



# Healthy Delawareans **with Disabilities**

..... *bridging the gap*



## **A PLAN FOR ACTION**

**A Strategic Plan for Delaware to Promote Health  
and Prevent Secondary Health Conditions in  
Individuals with Disabilities**

**2009-2012**







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## Healthy Delawareans with Disabilities: Bridging the Gap

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## **HEALTHY DELAWAREANS WITH DISABILITIES: BRIDGING THE GAP (HDWD:BtG) ADVISORY COUNCIL**

We would like to thank all HDWD: BtG Advisory Council members who have contributed to this strategic plan and helped move our project forward. Without our members, we could not accomplish our mission of being a “catalyst for systems change to make health and wellness programs more accessible and inclusive.” We are looking forward to working with our members to accomplish many of the goals and objectives of this strategic plan and to develop long-term, sustainable change for people with disabilities in Delaware.

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We would like to extend thanks to the workgroup members on ADA/accessibility, communication, and provider training: Advisory Council members Carol Barnett, Alice Coleman, Gerard Gallucci, Linda Heller, Kyle Hodges, Thomas Kelly, Eileen Mapes, Ann Phillips, Gloria Price, Nancy Ranalli, Al Rose, Paulette Smith, and Kathy Stroh and graduate students Natalie Bizzarro, Elizabeth Bozzo, and Paul Galonsky. Special thanks also go to Linda Gottfredson, Professor, School of Education, University of Delaware, who revised and edited the draft version of this strategic plan.

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## EXECUTIVE SUMMARY

### Background

Good health is a fundamental component of an individual's life and impacts an individual's access to school and employment, social and recreational activities, and community life. Due to inactive lifestyles, unhealthy habits such as smoking, poor nutrition, lack of insurance, and limited access to health and wellness services and resources, many individuals are not as healthy as they could be. While the nation faces these issues as a major public health issue and all Americans encounter challenges accessing health care, individuals with disabilities encounter numerous additional barriers. Yet, having a disability should not prevent an individual from leading a healthy life. With the appropriate information, supports, services, resources, policies, and laws in place, individuals with disabilities can lead, achieve, and maintain healthy lifestyles.

In 2007, the Center for Disabilities Studies (CDS) at the University of Delaware (UD) was awarded funding from the Centers for Disease Control and Prevention (CDC) for the Healthy Delawareans with Disabilities: Bridging the Gap (HDWD:BtG) project. HDWD:BtG was charged with promoting health and preventing secondary health conditions in individuals with disabilities. As part of its charge, HDWD:BtG developed this strategic plan for Delaware to guide the actions needed to improve the health and well-being of individuals with disabilities in Delaware. In addition, HDWD:BtG develops and implements various health initiatives and health promotion activities in collaboration with state and community partners, analyzes data related to health and disability, raises awareness about health and wellness issues encountered by individuals with disabilities, works to improve access to and inclusion in health care and wellness activities, and provides technical assistance to state and community agencies about health and disability-related issues.

### Method

The strategic plan was developed over the course of almost two years (2007-2009). National and Delaware data sources

regarding health and disability issues were analyzed to reveal health issues and gaps in services for individuals with disabilities. The Advisory Council, comprised of individuals with disabilities, family members, and representatives from state agencies, community health and disability organizations, and advocacy and support groups, reviewed data sources and created the goals, objectives, and activities in this plan. The HDWD:BtG project staff compiled the information and created the final strategic plan that was reviewed by the Advisory Council and various stakeholders in the disability and health communities.

## Target Audience

Target audiences of this plan are government officials, policy makers, health care and wellness professionals, community health and disability professionals, health educators, disability advocates, direct support professionals, individuals with disabilities, and family members. This plan will guide actions and activities to create improved systems that are accessible, inclusive, culturally competent, and consistent with the laws and policies put in place to help individuals with disabilities participate fully in their communities.

## Monitoring of Strategic Plan

The HDWD:BtG staff will continuously monitor progress on the strategic plan. While the HDWD:BtG project has its own project goals and objectives, they are aligned with the goals and objectives of the strategic plan. In addition, HDWD:BtG staff will work closely with the Advisory Council and other state and community partners, individuals with disabilities, and family members, on monitoring county and state-wide progress on the goals, objectives, and activities of this strategic plan. The strategic plan is a living document and new goals and objectives will be added and existing ones will be modified to reflect the needs of the community.

## Goals and Objectives

This strategic plan consists of four goals, each with multiple objectives. The four goals and their objectives are listed below. Each objective includes a list of strategies to accomplish the objective. A full listing of the goals, objectives, and strategies can be found beginning on page 21.

**Goal 1: Enhance the capacity of state-level institutions and collaborations to improve the health and wellness of individuals with disabilities and/or special health care needs.**

*This goal focuses on increasing the capacity of the state to address the health and well-being of individuals with disabilities. The nine objectives include state-wide, systemic changes to promote health and well-being for individuals with disabilities.*

1. Establish an office on disability and health as a centralized, state-wide resource for information, consultation, referral, training, and technical assistance.

2. Promote understanding throughout the state that health status and disability are two independent concepts and work to reduce stigma associated with disabilities, mental health conditions, and recovery from substance abuse.
3. Prepare and hold a Disability and Health Summit to address Delaware’s needs in helping individuals with disabilities live healthy lives.
4. Support initiatives in Delaware’s social, recreational, employment, housing, and transportation systems that would allow fuller participation of individuals with disabilities and/or special health care needs and improve their health, wellness, and quality of life.
5. Build more and stronger partnerships among state agencies, universities, colleges, and other community organizations that address the health care and wellness needs of individuals with disabilities and/or special health care needs.
6. Monitor, support, and advocate for legislation that enhances the health and well-being of individuals with disabilities.
7. Increase the state’s surveillance and data collection, analysis, and dissemination abilities.
8. Support the development and implementation of evidence-based services and interventions.
9. Increase the capacity of state agencies that address health and disabilities issues to conduct program evaluation and quality assurance activities.

**Goal 2: Enhance the capacity of health care systems and health and wellness programs within Delaware to provide comprehensive, accessible, and inclusive services for all individuals with disabilities and/or special health care needs.**

***The second goal of the strategic plan emphasizes the importance of organizational level changes to improve systems and supports for individuals with disabilities that are accessible and inclusive.***

1. Reduce the organizational barriers to accessible and comprehensive care in health and wellness settings.
2. Promote a climate that increases financial accessibility to health care.
3. Reduce barriers that prevent full access to healthy living in the community.
4. Increase the knowledge, skills, and capacity of the incoming health care and health and wellness workforce for working with, caring for, and supporting/assisting individuals with disabilities.
5. Increase the organizational capacity and skills of the established health care and health and wellness workforce.
6. Support existing health and disabilities initiatives to implement their goals, objectives, and activities.

