LURIE INSTITUTE FOR DISABILITY POLICY

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**Health Needs Assessment of People of Color with Disabilities in Massachusetts**

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10. **Executive Summary**

This community needs assessment is a systematic, data-driven approach to examining the public health needs of adults with disabilities from specific communities in Massachusetts, an urban, underserved community in Boston and a Latino community in Western Massachusetts. Subsequently, this information may be used by the Massachusetts Department of Public Health’s Health and Disability Program to inform decisions and guide their programmatic activities. It was conducted as a follow-up to a Health Needs Assessment conducted in 2013 by the University of Massachusetts Medical School (Health Needs Assessment of Adults with Disabilities in Massachusetts, 2013) to provide a more in-depth view of the needs of communities of color with disabilities. It was conducted by The Lurie Institute for Disability Policy at Brandeis University and the University of Massachusetts Medical School in 2015-16 on behalf of the Health and Disability Program (HDP), Office of Health Equity, Massachusetts Department of Public Health. Assessing the needs of adults with disabilities and their communities is a priority area for HDP and for the Centers for Disease Control and Prevention (CDC), which funds many of HDP’s activities. These assessments provide detailed information on the unmet public health needs and priorities of these two communities to enable HDP to prioritize its programmatic goals and objectives and better understand and meet the needs of Massachusetts residents with disabilities.

This needs assessment’s approach replicated that of the multi-pronged 2013 health needs assessment. Although the 2013 assessment provides a valuable overall picture of the needs of adults with disabilities in Massachusetts, adults with disabilities are a heterogeneous group. Therefore, it is important to examine the needs of underrepresented subgroups of people with disabilities, such as racial and ethnic minority groups. To achieve this, we conducted needs assessments of two communities in Massachusetts: an urban underserved community of color and a rural Latino community. We followed the same methodological approach in each of these communities: examination of existing population-based survey data, a community survey, and a community forum discussion. A community forum is a chance for a group of people to congregate and discuss issues that are important to them. These community forums focused on health and disability issues and the needs of the community.

**Data from the MA BRFSS**

Section 3 of this report presents findings from the analysis of data from the 2011-2014 Massachusetts Behavioral Risk Factor Surveillance System (MA BRFSS), a health survey of Massachusetts adults living in the community. This report includes health indicators broken down by race and ethnicity. The 2014 MA BRFSS data is the most recent data available as of the development of this report. However, certain health measures were not collected every year; for those measures the most recent data was included and is noted accordingly. This analysis does not compare people with and without disabilities; that information is presented in the 2013 needs assessment report (http://www.mass.gov/eohhs/docs/dph/health-equity/needs-assessment-report-for-health-and-disability.pdf).

**Major Findings**

Analysis of the MA BRFSS data identified several differences in the health status of adults with disabilities of different racial and ethnic groups.

* Hispanic adults with disabilities were more likely to report poor physical and mental health, as compared to their non-Hispanic counterparts.
* Black adults with disabilities were less likely to report having health insurance and were more likely to have lost six or more teeth due to decay than White adults with disabilities and Hispanic adults with disabilities.
* White adults with disabilities were more likely to report being former smokers, while Black adults with disabilities were more likely to report being a current smoker.
* Black and Hispanic adults with disabilities were more likely to be overweight and obese than other people with disabilities.
* Black adults with disabilities were more likely to report diabetes than other people with disabilities.
* Hispanic adults with disabilities were more likely to report asthma than other people with disabilities.

**Summary of Findings from Two Community Needs Assessments**

**Urban, Underserved Community of Color**

Our first community forum was conducted in partnership with the Multi-Cultural Independent Living Center of Boston (MILCB). The forum took place on October 8th, 2014 at MILCB in Jamaica Plain, a neighborhood of Boston. Approximately thirty-five people attended. At the beginning of the forum, attendees were asked to complete a survey. The survey was similar to the survey conducted as part of the 2013 needs assessment, with the addition of a set of questions about discrimination taken from the Behavioral Risk Factors Surveillance Survey (BRFSS). A question about employment was also added to this iteration of the survey. The survey gathered basic demographic data, and asked about participants’ perceptions of the importance of each of a series of health issues for adults with disabilities in their communities. For each health issue, participants were asked to identify whether the health issue was a “Small Problem,” a “Big Problem,” or “Not a Problem.” They could also reply “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 (see Appendix 1).

