



The Current Landscape

for Disability and Health in Delaware

PUBLIC HEALTH
ASSESSMENT REPORT
SUMMARY

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The complete report of the Statewide
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Part 1: Introduction

This statewide public health assessment for individuals with disabilities was developed as part of a Cooperative Agreement between the Centers for Disease Control and Prevention's (CDC) National Center on Birth Defects and Developmental Disabilities (NCBDDD) and the Center for Disabilities Studies (CDS) at the University of Delaware (UD), acting as the agent of the Delaware Department of Health and Social Services (DHSS). This collaboration has been in place for eight years and began from seeds that were sown at the national level.

In 2005, Surgeon General Richard H. Carmona, M.D., M.P.H., FACS released a *Call to Action to Improve the Health and Wellness of Persons with Disabilities*.



This call to action emphasizes the centrality of health to the quality of our lives. Developed by the Surgeon General in collaboration with the Department's Office on Disability, it describes the particular challenges

to health and well-being faced by persons of all ages with disabilities. It places their health squarely among the public health issues at the forefront of research, service delivery, financing, training and education and health care policy today.

- Secy. Of Health and Human Services Michael O. Leavitt in the Foreword

The *Call to Action* promoted accessible, comprehensive health care that enables persons with disabilities to have a full life in the community with integrated services. It was based on a simple principle: good health is necessary for persons with disabilities to secure the freedom to work, learn and engage in their families and communities. The *Call to Action* further delineated four specific goals:

GOAL 1:

People nationwide understand that persons with disabilities can lead long, healthy, productive lives.

GOAL 2:

Health care providers have the knowledge and tools to screen, diagnose and treat the whole person with a disability with dignity.

GOAL 3:

Persons with disabilities can promote their own good health by developing and maintaining healthy lifestyles.

GOAL 4:

Accessible health care and support services promote independence for persons with disabilities.



Community voices: suggested improvements

"I am surprised at how many doctors' offices cannot really accommodate people in wheelchairs. Exam rooms and hallways are very small and most outside entrances are manually opened."

Background: Delaware's Response

In 2005, the DHSS Division of Developmental Disabilities Services (DDDS) received a two-year planning grant from the CDC. In 2007, the CDS, acting as a bona fide agent of the DHSS, was awarded a five-year grant to continue this work focusing on the prevention of secondary conditions that may result from living with a disability. During the five-year funding cycle, Delaware made significant progress in moving toward the target of an inclusive, sensitive, and accessible system for individuals with disabilities.

In 2012, the CDS, continuing to act as a bona fide agent of the DHSS, applied for and was awarded a three-year grant to continue this work focusing on "Improving the Health of People with Disabilities through State-Based Public Health Programs." This shift toward the state health department was designed by CDC to embed disability-related considerations into the day-to-day operations of the public health infrastructure and enhance the likelihood of enduring system change.

Since the beginning of the disability and health work in Delaware in 2005, there has been an active, enthusiastic Advisory Council for the project, locally known as Healthy Delawareans with Disabilities (HDWD). The HDWD Advisory Council has guided the arc of progress for the project—from the initial planning grant awarded in 2005 to development of a plan to achieve health equity for Delawareans with disabilities. The HDWD Advisory Council consists of self-advocates, parents, advocacy groups, and state and community organizations dedicated to health promotion and wellness

for people with disabilities. The group established and articulated the mission, vision and values of the project in 2007, and updated these statements in 2012.



HDWD Mission

Through collaborative partnerships, act as a catalyst for systems change to make health and wellness programs more accessible and inclusive.

HDWD Vision

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.

This public health assessment is the foundation of a strategic planning process that began in 2014. The resulting *Plan to Achieve Health Equity for Delawareans with Disabilities* will guide ongoing work to improve and maintain health for all Delawareans with disabilities.



Community voices: suggested improvements

"Refocus the entire system on wellness and healthy lifestyle rather than treating a chronic condition as if it was acute. Services, such as therapies, PT, OT, speech need to be available for a lifetime, not limited to number of visits, time or cost."

Part 2: Methodology

CDS adapted the public health assessment process developed by CDC's sister agency, the Agency for Toxic Substances and Disease Registry, as a framework to guide the statewide public health assessment for the Delaware population with disabilities. Originally designed for use in communities impacted by environmental exposure to contaminants, the framework is very relevant and transferable. Three main types of information are contained in the assessment: community concerns, health data, and environmental data.

Community concerns were gathered from individuals through a variety of mechanisms: public availability sessions where CDS staff scheduled time in each of Delaware's three counties to meet with residents, key informant interviews, and an online survey.

Health data reviewed included up-to-date information on health and health outcomes, access to health care, and personal health behaviors for individuals with disabilities compared to national or state data. These data form the basis of a population profile.

Environmental data related to toxins was replaced with information about the accessibility of the environment in terms of health care (architectural barriers, medical equipment, barriers to effective communication). An abbreviated accessibility assessment tool was administered to a small sample of providers. In addition, we surveyed health promotion programs in the community and within DHSS for

a better understanding of the extent to which the programs were aware of the needs of people with disabilities, had the capacity to meet those needs, and offered services that were actually utilized by people with disabilities.

For the emergency preparedness portion of this public health assessment, we used existing survey data and the data collected during the initial phase (2010) of an inclusive emergency preparedness project funded by the Administration on Developmental Disabilities (ADD). These data include:

- the 2007 Delaware BRFSS module on emergency preparedness, and
- the data collected in 2010 which included interviews, public forums, and community workshops.

This document is a summary of the findings and provides a portrait of the population with disabilities in terms of demographics, health status, health care access and use, and disparities.



Part 3: Community Concerns

Community concerns were gathered from individuals through various methods: an online survey; public availability sessions where CDS staff scheduled time in each of Delaware's three counties to meet with residents; and key informant interviews. This inquiry addressed four major issues: 1) the availability of health care services; 2) access to health care facilities; 3) the quality of care received from providers; and 4) achieving and maintaining optimal health. For each issue participants were asked to identify: 1) areas in need of improvement and 2) difficulties or challenges faced in seeking services or maintaining health. The outline and focus of all methods was identical.

Community survey

The survey was delivered via an online survey tool. Open-ended questions were used to address the four key issues. Eligible respondents included adults with disabilities and caregivers of children or adults with disabilities. Overall, 43 online survey responses were received and analyzed to discern major areas of concern for people with disabilities.

Community interviews

Interviews were conducted with 18 individuals. Six key informants were referred by staff members at CDS. Twelve individuals were also interviewed at public community meetings in Georgetown, Dover and Wilmington. All 18 interviews were coded and analyzed to discern major areas of concern for people with disabilities.



For this summary, responses from all sources of our inquiry—online survey, interviews and community meetings—have been combined and organized around themes that emerged as community concerns.

Availability of services and providers

The availability of particular health care or health promotion services was mentioned by respondents when they were asked about improvements that could be made to services or barriers they have faced in accessing services. These respondents indicated that there are **not enough providers and specialists in Delaware**.



Community voices: suggested improvements

"I think there needs to be access to more respite care services. There needs to be a better program for helping caregivers...I am near the burn-out stage and don't know where to turn for help."



Other respondents noted that there is a lack of providers—primary care and specialists—who can accommodate the needs of people with disabilities, citing a specific need for **providers with knowledge of disability-related issues** or a specialization in disability-related issues. In searching for providers—not necessarily providers to address specific disability issues—some respondents reported that providers may not be prepared to assist some individuals with particular disabilities, such as hearing impairment, developmental disabilities or autism.

The availability of specialists such as **mental health providers** was noted as being problematic. Comments addressed a need for more therapists or psychiatrists, especially those taking new patients or more complex cases. Respondents also mentioned the need for improved coordination of care between mental health providers and other services such as substance abuse treatment providers or schools.

Many comments also addressed **dental care** for people with disabilities in Delaware. Many of the comments referred to lack of affordable dental care in Delaware, largely due to inadequate insurance coverage, specifically the lack of dental coverage for adults enrolled in Medicaid. Comments also referenced a lack of dentists prepared and willing to work with people with disabilities.

Other **specialty and support services** that were cited as difficult to access included speech language pathologists, audiologists, orthodontists, laboratories and providers specializing in movement disorders and brain injury.



Respite services for family caregivers was also reported as difficult to find and obtain coverage for.

