



# *The Plan to Achieve Health Equity*

*for Delawareans  
with Disabilities*



Delaware Health and Social Services





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## *for Delawareans with Disabilities*

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A listing of planning group members can be found on page 26.

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# TABLE OF CONTENTS

MESSAGE FROM THE SECRETARY .....	2
INTRODUCTION .....	3
MISSION AND VISION .....	4
PLANNING PROCESS .....	4
NEXT STEP: IMPLEMENTATION.....	5
GOAL 1: Strengthen the state’s capacity to promote health equity for people with disabilities .....	6
GOAL 2: Achieve full compliance with civil rights laws and regulations designed to protect people with disabilities .....	14
GOAL 3: Create a culture that is conducive to achieving health equity for people with disabilities .....	17
GLOSSARY .....	22
ACRONYMS & ABBREVIATIONS.....	25
PLANNING GROUP MEMBERSHIP LIST .....	26
REFERENCES .....	29





## MESSAGE FROM THE SECRETARY

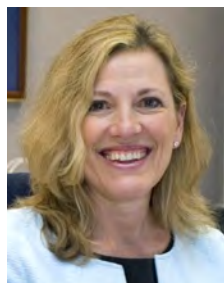
*For more than 30 years, I have supported individuals with disabilities—for the last six years as Cabinet Secretary. In that time, we have made incredible strides because of the Americans with Disabilities Act (ADA), the Olmstead decision, medical advances, innovations in technology, the strong voices of advocates and self-advocates, and, most importantly, the evolution of inclusion.*

*We are a stronger community because we value and experience the benefits of inclusion. Still, there is much more to be done – within DHSS and the greater community.*

*Achieving health equity for Delawareans with disabilities is the next phase of that evolution of inclusion. The development of the Plan to Achieve Health Equity for Delawareans with Disabilities offers a blue print for the transformation necessary to reach our goal.*

*With the release of this plan, I want to establish health equity for people with disabilities as a department-level priority. This is consistent with the work of our Bureau of Health Equity and will ensure that disability is integrated across divisions into the work of addressing disparities for the nearly one in five Delawareans who report having a disability.*

*This is our collective challenge: We must work upstream to find the factors that contribute to inequity in health access and outcomes. We must work across sectors whose primary goals are not necessarily health. As we do, you have my commitment that DHSS will continue our health equity work with a variety of partners within our traditional scope and beyond it. You have my promise that there will be a receptive climate to the strategies that are proposed in this plan. And we will embrace Public Health's health-in-all policies approach. Because that is truly how we will achieve a healthier Delaware for all of our residents.*



Secretary Rita Landgraf  
Delaware Department of Health  
and Social Services

# INTRODUCTION

Over the past several decades, progress has been made in equal access for individuals with disabilities as a result of federal legislation such as the Americans with Disabilities Act (1990). People with disabilities are increasingly visible in our communities, neighborhoods and workplaces. There are, however, domains that continue to present difficulties in fully realizing the spirit and intentions of our contemporary practices of inclusion. One critical area is the wide spread inequity in the area of health – in terms of access to services, the quality of service available and delivered, and the health outcomes experienced by individuals with disabilities.

*The Current Landscape for Disability and Health in Delaware – A Public Health Assessment Report* is a companion document to this plan that describes the health disparities reported by individuals with disabilities. The document also details the disproportionate burden of disease experienced by Delawareans with disabilities through a review of health data and highlights the findings of a survey of physical and programmatic access barriers that continue to exist. In addition, this assessment shares the personal stories of individuals with disabilities who face challenges in accessing health care and in maintaining a healthy, active lifestyle.

People with disabilities disproportionately bear the burden of disease and experience disparities in health care access and outcomes.

The Center for Disabilities Studies (CDS) at the University of Delaware (UD) has partnered closely with state government and the health community to address issues of health inequity. Beginning in 2005 through a CDC funded cooperative agreement, titled Healthy Delawareans with Disabilities (HDWD), work began in Delaware to increase awareness of the need for greater accessibility and inclusivity of health and wellness programs and facilities. This project has been a partnership between the CDC, the Delaware Department of Health and Social Services (DHSS) and CDS at UD (who acts as the bona fide agent of DHSS in the cooperative agreement). The HDWD Project has several key initiatives that were designed to capture the current status of health equity of individuals with disabilities in Delaware. These initiatives include: (1) an Advisory Council with representation from the disability and health care communities; (2) a Statewide Public Health Assessment of the population with disabilities; and (3) the creation of a statewide plan, this document - *The Plan to Achieve Health Equity for Delawareans with Disabilities*.

