

South Carolina: Persistence and Passion are the Rule

Don't tell the staff at South Carolina's Interagency Office of Disability and Health (SCIODH) that you can't or won't implement their recommendations for improving access to services for persons with disabilities. They won't take *no* for an answer.

"We are persistent," says Suzanne McDermott, Ph.D., and director of the program. "We don't just write things off. We keep them in our files, and we go back and follow up."

She calls it *sustained pressure*, and the passion and commitment behind that pressure, plus SCIODH's home within the University of South Carolina School of Medicine, and their partnership with the state Department of Health and Environmental Control, the state's Department of Disabilities and Special Needs (DDSN), and South Carolina's Developmental Disabilities Council, have paid big dividends.

Here are some examples of those dividends:

- Partnering with the state's Department of Transportation, SCIODH's rehabilitation engineer, Catherine Graham, trained the latter's planners and engineers on the regulations and requirements related to accessible streets and on how to communicate with persons with disabilities.
- Guiding the state's parks and recreation staff, SCIODH helped ensure renovations to public parks, such as modified facilities and walking paths, and added dance programs, arts and crafts, and sports programs that people with disabilities can enjoy.
- Working with state building-code officials and architects, SCIODH has made builders more knowledgeable of Americans with Disabilities Act (ADA)-required accessibility issues so they address those issues before applying for certificates of occupancy.
- Collaborating with a variety of agencies, the staff has ensured the inclusion of modifications and accommodations for the needs of people with disabilities in design of typical emergency-evacuation shelters and procedures, as well as in medical shelters.

These activities are all possible thanks to a grant from Centers for Disease Control and Prevention (CDC). The CDC has funded SCIODH since 1997. SCIODH is now in the fifth year of its most recent \$300,000 five-year grant.

That amount is quite a bit less than previous grants and has forced the elimination of about half the staff positions in the program. The SCIODH, housed in the University of South Carolina School of Medicine's Department of Family and Preventive Medicine, has had to cut programs too. But it still works in each of the five areas it has always worked in: promotion of health for people with disabilities; teaching health care professionals about their needs; improvement of the built environment for people with disabilities; emergency preparedness; and surveillance, compiling data on the health and employment experience of South Carolinians with disabilities.

A Large Network

People with disabilities account for about 20 percent of the state's population. "We are part of a large network in the state [serving that population]," says McDermott, who also is coeditor of *The Disability and Health Journal*, the only peer-reviewed professional publication that focuses on the health of people with disabilities.

Besides working with the DDSN, which serves persons with intellectual disabilities, autism, traumatic brain injury and spinal cord injury, the Developmental Disabilities Council and the state health department, SCIODH works closely with a variety of advocacy groups and individuals with disabilities.

For example, Graham, the department's rehabilitation engineer, has over the last five years conducted inspections of more than 100 of the state's rural primary-care facilities to assess their accessibility to people with disabilities. "We evaluate a core group of ADA accessibility requirements to determine what barriers limit accessibility for people who use mobility devices and have sensory limitations," she says. "We also determine if they have the right equipment for serving people with disabilities, such as height-adjustable exam tables and special scales for weighing patients in wheel chairs."

Graham, a wheelchair user herself, does all the inspections personally, for no fee, making recommendations such as the availability of parking spaces for vans carrying wheel chairs, braille, grab bars on doors, and removal of cabinets under sinks so wheel chair users can get closer to the sinks.

"We want people to be able to obtain primary medical care within their own community, and to be able to access all the services that others can access," Graham said.

In that effort, she partners with the American Cancer Society, the state Office of Rural Health and Blue Cross/Blue Shield, which has twice provided the funds to allow rural primary-care facilities to receive minigrants to make the recommended modifications to their facilities.

"Even if primary care providers don't implement all the recommendations, they've effectively had an awareness class during the inspections and that helps," said Graham, who has a master's degree in biomedical engineering. "My hope is that they'll make changes, even small ones, and that if they have a discussion with a patient with disabilities, they'll remember what we talked about."

Training for Future Doctors

Sensitivity to the needs of patients with disabilities comes naturally to future physicians at the University of South Carolina because they receive training. Using CDC funds and funds from the university, Dr. McDermott and Ms. Graham teach medical students about the special needs of people with disabilities. Among other things, students learn how to lift patients from their wheelchair onto an examination table, how to communicate in a sensitive way and what it means to have a disability.

Moreover, students are graded on their performance during a routine visit with "standardized" patients—actors with scripts—with disabilities.

Medical students at colleges and universities throughout the country do histories and physical examinations of standardized patients. The student is expected to order the correct tests, make a diagnosis and provide counseling.

But, South Carolina medical students must also diagnose a "problem" for a standardized patient with a disability. This allows the medical faculty to evaluate whether the student can see beyond the disability to diagnose a common health condition.

Do the students get the diagnosis right? “Generally, yes,” said McDermott, “though sometimes they don’t attend to the extra things physicians do in an exam, and so patients with disabilities don’t always get the same level of care as others.”

It’s not just the students who learn through that exercise. McDermott, Graham and the faculty learn too, and they change their lectures and course material to address emerging issues.

The Flexibility to Change

That ability to make changes and to constantly evaluate successes and failures is critical. Said McDermott, “We can try things without institutionalizing them as required practices, test them, and change them if they aren’t working.”

One of the many areas where that flexibility worked well was in teaching healthy living behaviors to people with intellectual-development issues. “Several years ago,” said Graham, “we tried integrating them into classes with other people to teach such things as healthy eating. They didn’t get much out of it.”

So, working with partners in DDSN and the state health department, they developed Steps to Your Health classes, especially for people with intellectual disabilities. The results were much better. More than 1,000 people have attended the classes so far, and SCIODH does a follow up with the attendees after one year to see if they have maintained the healthy life styles they learned.

McDermott and Graham say there is much more they could do with additional funding. “For example, we should be teaching nurses, social workers, and even pharmacists the same things we teach our medical students about how to work with and serve people with disabilities,” said McDermott.

Somehow, they’ll find a way to stretch the dollars they do have. “The people involved here are passionate about serving persons with disabilities,” she said. “It’s not just a job, it’s their reason to be.”

You can learn more about South Carolina’s programs for people with disabilities from these sources:

The South Carolina Interagency Office for Disability and Health
www.sciodh.com

South Carolina disability resources
<http://www.carolina-disability.com/south-carolina-social-security-benefits.php>

The South Carolina Developmental Disabilities Council
<http://www.sccddc.state.sc.us>

The South Carolina Department of Developmental Disabilities and Special Needs
<http://ddsn.sc.gov/about/contacts/Pages/DDSCommission.aspx>

The Disability and Health Journal
<http://www.disabilityandhealthjnl.com>



Disability and Health Case Studies

State budget cuts affecting people with disabilities

<http://www.thestate.com/2011/02/07/1682634/disabled-face-budget-cuts-state.html>