**Goal 3: Enhance the capacity of providers to help individuals with disabilities and/or special health care needs protect their health and minimize secondary health conditions.**

*The third goal of the strategic plan emphasizes a) the need for education about best practices for professionals who provide health information and services to individuals with disabilities, and b) the need for education about healthy living to individuals with disabilities.*

1. Promote the use of best practices in health care and health and wellness settings.
2. Promote healthy lifestyle choices to individuals with disabilities.
3. Promote early and adequate preparation for transition of care for children, adolescents, and adults with disabilities and/or special health care needs.
4. Promote the understanding that mental health and substance abuse are conditions that require the same quality of care as other health conditions.
5. Promote the understanding that dental conditions require the same quality of care as other health conditions.
6. Collaborate with existing organizations (e.g., schools, faith-based organizations, employers) to promote healthy lifestyles and provide information and services in an inclusive manner so that children, adolescents, and adults with disabilities can participate to their fullest abilities.
7. Reduce barriers to effective communication between health care providers and individuals with disabilities and their support persons and improve health literacy.

**Goal 4: Enhance the health and well-being of individuals who provide paid and unpaid support for individuals with disabilities and/or special health care needs.**

*The final goal focuses on addressing health and well-being with support persons of individuals with disabilities so that they will be able to live healthy lifestyles and promote healthy living to the individuals with whom they support.*

1. Promote healthy lifestyles for paid and unpaid caregivers.
2. Generate support mechanisms for caregivers of individuals with disabilities.
3. Support adequate training and professionalism of direct support professionals.



## INTRODUCTION

As a nation, the population of the United States faces serious health issues, such as obesity, cancer, cardiovascular disease, hypertension, diabetes, and asthma. If we want to become healthier as a nation, public health and systems-level changes are needed to address these conditions and prevent or reduce occurrences. This can partially be achieved by increasing the number of individuals living healthy lifestyles that include being active, eating nutritious meals, and receiving regular, preventive medical check-ups. While leading a healthy lifestyle can be challenging for everyone, individuals with disabilities face additional difficulties: medical offices, exercise facilities, and recreational settings may not be accessible; individuals with disabilities may not be included in health promotion and wellness activities; information may not be available in alternative formats; and needed medical interventions or equipment may not be covered by health insurance.

Approximately 15% of the Delaware population 5 years old and older have a disability (U.S. Census Bureau, 2008). Many of these individuals live with additional health issues (Center for Applied Demography and Survey Research, 2006). However, having a disability should not prevent an individual from being healthy, maintaining or improving his/her health, managing an existing secondary health condition, engaging in exercise and physical activity, eating nutritious meals, and having access to medical care and equipment. With appropriate and accessible service systems in place, individuals with disabilities can achieve and maintain healthy lives.

### Background

In 2007, the Center for Disabilities Studies (CDS) at the University of Delaware (UD) was awarded funding from the National Center on Birth Defects and Developmental Disabilities (NCBDDD) of the Centers for Disease Control and Prevention (CDC) for the Healthy Delawareans with Disabilities: Bridging the Gap (HDWD:BtG) project. HDWD:BtG was charged with promoting health and

preventing **secondary health conditions**<sup>1</sup> in individuals with disabilities. The project’s mission is to “act as a catalyst for systems change to make health and wellness programs more accessible and **inclusive**,” and its vision is that “all individuals with disabilities in Delaware will live active and healthy lives and will have the resources, supports, programs, and services necessary to do so.”

HDWD:BtG develops and implements various health initiatives and health promotion activities in collaboration with state and community partners, analyzes data related to health and disability, raises awareness about health and wellness issues encountered by individuals with disabilities, works to improve access to and inclusion in **health care** and wellness activities, and provides technical assistance to state and community agencies about health and disability-related issues.

## Method

As part of its charge, HDWD:BtG developed this strategic plan for Delaware that will guide the actions that need to be taken to improve health and well-being of individuals with disabilities. This plan was developed over the course of almost two years (2007-2009). Data from national and Delaware sources regarding health and disability issues were analyzed to reveal health issues and gaps in services for individuals with disabilities that need to be addressed. Additional data were gathered from state agencies and community organizations serving individuals with disabilities. Health promotion organizations and **health care providers** in Delaware were surveyed to explore their **accessibility**. The HDWD:BtG Advisory Council, comprised of individuals with disabilities, family members, and representatives from state agencies, community health and disability organizations, and advocacy and support groups, developed the goals, objectives, and activities of this strategic plan. The HDWD:BtG project staff compiled all the information and created the final strategic plan that was reviewed and approved by the Advisory Council and various stakeholders.

## Purpose of the Plan and Target Audiences

The plan provides the necessary steps to improve the health and wellness of Delawareans with disabilities. Target audiences of this plan are government officials, policy makers, health care and wellness professionals, community health and disability professionals, health educators, disability advocates, **direct support professionals**, individuals with disabilities, and family members. This plan should guide actions and activities to create an improved system that is accessible, inclusive, culturally competent, and consistent with the laws and policies put in place to help individuals with disabilities participate fully in their communities.

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<sup>1</sup> Definitions for the bolded words in the strategic plan can be found in the glossary at the end of this document.

## Monitoring and Evaluation

The HDWD:BTG project staff will continuously monitor progress on the strategic plan. First and foremost, the project will track accomplishment of project goals and objectives that are aligned with goals and objectives of the strategic plan. The project evaluator will provide an annual report to CDC on the progress that the HDWD:BTG staff has made on the goals and objectives. In addition, the project staff will work closely with the Advisory Council, state divisions, other state and community partners, individuals with disabilities, and family members on monitoring and tracking state-wide progress on the goals, objectives, and activities of this strategic plan. Project staff, Advisory Council members, and community partners will continuously raise awareness about the plan and encourage organizations and individuals to implement suggested activities so goals and objectives can be accomplished.

This plan is a living and evolving document that will be adjusted and modified by the HDWD:BTG staff with guidance from the Advisory Council and other state and community partners. The strategic plan will adapt to best address the changing needs of individuals with disabilities in achieving health and wellness.





## RATIONALE

### Disability is Not an Illness

Having a disability, whether it is the loss of a limb, a hearing impairment, or a cognitive disability, does not prevent an individual from feeling healthy, being physically fit, and maintaining good health. Having a disability does not mean having an illness. People with disabilities can achieve a healthy lifestyle. The HDWD: BtG project is examining the gap between what is defined as good health and what people with disabilities are experiencing in Delaware. The focus of this project is on health, wellness, the prevention of secondary conditions, and on factors that hinder achieving good health.

### People with Disabilities Face Additional Barriers to Health Care

Many people find quality health care costly, difficult to coordinate, and confusing. Individuals who have a disability or a special health care need face additional barriers (Institute of Medicine, 2007). They may have difficulty entering a building, using a scale or x-ray machine, or obtaining information about managing a health condition that comes in a visual or auditory form they can use. Barriers can take many forms. The six categories of barriers addressed in this strategic plan are: 1) physical, 2) financial, 3) transportation, 4) communication, 5) cultural, and 6) access to qualified providers. These barriers can affect anyone, but each can multiply or amplify the challenges of staying healthy when one has a disability. For example, for some individuals, loss of mobility not only increases the cost of equipment and services, but also reduces their earning potential. Barriers do not need to be disability-specific to disproportionately burden individuals with disabilities.

