

Wisconsin: Partnerships Across Systems

Wisconsin stands at a crossroads in its drive to improve health care for people with disabilities.

Like more than 40 other states, Wisconsin is facing budgetary red ink that has prompted intense scrutiny of program costs. At the same time, the state is trying to make continued headway in its goal of providing streamlined, community-based care, including more opportunities for people to have a greater say in the services they will receive.

Meanwhile, efforts at both the state and local levels are striving to forge partnerships with service providers, university-based health program developers and advocacy groups to develop new approaches for supporting people with disabilities and their families.

“One of the big challenges today in promoting health of those with disabilities is to find ways to merge efforts within the public health system that is working from a population-based health promotion and disease prevention perspective, with efforts in the disability system that are working from an eligibility determination and service delivery perspective. These systems do not typically think, plan and work together,” says Daniel Bier, associate director of the Waisman Center at the University of Wisconsin-Madison.

Creating Systems for Care

One of 67 University Centers for Excellence in Developmental Disabilities (UCEDD) funded by the Administration on Developmental Disabilities, the Waisman Center conducts research and provides training, services and outreach activities across a broad range of disability concerns. The Waisman Center often works in partnership with two key divisions of the Wisconsin Department of Health Services (DHS): public health and long-term care services. Waisman’s clinical programs alone serve about 3,000 families a year.

As an example of progress in merging public health practice with programs for people with disabilities, Bier points to the Children and Youth with Special Health Care Needs Program (CYSHCN) in the public health division of DHS. Supported by Title V Maternal and Child Health Services funds, the program begins with screening of newborns and concludes with the transition from youth to adulthood.

“Rather than providing direct services, our approach is help to build systems of care,” says Sharon Fleischfresser, M.D., MPH, a pediatrician who serves as medical director for the program, which targets children with special health care needs, a population that represents 15.5 percent of Wisconsin’s children.

She points, for example, to CYSHCN efforts aimed at parents. Family Voices of Wisconsin provides information, training and leadership opportunities so parents can be effective partners in their child’s care and in systems that support them. Among its resources are Webcasts, newsletters, blogs and advocacy opportunities. Another program, Parent to Parent, supports a parent matching program where trained parents support other parents on issues surrounding disability and special health care needs.

“The goal is to put parents in the driver’s seat, not the back seat,” notes Dr. Fleischfresser.

The Waisman Center in turn offers related efforts such as its Parents as Leaders training funded by the Birth to Three early intervention program. In addition, Waisman joins with several other sponsors in hosting an annual two-day “Circles of Life” conference that brings together health professionals and parents for sessions on a wide array of topics related to children with special health needs.

Statewide efforts also promote the concept of medical home as a team approach to primary care management in partnership with the family. This nationally recognized model includes planned visits, comanagement with specialists, coordination of medical and nonmedical services and connections with other community-based organizations.

Supporting medical home providers, as well as families, are CYSHCN’s five regional resource centers, including one located at the Waisman Center. Resource specialists at the centers help families solve problems, locate doctors and dentists, and assist youth moving to more independent settings. ABC for Health, Inc., a nonprofit law firm contracted by CYSHCN, also provides technical assistance and education to center staff in health care financing, insurance, and related issues, and also counsels families.

Building a Strong Data Base

A key starting point for creating such targeted programs as CYSHCN is developing a richer database on the health care needs of people with disabilities. Bier points out that Wisconsin has some data on the numbers of people with a disability enrolled in programs like Medicaid. But what is lacking, he adds, is more detailed health-related information. For example, how often do these individuals see a doctor or dentist? Do they have a secondary health condition, such as heart disease or diabetes? Do they have regular cancer screenings?

As a first step in building a data plan, the Waisman Center this summer will bring together representatives from many sectors, including public health, long-term care, vital statistics, advocacy groups and others, to explore what health data is now being gathered on people with disabilities and how those data bases can be improved. Bier notes, for example, that Wisconsin’s Behavioral Risk Factor Surveillance System surveys fall short in gathering detailed health data on people with disabilities.

