

Plan for Promoting the Health of People with Disabilities

The Massachusetts Department of Public Health Office of Health Equity Health and Disability Program

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Introduction

Since 1989, the Massachusetts Department of Public Health (DPH), Health and Disability Program (HDP) has been in the forefront in addressing the public health needs and concerns of people with disabilities in the Commonwealth. The Health and Disability Program is situated within the Office of Health Equity, which is part of the Commissioner's Office at DPH. HDP works collaboratively with key stakeholders to develop, implement, and evaluate efforts to improve the health and quality of life for people with disabilities. With funds from the U.S. Department of Health and Human Services, Centers for Disease Control and Prevention (CDC), HDP works to promote the health and well-being of persons with disabilities in Massachusetts and to prevent secondary conditions.

The Massachusetts Plan for Promoting the Health of People with Disabilities 2015 (the Plan) is the result of an eighteen month strategic planning process guided by the Massachusetts Health and Disability Partnership (the Partnership). The Partnership has been and will continue to be an essential partner for strategic planning and implementation efforts. In 2012-2015, the Partnership was expanded, bringing together people who are living with a disability and those who represent the disability community across the lifespan: children, youth, adults, and older adults. The membership of the Partnership and HDP worked collaboratively to involve a wide range of stakeholders and to ensure that their voices were heard in the planning process.

The Plan will guide HDP for the next three years and builds on past HDP initiatives and accomplishments. Overall the strategic plan will broaden and enhance statewide capacity to address the health of people with disabilities. Past accomplishments of HDP include: conducting a health needs assessment of people with disabilities in Massachusetts, development and implementation of the Massachusetts Facility Assessment Tool (MFAT) and related policies as part of MDPH vendor requirements, and provision of training and technical assistance to numerous internal and external stakeholders. In addition, MA is one of the few states in the US to include disability screeners in its high school and middle school health surveys, as well as in PRAMS, a health survey of women before, during, and shortly after pregnancy. HDP continually supports the development of policy and system changes for ADA compliance and disability inclusion and provides information needed to improve accessibility to healthcare and other community venues.

The Impact of Disability

According to the 2010 Census, 56.7 million individuals in the United States, that is 18.7% of the civilian, non-institutionalized population, live with at least one disability. *The Surgeon General's Call to Action to Improve the Health and Wellness of Peoples with Disabilities 2005* uses a general definition of disabilities:

"characteristics of the body, mind, or senses that to a greater or lesser extent, affect a person's ability to engage in some or all aspects of day-to-day life."

Not all disabilities are visible nor do they affect people in the same way. Disabilities may be physical, developmental or behavioral, visual or hearing, cognitive, or sensory. While some people are born with a disability, maybe one or more, many people acquire a disability, either permanent or temporary, over the course of their lives.

Health and disability are not exclusive. Though there has been misunderstanding in the past, disability is not an illness. All people need the knowledge, opportunities, and tools to fully participate in managing their health and preventing illness. People with disabilities need to have awareness of conditions that are secondary to a disability and have the means to access appropriate, culturally sensitive, quality health care to meet the needs of the whole person.

Data on disability in Massachusetts is drawn from a number of sources. The American Community Survey (ACS) provides community level data on the prevalence and socio-economic characteristics of children (5 years and over) and adults with disabilities. The principal data source for children with special health care needs is the 2009-2010 National Survey of Children with Special Health Care needs (NSCSHCN).

Data on the prevalence, risk behaviors, and health status of youth with disabilities is drawn from the Massachusetts Youth Health Survey (MYHS). The MYHS is self-administered survey among middle and high school students and includes questions on risk behaviors, safety, and measures of health status. The survey uses the following screeners to identify youth with disabilities:

- 1. Do you have any physical disabilities or long-term health problems?
- 2. Do you have any long-term emotional problems or learning disabilities?

Youth who answered "yes" to either of the screening questions are identified as having a disability.

The MA Behavioral Risk Factor Surveillance System (BRFSS) is the primary source of data on the health risk factors and preventive behaviors of adults in Massachusetts and also provides information on the health status, health care access, chronic conditions, and quality of life measures of people with disabilities in the state. The BFRSS is conducted in all states as a joint collaboration between the US. Department of Health and Human Services, Centers for Disease Control and Prevention and state departments of health. The Massachusetts BRFSS uses the following screening questions to identify adults with disabilities:

1. Do you have serious difficulty walking or climbing stairs?

2. Do you have difficulty dressing or bathing?

3. Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone, such as visiting a doctor's office or shopping?

4. Are you blind or do you have serious difficulty seeing, even when wearing glasses?

5. Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions?

