Improving the Health and Well-being of Delawareans with Disabilities

Here is growing awareness that people with disabilities can and should achieve a healthy lifestyle. Having a disability should not prevent an individual from maintaining good health, engaging in appropriate exercise and physical activity, and/or feeling good about his or her health status. With the nation facing such serious health issues as obesity, high blood pressure, and asthma, it is important to provide opportunities for everyone, including individuals with disabilities, to live healthy and active lives.

Through Healthy Delawareans with Disabilities: Bridging the Gap (HDWD:BtG), the Center for Disabilities Studies (CDS) at the University of Delaware is working to improve the health status and well-being of people with disabilities in Delaware. Led by Ikka Riddle, Ph.D., this five-year project (2007-2012) is funded by the National Center on Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention. HDWD:BtG staff members meet regularly with a 55-member advisory council representing 36 agencies. Together, they drafted a strategic plan for legislators, policymakers, state agencies, community organizations, and individuals with disabilities and their families. It is intended to serve as a blueprint to advance the health status and well-being of Delawareans with disabilities. The final plan will be published in late spring 2009. To read the draft plan, please visit www.GoHDWD.org/strategic_plan.html.

Prevalence of Secondary Conditions

Having a disability may affect one’s perception of his or her health as well as one’s actual health status, as indicated by responses to Delaware’s 2006 Behavioral Risk Factor Survey (BRFSS), conducted annually as part of the nationwide Behavioral Risk Factor Surveillance System (BRFSS). When this random-sample telephone survey asked Delaware’s adult population about behaviors that affect risk of disease and disability, 44 percent of adults with a disability considered themselves to have “fair” or “poor” health compared to fewer than 8 percent of adults without a disability. Adults with disabilities may give these responses because they view their disabilities as diminishing their health status, because they in fact do have more chronic diseases, or for other reasons.

Delaware’s 2006 survey also showed that people with disabilities appear to have a higher risk for and incidence of a number of preventable conditions, which are called secondary conditions. Examples are obesity, smoking, hypertension, and diabetes, all of which may develop as a result of the primary disabling condition. An article on page 3 explores the issue of secondary conditions and how early intervention may prevent or reduce them in people with disabilities.

Access to Health Care and Fitness Services

Many adults in Delaware and throughout the country are finding that quality health care is costly and difficult to access. For people with disabilities, there are often additional barriers, including inaccessible buildings, medical equipment, and information. Some of these barriers may play a role in the disparities that are seen between people who have disabilities and those without disabilities. Access to such health promotion programs as nutrition counseling, stress management, and smoking cessation also may be more limited for people with disabilities. For young adults with disabilities and special health care needs, there are additional challenges as they transition from pediatric to adult providers (see page 2).

Exercise, as well as health care, plays an important role in living a healthy lifestyle. However, people with disabilities often find it difficult to exercise because of their disabilities and the physical barriers at many fitness facilities. There are significantly lower participation rates in physical activity among people with disabilities, as reported in the 2007 BRFSS. To provide more opportunities for exercise for people with disabilities, HDWD:BtG worked with an area fitness center on accessibility issues through a grant it received from the Delaware Developmental Disabilities Council (see page 4).

Since adopting a healthy lifestyle is important for everyone, it is vital that people with disabilities have access to information, supports, and services that allow them to eat well, exercise regularly, and take care of their emotional health. Healthy Delawareans with Disabilities: Bridging the Gap is an important new resource for Delawareans with disabilities to help them achieve the best possible health.
Helping Young Adults Navigate the Health Care Transition Process

For many young adults, turning 21 is a milestone. They are legally old enough to do all the “adult” things that have been out of their reach. But for young adults with special health care needs—and their families—the approach of this milestone can cause feelings of uncertainty about the future of their health care.

Terri Hancharick, an advocate and parent of a child with multiple disabilities, can attest to this. After going through the process of health care transition within the past year with her daughter, Brigitte, Terri talked about their experiences. “We had a rapport with her pediatric orthopedic surgeon and a trust that developed over time,” Terri said. “Then, it seemed like the blink of an eye, Brigitte was 21. She was no longer able to go to her school or her surgeon. Our safety net had been pulled out from under us and we had to enter a new world of adulthood.”

For much of the twentieth century, many children with complex disabilities and health conditions, such as cystic fibrosis, pediatric heart conditions, and genetic disorders, did not survive into adulthood. Now, as a result of advances in technology, treatment, and care, more than 90% of children and young adults with a disability are living past the age of 20. As an example, the Cystic Fibrosis (CF) Foundation reports that when it was founded in 1955, the majority of children with CF did not live long enough to attend elementary school. Currently, the median age of survival for people with CF is approximately 37 years.

Contributing to the challenges of medical transition is the lack of physician training in treating childhood onset disorders. This has resulted in health care providers who are not prepared to treat the growing population of young adult patients with pediatric onset disabilities and special health care needs. In addition, they may not have the same rapport with the young adults as pediatric care physicians.

