

"Coordinated, barrier-free design is essential for easy-to-use community services, and this cannot be accomplished without cooperation among multiple stakeholders."

CYSHCN in Healthy People 2020: a collaboration among Genetic Alliance, Family Voices, and the Health Resources and Services Administration, Maternal and Child Health Bureau, Division of Children with Special Needs



National Performance Measure 5¹



WISCONSIN DISPARITIES

- Children with a medical home are more likely to easily access community-based services.
 - 77%** With a medical home
 - 55%** With no medical home
- Children with one or more emotional, behavioral or developmental (EBD) issues are less likely to easily access community-based services.
 - 72%** No EBD issues
 - 50%** EBD issues
- Hispanic children are least likely to easily access community-based services.
 - 66%** White
 - 60%** African American/ Black
 - 55%** Hispanic

Integrated Community-Based Service Systems

Community-based services for Children and Youth with Special Health Care Needs (CYSHCN) are organized so families can use them easily



Why is this important?

A community-based system of services is an infrastructure that operates across service sectors. The development of community-based systems of services is a response to the complexity and fragmentation of services for CYSHCN and their families. It facilitates the integration of services including organization, delivery, and financing. Multiple service programs – each with its own funding streams, eligibility requirements, policies, procedures, and service sites – serve CYSHCN.

Communities and their resources affect the way families of CYSHCN find and use services. Therefore, the health of communities themselves can have a positive effect on the growth and development of CYSHCN.

¹ This outcome comprises six difficulties with accessing care from the 2009-2010 National Survey of Children with Special Health Care Needs: 1) not eligible for services; 2) services not available in your area; 3) waiting lists/other problems getting appointments; 4) issues related to cost; 5) trouble getting the information you needed; 6) any other difficulties; AND an assessment of how often parents were frustrated in their efforts to get services.

Wisconsin Integrated Community-Based Service Systems by Subgroup

The percentage of families who feel community-based service systems are organized so they can be easily used 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 (74.5)
- Above routine need/use of services (69.3)
- Prescription medications and service use (62.3)
- Functional limitations (46.0)

By family structure (percent meeting the outcome)

- Two-parent biological or adoptive family (71.7)
- Two-parent family, at least one step-parent (62.6)
- Mother only—no father present (48.6)
- All other family structures (54.3)

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

- 400% FPL or more (74.3)
- 300-399% FPL (69.3)
- 200-299% FPL (60.6)
- 0-199% FPL (58.1)

By type of insurance (percent meeting the outcome)

- Private insurance only (75.7)
- Public insurance only (49.6)
- Both public and private insurance (57.8)
- Uninsured (NA*)

* Sample sizes too small to meet standards for reliability or precision

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 Integrated Community-Based Service Systems

Family Voices of Wisconsin is the CYSHCN Family Leadership Hub and Wisconsin's Family to Family Health Information Center. It is a statewide network of families who have CYSHCN and those who work on their behalf in the areas of health and community supports. The work of Family Voices focuses on three areas:

- Education and Information – ensuring that families are knowledgeable of systems and supports their children use.
- Public Policy – ensuring that diverse family viewpoints are incorporated into systems change activities.
- Family Leadership – ensuring that family members have the tools and support they need to be effective partners in decision-making and policy-setting.

Five **Regional Centers for CYSHCN** are staffed by specialists who can help get answers and connect families to community resources.

Wisconsin First Step is an information and referral service to assist Wisconsin families and providers working with CYSHCN.

Activities in 2013

The Children and Youth with Special Health Care Needs Program and the Regional Centers identify key committees and conferences in which CYSHCN representation is critical and will facilitate system coordination.

At the Regional Centers for CYSHCN:

Regional Centers for CYSHCN and CYSHCN contracted agencies made 2,294 referrals for 708 families. 1,421 (62%) of referrals resulted in services received.

At the CYSHCN Statewide Projects:

- ABC for Health has successfully implemented a referral form used by the Regional Centers for CYSHCN to refer families that are experiencing insurance or public benefits denials. From all referral sources, ABC served 792 CYSHCN-eligible children.
- ABC for Health transformed their internal resource guide into a comprehensive database searchable by type of resource or referral information to benefit clients who need services in addition to health benefits counseling. Searches can be based on county, keyword, or service. Referrals are now made regularly to Regional Centers for CYSHCN.
- Family Voices continues to add to their network of informed families of CYSHCN. They have 1,880 individuals in their database; approximately 80% are family members. The database is continuously expanded through sign-ups at trainings, conferences, meetings and general outreach activities.
- Family Voices held 12 trainings in 10 communities – 5 “Did You Know, Now You Know” and 7 “What’s After High School” – that attracted 277 participants, including 15 youth, 152 family members and 110 professionals. Each training was conducted in collaboration with the Regional Centers and with local partners, including ADRCs, county public health, children’s long term care, schools, and nonprofits.
- Wisconsin First Step made 1,614 referrals for 879 families. 821 referrals were to programs such as Birth to 3 (313/38%), Regional Centers for CYSHCN (246/30%), and the Family Support Program (108/13%).



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Children and Youth with
Special Health Care Needs
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