



Health Needs Assessment of People with Disabilities in Massachusetts, 2013

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“...people with disabilities are all too often still stigmatized and that stigma leads to being seen as a less important part of the landscape and so we become an afterthought.”

-Michael Muehe

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Executive Summary

The Disability, Health and Employment Unit, at the Center for Health Policy and Research, University of Massachusetts Medical School (UMMS) conducted an assessment of the health needs of people with disabilities on behalf of the Health and Disability Program (HDP), Office of Health Equity, Massachusetts Department of Public Health. The assessment was conducted to meet the Centers for Disease Control and Prevention (CDC) funding requirements of the Health and Disability Program and provided an in-depth examination of the health needs of people with disabilities in Massachusetts. This assessment provides comprehensive information on the unmet public health needs and priorities of the disability community in Massachusetts to enable HDP to prioritize its programmatic goals and objectives and better understand and meet the needs of Massachusetts residents with disabilities.

A multi-prong approach was used to collect data for this needs assessment. The sources of data include: (1) an existing health survey of adults in Massachusetts, (2) an online community survey of the health needs of people with disabilities in Massachusetts, and (3) interviews with key informants from the Massachusetts disability community.

(1) Data from the MA BRFSS

Section 1 of this report includes findings from the analysis of data from the 2011 Massachusetts Behavioral Risk Factor Surveillance System (MA BRFSS), a health survey of Massachusetts adults living in the community. The 2011 Massachusetts questionnaire can be found at <http://www.mass.gov/eohhs/docs/dph/behavioral-risk/survey-11.pdf>. The 2011 MA BRFSS data is the most recent data available as of the development of this report. However, certain health measures were not collected in the Massachusetts 2011 survey; for those measures the most recent data from 2010 was included and is noted accordingly. Most of the data in this

report were taken from *A Profile of Health Among Massachusetts Adults, 2011, Results from the Behavioral Risk Factor Surveillance System*.

Major Findings

Analysis of the MA BRFSS depicts significant differences in health among people with disabilities compared to those without disabilities in Massachusetts. Adults with disabilities were more likely to report poor physical and mental health, chronic conditions like diabetes and asthma, being current and lifetime smokers, lifetime sexual violence and unintentional falls in the past three months.

(2) Findings from the Survey of Health Needs of People with Disabilities in Massachusetts

The purpose of the online survey was to collect data on the health needs and priorities of the Massachusetts disability community and to seek data from sources other than traditional health surveys. 865 individuals representing the spectrum of the disability community in Massachusetts voluntarily completed the online survey. Respondents were more likely to be:

- Female (75%),
- Between the ages of 55-64 (32%),
- White (87%),
- Heterosexual (81%), and
- Identify their ethnicity as American (70%).

Thirty-nine percent of respondents identified themselves as being a person with a disability and 35% identified as family/guardian/caregiver of either an adult or child with a disability.

Major Findings

Each respondent answered a series of questions aimed at prioritizing the health needs of the disability community in Massachusetts. Respondents were asked to identify if the topic was a

“Big Problem,” “Small Problem,” or “No Problem.” The top ten categories identified as a “Big Problem” were:

1. Affordable housing (77%);
2. Adequate dental care (64%);
3. Adequate mental health services (62%);
4. Finding a doctor who is sensitive to disability issues (55%);
5. Transportation to doctor’s appointments (54%);
6. Communication supports, such as large print, Braille, CART readers, etc. (52%);
7. Managing chronic conditions, such as diabetes (50%);
8. Paying for prescription medications (48%);
9. Finding a doctor who accepts public health insurance (48%); and
10. Accessible gyms (45%).

(3) Personal Interviews

We collected in-depth qualitative data from six key informants of the Massachusetts disability community. The informants were selected by the UMMS evaluation team in collaboration with HDP staff. The selected individuals represented a spectrum of the disability community, including a parent advocate, leaders of independent living organizations and other disability advocacy groups, and a representative from a city commission for people with disabilities.

Major Findings

The stakeholders were asked to identify the most significant health concerns facing people with disabilities in Massachusetts. The findings from interviews with the six stakeholders were categorized into four themes:

1. Communication barriers faced by people with disabilities,
2. Need for cultural competency to address differences through the lens of race and ethnicity as well as disability,

3. Inaccessible and fragmented health care system which included a range of issues from inaccessible medical equipment to the lack of coordination in the delivery of health care and other services for people with disabilities, and
4. Lack of in-depth health data on people with disabilities in MA.

Introduction

On behalf of the Health and Disability Program (HDP), Office of Health Equity, Massachusetts Department of Public Health, the Disability, Health and Employment Policy Unit at the Center for Health Policy and Research, University of Massachusetts Medical School (UMMS) conducted a community health needs assessment to evaluate the unmet public health needs of people with disabilities in Massachusetts. The health needs assessment had three objectives:

1. To meet the funding requirements of the Centers for Disease Control and Prevention for HDP,
2. To provide in-depth data on the health needs of people with disabilities that went beyond the traditional public health data sources, and
3. To present comprehensive information on the unmet health needs and priorities of the disability community in Massachusetts to HDP.

This information is intended to enable HDP to prioritize its programmatic goals and objectives and better understand and meet the needs of Massachusetts residents with disabilities.

Background

Health and Disability Program

The Health and Disability Program (HDP) in the Office of Health Equity, Massachusetts Department of Public Health (MDPH) is funded through a state capacity-building grant from the Office of Disability and Health of the national Centers for Disease Control and Prevention (CDC). Massachusetts was one of the first nine states to apply for and receive funding under the CDC's Disabilities Prevention Program to establish the *Office of Disability Prevention* (ODP) in the MDPH. Over time, ODP evolved into the *Office on Health and Disability* with a focus on preventing secondary conditions among people with disabilities across the lifespan. HDP has

been a leader in Massachusetts in addressing the public health needs and concerns of people with disabilities.

The mission of HDP is to *“promote the health and well being of people with disabilities in Massachusetts and to prevent secondary conditions.”* This mission reflects the understanding that disability need not equal poor health; prevention and health promotion are as relevant for people with disabilities as for those without disabilities; and most secondary conditions or other health problems to which people with disabilities may be vulnerable, but which do not directly reflect their disabling conditions, are preventable.

HDP in collaboration with key stakeholders in the Massachusetts disability community developed the *2007 MA Strategic Plan for Promoting the Health of People with Disabilities*. The strategic plan includes the following goals:

1. Enhance program infrastructure and capacity
2. Improve State level surveillance and monitoring activities
3. Increase awareness of health-related disability policy initiatives
4. Increase health promotion opportunities for people with disabilities to maximize health
5. Improve access to health care for people with disabilities
6. Improve emergency preparedness among people with disabilities

Health and Disability Partnership

Since its inception, HDP has had a strong advisory committee whose members have included individuals with disabilities, their family members, advocates, state agency representatives, researchers, and disability or health service professionals. The current Massachusetts Health and Disability Partnership (the Partnership) is comprised of 58 individuals representing 32 organizations, advocacy groups, and state agencies. Also included in its membership are self-advocates, and parents of children with disabilities. The Partnership meets quarterly and is co-chaired by Dennis Heaphy, Policy Analyst of the Disability Policy Consortium and Bethlyn

Houlihan, Associate Director, Health & Disability Research Institute, Boston University School of Public Health.

The approach for this needs assessment was developed in consultation with the Partnership and HDP's Logic Model Workgroup which included a few members of the Partnership who volunteered to assist in the evaluation efforts of HDP.

Approach to Health Needs Assessment

HDP contracted with Monika Mitra, PhD from the Disability, Health and Employment Policy Unit at the Center for Health Policy and Research, University of Massachusetts Medical School (UMMS) to conduct the health needs assessment. Dr. Mitra, along with other members of the UMMS evaluation team, Christine Clifford and Lauren Smith conducted the needs assessment between March and June, 2013. Throughout the process, the UMMS evaluation team consulted with HDP staff and also sought advice from the Logic Model Workgroup of the Partnership. The needs assessment methodology was also shared with the Partnership during their quarterly meeting in March, 2013 and was further refined based on the suggestions of the Partnership members. This report builds on work by Dr. Shelley Goodgold, initial evaluation consultant to HDP. Between September and December 2012, Dr. Goodgold conducted an assessment of the existing secondary data on the health of people with disabilities in MA. She also engaged members of the Partnership in initially identifying and prioritizing the community health needs.

The assessment of the health needs of people with disabilities in Massachusetts involved a multi-pronged approach. First Dr. Goodgold and the UMMS evaluation team conducted an analysis and reporting of existing secondary data on adults with disabilities in Massachusetts. In order to reach people who may not be included in existing health surveys due to the methodology and limited accessibility of these surveys, the UMMS team developed two other approaches to complement the secondary data analysis: an anonymous survey on the health needs of people with disabilities, and personal interviews with selected members of the disability community in Massachusetts.

The methods of data collection for this report are described on the following pages.

Analysis of BRFSS Data

Population-based data on the health of adults with disabilities in Massachusetts is available through the Massachusetts Behavioral Risk Factor Surveillance System survey (MA BRFSS). The MA BRFSS is a random-digit-dial telephone survey of non-institutionalized adults ages 18 and over and provides data on a number of health-related measures including health status, risk behaviors, preventive behaviors, and health care utilization. It is an annual health survey conducted in all 50 states, the District of Columbia, and three territories, overseen by the Centers for Disease Control and Prevention (CDC) and administered by the individual states. Detailed information on the BRFSS can be found at <http://www.cdc.gov/brfss/index.htm>.

The Massachusetts 2011 BRFSS questionnaire can be found at <http://www.mass.gov/eohhs/docs/dph/behavioral-risk/survey-11.pdf>. The 2011 Massachusetts data is the most recent data available as of the development of this report. However, certain health measures were not collected in the 2011 survey. For those measures the most recent data from 2010 was included and is noted accordingly.

In the 2011 Massachusetts BRFSS the following questions were used to identify the disability status of survey respondents:

1. Are you limited in any way in any activities because of any impairment or health problem?
2. Because of any impairment or health problem, do you have any trouble learning, remembering, or concentrating?
3. If you use special equipment or help from others to get around, what type do you use?
4. Would you describe yourself as having a disability of any kind? A disability can be physical, mental, emotional, or communication-related.

Adults who answered yes to any of the screening questions were asked about the nature of their major impairment, health problem, or disability; how long their activities had been

limited; and whether they needed the help of other people in handling routine needs or personal care. People who responded yes to at least one of the screening questions and whose activities had been limited for at least one year were considered for this report as having disabilities. A total of 22,328 interviews including questions on disability were conducted in 2011, and a total of 5,772 individuals were identified as having disabilities. Detailed demographic information of all MA BRFSS respondents can be found in the report:

<http://www.mass.gov/eohhs/docs/dph/behavioral-risk/report-2011.pdf>. Detailed demographic information of adults with disabilities living in Massachusetts can be found in the 2008-2011 report: **A Profile of Health among Persons with Disabilities in Massachusetts, 2008-2011**

Andrews, B. K., & Wilson, T. (2012). *A profile of Health among Persons with Disabilities in Massachusetts, 2008-2011*. Boston: Massachusetts Department of Public Health.

Survey of Health Needs of People with Disabilities in Massachusetts

The 42-question web-based survey, titled *Survey of Health Needs of People with Disabilities in Massachusetts* was developed by the UMMS team with input from HDP staff. The purpose of the survey was to understand the health needs in the disability community in Massachusetts and to seek input beyond traditional health surveys. The survey was conducted from May 3-31, 2013.

Survey respondents were asked to rate how big a problem each of 20 health issues are for people with disabilities in Massachusetts. Response categories were “Not a Problem”, “Small Problem,” “Big Problem,” and “Don’t Know.” The health issues included access to health insurance, dental care, mental health services, transportation, and finding a doctor who is sensitive to disability issues among others.

An open-ended question was also included to allow respondents to address other health issues not addressed in the survey or to add other additional comments. Questions on demographics and disability status of the survey respondents were also included. The survey instrument is included in Appendix 3.

In collaboration with members of the Partnership, the UMMS and the HDP team it was decided that the best way to effectively disseminate the survey to the Massachusetts disability community was through a “snowball” sampling mechanism. The snowball sampling method consists of identifying potential respondents who in turn identify other respondents. It is particularly useful in populations who are difficult to reach and may generally be excluded from traditional survey methods. In addition this sampling method would allow for increased participation by those with disabilities, parents or guardians of someone with a disability and those closely involved with the disability community, through their professional or other affiliation. Participation in the survey was voluntary.

The online survey was intended for residents of Massachusetts, who:

- Had disabilities;
- Were caregivers or guardians of adults or children with disabilities;
- Were disability advocates, staff at community-based organizations or state and local government offices that serve people with disabilities;
- Were academic researchers, physicians, public health professionals, health and wellness promotion specialists, health administrators and health policy experts; and
- Had an interest in the health of people with disabilities in Massachusetts.

The online survey was initially disseminated on May 3, 2013 to the members of the Partnership (see Appendix 1 for a list of members of Partnership as of May 2013). Partnership members were asked to forward the survey throughout their respective disability networks. Many organizations sent the survey out to their members and also disseminated information about the survey via social networks (Facebook, Twitter, agency websites). Members of the UMMS evaluation team and HDP also reached out to other organizations including the Greater New England Chapter of the National Multiple Sclerosis Society, the Spina Bifida Association, Partners for Youth with Disabilities, and Easter Seals, among others. Jill Hatcher from DEAF, Inc. developed a vlog (video log) to inform the Deaf, DeafBlind, Hard of Hearing, and Late-Deafened community about the survey. In the vlog she mentioned that anyone could call Project HOPE (DEAF, Inc.) through videophone if they wanted an English to ASL translation. Captions were added to the vlog as well as a large-print transcript for increased accessibility. Respondents could also conduct the survey over the telephone by calling HDP staff.

A reminder email was distributed to the Partnership on May 21, 2013, asking the community to complete and forward the survey, if they had not already done so. The survey was closed on May 31, 2013 at 5 pm ET. The web-based survey was exempt from UMMS Institutional Review Board review.

Personal Interviews

Personal interviews were conducted with community stakeholders to develop a deeper understanding of the health issues and needs facing people with disabilities in Massachusetts. They were identified by the UMMS evaluation team with advice from HDP. The selected individuals were professionals and advocates with in-depth knowledge of the challenges and needs facing people with disabilities living in Massachusetts and agreed to be interviewed. A few of the stakeholders self-reported as having a disability. All interviews were conducted in May/June, 2013 either by Dr. Mitra or Ms. Clifford. The UMMS evaluation team developed a semi-structured guide, including key questions allowing them to delve deeper into issues and questions emerging from the interviews, while ensuring consistency in data collection between interviews.

All key informants were age 18 or older and had in-depth knowledge of the Massachusetts disability community. The UMMS and HDP teams attempted to cover a broad range of issues and organizations. Interviewees included staff members at disability-related community-based organizations, advocacy groups, a parent of a child with a disability and an individual who worked for a city commission for people with disabilities. They were:

- Derrick Dominique, Executive Director, Multi-Cultural Independent Living Center of Boston
- Jill Hatcher, Program Manager, Project HOPE, DEAF, Inc.
- Michael Muehe, Executive Director, Cambridge Commission for Persons with Disabilities, ADA Coordinator City of Cambridge
- Leo Sarkissian, Executive Director, Arc of Massachusetts
- Stacie Selfridge, Parent, Occupational Therapist
- Florette Willis, Disability Policy Consortium; Co-chair, Mass Health Implementation Plan-One Care Plan

The interviews were conducted in-person or over the telephone based on the preference of the interviewee and were audio-recorded with permission from the interviewees. Recordings will

be destroyed after the report is published. The interviews were between 30-45 minutes in length and were transcribed by the UMMS evaluation team. All interviewees agreed to be identified and quoted in this report (see Appendix 5 for the complete Interview Guide). The personal interviews were exempt from UMMS IRB review.

It should be noted that all comments and opinions recorded in this report are the opinions of the interviewees and do not necessarily represent the opinions of their respective employers or organizations.

Profile of Disability in MA

In this section we report the number of people with disabilities living in Massachusetts. Different ways of identifying disability in surveys result in different disability estimates. The prevalence of disability also depends on the mechanism used to administer the survey and the different populations of interest for the particular survey. A random-digit-dial telephone survey such as the BRFSS might reach a different set of people with disabilities compared to a mail survey such as the American Community Survey. In this report we show estimates from a variety of sources including the American Community Survey, the BRFSS, the National Survey of Children with Special Health Care Needs, and the Massachusetts Youth Health Survey. For the different definitions of disability used in these respective surveys, see Appendix 2.

A. Prevalence

Information in this section is based on the report *A Profile of Health among Persons with Disabilities in Massachusetts, 2008-2011* published in June 2012 by the Massachusetts Department of Public Health.

In 2011, 11% of the non-institutionalized Massachusetts population, or an estimated 740,400 individuals, reported having one or more disabilities (see Appendix 2 for definition of disability). Among the six types of disabilities identified in the ACS:

- 6% of people in Massachusetts of all ages reported having an ambulatory disability,
- 5% reported having an independent living disability,
- 5% had a cognitive disability,
- 2% had a vision disability,
- 3% had a hearing disability, and
- 3% had a self-care disability.

Table 1: Prevalence of Disability in Massachusetts Based on Data from Multiple National and State Surveys.

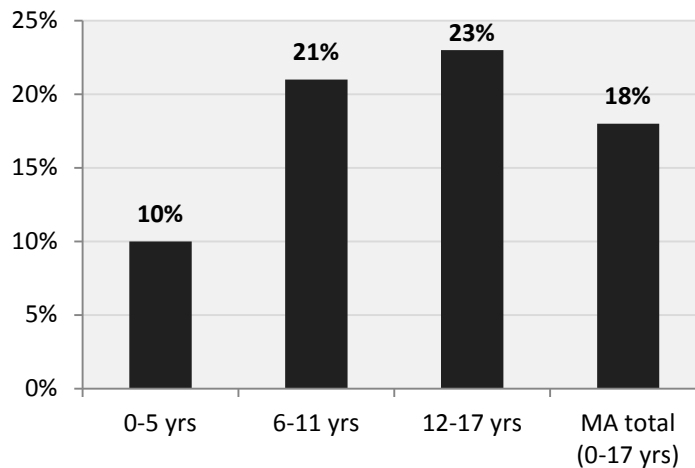
Data Source	Percentage	Age Group	Method
American Community Survey, 2008-10	11%	All ages	Mail Survey
National Survey of Children with Special Health Care Needs, 2009-2010	18%	0-17 years	Telephone, parent report
MA Youth Health Survey, 2011	19%	Middle School	Student report, paper and pencil
MA Youth Health Survey, 2011	28%	High School	Student report, paper and pencil
MA Behavioral Risk Factor Surveillance System, 2011	23%	18+ years	Random-digit-dial telephone survey

According to the 2011 MA BRFSS 23% of the non-institutionalized Massachusetts adult population ages 18 years and older have a disability. Approximately 5% of Massachusetts adults reported needing assistance with routine or personal care activities (see Appendix 2 for definition of disability). The differing definitions of disability between the ACS and the BRFSS as well as different data collection methods could account for the differing prevalence estimates of disability.

Children with Special Health Care Needs

Based on the 2009-2010 National Survey of Children with Special Health Care Needs (NS-CSHCN), a telephone-administered parent report survey, 18% of Massachusetts children, which represents an estimated 261,475 children, had a special health care need (see Appendix 2 for definition of disability). The prevalence in MA was higher than the national prevalence of 15%.

Chart 1: MA Children with Special Health Care Needs by Age Group, 2009-2010



Source: National Survey of Children with Special Health Care Needs

Prevalence of Disability among Middle and High School Students in Massachusetts

According to the 2011 Massachusetts Youth Health Survey (MA YHS), 19% of middle school students in Massachusetts reported a disability compared to 28% of high school students (see Appendix 2 for definition of disability).

Among middle school students, the prevalence of disability was lowest among sixth graders (15%) and highest among seventh graders (22%). Among high school students, there was less variation in the prevalence of disability by grade level.

MA YHS survey participants who responded positively to **either** of the two screener questions were considered to have a disability (see Appendix 2 for definition of disability).

B. Demographics

The estimates in this section are based on information from the *2011 Disability Status Report* for Massachusetts published by Cornell University.