NOTE: A list of all acronyms and abbreviations used in the plan can be found on p. 25.



## MISSION AND VISION



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.

## PLANNING PROCESS

This stakeholder-based strategic planning process had the unique feature of involving a group that was connected primarily by their relationship to health care and health promotion for individuals with disabilities. Planning was designed to promote consensus and result in a concise set of actions.

A statewide stakeholder group of approximately 50-60 people was identified and invited to participate in a strategic planning initiative. This initiative was designed to reflect parameters resulting from the statewide public health assessment (conducted in 2013), and with consideration of a review of work previously accomplished in existing health-related plans. The large group met monthly between April and July of 2014 and each meeting was led by a professional facilitator. Each workgroup met at least once between each of the large group meetings.

The stakeholder group included the HDWD Advisory Council, the Emergency Preparedness for Individuals with Disabilities Advisory Group, and the members of the Health Care Committee of the Governor's Commission on Building Access to Community-Based Services. Representatives from DHSS

divisions participated in all work groups. Additional invitations were extended to ensure representation from other community sectors such as corrections, education, people experiencing homelessness and foster care systems.

Initial planning exercises targeted five focus areas that included Inclusive Health Promotion; Data-Monitoring and Surveillance; Emergency Preparedness & Response; Access to Health Care; and At-Risk Groups (e.g., homeless). The stakeholders participated as a large group and each was further designated to one of five work groups that reflected the focus areas. Co-chairs were identified and a CDS staff member was assigned to work with each of the workgroups.

The foundation of the planning process was rooted in a modified creative problem solving approach in which the stakeholders were given specific tasks reflecting divergent thinking. This generated data at each of the large group and workgroup meetings that were analyzed (convergence) to generate progress toward the plan development. Each stage of the plan development, therefore, reflected the collective ideas and expertise of the stakeholders, yet were further refined and finalized by CDS staff. In addition, factors from outside data sources (e.g., Statewide Public Health Assessment) were integrated into the final draft of the plan.

*The Plan to Achieve Health Equity for Delawareans with Disabilities* represents the consensus of a committee of designated DHSS staff and community partner representatives on key focus areas. It is presented as a comprehensive collection of specific activities that will guide public health and community leaders in transforming our system of care to meet the needs of individuals with disabilities.



## NEXT STEP: IMPLEMENTATION

The implementation of *The Plan to Achieve Health Equity for Delawareans with Disabilities* will begin in February 2015. The process will be led by the Health Care Committee of the Delaware Governor's Commission on Building Access to Community-Based Services. This committee is made up of state government officials, policy makers, community health and disability professionals, disability advocates, direct support professionals, individuals with disabilities and family members. This group, with the help of its partners and other stakeholders, will determine the path forward in accomplishing the goals and objectives of this plan through sustainable systems change. The group will establish priorities for implementation, harness available resources, create timelines for action and identify DHSS staff and community partners to collaborate on achieving our goal of health equity for Delawareans with disabilities.

# GOAL 1:

## Strengthen the state's capacity to promote health equity for people with disabilities

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

Since then, numerous reports describing the specific challenges to health and well-being faced by people with disabilities have been released, including a comprehensive report issued by the National Council on Disability titled, *The Current State of Health Care for People with Disabilities* (2009). This report indicated that people with disabilities were not benefiting from equitable opportunities to participate in healthcare and health programs. A 2013 Delaware public health assessment of the population with disabilities further validated the overall findings of this national report. This statewide study indicated that people with disabilities in Delaware require improvements in systems and services for achieving optimal healthcare, accessing recreational facilities, and inclusion within health promotion activities and emergency planning and response initiatives. Referencing data from the 2012 Behavioral Risk Factor Surveillance System (BRFSS), the assessment indicated that compared to their counterparts without disabilities, Delawareans older than 18 years of age with disabilities had worse health status and outcomes.

The data indicate that compared to counterparts without disabilities, adults with disabilities are:

- more likely to report a delay in seeing a doctor due to cost (19.8% vs. 11.3%),
- more likely to be obese (39.7% vs. 23.7%),
- less likely to be physically active in the past month (59.7% vs. 80.6%),
- more likely to be current smokers (25.1% vs. 18.4%), and
- more likely to report chronic conditions of diabetes (20.4% vs. 7.0%), coronary heart disease (13.4% vs. 2.9%), and depression (33.8% vs. 10.1%).

Families of children with special health care needs (CSHCN) in Delaware also report barriers to care and services. Approximately one third (28%) of CSHCN and their families in Delaware reported, in 2009/2010, not having participated in the decision making process with health care providers, not having had adequate health insurance (30%), and having had difficulty accessing community based services (30%).