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#### *Physical barriers*

According to the Institute of Medicine (2007), surprising numbers of individuals with disabilities encounter barriers to care related to facilities and equipment. In its extensive review of studies, the Institute of Medicine reported the following statistics:

- One in five people had problems with the main entrance to his/her physician's office, and one in three had problems entering an exam room.
- People who use wheelchairs reported a broader scope of barriers: 45% had problems using mammography and other imaging equipment, 69% had difficulty with exam tables, and 60% had issues with inaccessible weight scales.
- More than 90% of people with visual impairments reported that they did not receive medical information in alternative formats.
- Nearly 100% of office managers thought their clinics were accessible. However, fewer than 18% had accessible exam tables, even though 40% said they had accessible tables.
- One in five physicians said he/she could not serve people with disabilities because he/she lacked accessible equipment.

### **Health insurance and financial barriers**

Lack of health insurance coverage, insufficient coverage, high premiums and/or co-payments, or coverage restrictions, such as once-in-a-lifetime provisions of wheelchairs or **prosthetics**, can prevent individuals from receiving the health care or equipment they need to live healthy lives.

According to the Delaware Health Care Commission's 2008 Annual Report, 105,000 Delawareans, or 12.5% of the Delaware population, are uninsured (Delaware Health Care Commission, 2008). About 26% of the uninsured, or 27,430 people, are actually eligible for but not enrolled in public coverage through either Medicaid or the Delaware Children's Health Insurance Program (S-CHIP). Another 20%, or 20,720 people, are eligible for the Community Health Care Access Program (CHAP), which helps provide access to eligible uninsured individuals in Delaware.

In 2005, more than 40 million adults nationally reported not receiving needed health services because they could not afford it. Nearly fifteen million could not get eyeglasses, 25 million did not receive dental care, more than 18 million did not receive prescription medication, and 15 million did not receive medical care (Centers for Disease Control and Prevention, 2007).

In a 2008 survey of the Delaware chapter of the AARP, formerly the American Association of Retired Persons, 27% of the members between 50 to 64 years of age claimed to have avoided going to the doctor altogether because they could not afford it (AARP, Delaware Chapter, 2008).

While the cost of care impacts access for the general population, having a disability may not only increase the cost of care required but also make it more difficult to find and sustain employment. Indeed, Americans who are poor are more likely to report limitations in activity due to a **chronic condition**. Twenty-three percent of individuals

living below federal poverty levels reported a limitation, compared to 9.2% of those above federal guidelines. People making less than \$15,000 were 2.7 times more likely to have physical limitations than people making more than \$50,000 per year (37.4% and 12.9%, respectively) (Office of Minority Health and Health Disparities, n.d.). In a 2006 retrospective analysis of the Behavioral Risk Factor Surveillance System's (BRFSS) Delaware survey, 16% of the respondents with disabilities reported not seeing a doctor because of the cost, compared to only 7.5% of those without a disability (Center for Applied Demography and Survey Research, 2006).

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### ***Transportation barriers***

The Delaware Governor's Commission on Community-Based Alternatives for Individuals with Disabilities (2007) identified reliable and flexible transportation as a key factor in achieving independence. Accessible transportation is essential for remaining active and healthy in the community, taking advantage of fitness opportunities, keeping doctor's appointments, and accessing healthy food.

Accessible public transportation for Delawareans with disabilities is limited in terms of both geographic coverage and schedules. The Governor's Commission on Community-Based Alternatives, therefore, recommended that the means of transportation available to individuals with disabilities be expanded to include additional forms of public transportation such as accessible taxis. More options for private transportation such as accessible driver education programs, vehicle ownership programs, and private car services that make accessible vehicles available, were also recommended.

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### ***Communication barriers***

Accessibility extends beyond physical and economic access to health care. Getting up the ramp, through the door, and onto the scale is not enough because good health requires that everyone actively participates in his/her own care. Good self-care requires knowing what to do, when to do it, and how to do it. An individual's daily experience is filled with hundreds of health-related messages. However, a sensory loss, such as low vision or impaired hearing, can prevent an individual from receiving those messages. Also, some messages can be too complicated or confusing for individuals to understand. Whether written or oral, communication with persons with disabilities must be clearly understandable. For example, after-care instructions following a surgery, instructions for monitoring target heart rate while exercising, or guidance about taking prescription medicine are provided in a way that individuals can perceive, understand, and then apply them on their own. Some individuals will require materials in Braille or large print, in an electronic format, written or spoken in simpler language, or with additional detailed instructions.

The HDWD:BtG project conducted a telephone assessment of nine major health promotion agencies in Delaware to assess the accessibility of health education and

promotion materials. These agencies have created and offer a wide range of valuable programs and information at their facilities, through their websites, and through printed and digital media. Integrating the needs of people with physical and intellectual disabilities, however, has been limited. Most agencies reported that facilities in which educational programs are offered are physically accessible and a few have incorporated some features that make their website accessible to persons with sensory impairments. The availability of materials in alternative formats was very limited. Local chapters of national organizations were more likely to provide **accessible materials** than state-specific organizations.

The U.S. Department of Education's National Adult Literacy Survey documented that over twice as many American adults who have a disability function at the lowest level of **functional literacy** (level 1 out of 5) compared to the percentage in the general adult population (Kirsch, Jungblut, Jenkins, & Kolstad, 1993). The same general pattern holds for the Health Activities Literacy Scale (HALS) (Rudd, Kirsch, & Yamamoto, 2004). These findings point to potential issues with understanding of health information materials, discharge instructions, and instructions for taking medication for individuals with disabilities.

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### **Cultural barriers**

As society becomes more diverse, an awareness is growing about the need for culturally competent professionals. Betancourt, Green, and Carrillo (2002) defined **cultural competence in health care** as the ability of the system to provide care to patients that have diverse values, beliefs, and behaviors and to deliver services in such a way that they meet each individual's social, cultural, and linguistic needs. However, despite the increased awareness about the need for cultural competence, racial and ethnic disparities (Gaston-Johansson, Hill-Briggs, Oguntomilade, Bradley, & Mason, 2007) as well as disabilities disparities (Reeves & Kokoruwe, 2005) within the health care field are still common. Health care providers may make assumptions about an individual's cognitive abilities based on his or her ability to communicate without necessarily providing the means needed to communicate effectively, such as medical translators or sign-language interpreters (Iezzoni, O'Day, Killen, & Harker, 2004; Reeves & Kokoruwe, 2005). Other issues may include inefficient office visits for patients of ethnically and culturally diverse backgrounds and with disabilities and substandard service delivery. Patients with mental health and substance abuse issues may also face the additional barrier of stigma.

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### **Insufficient provider training**

Often curricula used in medical schools do not address working with patients with disabilities, and students do not receive training about how to provide **accommodations**. The gaps in health care provider training have been clearly identified. Special Olympics (2005) captured the essence of the problem in its health

care provider survey. Seventy-four percent of medical students and 75% of dental students stated interest in treating people with intellectual disabilities during their career. However, 81% of students reported that they were not getting any clinical training regarding individuals with intellectual disabilities and 66% were not receiving enough classroom instruction.

