

North Carolina: Leveraging Resources and Partnerships

Visit the website of the North Carolina Department of Health and Human Services, and you will see a red navigation area on the home page with “People with Disabilities” as one of six main demographic groups served. Click on that listing, and you will find more than 80 different programs, organizations and services for virtually every category of disability. Services include targeted programs for the blind and deaf, Alzheimer’s support, vocational rehabilitation, residential centers for people with developmental disabilities, and others.

However, even with this array of services, advocates for those with disabilities say there is a need for an entity to promote the health of people with disabilities and eliminate health disparities experienced by them. In North Carolina, that entity is the state Office on Disability and Health (NCODH).

“The office’s greatest contribution is the way it has infused issues surrounding disability into the planning, programs and strategies of state public health,” said Annette Lauber, cochair of NCODH’s Advisory Committee. A wheelchair user as a result of cerebral palsy, Lauber knows firsthand the barriers to health access that many individuals with disabilities face.

A Blueprint for Action

North Carolina was one of the first states to receive funding under the federal Center for Disease Control’s Disability and Health program in the 1980s. Since 1994, the NCODH has operated as a partnership between the Division of Public Health of the N.C. Department of Health and Human Services (DHHS) and the FPG Child Development Institute at the University of North Carolina at Chapel Hill (UNC-CH).

“Over the years, the focus of our office has shifted from the prevention of disability to health promotion and prevention of secondary health conditions for people with disabilities,” notes Karen Luken, NCODH project director. “We also take a cross-disability approach, in that the office addresses the health of people with a wide range of disabilities and health conditions across the lifespan.”

The tie-in with UNC-CH, where Luken is based, links the office to researchers who work on a wide range of multidisciplinary projects that include child health and development, preventive health screenings and emergency preparedness.

For the last two years, NCODH has provided the lead in shaping a new 10-year state plan to address the health needs of people with disabilities, who make up about 31 percent of the state’s adult population and 22 percent of those under 18. The plan’s overarching goal is to ensure the same access to all aspects of healthy living for people with disabilities that is afforded other individuals in North Carolina.

Developing this new plan, called “North Carolina’s Plan to Promote the Health of People with Disabilities,” included a series of 13 informational conversations that brought together public health subject matter experts, community organizations, service providers, and people with disabilities and their families.

These meetings prompted discussion on 11 leading health indicators closely aligned to the federal HHS Healthy People 2020 recommendations, such as access to health care, injury and violence, physical activity and tobacco use. For each indicator, participants were asked to discuss public health priorities, current state initiatives, evidence-based practices and needs and gaps experienced by people with disabilities. They also considered possible action steps under each indicator across five major areas: data, policy, media and educational campaigns, health and social intervention, and environment.

Based on the input from these meetings, a draft plan was developed and circulated to stakeholders for additional comments and suggestions.

“This was a very careful, time-intensive process,” said Lauber, a meeting participant. “The result is a plan that incorporates services and programs for people with disabilities in the overall health strategy of the state—not as a separate agenda.”

“The plan is the result of an excellent collaboration between state public health and stakeholders all across the state,” adds Rene Cummins, executive director of the Alliance of Disability Advocates. Cummins has worked with NCODH on programs ranging from promoting accessible environments to workshops instructing women with disabilities on domestic violence issues.

Programs for People

While spearheading the development of the new state health plan has been a major focus in recent months, NCODH and its partners continue to implement several key programs. Women’s health issues, for example, have been a long standing focus of NCODH. Data from the state’s Behavioral Risk Factor Surveillance System (BRFSS) reveals that women with disabilities are less likely to receive regular screenings for breast and cervical cancer than are women without a disability—one of many health disparities affecting people with disabilities.

To address that issue, NCODH launched a health education program several years ago called “Women Be Healthy,” a curriculum to teach women with intellectual disabilities about reproductive health and the importance of cancer screenings. Over time, the office has forged partnerships with organizations such as the state’s compensatory education and vocational rehabilitation programs, to train instructors in this curriculum. “With this approach, we can potentially reach thousands of women, from teens on up,” said Luken.