The top issues were identified by the percentage of people reporting the issue as a “Big Problem.” The top identified issue among participants in the MILCB community forum were finding affordable housing (82% said this was a “Big Problem”). The second issue was employment (70%), followed by finding a doctor who uses communication supports (52%), managing chronic conditions (48%), and access to dental care services (48%).

After completing the surveys, participants engaged in a forum-style focus group, facilitated by Dr. Linda Long-Bellil of the Center for Health Policy and Research and an Assistant Professor at the University of Massachusetts Medical School. A community forum is a chance for a group of people to congregate and discuss issues that are important to them. These community forums focused on health and disability issues and needs of the community. Questions focused on participant perceptions of their health care needs and experiences, priorities, challenges and barriers to and facilitators of inclusion and positive health and health care outcomes. Several important themes emerged during the forum, including:

* Difficulties navigating the health care system and “pulling the pieces together”
* Accessible care environments and practices
* Attitudinal barriers and differential treatment
* Additional challenges encountered by people of color with disabilities

**Latino Community in Western Massachusetts**

The second community forum was conducted on October 14th, 2015 at the Stavros Center for Independent Living’s Springfield location. The forum was conducted entirely in Spanish and facilitated by Ms. Christine Roa, MPH, of the University of Massachusetts Medical School’s Center for Health Policy and Research. It was transcribed with remote CART reporting and later that transcript was professionally translated. The Stavros Center for Independent Living and the Health and Disability Partnership publicized the opportunity to participate in this forum by distributing a Spanish flyer and reaching out to their networks. Participants completed the same survey used at the MILCB forum (which had been translated into Spanish) at the beginning of the forum.

The top five health issues perceived as a “Big Problem” for adults with disabilities were as follows. Paying for prescription medications (reported as a“Big Problem” by 41.7% of respondents), finding affordable housing (reported by 33% as a “Big Problem”), managing chronic conditions like diabetes, asthma or high blood pressure, finding doctors who use communication supports like American Sign Language, large print, Braille or CART reporters, and finding employment opportunities (reported by 25% as a “Big Problem”).

After completing the surveys, the forum discussion commenced. Questions focused on participant perceptions of their health care needs and experiences, priorities, and challenges, barriers and facilitators of inclusion and positive health and health care outcomes. Several important themes emerged during the forum, including:

* Barriers and disconnects in the system
* Language barriers and information quality
* Lack of relationships and connection with the health care system
* “Fighting for our rights wherever we go”
1. **Introduction**

On behalf of the Health and Disability Program (HDP), Office of Health Equity, Massachusetts Department of Public Health, the Lurie Institute for Disability Policy at Brandeis University conducted two community health needs assessments to evaluate the unmet public health needs of adults with disabilities in two communities in Massachusetts. These health needs assessments had two objectives:

* + 1. To provide in-depth data on the health needs of adults with disabilities in these two communities, and
		2. To present information on the unmet health needs and priorities of adults with disabilities in communities of color in Massachusetts to HDP.

Adults with disabilities are not a homogenous group. HDP recognizes the importance of exploring different facets of diversity within the disability population including the interaction between race/ethnicity and health status. 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). In 1989, 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)at MDPH. Over time, ODP evolved into the *Health and Disability Program* with a focus on preventing secondary conditions among adults 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 adults 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 adults with disabilities as for those without disabilities; and most secondary conditions or other health problems to which adults 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 *Plan for Promoting the Health of People with Disabilities, July 2015-June 2018.* This strategic plan includes the following goals:

1. Ensure quality health promotion opportunities are available and accessible for people with disabilities to maintain maximal independence
2. Increase access to health services and facilities, emphasizing policy and systems change
3. Better define the impact of disability in Massachusetts, including the impact of secondary conditions among people with disabilities across the life-span
4. Ensure statewide emergency preparedness planning responds to the needs of 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 59 individuals representing 31 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 Mr. Dennis Heaphy, Policy Analyst, Disability Policy Consortium and Ms. Bethlyn Houlihan, Associate Director, New England Regional Spinal Cord Injury Center, Health & Disability Research Institute, Boston University School of Public Health.

The approach for these two needs assessments was developed in collaboration with the Partnership.