## **Good Health is Critical for the Prevention of Secondary Health Conditions**

Maintaining good health requires preventing avoidable illness and injury. When illness and injury do occur, they should be managed effectively to minimize the harm they cause. Good health depends at least as much on effective self care as good medical care (U.S. Department of Health and Human Services, 2000). All individuals need to be active partners in their health and wellness care. This life-long responsibility is often more important and more challenging for individuals with disabilities. Disabilities are not illnesses, but they do increase the need for avoiding preventable illness and injury. For example, some disabilities increase the risk of developing other health problems, such as hypertension and diabetes. Kinne, Patrick, and Doyle (2004) found that 87% of people with disabilities reported at least one health condition, while only 49% of people without disabilities reported a health condition.

This same pattern is found in Delaware. A review of Delaware BRFSS data from 2001, 2003, 2004, and 2005 (Center for Applied Demography and Survey Research, 2006) and a health survey conducted with adults with disabilities in Delaware (Riddle, 2007) indicated that individuals with disabilities are more likely to have high cholesterol, high blood pressure, diabetes and arthritis than are individuals in the general population in Delaware.

Individuals with disabilities are at higher risk of experiencing health problems than are persons without disabilities when they fail to guard their health. For instance, although overeating, smoking, and drinking are widespread in the general population, these unhealthy habits may be more risky for individuals with disabilities. A disability can make it more difficult to engage in typical health-enhancing activities, such as daily physical activities. The 2005 BRFSS survey found that only 37.7% of people with disabilities in the United States met the guidelines for physical activity, compared to 49.9% of people without disabilities. While 25.6% of people with disabilities reported being physically inactive, only 12.8% of people without disabilities reported inactivity (Centers for Disease Control and Prevention, 2007).

The 2007 Delaware BRFSS survey showed the same pattern. A majority of individuals with disabilities were overweight or obese, and almost half engaged in little or no exercise (State of Delaware, 2007). Like compound interest, unhealthy habits have escalating effects because the damage that they cause self-multiplies. Individuals with disabilities would be able to better protect their health if they had more access to fitness and wellness programs within their communities. For example, having accessible fitness facilities with inclusive wellness programs available in their living

environments would provide more opportunities for individuals with disabilities to participate in active lifestyles.

## **Challenges in Delaware**

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### ***Limited awareness of disability and health issues***

Mirroring the national environment, Delaware has only recently begun to focus on the challenges in promoting health and wellness among individuals with disabilities. Major health care and health promotion agencies have developed strategic plans for improving overall health care in Delaware but have not yet attended systematically to disability-related health issues. The HDWD:BTG project highlights the need to develop and sustain efforts to address disability and health on a systems level, however, the goals and objectives cannot be achieved without the support of state agencies, major health care and health promotion agencies, disability advocacy and service agencies, and others.

### ***Lack of coordination among health initiatives***

Little coordination exists among the diverse health initiatives that impact the health of individuals with disabilities, perhaps because disability issues intersect with many facets of life and health care. Insurance regulations may restrict access to the assistive devices necessary for good health. Lack of public transportation in rural areas may make it difficult to get to doctors' appointments. Public policy and legal reform could dramatically re-shape the landscape of health and disability, but Delaware lacks any central body to coordinate the various agencies that are currently developing policy and delivering services to Delawareans with disabilities.

### ***Lack of data about Delaware's population of individuals with disabilities***

Little is known about number, diversity, geographic distribution, and needs of Delawareans with disabilities, and the state currently lacks a means to paint an accurate portrait of people with disabilities in the state.

The Behavioral Risk Factor Surveillance System (BRFSS), one of few population-based health surveys in Delaware, includes two questions about disability. The first question asks if the person is "limited in any way in any activities because of physical, mental or emotional problems," and the second question asks whether he/she uses special equipment. In 2007, BRFSS researchers reported that 20.8% of the Delaware population reported limitations in activity and 7.5% reported they require the use of special equipment.

The BRFSS does not collect disability type or needs-specific data and does not

include individuals from all disabilities or age groups. While it provides a way to compare adults who do and do not have a disability, it does not allow for examining differences by type of disability or the impact of disability severity or duration.

The Centers for Disease Control and Prevention (CDC) are exploring ways to capture more information in the BRFSS about the nature and type of respondents' disabilities, as well as their severity and duration. Ensuring that Delaware also moves toward more frequently gathering this informative data is critical for better understanding the intersection between health and disability.

Existing data about the health and wellness of Delawareans with disabilities and **special health care needs** is sparse and fragmented. The definitions and types of data collected are not always consistent across agencies, which impedes effective collaboration and construction of a system-wide accounting of disability-related health resources and needs. Delaware needs, but lacks, a comprehensive, state-wide database system for tracking health conditions, individual needs, and services provided.

### *Shortage of providers*

Delaware has a shortage of health professionals. The federal Health Resources and Services Administration (HRSA) has designated Kent and Sussex counties, as well as parts of the City of Wilmington, as "health professional shortage areas." Particular shortages exist for primary care physicians, mental health professionals, and dentists. To meet the needs of Delaware's expanding and aging population, thousands of health professionals need to be recruited over the next 5 to 10 years (Delaware Health Care Association, 2004). While this shortage affects all Delawareans, individuals with disabilities face additional challenges in finding health care providers. Many providers are not educated about how to serve individuals with disabilities. Providers may be apprehensive about accepting patients with complex medical needs and disabilities into their practices. Established providers may not be familiar with the treatment and care of people with childhood onset medical conditions that until recently did not survive into adulthood. Providers may not know what resources are available and how to accommodate patients with disabilities. Successful **transition** from the pediatric to the adult health care system may, therefore, become difficult for young adults with disabilities.

In 2004, 29% of American adults who received some form of support or care reported that they paid someone for assistance (Institute of Medicine, 2007). In a survey conducted in Delaware in 2007, about 30% of survey respondents reported that they had a paid **caregiver** for personal assistance (Riddle, 2007). The shortage of qualified direct support professionals (DSPs) is an ongoing challenge. Larson, Hewitt, and Knoblauch (2005) indicate a significant increase in the need for DSPs in the United States. They expect that between the years 2002 and 2012 the number of personal and

home care aides will increase by 40%, and the number of home health aides is also expected to increase by 48%. Often, these paid caregivers work long hours for little pay. In addition, they receive little education about providing high quality support to individuals with disabilities living independently in the community.

Yet, turnover and the accompanying lack of staff continuity and training has a negative impact on the manner in which staff handle difficult situations and makes it difficult for people receiving support to develop relationships that foster independence and growth (Hewitt & Lakin, 2001).

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### **Caregiver challenges**

In 2004, an estimated 44.4 million caregivers age 18 and older in the United States, or 21% of the adult population, provided unpaid care to an adult family member or friend (National Alliance on Caregiving and AARP, 2004).

In Delaware, 130,000 adults are estimated to provide unpaid support and care to a relative or friend. These caregivers are likely to be female, married, and employed, and have an average age of 44 years (AARP, 2004). Caregivers assist with grocery shopping, transportation, medical care, and household chores.

The challenges that caregivers face include emotional strain, financial difficulties, and conflict with employment. In a survey of 66 caregivers of individuals with disabilities, many reported similar challenges in providing care (Riddle, 2007). Almost 40% reported that caregiving did not leave enough time for themselves, approximately 23% reported a financial burden, and 12% reported emotional stress.