Massachusetts

Overall population	6,646,144
Overall prevalence	11%

Gender, Race/Ethnicity, and Age

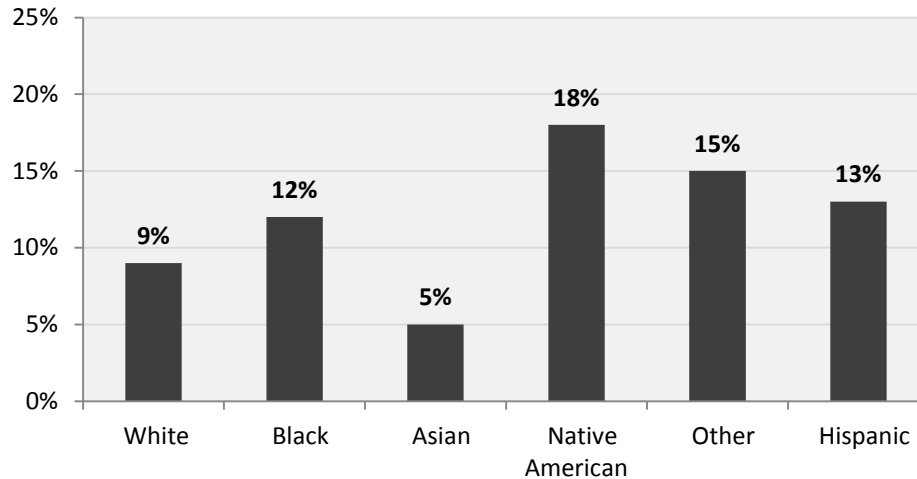
- People with disabilities are more likely to be older.
- Blacks, Native Americans, Hispanics, and those of other racial and ethnic minority groups are more likely to report a disability compared to those who are white.
- Asians are least likely to report a disability.

Table 2: Percentage of People with Disabilities by Gender and Age, 2011

Gender	
Male	11%
Female	12%
Age	
4 under	1%
5-15	6%
16-20	5%
21-64	9%
65-74	22%
75+	47%

Source: American Community Survey

Chart 2: Percentage of People with Disabilities in Massachusetts by Race/Ethnicity, 2011

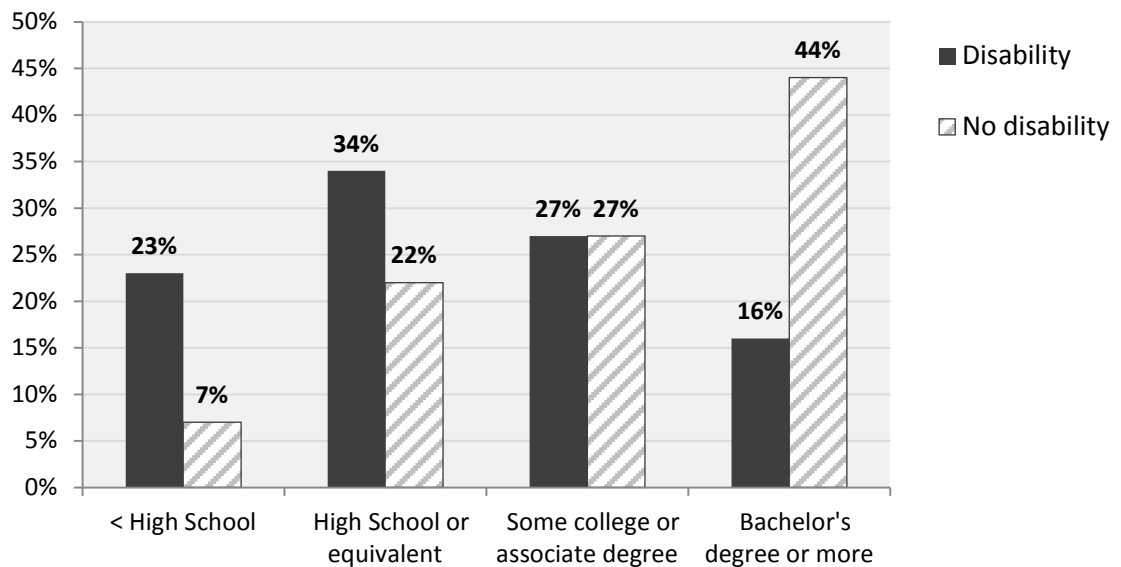


Source: American Community Survey

Education

People with disabilities are likely to be less educated than people without disabilities.

Chart 3: Education by Disability Status among Working-age People in Massachusetts in 2011



Source: American Community Survey

Income/Earnings

- Among working-age people who work full-time/full-year in Massachusetts, people with disabilities have lower annual earnings than those without disabilities.
- Within households that include any working-age people (age 21-64) in Massachusetts, households of people with disabilities have a lower median annual household income than households without people with disabilities.

Table 3: Earnings/Income by Disability Status

	Disability	No disability
Earning/income		
Annual earnings	\$40,700	\$52,900
Annual household income	\$37,600	\$78,400

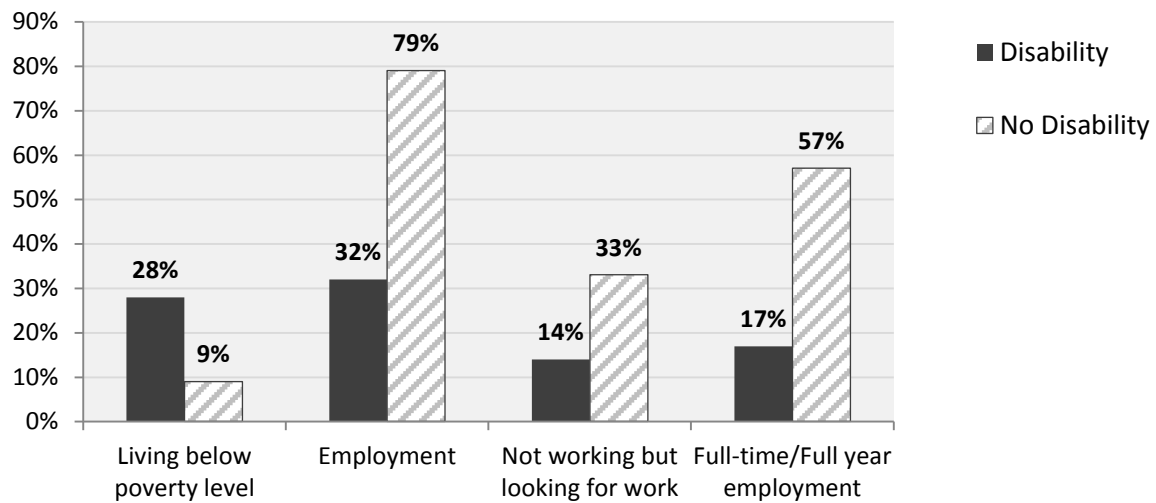
Source: American Community Survey, 2011

Poverty and Employment

Compared to people without disabilities, people with disabilities are:

- More likely to be living below the poverty level,
- Less likely to be employed, and
- Less likely to be employed full-time.

Chart 4: Poverty and Employment by Disability Status among Working-age People in Massachusetts in 2011



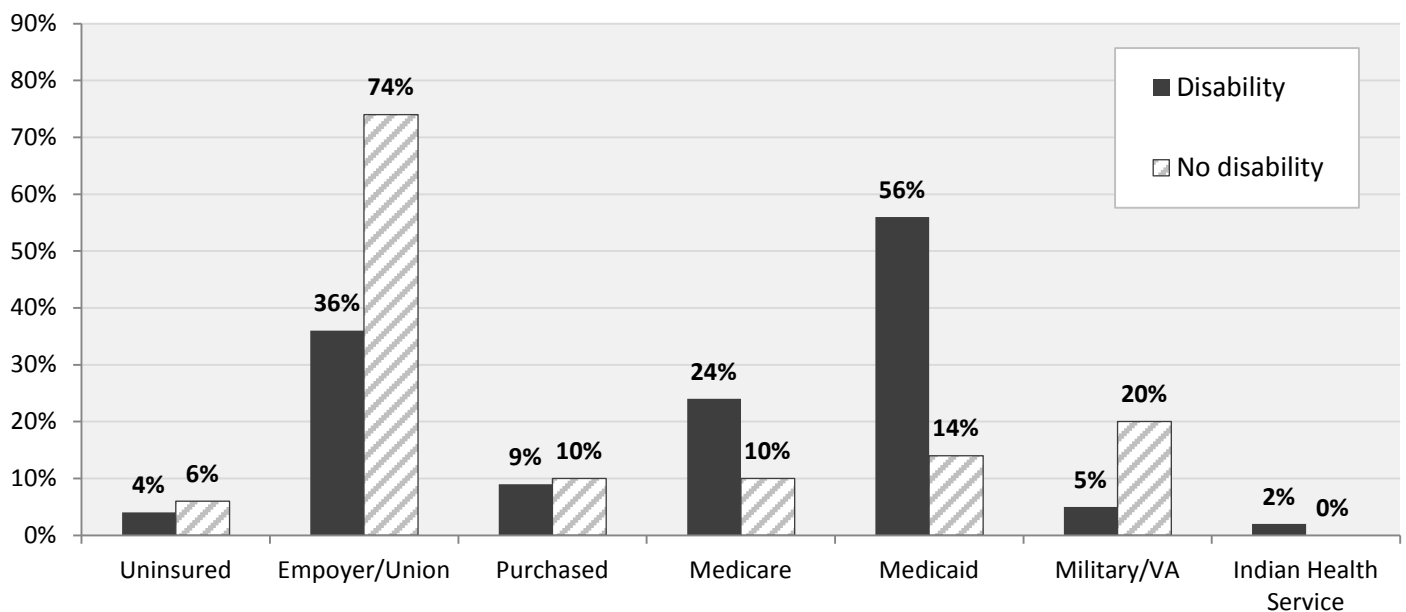
Source: American Community Survey

Health Insurance

Compared to people without disabilities, people with disabilities are:

- Less likely to have health insurance through an employer or union,
- More likely to have health insurance through Medicare,
- More likely to have health insurance through Medicaid, and
- Less likely to have health insurance through the military or US Department of Veterans Affairs (VA).

Chart 5: Type of Health Insurance Coverage among Working-Age People (age 21 to 64) by Disability Status in Massachusetts in 2011



Source: American Community Survey

Health Profile of Massachusetts Adults with Disabilities

Information in this section is from *A Profile of Health Among Massachusetts Adults, 2011, Results from the Behavioral Risk Factor Surveillance System* published in January, 2013 by the MDPH.

The 2011 Massachusetts data is the most recent data available as of the development of this report. However, certain health measures were not collected in the 2011 MA BRFSS. For those measures the most recent data from 2010 was included and is noted accordingly. Confidence intervals are included in Appendix 6.

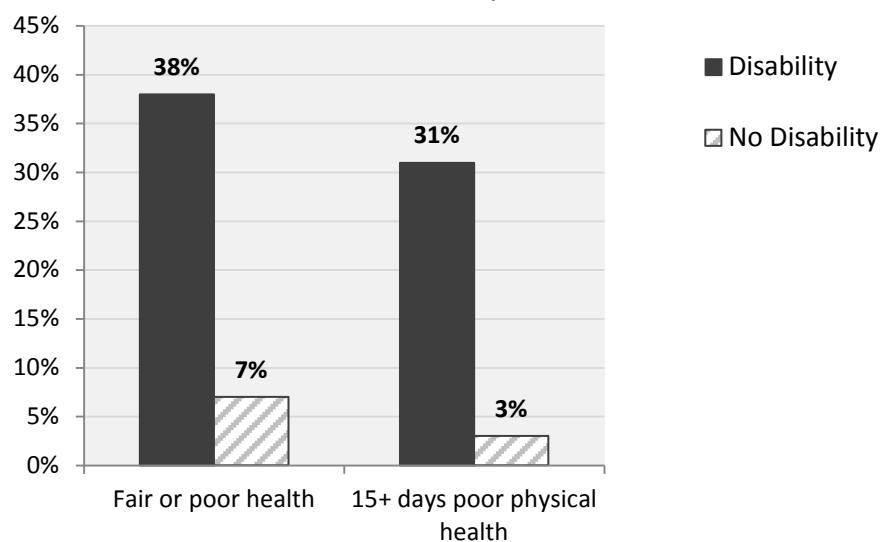
A. Quality of Life

General Health and Physical Health Status

Two different indicators were used to measure the overall health of an individual. All respondents in the MA BRFSS were asked to report:

1. Overall health as either excellent, very good, good, fair, or poor. Presented here are the percentages of adults who reported fair or poor overall health.
 2. Number of days during the past month that physical health, which includes physical illness and injury, had not been good. Presented here are the percentages of adults who reported 15 or more days of poor physical health.
- **Fair or poor health:** Adults with disabilities were more likely to report fair or poor health (38%) than those without disabilities (7%).
 - **Poor physical health:** Adults with disabilities were more likely to report 15 or more days of poor physical health (31%) than those without disabilities (3%).

Chart 6: Overall Health by Disability Status among Massachusetts Adults, 2011



Source: *A Profile of Health Among Massachusetts Adults, 2011, Results from the Behavioral Risk Factor Surveillance System*, January, 2013, Massachusetts Department of Public Health

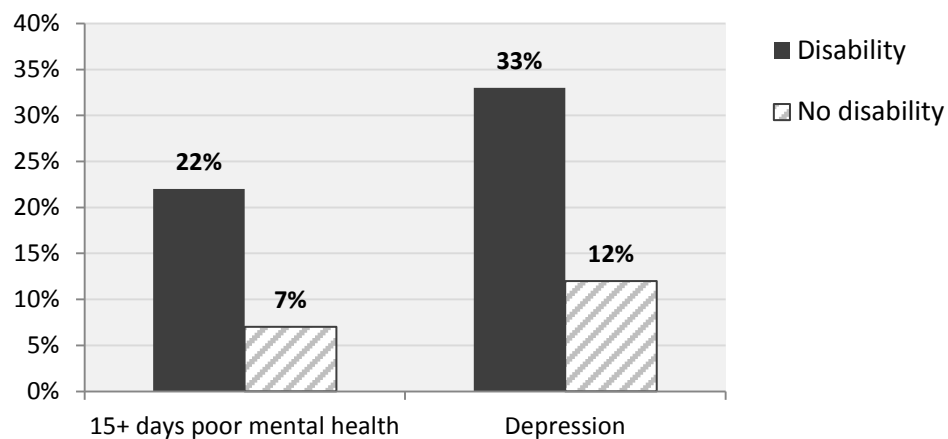
Mental Health

All respondents in the MA BRFSS were asked to report:

1. Number of days during the past month they would describe their mental health, which includes stress, depression, and problems with emotions, as not good. Presented here are the percentages of adults who reported 15 or more days of poor mental health.
2. Whether they were ever told by a doctor, nurse or other health professional that they had a depressive disorder (including depression, major depression, dysthymia, or minor depression).

- **Poor mental health:** Adults with disabilities were more likely to report 15 or more days of poor mental health (22%) than those without disabilities (7%).
- **Depression:** Adults with disabilities were more likely to report ever having had depression (33%) than those without disabilities (12%).

Chart 7: Mental Health by Disability Status among Massachusetts Adults, 2011



Source: *A Profile of Health Among Massachusetts Adults, 2011, Results from the Behavioral Risk Factor Surveillance System*, January, 2013, Massachusetts Department of Public Health

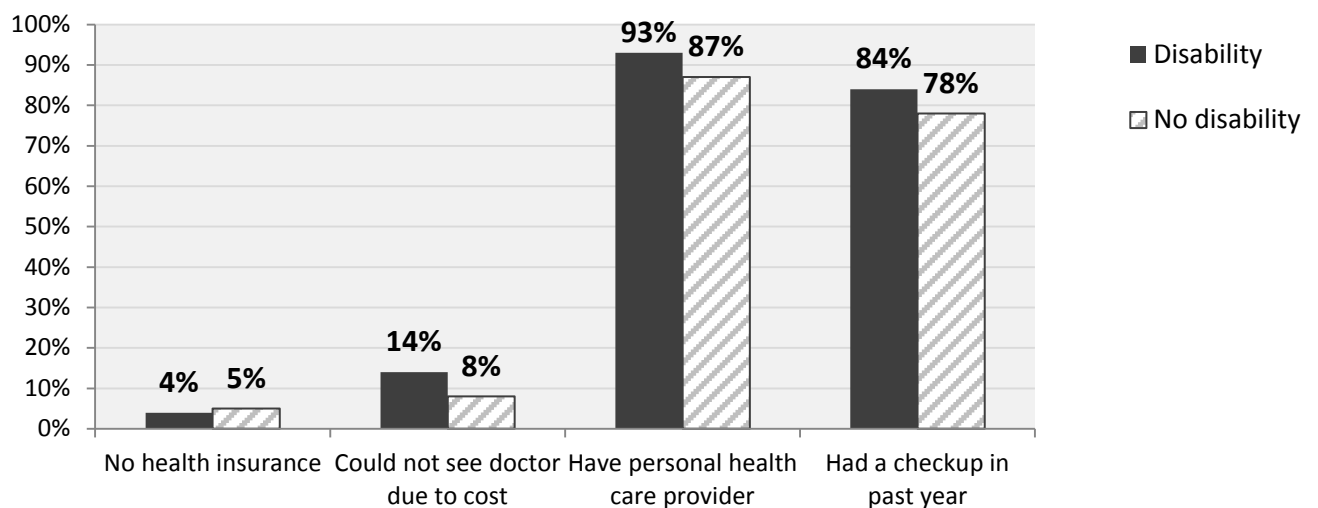
B. Health Care Access

Health Insurance and Doctor Visits

All respondents were asked to report if they:

1. Had health insurance coverage in 2011
 2. Had a personal doctor or health care provider
 3. Were unable to see a doctor in the past year due to cost
 4. How long since they last visited a doctor for a routine checkup.
- **No health insurance:** 4% of adults with disabilities and 5% without disabilities reported having no health insurance.
 - **Could not see doctor due to cost:** 14% of adults with disabilities and 8% without disabilities reported that during the past year they could not see the doctor due to cost.
 - **Have personal health care provider:** 93% of adults with disabilities and 87% without disabilities reported having a person they thought of as their personal doctor or health care provider.
 - **Had a checkup in past year:** 84% of adults with disabilities and 78% without disabilities reported visiting a doctor for a routine checkup in the past year.

Chart 8: Health Care Access by Disability Status among Massachusetts Adults, 2011



Source: *A Profile of Health Among Massachusetts Adults, 2011, Results from the Behavioral Risk Factor Surveillance System*, January, 2013, Massachusetts Department of Public Health

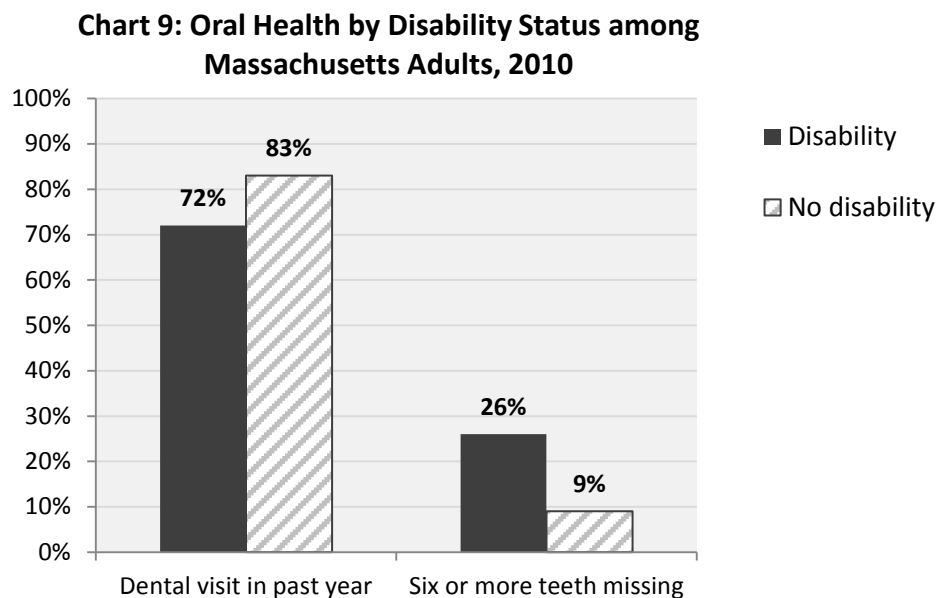
Oral Health

All respondents were asked to report:

1. How long it had been since they had last visited a dentist or a dental clinic.
2. How many of their teeth were missing due to decay or gum disease only.

Presented here is the percentage reporting they had been to a dentist or dental clinic within the past year and the percentage of adults with six or more teeth missing.

- **Dental visit in past year:** Adults with disabilities were less likely to report having had a dental visit in the past year (72%) compared to those without disabilities (83%).
- **Six or more teeth missing:** Adults with disabilities were more likely to report having six or more teeth missing (26%) than those without disabilities (9%).



