



OF WISCONSIN

The Home of Wisconsin's Family-to-Family Health Information and Education Network

**Summary of Comments from 2009 Parent/Provider Listening Session
Circles of Life Conference
April 30, 2009**

The listening session at the Circles of Life conference is held annually to help assess needs of families as they navigate health care and community supports for their children. The listening session is designed to give parents and providers an opportunity to reflect on services given and received during the past year, comment on challenging situations, and make suggestions for improving the way that services and supports are delivered to children, youth and their families.

Responses included:

- Difficulty finding resources when a family has recently moved to Wisconsin.
- Lack of understanding by educators regarding mental health and other disabilities.
- Families need support to participate in the planning process for their children.
- Problems navigating the system and receiving services when a child is attending private school.
- Children's Long Term Support (CLTS) waiting lists – these waiting lists differ substantially from county to county.
- Leadership in schools and districts vary in their support for inclusive education; many schools still support segregated settings.
- County under funding of CLTS services and infrastructure.
- Lack of providers who accept Medical Assistance (MA). MA does cover dental services but finding providers is difficult; family has to travel over 3 hours. Families also have difficulty finding psychiatrists, psychologists and personal care workers who accept MA.
- Children with mental illness who do not qualify for SSI.
- Families are noticing less flexibility of the MA program to cover services and equipment.
- Problems navigating the Birth-to-Three program and delays in starting services.
- Concerns around maintaining home care nursing services.
- Schools are unprepared to support children with challenging behaviors. We need to train schools and families, including guidelines for use of seclusion and restraints.
- Need for more information and training around transition services (moving from children's services to adult services).
- Lack of quality care for an adult needing institutional/nursing care.
- Nutritional supplements and special diets – these may be very helpful but are not covered by MA.
- A need for educators to raise their expectations of kids.

Family Voices uses information gathered from this listening session to inform its work with policy makers to improve care and coverage for children and youth. Specifically, this information informs the State Superintendent's Council on Special Education, the Survival Coalition of Disability

Organizations, staff at the Wisconsin Department of Health Services, the Birth-to-Three Interagency Coordinating Council, and the Council for Children with Long Term Support Needs about issues confronting children, youth and their families. Family Voices encourages parents and providers to tell us about their experiences by sending an email to Co-Directors Liz Hecht (liz@fvofwi.org) or Barbara Katz (barb@fvofwi.org)

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