

Spring 2009

DELAWARE



A collaborative effort of the Center for Disabilities Studies & the Delaware Developmental Disabilities Council

ABOUT THIS ISSUE

Whether you are healthy, deal with frequent acute illnesses, or live with a chronic illness, your health and the quality, availability, and cost of health care are likely to be very important to you. If you also have a disability, you and your family may be even more concerned about your health and the health care options available to you. This issue of *delAware* addresses some of these health concerns and the ways in which the Center for Disabilities Studies is working to improve the health and well-being of Delawareans with disabilities.

Health issues are an important and ever expanding focus for the Center. We in Delaware are fortunate that, through two Healthy Delawareans with Disabilities (HDWD) projects, CDS has been able to engage in many health-related activities. CDS conducted health status surveys for adults and children as part of the HDWD 2010 project. A report about each survey can be found at www.GoHDWD.org, the website recently developed through the Healthy Delawareans with Disabilities: Bridging the Gap (HDWD:BTG) project. This website is part of this project's efforts to make health and wellness services and programs more accessible and inclusive. It offers persons with disabilities, their families, and caregivers information about achieving a healthy lifestyle. I encourage you to visit the website often as new content is added.

I thought you'd be interested in some recent health-related news:

- HDWD:BTG has started the Mammography Accessibility Project, in partnership with the Delaware Breast Cancer Coalition (DBCC), to assess

Delaware's mammography facilities for accessibility. Funding is through a grant to DBCC from the Avon Foundation. This project will produce an online guide to mammography facilities to provide information for women with disabilities.

- Accessible recreation is being enhanced at some of Delaware's state parks, thanks to the efforts of HDWD:BTG staff member Terri Hancharick. She encouraged Rifton Equipment to donate an adaptive tricycle to the Delaware Bicycle Council for use by adults with disabilities at Bellevue State Park in New Castle County. Terri is working to place a tricycle from a different company at another state park.

This issue of *delAware* is the result of a great team effort, with contributions by CDS' University of Delaware graduate assistants Paul Galonsky, Natalie Bizzarro and Liz Bozzo and Healthy Delawareans team members Ilka Riddle and Eileen Sparling. CDS employees who shared their experiences with us are Paula Talarowski, featured in the article about accessible fitness centers, and Terri Hancharick, whose daughter, Brigitte, recently transitioned to the adult health care system. I hope the information in this issue of *delAware* is helpful to those in the community who are seeking to achieve a healthier lifestyle and better health care for themselves and their families. For information about other CDS programs and projects, and links to other organizations with an interest in disability related issues, please check our website, www.udel.edu/cds.

Sincerely,

Michele Sands, Editor

The mission of the Center for Disabilities Studies (CDS) is to enhance the lives of individuals and families in Delaware through education, prevention, service, and research related to disabilities. We promote independence and productivity so individuals and families can fully participate in the life of the community. As a research and public service center at the University of Delaware, CDS relies on public and private support from individuals, corporations, foundations and state and federal entities to operate its programs. All gifts to CDS are tax deductible to the extent provided by law. Please visit our website at www.udel.edu/cds or call 302.831.6974 for more information about supporting CDS' mission.

delAware is sponsored by the University of Delaware's Center for Disabilities Studies and the Delaware Developmental Disabilities Council. If you would like to contact CDS, please call 302.831.6974 or TDD at 302.831.4689; send a fax to 302.831.4690 or an e-mail to Michele Sands at msands@udel.edu; or write to *delAware*, University of Delaware, Center for Disabilities Studies, 461 Wyoming Road, Newark, DE 19716. Editor: Michele Sands, CDS. Designer: Cindy Dolan.

Improving the Health and Well-being of Delawareans with Disabilities

There 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 Ilka 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 family members. 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 (BRFS¹), conducted annually as part of the nationwide Behavioral Risk Factor Surveillance System (BRFSS²). 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 inci-

dence of a number of preventable conditions, which are called secondary conditions. Examples are obesity, arthritis, 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 often are 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 health possible.

1 www.dhss.delaware.gov/dhss/ Delaware Health and Social Services, www.dhss.delaware.gov/dhss/dph/ Division of Public Health, www.dhss.delaware.gov/dhss/dph/dpc/brfsurveys.html.
2 Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion, www.cdc.gov/BRFSS.