Source: *A Profile of Health Among Massachusetts Adults, 2011, Results from the Behavioral Risk Factor Surveillance System*, June, 2011, Massachusetts Department of Public Health

C. Risk Factors and Preventive behaviors

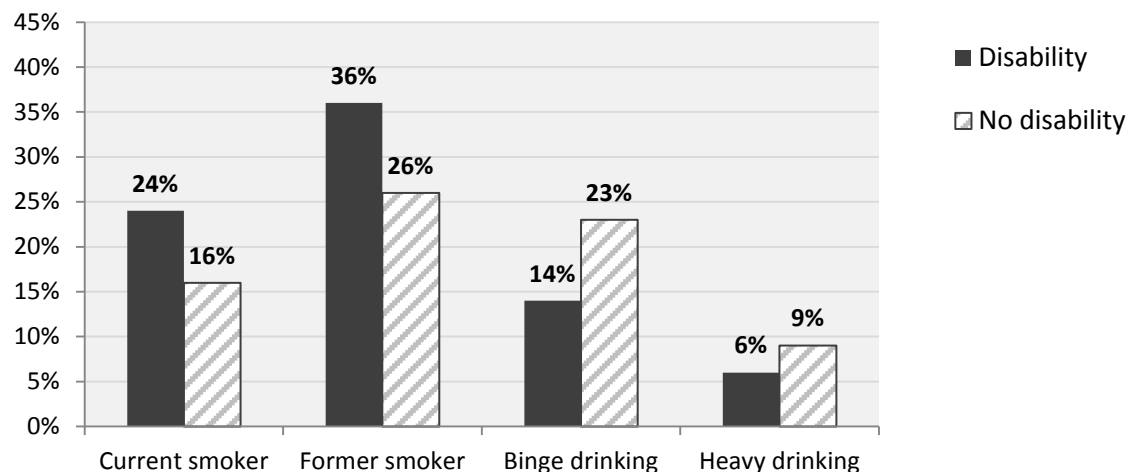
Smoking and Alcohol Use

A **current smoker** was defined as someone who has smoked at least 100 cigarettes in his/her lifetime and who currently smokes either some days or every day. A **former smoker** was defined as someone who has smoked at least 100 cigarettes in his/her lifetime but no longer smokes. Presented here are the percentage of adults who reported being current smokers and the percentage of adults who reported being former smokers.

All respondents were asked about their consumption of alcohol in the past month. A **drink of alcohol** was defined as one can or bottle of beer, one glass of wine, one can or bottle of wine cooler, one cocktail, or one shot of liquor. **Binge drinking** was defined as consumption of five or more drinks for men or four or more drinks for women, on any one occasion in the past month. **Heavy drinking** was defined as consumption of more than 60 drinks in the past month for men and consumption of more than 30 drinks in the past month for women. Presented here are the percentage of adults who reported binge drinking and the percentage of adults who reported heavy drinking.

- **Current smoker:** Among adults with disabilities in Massachusetts, 24% of those with disabilities and 16% of those without disabilities were current smokers.
- **Former smoker:** 36% of adults with disabilities and 26% of those without disabilities were former smokers.
- **Binge drinking:** 14% of those with disabilities and 23% of those without disabilities reported binge drinking.
- **Heavy drinking:** 6% of those with disabilities and 9% of those without disabilities were heavy drinkers.

Chart 10: Smoking and Alcohol Use by Disability Status among Massachusetts Adults, 2011



Source: *A Profile of Health Among Massachusetts Adults, 2011, Results from the Behavioral Risk Factor Surveillance System*, January, 2013, Massachusetts Department of Public Health

Overweight and Obesity Status

All respondents were asked to report their height and weight. Respondents' overweight and obesity status were categorized based on their Body Mass Index (BMI), which equals weight in kilograms divided by height in meters squared. **Overweight** was defined as a BMI between 25.0 and 29.9 and **obese** was defined as a BMI greater than or equal to 30.0. Presented here are the percentages of adults who were defined as overweight and obese.

Physical Activity

In 2011, all respondents who reported ANY leisure-time physical activity were asked what two activities gave them the most exercise in the last month. They were asked to report:

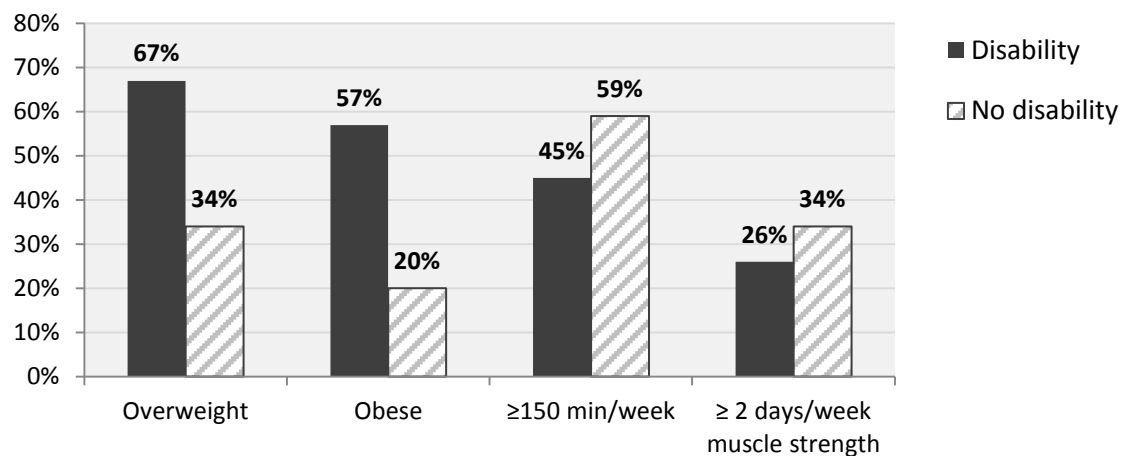
1. How frequently and for how long they took part in these activities.
2. How frequently they took part in activities or exercises to strengthen muscles.

Presented here are the percentages of respondents who meet the *Healthy People 2020* recommendations for 150-minute aerobic exercise and who meet the muscle-strengthening recommendation.

The categories represented in the chart are not mutually exclusive. For example, people who are overweight also includes those who are obese, and people doing aerobic activity may or may not also do muscle-strengthening activities.

- **Overweight:** Among adults in Massachusetts in 2011, those with disabilities were more likely to report being overweight (67%) than those without disabilities (34%).
- **Obese:** Those with disabilities were more likely to report being obese (57%) than those without disabilities (20%).
- **Physical activity, 150 minutes per week or more:** Adults with disabilities were less likely to report 150 minutes or more of aerobic activity per week (45%) than those without disabilities (59%).
- **Muscle strengthening, two or more days per week:** Those with disabilities were less likely to report muscle strengthening activity two or more days per week (26%) than those without disabilities (34%).

Chart 11: Overweight, Obesity, and Physical Activity by Disability Status among Massachusetts Adults, 2011



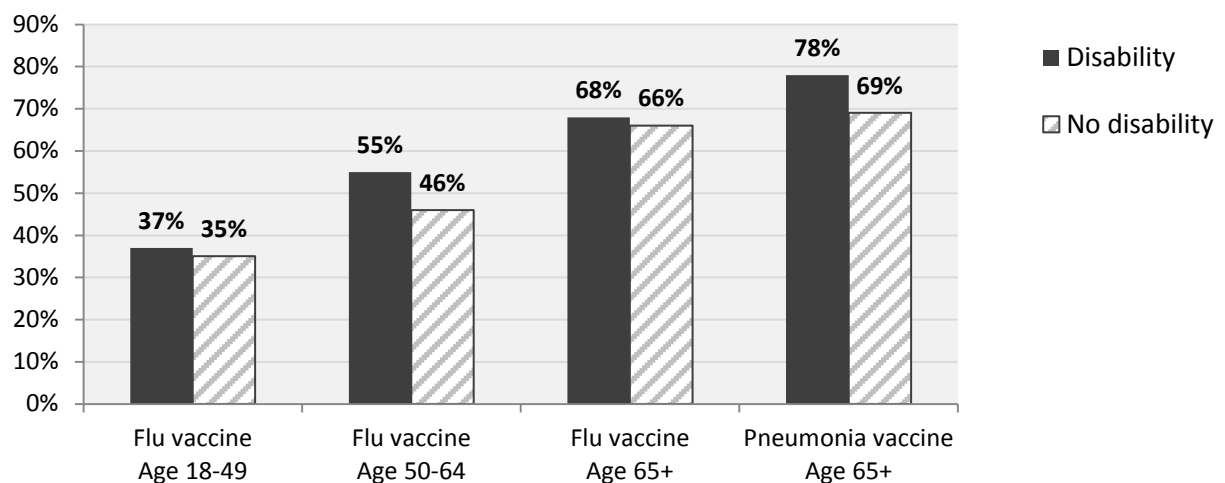
Source: *A Profile of Health Among Massachusetts Adults, 2011, Results from the Behavioral Risk Factor Surveillance System*, January, 2013, Massachusetts Department of Public Health

Flu Vaccine and Pneumonia Vaccine

All respondents were asked to report if they:

1. Had received an influenza vaccine (flu shot) or nasal flu spray (flu mist) within the past 12 months. Presented here are the percentages of adults ages 18-49 years, 50-64 years and ages 65 and older who received a flu vaccine or spray in the past year.
 2. Had ever received a pneumonia vaccine. Presented here is the percentage of adults, ages 65 and older, who reported that they had ever had a pneumonia vaccination.
- **Flu vaccine, age 18-49:** Among adults age 18-49, 37% with disabilities and 35% without disabilities reported having had a flu vaccination in the past 12 months.
 - **Flu vaccine, age 50-64:** Among adults age 50-64, 55% with disabilities and 46% without disabilities reported having had a flu vaccination in the past 12 months.
 - **Flu vaccine, age 65 and up:** Among adults age 65 and up, 68% with disabilities and 66% without disabilities reported having had a flu vaccination in the past 12 months.
 - **Pneumonia vaccine, age 65 and up:** Among adults age 65 and up, 78% with disabilities and 69% without disabilities reported ever having had a pneumonia vaccination.

Chart 12: Flu and Pneumonia Vaccinations among Massachusetts Adults, 2011



Source: *A Profile of Health Among Massachusetts Adults, 2011, Results from the Behavioral Risk Factor Surveillance System*, January, 2013, Massachusetts Department of Public Health

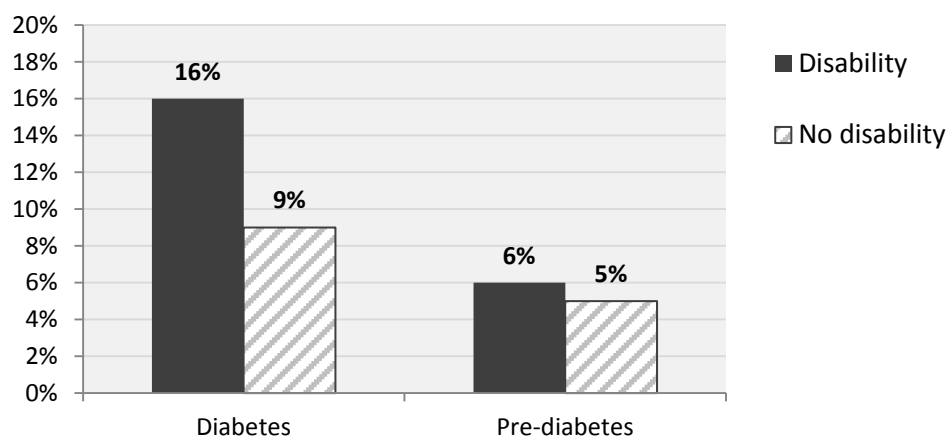
D. Chronic Health Conditions

Diabetes and Pre-diabetes

All respondents were asked if a doctor had ever told them that they had diabetes or pre-diabetes. Pre-diabetes is defined as a blood glucose level that is higher than normal but not yet diabetic. Presented here is the percentage of adults who reported that a doctor had ever told them that they had diabetes and the percentage of adults who reported that a doctor had ever told them that they had pre-diabetes.

- **Diabetes:** Among adults in Massachusetts in 2011, those with disabilities were more likely to report having diabetes (16%) compared to those without disabilities (9%).
- **Pre-diabetes:** 6% of adults with disabilities reported pre-diabetes compared to 5% of those without disabilities.

Chart 13: Diabetes and Pre-diabetes by Disability Status among Massachusetts Adults, 2011



Source: *A Profile of Health Among Massachusetts Adults, 2011, Results from the Behavioral Risk Factor Surveillance System*, January, 2013, Massachusetts Department of Public Health

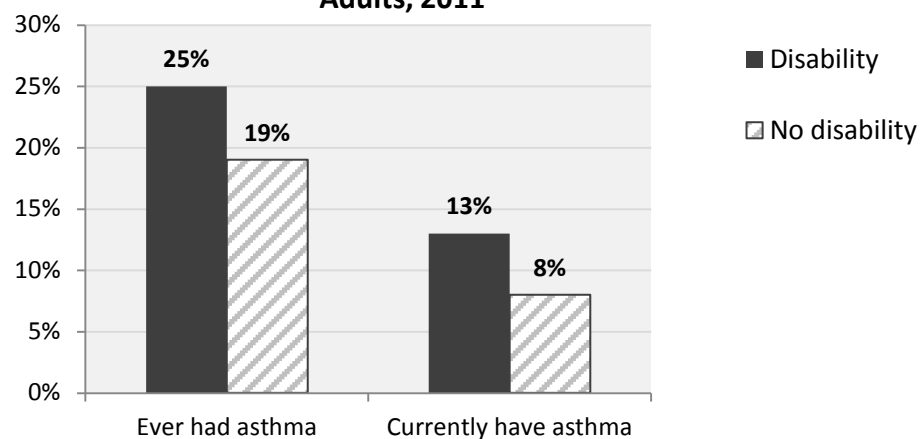
The pre-diabetes questions were asked only on the MA BRFSS landline survey in 2011 and not the cell phone survey; therefore the results presented represent the landline sample only.

Asthma

All respondents were asked if a doctor, nurse, or other health care professional had ever told them that they had asthma. Those who reported ever having asthma were then asked if they currently have asthma. Reported here are the percentages of adults who have ever had asthma and those who currently have asthma.

- **Ever had asthma:** Among adults in Massachusetts in 2011, those with disabilities were more likely to report ever having asthma (25%) compared to those without disabilities (19%).
- **Currently have asthma:** Those with disabilities were more likely to report currently having asthma (13%) than those without disabilities (8%).

Chart 14: Asthma by Disability Status among Massachusetts Adults, 2011

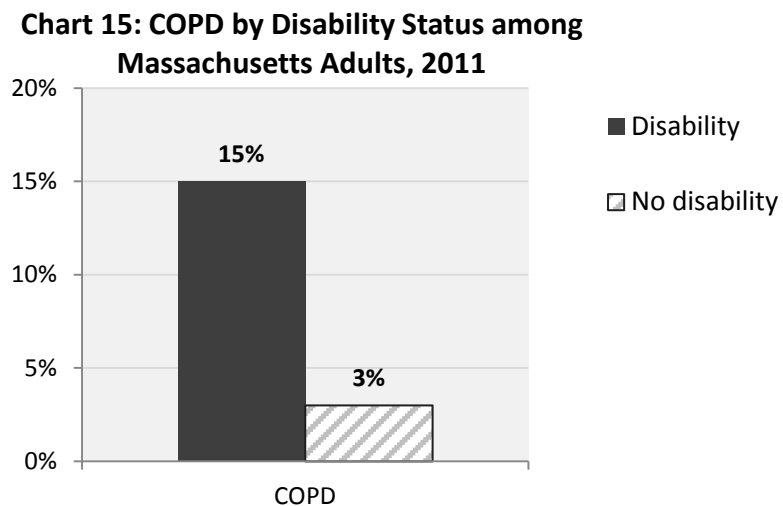


Source: *A Profile of Health Among Massachusetts Adults, 2011, Results from the Behavioral Risk Factor Surveillance System*, January, 2013, Massachusetts Department of Public Health

Chronic Obstructive Pulmonary Disease (COPD)

Presented here is the percentage of adults who reported that they had ever been diagnosed with COPD, emphysema or chronic bronchitis.

- **COPD:** Among adults in Massachusetts in 2011, those with disabilities were more likely to report ever being diagnosed with COPD (15%) than those without disabilities (3%).



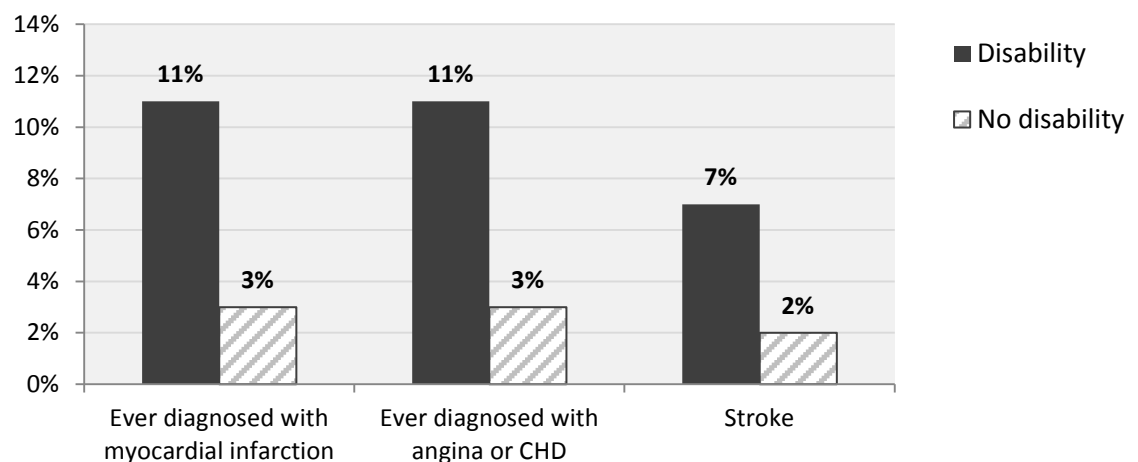
Source: *A Profile of Health Among Massachusetts Adults, 2011, Results from the Behavioral Risk Factor Surveillance System*, January, 2013, Massachusetts Department of Public Health

Heart Disease and Stroke

All respondents were asked whether a doctor, nurse, or other health professional had ever told them that they had had a myocardial infarction (“MI,” also called a “heart attack”), angina or coronary heart disease (CHD), or a stroke. Presented here are the percentages of adults 35 and older who reported being told that they had experienced a heart attack, had angina or coronary heart disease, or had a stroke.

- **Myocardial Infarction (heart attack):** Among Massachusetts adults in 2011, those with disabilities were more likely to report being told they had had a heart attack (11%) than those without disabilities (3%).
- **Angina or CHD:** Those with disabilities were more likely to report being told they had angina (11%) than those without disabilities (3%).
- **Stroke:** Those with disabilities were more likely to report having had a stroke (7%) than those without disabilities (2%).

Chart 16: Heart Disease and Stroke by Disability Status among Massachusetts Adults, 2011



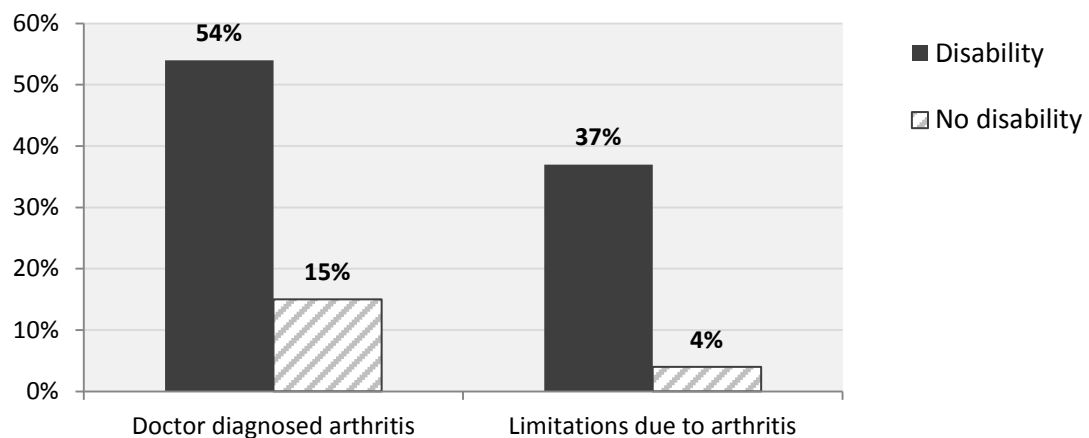
Source: *A Profile of Health Among Massachusetts Adults, 2011, Results from the Behavioral Risk Factor Surveillance System*, January, 2013, Massachusetts Department of Public Health

Arthritis

All respondents were asked if a doctor or other health professional had ever told them they had arthritis. Respondents who indicated that they had been diagnosed with arthritis or who indicated that they had “symptoms of pain, aching, or stiffness in or around a joint” that had begun more than three months ago were then asked if they were limited in any way in any of their usual physical activities due to the arthritis or joint symptoms. Presented is the percentage of respondents who indicated that they:

1. Had been diagnosed with arthritis or had the symptoms described above for more than three months
 2. Experienced limitations in their usual daily activities due to the arthritis or symptoms.
- **Arthritis:** Among Massachusetts adults in 2011, those with disabilities were more likely to report being diagnosed with or having symptoms of arthritis (54%) than those without disabilities (15%).
 - **Limitations due to arthritis:** 37% of those with disabilities reported limitations due to arthritis compared to 4% of those without disabilities.

