and with the changes proposed in the Governor's budget (and I live in Dane County which does not currently have Family Care) he will be put on a 20-30 year waiting list for services and supports. What will our children, who have been in the community, at school and involved in activities, going to do if they don't get any support?

- **Another transition comment** - we live in Grant County which is a Family Care county but we still have long waiting lists and I do worry what my son will do. We will have to quit our job (one of the parents) and so many young adults end of sitting at home with nothing to do ... they are used to being in the community but now they will be left at home. (Liz Hecht also commented that if we believe in having these individuals have a meaningful life as part of our communities we need to support them)
- **Medical Home:** I live in Marathon County (Wausau) and I have heard about the Medical Home concept. Our providers don't get it. I do have a good relationship with my child's pediatrician and have worked with him so that when I know my child is getting pneumonia he will prescribe what we need. However, we see many other specialists and they don't talk to each other and don't have a good way to share test results. When we saw the specialist recently he still had not seen the test results and had not talked to the other doctors - I was told I could buy some of the doctor's time so he would coordinate my child's care. What I see is that the doctor's spend more time because they don't work as a team and they don't talk to each other and share information with each other.

(Also related to Medical Home, the comment was made that in smaller communities many times specialists only see patients on one or 2 days per week so as a patient you are going back and forth to the clinic on multiple days in order to see the specialist you need. Also, when the doctors are not at the clinic on the same day it makes their communication harder and they don't necessarily share the important medical information.

- **Parent was Fired From Job due to Son's Disability:** A father of a young man with developmental disabilities shared his story - I received health care coverage from my employer and after his medical care cost the company a lot of money they asked me to have him diagnosed as "permanently disabled" so he would not be covered under our health plan. They even offered me counseling if I felt bad about that decision ... when I refused to do that, within 3 months I was fired.
- **Medical Home:** At Froedtert Hospital they use "my chart" which is a wonderful way to communicate with our doctors and for us to communicate with them. We can see the whole medical record, test results, etc. I just wish they would use this at Children's Hospital, because it still is hard to have everyone communicate with each other.
- **Budget Reductions Decrease Supports:** I live in Dane County and what I see is that the philosophy is "self-directed supports and services" but the budget reductions make this impossible. My son and his housemates (who all use wheelchairs) want to get out into the community but with the budget cuts they are not able to have the staff available. So the budget reductions will decrease their level of participation in the community.
- **Planning For My Child's Future:** I live in Price County and have a daughter (who is here with me tonight) who will need long term supports. I have asked about adult long term

support programs and options for her (so I can plan for her future) but whenever I inquire they say I have to wait until she is 18 - I do worry about her future and what will happen and I do lose sleep at night over this. (Liz stated that the ADRCs don't have to start working with families until their child is 17 ½ so even if you want to plan ahead it is really hard to do this.)

I think there is a big difference between what the state government (and the Governor) say, which is "We care about people" but with what they are doing to the budgets they really DON'T CARE. I think their attitude is that people with disabilities are disposable. Sometimes I think that I do want to outlive my daughter because I worry about her future.

- **Educating Health Care Professionals:** I work with People First WI and we have gone to Carroll University and the Medical College of Wisconsin to educate doctors, residents and nursing students. We have written material that we can share on how to treat a person with a disability. I agree that these students, including medical residents, need to learn to listen to parents and take their concerns into consideration when treating their patients.

The Special Olympics and their healthy athletes program was mentioned. It can provide physicals, eye glasses and other important health care for people who participate in the Special Olympics Programs around Wisconsin.

- **Get Involved and Concerns about MA and Prior Authorizations:** A staff member from New Berlin Clinic encouraged everyone to get involved and email, write and call their Representatives. She said the WI Physical Therapy Association has been working to change the prior authorization process for Medicaid. It takes clinic staff hours and hours and in the end most services are approved. It's really a waste of staff time and is a real hassle for families. She stated, "I spend many evenings contacting Legislators because I know many families can't."
- **Taking People Out of Institutional Settings:** A comment was made that when people are taken out of institutional settings and put back into the community sometimes they become invisible to the government and their services and supports can be cut because they are invisible to many officials.
- **Out of State Dental Coverage:** Parents who live in Superior (on the MN/WI border) stated that their son used to be able to receive dental services in Minnesota and have Medicaid pay for it but now it has been denied. We now have to wait 6 to 9 months in order to get in to see a dentist in Douglas County. For so many children in rural Wisconsin dental care is really non-existent. We don't know why they won't cover services in MN.

Another parent stated that she knows of a family who receive many health care services in Twin Cities and WI Medicaid will pay for the services. She said that her daughter

goes to Gillette Hospital and gets dental services in MN and has not had a problem with getting WI Medicaid to pay.

I want to tell Legislators who are cutting funding for our kids to “walk a mile in my child’s shoes” and then tell me if cutting funds will hurt our kids.

- **Cuts Impact Disabled Adults Quality of Life:** I am a guardian to several disabled adults who have moved out of Southern WI Center and the cuts to long term support services is definitely having a negative impact on their quality of life. In group homes they no longer can afford a van to take them out into the community so the most they can do is take them on a walk around the block. Their day program can’t bring them out into the community and they are stuck at home too many days.
- **Access to Dental Care:** A mom of a young adult who has Down syndrome said that she has a hard time finding a dentist who will take her daughter as a patient. Her daughter has a lot of orthodontic issues and “when I tell them that she has Down syndrome and is straight MA they immediately don’t want to take her as a new patient.” It was suggested that she contact the SE Regional Center who could help her find a dental provider in the Milwaukee area.