## OBJECTIVE 1.1:

### To establish health equity for people with disabilities as a department level (DHSS) initiative by June 2015

*In order to achieve health equity for Delawareans with disabilities across all subpopulations (racial, cultural and ethnic minorities, women, veterans, people experiencing homelessness and LGBT), a comprehensive set of initiatives must be undertaken on a department level, reaching across divisions and being embedded within all DHSS programs. Launching a department-level initiative by June 2015 will lay the foundation for the following activities designed to strengthen the state's capacity through training, technical assistance and policy change.*

1. Create a position to coordinate Disability and Health Initiatives at the department level to ensure system-level change and to coordinate implementation of this plan through the activities of the Health Care Committee of the Governor's Commission for Building Access to Community Based Services, the CDC-funded Disability and Health grant at the Center for Disabilities Studies, the Delaware State Health Care Innovation Plan implementation and the divisions of DHSS.
2. Establish and implement a Training and Technical Assistance Resource Center to support accessible and inclusive environments, targeting health care, prevention, fitness and recreation, building and renovation, and community living.
3. Establish an inclusion policy within DHSS that requires all contractors and grantees to address how their proposed program or service will reach people with disabilities across all racial and ethnic minorities and across the lifespan.
4. Provide on-demand technical assistance to DHSS contractors and grantees regarding inclusion policy.
5. Include disability status (when available) in regularly published public health reports (i.e., cancer, tobacco, cardiovascular disease).



*continued on p. 8*

## GOAL 1: OBJECTIVE 1.1 (CONTINUED)

6. Publish or distribute online regular reports on health disparities of people with disabilities.
7. Establish a mandate that disability service organizations contracted with DHSS are required to assist their clients in preparation of emergency plans for evacuation and sheltering in place.



8. Establish a policy to include disability representation in all health planning initiatives (review of government emergency operational plans; public health promotion programs, etc.).

**Establish  
a policy  
to include  
disability  
representation  
in all health  
planning  
initiatives.**

## OBJECTIVE 1.2:

**To create a training and technical assistance system to build an adequate workforce that is skilled and culturally competent in meeting the needs of people with disabilities by June 2016**

*In order to address the lack of cultural competency including awareness and understanding of disability in professional preparation within health care, education and community training programs, the plan includes a multi-faceted training and technical assistance strategy. This strategy focuses on increasing awareness and knowledge of people with disabilities and building skills for improving quality of care. This includes a core set of competency trainings available and in use by June 2016.*

1. Identify, or develop, and implement training (web-based, live and conference) and technical assistance for health care providers (medical, dental, behavioral, social workers, support professionals and navigators) on the following topics:
  - methods to improve accessibility through principles of universal design,
  - building cultural competency,
  - quality indicators and skills needed to care for people with disabilities,
  - accessible communications and alternate formats,
  - routine protocols for inquiring about needed accommodations by providers and others,
  - ADA requirements,
  - trauma-informed care,
  - access to assistive technology and durable medical equipment, and
  - community resources.



2. Develop and implement training and technical assistance to municipalities and the building trades community on the following topics:

- ADA requirements and best practices for retrofitting existing structures,
- integration of principles of universal design, and
- identifying funding sources for repair of inaccessible or unsafe sidewalks.



3. Deliver training and technical assistance to community service agencies on the following topics:
  - providing safe and accessible environments for people with disabilities and mental illness,
  - the importance of a welcoming “point of entry” for services, and
  - the need for a trauma-informed approach to the unique needs of trauma survivors with disabilities and/or mental illness.
4. Develop and implement training and technical assistance to health educators, promotion planners, and exercise, sports, recreation and fitness professionals in the provision of inclusive services.
5. Identify and disseminate the benefits and availability of financial incentives to promote Certified Inclusive Fitness Trainers in Delaware.
6. Increase the availability and impact of trainings through:
  - partnering with professional organizations to offer continuing education credits for training of skills regarding disability cultural competency,
  - integrating disability cultural competency into existing staff development initiatives within DHSS and community partner agencies,
  - incorporating disability cultural competency training into state-mandated trainings for health professionals, and
  - integrating disability cultural competency and accessibility into higher education pre-service training for allied health, physicians, nurses, and navigators.
7. Revise recruitment and credentialing policies to support building an adequate supply of professionals (dentists, audiologists, behavioral health providers, speech-language pathologists, sign language interpreters) that provide specialized services to individuals with disabilities.
8. Identify and develop a listing of health professionals who provide specialized services for individuals with disabilities.