Chart 17: Arthritis by Disability Status among Massachusetts Adults, 2011



Source: *A Profile of Health Among Massachusetts Adults, 2011, Results from the Behavioral Risk Factor Surveillance System*, January, 2013, Massachusetts Department of Public Health

E. Cancer Screening

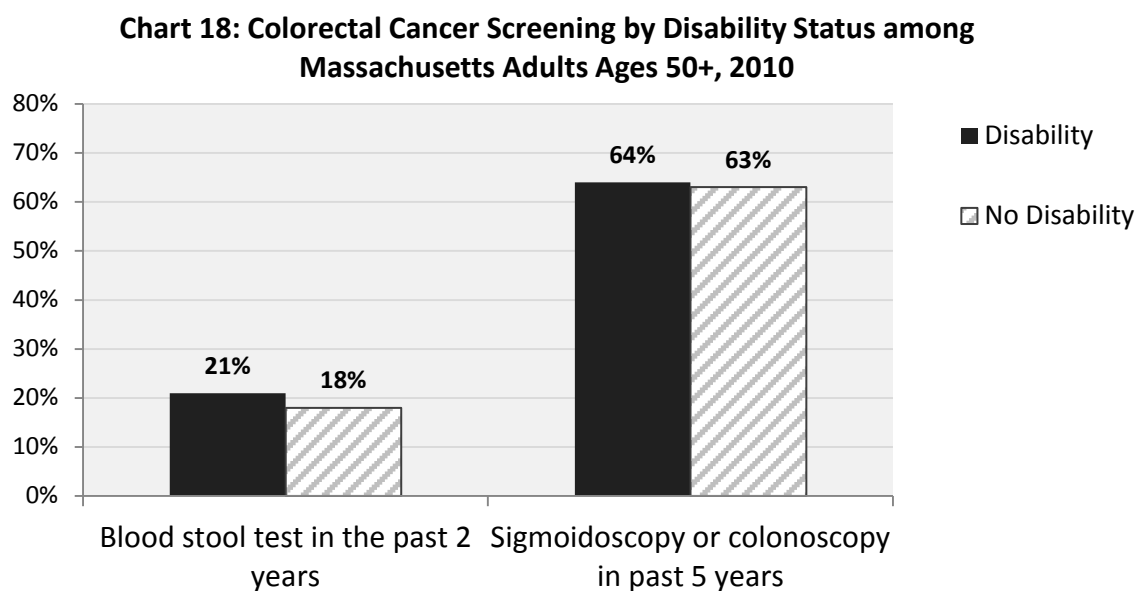
Colorectal Cancer Screening

Respondents ages 50 and older were asked if they:

1. Had ever had a blood stool test using a home test kit to determine if their stool contained blood.
2. Had ever had a sigmoidoscopy or colonoscopy tests that examine the bowel for signs of cancer or other health problems.

Presented below is the percentage of adults who had a blood stool test using a home test kit in the past two years and the percentage of adults who had a sigmoidoscopy or colonoscopy in the past five years.

- **Blood stool test in past two years:** Among respondents ages 50 and up in Massachusetts in 2010, 21% of those with disabilities and 18% of those without disabilities reported having a blood stool test in the past 2 years.
- **Sigmoidoscopy or colonoscopy in past five years:** 64% of adults ages 50 and up with disabilities and 63% of those without disabilities reported a sigmoidoscopy or colonoscopy in the past 5 years.



Source: *A Profile of Health Among Massachusetts Adults, 2010, Results from the Behavioral Risk Factor Surveillance System*, June, 2011, Massachusetts Department of Public Health

Prostate Cancer Screening

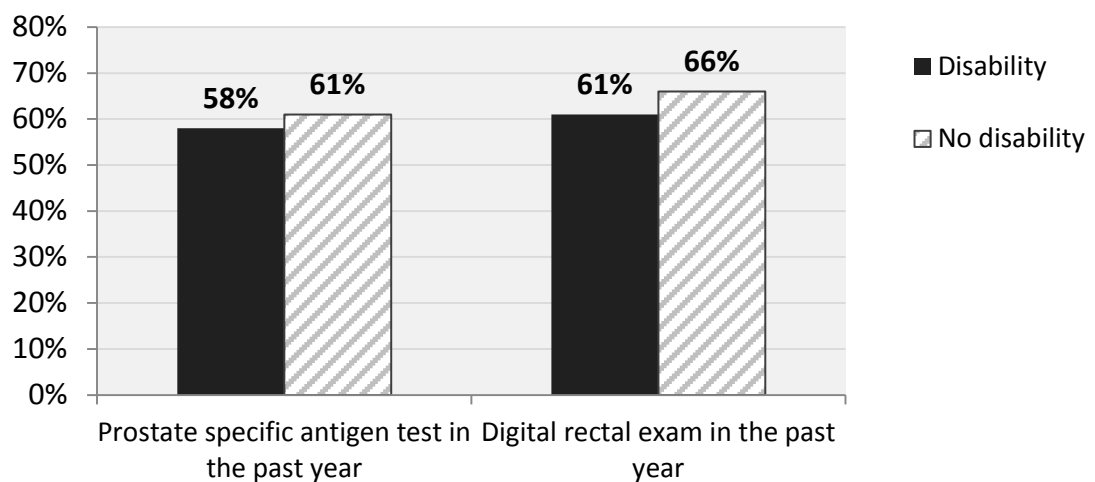
A prostate-specific antigen (PSA) test is a blood test used to indicate an increased risk of prostate cancer. A digital rectal exam (DRE) is an exam in which a doctor, nurse, or other health professional places a gloved finger into the rectum to feel the size, shape, and hardness of the prostate gland. Men age 50 and older were asked if they:

1. Had ever had a prostate-specific antigen test (PSA), and if so how long it had been since their last PSA test.
2. Had ever had a digital rectal exam (DRE), and if so, how long it had been since their last DRE.

Presented below is the percentage of males aged 50 and older who have had a DRE in the past year and the percentage of males ages 50 and older who have had a PSA test in the past year.

- **Prostate specific antigen test in the past year:** 58% of men with disabilities and 61% of men without disabilities reported having had a prostate specific antigen test in the past year.
- **Digital rectal exam in past year:** 61% of men with disabilities and 66% of men without disabilities reported having had a digital rectal exam in the past year.

Chart 19: Prostate Cancer Screening by Disability Status among Massachusetts Men Ages 50+, 2010



Source: *A Profile of Health Among Massachusetts Adults, 2010, Results from the Behavioral Risk Factor Surveillance System*, June, 2011, Massachusetts Department of Public Health

Breast Cancer Screening

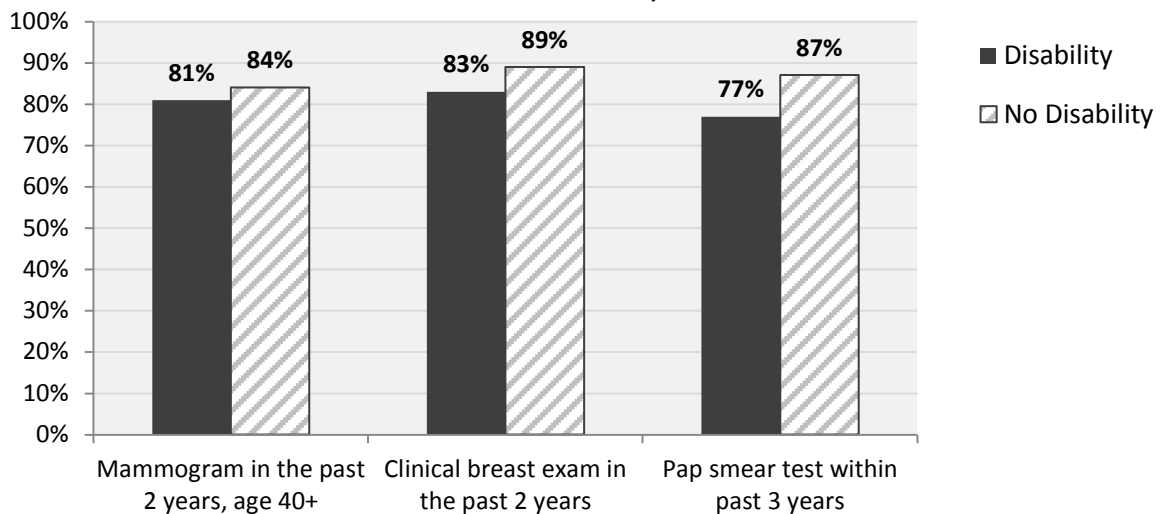
All female respondents were asked about breast cancer screening. Those women who reported that they had ever had a mammogram were asked how long it had been since their last mammogram. Those women who reported that they had ever had a clinical breast exam (when a doctor, nurse or other health professional feels the breast for lumps) were asked how long it had been since their last clinical breast exam. The percentage of women ages 40 and older in Massachusetts who reported that they had had a mammogram in the past two years is presented on the following page.

Cervical Cancer Screening

All women were asked if they ever had had a Pap smear, a screening test for cancer of the cervix. Those who reported that they had had a Pap smear were then asked how long it had been since their last Pap smear. The percentage of women who reported having had a Pap smear in the past 3 years is presented on the following page.

- **Mammogram in past two years, ages 40 and up:** Among women age 40 and up in Massachusetts in 2010, 81% of those with disabilities and 84% of those without disabilities reported having had a mammogram in the past 2 years.
- **Clinical breast exam in the past two years:** Among adult women in Massachusetts in 2010, 83% of those with disabilities and 89% of those without disabilities reported having had a clinical breast exam in the past 2 years.
- **Pap smear test within past three years:** Among adult women, 77% of those with disabilities and 87% of those without disabilities reported having had a Pap smear in the past 3 years.

Chart 20: Breast and Cervical Cancer Screening by Disability Status among Massachusetts Adult Women, 2010



Source: *A Profile of Health Among Massachusetts Adults, 2010, Results from the Behavioral Risk Factor Surveillance System*, June, 2011, Massachusetts Department of Public Health

F. Other Topics

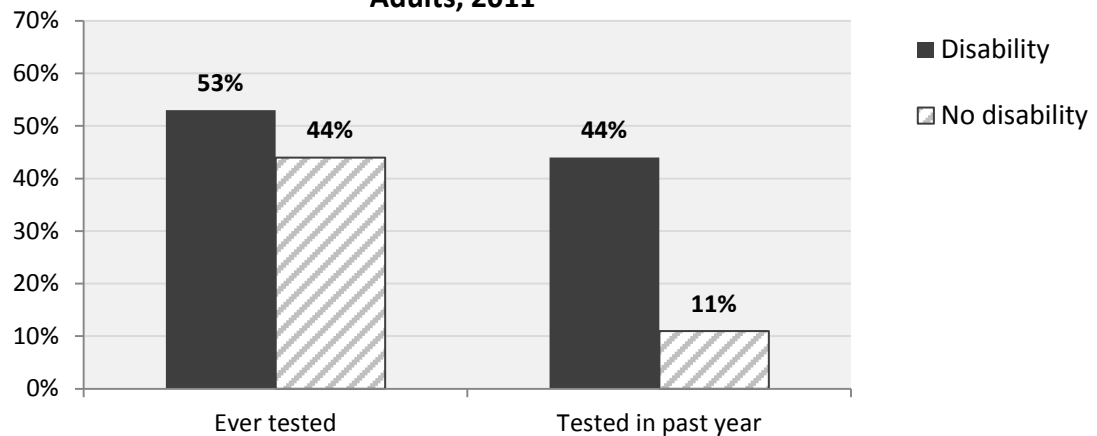
HIV Testing

All respondents ages 18-64 were asked if they had ever been tested for HIV. Respondents were told not to include times that HIV testing had been done as part of a blood donation.

Respondents who reported that they had ever been tested for HIV were asked the date of their most recent HIV test. Presented here is the percentage of adults ages 18-64 who report ever having been tested for HIV and the percentage who had been tested in the past year.

- **Ever tested for HIV:** Among adults in Massachusetts in 2011, 53% of those with disabilities and 44% of those without disabilities were ever tested for HIV.
- **Tested for HIV in past year:** Those with disabilities were more likely to report being tested for HIV in the past year (44%) compared to those without disabilities (11%).

Chart 21: HIV Testing by Disability Status among Massachusetts Adults, 2011



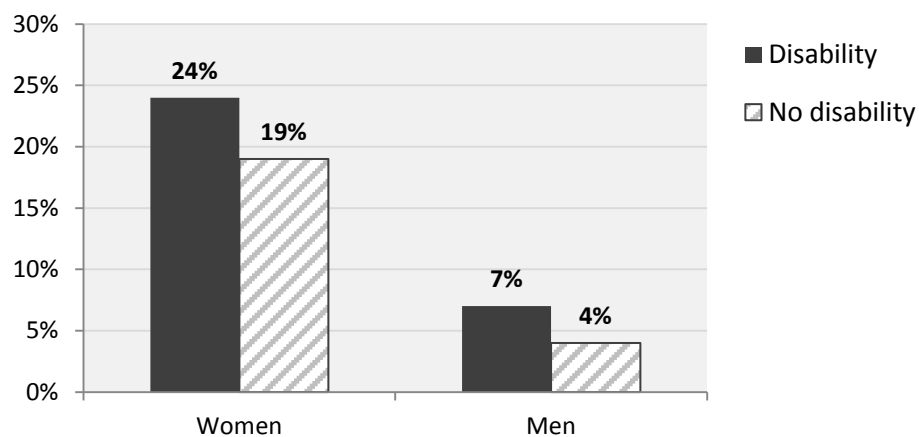
Source: *A Profile of Health Among Massachusetts Adults, 2011, Results from the Behavioral Risk Factor Surveillance System*, January, 2013, Massachusetts Department of Public Health

Sexual Violence

Respondents were asked if they had experienced sexual violence at any time in their lifetime. Sexual violence was defined as having the sexual parts of the body touched without consent or attempted or completed sex without consent. Presented here are the percentages of men and women who reported that they had experienced sexual violence at some time in their lifetime.

- **Sexual violence, women:** Among adult women in Massachusetts in 2011, women with disabilities were more likely to report lifetime sexual violence (24%) than those without disabilities (19%).
- **Sexual violence, men:** Among adult men in Massachusetts in 2011, men with disabilities were more likely to report lifetime sexual violence (7%) than those without disabilities (4%).

Chart 22: Lifetime Sexual Violence by Disability Status among Massachusetts Adults, 2011



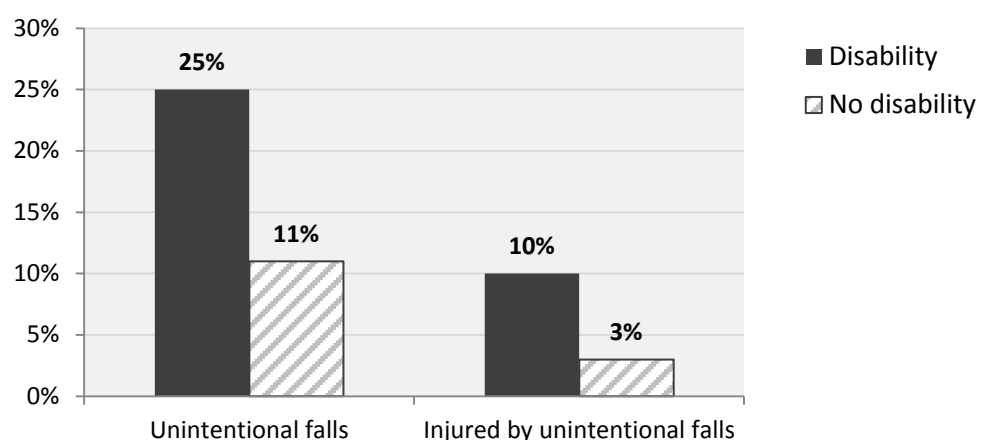
Source: *A Profile of Health Among Massachusetts Adults, 2011, Results from the Behavioral Risk Factor Surveillance System*, January, 2013, Massachusetts Department of Public Health

Unintentional Falls

Respondents ages 45 and older were asked if they had fallen in the past three months. A fall was defined as unintentionally coming to rest on the ground or another lower level. They were also asked if they were injured by a fall in the past three months. An injury from a fall was defined as one that caused the respondent to limit regular activities for at least a day or to go see a doctor. Presented here is the percentage of adults ages 45 and older who reported falling in the past 3 months and the percentage that were injured from a fall in the past three months.

- **Unintentional falls:** Among adults age 45 and up in Massachusetts in 2011, those with disabilities were more likely to report unintentional falls in the past 3 months (25%) than those without disabilities (11%).
- **Injured by unintentional falls:** Those with disabilities were also more likely to report being injured from an unintentional fall (10%) than those without disabilities (3%).

Chart 23: Unintentional Falls by Disability Status among Massachusetts Adults Age 45+, 2011



Source: *A Profile of Health Among Massachusetts Adults, 2011, Results from the Behavioral Risk Factor Surveillance System*, January, 2013, Massachusetts Department of Public Health

Survey of Health Needs of People with Disabilities in Massachusetts

This section includes the results from the Survey of Health Needs of People with Disabilities that was conducted in May 2013. The purpose of the online survey was to collect data on the health needs and priorities of the Massachusetts disability community and to seek data from sources other than traditional health surveys. Survey respondents were asked how big a problem each of 20 selected health issues are for people with disabilities in Massachusetts. Response categories were “Not a Problem,” “Small Problem,” “Big Problem,” and “Don’t Know.” The health issues included access to health insurance, finding a doctor who is sensitive to disability issues, dental care, mental health services, and transportation, among others. Respondents were also given an open-ended response option if they had anything else they wanted to add regarding the health needs of people living with disabilities in Massachusetts. Demographic data and disability status of the survey respondents were also collected. Selected responses to the open-ended question are included in text boxes in this section and have been edited for purposes of this report. The complete survey can be found in Appendix 3.

The results for the top health care needs are presented by population categories including All Respondents, People with Disabilities, Family/Caregivers, and Staff/Community Leaders.

A. Demographics

The total number of respondents to the online needs assessment survey was 865. Most of the respondents were female (75%), between the ages of 55-64 (32%), White (87%), heterosexual (81%), and identified their ethnicity as American (70%). Additionally, the majority of respondents preferred to both read and discuss their health care in English. Respondents also reported the city or town in which they live. These data are presented in Appendix 4.

Table 4: Demographics All Respondents, N=865

Gender	
Male	21%
Female	75%
Other	4%
Sexual Orientation	
Heterosexual/Straight	80%
Prefer Not to Respond	7%
Gay or Lesbian	7%
Other	6%
Age	
18-24	2%
25-34	12%
35-44	17%
45-54	27%
55-64	32%
65+	10%
Race*	
White	87%
Black	5%
Hispanic	3%
Other	8%
Ethnicity*	
American	70%
European	13%
African-American	4%
Other	18%
Unknown	4%

Source: Survey of Health Needs of People with Disabilities in Massachusetts, 2013

*Note: Some categories total more than 100% as respondents identified as being in more than one category.

Among the 865 respondents, 39% reported having a disability, 35% reported being a family member/guardian/caregiver to an adult or child with disabilities, and 57% reported being a staff/advocate of people with disabilities. Approximately one-third of the respondents identified as being in more than one category. Respondents were asked to describe their affiliation with the disability community. For purposes of this assessment, the analysis was conducted based on the total number of respondents (**“All”**) and 3 population sub-groups of the respondents. The subgroups are defined in Table 5.

Table 5: Please describe yourself (check all that apply)

Respondent Type	%	#
All		
Total of all respondents	100%	865
Person with a disability	39%	333
Family/Caregiver		
Family/guardian/caregiver of an adult or a child with disabilities	35%	299
Staff/Community Leader		
Staff at an organization (agency/provider/advocate) working with people with disabilities, staff at a government agency, or community leader	57%	496

Note: Sub-categories total more than 100% as approximately one-third of respondents identified as being in more than one category.

Source: Survey of Health Needs of People with Disabilities in Massachusetts, 2013

To be included in a particular category, the respondent must have checked at least that category; however because respondents could check “all that apply,” no category is mutually exclusive.

Twenty respondents selected only “other”. These respondents were appropriately assigned to one of the above categories based on their response. For example, “pediatrician” was assigned to Staff/Community Leader at an organization.

Respondents were asked to identify which populations their organizations served. The most frequent organizations identified were those serving people with physical disabilities (75%) and people with intellectual and developmental disabilities (75%). Approximately 80% of respondents indicated that their organization served more than one population.