One respondent talked about difficulties with **home health agencies**. This respondent explained that the policies and rules used by home health agencies are a hindrance to adequate treatment. This respondent's doctor specified that a home health aide overnight was warranted in case a particular medication is needed, but the home health agency won't administer that medication citing liability and restrictions on activity of home health aides.

The availability of services in particular **geographic areas** within Delaware was mentioned as a barrier to receiving needed services. Respondents from rural areas, particularly parts of Sussex and Kent, described long journeys, sometimes out of state, to find providers to meet their needs.

Respondents also referenced needed improvements to **available hours and**

scheduling when talking about the availability of services.

Respondents expressed a desire for a **directory of providers** who provide quality care to people with disabilities. For example, four respondents indicated that an online resource listing information regarding services for people with disabilities would be beneficial. Respondents suggested that such a directory include information about provider training related to disability, accessibility of facilities, and the availability of accessible equipment such as scales, exam tables and x-ray imaging.

Respondents also noted that there are not enough available opportunities for **recreation or health promotion activities** for people with disabilities. Respondents noted that the cost of some opportunities was prohibitive, as in the case of community recreation and fitness facilities (i.e., the Boys and Girls Club and the YMCA). One respondent noted that physical access prohibited his son from using a fitness facility because he uses a wheelchair. Another respondent noted that there weren't options for her to participate in recreational activities.

Two respondents mentioned **access issues that were specific to individuals with autism or other behavioral disorders**. For example, one respondent explained how her child didn't have a lot of experience on playgrounds because of how difficult it was for a child with autism to manage new people and the stimulation of a busy playground. Another respondent similarly explained that improvements could be necessary because of sensory issues with some children. This respondent went on to

suggest that parks could accommodate more children.

Physical access to health care services

Respondents identified physical access to providers' offices or equipment within the offices as sometimes difficult.

Issues regarding accessible parking spaces and entrances and pathways in buildings

Respondents noted that it could be difficult for someone in a wheelchair to move around offices due to narrow hallways and small exam rooms. One respondent described a medical office where a ramp had been installed but there was no curb cut to get to the ramp. Another respondent also explained that parking spaces were not always ADA compliant, with no, or inadequate, aisles for people in wheelchairs to exit a vehicle.

The **lack of accessible equipment** within doctor's offices was also cited as a barrier to equitable care. Exam tables and medical equipment are not always accessible, making it difficult for people with physical disabilities to get the proper examination or treatment. Many respondents who used wheelchairs reported not being able to be weighed



Community voices: suggested improvements

"If my aide takes me to a doctor, a lot of times they'll talk to her first instead of asking me. So I usually jump in and say, 'Hey, she doesn't know anything about it, I do.'"

in their doctor's office. A number of respondents reported being unable to get services such as cervical cancer screenings or sleep studies in outpatient settings. Inaccessible equipment, **the absence of lifts or staff trained to use them**, resulted in individuals being referred to hospital settings for procedures routinely performed in non-hospital settings for individuals without disabilities. Caretakers of individuals with intellectual disabilities such as autism also indicated it was difficult for people with autism to be in a **waiting room with multiple distractions and stimuli**.

Transportation in the form of paratransit, or a lack of affordable public transportation, was noted as an obstacle for getting to health care appointments. Difficulties in qualifying for paratransit presented challenges in seeking accessible transportation. The schedules and policies of paratransit were also cited as being problematic and time consuming for individuals to use the service for scheduled medical appointments.

Access in recreational facilities also presented challenges for respondents. One respondent noted that it was difficult for her child to navigate through parks because of few paved areas that would provide wheelchair access to take walks through the woods.

Two respondents identified the equipment within recreational facilities as something that could be improved to facilitate access. One respondent explained that facilities don't have the equipment necessary to accommodate individuals with disabilities, citing a lack of accessible gym equipment and lifts to get into pools.



Communication and sensitivity issues

Communication with providers was repeatedly mentioned by respondents when discussing improvements to services, facilities and the quality of care received from providers.

Follow up in the form of telephone **communication from providers or staff at providers' offices** was mentioned as something that could be improved by respondents. For example, some indicated that it was hard to contact providers or receive a call-back from providers in response to specific questions. Respondents suggested the use of email or text as preferred methods of communication for individuals with communication disorders.

The lack of **accommodations for individuals who are deaf or hearing impaired** to facilitate communication was a common theme. Issues specifically pertaining to deaf or hard of hearing individuals also included answering machine messages being left for the hearing-impaired individuals

by providers and a lack of captioned televisions in providers' offices to facilitate communication. Individuals who are deaf and use sign language reported a lack of willingness or acceptance, on the part of the provider, of their responsibility when sign language interpreters were requested.

Coordination with guardians or other health services was also mentioned by respondents. A family member emphasized the importance of caregivers being informed about treatment plans.

Respondents noted attitudinal barriers and noted that some providers are **not sensitive to the needs of people with disabilities**. Numerous respondents mentioned that health care providers will often not talk directly to them, but rather to the aide or caregiver that brings them to the office. In addition, respondents noted that some providers did not seem patient, willing to listen or willing to learn about treating people with disabilities. Other respondents reported experiences of being turned away from a provider's office with vague indications that the provider was not accepting patients with disabilities.

Prescription policies

Respondents were asked to describe any limitations they have faced in filling prescriptions. One respondent discussed some of the coordination he has had to do to ensure that his daughter has enough of a prescription on hand, which can be complicated by managing multiple medications. This respondent described managing 12 medications with each **eligible for refills** at different times, and an incident where

medication was accidentally spilled and couldn't be refilled because it was "too soon."

Another respondent described a similar struggle with certain drugs that can only be refilled once every 30 days. This respondent shared the challenge of replenishing medications that are to be taken "as needed" but are consumed well before the 30 day refill window but can't be refilled prior to 30 days.

Insurance and financial barriers

Insurance or financial concerns were noted when discussing filling prescriptions, receiving care or obtaining assistive devices.

Four respondents described facing obstacles related to coordinating or accessing services due to insurance restrictions. For example, one respondent described the time spent filling out **insurance paperwork** for different services, citing the inconvenience of having to complete forms multiple times when working within the same system (Medicaid). Respondents felt the systems weren't communicating and sharing digital information in an efficient way.



Community voices: suggested improvements

"Even if a doctor only needs to see my son once every few months, we must still spend the money for a visit since the medicine cannot be prescribed with refills..." Similarly, another respondent explained about monthly limitations on refills: "We have had to pay for prescriptions if they need to be filled early."

Two other respondents cited problems with **insurance approving certain tests or procedures**. One of these respondents explained that her child has Asperger's and requires sedation at the dentist, but has a difficult time getting the insurance company to understand that without sedation delivering the service would be difficult or impossible. Respondents also indicated that the process of obtaining approval from insurance companies was restricting their ability to receive the treatment or the assistive devices that they needed. One respondent noted that insurance restrictions made it difficult to get health care equipment such as a wheelchair.

One respondent indicated that his insurance wouldn't pay for prescriptions purchased out of state, even though they were cheaper. Another respondent indicated that his pharmacy plan required him to purchase 90 days of medication, which was a problem because his son changed medication often. A third respondent described the challenge associated with an asthma prescription for her son. This respondent explained that a medication was working for the client, but the insurance company wanted him to use an inhaler. The insurance company said he was old enough to use an inhaler and denied the oral medication.

Three respondents identified the cost of prescriptions as a limitation. One respondent explained the challenge of navigating the balance between newer drugs that are available, and might be better, but may not be covered or affordable. Similarly, the cost of prescriptions or co-pays was also noted as prohibitive by several respondents.

Two respondents indicated that they would like access to opportunities that were either more affordable or covered by insurance. One respondent wanted easier access to nutritionists. Another respondent wished recreational opportunities for children with autism were more affordable.

Coordination of services

The need for better case management, communication between providers and coordination of services were often mentioned by respondents. Two respondents noted that the sharing of information among providers, patients and caretakers would improve access to services. One respondent suggested that coordination of care would be enhanced by having a central location where all information is kept in electronic format, facilitating sharing among partners.

The transition from pediatric to adult care was also mentioned by respondents as difficult, citing the transition from a children's hospital to an adult provider who may not be familiar with the child's history or condition.



