

Delaware: Easing the Transition to Adulthood

Like most states, Delaware has a host of programs to serve its residents with disabilities, including early-childhood screening for signs of potential problems, assistive technology, and programs to help adults and the aging remain in their communities rather than being forced to enter institutions.

However, there is one group that is underserved: children with special health-care needs who were about to enter adulthood.

There were several programs and medical facilities for them as children, through the state's Department of Education and other agencies. The Nemours/Alfred I. duPont Hospital for Children in Wilmington is one of the leading medical institutions in the nation for children, including those with disabilities.

However, as these children transitioned into adulthood, around age 17, and left the school system or were no longer under the care of the hospital, they received no guidance on how to find health care providers, obtain health insurance or manage their lives. "It was like falling off a cliff," according to one parent of a child with complex needs.

Enter the Center for Disabilities Studies (CDS) at the University of Delaware. CDS and its Healthy Delawareans with Disabilities project, in partnership with others, established programs to ease the transition for these new adults and their families.

Working with funding from the Division of Public Health in the state's Department of Health and Social Services, CDS and the duPont Hospital studied the experiences of the 500 to 700 children transitioning into adulthood and out of the hospital's care during a given year. "We found that some [children] had nowhere to go, and didn't even have a primary-care provider," says Dr. Ilka Riddle, who directs the CDS Health and Wellness Unit. "In focus groups, we learned that they got no help in finding insurance or even finding a doctor."

From Research to Action

Armed with those findings, the duPont Hospital for Children established the division of transition of care. The division now has a part-time physician and a full-time social worker who assist transitioning youth and their families in finding medical specialists who work with adults with complex needs. They also show them how to get insurance and help them think about all the issues they will have to face as they leave the hospital's care. Simultaneously, the division works within the hospital to help other physicians understand the needs of people with disabilities and assist their patients in their transition.

Although the transition can be difficult, the children are able to reach the point of leaving pediatric care, which is a minor miracle and due to achievements in medical research and treatment. "Twenty-five-years ago, many of these children with complex medical conditions, like congenital heart disease, might not have survived," says Eileen Sparling, project coordinator for Healthy Delawareans with Disabilities. "Yet, despite the excellent care at duPont Hospital, these kids transition to a world where many health care providers don't have the training to work with them," said Sparling.

Beyond that, there is a dearth of professionals who can provide coordinated care for such patients. To solve this problem, Delaware's largest health care provider, Christiana Care Health System, provided a small grant to start the Transition Care Practice, an adult transition clinic, at its Wilmington Hospital. Staffed with two part-time physicians and a social worker, the practice provides care to patients with complex medical needs and helps with coordination of care.

Among other achievements, the CDS Health and Wellness Unit and Healthy Delawareans with Disabilities have helped to:

- Establish Healthy Transitions workshops in the community and in schools for youth and young adults ages 14 to 30 and their families to help them take responsibility for their health care. These workshops are in addition to the transitional services provided at the duPont and Christiana Care Hospitals. The workshops consist of four sessions and cover issues such as insurance; making appointments with physicians; healthy lifestyles, including nutrition, oral health care, and social and recreational opportunities; and healthy relationships.
- Promote 14-Weeks to a Healthier You, an online program created by the National Center on Physical Activity and Disability called. Program participants receive weekly tips on staying fit, physical exercise routines, and have access to nutrition and exercise experts.

"We feel that with our partners, we have created a network so people don't fall through the cracks anymore," says Riddle.

An Emphasis on Community

These activities support a larger state effort to develop community-based rather than primarily institution-based care. In 2009, Rita Landgraf became secretary of Delaware's Health and Social Services Department (HSS) and put the focus on community-based support. "Previously, she had been an advocate for the elderly and people with disabilities," says Riddle, "and she made that segment of the population a priority."

Landgraf emphasized that program funding should be based on need and not on what might be available from funding sources. The need for funding of programs for people with disabilities is evident in the results of the most recent Centers for Disease Control and Prevention-funded Behavioral Risk Factor Surveillance Survey for the state: the study showed that about 20percent of the state's adults are persons with disabilities.

CDS gets its funding from a variety of federal, state and foundation grants and contracts. Its funding agencies include the US Departments of Education and Justice, the federal Maternal Child Health Bureau, and the CDC. The CDC grant, which was for \$1 million over five years and funds many of the health-related activities, is in its final year.

In all cases, CDS coordinates and carries out service, policy and research programs and activities. Its Healthy Delawareans with Disabilities project analyzes data on health and disabilities, promotes awareness of health and wellness issues of people with disabilities, works to improve access to and inclusion in health and wellness activities for people with disabilities, and provides technical assistance.

Riddle and Sparling also sit on a variety of state councils, work groups and committees to educate state and community personnel who work on health and disability issues. Their goal is to help those groups learn about the health disparities that individuals with disabilities face and provide strategies to increase accessibility and inclusiveness of health care and health and wellness facilities and programs.

Despite all their accomplishments, Riddle and Sparling know that there is much more they could do. However, it takes continued funding, and they are hoping CDC will renew their grant. They are also researching other funding to expand their technical assistance on accessibility and inclusion, but they would also like to do more research on health disparities and establish evidence-based health promotion and health-maintenance activities for Delawareans with disabilities. Riddle says there are few evidence-based programs for people with disabilities in Delaware, which makes it difficult to offer health programs that show proven results.

“It’s all about understanding needs and community outreach to find ways to meet those needs,” says Riddle. With that outlook, Delaware is helping people with disabilities cross the bridge to healthy community living rather than fall off that proverbial cliff.

You can learn more about Delaware’s programs for people with disabilities by checking these sources:

The Center for Disabilities Studies (CDS) at the University of Delaware. The center enhances the lives of individuals and families through education, prevention, service and disabilities-related research.

<http://www.udel.edu/cds>

Healthy Delawareans with Disabilities website. This CDS’ project’s website provides many resources for individuals with disabilities, family members, health care providers, community and state agency staff and policy-makers regarding health and disability related topics.

<http://www.gohdwd.org>

Delaware Department of Health and Social Services. Lists all services and divisions that address the needs of various populations, including individuals with disabilities.

<http://dhss.delaware.gov/dhss/>

The Division of Developmental Disabilities Services. It offers an array of services for individuals with intellectual disabilities and other specific developmental disabilities (e.g. Autism, Prader Willie Syndrome) and their families, who meet eligibility criteria.

<http://dhss.delaware.gov/dhss/ddds/index.html>

<http://dhss.delaware.gov/dhss/ddds/services.html>

Delaware Behavioral Risk Factor Surveillance System

<http://dhss.delaware.gov/dph/dpc/files/disabilityandhealth2009data.pdf>

The Division of Transition of Care at Nemours/Alfred I. duPont Hospital for Children. Helps adolescent patients with disabilities and their families make the transition to adult services and finds physicians and other health care providers and help with insurance and medical summaries.

http://kidshealth.org/teen/centers/medical_care_center.html