Table 6: What type of organization do you represent (check all that apply)

Organization Serves:	
People with physical disabilities	75%
People with intellectual/developmental disabilities	75%
People with mental illness	72%
Older adults with disabilities	64%
People who are Deaf or Hard of Hearing	62%
People who are blind	47%
Youth with disabilities	46%
Children with disabilities	36%
Other	10%

Note: Percentage does not total 100% as respondents could identify as being in more than one category. Examples in "Other" include: brain injury survivors, victims of domestic violence, etc.

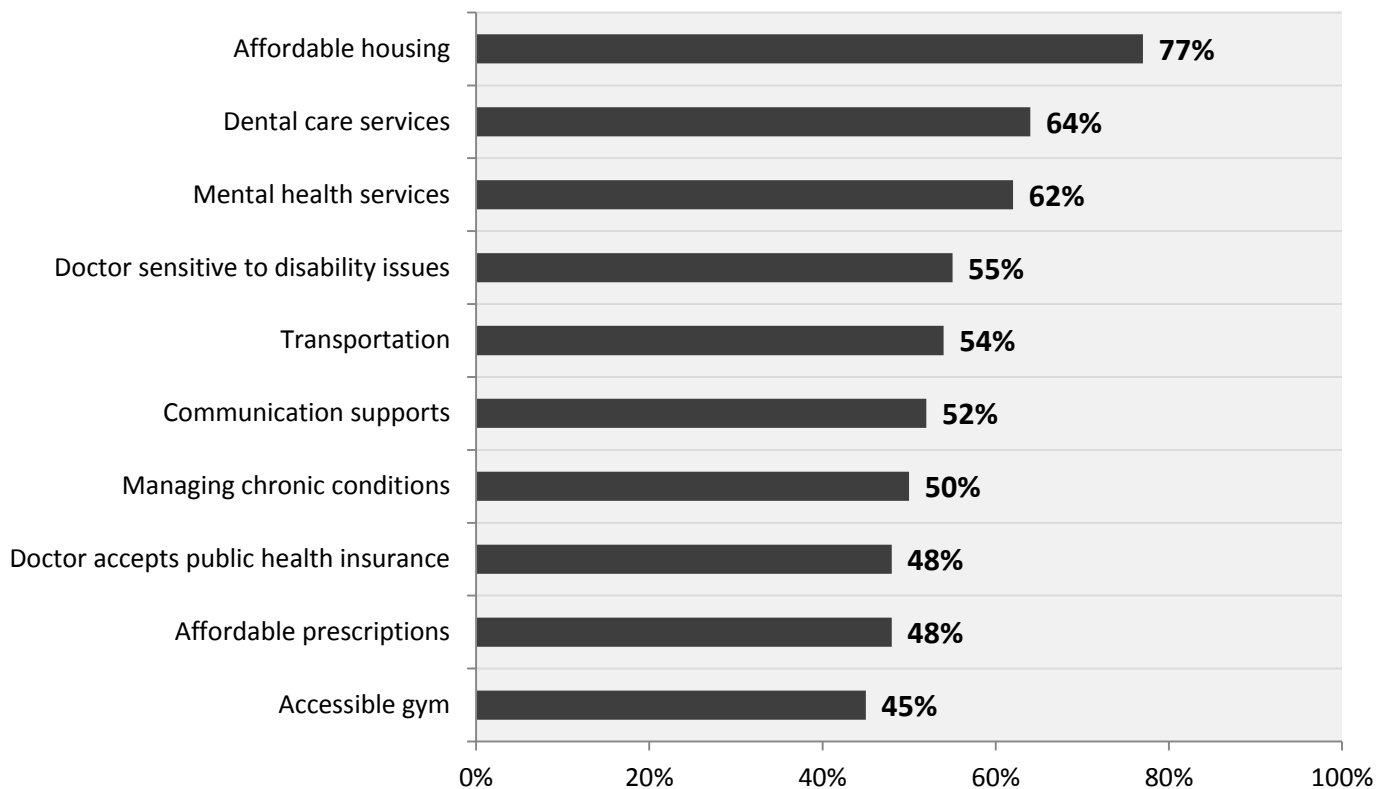
Source: Survey of Health Needs of People with Disabilities in Massachusetts, 2013

B. Level of Need: Top 10 “Big Problems”

Each respondent answered a series of questions aimed at assessing the level of need for a specific health indicator. The questions began “In your opinion, is it a problem for people with disabilities in Massachusetts to.....” Categories included items such as health insurance, transportation, housing, preventive care, and healthy foods, among others.

Below are the top 10 categories for all respondents who reported that indicator as a “Big Problem” for people with disabilities in Massachusetts.

Chart 24: Top 10 Health Issues Identified by All Survey Respondents

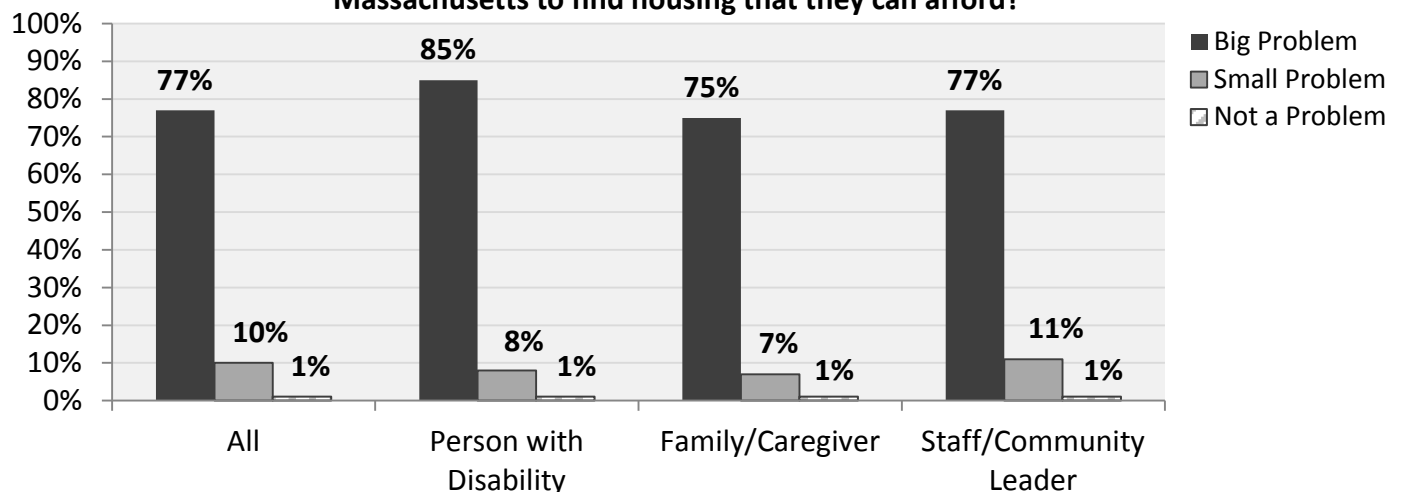


Source: Survey of Health Needs of People with Disabilities in Massachusetts, 2013

1. Housing

- Finding affordable housing ranked as the #1 most frequently reported health need among all survey respondents; 77% reported affordable housing as a “Big Problem” for people with disabilities in Massachusetts.
- Among respondents with disabilities**, 85% reported that finding affordable housing as a significant health need.
- Similarly 75% of **Family/Caregivers** of adults or children with disabilities and 77% of **Staff/Community Leaders** reported affordable housing as a significant health need.

Chart 25: In your opinion, is it a problem for people with disabilities in Massachusetts to find housing that they can afford?



Source: Survey of Health Needs of People with Disabilities in Massachusetts, 2013

“ I work with some of the most vulnerable individuals.....and if they aren’t lucky enough to have a Section 8 apartment, they are left virtually homeless. It’s disgraceful.... ”

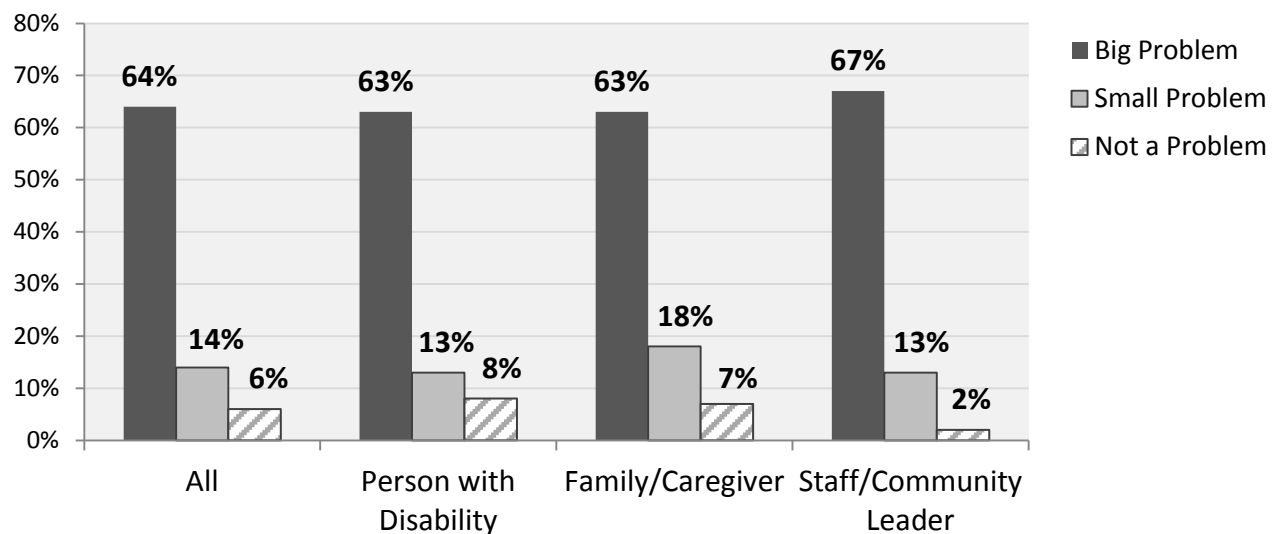
“ Housing is a huge problem. When you’re on such a small income it is really hard to find housing that is affordable. You can be put on a waiting list but it is so long taking years and years to get it. Need more housing built.... ”

“ There is a lack of affordable, wheelchair accessible housing state-wide, including within assisted living.... ”

2. Access to Dental Care

- Finding and accessing dental care was the second most frequently reported health need among all of the survey respondents; 64% reported access to dental care as a “Big Problem” for people with disabilities in Massachusetts.
- 67% of **Staff/Community Leaders** reported finding and accessing dental care to be a substantial problem.
- Similarly 63% of **respondents with disabilities** responded that access to dental care was a substantial problem for people with disabilities in MA.

Chart 26: In your opinion, is it a problem for people with disabilities in Massachusetts to find a dentist and to get adequate dental care?



Source: Survey of Health Needs of People with Disabilities in Massachusetts, 2013

“ Deaf people often feel prevented from getting quality dental care because dentists don't want to provide interpreters. ”

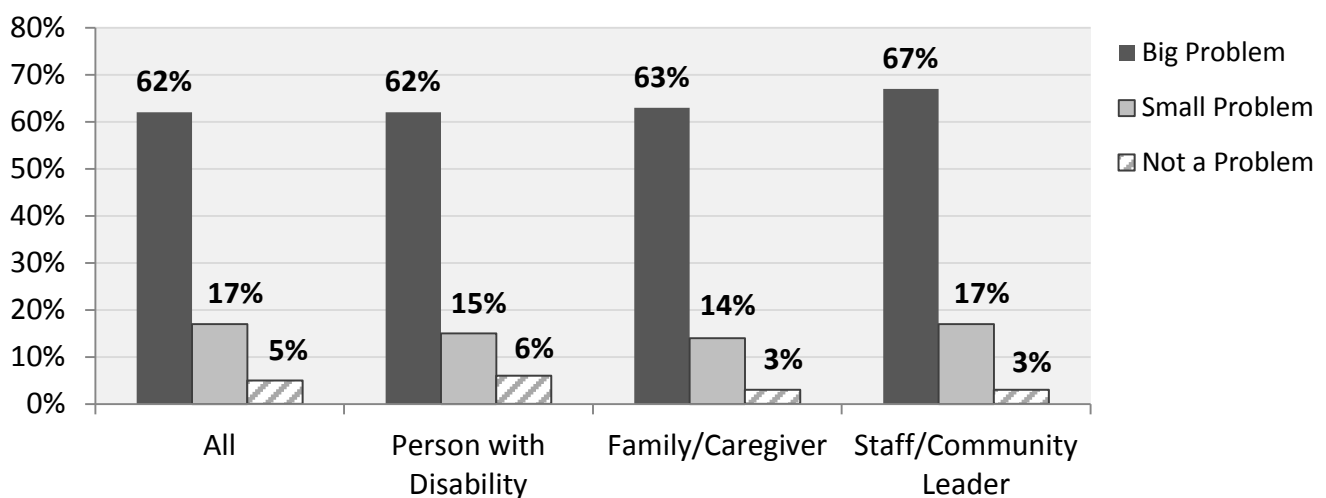
“ Why is there no provider offering affordable dental care for a non-employed person living with a disability? Good oral health is just as important as physical and mental health, but if you're not employed, there isn't any dental insurance available. ”

“ My biggest problem is finding an oral surgeon to have my daughters wisdom teeth removed. Multiple surgeons have said they won't do it cause of her special needs. And [they are] unable to refer me to someone who would be able to help. ”

3. Mental Health Services

- Finding a mental health provider and obtaining adequate mental health services ranked as the third most frequently reported health need among all survey respondents; 62% reported finding a mental health provider and getting adequate mental health services as a “Big Problem”.
- **Among respondents with disabilities**, 62% reported this issue as a significant problem..
- Similarly 67% of **Staff/Community Leaders** ranked access to mental health services as a significant problem for people with disabilities in MA.

Chart 27: In your opinion, is it a problem for people with disabilities in Massachusetts to find a mental health provider and get adequate mental health services?



Source: Survey of Health Needs of People with Disabilities in Massachusetts, 2013

“ A big problem is the number of mental health providers that accept MassHealth AND have an office that is accessible. ”

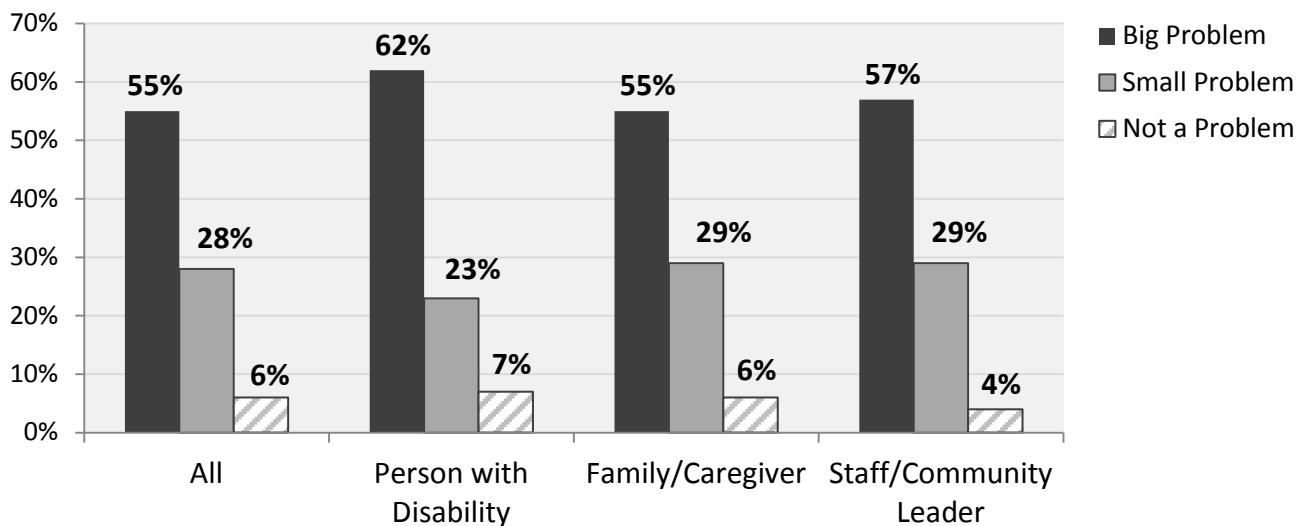
“ [There is a] lack of access to quality mental health services from providers who have the needed skills - due to lack of adequate reimbursement - for the people who need help the most. By pure luck, I have the first mental health therapist who is actually qualified to treat me - and help me stop deteriorating, maybe improve..... ”

“ Mental health care is not preventative- it is reactive in Massachusetts, which is very costly and risky. The only way to change this is if mental health medical needs [were] based on [physician] recommendations, not insurance requirements. ”

4. Provider Sensitivity

- Finding a doctor who is sensitive to disability issues was the fourth most frequently reported health need among all respondents to the online survey; 55% reported provider sensitivity as a “Big Problem” for people with disabilities in Massachusetts.
- 62% of **respondents with disabilities** reported finding doctors sensitive to disability issues as a significant problem.
- 55% of **Families/Caregivers** of children and adults with disabilities and 57% of **Staff/Community Leaders** ranked provider sensitivity to be a substantial health need.

Chart 28: In your opinion, is it a problem for people with disabilities to find a doctor that is sensitive to disability issues?



Source: Survey of Health Needs of People with Disabilities in Massachusetts, 2013

“ For people who are non-verbal, finding a care giver who can look at and take time to understand the individual. This should be taught to physicians and other health care providers as part of their training. ”

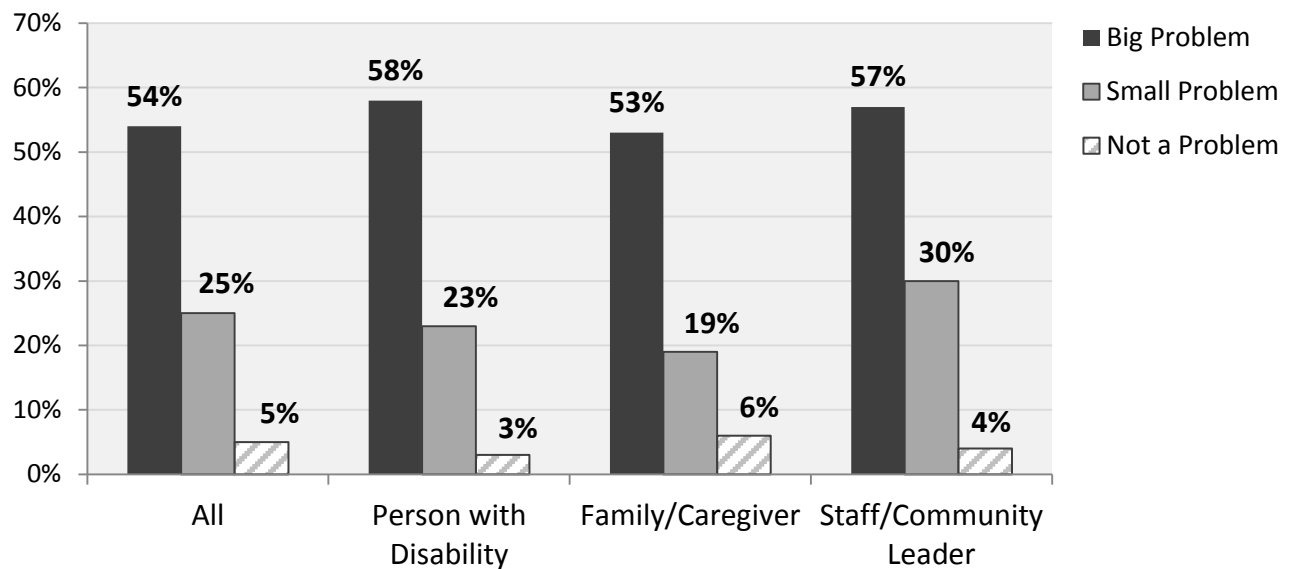
“ Sensitivity needs to improve in the medical community to the needs/fears of individuals with developmental disabilities, particularly as the population ages within the community i.e. those NOT living in institutions, group homes, assisted living facilities or in adult foster care. Better education of health care providers regarding people with disabilities. We are not just our disability, and our disability may not be always be manifested as described in any textbook... ”

“ It's not just sensitivity doctors lack. It's knowledge about different disabilities. ”

5. Transportation

- Transportation was reported as a “Big Problem” by 54% of all survey respondents, ranking it as the fifth largest health need for people with disabilities.
- 58% of **respondents with disabilities** reported finding transportation to doctor’s appointments as a significant problem.

Chart 29: In your opinion, is it a problem for people with disabilities in Massachusetts to find transportation to doctor’s appointments?