Community voices: suggested improvements

"There should be a bridge of some sort to transition the patient, caregivers, and new doctors. In my case from age 2 to 21 we went to A.I. duPont then all of sudden new doctors that did not know anything about my daughter"

Part 4: Health Data

In reporting the findings from secondary data analyses, we note when findings are statistically significant. Statistical significance refers to whether an event or difference occurs by chance alone. When we report statistical significance throughout this document, we compared Delawareans with disabilities to those without disabilities in Delaware, not to the U.S. general population. Thus, when we reported that one thing is statistically significant at $p < 0.05$, it indicates there is a likelihood that the difference between those with and without disabilities in Delaware happened by chance alone less than five times out of 100. Likewise, with $p < 0.01$, it means that there is a likelihood that the difference between the two groups happened by chance alone less than one time out of 100. The term “ p ” is used to describe the probability of observing the difference by chance alone.

4.1 Behavioral Risk Factor Surveillance System

The Behavioral Risk Factor Surveillance System (BRFSS) is a collaborative project of the Centers for Disease Control and Prevention (CDC) and all U.S. states and territories. The on-going annual national telephone survey collects information about health-related risk behaviors, health conditions including chronic conditions, health care access, and use of preventive services in the non-institutionalized civilian population ages 18 and older. State health departments conduct the telephone survey monthly in accordance with a protocol, as well as technical and

methodological assistance, from the CDC. Selected findings from the 2012 Delaware BRFSS are below.

Disability status

BRFSS for 2012 used two questions to measure disability: a) “Are you limited in any way in any activities because of physical, mental, or emotional problems?” and b) “Do you now have any health problem that requires you to use special equipment, such as a cane, a wheelchair, a special bed, or a special telephone?” (CDC 2012, p. 18). Individuals who responded “yes” to either question were identified as having disabilities and individuals who responded “no” to both questions as not having any disabilities. In 2012, 19.7 percent of residents ages 18 and older in Delaware reported having a disability compared to 22.2 percent of their counterparts in the U.S. general population.

Summary of the findings

Compared to their counterparts without disabilities, a larger percentage of adults aged 18 and older with disabilities in Delaware were older and had lower socioeconomic status. A significantly higher proportion of people with disabilities also reported their general health status as “fair or poor,” having more unhealthy days for both physical and mental health, and having chronic diseases. Although a higher percentage of adults with disabilities reported having health insurance and a usual source of care, those with disabilities reported more difficulty having health care access: delay in seeing a doctor because of

Table 1. Disability Status

Variables	Delaware		U.S. General Population*	
	Disability	No Disability	Disability	No Disability
Disability status	19.7%	80.3%	22.2%	77.8%

* 50 States and District of Columbia

cost and last dental visit within the past year. While Delawareans with disabilities reported more positive behaviors in terms of alcohol consumption and getting a flu shot, a larger proportion of adults with disabilities were current smokers, less physically active, and obese. Differences between Delawareans with and without disabilities were not statistically significant in screening tests, and yet a significantly larger percent of adults with disabilities reported having had a hysterectomy.

Demographics

Compared with their counterparts aged 18 and older without disabilities in Delaware, a larger portion of Delawareans with disabilities was female, older, less educated, and less frequently employed, and had lower annual household income.

Health status and health outcomes

Respondents' physical health was measured with the following question: "Now thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good?" (CDC 2012, p. 7). Mental health was measured with the following question: "Now thinking about your mental health, which includes stress, depression, and problems with emotions, for how many

days during the past 30 days was your mental health not good?" (CDC 2012, p. 8). For physical and mental health, the number of days the respondents said their health was not good was grouped into two categories: (a) less than 14 days and (b) 14–30 days. This cutoff is often used as a clinical indicator of depression and anxiety disorders (CDC 2004, 2011). In regard to chronic health conditions, BRFSS asked the respondents whether a doctor, nurse, or other health professional had ever told them that they had any of the chronic conditions.

Compared to their counterparts with disabilities in Delaware, a significantly higher proportion of adults with disabilities reported having poorer perceived health status, more unhealthy days for both physical and mental health and all chronic health conditions. In addition, a larger portion of Delawareans age 65 and older with disabilities reported having lost all of their natural teeth.



Community voices: suggested improvements

"Improving access to mental health services, coordinating care between psychiatric and counseling providers, also work between the psych, counseling and school services."

Table 2. Demographics

Variables	Delaware Disability	Delaware No Disability	U.S. Disability	U.S. No Disability
Sex				
Male	44.2%	48.6%	46.3%	49.2%
Female	55.9%	51.4%	53.8%	50.8%
Age ^{§§}				
18 to 44	25.6%	49.8%	27.7%	52.5%
45 to 64	42.4%	33.4%	43.1%	32.3%
65 or more	32.0%	16.9%	29.2%	15.2%
Race ^{§§}				
Non-Hispanic White	71.7%	66.3%	70.6%	64.5%
Non-Hispanic African American	20.0%	20.0%	12.4%	11.5%
All others ⁺	8.3%	13.7%	16.9%	24.0%
Marital Status ^{§§}				
Married/Unmarried Couple	52.9%	57.3%	49.3%	56.7%
Divorced/Widowed/Separated	29.0%	15.8%	31.7%	16.3%
Never married	18.1%	26.9%	19.0%	27.1%
Education Level ^{§§}				
College or more	17.2%	27.6%	18.6%	27.9%
Some college or technical school	31.6%	29.3%	31.2%	30.5%
High school or GED	34.4%	30.6%	29.9%	28.5%
Less than high school	16.8%	12.4%	20.4%	13.1%
Annual Household Income ^{§§}				
\$50,000 or more	34.3%	52.9%	29.3%	47.8%
\$35,000 to less than \$50,000	15.2%	14.5%	12.9%	14.5%
\$25,000 to less than \$35,000	7.9%	11.0%	11.3%	11.0%
\$15,000 to less than \$25,000	23.0%	10.0%	23.2%	16.7%
Less than \$15,000	19.6%	11.8%	23.3%	10.1%
Employment Status ^{§§}				
Employed	31.3%	65.5%	30.0%	63.2%
Unemployed	68.7%	34.5%	70.0%	36.8%

^{§§} Statistically significant at $p < 0.01$; ⁺ Hispanic, other races, or multiracial



Community voices: suggested improvements

"I was in a car accident eight years ago and was prescribed 'water therapy' and other physical therapy. There was no access to any of the therapy I needed...I was not able to drive for several weeks, yet the facility provided transportation [that] was not available to me since I used a wheelchair...I never got any PT."

Table 3. Health Status and Health Outcomes

Variables	Delaware Disability	Delaware No Disability	U.S. Disability	U.S. No Disability
General health status ^{§§}				
Excellent, very good, or good	55.1%	90.6%	52.9%	90.5%
Fair or poor	44.9%	9.4%	47.1%	9.5%
Physical health ^{§§}				
Less than 14 days	58.6%	95.3%	61.1%	95.1%
14 days to 30 days	41.4%	4.7%	38.9%	4.9%
Mental health ^{§§}				
Less than 14 days	73.8%	92.0%	72.5%	92.3%
14 days to 30 days	26.2%	8.0%	27.5%	7.7%
Diabetes ^{§§+}	20.4%	7.0%	20.7%	7.1%
Asthma ^{§§+}	23.4%	11.1%	22.2%	10.7%
Heart attack ^{§§+}	11.9%	3.4%	11.3%	2.5%
Coronary heart disease ^{§§+}	13.4%	2.9%	11.8%	2.5%
Stroke ^{§§+}	7.8%	2.4%	8.1%	1.4%
Skin cancer ^{§§+}	10.1%	5.5%	9.3%	4.6%
Other cancer ^{§§+}	12.1%	6.1%	12.0%	4.8%
Chronic obstructive pulmonary disease ^{§§+}	21.4%	3.6%	17.8%	3.2%
Arthritis ^{§§+}	59.7%	20.2%	56.7%	17.0%
Depression ^{§§+}	33.8%	10.1%	37.1%	11.4%
Kidney disease ^{§§+}	5.6%	1.7%	6.7%	1.5%
Loss of all teeth (for age 65 and older) [§]	22.8%	14.2%	20.9%	13.6%

^{§§} Statistically significant at $p < 0.01$; [§] Statistically significant at $p < 0.05$; ⁺ Yes

Health care access

BRFSS had one question asking respondents whether they had any health insurance: “Do you have any kind of health care coverage, including health insurance, prepaid plans such as HMOs, or government plans such as Medicare?” (CDC 2012, p. 8).

