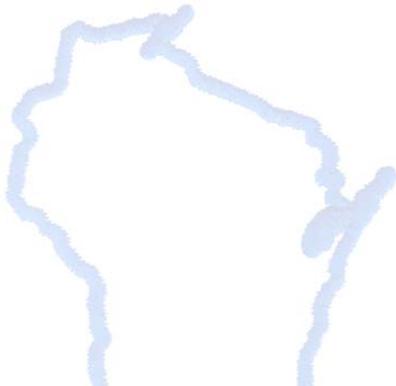


"We know that parents who are supported by other parents begin to appreciate early on the gifts, capacities and talents their children with disabilities bring to the community. They learn how to move from advocating for their child to advocating with their young adult and supporting their self-determination and self-advocacy."

Parent Advocate



National Performance Measure 1¹



WISCONSIN DISPARITIES

- Parents of children with a medical home are more likely to report they are partners in decision-making.
 - 92%** With a medical home
 - 62%** With no medical home
- Parents of children with emotional, behavioral or developmental (EBD) issues are less likely to report they are partners in decision making.
 - 80%** With no EBD issues
 - 64%** With EBD issues
- Hispanic parents are significantly less likely to report they are partners in decision-making than other parents.
 - 76%** White
 - 71%** African American/Black
 - 54%** Hispanic

Parents as Partners

Children and Youth with Special Health Care Needs (CYSHCN) whose families are partners in shared decision-making for child's optimal health



Why is this important?

Family-centered care is based on the recognition that children live within the context of families – which may include biological, foster, and adoptive parents, step-parents, grandparents, other family caregivers, and siblings.

Family-centered care ensures that the organization and delivery of services meets the emotional, social, and developmental needs of children; and that the strengths and priorities of their families are integrated into all aspects of the service system.

Family-centered care recognizes that families are the ultimate decision-makers for their children, with children gradually taking on more and more of this decision-making as they mature.

This outcome is achieved when families report that they usually or always feel that:

- 1) They discuss with providers a range of options to consider for their child's treatment;
- 2) They are encouraged to ask questions or raise concerns;
- 3) They feel it is easy to ask questions or raise concerns; and
- 4) Their health care providers consider and respect the treatment choices the parent feels would be best for the child.

¹ This outcome was evaluated using four questions from the 2009-2010 National Survey of Children with Special Health Care Needs: whether the doctor or other health care provider discusses options to consider for the child's care/treatment, encouraged and made it easy to ask questions or raise concerns, and considered and respected the parent's choices. "Usually" or "always" responses to all four questions counted as meeting the outcome.

Wisconsin Parents as Partners by Subgroup

The percentage of families that report they are partners in decision-making varies by the type of special health care need, family structure, household income and type of insurance.

By type of special health care need (percent meeting the outcome)

- Managed by prescription medications (83.4)
- Above routine need/use of services (66.3)
- Prescription medications and service use (72.4)
- Functional limitations (66.0)

By family structure (percent meeting the outcome)

- Two-parent biological or adoptive family (79.4)
- Two-parent family, at least one step-parent (70.4)
- Mother only—no father present (67.3)
- All other family structures (60.8)

By household income as measured by Federal Poverty Level [FPL] (percent meeting the outcome)

- 400% FPL or more (83.9)
- 300-399% FPL (77.7)
- 200-299% FPL (70.4)
- 0-199% FPL (68.6)

By type of insurance (percent meeting the outcome)

- Private insurance only (79.7)
- Public insurance only (72.3)
- Both public and private insurance (60.9)
- Uninsured (59.6)

Data Source: Data in this report are from the National Survey of Children with Special Health Care Needs. NS-CSHCN 2009/10. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website www.childhealthdata.org

Wisconsin CYSHCN Parent Support Organizations

Family Voices of Wisconsin (FVW), the Family Leadership Hub and Wisconsin's Family to Family Health Information Center is a statewide network of families who have CYSHCN and those who work on their behalf in the areas of health and community supports. Their focus is on education and information, public policy, and family leadership.

Parent to Parent of Wisconsin (P2PWI) is a statewide network of families who support each other in parenting children with special health-care needs, providing formal parent-to-parent matching. P2P has over 400 trained support parents ready to be matched with another parent whose child has a similar diagnosis or special health care need.

Activities in 2013

At the CYSHCN Statewide Projects:

- Family Voices of Wisconsin hosted its fourth annual "Advocacy for Change Parent Leadership Institute". As a result, 96 percent of the participants "felt better prepared to partner with decision makers."
- In collaboration with the CYSHCN Regional Centers and community partners, Family Voices conducted "Did You Know, Now You Know!" and "What's After High School?" trainings in eight Wisconsin communities, attracting more than 300 family, youth and professional participants.
- For the first time, Family Voices of Wisconsin, in collaboration with its Milwaukee advisory group, held a transition conference for families living in Milwaukee. 140 youth and family members participated in the event, "Transition: One Size Does NOT Fit All."
- Parent to Parent of Wisconsin matched 108 parents in a one-to-one match. Ninety percent of matched parents reported they had made progress on the need they identified when they contacted the program and that they were satisfied with their match.
- The Wisconsin Statewide Medical Home Initiative (WiSMHI), Parent to Parent of Wisconsin, and the Great Lakes Inter-Tribal Council CYSHCN Program provided the "Partnering with Your Doctor: A Conversation with Parents" training to 32 Native American family members.
- Parent to Parent of Wisconsin and Alianza Latina Aplicando Soluciones provided two Spanish language "Partnering with Your Doctor: A Conversation with Parents" trainings to 49 Latino families. All of the participants reported increased knowledge about new ways to partner with their child's doctor.

At the Regional Centers for CYSHCN

- Individual assistance was received by 620 families through the Regional Centers for CYSHCN, enhancing family decision-making skills and supporting informal networks of support.
- Parent to Parent of Wisconsin, Alianza Latina Aplicando Soluciones, the State CYSHCN Program, Regional Centers for CYSHCN, CYSHCN Statewide Projects and other state agencies collaborated to convene the annual Circles of Life Conference for families of CYSHCN. 456 families and providers attended including 20 Latino families supported by the Elsie Shaw Parent Scholarship Fund (Southeast Regional Center).



Wisconsin Department of Health Services
Division of Public Health
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Children and Youth with
Special Health Care Needs
<https://www.dhs.wisconsin.gov/cyshcn/>