Source: Survey of Health Needs of People with Disabilities in Massachusetts, 2013

“ Again my big issue is, affordable/reliable transportation for us wheelchair users, no transportation, no medical care... ”

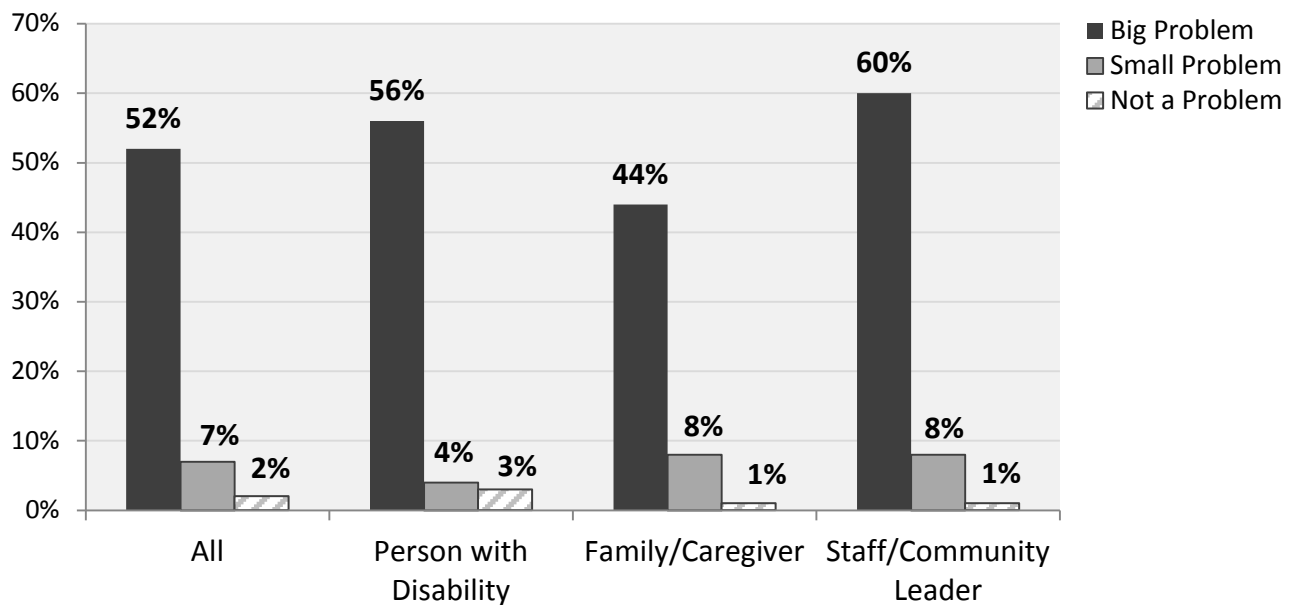
“ This is a HUGE problem. I hear over and over from people all across the state that MassHealth AND paratransit options to get to medical appointments is horrible. It is not reliable, they've been deserted, picked up so late that they miss appointments, etc. This needs some major major attention.”

“ The MBTA is STILL not completely accessible and it has been 23 years. What is the deal???? ”

6. Communication Supports

- Among all respondents, 52% reported finding a doctor that uses communication supports such as ASL, large print, Braille, or CART reporters as a “Big Problem” for people with disabilities in Massachusetts.
- 60% of **Staff/Community Leaders** reported finding a doctor that uses communications supports as a substantial health need.
- 44% of **Family/Caregivers** reported finding a doctor that uses communications supports as a significant issue.

Chart 30: In your opinion, is it a problem for people with disabilities in Massachusetts to find a doctor that uses communication supports such as American Sign Language, large print, Braille, or CART reporters?



Source: Survey of Health Needs of People with Disabilities in Massachusetts, 2013

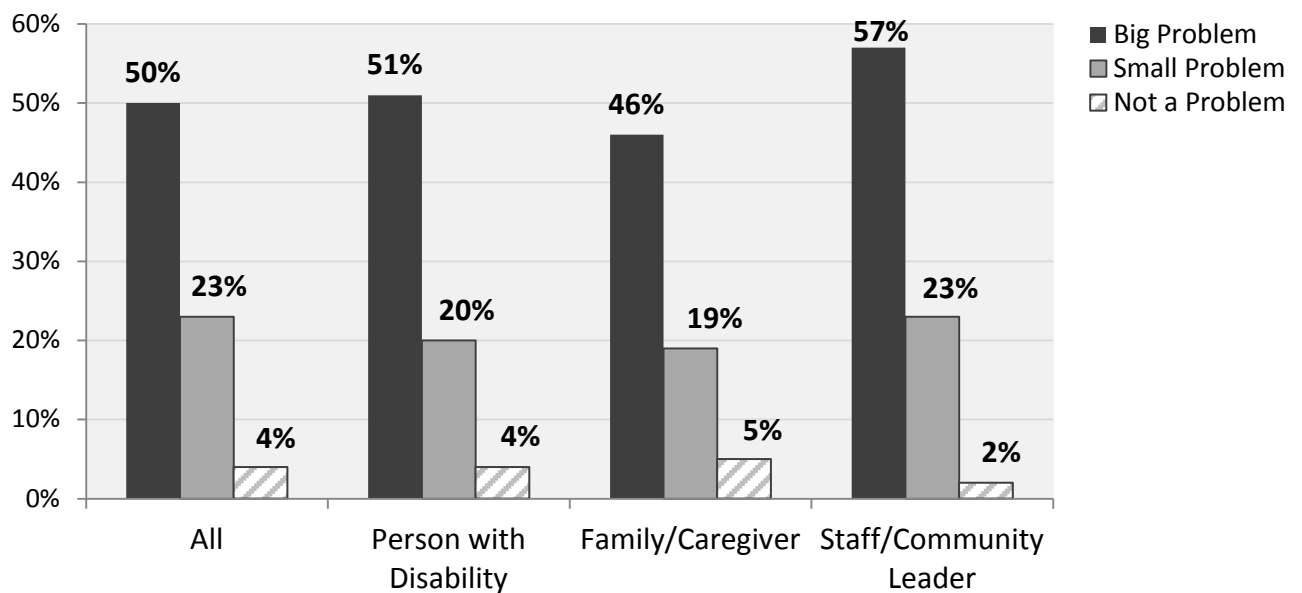
“ More ASL interpreters needed ”

“ Many medical professionals (health/dentists) have been refusing to accommodate Deaf/Hard of Hearing clients’ needs. Many of them requested sign language interpreters and were denied. ”

7. Chronic Conditions

- Among all respondents, 50% reported managing chronic conditions such as diabetes, asthma, or high blood pressure as a “Big Problem” for people with disabilities in Massachusetts.
- **Staff/Community Leaders** responded more frequently, with 57% reporting managing chronic conditions as a significant problem.
- 51% of **respondents with disabilities** and 46% of **Family/Caregivers** reported managing chronic conditions as a substantial health need.

Chart 31: In your opinion, is it a problem for people with disabilities in Massachusetts to manage chronic conditions such as diabetes, asthma or high blood pressure?



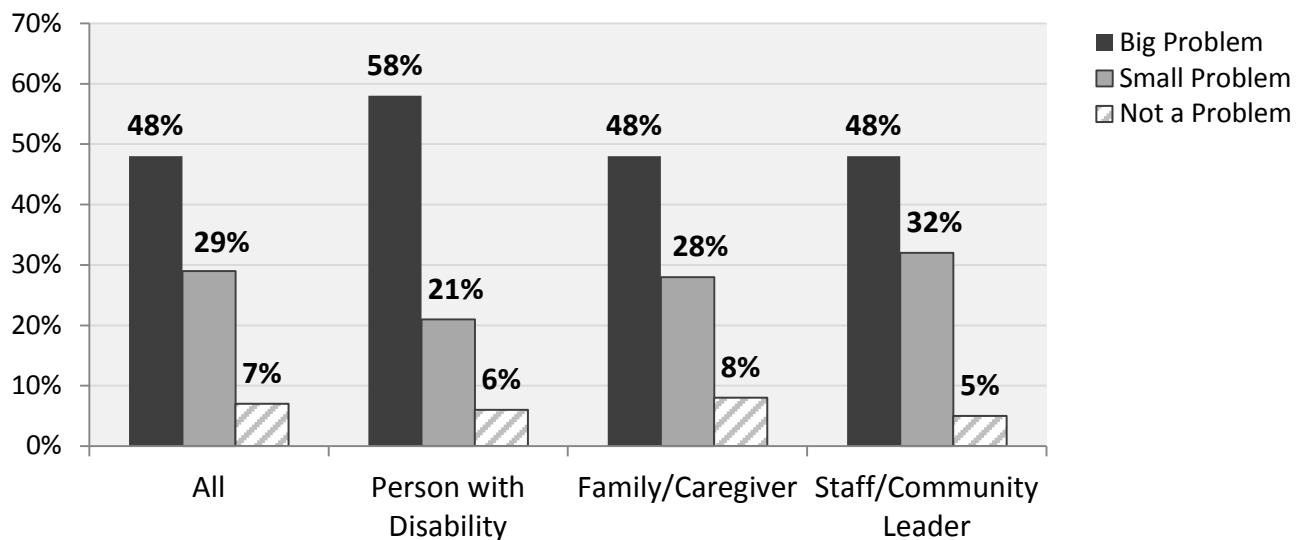
Source: Survey of Health Needs of People with Disabilities in Massachusetts, 2013

“ Also, [there is] no understanding [of] dual serious illnesses - I have incurable cancer and depression - this changes the services I need - adds to them - but no one acknowledges or serves the needs of people with a disability who also has a serious illness - heart disease, stroke, chronic pain, etc...”

8. Prescription Medications

- Among all respondents, 48% reported paying for prescription medications as a “Big Problem” for people with disabilities in Massachusetts.
- **People with Disabilities** responded even more frequently, with 58% reporting paying for prescription medications as a significant health need.
- Similarly, 48% of **Family/Caregivers** of adults or children with disabilities and 48% of **Staff/Community Leaders** reported paying for prescription medications as a significant issue.

Chart 32: In your opinion, is it a problem for people with disabilities in Massachusetts to pay for their prescription medications?



Source: Survey of Health Needs of People with Disabilities in Massachusetts, 2013

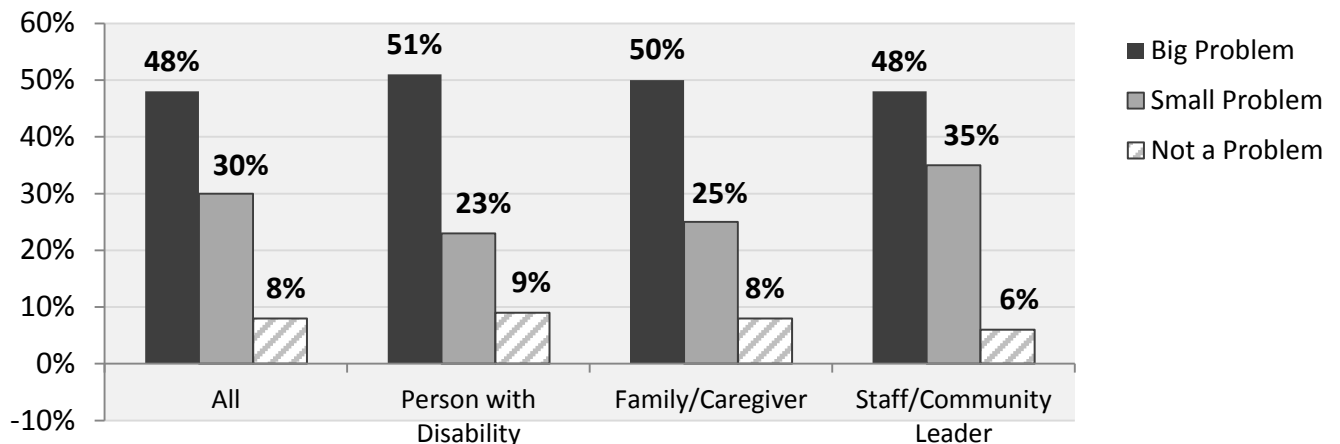
“I have found this state supportive of my needs for the most part, except for a recent change in drug payments due to Medicare Part D changes.”

“...there is a large gap between services available to people with disabilities who are not receiving government assistance- specifically case management with regards to medical appointments/diagnosis and coverage of prescriptions (I make less than \$20,000 a year and pay over \$3,000 out of pocket (not including pretax payroll deductions) for medical expenses despite having employer sponsored health insurance.”

9. Finding a provider who accepts public health insurance

- Among all respondents, 48% reported finding a provider that accepts public health insurance as a “Big Problem” for people with disabilities in Massachusetts.
- Similarly, 51% of **People with Disabilities**, 50% of **Family/Caregivers**, and 48% of **Staff/Community Leaders** reported finding a provider that accepts public health insurance as a significant health need.

Chart 33: In your opinion, is it a problem for people with disabilities in Massachusetts to find a doctor that accepts public health insurance (e.g., Medicaid/MassHealth, Medicare)?



Source: Survey of Health Needs of People with Disabilities in Massachusetts, 2013

“ Payment standards for MassHealth make it difficult to find doctors who will accept Medicaid. I tried to find a psychiatrist for someone to do an evaluation for someone that was to take 1 and 1/2 hours, but no one would do it for the \$86 reimbursement rate.... ”

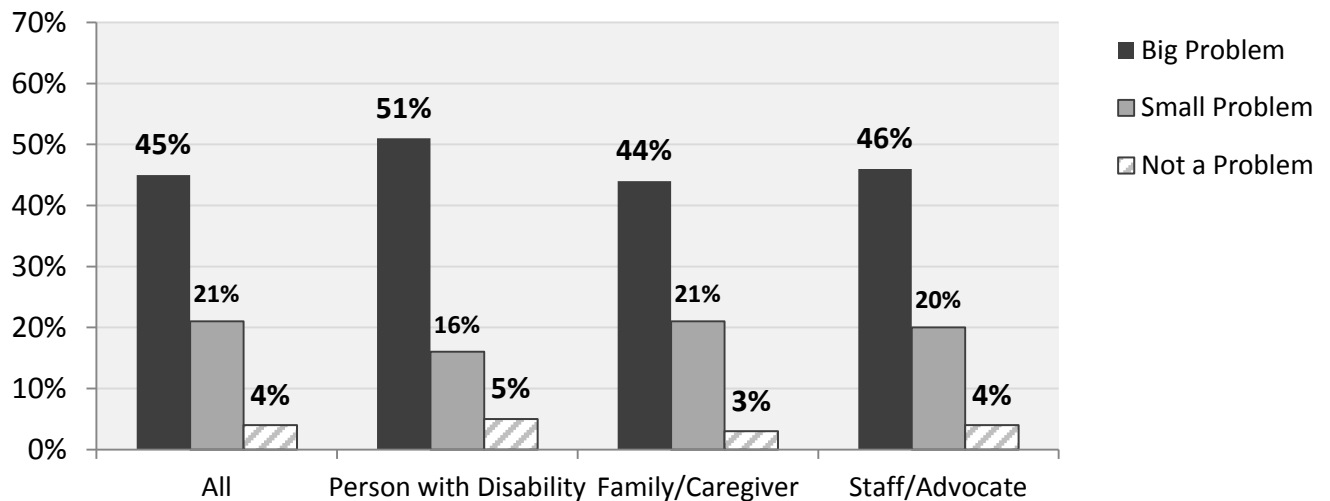
“ Reimbursement rates for MassHealth to providers are very bad. Providers do not want to take MassHealth because they lose money on every patient. This is especially true for allied health such as audiology. ”

“ One of the biggest challenges....is that for any serious medical concerns, our families end up having to travel to Springfield or Boston; it's a huge expense, time-consuming, and very difficult for individuals and families alike. We are in desperate need for more quality physicians in the Berkshires, especially those that understand the complex needs of people with disabilities and doctors that accept Medicaid and Medicare. ”

10. Accessible gym

- Among all survey respondents, 45% reported that finding an accessible gym or place to get exercise is a “Big Problem” for people with disabilities in Massachusetts.
- Similarly, 44% of **Family/Caregivers** and 46% of **Staff/Community Leaders** reported finding an accessible gym or place to get exercise as a substantial health need.
- **People with Disabilities** responded even more frequently, with 51% reporting that finding an accessible gym or place to get exercise is a significant issue.

Chart 34: In your opinion, is it a problem for people with disabilities in Massachusetts to find an accessible gym or a place to get exercise?



Source: Survey of Health Needs of People with Disabilities in Massachusetts, 2013

“ ...Most gyms are accessible, but less than 25% can be utilized with a spinal cord injury, which then leads to being overweight if one cannot exercise! ”

“obese [people are] discriminated against, no benefits or reimbursement for gym membership, weight loss drinks supervised by medical professionals ...no medical transportation to the gym for obese patients ... ”

“ There is a very serious issue affecting families with a member with intellectual disabilities. That problem is appropriate nutrition, exercise and engagement in regular activities that require physical effort. We need to take a close look at how people who cannot advocate for themselves and who cannot make informed food choices are living. Their bodies become painful prisons that they cannot escape. It is a very serious problem. ”

Personal Interviews

This section includes information from interviews with six stakeholders from the Massachusetts disability community. The interviews were conducted in May and June, 2013 by Dr. Mitra and Ms. Clifford from UMMS. The interviews were conducted by either telephone or in-person, based on the preference of the interviewee. The interviews were audio-taped with permission from the interviewee. The recordings will be deleted after the completion of the report. The assessment was exempt from UMMS Institutional Review Board approval. The names and affiliations of the interviewees are included in the Introduction section (page 17 of this report).

The primary question posed to the six interviewees was “What are the most significant health concerns of people with disabilities in Massachusetts?” It is important to note that the interview respondents were asked to focus on the health issues of people with disabilities in Massachusetts and to speak from their experience and the community that they served.

It should be noted that all comments and opinions recorded in this report are the opinions of the interviewee and do not necessarily represent the opinions of their respective employers or organizations.

The findings are categorized into four themes, each theme reflecting the information shared by the key informant interviewees. They included:

1. Communication barriers,
2. Inaccessible and fragmented health care,
3. Cultural competency, and
4. Data on the health of people with disabilities in MA.

The first theme, “Communication barriers faced by people with disabilities” reports respondents’ understandings of the common communication barriers faced by people with disabilities including the reluctance of health care professionals to provide ASL interpreters and

the lack of accessible health information. The second theme, “Inaccessible and fragmented care,” outlines both the lack of accessibility of provider offices and equipment as well as the lack of coordination in the delivery of health care services and programs. The third theme, “cultural competency” highlights the need for cultural competency in the delivery of services to those with disabilities, including cultural issues related to communications with doctors. Finally the last theme “availability of data on the health of people with disabilities” addresses the need for improved data collection methods on the health of people with disabilities as well as privacy of electronic medical records particularly for those with mental illness.

Theme 1: Communications Barriers

Communication barriers is an area of great concern in the disability community, with community stakeholders describing a broad range of communication barriers in the delivery of health care services to those with disabilities. Although this issue was frequently addressed, there was considerable breadth in how communication barriers were approached by the different stakeholders. For example, Jill Hatcher described the lack of accessible health information to be the primary health issue for people with disabilities in Massachusetts.

“ Because ASL is a visible language much of the health information that is passed around, that is out in the world, is done through hearing, spoken language, or written English, and for many Deaf people English is not their first language and that causes a lot of miscommunication. ”

-Jill Hatcher

The lack of accessible health information ranged from the publication of written material in alternative formats, including materials published on the internet that may not be “tagged” for text readers, to the high literacy levels of the materials. Much of the published information on health care services and prevention is complex and is not written at an appropriate grade-level. This barrier was particularly important for people with intellectual and developmental disabilities and also as noted by Leo Sarkissian, for caregivers and support staff of people with intellectual and developmental disabilities who often speak English as a second language.

Stakeholders also voiced their concern about the reluctance of health care professionals to provide ASL interpreters. Most providers do not communicate using ASL and are often reluctant to provide an interpreter because of cost. For example, one stakeholder noted

“ Many of them tell us that the Deaf person has to bring their own person, a friend, or a family member, and it doesn’t need to be an interpreter. ”

-Jill Hatcher

Theme 2: Cultural Competency

Another common theme among stakeholders is the need for cultural competency, not only among health care professionals but also among those who develop and disseminate intervention programs and services for people with disabilities. Stakeholders voiced the importance of cultural competency in addressing differences through the lens of race and ethnicity, as well as disability.

“ Cultural competency should be also embedded in the ‘front line’ among those who act as the primary contact, which is interestingly not the healthcare professional but those who are representing the agency. ”

-Derrick Dominique

Everyone who comes in contact with an individual, not just the doctors and nurses, needs to be culturally sensitive. Stakeholders felt strongly about integrating cultural sensitivity into the heart of the design of the delivery of health care services. The lack of cultural competency along with communication barriers leads to a lack of trust between the disability community and the health care professionals.