Transition Resources and Partnerships

In Delaware, the concerns about health care transitions have led to the development of new services and resources. A partnership between the Center for Disabilities Studies and KentCrest Services led to the creation of the TransitionMap Delaware website (www.transitionmapdel.org). The medical section of this website provides access to transition toolkits and checklists for families and patients, a database of accessible medical offices throughout the state, and other resources.

The Delaware Family Voices Family to Family Health Information Center opened at CDHS in June 2008 to serve as a resource and provide help to families new to the world of children with disabilities, chronic illnesses, and physical or mental health conditions (see page 3). At Nemours/Alfred I. duPont Hospital for Children (AIDHC), a transition committee composed of physicians, parents, and other medical professionals has been meeting regularly for several years to discuss the transition gap in medical services. Last year, the hospital established the Transition of Care project with a full-time social work position and a part-time physician position. Cory Nourse, the Patient Transition Social Work Coordinator, describes it as an exciting new opportunity to improve health care transitions for pediatric patients.

Cory works with Dr. Rita Meek, a pediatric oncologist and former Medical Director of AIDHC, to help facilitate conversations and opportunities with patients, families, and doctors. They also identify gaps in the services provided by the adult health care community and find adult providers who are willing to build partnerships. Transition of Care has helped facilitate transition partnerships with Christiana Care Health Systems (CCHS) in cystic fibrosis, cardiology, and oncology programs. Further partnerships are being explored within primary care and endocrinology.

These partnerships are opening doors for many patients and families in the area of health care transitions. However, there is still much work to be done. For example, points out Cory, transition preparation should begin early in adolescence, not right before a young adult is going to be discharged from pediatric services.

“By starting conversations at age 13 about what the young adult wants for his future, as well as supporting his parents to encourage this self-direction, young adults experience less shock as they transition into services in the adult world,” she says, adding, “In seeking out an adult provider before it’s a necessity, families experience a continuity of care that they and the pediatric physicians are more comfortable with.”

For more information on Transition of Care, contact Cory Nourse at 302.651.4812 or cnourse@nemours.org.

Accessible Outdoor Recreation

In 2008, the federal government issued its first-ever Physical Activity Guidelines for Americans. They describe the types and amounts of physical activity that offer substantial health benefits to Americans. The guidelines recommended that adults with disabilities follow the adult guidelines and be as physically active as their abilities allow and avoid inactivity. Delaware has many opportunities for accessible outdoor physical activity. Here are a few to consider – many more are listed at www.GoHDWD.org.

Can-Do Playground

4361 Weldin Road, Wilmington

www.canplayground.org

The Can-Do Playground, which opened in July 2007 as a Wilmington Rotary Club project, is a 23,000 square foot playground where children of all abilities can play together. The objective of this “boundless playground” was to design an area that is barrier free, socially inviting, and contains play environment groupings. It also provides fun challenges that promote sensory, physical, and creative growth. More than 70 percent of the play activities are accessible.

Trap Pond State Park

33587 Baldcypress Lane, Laurel

www.destateparks.com/park/trap-pond

Open daily 8 a.m. until sunset year-round.
302.875.5153

Trap Pond includes ADA accessible camping cabins and accessible sites in its campground (302.875.3932). Accessible playgrounds are located at the day use area of the campground. On weekends and holidays from Memorial Day weekend through Labor Day there are naturalist-led pontoon boat rides in the Cypress Swamp that can be accessed in a wheelchair. These boats can be rented during the summer season along with rowboats, pedal boats, surf bikes, canoes, and kayaks. Trap Pond also has a 4.9-mile stone dust trail, volleyball courts and horseshoe pits. The Baldcypress Nature Center (302.875.5163), which is ADA accessible, features a variety of displays and programs.

Glasgow Park

Route 40 at Route 896, Glasgow

www.friendsofglasgowpark.org

Glasgow Park is a 300 acre New Castle County park that strives to be all inclusive through the efforts of the Friends of Glasgow Park. The park contains a 2.75 mile multi-use trail for walking, bicycling, or roller skating, a wooded walking path, children’s playgrounds, and Bear Mountain for walking and winter sledding. Future plans include a skateboard park and basketball and tennis courts.


The Challenge of Preventing Secondary Health Conditions

I don’t know what tomorrow will bring. You think you’re doing well and then all of sudden something else in your body goes wrong.” These are the words of Middletown resident Lea Castelli, who was diagnosed with multiple sclerosis (MS) in 1990. MS is a chronic disease that attacks the central nervous system, with symptoms ranging from mild, such as numbness in the limbs, to severe, including paralysis or loss of vision.