Helping Young Adults Navigate the Health Care Transition Process

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

Terri Hancharick, an advocate and parent of a child with severe 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 in the blink of an eye, Brigitte was 21. She was no longer able to go to her school or to her surgeon. Our safety nets had been pulled out from under us and we had to enter a new world of adulthood.”

Terri’s comments echo the thoughts of many families and young adults in this country who are navigating the health care transition process. They have become accustomed to the warm, personal, and family-centered team approach of their pediatric care professionals. However, when they turn 21 (or, in some cases, 18), young adults have to transition out of the pediatric system and can no longer receive services in this familiar setting. Instead, they have to learn to navigate the adult health care system with its unfamiliar culture, policies, and practices.

Longer Life Spans

Why have health care transitions become such an important issue for adolescents and young adults with disabilities and special health care needs? The simple answer is longer life spans.

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 20.¹ 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.²

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 some new services and resources. A partnership between the Center for Disabilities Studies and KenCrest Services led to the creation of the TransitionMap Delaware website

(www.transitionmapde.org). The medical section of this website provides access to transition booklets 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 CDS 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 Nourie, 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 new 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 Nourie at 302.651.4812 or cnourie@nemours.org.

¹ Blum, R. W. (1995). Transition to adult health care: Setting the stage. *Journal of Adolescent Health*, 17, 3-5.

² Living with cystic fibrosis: Care center network. (2008). www.cff.org/LivingWithCF/CareCenterNetwork.



Brigitte Hancharick is shown at age 2 and as a 21-year-old high school graduate.

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.candoplayground.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 (302.875.2392). 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
302.571.4006

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 Wellness 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 2010 (HDWD) project created two health surveys for people with all types of disabilities: the 2005 adult study was published in 2007² and the 2006 children's study was published in 2008.³ 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 because of poor health and disabilities. In another survey that compared responses of individuals with disabilities and Delaware's general population,⁴ individuals with disabilities were more

likely to report secondary health conditions. They had higher rates of arthritis, diabetes, high blood pressure, and high cholesterol.

Prompt Intervention May Alleviate Secondary Conditions

For some people with disabilities, it is a challenge to prevent secondary health conditions. Sitting in one position for prolonged periods of time can contribute to bones fusing together, obesity, skin breakdown, joint stiffness, cardiac problems, and muscle atrophy. Lea Castelli's use of a wheelchair throughout the day, 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 so weak 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,TM an innovative fitness program offered at the Brandywine YMCA in New Castle County, keeps them from weakening.

Yes U CanTM 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



Vickie George mounts her horse with assistance from staff and volunteers at Carousel Park and Equestrian Center.

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 CanTM program, contact Vickie George at 302.286.1399 or info@yesyoucanusa.com, or visit www.yesyoucandelaware.com.

¹ U.S. Department of Health and Human Services, Office of the Surgeon General, www.surgeongeneral.gov/library/disabilities/calltoaction/whatitmeanstoyou.html.

² Riddle, I.K. (2007). *Delaware Health Status Report for Adults with Disabilities*. Center for Disabilities Studies, University of Delaware, Newark, DE, www.udel.edu/cds/downloads/hdwd_report_June2007.pdf.

³ Riddle, I.K. (2008). *Delaware Health Status Report for Children with Disabilities and Special Health Care Needs*. Center for Disabilities Studies, University of Delaware, Newark, DE, www.udel.edu/cds/documents/childhood_008.pdf.

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.

A New Health Information Resource for Families

Delaware Family Voices[®] Family to Family Health Information Center opened in June 2008 at the Center for Disabilities Studies. F2F, as it is commonly referred to, is operated and staffed by and for families of children and youth with disabilities and special health care needs. According to project coordinator Ann Phillips, "We are families just like you who are raising a child with special health care needs: disability, chronic illness, and physical or mental health conditions. These children have chronic and complex needs, and parents and caregivers struggle to find services critical to their child's well-being."