“Improving the quality of data is essential,” adds Liz Hecht, project coordinator for the Waisman-based CYSHCN Center. “No matter what program you’re considering, the first question people will ask is: ‘What is your data?’ ”

Wisconsin has already gathered important data on children with autism as one of 13 states funded by the Centers for Disease Control and Prevention’s Autism and Developmental Disabilities Monitoring Network. With Waisman Center epidemiologist Maureen Durkin serving as principal investigator, the Wisconsin study looked at 8-year-olds born in 1994 in 10 counties in southeastern Wisconsin. Researchers found evidence of autism in 5.2 percent of the children.

That research in turn has helped shape such initiatives as the Combating Autism program, which trains health care providers to detect autism and other developmental disabilities as early as possible. Combating Autism also funds Leadership Education in Neurodevelopmental and Related Disabilities (LEND), an interdisciplinary, graduate-level program offered at the Waisman Center and 38 other settings nationwide.

All these efforts are consistent with the need to increase the visibility of people with disabilities as a recognized population within public health. Bier notes, for example, that advocates have successfully pushed for objectives in Wisconsin's strategic health plans that refer directly to people with disabilities. An example from the Healthiest Wisconsin 2020 plan: *Reduce the rate of depression, anxiety and emotional problems among children with special health care needs.*

Dr. Fleischfresser also notes progress in including people with disabilities among other populations targeted in Wisconsin's ongoing public health programs, such as the Living with Chronic Disease self-management program and the Stepping On falls-prevention program.

Fostering Community-Based Services

Meanwhile, Wisconsin has moved steadily toward its goal of moving people with disabilities out of institutions and into community settings. The centerpiece of that effort is Family Care, which serves more than 35,000 people in 48 counties.

Family Care features a network of Aging and Disability Resource Centers (ADRCs), which serve as the conduit for information on community services, including health care, housing and transportation. The centers also provide counseling, emergency help and prevention services. In addition, managed care organizations combine funding and services from a variety of programs, such as Medicaid, into one flexible long-term care benefit, tailored to each individual's needs. The annual budget, is about \$1.4 billion, with about 60 percent from the federal government and the rest from the state.

The current budget squeeze in state government threatens to delay Wisconsin's longstanding goal to extend family care throughout the state, and waiting lists for the program are growing. Even so, that setback should not overshadow the state's many accomplishments on behalf of people with disabilities, argues Kyle Kleist, who directs the undergraduate program in rehabilitation & counseling at the University of Wisconsin-Stout and chairs the state's Assistive Technology Advisory Council. Living with a spinal cord injury himself, Kleist formerly worked at an independent living center, serving a broad spectrum of people with disabilities.

"Compared to what other states are doing, I would give Wisconsin an 'A' on its record of serving the health needs of people with disabilities," says Kleist. "In particular, the state has done a phenomenal job implementing community-based services."

You can learn more about Wisconsin's health programs for people with disabilities by consulting these information sources:

Wisconsin Department of Health Services
<http://www.dhs.wisconsin.gov/programs.htm>

Report on the Health Status of Wisconsin (2010)
<http://www.dhs.wisconsin.gov/publications/p0/p00131.pdf>

Wisconsin Department of Health Services 2007-2009 Biennial Report
<http://www.dhs.wisconsin.gov/aboutdhs/2007-09BiennialReport.pdf>

Wisconsin State Health Plan: Healthiest Wisconsin 2020

<http://www.dhs.wisconsin.gov/hw2020/index.htm>

Waisman Center (Univ. Center for Excellence in Developmental Disabilities)

<http://www.waisman.wisc.edu/cedd/about.php>

Wisconsin Board for People with Developmental Disabilities

<http://www.wi-bpdd.org/>

DHS Children and Youth with Special Health Care Needs Program

<http://www.dhs.wisconsin.gov/health/children/index.htm>

Wisconsin Surveillance of Autism & Other Developmental Disabilities System

<http://www.waisman.wisc.edu/wisadds/>

Leadership Education in Neurodevelopmental and Related Disabilities (LEND)

<http://www.aucd.org/template/page.cfm?id=473>

Department of Health Services Family Care Program

<http://www.dhs.wisconsin.gov/lcure/generalinfo/WhatisFC.htm>