Adults who answered "yes" to any of the screening questions are counted as having a disability.

Prevalence of Disability in Massachusetts

According to the 2011-2012 National Survey of Children's Health, 22.3% of children in MA have a special health care need compared to 19.8% in the US. The prevalence of disability among children increases with age from 14.5% for children less than five years old, to 27.2% for those between 6-11, and then decreases to 24.6% among those between twelve and seventeen years of age. Almost a quarter (24.2%) of males and 20.4% of females under age 18 in MA have a special health care need compared to 22.5% and 17% nationally. The survey also reports a higher percentage of white Non-Hispanic (23.3%) and Hispanic (22.7%) children with special

health care needs in Massachusetts than in the US (21.6% and 14.7%, respectively). Black non-Hispanic children are less likely to have special health care needs in Massachusetts than nationally (19.6% vs. 24.2%). Data for Asians and other race/ethnicities are consolidated in this study due to insufficient numbers.

Approximately 20.2% of middle school youth in MA reported having a disability compared to 27% of high school youth (MYHS 2013). Just over 22% of female middle school students and 18.4% of male middle school students reported having a disability compared to 24.1% of high school males and 29.8% of high school females. The percentage of middle school students with a disability was 19.7% for white non-Hispanics, 18.6% for black non-Hispanics, 21.8% for Hispanics, and 22% for Asian non-Hispanics/Pacific Islanders and students of other or multiple races/ethnicities. Among high school students, the percentage of students with a disability was 29% for white non-Hispanics, 23% for black non-Hispanics, 29% for Hispanics, 10.8% for Asian non-Hispanics/Pacific Islanders and 40.0% for other or multiple races/ethnicities.

Based on 2012 BRFSS data, 19% of the non-institutionalized adults or an estimated 760,000 people in Massachusetts reported having a limitation or disability due to impairment or health problem.

People with disabilities are at greater risk for negative health outcomes and secondary conditions than people without disabilities and these disparities begin in adolescence and continue throughout the lifespan. Youth with

disabilities are more likely to engage in risky behaviors such as alcohol use, tobacco use and also more likely to report fair to poor health and poor mental health (MYHS 2013). There are substantial differences in the smoking rates between youth with and without disabilities. Middle school youth with disabilities were significantly more likely to smoke in the past thirty days (5.8%) compared to 1.7% of youth without disabilities. Among high school youth, youth with disabilities were more than twice as likely (16.1%) to be current smokers compared to those without disabilities (6.6%).

As youth with disabilities transition into adulthood, they are also more likely to engage in risky behaviors and experience secondary conditions such as depression, diabetes, asthma, high blood pressure, heart disease, and other chronic conditions (BRFSS 2012). One in four adults with disabilities is a current smoker compared to 16% of adults without disabilities. Similarly, 57% of adults with disabilities are obese compared to 20% of adults without disabilities. Two-thirds (66%) of adults with disabilities participated in leisure time physical activity in the past month compared to 83% of their counterparts without disabilities. Adults with disabilities are also more likely to report chronic conditions than those without disabilities. For example, 13% of adults with disabilities; 16% of those with disabilities have diabetes compared to only 9% of those without disabilities and 11 of adults 35 years and older with a disability were told by a health professional that they had had a heart attack compared to only 3% of their non-disabled

counterparts. In addition, 38% of adults with disabilities report being in fair to poor health compared to 7% of those without disabilities.

The Massachusetts Plan for Promoting the Health of People with Disabilities is the guiding document for the Health and Disability Program and reflects collective input from self-advocates, parents/care providers, service organizations, disability advocacy organizations, state agencies, and other key stakeholders. HDP will continue to review and update the plan annually to determine progress toward meeting goals and to make necessary changes to promote the health and well-being of people with disabilities in Massachusetts. Adjustments will be made based on HDP progress reports, surveillance, and strategic priorities expressed by the Partnership members. <u>Mission:</u> The mission of the MDPH Health and Disability Program is to promote the health and well-being of people with disabilities in Massachusetts and to prevent secondary conditions.

<u>Guiding Principles:</u> Program goals, objectives, and activities must incorporate:

- Examination of the impact of social determinants of health
- Emphasis on cultural humility, self-determination, self-advocacy, equity, and intersectionality, with particular focus on issues of race, ethnicity, geography, gender, sexual identity, sexual orientation, and socioeconomic status
- Exploration of economic and other costs of discrimination
- Respect for multiple, flexible, and self-determined definitions of independence
- Prioritizing the provision of health care in the least restrictive setting possible
- Inclusion of and respect for people and populations with functional needs who may not identify as having disabilities (e.g., the culturally Deaf community, older adults, etc.)
- Inclusion of and respect for people and populations who have been marginalized within the disability community (e.g., populations of color, people with lived psychiatric experience, people with intellectual/developmental disabilities, etc.)