**Approach to Health Needs Assessment:**

*Health Needs Assessment of People of Color with Disabilities in Massachusetts*

HDP contracted with Dr. Monika Mitra, PhD from the Lurie Institute for Disability Policy at Brandeis University to conduct these two health needs assessments. To note, Dr. Mitra and her team began this project at the University of Massachusetts Medical School and concluded it under contract at the Lurie Institute. Dr. Mitra, Ms. Lauren Smith, and Ms. Nechama Sammet Moring conducted the needs assessments between October 2014 and June 2016. Throughout the process, the Lurie Institute for Disability Policy evaluation team consulted with HDP staff and the Partnership. The methodology was based on the 2013 needs assessment and modified for the specific purpose of examining the needs of adults with disabilities in these two specific communities.

These two needs assessments involved a multi-pronged approach. Dr. Mitra and the Lurie Institute for Disability Policy evaluation team conducted an analysis of existing secondary data on adults with disabilities in Massachusetts, broken down by race/ethnicity. 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 evaluation team used supplemental approaches to complement the secondary data analysis: the aforementioned survey on the health needs of adults with disabilities living in communities of color, and community forums with members of the disability community living in Massachusetts.

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

**Analysis of Massachusetts 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. In 2011 the MA BRFSS added a cell phone component. The BRFSS 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. Thus, the MA BRFSS is a survey given to adults with and without disabilities in Massachusetts that asks questions about health and healthcare. Detailed information on the BRFSS can be found at <http://www.cdc.gov/brfss/index.htm>.

The Massachusetts 2011-12 BRFSS questionnaire can be found at <http://www.mass.gov/eohhs/docs/dph/behavioral-risk/survey-11.pdf>. We analyzed data from the MA BRFSS from the years 2011-2014. However, certain health measures were not collected in all years of the survey. For those measures the most recent available data is included and noted accordingly.

The following questions were used to identify the disability status of survey respondents in the MA BRFSS:

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.

Respondents 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. Detailed aggregate demographic information of all MA BRFSS respondents can be found in this report: <http://www.mass.gov/eohhs/gov/departments/dph/programs/admin/dmoa/health-survey/brfss/statewide-reports-and-presentations.html>. Detailed aggregate 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.** It is important to note that the BRFSS disability screeners do not include a way to identify oneself as a person with a hearing impairment. This is an area of policy that needs to be addressed. Therefore these data are not useful for reporting on health indicators in the Deaf community. Making the BRFSS inclusive of Deaf and hard of hearing (DHH) people is an important and necessary step to availability of health information on DHH people.

**Community Forums and Survey**

***Community 1: Urban, Underserved Community of Color***

Survey

At the beginning of the forum, attendees were asked to complete a paper survey with the option to have it emailed to be completed electronically. Most people completed the survey on site either on their own or with the assistance of a staff person. The survey was similar to the survey conducted as part of the Health Needs of Adults with Disabilities in Massachusetts 2013 needs assessment with the addition of a set of questions about discrimination called Reactions to Race from the Behavioral Risk Factors Surveillance Survey (BRFSS). A question about employment was also included in this version of the survey. The survey gathered basic demographic data, and asked about participants’ perceptions of the importance of each of the health issues for adults with disabilities in their communities. For each health issue, participants were asked to identify whether each health issue was a “Small Problem,” a “Big Problem,” or “Not a Problem.” Respondents could also reply “Don’t Know.” The health issues included accessing health insurance and 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 their communities. Participation in the survey was voluntary. The survey instrument is included in Appendix 1.

The survey was intended for members of the community who:

* Had disabilities;
* Were caregivers or guardians of adults or children with disabilities;
* Were advocates for people with disabilities, staff at community-based organizations or state and/or 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; or
* Had an interest in the health of adults with disabilities in communities of color in Massachusetts.

Community Forum Discussion

After completing the surveys, participants engaged in a forum-style focus group, facilitated by Dr. Linda Long-Bellil, Assistant Professor at the University of Massachusetts Medical School. This community forum was conducted to develop a deeper understanding of the health issues and needs facing adults with disabilities in a community of color in Massachusetts. Questions focused on participants’ perceptions of their health care needs and experiences, priorities, and challenges, barriers and facilitators of inclusion and positive health and health care outcomes. Dr. Long-Bellil used a facilitator’s guide to lead the discussion. Participants took turns speaking to share their views, allowing discussion to build off each other’s ideas. The discussion lasted approximately 2 hours with a 20 minute break in the middle.