A survey of parents of children with disabilities or special health care needs in Delaware found that most parents provided a large amount of care for their child(ren). On average, parents or caregivers provided 96.6 hours of care per week. Approximately 35% of caregivers provided around-the-clock care, followed by 25% who provided 70 to 148 hours of care per week (Riddle, 2008). The majority of parents caring for children with disabilities, therefore, need supports and services, such as **respite care** and flexibility in their workplace, to stay healthy and care for their child.





## MAKING A DIFFERENCE

All people, including individuals with disabilities, require a comprehensive system of health care and health promotion. This means a system that is accessible, inclusive, culturally competent, and consistent with the laws and policies intended to help all people participate fully in their communities. This notion implies access to health promotion, health care, and health and wellness services provided by well trained and knowledgeable professionals. Such a system can meet the needs of individuals with disabilities and special health care needs, in part by helping them to become well informed, active citizens who take charge of their health and wellness, strive to prevent or minimize secondary health conditions, and enjoy healthy lives. This plan is a first step in achieving this overarching goal.

The following pages outline a broad range of goals, objectives, and activities that address how to improve the health and well-being of Delawareans who have a disability or special health care need. They show the great variety of opportunities for making a difference to improve the health of people with disabilities. They point to opportunities for bottom-up as well as top-down efforts; to initiatives by diverse organizations and community networks, public and private, non-profit and for-profit, professional and non-professional, state-wide and site-specific; and to steps that individuals can take, most especially individuals with disabilities and their families, caregivers, friends, coworkers, allies, and advocates. While the plan outlines constructive steps that health care providers and other organizations can take, it also shows how individuals with disabilities can and must be active partners in promoting their own health and wellness. Much progress can be made if many contributors move in the same direction.

Change requires motivation, but effective change requires more: good information about needs, prudent investment of scarce resources, and monitoring returns from those investments. This plan begins with identifying information needed to move forward. We must explore how many Delawareans have a disability, what types of disabilities they have and how severe they are, and what the most urgent unmet disability-related needs are. We need to investigate what resources Delaware already has that might be

better utilized or coordinated to lower the hurdles to good health and well-being. And finally, we need to explore what effective health-related tools have been developed that can be adapted for use in Delaware.

This strategic plan is based on four goals that each have objectives and specific activities that outline how the goals can be accomplished. The first goal addresses state-level capacity for improving health, health promotion, and wellness for individuals with disabilities. The second goal addresses individual organization and network capacities for improving **accessibility** of health care and wellness facilities and inclusion of individuals with disabilities in existing programs and activities. The third goal addresses providers' capacities to support individuals with disabilities to protect their health and minimize or prevent secondary health conditions, and the final goal focuses on the capacity of paid and unpaid caregivers to protect their own health and prevent secondary health conditions in the people they support.

A glossary in the back of this document provides definitions for all terms bolded in the narrative and goals sections of this strategic plan.



## GOALS AND OBJECTIVES

### Goal 1:

**Enhance the capacity of state-level institutions and collaborations to improve the health and wellness of individuals with disabilities and/or special health care needs.**

#### Objectives:

- 1. Establish an office on disability and health as a centralized, state-wide resource for information, consultation, referral, training, and technical assistance.**
  - Fully implement and maintain the Healthy Delawareans with Disabilities: Bridging the Gap website ([www.gohdwd.org](http://www.gohdwd.org)) as a first step in establishing a centralized, state-wide resource that provides information about disabilities and health and technical assistance to the community.
  - Develop a network of partnerships among the health care, health and wellness, and disability communities with expertise in various areas pertaining to disability and health (e.g., health care, insurance, prevention of secondary health conditions, nutrition, physical activity, emergency preparedness, and policy) that can serve as a resource for individuals with disabilities, their families, health care professionals, health and wellness professionals, disability advocates, and human service workers.
  - Increase collaboration between state agencies, universities, colleges, and other community organizations to leverage more funding for health and wellness initiatives through federal, state, grant and foundation resources.
  - Develop a plan for an office on disability and health that outlines goals, scope of work, and structure of that office within Delaware's public and private sectors.
  - Propose the plan for the office to leaders and administrators of pertinent state agencies (e.g., Delaware Health and Social Services, the Division of

Public Health, Division of Developmental Disabilities Services, Division for Services for the Aging and People with Physical Disabilities, and Division of Substance Abuse and Mental Health) to gain buy-in and support from these agencies.

- Identify and pursue funding opportunities to help establish and maintain the office.
- Include a representative from that office on relevant disability and health councils and committees so that initiatives, activities, and programs can be coordinated and accomplished in collaboration with the office.

## **2. Promote understanding throughout the state that health status and disability are two independent concepts and work to reduce stigma associated with disabilities, mental health conditions, and recovery from substance abuse.**

- Assess current perceptions among health care providers, health and wellness professionals, and the public in Delaware about how disability relates to health status.
- Promote positive images of healthy Delawareans with disabilities using media outlets, such as local newspapers, radio, and TV stations.
- Disseminate accurate information on disabilities, mental health conditions, and substance abuse and positive images of Delawareans with those conditions using media outlets.
- Produce and disseminate articles and photographs that portray Delawareans with disabilities as healthy and active citizens who participate in health and wellness activities.
- Develop messages that debunk myths and help eliminate the stigma associated with disabilities, mental health conditions, and substance abuse.

## **3. Prepare and hold a Disability and Health Summit to address Delaware's needs in helping individuals with disabilities live healthy lives.**

- Identify nationally and regionally known speakers who can address topics of interest and provide useful information for improving health care and the health and wellness of Delawareans with disabilities and special health care needs.
- Identify collaborators and funding sources.
- Plan, carry out, and evaluate summit.
- Distribute the proceedings to key policy makers and constituencies in Delaware.

## **4. Support initiatives in Delaware's social, recreational, employment, housing, and transportation systems that would allow fuller participation of individuals with disabilities and/or special health care needs and improve their health, wellness, and quality of life.**

- Support social and recreational programs and initiatives in the community that provide access to and fully integrate persons with disabilities.

- Support initiatives that focus on improving the Delaware transportation system so that **individuals with disabilities** and the elderly can more easily access health care, work, community resources, and leisure activities.
- Support employment initiatives that allow individuals with disabilities to obtain appropriate education, participate in the workforce, choose their occupation, earn their own living, and feel productive and fulfilled.
- Support initiatives that increase the quantity and quality of accessible and affordable housing for persons with disabilities.
- Support initiatives in public schools that promote accessible and inclusive physical activities, healthy nutrition programs, and school environments.

**5. Build more and stronger partnerships among state agencies, universities, colleges, and other community organizations that address the health care and wellness needs of individuals with disabilities and/or special health care needs.**

- Increase and strengthen partnerships among state agencies, universities, colleges, and other health care and wellness organizations in the community that do or could address disability and health issues.
- Assess the programs, activities, and resources of individual organizations for addressing the health care and wellness needs of individuals with disabilities and special health care needs.
- Work collaboratively to avoid duplication of services, combine resources, and coordinate needed services and treatments.