BRFSS also asked respondents about their usual source of care with the following question: “Do you have one person you think of as your personal doctor or health care provider?” (CDC 2012, p.8). Last dental visit was defined as the last visit to a dentist or a dental clinic for any reason, including visits to dental specialists. Compared to their

counterparts without disabilities, a higher percentage of those aged 18 and older with disabilities in Delaware reported having health insurance, a usual source of care, and routine physical checkups. Nonetheless, a greater percentage of Delawareans with disabilities experienced difficulty accessing health care. A larger portion of those with disabilities reported a delay in seeing a doctor because of cost and having no dental visit or their last dental visit one or more years ago. As reported previously, adults with disabilities in Delaware had lower socioeconomic status.

Table 4. Health Care Access

Variables	Delaware Disability	Delaware No Disability	U.S. Disability	U.S. No Disability
Health insurance for adults ages 18 and older ^{§§+}	92.3%	87.6%	85.0%	80.7%
ages 18-64 ^{§+}	89.8%	85.3%	79.4%	77.5%
Usual source of care ^{§§+}	91.2%	86.0%	86.1%	75.7%
Routine physical checkup ^{§§}				
Within the past year	85.4%	78.8%	74.0%	65.9%
More than one year ago or never	14.6%	21.2%	26.0%	21.2%
Delay in seeing a doctor due to cost ^{§§+}	19.8%	11.3%	25.3%	14.0%
Last dental visit ^{§§}				
Within the past year	58.6%	72.8%	56.8%	67.9%
More than one year ago or never	41.4%	27.2%	43.2%	32.1%

^{§§} Statistically significant at $p < 0.01$; [§] Statistically significant at $p < 0.05$; ⁺ Yes

Personal health behaviors

BRFSS asked respondents about their attempts to quit smoking with the following question: “During the past 12 months, have you stopped smoking for one day or longer because you were trying to quit smoking?” (CDC 2012, p. 19). Binge drinking was defined as having five or more drinks for men or four or more drinks for women on an occasion within the past 30 days. Heavy drinking was defined as having more than two drinks per day for adult men or more than one drink per day for adult women. BRFSS had one question asking respondents whether they had a flu shot or a flu vaccine within the past 12 months: “During the past 12 months, have you had either a seasonal flu shot or a seasonal flu vaccine that was sprayed in your nose?” (CDC 2012, p. 21). BRFSS also asked respondents

about their physical activity in the past month with the following question: “During the past month, other than your regular job, did you participate in any physical activities or exercises such as running, calisthenics, golf, gardening, or walking for exercise?” (CDC 2012, p. 9). Body Mass Index was calculated by dividing weight (in kilograms) by height (in meters) squared.

In regard to personal health behaviors, the analyses showed mixed findings for adults ages 18 and older with disabilities in Delaware. Delawareans with disabilities reported more positive behaviors in terms of current drinking, binge drinking, and getting a flu shot. But, a higher proportion of those with disabilities were current smokers, less physically active, and obese.

Table 5. Personal Health Behaviors

Variables	Delaware Disability	Delaware No Disability	U.S. Disability	U.S. No Disability
Current smoking ^{ss}	25.1%	18.4%	26.0%	16.9%
Attempt to quit smoking	59.5%	56.8%	64.0%	58.8%
Current drinking ^{ss}	44.1%	57.8%	41.8%	56.6%
Heavy drinking	5.8%	7.1%	4.9%	6.1%
Binge drinking ^{ss}	12.3%	20.1%	11.8%	18.4%
Flu shot within the past 12 months ^{ss}	49.3%	38.7%	44.8%	33.8%
Physical activity in the past month ^{ss}	59.7%	80.6%	60.5%	81.4%
Body mass index (BMI) ^{ss}				
Neither overweight nor obese (BMI under 25)	27.8%	35.6%	28.4%	38.9%
Overweight (BMI 25 to under 30)	32.5%	40.8%	32.4%	36.7%
Obese (BMI 30 or higher)	39.7%	23.7%	39.1%	24.5%

^{ss} Statistically significant at $p < 0.01$

Preventive cancer screening and women's health

The United States Preventive Services Task Force (USPSTF) recommends that adults aged 50 to 75 receive fecal occult blood testing (FOBT), sigmoidoscopy, and colonoscopy for colorectal cancer (USPSTF, 2008), that women aged 50 to 74 receive mammogram every two years for breast cancer screening (USPSTF, 2009), and that women aged 21 to 65 receive a Pap test every three years for cervical cancer screening (Moyer & USPSTF, 2012). Given these recommendations, the screening tests were examined for those specific age groups.

BRFSS asked whether respondents had ever had a blood stool test using a home kit, and it also had one question asking respondents whether they had ever had either sigmoidoscopy or colonoscopy.

Approximately 30 percent and 75 percent of those with disabilities reported that they had ever had the blood stool test and sigmoidoscopy/ colonoscopy, respectively. More than 80 percent of Delawareans with disabilities also reported that they had a mammogram and Pap test within the aforementioned recommended timeframe. It should be noted that the differences between Delawareans with and without disabilities for those screening tests were not statistically significant. However, a significantly higher percent of Delawareans with disabilities reported having had a hysterectomy, which is statistically significant.

Table 6. Preventive Cancer Screening and Women's Health

Variables	Delaware Disability	Delaware No Disability	U.S. Disability	U.S. No Disability
Ever had blood stool test [¶]	30.2%	28.1%	37.6%	32.8%
Ever had sigmoidoscopy or colonoscopy [¶]	74.6%	73.6%	68.5%	65.2%
Mammogram within past two years [§]	83.3%	84.7%	75.0%	80.3%
Pap smear test within past three years [‡]	86.6%	89.2%	79.7%	85.0%
Hysterectomy ^{**}	34.4%	17.6%	35.8%	17.8%

^{**}Statistically significant at $p < 0.01$; [¶]Only men and women ages 50 to 75; [§]Only women ages 50 to 74;

[‡]Only women ages 21 to 65

4.2 Youth Risk Behavior Survey

The Youth Risk Behavior Survey (YRBS) is a self-administered health questionnaire distributed through schools for students in grades 9 through 12 in the United States. YRBS is conducted in all 50 states and the District of Columbia in collaboration with the CDC, and it provides data representative of U.S. high school students (CDC, 2004). The goal of the YRBS is to monitor and document risky behaviors that may negatively affect the health of youth in the United States. The Delaware YRBS includes all public schools (including charter and vocational schools), but it does not include special education schools.

YRBS includes the following two disability questions: 1) Do you have any physical disabilities or long-term health problems? (Long-term means 6 months or more), and 2) Do you have any long-term emotional problems or learning disabilities? (Long-term means 6 months or more). Youth were defined as having a disability if they positively responded to at least one of these two questions. 17.9 percent of youth in Delaware reported having a disability in 2011. Selected findings from the 2011 YRBS comparing youth with and without disabilities are below.

In summary, compared to youth without disabilities, youth with disabilities were:

- more likely to be overweight or obese (34.0% vs. 28.2%),
- more likely to use harmful weight loss strategies,
 - fasting (17.8% vs. 8.3%),
 - pills (8.0% vs. 4.1%),
 - vomiting (7.0% vs. 3.1%),
 - ate less (45.3% vs. 37.8%),



- less likely to be physically active for at least one hour per day on previous seven days (17.6% vs. 26.5%),
- less likely to play on one or more sports teams in the past year (40.9% vs. 58.2%),
- more likely to be current smokers (28.6% vs. 16.1%),
- more likely to engage in alcohol and other drug use behaviors during their lifetime,
 - ever drank alcohol (80.7% vs. 70.1%),
 - ever used marijuana (57.2% vs. 43.5%),
 - ever used cocaine (10.4% vs. 4.2%),
 - ever used heroin (7.6% vs. 2.1%),
- more likely to report being depressed (48.0% vs. 22.1%),
- more likely to report having considered suicide (28.2% vs. 10.2%),
- more likely to report having ever having been forced to have sex (20.6% vs. 5.8%), and
- more likely to report having been bullied at school in the past 12 months (30.8% vs. 13.4%).