Health Promotion

Goal I Ensure quality health promotion opportunities are available and accessible for people with disabilities to maintain maximal independence.

Rationale

Health promotion opportunities are critical for people with disabilities to prevent or reduce secondary conditions, chronic disease and to decrease health disparities between people with and without disabilities. Disabling conditions exist along a continuum, varying in intensity from person to person, across the lifespan. Despite the age of onset of a disability, people with disabilities are now living or exceeding the expected lifespan of 78.8 years for all Americans. Increasing health promotion opportunities for persons with disabilities will reduce secondary conditions and decrease health disparities. "

- Increase skills of healthcare and support service personnel to provide appropriate, integrated, culturally sensitive, and respectful health care that meets the needs of the whole person, not just their disability.
- Implement evidence based health and wellness promotion programs to enable people with disabilities to manage their health care and prevent secondary conditions.
- Build awareness programs for hospitals and other medical systems in preparation for adding health and wellness promotion programing for people with disabilities.

Access to Health Care through Policy and Systems Change

Goal II Increase access to health services and facilities, emphasizing policy and systems change.

Rationale

When the comprehensive health needs of persons with disabilities go unaddressed secondary conditions can result. People with disabilities encounter barriers to fully participating in managing their health.

Often healthcare providers lack the knowledge and disability awareness necessary to treat people with disabilities. Accessible healthcare facilities and equipment are critical for receiving quality healthcare. HDP simultaneously targets and facilitates collaboration among providers and state agencies to bring about changes necessary to support the health of people with disabilities.

- Promote policy and systems change to increase access to primary healthcare.
- Update the Massachusetts Mammography Facility Assessment Tool for inclusion of the 2010 ADA updates and streamlined use in health care settings.
- Use findings from the MA Health Needs Assessment of People with Disabilities in Massachusetts, 2013 to target interventions that can improve health access for people with disabilities.

 Examine the specific impact of homelessness and housing instability on people with disabilities and promote policy and systems change to address housing and related issues.

Data and Surveillance

Goal III Better define the impact of disability in Massachusetts, including the impact of secondary conditions among people with disabilities across the life-span.

Rationale

Approximately 19% of Massachusetts' population has a disability or a limitation due to an impairment or health problem. Measuring the impact of disability in Massachusetts is essential for monitoring the health and wellbeing of the population. HDP is committed to better defining the impact of disability in Massachusetts including the impact of secondary conditions among people with disabilities.

- Ensure the continued inclusion in all relevant statewide surveillance instruments standard questions that identify people with disabilities.
- Provide relevant disability data and information for datadriven/evidence-based planning, implementation, and evaluation of programs and services for people with disabilities in Massachusetts.
- Ensure the inclusion of disability as a demographic variable in the MDPH surveillance and programmatic data systems to better define the impact of disability in Massachusetts.

- Track consistent disability data regarding people with disabilities and compare data relevant to people with and without disabilities.
- Mine existing state surveillance and programmatic data systems to measure the impact of disability in Massachusetts.
- Expand systematic dissemination of disability data to key stakeholders.
- Continue to conduct statewide health needs assessments of people with disabilities living in underserved communities.
- Conduct assessment of inclusion of people with disabilities in all MDPH programs.
- Work with the Division of Health Care Safety and Quality to create implement policy mandating accessibility assessments as part of MDPH licensure and certification processes.

Emergency Preparedness

Goal IV Ensure statewide emergency preparedness planning responds to the needs of people with disabilities.

Rationale

Although strides in public health disaster preparedness and response have been made, most communities remain unprepared to address the needs of individuals with disabilities. Lessons learned from 9/11 and Hurricanes Katrina and Rita, and more recently from Superstorm Sandy, show that there is still much work to be done to bolster the public health infrastructure through state and local partnerships and relationships for adequate preparedness and response to special populations.^w

- Utilize the Community Outreach Information Network (COIN).
- Make COIN part of the recruitment process for any emergency exercises.
- Partner with state agencies, the National Weather Service, and local weather services to make sure that their briefings include accessible information.

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Surgeon Generals' Call to Action, US Department of Health and Human Services, Public Health Service, Office of the Surgeon General, 2005.

Surgeon Generals' Call to Action

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Disability Policy Consortium, Emergency Preparedness and People with Disabilities #1