**6. Monitor, support, and advocate for legislation that enhances the health and well-being of individuals with disabilities.**

- Support the efforts of the Governor’s Commission on Community-Based Alternatives for Individuals with Disabilities, Developmental Disabilities Council, State Council for Persons with Disabilities, Governor’s Advisory Council for Exceptional Citizens, Interagency Coordinating Council, and other health- and disability-related commissions, councils, and task forces in monitoring policies and legislation about health and disabilities issues, and routinely share proposed legislation and needed actions with interested parties.
- Support legislation that would establish standards for accessible **durable medical equipment**.
- Support federal and state legislation that would increase the accessibility of health care and wellness services.

**7. Increase the state’s surveillance and data collection, analysis, and dissemination abilities.**

- Strengthen epidemiological efforts at the state level to provide consistent and continuous surveillance of the health status of individuals with disabilities.
- Expand the Delaware Behavioral Risk Factor Surveillance System (BRFSS) Advisory Committee to include at least one individual with a disability.
- Increase the number of disability questions included in the Delaware BRFSS and administer questions every two years to increase epidemiological knowledge of Delaware persons with disabilities.

- Promote the use of disability status as a demographic variable within the BRFSS.
- Review existing data collection and data sharing capacities of state and community organizations that serve individuals with disabilities and special health care needs (e.g., Division of Public Health, Division of Developmental Disabilities Services, Division of Services for Aging and Adults with Physical Disabilities, Division of Substance Abuse and Mental Health, Division of Medicaid and Medical Assistance, Quality Insights, and Delaware Breast Cancer Coalition).
- Identify gaps in current data collection on health, wellness, and secondary health conditions in individuals with disabilities.
- Recommend and implement improvements to the existing data collection and sharing systems of state and community organizations.
- Identify, analyze, and report about existing national data sets that may capture relevant data for health and disability (e.g., Healthcare Effectiveness Data and Information Set (HEDIS)).

## **8. Support the development and implementation of evidence-based services and interventions.**

- Develop a network in Delaware for best practices research findings that will allow professionals from different health and disabilities agencies and organizations at the state and community levels to share and contribute to best practices knowledge and practice.
- Review and add to the existing portfolio of Delaware needs assessments and other studies conducted on health care and the health and wellness of individuals with disabilities to fill current gaps in knowledge.
- Conduct epidemiological, outcomes, and services research studies pertaining to health and disability issues (e.g., prevalence and incidence of particular secondary health conditions in individuals with various types of disabilities, effectiveness of health-related prevention and intervention programs, cost-benefits analyses of services, availability and accessibility of services).
- Based on findings about best practices and Delawareans' needs, design and implement a plan for delivering more effective health and wellness services and interventions to Delawareans with disabilities.

## **9. Increase the capacity of state agencies that address health and disabilities issues to conduct program evaluation and quality assurance activities.**

- Conduct a review of agency capacities and needs in program evaluation and quality assurance.
- Develop recommendations to enhance their program evaluation and quality assurance capacities.
- Assist state agencies and other organizations, as necessary, to implement recommendations.

## Goal 2:

**Enhance the capacity of health care systems and health and wellness programs within Delaware to provide comprehensive, accessible, and inclusive services for all individuals with disabilities and/or special health care needs.**

### Objectives:

#### 1. Reduce the organizational barriers to accessible and comprehensive care in health and wellness settings.

- Develop and provide education for professionals (e.g., physicians, nurses, fitness coaches, massage therapists) in health care, allied health, exercise, and health and wellness settings that addresses best practices in accessibility, Americans with Disabilities Act (ADA) standards, Universal Design, and **People First Language**.
- Provide standardized accessibility assessments in the health care and wellness facilities of interested providers.
- Promote knowledge and use of **assistive technology** and alternative format materials in health care and wellness facilities and settings by providing them with educational materials.
- Provide technical assistance on accessibility to interested health care and health and wellness facilities.
- Promote the purchase and use of accessible medical and exercise equipment by providing information to health care and exercise facilities about the importance and feasibility of accessible medical, health care, and wellness and exercise facilities for persons with disabilities.
- Provide technical assistance on the purchase and use of accessible medical and exercise equipment to all interested health care and exercise providers.
- Increase accessibility of health care and health and wellness facilities by promoting collaboration between facilities successful in becoming more accessible and those that are interested in accessibility.
- Ensure ADA compliance and promote Universal Design of health care and health and wellness facilities.
- Reduce Delaware's shortage of primary care physicians, mental health professionals, and dentists in Kent and Sussex counties and parts of the City of Wilmington by offering incentives for early career health care professionals to practice in underserved areas.

#### 2. Promote a climate that increases financial accessibility to health care.

- Work with major health care plans in Delaware (e.g., Blue Cross Blue Shield of Delaware, UnitedHealthcare, CIGNA, Coventry, Aetna, Independence Blue Cross/Amerihealth, Delaware Physicians Care) to provide incentives for health care providers to serve individuals with disabilities.
- Identify funding opportunities that can assist providers to upgrade their

- equipment and facilities with more accessible features.
- Disseminate information to health care and health and wellness facilities about tax credits for office improvements to increase accessibility.
  - Advocate for better health care provider reimbursement rates for rendered health care services that incentivize serving individuals with disabilities.
  - Address limitations, caps, and other barriers in Medicaid and Medicare coverage, S-CHIP, and private health insurance companies that prevent individuals with disabilities from receiving quality health care.
  - Promote better insurance coverage for evidence-based pharmacological interventions.
  - Promote the use of sliding scales and adjustable fees for health and wellness activities (e.g., nutrition counseling services, weight reduction programs, fitness activities, massage therapy, acupuncture) for low-income Delawareans with disabilities.

### **3. Reduce barriers that prevent full access to healthy living in the community.**

- Initiate and support partnerships that address accessibility issues in the community ranging from physically inaccessible buildings to inaccessible health promotion materials, recreation programs, and activities.
- Advocate for accessible community spaces such as neighborhoods, playgrounds, parks, shopping centers, and other leisure activities areas that are inclusive of individuals with disabilities and special health care needs.
- Collaborate with the Delaware Department of Transportation to address transportation barriers for individuals with disabilities and special health care needs and the elderly by improving paratransit and fixed routes services.
- Develop and provide accessibility workshops that address ADA standards and People First Language for state-wide transportation system personnel, including paratransit and fixed route personnel.
- Develop and provide accessibility workshops that address ADA standards and Universal Design for planners, builders, contractors, local government officials, and other interested parties in Delaware.

### **4. Increase the knowledge, skills, and capacity of the incoming health care and health and wellness workforce for working with, caring for, and supporting/assisting individuals with disabilities.**

- Provide sensitivity and awareness training for medical, dental, allied health, and exercise sciences/health promotion students, both in their professional curricula and through hands-on learning experiences, that addresses topics such as People First Language, cultural competence, and family-centered care.
- Expand existing curricula for college and continuing education students in the fields of health, exercise, wellness, nutrition, disability, social work, and human services at Delaware universities, colleges, and technical



schools so that health is included in their disability curricula and disability in their health curricula.

- Establish and require internships, clerkships, and rotations for medical and allied health students that provide first-hand experience working with individuals with disabilities and special health care needs and their families.