4.3 National Survey of Children with Special Health Care Needs

The 2009-2010 National Survey of Children with Special Health Care Needs (NS-CSHCN) is a cross-sectional telephone survey of US households with at least one resident child ages 0-17 (CDC, n.d.). The findings reported were compiled from the State Profile results of the Data Resource Center for Child and Adolescent Health at Johns Hopkins University. This chapter reports the findings on Maternal Child Health Bureau (MCHB) core outcomes for children with special health care needs (CSHCN), CSHCN and their families' experiences in transitions to adult health care and coordinated care within a medical home, and impacts of caring for CSHCN on their families' finances and employment status in Delaware. CSHCN are those who currently experience a health consequence because of a physical, mental, behavioral, or other type of health condition that has lasted or is expected to last at least 12 months (Data Resource Center for Child and Adolescent Health, n.d.). The summary of the findings is as follows.

- The percentage of CSHCN who reported having received coordinated and comprehensive care within a medical home decreased from 48.1% to 41.4% between the two surveys conducted in 2005/2006 and 2009/2010, respectively.
- The proportion of youth with special health care needs who reported having received services necessary for transition to adulthood decreased from 42.4% to 38.4% over the same time period.
- 51% of the respondents reported that their child's doctors did not talk about



the child's health care needs as the child becomes an adult.

- Approximately 74% of the respondents reported that no one discussed with them how to obtain or keep some type of health insurance coverage as their child becomes an adult.
- More than one third of the respondents reported that they did not receive family-centered care (35.8%).
- More than one-fifth of families of CSHCN reported that they had paid \$1,000 or more in out-of-pocket medical costs for CSHCN (22.5%).
- More than one-fifth of families of CSHCN needed to cut back or stop working because of their child's health condition (21.6%).



Community voices: suggested improvements

"More access to programs for kids with emotional problems—day care programs and summer camps for kids with problems, especially over 11 or 12 years old."

Maternal and child health bureau core outcomes for CSHCN

Two MCHB outcomes—medical home and transition—warrant attention. The percentages of CSHCN who reported having received coordinated care through a medical home and youth with special health care needs (YSHCN)

who reported having received transition services to adulthood decreased by seven percent and four percent, respectively, over time in Delaware.

Approximately one-third (28%) of CSHCN and their families in Delaware reported in 2009/2010 not having participated in the decision making process with care providers, not having had adequate health insurance (30.1%), and having had difficulty accessing community based services (30.1%).



Community voices: suggested improvements

“Access...to social or extracurricular activities that disabled people can do after they become 21 and continue through life.”

Transition services, medical home, and financial challenges

For a significant portion of CSHCN in Delaware, appropriate transition planning did not occur with their health care providers. More specifically, a high percentage of YSHCN did not have a chance to discuss with their doctors their transition to the adult care system. This includes a discussion of the youth's health care needs, insurance coverage, and their responsibility for their own health and health care. For instance, 74% of the respondents reported that no one discussed with them obtaining and keeping health insurance coverage as the youth becomes an adult. In addition, more than one-third of the respondents in Delaware reported that they did not receive family-centered care (35.8%); 81% of families of CSHCN reported they did not receive help with health care coordination.

Parents also reported that caring for CSHCN had a financial impact on their families. Approximately 23 percent of families in Delaware reported they

spent \$1,000 or more on out-of-pocket medical costs for their children in the previous year. The needs of CSHCN also affected their family members' employment status; approximately 22 percent of family members of CSHCN in Delaware reported that they needed to cut back or stop working because of their children's health conditions.



4.4 National Survey of Children's Health

The 2011-2012 National Survey of Children's Health (NSCH) is a cross-sectional telephone survey of US households with at least one resident child ages 0-17 and collects information about the physical and emotional health of the children.

This section reports the findings on health status, health care, the child's family, and their family's neighborhood by special health care needs (SHCN) status. CSHCN are those who currently experience a health consequence because of a physical, mental, behavioral, or other type of health condition that has lasted or is expected to last at least 12 months (Data Resource Center for Child and Adolescent Health, n.d.).

In summary, compared to children without special health care needs in Delaware, CSHCN in Delaware were:

- less likely to have excellent/very good overall health status (71.8% vs. 87.6%) and oral health status (67.0% vs. 74.0%) ,
- more likely to be born prematurely (16.8% vs. 10.1%),
- more likely to be overweight or obese (33.0% vs. 31.6%),
- more likely to miss school days in the past 12 months because of illness or injury (children ages 10-17, 86.9% vs. 75.1%),
- more likely to have health insurance and remain insured for all 12 months (92.6% vs. 88.9%),
- more likely to have both medical and dental preventive care visits in the past 12 months (82.7% vs. 68.4%), and
- less likely to receive health care meeting Medical Home criteria (51.3% vs. 57.2%).



Community voices: suggested improvements

"All public pools should have lifts for people with disabilities to get in and out of them. Many of us can swim, float or splash in the water but, just can't get into the pool or out of it..."

4.5 Medicaid Claims Data

This report used data from the Delaware Medicaid claims data for Fiscal Year 2012. People with disabilities were identified as those receiving SSI disability benefits. It should be noted that individuals who did not have any claims during the year were not included in the analyses. The summary of the findings are as follows.

- Delaware Medicaid clients with claim data who had disabilities accounted for 6% of all clients. Examination by county shows similar patterns in Kent and New Castle (7%) but a lower percentage of clients with disabilities in Sussex (4%).
- Examination of Medicaid clients with claims by minority status (Caucasian=non-minority, all other

- The proportion of adults age 18 or older with disabilities who had Medicaid claims was similar in Kent and New Castle (9%) but lower in Sussex County (6%).
- Although the proportion of clients with disabilities was smaller than that of clients without disabilities, the average number of claims for a client with disabilities was higher.
- In all categories of claims except for surgical centers and urgent care facilities (primary doctor visits, hospital inpatient/outpatient, and Emergency Department [ED]), Medicaid clients with disabilities had a higher average number of claims than clients without disabilities.
- Medicaid clients with disabilities had a higher proportion of ED claims than clients without disabilities (44% vs. 34%). Eleven percent of clients with disabilities had more than three ED visits compared to four percent of clients without disabilities.**
- Children with disabilities on Medicaid had a higher proportion of ED claims than their counterparts without disabilities (37% vs. 29%). Of the Medicaid enrollees, children with disabilities who did go to the ED also had a larger proportion who visited the ED more than three times, compared to those without disabilities (16% vs. 8%).**
- “Injury and poisoning,” “other symptoms involving abdomen and pelvis” and “chest pain” were the three top ED diagnoses groupings for both Medicaid clients with and without disabilities.
 - The same diagnoses groupings were the top three ED diagnoses for clients with nine or more visits to the ED.



Community voices: suggested improvements

“Newer drugs are usually not covered by Medicare or Medicaid, but when I contact the manufacturers, they specifically say that their discounts are not available for Medicare recipients. So I cannot take the medications that actually treat my conditions, I have to settle for minimal symptom management...”

ances=minority) showed an almost equal proportion of clients with disabilities between the two groups (6% for non-minority and 7% for minority).

- Children under age 18 accounted for 46% of the claims, and children with disabilities accounted for 29% of the claims made by persons with disabilities.
 - The proportion of children with disabilities who had Medicaid claims was similar among counties (3-5% of all children claims).

**** Clarification:** A print version of this report includes incorrect statistics in these two paragraphs. The statistics are correct in this digital version.

4.6 Medicaid Claims Data: Cancer Screening

Table 7 shows the percentages of the Medicaid clients who received cancer screening tests. People who had more than one test per screening were included in those who received screening tests in Table 7, but their inclusion didn't affect the findings. After controlling for county, a larger portion of people with disabilities had a mammogram than those without disabilities in the fiscal year 2012, whereas a smaller percentage of those with disabilities had a Pap test and a colonoscopy.

Table 7. Cancer Screening Tests among Medicaid Clients with Claims for FY 2012

Variables	Disability	No Disability
Mammogram ^{**§}	20%	16%
Pap smear test ^{**‡}	1%	2%
Colonoscopy ^{*¶}	3%	4%

* Statistically significant at $p < 0.05$; ** statistically significant at $p < 0.01$;

§ Only women ages 50 to 74; ‡ Only women ages 21 to 65;

¶ Only men and women ages 50 to 75



Community voices: suggested improvements

"I am required to go to [hospital] since the office I get mammograms in is unable to do a pap smear because I cannot get on the table."

PART 5: Environmental Assessment

The Environmental Assessment was designed to explore the impact that the accessibility of health care facilities and health promotion programs had on the health status of people with disabilities. This assessment contains two elements: a) a survey of physical features of health care facilities, and b) a survey of health department and community health promotion program managers.

