

Utah: Collaboration is Key

The next time the staff in the Utah Department of Health's (UDOH) Children with Special Health Care Needs Bureau order new business cards, they should consider changing their titles to a single word: "collaborator."

They collaborate daily with eight state agencies and offices from the departments of Health, Education and Human Services as well as the University of Utah and Utah State University on research, program development, program implementation, and grants-proposal writing, among other tasks, to meet the needs of the nearly 300,000 persons in Utah who have disabilities. That's about 10 percent of the state's total population, according to the latest U.S. census.

Working with a network of health care providers, including the state's universities and community groups, the UDOH coordinates and consults on programs to help people with arthritis, diabetes, asthma, autism, and children with special health care needs, among other programs. The UDOH/Children with Special Health Care Needs (CSHCN) bureau also coordinates care with the Utah Department of Human Services, which provides support for adults with disabilities. A legislatively mandated Coordinating Council for People with Disabilities meets monthly to review and coordinate services.

Additionally, thanks to initial funding from the Centers for Disease Control and Prevention (CDC), UDOH collaborated with Utah State University's Center for Persons with Disabilities to improve the health of Latinos with disabilities. At 14 percent, Latinos make up the largest ethnic group in the state. Although the CDC funding ended for the Latino project, that work continues, as do other programs.

A Variety of Programs

The number of UDOH programs serving people with disabilities is indeed impressive. Just consider the programs for children alone:

- Early intervention for children up to age three, funded by the U.S. Department of Education and state general funds. The program serves over 7,000 children per year with moderate-to-severe disabilities.
- Children's developmental clinics, funded by the U.S. Department of Health and Human Services, Maternal Child Health Program and Medicaid matching funds. It serves about 3,000 children per year and is a collaboration between Utah's CSHCN and the University of Utah Department of Pediatrics.
- Fostering Healthy Children Program, funded by the state and the U.S. Department of Health and Human Services, works with about 5,000 children per year. The Utah Department of Human Services provides state funding, which is matched with Medicaid funding to provide nurse health care management.
- A traumatic-brain-injury (TBI) awareness program, funded by the U.S. Department of Health and Human Services, develops training for health care providers, who work with children with TBI up to age four and their families, as well as veterans.
- The newborn hearing and blood screening programs, funded through the U.S. Department of Health and Human Services and the sale of blood screening kits, screen 55,000 newborns per year.

- The Technology Dependent Child program follows up on home treatment of children who have started life with medical complications and who must rely on ventilators or other technology to live. The Medicaid Waiver program is managed in the bureau of CHSCN.

Meanwhile, the bureau lost over \$2.5 million in state general funds and 15 employees in the past two years. Nevertheless, ongoing Health Resources and Services Administration Maternal and Child Health Bureau (HRSA/MCH) funding and CDC funding have allowed most bureau programs to continue.

Collaboration is a Way of Life

“Collaboration brings us all together,” said Holly Williams, director of DSPD’s Children With Special Health Care Needs programs. Adds Deputy Director Nan Streeter: “You just can’t do this work in isolation.”

Fortunately, collaboration comes naturally in this rural state. Dr. Judith Holt, associate professor at Utah State University and division director of the Center for Persons with Disabilities, said she has never seen a state where collaboration is so pervasive. “Part of the reason for the collaborative spirit is that the state isn’t big enough to have developed silos,” she said.

One of many areas where collaboration has been critical is the Utah Autism Initiative (UAI). Led by the CSHCN bureau of Utah’s Department of Health, it’s a forum for all state agencies and citizen advocates. Thanks to UAI, support from the USU Center for People with Disabilities, and grants from the U.S. Department of Health and Human Services and the CDC Learn-the-Signs, Act-Early program, there is now a state plan to improve services to adults and children with autism spectrum disorders.

Family leaders from the Utah Parent Center, Utah Family Voices and the Utah Autism Council have sponsored and collaborated on several autism events, conferences and trainings. UDOH’s Children with Special Health Care Needs bureau partners with community and state organizations on planning, program development and identifying funding sources. Funding for much of the training has come in part from the HRSA/MCH Autism Infrastructure Building grant.

Another ongoing initiative, the Utah Medical Home Collaborative, is a statewide program that grew out of a HRSA/MCH-funded Medical Home implementation project in 2001. It was a response to a 1998 survey of the state’s pediatricians, which found that the top three needs for improving care of children with chronic conditions are better knowledge of local resources for their care, practice-based case managers to link families and resources, and best-practice guidelines for common chronic conditions in children.

To address these needs, Williams and her team, with the support of grant funding, contracted with the University of Utah’s Utah Pediatric Partnership to Improve Quality (UPIQ) to develop medical home, early screening, and autism learning collaboratives. Twenty-eight pediatric practices throughout Utah participated in Medical Home training in caring for children with disabilities. Also through this funding, the university developed the <http://www.medicalhomeportal.org/> an online resource for pediatricians and other health care providers, educators and families.

One Grant, One Big Impact

Though the initial CDC funding for the program to improve the health of the state's Latinos has ended, it has spawned several other efforts, some of them with state funding. Nearly one-fourth of Latino adults in the state are in poor health. As part of that initial CDC grant, Holt and her staff at the center did 21 focus groups across the state with community leaders to determine the extent of the health problems. However, the center did not get an implementation grant to pursue programs after the study. With carryover money from the grant, the center did a project in the West Valley of Salt Lake City to help Latinos with disabilities access services. That effort led to a similar program with another clinic in the state and to collaboration with other groups such as the Holy Cross Ministries, to provide training to Latinos on how to find health care services.

Separate CDC grants helped the center develop public health awareness campaigns targeted to the Latino population and to research the effectiveness of evacuation procedures for Latinos during health emergencies.

"The initial planning grant was minimal, but it has allowed us to make a big impact," Holt said.

Williams, Streeter, Holt and their colleagues still have several items on their to-do lists. Holt wants to continue work helping Latinos and other minorities gain better access to medical care and insurance coverage. Williams and Streeter are working with Medicaid to see if an autism waiver is possible so that all children and adults with autism can have medical coverage, not just those who meet certain income standards. There are also plans to help young adults with intellectual disabilities to have some kind of college experience through the Think College pilot project for youth with disabilities.

"It's easy to sit back and say we can't do something because of lack of funds," said Holt. "But, the state has a can-d' attitude. We know making incremental improvements is important."

You can learn more about Utah's programs for people with disabilities from these sources:

A summary of all disabilities programs in Utah

<http://www.aahd.us/site/static/pdfs/states/Programs-UT.pdf>

Utah's Children with Special Health Care Needs Bureau

<http://health.utah.gov/cshcn/>

Utah Center for Persons with Disabilities

<http://www.aahd.us/page.php?pname=publications/newsletters/2005/spring/stateGrantee2>

2010 Annual Report of the Utah State University's Center for Persons with Disabilities

http://www.cpdusu.org/about/annual_report/2010/AR%202010.pdf

2010 Annual Report of the Utah Division of Services for People with Disabilities

http://www.dspd.utah.gov/reports_pdf/DSPD%202010%20Annual%20Report.pdf

The Autism Council of Utah

<http://autismcouncilofutah.org/>



Disability and Health Case Studies

Projects for children with disabilities at The University of Utah's Utah Pediatric Partnership to Improve Health Care Quality.

http://medicine.utah.edu/upiq/Improvement_Projects/index.htm

<http://www.medicalhomeportal.org/> an online resource for pediatricians and other health care providers, educators, and families.