In addition to MS symptoms, Lea experiences the troubling effects of secondary health conditions. These are physical, emotional, or psychosocial problems that occur as a direct or indirect result of a primary disability or health condition. Many surveys and studies show that people with disabilities are at an increased risk of developing secondary health conditions. According to the 2005 Surgeon General’s Call to Action to Improve the Health and Well-being of Persons with Disabilities,1 more people with disabilities experience obesity than those without disabilities. This report noted that secondary health conditions such as obesity and hypertension can lead to life-threatening events, including heart attacks and strokes.

To learn more about health and disability, the Healthy Delawareans with Disabilities (HDWD) project created two health surveys for people with all types of disabilities: the 2005 adult study was published in 2007 and the 2008 children’s study was published in 2008. The majority of respondents to the HDWD adult survey reported their overall health to be fair or poor. Furthermore, almost half could not participate in their usual activities due to MS, has led to the development of painful pressure sores on her buttocks and foot. Because she can exercise only her upper body, Lea has gained considerable weight. If she does not exercise her arms, Lea has found that her muscles become weak so she cannot brush her teeth or pick up a spoon.

Intervention shortly after the onset of MS may have prevented some of Lea’s secondary health conditions from occurring. However, even though delayed, appropriate intervention and treatment may reduce the severity of existing secondary health conditions or stop further decline in her health. Although Lea’s disability prevents her muscles from becoming stronger, her participation in Yes U Can™, an innovative fitness program offered at the BrandYWyn YMCA in New Castle County, keeps them from weakening.

Yes U Can™ is a series of staff-assisted group and individual exercise and weight-training programs geared toward people with disabilities or limited mobility. It was created by Vickie George, who also has MS, to help others with disabilities gain more control over their health. It is based on her own positive experiences with a regular exercise program. Vickie is a former professional athlete who always has been a healthy eater and avid exerciser. Although her disease has progressed to the extent that she has limited use of her limbs, Vickie has continued to exercise. A regular exercise program that includes stretching is helping her body systems continue to work effectively and helping to prevent secondary health conditions from occurring, she says. Vickie believes that her MS has not progressed as rapidly as expected because she is challenging her muscles. As a result, she is still able to shift her weight as well as stand to shower and brush her teeth. With assistance, she is able to push 200 pounds on a leg press and do standing pushups. Vickie also participates in a weekly therapeutic horseback riding program.

Vickie explains how exercise has been a positive force in her life: “I can tell you that the psychological benefits I receive through exercise and weight training sometimes outweigh the physical benefits. When I began to exercise, I felt like I was back in control again. I felt empowered to do things. I didn’t feel helpless. I started to feel alive again. I started to accept what I could not change, but I realized that there was a lot that I could change.”

For more information about the Yes U Can™ program, contact Vickie George at 302.286.1399 or info@yesyoucanusa.com, or visit www.yesyoucanusa.com.

4 Health Risks of Adults with Disabilities in the State of Delaware: A Retrospective Analysis of Data from the Behavioral Risk Factor Surveillance System; Center for Applied Demography and Survey Research, University of Delaware, June 2006.
Improving Fitness Center Accessibility

AFTER spending close to 20 years in a wheelchair following an automobile accident that resulted in a spinal cord injury, Paula Talarowski joined a fitness center. “I started going to 1614 to build my upper body strength to help me get in and out of my chair,” said the Newark resident, a member of 1614 since 2002.

“Exercising a few times a week is now an important part of my life that helps improve my overall health,” she added. With her desire to exercise regularly, Paula serves as a role model for all who want to incorporate fitness into their lifestyle. She is fortunate to have found a fitness center that is committed to accessibility for all of its members. This is not the case for everyone. While fitness plays an important role in living a healthy lifestyle, it is often difficult for people with disabilities, particularly those using wheelchairs, to find accessible exercise facilities.

Healthy Delawareans with Disabilities: Bridging the Gap, a project of the Center for Disabilities Studies, promotes inclusion of people with disabilities in recreation and exercise facilities. In October 2007, HDWD:Bg received a one-year grant from the Delaware Developmental Disabilities Council to address this issue. Its partners in the Inclusive Exercise and Fitness Project are the University of Delaware’s Department of Health, Nutrition, and Exercise Sciences and the Delaware Assistive Technology Initiative.

Creating Disability Friendly Environments

Using 1614’s two locations in Bear and Newark as the pilot sites, Inclusive Exercise and Fitness Project staff conducted an accessibility assessment that addressed physical and attitudinal accessibility within the health club. Mike Womier, owner of 1614, agreed to have an accessibility assessment conducted that addressed physical and attitudinal accessibility within the health club. The assessment of 1614 has led to positive changes, explaining, “The Healthy Delawarean team has provided us with tremendous support in assisting people who have additional challenges. Learning about such details as soap placement in the locker room and the size of the print in our literature has helped us make our fitness centers easier for all to enjoy. This guidance is valuable as we try to help others.”

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Mike Womer helps Paula Talarowski with exercises to develop greater strength in her upper body.