*continued on p. 10*

## GOAL 1: OBJECTIVE 1.2 (CONTINUED)

**Provide technical assistance to emergency planners regarding including people with disabilities in government emergency preparedness and response planning exercises.**

9. Establish joint training and dissemination activities with the Medical Society of Delaware and the American Academy of Pediatrics to encourage Delaware physicians to promote physical activity for people with disabilities.
10. Develop and conduct a statewide conference for public health professionals to promote disability cultural competency and accessibility in clinical services, health promotion and allied health services.
11. Conduct a statewide assessment of existing training (pre-service and in-service) regarding inclusive physical education and adapted physical education.
12. Identify and/or develop opportunities to enhance and implement training for physical education teachers regarding inclusive and adapted physical education.
13. Develop a pre-service training program at the college level to provide certification in inclusive fitness training.
14. Provide training on preparing a personal emergency plan to evacuate or shelter in place for people with disabilities through partnerships with: civic and home owners' associations, community organizations (e.g., Rotary, Kiwanis, Lions Clubs), Citizens Corps, Centers for Independent Living (CIL), DHSS agencies, CIL, CDS, Developmental Disabilities Council (DDC), group homes, and residential facilities' staff.
15. Provide training to shelter workers regarding best practices in assisting people with disabilities during an emergency.
16. Provide training to staff at information and referral services (ADRC, 211, etc.) for the purpose of building capacity for serving people with disabilities.

## OBJECTIVE 1.3:

**To adopt and implement evidence-based practices and tools for improving accessibility, inclusion and cultural competency by June 2016**

*To address the lack of widespread information about how to achieve accessibility and inclusion, the plan promotes the use of evidence-based tools and guidelines to facilitate change that will promote health equity.*



1. Establish an information and dissemination initiative that summarizes ADA regulations for Medicare and Medicaid providers.
2. Establish guidelines on accessible materials and assistive technology.
3. Establish policies and standards for development of an epidemiology and surveillance program for disability.
4. Identify and develop standards for accessible communication and messaging systems for use during emergencies.
5. Establish a toll-free medical insurance specialty counseling service for people with disabilities and their caregivers.
6. Establish, or strengthen, office practice policies and procedures to include routine discussion of accessibility and needed accommodations (i.e., at time of appointment scheduling).
7. Identify and disseminate information on funding sources/financial incentives for accessibility improvements in health care settings, fitness/recreation settings, and to promote the use of Certified Inclusive Fitness Trainers.
8. Identify and implement best practices for an inclusive assessment of fitness level for all students in Delaware to ensure inclusion of students with disabilities.
9. Provide technical assistance to emergency planners regarding the inclusion of people with disabilities in government emergency preparedness and response planning exercises by:
  - a. creating a database of volunteers for emergency training exercises and tracking the number of participants, and
  - b. developing and disseminating a list of essential resources needed to ensure safety and independence of people with disabilities in emergency shelter settings.
10. Identify or develop a self-assessment tool to assess accessibility in home settings for use by hospitals and institutions prior to discharge.



*continued on p. 12*

## GOAL 1: OBJECTIVE 1.3 (CONTINUED)

11. Identify or develop a self-assessment tool for use in community health promotion activities and services.

### OBJECTIVE 1.4:

**To increase public awareness of opportunities for achieving health equity for people with disabilities by June 2018**

*As capacity grows within the system, the plan promotes mechanisms to inform the public of information about access to available services.*

**Develop  
a public  
awareness  
campaign on  
how to be a  
self-advocate  
for accessibility**

1. Develop and implement a public awareness campaign targeted to people with disabilities and caregivers on the following topics:
  - a. availability of local health services,
  - b. availability of assistive technology, accessible equipment and devices,
  - c. nutrition programs and resources (Supplemental Nutrition Assistance Programs [SNAP]), and
  - d. benefits of health promotion activities and locations of accessible gyms, fitness classes, and accessible outdoor recreation areas.
2. Create and launch a marketing campaign to promote the benefits of having Certified Inclusive Fitness Trainers within public and private fitness facilities.
3. Develop and disseminate inclusive and accessible health promotion and health education materials on the following topics:
  - a. oral health,
  - b. mental health,
  - c. physical activity,
  - d. tobacco,
  - e. home safety,
  - f. domestic violence, and
  - g. hearing loss.
4. Develop a public awareness campaign targeted to people with disabilities, policy makers, legislators and stakeholders about the following topics:
  - a. the importance of having one statewide registry for people with functional and access needs,
  - b. the need for a mechanism to fill prescriptions during emergency situations, and
  - c. the Preparedness Buddy model.