F2F Health Information Center provides information to parents who are new to the world of disabilities or to the issues that face families of a child with a disability or special health care needs. Parent Leader Liaisons and Resource Parents help other parents navigate the health care system, access resources and services, and find the answers to their questions. Valuable support is offered to save families time and frustration on such tasks as solving medical insurance



issues, seeking insurance and SSI (Supplemental Security Income) benefits, and obtaining proper assistive technology and therapy services. Workshops and training are offered for families and professionals on topics such as advocacy and Medicaid.

F2F is always looking for parents who are interested in giving a little time each month to speak with other parents. "Our children have taught us so much. Please consider sharing your expertise with other parents in Delaware," states parent leader liaison Valerie Werner.

Delaware Family to Family is made possible by a grant from the Maternal and Child Health Bureau of the Health Resources and Services Administration, U.S. Department of Health and Human Services.

Contact information:

Toll-free phone number: 877.235.3588

Ann Phillips: 302.831.1705 or aphillip@udel.edu

Valerie Werner: 302.831.0140 or vwerner@udel.edu

Website: www.delawarefamilytofamily.org

Share Your First Person Health Stories with CDS

First Person
HEALTH
stories about access

A disability is not an illness. Living with a disability, however, can sometimes make it more difficult to access quality health care and maintain an active and healthy lifestyle.

Healthy Delawareans with Disabilities: Bridging the Gap is gathering stories about health care access for people with disabilities. You can help by identifying the issues and barriers you encounter in your efforts to lead a healthy active life. Be part of improving access by sharing a service, facility, or provider that works well for you or an area that needs improvement regarding such health care issues as:

Physical access	Nutrition and healthy eating
Communication	Insurance and finances
Exercise and fitness	Transportation

We will use your "first person" health stories to illustrate the state of health care for people with disabilities in Delaware and to develop an action plan to address issues that are important to your health. We will never share your name without your permission. Tell us your story at www.GoHDWD.org or call Eileen Sparling at 302.831.8802 if you do not have access to the Internet. If you have questions about this project, call Eileen or contact her at sparling@udel.edu.

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 Fitness & Aerobics 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:BtG 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 Womer, owner of 1614, agreed to have an assessment of each facility to help him better achieve 1614’s mission of creating an inclusive environment for all people. Mike estimates that at least 50 of his 2,000 fitness center members have a disability.

While the 1614 Fitness & Aerobics locations were found to be compliant with parking, access to



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

walkways, and providing closed captioning on TVs, changes were recommended to provide better accessibility for people with disabilities. HDWD:BtG staff developed a plan of action with 1614 that provides guidance in making some changes immediately and others mid-range, long-range, and ongoing. HDWD:BtG research assistant Dannielle Miccinello put together resource lists for 1614. Some of the improvements she suggested were simple to achieve, such as providing large print or pictogram instructions for using exercise machines, while others require more extensive and long-term planning, including the installation of more accessible sinks in bathrooms and locker rooms.

Mike Womer believes the assessment of 1614 has led to positive changes, explaining, “The Healthy Delawareans 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.”

Accessibility Booklets

The HDWD:BtG Project is currently developing resources to improve accessibility statewide, including the following publications: *Guidelines for Improving Accessibility: Health Care Facilities* and *Guidelines for Improving Accessibility: Fitness Facilities*. The booklets contain information about regulations, resources, funding assistance, and facility improvements. To obtain copies, which will be available in late spring 2009, please call 302.831.8802.

Following the accessibility assessment, HDWD:BtG conducted a “facilitating inclusion” workshop for staff at 1614. The full-day training session explored issues related to people first language, interacting with people with physical and cognitive disabilities, interacting with people with vision and hearing loss, and adapting exercise equipment for individuals with disabilities.

Mike Womer’s desire to create a more accessible and friendly environment at 1614 for people with disabilities seems to be paying off. Paula Talarowski finds her experiences at the fitness center to be positive and rewarding. She notes, “Mike has helped me train since I became a member. He arranges my workout program, shows me how to do the training, and always challenges and encourages me. When I come in to work out on my own, the staff is great, too – they all help me out if I need it. They are kind of like a family to me because they make me feel real comfortable while exercising.”



Jon Stoklosa, who keeps fit as a powerlifter, compares biceps with Paula.