## **5. Increase the organizational capacity and skills of the established health care and health and wellness workforce.**

- Provide sensitivity and awareness training for established health care professionals, office staff, and health and wellness professionals that addresses topics such as People First Language, cultural competence, and family-centered care and which is accredited through CME, CEU, or other accreditation bodies.
- Provide education to health care providers such as pediatricians, family physicians, nurses, and office staff about the importance of standardized developmental screening during baby and child wellness visits in order to identify potential developmental delays and the need for referral to early intervention services for children identified with delays.
- Assess the need for leadership training and development in state agencies and community organizations that serve individuals with disabilities and special health care needs.
- Provide leadership training to personnel in state and community agencies and to emerging leaders in the fields of health and disabilities in Delaware.
- Encourage health care providers to use health care visits as an opportunity to promote wellness and to identify, address, and prevent secondary health conditions in individuals with disabilities.
- Train and support Emergency Medical Services (EMS) professionals and staff to respond to the needs of persons with disabilities in emergency, crisis, and disaster situations.

## **6. Support existing health and disabilities initiatives to implement their goals, objectives, and activities.**

- Support implementation of significant state and organizational plans pertaining to health, wellness, inclusion, and quality of life of individuals with disabilities and special health care needs (e.g., strategic plans of the Governor's Commission on Community-Based Alternatives for Individuals with Disabilities, Office on Children with Special Health Care Needs, Nemours Health & Prevention Services).
- Support the work of organizations addressing health and disabilities issues (e.g., Alfred I. duPont Hospital for Children Transition of Care, Practice Without Pressure, Inc.).

## Goal 3:

**Enhance the capacity of providers to help individuals with disabilities and/or special health care needs protect their health and minimize secondary health conditions.**

### Objectives:

#### 1. Promote the use of best practices in health care and health and wellness settings.

- Identify, develop, and disseminate best practices guidelines for health care and health and wellness facilities and settings.
- Urge adoption of the **medical home** concept in all medical settings that work with children, adolescents, and adults with disabilities, such as hospitals, physicians' offices, and nursing facilities.
- Disseminate information about best practices to organizations that work with individuals with disabilities.

#### 2. Promote healthy lifestyle choices to individuals with disabilities.

- Identify and develop health promotion programs for individuals with disabilities (e.g., workshops, presentations, events) about healthy living, healthy behaviors, and quality of life that are accessible and inclusive.
- Provide health promotion programs and activities to specific target audiences (e.g., individuals with multiple sclerosis, individuals with hearing loss).
- Educate individuals with disabilities, their family members, and direct support professionals about the importance of preventive health care (e.g., health screenings, regular medical and dental check-ups) using accessible educational materials, health awareness activities, free screenings at health fairs, and other means.
- Disseminate accessible information about prevention activities of various state and community health care and wellness organizations using online resources (websites, e-newsletters) and informational materials (flyers, hand-outs, brochures).
- Disseminate information about health and wellness support groups that address chronic health conditions, mental health and substance abuse conditions, disabilities, risky health habits and behaviors, and positive lifestyle changes.

#### 3. Promote early and adequate preparation for transition of care for children, adolescents, and adults with disabilities and/or special health care needs.

- Support existing transition efforts that address transition of care coordination within all settings and stages of life.
- Support existing online and community resources for early interventionists, educators, health care professionals, individuals with

disabilities, and families about transition planning, preparation, and the transition process.

- Educate early interventionists, educators, school nurses, health care professionals, and their office staff on the importance of early and quality transition preparation in which children, adolescents, and adults with disabilities take an active role and acquire the skills needed to successfully transition.

**4. Promote the understanding that mental health and substance abuse are conditions that require the same quality of care as other health conditions.**

- Raise awareness among health care providers, legislators, and the public about barriers that prevent all people from receiving adequate, affordable, and quality mental health and substance abuse care services.
- Work with legislators and insurers to improve coverage of mental health and substance abuse prevention, intervention, and treatment for adults with disabilities.

**5. Promote the understanding that dental conditions require the same quality of care as other health conditions.**

- Raise awareness among health care providers, legislators, and the public about barriers that prevent individuals with disabilities from receiving adequate, affordable, and quality dental care.
- Work with individuals with disabilities, family members, support staff, and service providers on establishing good oral hygiene routines to reduce or prevent dental health conditions.
- Work with legislators and insurers to improve public and private coverage of dental care for individuals with disabilities.

**6. Collaborate with existing organizations (e.g., schools, faith-based organizations, employers) to promote healthy lifestyles and provide information and services in an inclusive manner so that children, adolescents, and adults with disabilities can participate to their fullest abilities.**

- Assess the content and inclusiveness of current health promotion activities in order to identify unmet needs of children, adolescents, and adults with disabilities who receive health care, health and wellness information and services in those settings.
- Identify opportunities in the community to make health and wellness presentations and disseminate information about healthy living.
- Implement healthy lifestyle activities in collaboration with various community organizations that reach individuals with disabilities in their school, work, and home settings.

**7. Reduce barriers to effective communication between health care providers and individuals with disabilities and their support persons and improve health literacy.**

- Educate health care professionals and their office staff about how to help individuals with disabilities, family members, and support personnel “to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (U.S. Department of Health and Human Services, 2000).
- Promote an individualized approach to communicating health information as challenges in learning and understanding differ across individuals, health conditions, and family circumstances.
- Promote patient engagement in obtaining, processing, and understanding health information as active learning partners in maintaining their health and wellness.
- Educate health care professionals and their office staff about how to verify a patient’s, family’s, and support person’s understanding of the information provided, how to minimize likely difficulties for them applying it, and about the need to follow-up on actual use.
- Develop and disseminate accessible information about how to navigate the health care system and its services.
- Teach and reinforce crucial health knowledge and self-management skills through workshops, training, and seminars held at institutional settings, group homes, day programs, independent living offices, senior centers, and other community living environments of individuals with disabilities.

## Goal 4:

**Enhance the health and well-being of individuals who provide paid and unpaid support for individuals with disabilities and/or special health care needs.**

### Objectives:

#### 1. Promote healthy lifestyles for paid and unpaid caregivers.

- Include caregivers and direct support professionals in the development and implementation of health and wellness programs and activities that are provided to individuals with disabilities.
- Provide caregivers and direct support professionals with health and wellness information (e.g., educational materials) that is specific to the needs of support persons and caregivers (e.g., managing stress, coping strategies, specific disabilities, health conditions).
- Review existing training curricula for direct support professionals and add self-care modules as needed to address health and wellness issues.

#### 2. Generate support mechanisms for caregivers of individuals with disabilities.

##### *Respite Care*

- Encourage the development and implementation of the Delaware Lifespan Respite Information Network to increase the availability and access of respite care.
- Develop a cooperative system in which caregivers provide respite care for each other.
- Provide information to caregivers about existing respite care services.
- Investigate incorporating respite care information and supports into existing networks that individuals contact in seeking help (e.g., Delaware Helpline, CONTACT Delaware).
- Educate employers about the economic and social benefits of supporting respite care for employees who care for other family members.