## OBJECTIVE 1.5:

**To create a coalition of advocates to take action on key disability issues related to health and wellness by December 2015**

*There are many disability advocacy groups in Delaware. The plan proposes harnessing and expanding their collective energy to focus on health and wellness system change. This collaboration would promote self-advocacy and an advocacy action network.*



1. Identify, or develop, and implement an awareness campaign which includes a tool kit for people with disabilities of all ages regarding how to be a self-advocate for accessibility. This would include knowledge of rights to accessible health care and procedures for filing complaints.
2. Integrate a self-advocacy awareness campaign into school curricula and recreation programs (e.g., camps, after-school programs).
3. Create an advocacy action network on key issues such as assistive technology, dental and hearing aid coverage, and service coordination. This network will include self-advocates and agencies serving people with disabilities and at-risk populations.



4. Recruit and train volunteers with disabilities to participate in: accessibility assessments, information and referral services on medical/insurance issues related to disability, and emergency planning and response exercises.

## GOAL 2:

Achieve full compliance with civil rights laws and regulations designed to protect people with disabilities



**Rationale:** Civil rights laws and regulations have been established which, if properly enforced, can aid in achieving this goal. The Americans with Disabilities Act (ADA) is a comprehensive civil rights federal law that prohibits discrimination and guarantees that people with disabilities have the same opportunities as everyone else to participate in the mainstream of American life including equal access to health care and related services (<http://www.ada.gov/>). The ADA mandates medical care providers and public health systems and institutions to make services accessible to individuals with disabilities. These statutes require that people with disabilities are provided access to medical care services and facilities such as public and private hospitals or medical offices and clinics, health promotion programs, recreational activities, and emergency shelters.

*It is well established that people with disabilities are at a disadvantage to access general medical and preventive medical care (Iezzoni, 2011). In Delaware, 19.8% of adults with disabilities reported a delay in seeing a doctor due to cost compared to 11.3% of adults without disabilities (BRFSS, 2012). Individuals with disabilities are less likely to receive adequate oral*

*health care. For instance, in Delaware in 2012, 58.6% of adults with a disability reported visiting their dentist within the last 12 months compared to 72.8% of adults without a disability. In Delaware, 10.1% of adults with a disability reported having skin cancer, compared to 5.5% of adults that do not have a disability. Finally, 12.1% of adults with a disability reported having another type of cancer, compared to 6.1% of adults that do not have a disability (BRFSS, 2012).*

*The strategic planning stakeholders meetings held in the spring of 2014 yielded qualitative data to support the statewide public health assessment data that captured lapses in the implementation of disability-related discrimination laws, specifically those related to health care access and promotion. There exists a need for a more consistent commitment to identifying and reporting violations as a mechanism for promoting improved access.*

Create a public health surveillance system for disability.



*A system that tracks the access and outcomes of an identified population with disabilities will provide data to facilitate monitoring of compliance with civil rights legislation.*

## OBJECTIVE 2.1:

### **To strengthen the system to monitor and report compliance with current federal and local laws and regulations by December 2017**

*Laws related to equal access for people with disabilities are tools for achieving health equity that have been underutilized. Although these laws and regulations exist, active enforcement needs to be improved.*

1. Promote enforcement of compliance with federal and state accessibility requirements for public and private facilities by integrating accessibility measures into existing routine facility and provider licensing/accreditation/certification (e.g., Medicaid managed care contracts, PLUS checklist).
2. Promote enforcement of compliance with federal and state accessibility requirements for public and private facilities by integrating accessibility compliance into the quality score card proposed in the State Health Care Innovation Plan.
3. Identify, or create, a system to report and monitor state, county and local compliance with ADA accessibility requirements of sidewalks and crosswalks.

**Introduce legislation to expand Medicaid coverage to include oral health services for adults.**

## OBJECTIVE 2.2:

### **To identify gaps in equity and introduce legislation to strengthen enforcement strategies by June 2016**

*Barriers exist for people with disabilities across services and settings. Creating legislation that would address the disparities resulting from these barriers would promote equitable access to health care.*

1. Introduce legislation to expand Medicaid coverage to include oral health services for adults.

*continued on p. 16*



## GOAL 2: OBJECTIVE 2.2 (CONTINUED)

2. Identify (existing or new) opportunities to integrate universal design principles into community development in Delaware through building code amendments or new legislation.
3. Require the use of accessible medical equipment (i.e., scales, lifts, adjustable height exam tables) in medical settings to align with national standards through amended or new legislation.