The discussion was audio-recorded and transcribed and analyzed using qualitative analysis techniques. This report presents the important themes that emerged from our analysis.

***Community 2: Latino Community in Western MA***

Survey

Similar to the previously described forum, attendees were asked to complete a paper survey at the start of the forum. Most people completed the survey on site either on their own or with the assistance of a staff person. The survey questions were the same and the survey was translated into Spanish ahead of time by a professional translator. Participation in the survey was voluntary. The survey instrument is included in Appendix 2.

Community Forum Discussion

After completing the surveys, participants engaged in a forum-style focus group, facilitated by Ms. Christine Roa of the Center for Health Policy and Research at the University of Massachusetts Medical School. This community forum was conducted to develop a deeper understanding of the health issues and needs facing adults with disabilities in a Latino community in Massachusetts. The forum was conducted entirely in Spanish with remote CART reporting in Spanish. Questions were centered around the same health care issues as in the first community discussion and the forum followed the same format. Ms. Roa used a facilitator’s guide to lead the discussion. The discussion lasted for the same amount of time, 2 hours with a 20 minute break in the middle.

The discussion transcript was translated from Spanish to English by a professional translator and analyzed using qualitative analysis techniques. This report presents the important themes that emerged from our analysis.

***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***.

1. **Profile of Disability in Massachusetts by Race/Ethnicity**

The following section examines established data from the Massachusetts Behavior Risk Factor Surveillance System (MA BRFSS).

**A. Quality of Life**

**General Health and Physical Health Status**Two different indicators were used to measure the general health of an individual. All respondents in the MA BRFSS were asked to report:

1. General health status as either excellent, very good, good, fair, or poor. Presented here are the percentages of adults with disabilities by race/ethnicity 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 with disabilities by race/ethnicity who reported 15 or more days of poor physical health.

 ǂ Suppressed due to insufficient data (n < 11)

Source: *Behavioral Risk Factor Surveillance System*, 2012-2013, Massachusetts Department of Public Health

* 40 percent of adults with disabilities reported fair or poor health.
* 64 percent of Hispanic adults with disabilities reported poor health compared to 43 percent of Black/non-Hispanic adults with disabilities and 37 percent of White/non-Hispanic adults with disabilities.

ǂ Suppressed due to insufficient data (n < 11)

Source: *Behavioral Risk Factor Surveillance System*, 2011-2014 Massachusetts Department of Public Health

* 34 percent of all adults with disabilities reported experiencing 15 or more days of poor physical health in the past month.
* 39 percent of Hispanic adults with disabilities reported 15 or more days of poor physical health compared to 34 percent of Black/non-Hispanic adults with disabilities and 34 percent of White/non- Hispanic adults with disabilities.

**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 with disabilities by race/ethnicity who reported 15 or more days of poor mental health in the past month.
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).

ǂ Suppressed due to insufficient data (n < 11)

Source: *Behavioral Risk Factor Surveillance System*, 2011-2014, Massachusetts Department of Public Health

* 28 percent of adults with disabilities reported experiencing 15 or more days of poor mental health in the past month.
* 35 percent of Hispanic adults with disabilities reported 15 or more days of poor mental health in the past month compared to 29 percent of Black/non- Hispanic adults with disabilities and 27 percent of White/non- Hispanic adults with disabilities.

ǂ Suppressed due to insufficient data (n < 11)

Source: *Behavioral Risk Factor Surveillance System*, 2011-2014, Massachusetts Department of Public Health

* 43 percent of adults with disabilities reported ever having been diagnosed with depression.
* 62 percent of Hispanic adults with disabilities reported ever having been diagnosed with depression compared to 47 percent of Black/non- Hispanic adults with disabilities and 41 percent of White/non- Hispanic adults with disabilities.
1. **Health Care Access**

**Health Insurance and Doctor Visits**

All respondents were asked to report:

1. If they had health insurance coverage in 2011.
2. If they had a personal doctor or health care provider.
3. If they 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.