5.1 Health Care Facility Accessibility

This assessment was designed to capture the level of accessibility in health care facilities in Delaware using an on-site walkthrough guided by a survey tool.

The Delaware Accessibility Survey was adapted from assessment tools developed by CDC partners in North Carolina and Oregon. The survey consists of 91 questions that evaluate the accessibility of health care facilities. There are ten sections of the survey: customer service, appointments, parking, circulation paths and entrances, elevators, signage, reception/waiting area, exam room, restrooms, and emergency procedures. Each question is dichotomous with a “yes” or “no” response, and each section has a blank space for explanations, if needed.

Our original goal was to reach 20 facilities, but the reluctance of providers to participate limited the number of facilities assessed to five.

The provider pool for this assessment was drawn from primary care and specialty

providers who were contractors with the Division of Public Health through the Screening for Life program and the pediatric provider system. An invitation to participate in an accessibility assessment was mailed to a total of 324 providers.

The initial response to the mailing was one provider responding by phone with interest in the Accessibility Assessment. This provider scheduled an appointment, and the assessment was performed. Follow-up phone calls were made to the remaining 323 providers over the next month and generated four additional assessments bringing the total number of participating facilities to five. Findings from the assessments are summarized by survey sections.

The findings from the environmental accessibility assessments revealed mixed findings on building access. Structural elements that are common to all types of facilities, not just health care facilities, were more likely to be accessible. Parking, entrances, signage, bathrooms and reception areas were less likely to have barriers.

Program elements that were more specific to the type of encounters associated with health care were less likely to be fully accessible. Exam rooms and equipment such as scales, exam



Community voices: suggested improvements

“Some sort of directory available listing providers who are willing and able to treat those with disabilities.”

tables and lifts were likely to be absent or not accessible. Communication methods used by practices were less likely to be fully accessible, including staff knowledge of TTY or relay services.

Emergency procedures were in place but may not have fully integrated persons with disabilities into the existing procedures.

Hospitals were more accessible than private practice facilities.

Findings from the assessments are summarized by survey sections.

Customer service and making the appointment

- Three out of five facilities trained staff members in providing services to people with disabilities.
- Two out of five facilities had organizational materials available in alternative format, such as braille, diskette, large print, etc.
- All five facilities were able to provide a sign language interpreter, if needed.

Parking

- All facilities had accessible parking and were ADA compliant with regard to parking.

Circulation paths and entrances

- All facilities had a circulation path of adequate, accessible width.
- Four out of five facilities had an automatic door.

Signage

- All facilities had accessible signage.
- One facility lacked signage with braille, and another facility lacked signage directing people to the accessible entrances and bathrooms.



Reception/waiting area

- Three out of five facilities had an acceptable reception counter height (no more than 36" above the floor).
- Four out of five facilities had intake material available in alternate format (i.e., audio, large print).

Exam room

- Two out of five facilities had a method to weigh a wheelchair user.
- Three out of five facilities had a height-adjustable exam room table.
- Three out of five facilities had at least one lift or transfer device.

Bathrooms

- Bathrooms were accessible, with one exception.
- Only one out of five facilities had an accessible bathroom stall with a self-closing door.

Emergency procedures

- Four out of five facilities offered staff training on emergency procedures for people with disabilities.
- Only one out of four facilities with floors above the first floor had an evacuation chair for people with disabilities.

5.2 Health Promotion Programs Assessment

The Assessment of Health Promotion Programs and Activities in the State of Delaware survey consisted of two different components: a) a Health Promotion Programs and Activities Assessment survey administered to DHSS programs, and b) an adapted version sent to community groups, non-profit organizations, school-based health centers, medical centers, academic institutions, and foundations in Delaware. These community programs were not funded by the DHSS and data were collected as part of a separate project. All surveys were completed electronically and were administered between April and June 2013.

Survey overview

DHSS programs

Of the 12 divisions within DHSS, responses were obtained from eight divisions. Four divisions not involved in direct client services were not included. The divisions included were the Division of Public Health (DPH), Division of Substance Abuse and Mental Health (DSAMH), Division for the Visually Impaired (DVI), Division of Medicaid and Medical Assistance (DMMA), Division of Services for Aging and Adults with Physical Disabilities (DSAAPD), Division of Child Support Enforcement (DCSE), Division of Management Services (DMS), and the Division of Developmental Disabilities Services (DDDS).

From inquiries to Division Directors, 38 programs that were currently being funded by the DHSS were identified. Of the 38 programs, 32 programs returned the survey, and 28 completed the survey in its entirety. Since the

four incomplete surveys included only contact information, they were excluded from the results.

Community programs

Surveys were sent to 121 different community programs in the state of Delaware. Of the 121 programs, 79 programs returned the survey and 67 completed the survey in its entirety. Since the 12 incomplete surveys included only contact information, they were excluded from the results.

Overview of survey findings related to barriers serving individuals with disabilities

Program managers varied in their reports of how people with disabilities were integrated into their programs. The vast majority of program managers who responded to the survey did not know how many people with disabilities they were serving (85.7% of DHSS programs and 68.7% of community programs).

When asked about barriers to inclusion of people with disabilities in their programs, some reported anticipating few barriers to inclusion while others had specific concerns. Managers' responses about potential barriers clustered in three areas: data collection, accessibility and resources.



Community voices: suggested improvements

"Be more trained to work with disabled people," or "more willing or interested in working with those with disabilities."

Data collection of disability status

- Application materials do not have a field to collect disability status.
- DHSS program managers reported that data are often collected at the community level leaving them less control over data capture.
- There is no requirement to track data.
- Concerns about violations of HIPAA privacy requirements.

Concerns about accessibility and inclusion of people with disabilities

- Transportation is an issue for people with disabilities in accessing programs.
- Concern about a person with a cognitive disability being able to respond to the program structure.
- Physical barriers exist in program sites.

Resources

- Managers reported a lack of resources to accommodate variations in ability and physical barriers to participation.
- Lack of staff knowledge, communication skills and a shortage of medical professionals may be challenges.
- This is not an area of focus for our program.
- Insurance issues, family support and respite availability are challenges.

Program demographics overview

DHSS programs

All programs (n=28) indicated they served all counties (New Castle, Kent and Sussex) in the state of Delaware. The reach per year for the programs ranged from 80 people to 181,000 people. Four programs had a small reach (fewer than 1,000 people per year), six programs had a medium reach (1,000-5,000 people per year), four had a large reach



(5,001-20,000 people per year), and five programs had an extra large reach (more than 20,000 people per year). Nine programs did not know how many people their program reached each year.

The programs reached many different target populations. These populations included adults (five programs), older adults (one program), youth/adolescents (seven programs), women/youth (four programs), adults with diabetes (one program), and adults with intellectual/developmental disabilities (one program). The remaining nine programs focused on all demographics or multiple demographics.

Eleven of the DHSS programs did not charge individuals a fee to participate. One program is primarily paid for by the participant, one program is primarily covered by Medicare or Medicaid, and three programs are primarily covered by grants and donations. No programs are primarily paid for by private insurance. To cover the cost of the program, three programs indicated they used another method (i.e., state/federal funding), and nine programs indicated they used a mix of the above methods to cover the costs.

Community Programs

Eighteen community programs are implemented statewide, serving all three counties. Twenty-four programs only serve the upstate population (New Castle County), whereas 25 programs only serve the downstate population (Kent and Sussex Counties).

The reach per year for the programs ranged from 20 people to 400,000 people. Thirty programs had a small reach (fewer than 1,000 people per year),

Five programs are primarily paid for by the participant, four programs are primarily covered by Medicare or Medicaid, and six programs are primarily covered by grants and donations. No programs are primarily paid for by private insurance. To cover the cost of the program, 10 programs indicated they used another method (i.e., state/federal funding), and 37 programs indicated they used a mix of the above methods to cover the costs.

People with disabilities overview

DHSS programs

Of the 28 programs that responded to the survey, 85.7% (24 programs) did not know how many people with disabilities the program was serving. Independent Living Services, Newborn Screenings, Birth-to-Three Intervention, and Division of Developmental Disabilities Services (DDDS) were the only programs that knew at least approximately how many people with disabilities the program was serving.