## OBJECTIVE 2.3:

**To create and implement a public health surveillance system to monitor the health status, health needs, and health care access and utilization of people with disabilities by 2019**

*Disability status indicators are not routinely collected in health settings within Delaware. To monitor and improve the health of Delawareans with disabilities, the plan articulates consistent collection and analysis of disability status as a demographic variable.*

1. Establish a Data Coordination Project that explores and identifies appropriate disability indicators as a demographic variable, including current use in Delaware, existing models outside of Delaware, and opportunities and obstacles for expansion in Delaware.
2. Create a public health surveillance system for disability that requires DHSS programs and community partners to collect and report disability status as a demographic variable.
3. Integrate disability status into electronic health records, all DHSS service intake forms, the Delaware Health Information Network (DHIN), and other public health service systems.
4. Assess and provide technical assistance to existing vendors of online health vault systems to ensure that patients with disabilities can access health and social services records.
5. Develop and implement a mechanism to identify needed accommodations as part of an individual's medical record.
6. Conduct a statewide assessment of where people with disabilities live and, using geographic information system (GIS) mapping, identify missing, unsafe, inaccessible, or needed sidewalks.

# GOAL 3:

## Create a culture that is conducive to achieving health equity for people with disabilities

**Rationale:** *In addition to the need for enforcement of the federal and state civil rights laws, the planning stakeholders identified a strong need for awareness and acceptance in the community.*

*Disability is part of the human condition – almost everyone will be temporarily or permanently impaired at some point in life, and those who survive to old age will experience increasing difficulties in functioning (WHO, 2011). Promoting acceptance of disability as a natural part of community life requires deliberate action. We must build a common understanding of the nature and needs of people with disabilities and share a sensitivity to the cultural aspects of disability, as well.*

*The stakeholders recognized the interdependence of the “health” system on other systems within the state – education, transportation, and land use and development, for example. Within these systems, there is often a lack of awareness that people with disabilities are being served and of the unique requirements for delivering accessible, inclusive service.*



*Providing this elevated level of service requires a heightened commitment to coordination and attention to the intricate details of transitioning smoothly from one system to the next. There is evidence that these coordination and transition needs are often not addressed for people with disabilities. Stakeholders concluded that the reason for this lack of service coordination is related to inconsistent assessment for disability indicators and insufficient accommodations built into these complex systems. With increased awareness and access to supports and accommodations, individuals with disabilities and their families will be able to navigate systems to receive comprehensive, coordinated care.*



## OBJECTIVE 3.1:

### To improve service coordination and continuity for people with disabilities by December 2019

*The inadequate connections between services present particular challenges for people with disabilities. Identification of unique needs or accommodations at the point of entry into or discharge from a program or service would facilitate continuity of care and improve its quality.*

**Establish  
a Patient  
Centered  
Medical Home  
pilot project  
for individuals  
with intellectual  
disabilities.**

1. Assess current practices for planning the transition of people with disabilities as they navigate between agencies in Delaware.
  - a. Review discharge protocols and receiving agency's procedures for health assessment and referral (hospitals, including VA system, rehabilitation facilities, emergency and domestic violence shelters, foster care, behavioral health treatment centers, and correctional facilities).
  - b. Identify barriers to successful discharge by surveying case managers and conducting focus groups with at-risk populations (youth in foster care, veterans, victims of domestic violence, and others).
2. Identify and promote best practices for service coordination and continuity between agencies (transition and discharge) through a "best practices" document to be disseminated across divisions.
3. Identify and provide training on effective and efficient models of information and referral, care coordination and accountability for adults with disabilities (e.g., Family SHADE, existing Disability Councils, and Child Protection Accountability Commission).
4. Establish a Patient Centered Medical Home pilot project that focuses e.g., on individuals with intellectual disabilities.
5. Advocate for care coordination as a reimbursable service (align with SIM, patient centered medical home, and telehealth initiatives).
6. Advocate for care coordinators (e.g., navigators) in all primary care practices.
7. With partners (e.g., FQHCs, SIM, DOHC), advocate for more medical and dental homes with culturally competent providers.
8. Expand the use of DPH mobile dental care unit to include specialized services for people with disabilities.

9. Identify existing efforts around health care transition for youth with disabilities and establish a statewide alliance (A.I. duPont Transition of Care, State Transition Task Force, etc.).
10. Assess relationship between mental health, medication and overweight/obesity and use results to establish a mechanism to trigger nutritional counseling.
11. Develop, test and implement a mechanism for refilling prescriptions during an emergency.
12. Establish an ongoing relationship and reporting structure between the Governor's Commission and disability-related initiatives that support the plan (Telehealth Coalition, DSAMH, DPH, etc.)