ǂ Suppressed due to insufficient data (n < 11)

Source: *Behavioral Risk Factor Surveillance System*, 2012-2014, Massachusetts Department of Public Health

* 4 percent of adults with disabilities ages 18-64 reported not having health insurance.
* 8 percent of Black/non- Hispanic adults with disabilities reported not having health insurance, compared with 5 percent of Hispanic adults with disabilities and 3 percent of White/non- Hispanic adults with disabilities.

ǂSuppressed due to insufficient data (n < 11)

Source: *Behavioral Risk Factor Surveillance System*, 2011-2014, Massachusetts Department of Public Health

* 15 percent of adults with disabilities reported not being able to see a doctor at some time in the past year due to cost.
* 24 percent of Hispanic adults with disabilities reported not being able to see a doctor at some time in the past year due to cost, compared to 18 percent of Black/non- Hispanic adults with disabilities and 13 percent of White/non- Hispanic adults with disabilities.

ǂ Suppressed due to insufficient data (n < 11)

Source: *Behavioral Risk Factor Surveillance System*, 2011-2014, Massachusetts Department of Public Health

* 93 percent of adults with disabilities reported having a personal physician.
* 94 percent of White/non- Hispanic adults with disabilities reported having a personal physician compared to 93 percent of Black/non- Hispanic adults with disabilities and 87 percent of Hispanic adults with disabilities.

Source: *Behavioral Risk Factor Surveillance System*, 2011-2014, Massachusetts Department of Public Health

* 83 percent of adults with disabilities reported having had a routine check-up in the previous year.
* 93 percent of Asian/non- Hispanic adults with disabilities reported having had a routine check-up in the previous year, compared to 87 percent of Black/non- Hispanic adults with disabilities, 86 percent of Hispanic adults with disabilities, and 83 percent of White/non- Hispanic adults with disabilities.

**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.

ǂ Suppressed due to insufficient data (n < 11)

Source: *Behavioral Risk Factor Surveillance System*, 2012, 2014, Massachusetts Department of Public Health

* 68 percent of all adults with disabilities reported having had a dental visit in the previous year.
* 69 percent of White/non- Hispanic adults with disabilities reported having had a dental visit in the past year, compared to 66 percent of Hispanic adults with disabilities, and 62 percent of Black/non- Hispanic adults with disabilities.

ǂ Suppressed due to insufficient data (n < 11)

Source: *Behavioral Risk Factor Surveillance System*, 2012, 2014, Massachusetts Department of Public Health

* 31 percent of adults with disabilities reported having lost 6+ teeth due to decay.
* 44 percent of Black/non- Hispanic adults with disabilities reported having lost 6+ teeth due to decay, compared to 31 percent of White/non-Hispanic adults with disabilities, and 27 percent of Hispanic adults with disabilities.
1. **Risk Factors and Preventative 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 with disabilities who reported being current smokers and the percentage of adults with disabilities by race/ethnicity 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 with disabilities by race/ethnicity who reported binge drinking and the percentage of adults with disabilities who reported heavy drinking.

ǂ Suppressed due to insufficient data (n < 11)

Source: *Behavioral Risk Factor Surveillance System*, 2011-2014, Massachusetts Department of Public Health

* 25 percent of adults with disabilities reported currently smoking.
* 31 percent of Black/non- Hispanic adults with disabilities reported currently smoking, compared to 26 percent of Hispanic adults with disabilities, and 25 percent of White/non- Hispanic adults with disabilities.

Source: *Behavioral Risk Factor Surveillance System*, 2011-2014, Massachusetts Department of Public Health

* 34 percent of adults with disabilities reported being former smokers.
* 37 percent of White/non- Hispanic adults with disabilities reported being former smokers, compared to 22 percent of Black/non- Hispanic adults with disabilities, 21 percent of Latino adults with disabilities, and 15 percent of Asian/non- Hispanic adults with disabilities.

ǂ Suppressed due to insufficient data (n < 11)

Source: *Behavioral Risk Factor Surveillance System*, 2011-2014, Massachusetts Department of Public Health

* 15 percent of adults with disabilities reported binge drinking.
* 16 percent of White/non- Hispanic adults with disabilities reported binge drinking, compared to 15 percent of Hispanic adults with disabilities, and 15 percent of Black/non- Hispanic adults with disabilities.

