

Family Voices of Wisconsin Listening Session
Thursday, April 29, 2010
Circles of Life Conference
Stevens Point, WI

This is the fifth annual Family Voices of Wisconsin Listening Session as part of the Circles of Life Conference. Approximately 80 individuals participated in the listening session, including parents and grandparents of children with special health care needs, individuals with disabilities and/or special health care needs, providers, and representatives from the Department of Health Services, the Department of Public Instruction, the Survival Coalition, the Board for People with Developmental Disabilities, the Council on Children's Long Term Support Needs, and Family Voices of Wisconsin.

The comments and concerns raised at this session are noted and will be used as to inform priorities for the next state budget cycle. In addition, the Board of People with Developmental Disabilities (BPDD) will be developing their next 5-year plan this year, so these comments and concerns can be very helpful for them. Family Voices of Wisconsin includes these comments on our website and in our newsletter, and we communicate this to the appropriate state agencies and policy makers. When possible, parents who raise concerns at the listening session will be informed of where they can find answers to their questions. If it is not possible to provide resources to families at the listening session, Family Voices of Wisconsin follows up with them to provide them with the information they need to begin to address their issue.

Below is a listing of the comments and questions raised during the listening session.

COMMENT/QUESTION 1 - Transitioning to Adult Services and Supports

“How can we get the Department of Vocational Rehab (DVR) to start working with us and our children before their Junior year of High School?”

Another parent stated, “I have worked with DVR and they do not listen to what my child wants or what our family wants for our youth. How can we get DVR to listen to what our kids want?”

Another parent commented that she has real concerns about what will be available for her youth after High School and she hears from other parents (in the Milwaukee area) that their children sit home and have nothing to do and no resources are available for their youth with disabilities after high school.

COMMENT/QUESTION 2 - Partnering with Regular Ed and Special Ed Teachers

“How can we work more effectively to teach the regular education teachers to work with our children with special needs? My son is in an integrated classroom and interacts with both special education and regular education environments. The special ed teachers work wonderfully with my son but the regular ed teacher does not understand how to effectively teach him or interact with him.”

(1)

COMMENT/QUESTION 3 - Respite Providers in Rural Areas

“Respite providers are hard to find in rural areas of Wisconsin. Even if we have funding (or the issue is not paying for respite services) we struggle constantly with finding good, qualified providers who are available to care for our son.”

COMMENT/QUESTION 4 - Qualifications of Respite Providers

“What are the rules for who can be a Respite Provider? Are there state or county or federal rules or qualifications and how do I find out what the rules are? “

COMMENT/QUESTION 5 - Finding providers, including psychologists, who serve CYSHCN

“Does anyone have listings of psychologists in certain counties (Columbia County) who work with children with developmental delays? “

COMMENT/QUESTION 6 - Finding Resources for Down Syndrome Parent Group

(Translated into English by Interpreter)

“We have started a Down Syndrome Support Group in Milwaukee and we are looking for resources. Do you know of any information or resources that we could provide to our members? (We do not need them in Spanish because we do have translators available.)”

COMMENT/QUESTION 7- Medicaid Prior Authorization

(This comment was echoed by several family members)

“Why does it take so long for DME (durable medical equipment) to get approved by Medicaid? What can we do to change the prior authorization process? Long waiting times for Medicaid approval also impacts medications. It can take 4 to 5 days for Medicaid to approve a new medication for my child and that is too long to wait.”

COMMENT/QUESTION 8 - Paperwork Hassles and State Programs

“Why do I have to fill out Katie Beckett and disability determination paper work for my child every year? My county is requiring me to fill out forms for my entire family and is requiring me to fill out forms for a disabled adult.”

(2)

COMMENT/QUESTION 9 - Quality Assurance Concerns

“What kind of quality assurance measures are in place for special education teachers? Also, what tools are both special ed and regular ed teachers given?”

COMMENT/QUESTION 10 - Resources for Families

“How do families get their information? How can we (Family Voices and other organizations) reach out to families so that they are informed and educated? Should we be working with schools? How can Family Voices (and other organizations) more effectively reach parents?”

COMMENT/QUESTION 11 - Use of CLTS Waiver Funds and Medicaid Funding

“Can the Children’s Long Term Support (CLTS) waiver funds be used if MA has denied covering an item or service? Medicaid denied covering an item for my child but we still need it and are hoping that the children’s waiver could help provide funding for this equipment. “