## OBJECTIVE 3.2:

**To amend the language within state policies related to medical and dental insurance that present barriers to health equity by June 2018**



*Comprehensive care addresses not only the general health needs of individuals, but also includes mental health, oral health, assistive technology and equipment, and wellness. To facilitate the delivery of comprehensive care, policy language and coverage will be amended to broaden the services available to individuals with disabilities.*

1. Develop policies and/or legislation to address inadequacies of health insurance coverage in meeting the needs of people with disabilities (including dental, behavioral health and durable medical equipment).
  - a. Extend dental coverage to adults enrolled in Medicaid.
  - b. Expand definition of medically necessary services to address needs of people with disabilities.
2. In partnership with the Oral Health Coalition, the Governor's Commission will advocate for inclusion of dental coverage for adult Delawareans who are enrolled in Medicaid.
3. Integrate comprehensive behavioral health services into essential health benefits coverage.
4. Promote inclusion of assistive technology and accessible medical equipment in covered insurance services.

*continued on p. 20*

## GOAL 3: OBJECTIVE 3.2 (CONTINUED)

5. Review and evaluate existing legislation, regulations, policies and plans regarding the availability of prescription refills and related supplies during or preceding a declared emergency.
6. Develop and implement adjusted reimbursement rates to allow for the services (e.g., longer appointment times, care coordination) needed to provide comprehensive care for people with disabilities.

## OBJECTIVE 3.3:

**To create accessible and inclusive environments to promote community living for people with disabilities by end of 2019.**

*Maintaining a healthy lifestyle requires equal access to services that enable individuals with disabilities to participate fully in community life. This includes transportation, trails and pathways, schools, fitness and recreation settings and services, food venues and community gardens.*

1. Review the Delaware Human Relations Committee activities to assess accessibility of businesses in Delaware.
2. Advance the use of universal design in new building construction (e.g., in PLUS review).
3. Identify professional resources to conduct home and facility accessibility assessments and disseminate a listing.
4. Provide technical assistance to garden projects about accessibility and inclusion.
5. Identify and promote use of an assessment tool (e.g., Community Health Inclusion Index) to assess accessibility in food venues (supermarkets, restaurants, farmer's markets, etc.), and publish the findings.
6. Review and consider feasibility of expanding Goodwill Reuse Equipment Program.
7. Support legislation requiring 150 minutes per week of physical activity in schools and ensure such legislation is inclusive of students with disabilities.

Add physical education as a required goal in Individualized Education Programs (IEP).



8. Add physical education as a required goal in Individualized Education Plans (IEP).
9. Add nutrition and health education as a required component of the Essential Lifestyle Plan (ELP).
10. Monitor development of the Delaware Statewide Trails and Pathways Initiative to ensure accessibility.
11. Review algorithm for timing signals at pedestrian crosswalks (DelDOT/ADA standards) and advocate for increased time to allow for pedestrians with disabilities.
12. Identify and disseminate existing incentives for municipalities to make walkways more accessible.
13. Advocate for a reliable, efficient and affordable transportation system to impact access on health care by aligning with existing initiatives (Wilmapco, Transportation Equity and Justice Plan, DART/paratransit).
14. Compile listing of and assess private transportation services available in Delaware and make recommendations to address gaps in service.
15. Conduct a Statewide Health Impact Assessment of proposed changes to the state para-transit system to guide policy recommendations for improvement.



## GLOSSARY

*Definitions that do not indicate a reference source were defined by the Healthy Delawareans with Disabilities Advisory Council for use in the 2009 strategic plan, and reviewed by the Health Equity Planning Group.*

### **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 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 Competency in Health Care**

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. 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.

### ***Family SHADE (Support Healthcare Alliance Delaware)***

Delaware's Family SHADE is a collaborative alliance of family partners and organizations committed to improving the quality of life for children and youth with special health care needs by connecting families and providers to information, resources and services ([www.familyshade.org](http://www.familyshade.org)).

### ***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.

### ***Health Disparity***

A particular type of health difference that is closely linked with social or economic disadvantage. Health disparities adversely affect groups of people who have systematically experienced greater social and/or economic obstacles to health and/or a clean environment based on their racial or ethnic group; religion; socioeconomic status; gender; age; mental health; cognitive, sensory, or physical disability; sexual orientation; geographic location; or other characteristics historically linked to discrimination or exclusion. (DHHS: National Partnership for Action to End Health Disparities) (USDHHS: National Partnership for Action to End Health Disparities; <http://minorityhealth.hhs.gov/npa/templates/browse.aspx?lvl=1&lvlid=34>).