ǂ Suppressed due to insufficient data (n < 11)

Source: *Behavioral Risk Factor Surveillance System*, 2011-2014, Massachusetts Department of Public Health

* 6 percent of adults with disabilities reported heavy drinking
* 7 percent of White/non- Hispanic adults with disabilities reported heavy drinking, compared to 5 percent of Black/non- Hispanic adults with disabilities, and 4 percent of Hispanic adults with disabilities.

**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 with disabilities by race/ethnicity who were defined as overweight and obese.

**Physical Activity**

In 2011, all respondents who reported ANY leisure-time physical activity were asked which 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 with disabilities by race/ethnicity who meet the *Healthy People 2020* recommendations for 150-minute aerobic exercise weekly 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.

Source: *Behavioral Risk Factor Surveillance System*, 2011-2014, Massachusetts Department of Public Health

* 68 percent of adults with disabilities reported being overweight.
* 77 percent of Black/non Hispanic adults with disabilities reported being overweight, compared to 76 percent of Hispanic adults with disabilities, 67 percent of White/non- Hispanic adults with disabilities, and 43 percent of Asian/non- Hispanic adults with disabilities.

ǂ Suppressed due to insufficient data (n < 11)

Source: *Behavioral Risk Factor Surveillance System*, 2011-2014, Massachusetts Department of Public Health

* 35 percent of adults with disabilities reported being obese.
* 47 percent of Black/non- Hispanic adults with disabilities reported being obese, compared to 45 percent of Hispanic adults with disabilities, and 34 percent of White/non- Hispanic adults with disabilities.

Source: *Behavioral Risk Factor Surveillance System*, 2011, 2013, Massachusetts Department of Public Health

* 44 percent of adults with disabilities reported meeting the guidelines for aerobic activity.
* 46 percent of White/non- Hispanic adults with disabilities reported meeting the guidelines for aerobic activity, compared to 43 percent of Black/non- Hispanic adults with disabilities, 39 percent of Hispanic people with disabilities, and 36 percent of Asian/non- Hispanic adults with disabilities.

Source: *Behavioral Risk Factor Surveillance System*, 2011-2014, Massachusetts Department of Public Health

* 63 percent of adults with disabilities reported any leisure-time physical activity.
* 65 percent of White/non- Hispanic adults with disabilities reported any leisure-time physical activity, compared to 60 percent of Black/non- Hispanic adults with disabilities, 55 percent of Asian/non- Hispanic adults with disabilities, and 54 percent of Hispanic adults with disabilities.

Source: *Behavioral Risk Factor Surveillance System*, 2011, 2013, Massachusetts Department of Public Health

* 26 percent of adults with disabilities reported meeting the guidelines for muscle strengthening activity.
* 27 percent of Black/non- Hispanic adults with disabilities reported meeting the guidelines for muscle strengthening activity, compared to 26 percent of White/non- Hispanic adults with disabilities, 25 percent of Asian/non- Hispanic adults with disabilities, and 22 percent of Hispanic adults with disabilities.

**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 with disabilities ages 18-49 years, 50-64 years and ages 65 and older by race/ethnicity 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 with disabilities, ages 65 and older, by race/ethnicity who reported that they had ever had a pneumonia vaccination.
* **Flu vaccine, ages 18-49:** Among adults ages 18-49, 37% with disabilities and 35% without disabilities reported having had a flu vaccine in the past 12 months.
* **Flu vaccine, ages 50-64:** Among adults ages 50-64, 55% with disabilities and 46% without disabilities reported having had a flu vaccine in the past 12 months.
* **Flu vaccine, ages 65 and up:** Among adults ages 65 and up, 68% with disabilities and 66% without disabilities reported having had a flu vaccine in the past 12 months.
* **Pneumonia vaccine, ages 65 and up:** Among adults ages 65 and up, 78% with disabilities and 69% without disabilities reported ever having had a pneumonia vaccine.

ǂ Suppressed due to insufficient data (n < 11)

Source: *Behavioral Risk Factor Surveillance System*, 2011-2014, Massachusetts Department of Public Health

* 40 percent of adults with disabilities ages 18-49 reported receiving a flu vaccine in the previous year.
* 45 percent of Hispanic adults with disabilities ages 18-49 reported receiving a flu vaccine in the previous year, compared to 40 percent of White/non- Hispanic adults with disabilities ages 18-49, and 32 percent of Black/non- Hispanic adults with disabilities ages 18-49.

