Florida: Data is the Foundation

Scroll through the Florida Department of Health’s website and you will find about 32 separate divisions. However, you will not find one single department that works exclusively to provide services to all people with disabilities. Instead, the state has several agencies—some within the Department of Health, and many outside its purview—that do that for separate constituencies.

Still, despite having such a decentralized system, Florida scored several successes in its disparate efforts to help its disabled citizens, who number about 3 million people, or nearly 21 percent of the state’s population, according to the latest Florida Behavioral Risk Factor Surveillance System report.

Underlying many of the achievements is solid demographic data and in depth information on common needs of people with disabilities and their health care providers.

A partial list of the successes that data has led to includes:

- The Department of Health’s Bureau of Chronic Disease Prevention and Health Promotion implementing a Stanford University-developed evidence-based program to train trainers in how to help arthritis sufferers manage their disease. Funding was from the Center for Disease Control and Prevention (CDC). Results included fewer emergency-room and physician visits, more recognition of the value of exercise, and generally lower health-care costs. The Bureau also oversees a program addressing early detection of breast and cervical cancer in low-income women ages 50 to 64, and emphasizes access to mammography services for women with disabilities.
- The Florida Office for Disability and Health (FODH) and its partners at the University of South Florida developing an education module on disabilities and video training for law-enforcement personnel. The training regimen, developed with CDC funding, is on track to be required for all law-enforcement officers in the state.
- A robust program by the DOH’s Children’s Medical Services Network implementing a managed-system of care for children with special health-care needs, with an emphasis on medical homes. The goal: to provide a family-centered system of services for children with special needs. The Network’s budget is funded largely by Medicaid and Children’s Health Insurance Program funds.

A Push to the Community Level

Those and other successes are the result of a cadre of knowledgeable and dedicated staff at the state-government level and among hundreds of health-care providers. For example, the Division of Chronic Disease Prevention supports programs with funds from eight different grants from the CDC. Besides arthritis, the programs target heart disease, diabetes, and several forms of cancer, providing data, education and examples of effective strategies to communities so they can advocate for and develop their own programs.

“We facilitate local decision-making, but we don’t lead,” says Betsy Wood, Chief of the Bureau, which receives no state funds for its work. “We help communities make the changes that will be most effective for making the healthy choice the easy choice.”
Likewise, the DOH’s Children’s Medical Services Network (CMS) delivers services through 157 separate contracts with providers across the state. The division gets some state funds and has a $200,000 CDC grant for newborn-hearing screening, says the director, Dr. Phyllis Sloyer.

And the same mode of operation applies to the state’s Agency for Persons with Disabilities (APD). Director Bryan Vaughan says the agency serves people with autism, spina bifida, intellectual disabilities, and other developmental problems. Reporting to the Governor’s office rather than the DOH, the agency operates with funds from the state and from the federal Centers for Medicare/Medicaid Services.

Among other activities, Vaughan says, his agency is working with the University of Florida on an emergency-management process and studying how effective communications are during emergencies. His office is also working with the State Department of Elder Affairs.

The fragmentation of efforts for the population with disabilities – there are also, for example, separate agencies for elderly affairs and veterans – makes it difficult to coordinate programs. Complicating efforts further are major cuts in state spending for programs for the disabled.

CDC funds have helped to make up part of the budget shortfalls for some agencies, though not the APD. The FODH is solving the coordination, evaluation, and data/policy problems.

Formed four years ago at the University of Florida and led by Dr. Elena Andresen, Professor of Epidemiology in the College of Public Health and Health Professions, the CDC-funded Office provides research and data for all health-care and public-health agencies in the state to help them set policy and develop programs. Separately, it also develops education programs on mammography and for training of health-care providers.

“We look at topics, such as transportation for people with disabilities, education for law-enforcement agencies on disabilities and how to interact with persons having disabilities, and accessibility of housing, among others, that are common to the clients of all the agencies,” says Andresen.

**The Search for Common Ground**

The commonality is key. “It’s hard to bring people with different interests together because they naturally want to concentrate on their own specific topics,” she says. So, Andresen continues, “we tell the agencies that we don’t have a stake in any one group, and that we want to research issues that cut across all disabilities.”

Among areas the FODH has developed data for are the stresses on care providers, overall access to care for the disabled in the state, perceptions about the disabled population, and accessibility issues in Florida homes. When the data for the latter report are complete, the FODH will give it to the housing-construction industry for its use.

Additionally, Andresen’s staff recently produced a report on the immediate and long-term needs of the 17,000 disabled Floridians on a wait list to receive services from the state’s Agency for Persons with Disabilities. Among the conclusions: Individuals on the wait list need a variety of services they are not receiving, including, for those under 21, behavioral analysis and speech theory, and, for those over 21, transportation and in-home support.
A statewide disability profile
The FODH’s work for the disabled actually started with funding from the University of Florida. “The university gave me seed money to start program development that would lead us to accreditation as a school of public health, and with it I was able to fund research that resulted in a statewide profile on disability at the county level,” Andresen says. It was the first such research effort in the state, but, she says, “we knew that the local data would help people examine their own programs versus the problems in their areas.” The report was called the Florida Chartbook on Disability and Health, and it was a factor in the approval by the CDC of an FODH request for funding of a five-year program.

At about the same time the CDC granted the funding, the then Governor, Jeb Bush, formed a Commission on Disabilities, with Vaughan as chairman. It serves as a clearing house on where to find services for the disabled in the state. Andresen’s FODH has been a key partner of the Commission, building the epidemiological data needed for setting policies and developing programs.

The leaders of the separate agencies all have plans to do more if only they can get funding. For example, Vaughan, at the Agency for Persons with Disabilities, would like to have more mobile units to work with clients in rural areas of the state.

Wood, of the Bureau of Chronic Disease Prevention and Health Promotion, states that the Bureau would use additional funds for education regarding prevention of chronic disease and disability and to support local evidence-based strategies related to these issues.

Andresen and the FODH will be providing the necessary data for development of their programs.

“We synthesize ideas already in place and develop the necessary data,” Andresen says. “And that gets more people involved.”

You can learn more about Florida’s programs for people with disabilities from these sources:
Florida’s Behavioral Risk Factor Surveillance Report for 2009

Florida Coming Together for Public Health (2007)

The Florida Office on Disability and Health
http://fodh.phhp.ufl.edu

Disability determinations in Florida
http://www.doh.state.fl.us/dd/dddescription.html

Review of Findings on Chronic Disease Self-Management Outcomes

Florida Department of Health’s public health service
http://www.doh.state.fl.us/planning_eval/phealth/services.htm
Agency for Persons with Disabilities Agency Wait List Survey
http://fodh.phhp.ufl.edu/publications/docs/APD%20Final%20Report_08.08.08_Revised.pdf

Florida Chartbook on Disability and Health