### ***Health Equity***

Health equity is attainment of the highest level of health for all people. Achieving health equity requires valuing everyone equally with focused and ongoing societal efforts to address avoidable inequalities, historical and contemporary injustices, and the elimination of health and healthcare disparities. (USDHHS: National Partnership for Action to End Health Disparities; <http://>

[minorityhealth.hhs.gov/npa/templates/browse.aspx?lvl=1&lvlid=34](http://minorityhealth.hhs.gov/npa/templates/browse.aspx?lvl=1&lvlid=34))

### ***Health Literacy***

Health literacy is defined in the Institute of Medicine report, *Health Literacy: A Prescription to End Confusion*, as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions." Health literacy is not simply the ability to read. It requires a complex group of reading, listening, analytical, and decision-making skills, and the ability to apply these skills to health situations (<http://nnlm.gov/outreach/consumer/hlthlit.html>).

### ***Homelessness***

An individual who lacks a fixed, regular, and adequate nighttime residence is considered a person experiencing homelessness. There are many definitions of homelessness. For a more detailed explanation, see <http://www.nhchc.org/faq/official-definition-homelessness/>.

### ***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)).

*continued on p. 24*



### ***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. The International Classification of Functioning, Disability and Health (ICF) defines disability as an umbrella term for impairments, activity limitations and participation restrictions. Disability is the interaction between individuals with a health condition (e.g., cerebral palsy, Down syndrome, depression) and personal and environmental factors (e.g., negative attitudes, inaccessible transportation and public buildings, limited social supports). (<http://www.who.int/mediacentre/factsheets/fs352/en>).

### ***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 with a disability, not as a disabled 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***

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

### ***Surveillance***

Public health surveillance is the ongoing systematic collection, analysis and interpretation of health data to set priorities and inform program planning and implementation for purposes of improving health.

### ***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.

## ACRONYMS AND ABBREVIATIONS

**AARP:** American Association of Retired Persons

**ACSM:** American College of Sports Medicine

**ADA:** Americans with Disabilities Act

**AT:** Assistive Technology

**ADRC:** Aging and Disability Resource Center

**BRFSS:** Behavioral Risk Factor Surveillance System

**CAPS:** Certified Aging in Place Specialist

**CCHS:** Christiana Care Health System

**CDC:** Centers for Disease Control and Prevention

**CDS:** Center for Disabilities Studies

**CHAP:** Community Health Access Program

**CIL:** Center for Independent Living

**CMMI:** Center for Medicare and Medicaid Innovation

**DAN:** Delaware Aging Network

**DATI:** Delaware Assistive Technology Initiative

**DD:** Developmental Disability

**DDC:** Developmental Disabilities Council

**DDDS:** Division of Developmental Disabilities Services

**DE HEAL:** Delaware Coalition for

Healthy Eating and Active Living

**DeIDOT:** Delaware Division of Transportation

**DHIN:** Delaware Health Information Network

**DHSS:** Delaware Health and Social Services

**DLTCRP:** Division of Long Term Care Residents Protection

**DMMA:** Division of Medicaid and Medical Assistance

**DNREC:** Department of Natural Resources and Environmental Control

**DOE:** Department of Education

**DOHC:** Delaware Oral Health Coalition

**DOI:** Department of Insurance

**DOL:** Department of Labor

**DPH:** Division of Public Health

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

**DSAMH:** Division of Substance Abuse and Mental Health

**DSP:** Direct Support Professional

**DSS:** Division of Social Services

**DSSC:** Division of State Service Centers

**DSU:** Delaware State University

**DVI:** Division for the Visually Impaired

**DVR:** Division of Vocational Rehabilitation

**EHR:** Electronic Health Record

**ELP:** Essential Lifestyle Plan

**FQHC:** Federally Qualified Health Centers

**GACEC:** Governor's Advisory Council for Exceptional Citizens

**HDWD:** Healthy Delawareans with Disabilities

**ID:** Intellectual Disability

**IEP:** Individualized Education Program

**LTC:** Long Term Care

**MCO:** Managed Care Organization

**MSD:** Medical Society of Delaware

**NAMI:** National Alliance on Mental Illness

**NCHPAD:** National Center on Health Physical Activity and Disability

**NCI:** National Core Indicators

**OMB:** Office of Management and Budget

**PIC:** Parent Information Center

**PLUS:** Preliminary Land Use Service

**SCPD:** State Council for Persons with Disabilities

**SHIP:** State Health Improvement Plan

**SIM:** State Innovation Model

**UD:** University of Delaware

**VA:** Veterans Affairs

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Or contact the U.S. Department of Education - Office for Civil Rights  
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