##### *Other Supports*

- Educate foundation managers about the importance of caregiver issues so they will consider funding caregiver support projects.
- Create a pool of seed money for individuals who want to start support groups for caregivers.
- Assess availability of trainings, workshops, and seminars for caregivers and, if inadequate, develop workshops, seminars, and other forms of training, as needed, on both general and specific topics in support and caregiving (e.g., caring for someone with Alzheimer's disease).
- Support adequate training and professionalism of direct support professionals.
- Support existing workforce initiatives to better educate and train direct

- support professionals in Delaware and nationally.
- Include knowledge of healthy lifestyle choices and respite care in the licensing/certification requirements for direct support professionals.



## GLOSSARY<sup>2</sup>

### Accessibility

The degree to which an environment (physical, social, or attitudinal) makes appropriate accommodations to eliminate barriers or other impediments to equality of access to facilities, services, and the like for persons with disabilities ([www.surgeongeneral.gov/](http://www.surgeongeneral.gov/)).

### Accommodations

Any modifications or adjustments to an environment that will enable an individual with a disability to access and participate in health care and wellness settings. For example, a sign language interpreter will be provided to an individual who is deaf when he/she is receiving a health exam so he/she and the health care provider can communicate effectively.

### Assistive Technology

Assistive technology (AT) is any item, piece of equipment, or product system, whether acquired commercially, off-the-shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities (20 U.S.C. §1401 [25]) ([www.DATI.org](http://www.DATI.org)).

### Caregiver

A caregiver is a paid or unpaid support person who assists a child or adult with a disability or special health care need in their daily life activities and routines. This includes family members, friends, volunteers, and paid professionals who provide support.

### Chronic Condition

A chronic condition is defined as one that lasts or is expected to last a year or longer, limits what a person can do, and may require ongoing care. Some conditions cause few problems; others cause episodic problems or symptoms that can be controlled with medication. But in some cases, the condition may severely limit a person's ability to work, go to school, or take care of routine needs ([www.partnershipforsolutions.org/problem/chronic\\_conditions.html](http://www.partnershipforsolutions.org/problem/chronic_conditions.html)).

### Comprehensive Care

A health care model that provides for preventive medical care and rehabilitative services in addition to traditional chronic and acute illness services (Mosby's Medical, Nursing, & Allied Health Dictionary, 5th ed., 1998).

### Cultural Competence in Health Care

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<sup>2</sup> Glossary definitions that do not indicate a reference source have been defined by the Healthy Delawareans with Disabilities: Bridging the Gap Advisory Council for the use in this strategic plan.

The ability of the system to provide care to patients that have diverse values, beliefs, and behaviors and to deliver services in such a way that they meet individuals' social, cultural, and linguistic needs (Betancourt, J., Green, A. & Carrillo, E. (2002)).

### **Direct Support Professionals (DSPs)**

DSPs provide a wide range of supportive services to individuals with intellectual and developmental disabilities on a day-to-day basis, including habilitation, health needs, personal care and hygiene, employment, transportation, recreation, housekeeping and other home management-related supports and services so that these individuals can live and work in their communities and lead self-directed, community and social lives (<http://aspe.hhs.gov/daltcp/reports/2006/DSPsupply.htm>). DSPs also support individuals with physical, sensory, and mental health conditions in similar ways.

### **Durable Medical Equipment**

Durable medical equipment is reusable, medically necessary equipment that a doctor prescribes to use in one's home. Durable medical equipment includes, but is not limited to: diabetes supplies, canes, crutches, walkers, commode chairs, home oxygen equipment, hospital beds, power operated vehicles (POVs or scooters), seat lift mechanisms, traction equipment, and wheelchairs.

### **Functional Literacy**

A functional literacy approach is a method used to teach people how to read well enough to function in a complex society. Functional literacy incorporates reading materials that relate directly to community development and to teaching applicable or useful life skills ([www.sil.org/lingualinks/literacy/referencematerials/glossaryofliteracyterms/WhatIsFunctionalLiteracy.htm](http://www.sil.org/lingualinks/literacy/referencematerials/glossaryofliteracyterms/WhatIsFunctionalLiteracy.htm)).

### **Health Care**

The maintaining and restoration of health by the treatment and prevention of disease especially by trained and licensed professionals (as in medicine, dentistry, clinical psychology, and public health) ([www.nlm.nih.gov/medlineplus/mplusdictionary.html](http://www.nlm.nih.gov/medlineplus/mplusdictionary.html)).

### **Health Care Providers**

Health care providers are persons who provide health care as part of their job responsibilities. This includes physicians, dentists, psychiatrists, psychologists, nurses, social workers, physical-, occupational-, and speech-language therapists. In most instances these health care providers operate in settings such as hospitals, clinics, emergency services, and doctors and dentists offices.

### **Health Literacy**

Health literacy is “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (U.S. Department of Health and Human Services, Healthy People 2010) ([www.healthypeople.gov/document/HTML/Volume1/11HealthCom.htm](http://www.healthypeople.gov/document/HTML/Volume1/11HealthCom.htm)). In addition, it may also include the capacity to successfully navigate the health care system.

### **Inclusive**

Inclusive means to create a hospitable and welcoming environment, in which interactions occur with all members of the community regardless of their individual characteristics ([www.umw.edu/bias/terms/default.php](http://www.umw.edu/bias/terms/default.php)).



### **Individual with a Disability**

An individual with a disability or special health care need is any person across the lifespan who has a condition that affects his/her participation in daily life activities and routines. This includes any physical, vision, hearing, intellectual/cognitive, learning, and mental health/psychological conditions.

### **Medical Home**

A medical home is a health care model of delivering primary care to all individuals that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective ([www.medicalhomeinfo.org/index.html](http://www.medicalhomeinfo.org/index.html)).

### **People First Language**

People First Language puts the person before the disability and describes what a person has, not who a person is ([www.kidstogether.org/pep-1st.htm](http://www.kidstogether.org/pep-1st.htm)). For example, a person would be referred to as a person who is blind, not as a blind person.

### **Prosthetics**

Refers to an artificial substitute or replacement of a part of the body such as a tooth, eye, a facial bone, the palate, a hip, a knee or another joint, the leg, an arm, etc. A prosthesis is designed for functional or cosmetic reasons or both ([www.medterms.com/script/main/art.asp?articlekey=15985](http://www.medterms.com/script/main/art.asp?articlekey=15985)).

### **Respite Care**

The temporary relief for caregivers and families who are caring for those with disabilities, chronic or terminal illnesses, or the elderly ([www.archrespite.org](http://www.archrespite.org)).

### **Secondary Health Condition**

A secondary health condition is any condition to which a person is more susceptible by virtue of having a primary disabling condition ([www.cdc.gov/ncbddd/factsheets/DH\\_sec\\_cond.pdf](http://www.cdc.gov/ncbddd/factsheets/DH_sec_cond.pdf)).

### **Special Health Care Needs**

Special health care needs include any chronic physical, sensory, intellectual, behavioral, or mental health conditions that require health and/or other services that go beyond what is required by individuals in general.

### **Transition**

Transition is a deliberate and complex process in which a child, adolescent, or young adult develops the skills and knowledge that are necessary to successfully move on to the next stage in their development, schooling, or life. This process may include transition from the early intervention system to school, from school to higher education or the workforce, and transition from the pediatric health care system to the adult health care system. Children and youth may be aided in this process by family members and/or professionals but may become increasingly independent with age and/or newly acquired skills.



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