There were many barriers in collecting data about people with disabilities. Some of the common barriers included not being required to track the data, lack of resources, and communication issues, such as anonymity and HIPAA privacy regulations. Seven programs were also unaware of, or did not identify, any barriers to identifying the number of people with disabilities participating in the program; two programs believe there were no barriers to collecting this data, but still

Community voices: suggested improvements

"I have been wanting to join one of the adult sports teams and/or take horseback riding lessons, but they are prohibitively expensive."

24 programs had a medium reach (1,000-5,000 people per year), 6 had a large reach (5,001-20,000 people per year), and one program had an extra large reach (more than 20,000 people per year). Six programs did not know how many people their program reached each year.

The programs reached many different target populations. These populations included adults (21 programs), older adults (10 program), college students (7 programs), adolescents (21 programs), youth (8 programs), adults with cancer (2 programs), and adults with multiple sclerosis (1 program). The remaining nine programs focused on all demographics or multiple demographics.

Six of the community programs did not charge individuals a fee to participate.

did not know the reach to the people with disabilities population.

Many challenges that people with disabilities may encounter when participating in the programs were also identified. Some of the common challenges included transportation, insurance issues, family support, and physical barriers. Five programs indicated they were unaware of, or did not identify, any challenges people with disabilities may encounter when participating in the program. Eleven programs believed there were no challenges that people with disabilities would encounter if they participated in the program.

Community programs

Of the 67 programs that responded to the survey, 68.7% (46 programs) did not

know how many people with disabilities the program was serving. Nineteen programs knew at least approximately how many people they were serving, but almost all of the programs did not have exact data.

There were many barriers in collecting data about people with disabilities. Some of the common barriers included not being required to track the data, lack of resources, and communication. Other barriers included parents not providing information (in youth/adolescent settings), lack of technology, and lack of training. Twelve programs were unaware of, or did not identify, any barriers to identifying the number of people with disabilities participating in the program. Four programs believed there were no barriers to collecting this data.



Many challenges that people with disabilities may encounter when participating in the programs were also identified. Some of the common challenges included transportation, physical barriers, lack of staff, lack of training, poverty, and financial challenges. Eight programs indicated they were unaware of, or did not identify, any challenges people with disabilities may encounter when participating in the program. Twenty-seven programs believed there were no challenges that people with disabilities would encounter if they participated in the program.

PART 6: Emergency Preparedness

The program on inclusive emergency preparedness at CDS began in 2010 when it received a one-year planning grant followed by a two-year implementation grant from the federal Administration on Developmental Disabilities (ADD). These funds were used to investigate whether people with disabilities and their families were adequately prepared for an emergency and to promote the seamless integration of emergency planning for people with access, functional and medical needs (PWAFFMN) into existing emergency operational plans in Delaware. This initiative was

continued through a 2012 award from the CDC that integrated emergency preparedness into the CDS/DHSS project.

For this public health assessment, we used existing survey data and the data collected during the initial phase (2010) of the inclusive emergency preparedness project. More specifically, these data include:

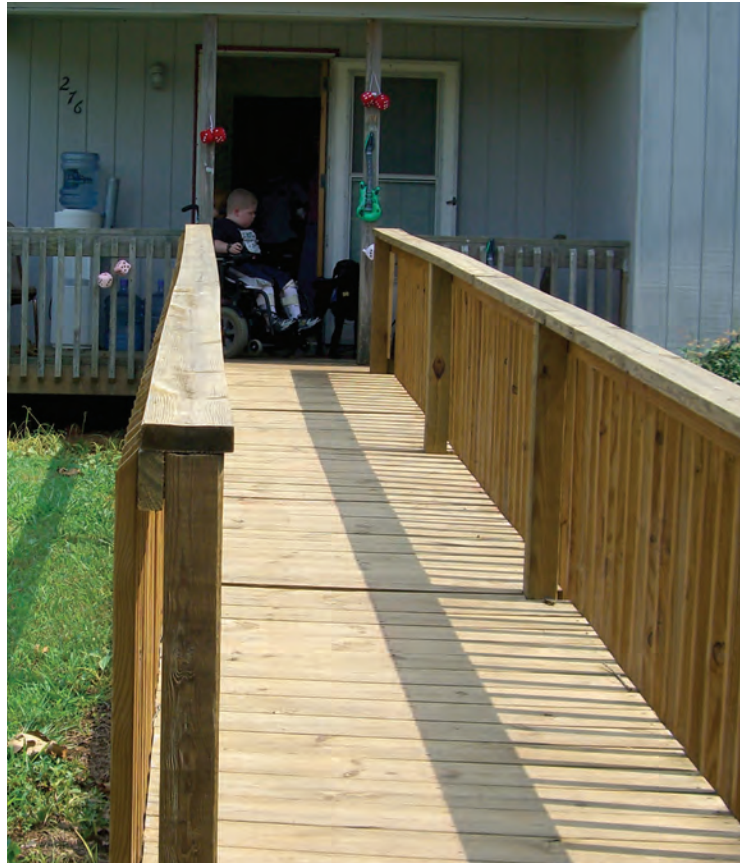
- the 2007 Delaware BRFSS module on emergency preparedness, and
- the data collected in 2010 which included interviews, public forums, and community workshops.



6.1 Behavioral Risk Factor Surveillance System 2007 Emergency Preparedness Module

The 2007 BRFSS module included eleven survey questions about household emergency preparedness, evacuation planning and communication during emergencies. The findings are listed below.

- Twenty-three percent (22.8%) of respondents with disabilities indicated that their household was not prepared for an emergency compared to 18.5% of respondents without disabilities.
- Twenty-six percent (25.8%) of respondents with disabilities indicated that their household had an evacuation plan compared to 22.0% of respondents without disabilities.
- The majority of survey respondents (94.6%) regardless of disability status indicated that they would leave their home in the event of a mandatory evacuation.
- The majority of survey respondents (97.4%) regardless of disability status would communicate with relatives in an emergency by land or cellular phone.
- Eighty-five percent (84.6%) of all respondents indicated that the main method of getting information about an emergency would be through the TV or radio.



Community voices: suggested improvements

"Communication—as I am Deaf and require an interpreter—and sensitivity and patience to communicate with me so that I can understand.. understand that fingerspelling is not sign language... understand that lip reading may not be enough for me to fully understand the conversation... understand that just because you write something down in English that Deaf will not comprehend as English is primarily for hearing people."

6.2 Data Collected During Inclusive Emergency Preparedness Project Baseline Inquiry

Interviews were conducted with stakeholders (people with disabilities and their families, caregivers, community and state service providers, emergency management professionals, medical professionals and advocacy groups) regarding the status of emergency preparedness and response as it relates to PWAFMN.

In addition, four public forums on emergency preparedness for PWAFMN and their families were held throughout Delaware, one in each county and one in the city of Wilmington. The forums included presentations by state, county and local emergency professionals about local resources, emergency alerts, and the importance of preparedness. The Inclusive Preparedness Center from Georgetown, D.C., moderated the forums and used an emergency scenario to help attendees think through the challenges that people with various disabilities or medical needs would face if they needed to shelter in place or evacuate during an emergency. At the conclusion of each forum, attendees were asked how prepared to shelter in place or evacuate they felt both before and after the forum and whether they had a plan to address specific disability-related challenges such as transportation, communication, medication or adaptive equipment.

- Preparedness levels for sheltering-in-home indicated that 15% were not at all prepared to do so, 44% not well prepared, and 37% somewhat prepared to shelter in their own home.

Emergency preparedness community workshops were also conducted under the ADD grant and continue to be conducted under the CDC grant to CDS. Input was obtained from participants following each workshop. The data from the interviews, forums and workshop evaluations were compiled and analyzed and reported below.

Interview summary

In 2010, CDS staff conducted interviews to determine whether emergency operational plans were inclusive and would effectively address the challenges faced by people with disabilities during a disaster. The interviews included professionals at the Delaware Emergency Management Agency (DEMA), the Division of Public Health (DPH), the Department of Health and Social Services (DHSS), the Division of Aging and Adults with Physical Disabilities (DSAAPD), the Division of Substance Abuse and Mental Health (DSAMH), Delmarva Red Cross, the National Guard, Citizen Corps and Volunteers Active in Disasters (VOAD). In addition, people with disabilities and advocacy groups (e.g., the Delaware Developmental Disabilities Council [DDC], the State Council for Persons with Disabilities [SCPD], a Center for Independent Living, the Special Needs Alert Program [SNAP]) were interviewed and asked to identify issues of concern related to individual emergency preparedness and access to emergency services by people with disabilities.