ǂ Suppressed due to insufficient data (n < 11)

Source: *Behavioral Risk Factor Surveillance System*, 2011-2014, Massachusetts Department of Public Health

* 54 percent of adults ages 50-64 reported receiving a flu vaccine in the previous year.
* 56 percent of White/non- Hispanic adults with disabilities ages 50-64 reported receiving a flu vaccine in the previous year, compared to 55 percent of Hispanic adults with disabilities ages 50-64, and 38 percent of Black/non- Hispanic adults with disabilities ages 50-64.

ǂ Suppressed due to insufficient data (n < 11)

Source: *Behavioral Risk Factor Surveillance System*, 2011-2014, Massachusetts Department of Public Health

* 69 percent of adults with disabilities ages 65+ reported receiving a flu vaccine in the previous year.
* 69 percent of White/non- Hispanic people with disabilities ages 65+ reported receiving a flu vaccine in the previous year, compared to 65 percent of Black/non- Hispanic adults with disabilities ages 65+, and 64 percent of Hispanic adults with disabilities ages 65+.

ǂ Suppressed due to insufficient data (n < 11)

Source: *Behavioral Risk Factor Surveillance System*, 2011-2014, Massachusetts Department of Public Health

* 76 percent of adults with disabilities ages 65+ reported ever receiving a pneumonia vaccine.
* 78 percent of White/non- Hispanic people with disabilities ages 65+ reported ever receiving a pneumonia vaccine compared to 61 percent of Black/non- Hispanic adults with disabilities ages 65+, and 52 percent of Hispanic adults with disabilities ages 65+.
1. **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 with disabilities by race/ethnicity who reported that a doctor had ever told them that they had diabetes and the percentage of adults with disabilities by race/ethnicity 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.

ǂ Suppressed due to insufficient data (n < 11)

Source: *Behavioral Risk Factor Surveillance System*, 2011-2014, Massachusetts Department of Public Health

* 18 percent of adults with disabilities reported ever being diagnosed with diabetes
* 28 percent of Black/non- Hispanic adults with disabilities reported ever being diagnosed with diabetes, compared to 25 percent of Hispanic adults with disabilities, and 16 percent of White/non- Hispanic adults with disabilities.

ǂ Suppressed due to insufficient data (n < 11)

Source: *Behavioral Risk Factor Surveillance System*, 2011-2014, Massachusetts Department of Public Health

* 12 percent of adults with disabilities reported ever being told they had pre-diabetes.
* 22 percent of Black/non- Hispanic adults with disabilities reported ever being told they had pre-diabetes, compared to 11 percent of White/non- Hispanic adults with disabilities.

**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 with disabilities by race/ethnicity 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%).

Source: *Behavioral Risk Factor Surveillance System*, 2011-2014, Massachusetts Department of Public Health

* 26 percent of adults with disabilities reported ever being diagnosed with asthma.
* 40 percent of Hispanic adults with disabilities reported ever being diagnosed with asthma, compared to 30 percent of Asian/non- Hispanic adults with disabilities, 28 percent of Black/non- Hispanic adults with disabilities, and 25 percent of White/non- Hispanic adults with disabilities.

Source: *Behavioral Risk Factor Surveillance System*, 2011-2014, Massachusetts Department of Public Health

* 20 percent of adults with disabilities reported currently having asthma.
* 32 percent of Hispanic adults with disabilities reported currently having asthma, compared to 21 percent of Black/non-Hispanic adults with disabilities, 19 percent of White/non- Hispanic adults with disabilities, and Asian/non- Hispanic adults with disabilities.

**Chronic Obstructive Pulmonary Disease (COPD)**

Presented here is the percentage of adults with disabilities by race/ethnicity 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%).

ǂ Suppressed due to insufficient data (n < 11)

Source: *Behavioral Risk Factor Surveillance System*, 2011-2014, Massachusetts Department of Public Health

* 16 percent of adults with disabilities were ever diagnosed with COPD.
* 17 percent of White/non- Hispanic adults with disabilities were ever diagnosed with COPD, compared to 10 percent of Hispanic adults with disabilities, and 9 percent of Black/non- Hispanic adults with disabilities.