“ When we are devising our service delivery models the multicultural sensitivity really has to be a very significant proportion of the devising of the delivery. ”

-Derrick Dominique

“ ...For Latinas and African American groups spirituality is a big aspect of recovery, our technology relies a lot on medication to help people recover; I just think understanding that aspect and maybe even finding some sort of balance, that supports that can reach people ... ”

-Florette Willis

Others also noted the general sense of discomfort among health care professionals in working with people with disabilities. Health care providers too often don't address the consumer with the disability and instead address the interpreter or guardian in the room. For example one stakeholder mentioned that *"even the most well-intentioned primary care people aren't always attuned to the needs of people with disabilities."* Another concern that was voiced was the need for cultural competency and training in providing health care to those with intellectual and developmental disabilities. There is a sense of not being heard, of not being spoken to directly, of providers not conducting appropriate preventive tests based on assumptions of the individual.

"I think the biggest thing is the biases and the negative assumptions whether it is about behaviors, or it is about the person not really taking a look. "

-Leo Sarkissian

Other interviewees reported there is a feeling that physicians in general, when treating a person with a disability, do not see the whole person. This is particularly evident among those with invisible disabilities particularly those with mental illness. As noted by Florette Willis, health care professionals when caring for those with mental illness too often focus on the mental illness which often delays treatment or care for other health issues –*"the focus goes towards their mental illness and by the time they do receive the treatment the [physical] condition is pretty close to full blown."*

Theme 3: Inaccessible and Fragmented Health Care

Difficulties with accessing health care and related services and the fragmentation of the healthcare delivery system was a dominant health issue across the interviews. While the issue of health care was addressed by all six stakeholders, they addressed different aspects of the issue. Their comments ranged from fragmentation of the health care system, the inaccessibility of health care offices and medical equipment and devices, and the impacts of low reimbursements rates set by public health insurance.

Fragmented health care system: Many people with disabilities have to piece together health insurance coverage which may include some type of private insurance along with public sources of health insurance. The lack of access to broad-based insurance coverage and services and having to “cobble together” coverage is detrimental to the health of people with disabilities. Individuals with disabilities and families of children with disabilities “*are always having to gamble on their health*” because they are “*having to battle the bureaucracy for the coverage*” (Michael Muehe).

“...just the idea that you're always having to be battling the bureaucracy for the coverage you need and it's just the same for children and adults and always having to figure out well how can I, what's the best approach and people are always having to gamble on their health.... ”

-Michael Muehe

Interviewees also spoke extensively about the lack of coordination in the delivery of health care and other services for people with disabilities across the lifespan. They commented on the lack of the coordination of care, both across government agencies and across provider specialties. For example, Stacie Selfridge, as parent of a child with complex medical needs, needs to interact with a variety of government agencies in order to adequately provide services for her

daughter. Based on her daughter's needs, she must coordinate services with the Massachusetts Department of Public Health, Massachusetts Department of Developmental Services and MassHealth (Massachusetts Medicaid). In addition she has to coordinate the services provided by the Massachusetts Rehabilitation Commission (for her daughter's assistive technology needs) and the supports provided by the school system. In each agency she faces a different set of rules and interacts with different staff most of whom are not knowledgeable about the services her daughter is receiving from other agencies.

" ... [It] shouldn't have to be up to the individual to put together a team of clinicians that are going to be talking to each other. The burden ends up being on the individual with disability to put the group together...There's just so much fragmentation. "

-Michael Muehe

" [We] can do great things if we work together. "

-Stacie Selfridge

In addition there is a shortage of appropriate providers to meet the diverse needs of the disability community. For example, there are very few known health care providers in Massachusetts who can communicate with ASL. Individuals with physical disability have difficulty finding primary care providers who understand the long-term needs of the disability. Finally there is a shortage of providers who accept MassHealth.

" There is a shortage of healthcare professionals that accept public health insurance so when you find someone who accepts MassHealth, sometimes they get overburdened. "

-Leo Sarkissian

The issue of transitioning from pediatric to adult care was also noted. Many adults with intellectual and developmental disabilities still visit their pediatrician because there are so few primary care providers that are familiar with intellectual and developmental disabilities.

“ [My daughter] ...will be transitioning into adulthood. She has a right to be treated as a citizen. ”

-Stacie Selfridge

“ Access to services can be a problem, and one of the biggest access issues is adults remaining with pediatricians. ”

-Leo Sarkissian

Inaccessibility of Provider Offices and Equipment: Individuals with disabilities also have difficulty gaining access to medical and diagnostic equipment necessary to provide preventive health care such as mammography machines or exam tables that raise and lower. Stakeholders felt that accessibility issues went across the different types and sizes of provider settings from large hospitals to smaller community-based settings. The cumulative effect of having to overcome barriers to health care offices and equipment everyday and the feeling of *“getting humiliated by clinical staff”* resulted in people with disabilities *“giving up”* and not seeking relevant preventive care and diagnostic tests.

“ The issue of people with disabilities just being able to go in and get weighed, sometimes you know a year or more can go by because the doctor’s office is not well equipped to weigh them.”

-Florette Willis

“ Can I get onto the exam table? Can I get access to their radiological equipment that I need access to for tests or am I going to encounter barriers along the way? ”

-Michael Muehe

Stakeholders also noted the need for full access to schools, social activities, gyms, transportation, and playgrounds to improve the quality of life and by extension health of individuals with disabilities.

Provider Training and Sensitivity: Several stakeholders brought up the issue of “lack of knowledge as a huge issue for healthcare professionals.” Health care professionals don’t have sufficient training to provide care to people with intellectual and developmental disabilities and are often trained by parents and caregivers during appointments. Parents of children with developmental or intellectual disabilities, for example, bring pictures and materials to appointments and find themselves in the position of being educators to healthcare professionals. Similarly support and residential staff are also often not appropriately trained or experienced to provide adequate supports to the individuals they serve.

“ ... [The] doctor is not going to understand me, they’re going to judge me, there’s going to be miscommunication anyway.... ”

-Jill Hatcher

“even though this person may have a severe disability They’re the best people who know themselves and if you only listen to these individuals they’ll be able to tell you what they need. So it’s listening, it’s taking the whole person approach, it’s listening to the individual, it’s being respectful, it’s providing integrated care. ”

-Michael Muehe

“ There are some testimonies of their experience with healthcare providers who have provided their services with what the consumer/patient feels is a certain level of prejudice. A feeling that they are not being heard, not being listened to, not asked a sufficient amount of questions for what they the consumer feels is a proper diagnosis. ”

-Derrick Dominique

Theme 4: Data on the Health of People with Disabilities

Two issues related to data collection of people with disabilities emerged: the need for better data on the health of people with disabilities, and the need for strict data privacy standards related to the release of electronic health records.

Traditional telephone surveys such as the BRFSS do not reach most people who are Deaf or Hard of Hearing as well as many individuals who have intellectual and developmental disabilities. In order to better understand the needs of the disability community, new and innovative ways are needed to survey the population and measure their health needs. Data will help *“...justify more education and more programs, and more community health programs in the community.”*

Another stakeholder voiced the need for alternate approaches to data collection including conducting focus groups among people with disabilities who cannot participate in traditional survey methods. It is important to examine different approaches to data collection in order to get a *“a better handle on our population and research.”* Leo Sarkissian

An alternative data collection approach that more accurately reflects that needs of individuals with disabilities were the methods employed by this needs assessment including the survey of health needs of people with disabilities in Massachusetts and the personal interviews.

“The DPH survey that we are doing right now is the exception to the rule.”

-Jill Hatcher

Stakeholders raised another perspective on data collection related to the privacy of data, particularly related to electronic health records and access to the mental health records of people with mental illness. Concern was raised that leakage of confidential health information about those in recovery, particularly those recovering from extreme states, might be devastating for the individuals.

“ You don’t want your records going anywhere, and it is really important for consumers to have control meaning that each time their records are being accessed by someone other than their provider, or someone that needs to access them, they should be allowed [to know] or at least a request goes out for their consent. ”

-Florette Willis

Summary

The purpose of this needs assessment was to inform the Health and Disability Program (HDP) of the Massachusetts Department of Public Health (MDPH) of the public health needs of people with disabilities in Massachusetts and to assist HDP in prioritizing their programmatic and policy goals. The needs assessment utilized a multi-pronged analytic approach, including quantitative and qualitative methods. Quantitative methods included an analysis of Massachusetts Behavioral Risk Factor Surveillance System (MA BRFSS) data and interpretation of the findings from a survey of the health needs of people with disabilities in MA. Qualitative methods included key informant interviews with local stakeholders from the Massachusetts disability community. Taken together, this rich array of qualitative and quantitative data provides a wealth of information on the health needs of people with disabilities and should help HDP to develop goals and objectives to address these needs.

Common themes were evident across the different assessment methods. People with disabilities in Massachusetts face substantial health disparities and unmet public health needs, as seen in all components of the needs assessment. The findings from the MA BRFSS suggest great disparities between those with and without disabilities in multiple health indicators including: health care access, particularly access to oral health care; in overall health; mental health; sexual violence; unintentional falls; chronic disease; obesity rates and physical activity.

Interpretation of the findings from the online survey indicate that the greatest health needs are in the domains of housing, access to mental and oral health providers, access to providers who accept public health insurance, prescription medications, transportation to medical appointments, and accessible gyms. Also notable were the need for provider sensitivity to disability issues and the need for communication supports during health care visits. The findings from the online survey point to some of the risk factors and unmet needs that may contribute

to the disparities between people with and without disabilities in the health indicators identified through the MA BRFSS.

Finally, the qualitative component of the assessment highlights difficulties in navigating the health care system due to lack of accessible equipment, fragmented health care, communication barriers and a lack of culturally competent health care professionals. The need for more data and improved methods to collect data on the health of people with disabilities was also raised as an area of concern among the stakeholders.

Taken together, the three different approaches provide vital information on the public health needs of people with disabilities in Massachusetts and are a rich source of information for HDP at MDPH as they prioritize their strategies for improving the health and quality of life of people with disabilities across the Commonwealth.

Strengths and Limitations of the Health Needs Assessment

All of the datasets described in this report have limitations. The MA BRFSS data and the online needs assessment survey have potential limitations inherent to all surveys.

The MA BRFSS survey is inaccessible to those who do not use telephones, who live in institutional settings, or are homeless. In addition, the MA BRFSS survey methodology precludes participation by those who need assistance in completing the interview due to cognitive, developmental or other disabilities, and others who rely on forms of communication other than a telephone.

The survey of the health needs of people with disabilities in Massachusetts was intended to complement the available data from the MA BRFSS. However, the online survey methodology, while intended to reach people who are generally underrepresented in random-digit-dial telephone surveys such as the BRFSS, may not be representative of all people with disabilities in Massachusetts. The survey is only accessible to those who have access to a computer and the internet, are comfortable with using an online survey, and are able to respond to a written survey in English. Due to resource limitations, we were unable to conduct the survey in other languages.

Qualitative evaluation via personal interviews with six selected stakeholders also has its limitations. Including personal interviews in the needs assessment provided rich information on the health of the disability community in Massachusetts from a broad array of community stakeholders. As is common with qualitative evaluation, key stakeholders were purposely selected for the interviews. This helped ensure broad representation of disability perspectives. However, there are likely certain disability sub-groups whose opinions are not represented in this report as well as many cultural, ethnic, racial, and geographic sub-groups. Moreover, the

nature of the ‘snowball’ sampling strategy inhibits the ability to generalize to the larger population of people with disabilities in Massachusetts.

Notwithstanding, this needs assessment provides a starting point for assessing the unmet needs of people with disabilities in Massachusetts. This evaluation’s strengths help moderate many of the above-mentioned limitations. Common themes emerged across the different quantitative and qualitative data collection methods used in this assessment. This strengthens the reliability and generalizability of the findings of the needs assessment. Another strength of this assessment is that input was collected via the online survey from individuals who may be traditionally excluded from surveys such as the MA BRFSS. Finally, to our knowledge this is the first health needs assessment of people with disabilities in Massachusetts and will be a rich source of information for HDP as it prioritizes its programmatic goals and objectives.

Sources

2011 Disability Status Report (American Community Survey)

Massachusetts

Complete report: www.disabilitystatistics.org

A Profile of Health Among Massachusetts Adults, 2011

Results from the Behavioral Risk Factor Surveillance System

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Results from the Behavioral Risk Factor Surveillance System

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A Profile of Health among Persons with Disabilities in Massachusetts, 2008-2011

Andrews, B. K., & Wilson, T. (2012). *A profile of Health among Persons with Disabilities in Massachusetts, 2008-2011*. Boston: Massachusetts Department of Public Health.

Massachusetts Youth Health Survey (MYHS)

Complete report: <http://www.mass.gov/eohhs/docs/dph/behavioral-risk/2011-yhs.pdf>

National Survey of Children with Special Health Care Needs

<http://childhealthdata.org/learn/ns-cshcn>

Acknowledgements

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We are deeply grateful to the respondents of the needs assessment without whose time and commitment this needs assessment would not have been possible. We thank the Health and Disability Partnership members for their help in designing the approach and methods of the needs assessment. In addition, we thank the six community stakeholders: Derrick Dominique, Jill Hatcher, Michael Muehe, Leo Sarkissian, Stacie Selfridge, and Florette Willis, who graciously agreed to be interviewed for this project. We would like to thank the respondents to the MA BRFSS survey for their participation.

We are also thankful to Bonnie Andrews Deputy Director of the Office of Statistics and Evaluation in the Bureau of Community Health and Prevention for her invaluable and timely assistance in developing the map of survey respondents and Dr. Shelley Goodgold for her work as initial needs assessment consultant to HDP.

Appendix 1: Listing of Partnership Members

- Blue Cross Blue Shield of Massachusetts
- Boston Medical Center- Research Institute-NERSIC- New England Regional Spinal Cord Center
- Cambridge Commission for Persons with Disabilities
- DEAF, Inc.
- Disability Law Center
- Disability Policy Consortium
- Disabled Persons Protection Commission
- DPH Community Transformation Grant/ Mass-in-Motion
- Massachusetts Commission for the Blind
- Massachusetts Commission for the Deaf & Hard of Hearing
- Massachusetts Department of Developmental Services
- Massachusetts Department of Public Health
- Massachusetts Department of Mental Health
- Massachusetts Office on Disability
- Massachusetts Rehabilitation Commission
- Multi-Cultural Independent Living Center of Boston
- The Arc of Massachusetts
- Tufts University School of Medicine
- University of Massachusetts Medical School

New Members

- Asperger's Association of New England
- Commonwealth Care Alliance
- DPH Children and Youth with Special Health Care Needs Program
- DPH Division of Violence and Injury Prevention
- Executive Office of Elder Affairs
- Health and Disability Working Group, BU School of Public Health
- Hockomock Area YMCA
- Massachusetts Emergency Management Agency
- Massachusetts Association for The Blind And Visually Impaired (MAB)
- MassMATCH
- MS Society, Greater New England Chapter
- New England Paralyzed Veterans of America
- Perkins School for the Blind
- Self-advocate
- The Autism Resource Center of Central Massachusetts

Appendix 2: Definitions of Disability

Different ways of identifying disability in surveys result in different disability estimates. The prevalence of disability also depends on the mechanism used to administer the survey and the different populations of interest for the particular survey. A random-digit-dial telephone survey such as the Behavioral Risk Factor Surveillance System might reach a different set of people with disabilities compared to a mail survey such as the American Community Survey.

American Community Survey (ACS)

The ACS is an annual mailed household survey conducted by the United States Census Bureau to collect socio-economic information. The survey provides information which helps communities plan investments and services and the national and state governments allocate funds.

Disability Screener in ACS

The disability questions used in the ACS are listed below.

- **Hearing Disability** (asked of all ages): Is this person deaf or does he/she have serious difficulty hearing?
- **Visual Disability** (asked of all ages): Is this person blind or does he/she have serious difficulty seeing even when wearing glasses?
- **Cognitive Disability** (asked of persons ages 5 or older): Because of a physical, mental, or emotional condition, does this person have serious difficulty concentrating, remembering, or making decisions?
- **Ambulatory Disability** (asked of persons ages 5 or older): Does this person have serious difficulty walking or climbing stairs?
- **Self-Care Disability** (asked of persons ages 5 or older): Does this person have difficulty dressing or bathing?

- **Independent Living Disability** (asked of persons ages 15 or older): Because of a physical, mental, or emotional condition, does this person have difficulty doing errands alone such as visiting a doctor's office or shopping? 2011

Behavioral Risk Factor Surveillance System

The Behavioral Risk Factor Surveillance System (BRFSS) is an annual telephone survey that collects data on emerging public health issues, health conditions, risk factors and behaviors. It collects information on topics such as racial discrepancies in health and health care, trends in chronic diseases, and health risk factors. Results are used for health care policy planning, as a guide for developing preventive health interventions, and as an assessment of health status in Massachusetts.

Disability Screener in MA BRFSS

In the Massachusetts Behavioral Risk Factor Surveillance System (MA-BRFSS) disability was defined as having one or more of the following:

- Are you limited in any way in any activities because of physical, mental, or emotional problems?
- 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?
- Because of any impairment or health problem, do you have any trouble learning, remembering, or concentrating?
- A disability can be physical, mental, emotional, or communication-related. Would you describe yourself as having a disability of any kind?

Respondents who answered “Yes” to one or more of the screening questions were classified as having a disability and those whose activities had been limited for at least a year or more were considered for this report to have a disability. Adults who were classified as having a disability were also asked whether they needed the help of other persons in handling routine or personal care.

National Survey of Children with Special Health Care Needs

The National Survey of Children with Special Health Care Needs (NS-CSHCN) takes a close look at the health and functional status of children with special health care needs in the U.S.—their physical, emotional and behavioral health, along with critical information on access to quality health care, care coordination of services, access to a medical home, transition services for youth, and the impact of chronic condition(s) on the child’s family.

Disability Screener in NS-CSHCN

To meet the CSHCN Screener criteria a child’s parent must report the child has an ongoing health condition for which he/she experiences one or more of the following:

- need or use of prescription medications;
- an above routine use of services;
- need or use of specialized therapies or services;
- need or use of mental health counseling;
- a functional limitation.

Youth Health Survey

The Massachusetts Youth Health Survey (MAYHS) is the Massachusetts Department of Public Health's (MDPH) surveillance project to assess the health of youth and young adults in grades 6-12. It is conducted by the MDPH Health Survey Program in collaboration with the Massachusetts Department of Elementary and Secondary Education (DESE) in randomly selected public middle and high schools in every odd-numbered year. The anonymous survey contains health status questions in addition to questions about risk behaviors and protective factors.

Disability Screener in YHS

All respondents were asked if they had any physical disabilities or long-term health problems, with long-term defined as six months or more.

Appendix 3: Survey of Health Needs for People with disabilities in Massachusetts, 2013

Page One

The Health and Disability Program in the Office of Health Equity, Massachusetts Department of Public Health is conducting a survey of the health needs of people with disabilities in Massachusetts. The aim of this survey is to understand and prioritize the health needs of people with disabilities living in Massachusetts. We are asking you to complete this brief survey by **May 31, 2013**.

Participation in the survey is voluntary. All responses are completely anonymous. Individual responses will not be released and we will not be able to identify the names of individual respondents. There are no right or wrong answers; it's your opinion that matters!

Who should complete this survey: Residents of Massachusetts who have disabilities; caregivers or guardians of adults or children with disabilities; disability advocates; staff at community based organizations or state and local government offices that serve people with disabilities; academic researchers, physicians, public health officials and professionals, health and wellness promotion specialists, health administrators and health policy experts and anyone who has an interest in the health of people with disabilities in Massachusetts.

If you need assistance accessing this survey or would like to complete by telephone, please contact Ashley Martinez at 617-624-5960 or Ashley.Martinez@state.ma.us

Your feedback is important and will be used to help the Health and Disability Program set priorities for taking action to improve the health of people with disabilities in Massachusetts. Thank you for your participation.