Responses to the interviews revealed enormous cultural differences between the disability community and emergency professionals in language, perspective and collaboration style. There was little communication between emergency managers and people with disabilities, and participation of people with disabilities in the development of emergency operational plans generally did not occur. Emergency professionals reported that operational plans in 2010 did not specifically address issues faced by people with disabilities in accessing emergency services but rather plans adopted an “all hazards, all people” approach. The two groups, emergency professionals and people with disabilities, had little knowledge of each other’s concerns and the issues that each must address during an emergency or a disaster.

Shelter accessibility, transportation and accommodations were issues of concern to people with disabilities. Access to prescription medicine during an emergency was another frequently-expressed topic of concern. Individuals with disabilities did not know what services and accommodations they would be able to access during an emergency or disaster, and they did not know the location of potential shelters and whether their families could stay together in one shelter. People with disabilities and advocacy groups also recognized the need for training regarding the development of a personal emergency plan.

Emergency personnel noted that all shelters are physically accessible, but personnel were generally not aware of training regarding assisting people with disabilities during an emergency



and the specific challenges that might need to be accommodated during an emergency. Emergency personnel also expressed concern about identifying people who are nonverbal or incompetent during a disaster and obtaining informed consent on forms. It was clear that cross-training is needed so first responders will have a better

understanding of the needs of people with disabilities and so that people with disabilities will understand the perspective of emergency personnel. Training should be widely available, accessible and approachable for both groups.

Finally, it was noted that multiple registries exist within Delaware for PWAFFMN, and that one, state-wide, coordinated system would be preferable.

Public forums

Public forums on emergency preparedness were held in August 2010 in four locations across the state—Wilmington, Stanton, Dover and Georgetown. There were 142 participants and 93 completed the evaluation questionnaires (64 percent return). Participants included individuals with disabilities (18), family members (23), providers (25), emergency managers or planners (6), and others including volunteers, interpreters and members of the Medical Reserve Corps (17).

The four Delaware public forums provided valuable information to residents, individuals with disabilities and their families, human service providers, and volunteers serving individuals with disabilities about the importance of individuals and families planning for emergencies, or disasters.

Summary of findings

The collaboration and coordination among Delaware Department of Homeland Security, DEMA, local emergency managers, Delaware DDC and working group members, human



service providers, the Inclusion Research Institute, as well as the Project Coordinators from the CDS at UD provided an opportunity to build relationships and provide valuable information to Delaware residents about the importance of being self-reliant and resilient to best meet the challenges of an unexpected emergency or disaster.

Participants who attended each forum had an opportunity to express special

concerns about their readiness for an emergency, especially regarding special needs for individuals with disabilities. Highlights of some of the concerns expressed by the participants in the discussion included: knowing who to call; developing an evacuation plan and understanding how to execute it, if needed; developing personal plans for sheltering-in-place; building neighborhood networks of support; and planning ahead for medications, equipment, and daily medical needs, including emergency transportation and medical equipment back-up support systems. Delaware's Citizen Corps addressed the importance of self-reliance and resiliency and how residents need to discuss and develop an emergency plan with family members and neighbors, prior to any emergency or disaster.

Important summary comments from participants included the need for developing individual plans and practicing them to enhance recovery after a disaster. Cultivating a sense of preparedness within family and community routines, to improve the confidence, capabilities, and resilience of individuals, families, organizations and communities, was highlighted as critical information to know ahead of time.

The forums provided a platform for individuals to take a first step in planning, if they had not already done so, by receiving a personal "GO-KIT" as well as literature and resources for assisting individuals with disabilities and their families to better plan and prepare for emergencies/disasters. The information gained at the forums, and the discussions that took place, can serve as groundwork

for continued collaboration and planning efforts within the Delaware community.

- Roughly 88% of all individuals were at varying degrees of preparedness, with only 10% feeling they were prepared.
- Roughly 93% of individuals with special needs and their families were at varying degrees of preparedness, with only 7% feeling they were prepared.
- Television, radio, phone and computers were used to receive emergency warnings by both groups, at about the same percentage of usage.
- If needing to shelter-in-place, 59% of participants felt they were not well prepared to do so, with 66% of individuals and their families, slightly higher. This may indicate the need for additional supports, programs, information, and outreach to improve this capacity.
- Medications and medical equipment were indicated in both groups, individuals with disabilities and their families, as the top needs, if an emergency occurred.
- If evacuation were mandated, roughly 31% of participants felt they were prepared to do so, compared to 22% of individuals with special needs and their families. This may indicate the need for additional supports, programs, outreach to improve the capacity for Delaware residents to be able to evacuate, if mandated.

PART 7: References

4.1 Behavioral Risk Factor Surveillance System

Centers for Disease Control and Prevention (2004). Self-Reported Frequent Mental Distress among Adults—United States, 1993–2001. *MMWR*, 53, 963–966. Retrieved from <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5341a1.htm>

Centers for Disease Control and Prevention (2011). Burden of mental illnesses. Retrieved from <http://www.cdc.gov/mentalhealth/basics/burden.htm>

Centers for Disease Control and Prevention (2012). 2012 Behavioral Risk Factor Surveillance System Questionnaire. Retrieved from http://www.cdc.gov/brfss/questionnaires/pdf-ques/2012_BRFSS.pdf

Moyer, V.A., & U.S. Preventive Services Task Force (2012). Screening for cervical cancer: U.S. Preventive Services Task Force recommendation statement. *Annals of Internal Medicine*, 156(12), 880–891.

U.S. Preventive Services Task Force (2008). Screening for colorectal cancer: U.S. Preventive Services Task Force recommendation statement. *Annals of Internal Medicine*, 149(9), 627–637.

U.S. Preventive Services Task Force (2009). Screening for breast cancer: U.S. Preventive Services Task Force recommendation statement. *Annals of Internal Medicine*, 151(10), 716–726.

4.2 Youth Risk Behavior Survey

Centers for Disease Control and Prevention (2004). Methodology of the Youth Risk Behavior Surveillance System. *MMWR*, 53, 1–13. Retrieved from <http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5312a1.htm>

4.3 Survey of Children with Special Health Care Needs

Centers for Disease Control and Prevention (n.d.). Frequently asked questions: 2009–2010 national survey of CSHCN. Retrieved from <http://www.cdc.gov/nchs/data/slaits/NSCSHCNfaqs2009.pdf>

Data Resource Center for Child and Adolescent Health (n.d.). Children with special health care needs screener: Fast facts. Retrieved from <http://www.childhealthdata.org/docs/cshcn/cshcn-screener-cahmi-quickguide-pdf.pdf>

4.4 National Survey of Children's Health

Data Resource Center for Child and Adolescent Health (n.d.). Children with special

health care needs screener: Fast facts. Retrieved from <http://www.childhealthdata.org/docs/cshcn/cshcn-screener-cahmi-quickguide-pdf.pdf>

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Acronyms and Abbreviations

ADA: Americans with Disabilities Act

BRFSS: Behavioral Risk Factor Surveillance System

CDC: Centers for Disease Control and Prevention

CDS: Center for Disabilities Studies

DCSE: Division of Child Support Enforcement

DDC: Developmental Disabilities Council

DDDS: Division of Developmental Disabilities Services

DEMA: Delaware Emergency Management Agency

DHSS: Department of Health and Social Services

DMMA: Division of Medicaid and Medical Assistance

DMS: Division of Management Services

DPH: Division of Public Health

DSAMH: Division of Substance Abuse and Mental Health

DSAAPD: Division of Services for Aging and Adults with Physical Disabilities

DVI: Division for the Visually Impaired

ED: Emergency Department

FOBT: Fecal Occult Blood Testing

HDWD: Healthy Delawareans with Disabilities

HMO: Health Maintenance Organization

OT: Occupational Therapy

PWAFMN: Persons with Access, Functional, and Medical Needs

SCPD: State Council for Persons with Disabilities

SNAP: Special Needs Alert Program

SSI: Supplemental Security Income

TA: Technical Assistance

UD: University of Delaware

USPSTF: United States Preventive Services Task Force

VA: Veterans Affairs

VOAD: Volunteers Active in Disasters

YRBS: Youth Risk Behavior Survey