NCODH is now engaged in a three-year study, funded by the U.S. Department of Education’s, National Institute on Disability and Rehabilitation Research, on how the Women Be Healthy curriculum is affecting women’s knowledge and screening behaviors.

“Although the program we’ve developed is specific to women with intellectual disabilities,” adds Luken, “we know community partners have adapted it for women with psychiatric difficulties, teens in foster care and women in correctional institutions.”

With the growing concern about obesity and lack of quality physical education—problems that are more prevalent among children and youth with disabilities—NCODH and its community partners have worked extensively with YMCAs and fitness centers, both to make facilities more accessible and to educate personal fitness instructors about exercise assessment and programs that are more inclusive of the

needs of people with disabilities. This effort includes enlisting the help of people with disabilities to serve as cotrainers during community workshops.

Other health and fitness initiatives include Work Healthy, Live Healthy, a work site health program targeting adults with significant disabilities served by community rehabilitation programs. NCODH also is supporting a new state initiative on childhood obesity, with an eye toward insuring that school physical education programs address the needs of children with disabilities and track their performance with standardized testing.

An agenda for the Future

Moving forward, NCODH would like to continue to take on more challenges, such as access to oral health, reproductive health education and tobacco use prevention. “We also want to reach more diverse populations,” said Gerlene Ross, Ph.D., who serves as the NCODH program director at the Division of Public Health’s Children and Youth Branch. “But, it can be a tough challenge to overcome language and cultural barriers.”

NCODH’s philosophy is not to launch a pilot program unless it feels confident that sufficient support exists in the community to sustain the effort. “We don’t want to do one, and then none,” explains Luken.

As with other states, resources are a major concern. “Being part of the Division of Public Health allows us also to leverage resources from critical health partners such the Children and Youth Branch, Immunization Branch, and the Physical Activity and Nutrition Branch,” adds Dr. Ross.

External partners that have funded NCODH work include the National Center on Physical Activity and Disability, Susan G. Komen for the Cure on a national and state level and the North Carolina’s Governor’s Crime Commission.

“Leveraging other dollars is critical,” said Dr. Ross. For example, the CDC Disability and Health funds can’t be used for research projects, so if important research is needed, NCODH needs to approach researchers and funders with an interest in a specific health topic, such as breast cancer, heart disease, or obesity.

Funding worries aside, advocates for people with disabilities insist that NCODH has made a major impact on the state, said Cummins of the Alliance of Disability Advocates: “What the office has been able to accomplish, despite a small staff and limited resources, is far-reaching.”

You can learn more about North Carolina’s programs for people with disabilities by consulting these sources:

North Carolina Office on Disability and Health

<http://www.fpg.unc.edu/~ncodh/>

<http://ncdhhs.gov/dph/wch/aboutus/disability.htm>

UNC FPG Child Development Institute

<http://www.fpg.unc.edu/>

North Carolina Department of Health and Human Services

<http://www.ncdhhs.gov/>

DHHS People with Disabilities, Services, hotlines, Fact Sheets, Advocacy

<http://www.ncdhhs.gov/disabilities/index.htm>

Health and Disability in North Carolina (2003 report)

<http://www.fpg.unc.edu/~ncodh/pdfs/hdreport2003.pdf>

Alliance of Disability Advocates

www.alliancecil.org

North Carolina State Center for Health Statistics, Behavior Risk Factor Surveillance System

<http://www.schs.state.nc.us/SCHS/brfss/2009/nc/all/topics.html#dis>

North Carolina Division of Public Health Early Intervention Program

<http://www.bearly.nc.gov>

Children with Special Health Care Needs, NC 2007

<http://www.epi.state.nc.us/SCHS/pdf/CHAMPCSHCN.pdf>