If you have any questions regarding this survey, please contact Monika Mitra at Monika.Mitra@umassmed.edu or Georgia Simpson May at Georgia.Simpson.May@state.ma.us

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1. Please describe yourself (check all that apply): *

- ☐ Person with a disability
- ☐ Family/guardian/caregiver of an adult with disabilities

- ☐ Family/guardian/caregiver of a child or youth with disabilities
 - ☐ Staff at organization (agency/provider/advocate) that works with people with disabilities
 - ☐ Staff at government agency
 - ☐ Community leader
 - ☐ Other
-

2. Does your organization serve: (Check all that apply.)

- ☐ People with physical disabilities
 - ☐ People with intellectual or developmental disabilities
 - ☐ People with mental illness
 - ☐ People who are deaf or hard of hearing
 - ☐ People who are blind
 - ☐ Children with disabilities
 - ☐ Youth with disabilities
 - ☐ Older adults with disabilities
 - ☐ Other
-

3. Are you a member of the Massachusetts Department of Public Health, Health and Disability Partnership? *

- ☐ Yes
 - ☐ No
-

4. Do you live in Massachusetts? *

5. What city or town do you live in?

6. Do you work in Massachusetts? *

-- Please Select --	▲
Yes	≡
No	▼

7. Do you, or a person you care for, have difficulty dressing or bathing? *

-- Please Select --	▲
Yes	≡
No	▼

8. Do you, or a person you care for, have serious difficulty walking or climbing stairs? *

-- Please Select --	▲
Yes	≡
No	▼

9. Because of a physical, mental, or emotional condition, do you, or a person you care for, have serious difficulty concentrating, remembering, or making decisions? *

-- Please Select --	▲
Yes	≡
No	▼

10. Are you, or a person you care for, blind or have serious difficulty seeing even when wearing glasses? *

-- Please Select --	▲
Yes	≡
No	▼

11. Are you, or a person you care for, deaf or have serious difficulty hearing? *

-- Please Select --

Yes

No

New Page

12. In your opinion, is it a problem for people with disabilities in Massachusetts to get health insurance? *

Not a problem

☐

Small Problem

☐

Big Problem

☐

Don't Know

☐

13. In your opinion, is it a problem for people with disabilities in Massachusetts to find a doctor that accepts **public** health insurance (e.g. Medicaid/MassHealth, Medicare)? *

Not a problem

☐

Small Problem

☐

Big Problem

☐

Don't Know

☐

14. In your opinion, is it a problem for people with disabilities in Massachusetts to find a doctor that accepts **private** health insurance (e.g., Blue Cross/Blue Shield)? *

Not a problem

☐

Small Problem

☐

Big Problem

☐

Don't Know

☐

15. In your opinion, is it a problem for people with disabilities in Massachusetts to find a doctor who is sensitive to disability issues? *

Not a problem

☐

Small Problem

☐

Big Problem

☐

Don't Know

☐

16. In your opinion, is it a problem for people with disabilities in Massachusetts to find a dentist? *

Not a problem

☐

Small Problem

☐

Big Problem

☐

Don't Know

☐

17. In your opinion, is it a problem for people with disabilities in Massachusetts to get adequate dental care? *

Not a problem



Small Problem



Big Problem



Don't Know



18. In your opinion, is it a problem for people with disabilities in Massachusetts to find a mental health provider? *

Not a problem



Small Problem



Big Problem



Don't Know



19. In your opinion, is it a problem for people with disabilities in Massachusetts to get adequate mental health services? *

Not a problem



Small Problem



Big Problem



Don't Know



20. In your opinion, is it a problem for people with disabilities in Massachusetts to pay for their prescription medications? *

Not a problem



Small Problem



Big Problem



Don't Know



21. In your opinion, is it a problem for people with disabilities in Massachusetts to manage chronic conditions such as diabetes, asthma or high blood pressure? *

Not a problem



Small Problem



Big Problem



Don't Know



22. In your opinion, is it a problem for people with disabilities in Massachusetts to get routine medical tests such as an annual physical, mammogram or colonoscopy? *

Not a problem



Small Problem



Big Problem



Don't Know



23. In your opinion, is it a problem for people with disabilities in Massachusetts to get vaccines such as the flu or pneumonia vaccine? *

Not a problem



Small Problem



Big Problem



Don't Know



24. In your opinion, is it a problem for people with disabilities in Massachusetts to find a doctor's office that is accessible, e.g., has wheelchair ramps, exam tables that raise & lower, etc.? *

Not a problem



Small Problem



Big Problem



Don't Know



25. In your opinion, is it a problem for people with disabilities in Massachusetts to find a doctor that uses communication supports such as American Sign Language, large print, Braille, or CART reporters? *

Not a problem



Small Problem



Big Problem



Don't Know



26. In your opinion, is it a problem for people with disabilities in Massachusetts to find transportation to doctor's appointments? *

Not a problem



Small Problem



Big Problem



Don't Know



27. In your opinion, is it a problem for people with disabilities in Massachusetts to get durable medical equipment (DME) such as wheelchairs, scooters, hospital beds? *

Not a problem



Small Problem



Big Problem



Don't Know



28. In your opinion, is it a problem for people with disabilities in Massachusetts to find accessible supports and programs if experiencing violence or abuse? *

Not a problem



Small Problem



Big Problem



Don't Know



29. In your opinion, is it a problem for people with disabilities in Massachusetts to find housing that they can afford? *

Not a problem



Small Problem



Big Problem



Don't Know



30. In your opinion, is it a problem for people with disabilities in Massachusetts to find an accessible gym or a place to get exercise? *

Not a problem



Small Problem



Big Problem



Don't Know



31. In your opinion, is it a problem for people with disabilities in Massachusetts to find a grocery store that sells healthy food, such as fruits and vegetables? *

Not a problem



Small Problem



Big Problem



Don't Know



32. In your opinion what are the top five (5) health-related issues that affect people with disabilities in Massachusetts? Please select your **top 5**. *

☐ Accessible affordable housing

☐ Cancer

☐ Quality public education

☐ Accessible doctor's offices

☐ Dental care

☐ Safe neighborhoods

☐ Accessible gyms or place to get physical exercise

☐ Diabetes

☐ Sexually transmitted infections (HIV/AIDS, chlamydia, etc.)

☐ Access to healthy food such as fruits or vegetables

☐ Durable medical equipment (wheelchair, hospital bed, etc.)

☐ Smoking

☐ Accessible public transportation

☐ Heart disease (stroke, hypertension, etc.)

☐ Teen pregnancy

☐ Access to health insurance

☐ Infectious/contagious disease (tuberculosis, pneumonia, flu, etc.)

☐ Vaccinations

☐ Affordable prescription drugs

☐ Violence (gangs, street or domestic violence)

☐ Aging problems (Alzheimer's, arthritis, dementia, etc.)

☐ Mental health issues (anxiety, depression, etc.)

☐ Other (please specify)

☐ Asthma

☐ Overweight or obesity

33. Do you have anything else you would like to add regarding the health needs of people living with disabilities in Massachusetts?

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34. Do you consider yourself to be one or more of the following (check all that apply): *

- ☐ Male
- ☐ Female
- ☐ Transgender
- ☐ Prefer not to respond
- ☐ Something else (please indicate)

35. Do you consider yourself to be one or more of the following (check all that apply): *

- ☐ Heterosexual/straight
- ☐ Gay or lesbian
- ☐ Bisexual
- ☐ Prefer not to respond
- ☐ Something else (please indicate)

36. What is your age? *

- ☐ 18-24 years
- ☐ 25-34 years
- ☐ 35-44 years
- ☐ 45-54 years
- ☐ 55-64 years
- ☐ 65 years and older

37. What is your ethnicity? (you can specify one or more) *

- | | | |
|---|-------------------------------------|---|
| <input type="checkbox"/> African (specify)
<input type="text"/> | <input type="checkbox"/> Cuban | <input type="checkbox"/> Mexican, Mexican American, Chicano |
| <input type="checkbox"/> African American | <input type="checkbox"/> Dominican | <input type="checkbox"/> Middle Eastern (specify)
<input type="text"/> |
| <input type="checkbox"/> American | <input type="checkbox"/> European | <input type="checkbox"/> Portuguese |
| <input type="checkbox"/> Asian Indian | <input type="checkbox"/> Filipino | <input type="checkbox"/> Puerto Rican |
| <input type="checkbox"/> Brazilian | <input type="checkbox"/> Guatemalan | <input type="checkbox"/> Russian |
| <input type="checkbox"/> Cambodian | <input type="checkbox"/> Haitian | <input type="checkbox"/> Salvadoran |
| <input type="checkbox"/> Cape Verdean | <input type="checkbox"/> Honduran | <input type="checkbox"/> Vietnamese |
| <input type="checkbox"/> Caribbean Islander (specify)
<input type="text"/> | <input type="checkbox"/> Japanese | <input type="checkbox"/> Other (specify)
<input type="text"/> |
| <input type="checkbox"/> Chinese | <input type="checkbox"/> Korean | <input type="checkbox"/> Unknown/not specified |
| <input type="checkbox"/> Colombian | <input type="checkbox"/> Laotian | |

38. What is your race? (you can specify one or more) *

- | | |
|--|----------------------|
| <input type="checkbox"/> American Indian/Alaska Native (specify tribal nation) | <input type="text"/> |
| <input type="checkbox"/> Asian | |
| <input type="checkbox"/> Black | |
| <input type="checkbox"/> Hispanic/Latino/Black | |
| <input type="checkbox"/> Hispanic/Latino/White | |
| <input type="checkbox"/> Hispanic/Latino/Other | |
| <input type="checkbox"/> Native Hawaiian or other Pacific Islander (specify) | <input type="text"/> |
| <input type="checkbox"/> White | |
| <input type="checkbox"/> Other (specify) | <input type="text"/> |

☐ Unknown/not specified

39. In what language do you prefer to discuss your health care? *

☐ English

☐ Somali

☐ Spanish

☐ Arabic

☐ Portuguese

☐ Albanian

☐ Cape Verdean Creole

☐ Chinese (specify dialect)

☐ Haitian Creole

☐ Khmer

☐ Russian

☐ Vietnamese

☐ ASL

☐ Other (specify)

40. What language do you prefer to read health-related materials? *

Thank You!

Thank you for completing the survey. Your input is important to us. The data collected will be aggregated and, along with other data collected, used by the Massachusetts Department of Public Health to plan priorities to improve the health of people with disabilities.

Any questions, please contact:

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University of Massachusetts Medical School

508-856-8548

Monika.Mitra@umassmed.edu

Georgia Simpson May

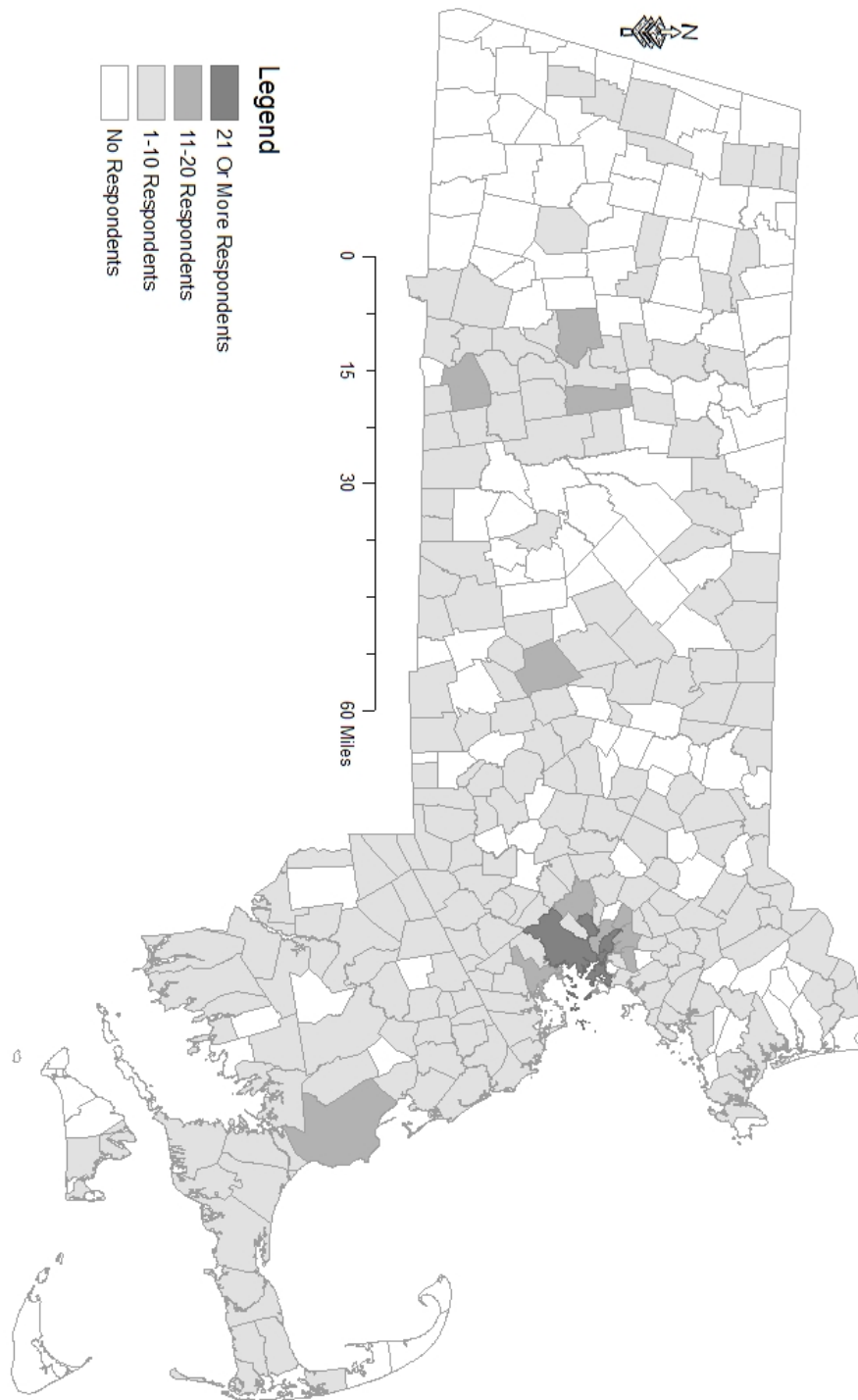
Director, Office of Health Equity

Massachusetts Department of Public Health

617-624-5590

Georgia.Simpson.May@state.ma.us

Appendix 4: Map of Respondents to the Survey of Health Needs for People with Disabilities in Massachusetts, 2013



Appendix 5: Moderator's Guide to Personal Interviews

Key Informant Interview

Health & Disability Partnership

Health Needs Assessment for People with Disabilities 2013

Name:

Date:

Organization:

Contact information:

Interviewer Name:

Intro to project: The Health and Disability Program in the Office of Health Equity, Massachusetts Department of Public Health is conducting an assessment of the health needs of people with disabilities in Massachusetts. The aim of this interview is to collect information to help us understand and prioritize the health needs of people with disabilities. We are requesting your input because *of your long-standing involvement and interest with people with disabilities* [fill in depending on informant]. Along with interviews, we are conducting a health needs assessment survey and a scan of available secondary data. Your feedback is important and will be used to help the Health and Disability Program set priorities to take action to improve the health of people with disabilities in Massachusetts.

We will be developing a report using the responses from these interviews as well as other sources. The report will highlight the health needs of people with disabilities in Massachusetts and will be a public document.

(a) Would you be okay if we included your name, affiliation, and quotes from this interview in the report?

Yes

No

(b) If no Would you prefer to remain anonymous in the report? We will still include quotes from the interview but will remove any references to you or your affiliation.

Yes

No

1. Can you tell me a bit about yourself?

Prompts: Who you are? What do you do? Do you have a disability or know someone who does? Do you work for an organization that provides services to people with disabilities? Can you tell me a bit about the organization? What is your role in the Massachusetts disability community?

2. What in your mind are the most critical health issues facing people with disabilities in Massachusetts?

Prompts: Is it access to health care, mental health, dental, etc? Is it lack of accessibility to care? What do you think are the top 3 issues? Same for children/youth/adults

3. Of all the health needs for people with disabilities in Massachusetts, if you had to pick one (or more?) which do you feel is the most important?

Prompts: Why do you feel this is the most important? Children/youth/adults.

4. What do you think are the factors contributing to these critical health needs?

Prompts: Children/youth/adults?

5. What are the biggest barriers to addressing these the health needs?

Prompts: Children/youth/adults? How can they be addressed?

6. How do you think the Department of Public Health can best remove these barriers to health?

Prompts: Age? Disability type? Data? Report?

7. Do you know of any programs that have been successful at addressing these needs?

Prompts: What are they? Can they be administered state-wide?

8. Do you see yourself using the results of the needs assessment?

Prompts: What do you think of the needs assessment – is it important to you or your work? How can you see yourself using it?

9. Do you have any additional comments you would like to share?

Prompts: Is there anything we did not cover in the meeting that is relevant to the health needs of people with disabilities?

Thank you for your participation. The information collected from the interviews, surveys and secondary data will be compiled into a report and distributed in the summer of 2013. We will send you a copy of the report after it is complete.

Appendix 6: Summary of Data from the MA-BRFSS

	Disability 5,772		No Disability 14,522	
	%	95% CI	%	95% CI
Overall Health Status				
Fair or Poor Health	37.8	35.7 - 39.9	6.7	6.1 - 7.4
15+ Days Poor Physical Health	31.2	29.2 - 33.2	3.2	2.7 - 3.7
Quality of Life				
15+ Days Poor Mental Health	22.4	20.6 - 24.3	6.7	6.0 - 7.4
Depression	32.9	30.8 - 35.0	11.8	10.9 - 12.8
Health care access and utilization				
No health insurance	3.6	2.7 - 4.5	4.5	4.0 - 5.1
Could not see doctor due to cost	13.6	12.0 - 15.2	7.9	7.1 - 8.7
Have personal health care provider	93.0	91.7 - 94.2	87.0	86.0 - 88.1
Had a checkup in past year	83.8	82.0 - 85.6	77.5	76.3 - 78.7
Dental visit in past year (2010)	71.8	69.4 - 74.2	82.9	81.8 - 84.0
Six or more teeth missing (2010)	26.9	24.7 - 29.1	9.2	8.5 - 9.9
Risk factors and preventive behaviors				
Tobacco use				
Current smoker	24.1	22.0 - 26.1	15.8	14.7 - 16.9
Former smoker	36.3	34.2 - 38.3	26.1	25.0 - 27.2
Alcohol use				
Binge drinking	14.3	12.6 - 16.0	22.5	21.2 - 23.7
Heavy drinking	6.2	5.2 - 7.3	8.5	7.7 - 9.3
Overweight and obesity status				
Overweight	67.1	64.9 - 69.2	33.7	31.6 - 35.8
Obese	57.1	55.7 - 58.5	19.7	18.6 - 20.8
Physical activity				
≥150 min/week	45.3	43.1 - 47.5	59.4	58.0 - 60.7
2+ days/week muscle strength	26.4	24.4 - 28.4	33.7	32.3 - 35.0
Vaccinations				
Flu vaccination in past year				
Age 18-49	37.3	33.3 - 41.4	34.6	32.8 - 36.5
Age 50-64	54.9	51.5 - 58.3	46.3	44.1 - 48.6
Age 65+	68.4	65.3 - 71.5	65.9	63.5 - 68.3
Pneumonia vaccination in past year				
Age 65+	78.2	75.2 - 81.1	68.7	66.3 - 71.1

Source: A Profile of Health Among Massachusetts Adults, 2011, Results from the Behavioral Risk Factor Surveillance System

	Disability		No Disability	
Chronic health conditions	%	95% CI	%	95% CI
Diabetes				
Diabetes	8.6	7.2 - 10.0	4.5	3.9 - 5.1
Pre-diabetes	16.1	14.6 - 17.5	5.7	5.2 - 6.3
Asthma				
Ever	25.2	23.2 - 27.2	19.0	17.3 - 20.8
Currently	12.5	11.5 - 13.5	8.2	7.4 - 9.0
COPD	15.0	13.5 - 16.5	2.9	2.5 - 3.3
Heart disease and stroke				
Ever dx with myocardial infarction	11.0	9.7 - 12.3	3.0	2.5 - 3.5
Ever dx with angina or CHD	11.1	9.8 - 12.5	3.0	2.6 - 3.5
Stroke	7.1	6.0 - 8.2	1.6	1.2 - 2.0
Arthritis				
Doctor diagnosed arthritis	53.7	51.4 - 55.9	36.5	34.4 - 38.6
Limitations due to arthritis	15.0	14.2 - 15.9	3.5	3.1 - 3.9
Cancer screening- use 2010 data				
Colorectal cancer				
Blood stool test in the past 2 years	21.0	18.7 – 23.4	17.5	16.2-18.8
Sigmoidoscopy or colonoscopy in past 5 years	64.0	61.2 – 66.7	63.3	61.6 – 65.1
Prostate cancer- ages 50+				
Prostate specific antigen test in the past year	58.2	53.4 – 62.9	61.0	57.9 – 64.0
Digital rectal exam in the past year	60.8	56.1 - 65.5	65.9	63.0 – 68.8
Breast cancer				
Mammogram in the past 2 years	81.2	78.4 – 84.0	84.4	82.7 – 86.0
Clinical breast exam in the past 2 years	82.6	80.2 -85.0	88.5	87.1 – 89.8
Cervical cancer				
Pap smear test within past 3 years	76.6	73.9 – 79.2	87.3	86.1 – 88.5
Other topics				
HIV testing				
Ever tested	52.9	50.0 - 55.8	43.5	42.0 - 45.1
Tested in past year	13.0	10.8 - 15.2	10.8	9.6 - 11.9
Sexual violence				
Women	24.0	17.8 - 30.2	19.0	14.6 - 23.3
Men	6.8	3.3 - 10.4	3.9	2.0 - 5.8
Unintentional falls				
Unintentional falls	25.4	23.1 – 27.7	10.6	9.5 - .6
Insured by unintentional falls	9.9	8.4 – 11.5	3.0	2.4 - 3.5

Source: A Profile of Health Among Massachusetts Adults, 2011, Results from the Behavioral Risk Factor Surveillance System

For more information, please contact:

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