**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 with disabilities ages 35 and older by race/ethnicity 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 ages 35 and older 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%).

ǂ Suppressed due to insufficient data (n < 11)

Source: *Behavioral Risk Factor Surveillance System*, 2011-2014, Massachusetts Department of Public Health

* 12 percent of adults with disabilities reported ever being diagnosed with heart attack.
* 13 percent of Black/non- Hispanic adults with disabilities reported ever being diagnosed with heart attack, compared to 12 percent of White/non- Hispanic adults with disabilities, and 11 percent of Hispanic adults with disabilities.

ǂ Suppressed due to insufficient data (n < 11)

Source: *Behavioral Risk Factor Surveillance System*, 2011-2014, Massachusetts Department of Public Health

* 11 percent of adults with disabilities reported ever being diagnosed with CHD or angina.
* 12 percent of White/non- Hispanic adults with disabilities and Hispanic adults with disabilities reported ever being diagnosed with CHD or angina, compared to 7 percent of Black/non- Hispanic adults with disabilities.

ǂ Suppressed due to insufficient data (n < 11)

Source: *Behavioral Risk Factor Surveillance System*, 2011-2014, Massachusetts Department of Public Health

* 7 percent of adults with disabilities reported ever being diagnosed with a stroke.
* 8 percent of Black/non- Hispanic adults with disabilities reported ever being diagnosed with a stroke, compared to 7 percent of White/non- Hispanic adults with disabilities, and 6 percent of Hispanic adults with disabilities.

**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 with disabilities by race/ethnicity 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.

Source: *Behavioral Risk Factor Surveillance System*, 2011, 2013, Massachusetts Department of Public Health

* 37 percent of adults with disabilities reported limitations due to arthritis.
* 39 percent of Hispanic adults with disabilities reported limitations due to arthritis, compared to 37 percent of White/non- Hispanic adults with disabilities, 34 percent of Black/non- Hispanic adults with disabilities, and 30 percent of Asian/non- Hispanic adults with disabilities.

**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 (FOBT) to determine if their stool contained blood.
2. Had ever had sigmoidoscopy or colonoscopy tests that examine the bowel for signs of cancer or other health problems.

Presented below is the percentage of adults with disabilities by race/ethnicity 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.

ǂ Suppressed due to insufficient data (n < 11)

Source: *Behavioral Risk Factor Surveillance System*, 2012, 2014, Massachusetts Department of Public Health

* 18 percent of adults with disabilities reported using a FOBT in the previous 2 years.
* 19 percent of White/non- Hispanic adults with disabilities reported using a FOBT in the previous 2 years, compared to 14 percent of Black/non-Hispanic adults with disabilities, and 9 percent of Hispanic adults with disabilities.

ǂ Suppressed due to insufficient data (n < 11)

Source: *Behavioral Risk Factor Surveillance System*, 2012, 2014, Massachusetts Department of Public Health

* 60 percent of adults with disabilities reported a sigmoidoscopy or colonoscopy in the previous 5 years.
* 60 percent of White/non- Hispanic adults with disabilities reported a sigmoidoscopy or colonoscopy in the previous 5 years, compared with 58 percent of Hispanic adults with disabilities, and 56 percent of Black/non- Hispanic adults with disabilities.

**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 with disabilities 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 with disabilities by race/ethnicity 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 ages 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.

ǂ Suppressed due to insufficient data (n < 11)

Source: *Behavioral Risk Factor Surveillance System*, 2012, 2014, Massachusetts Department of Public Health

* 81 percent of females ages 40+ reported receiving a mammogram in previous 2 years.
* 81 percent of White/non- Hispanic females with disabilities ages 40+ reported receiving a mammogram in previous 2 years, compared to 80 percent of Black/non- Hispanic females ages 40+ and 74 percent of Hispanic females with disabilities ages 40+.

ǂ Suppressed due to insufficient data (n < 11)

Source: *Behavioral Risk Factor Surveillance System*, 2012, 2014, Massachusetts Department of Public Health

* 80 percent of females with disabilities ages 40+ reported having a clinical breast exam in the previous 2 years.
* 81 percent of Black/non- Hispanic females with disabilities ages 40+ reported having a clinical breast exam in the previous 2 years, compared to 80 percent of White/non- Hispanic adults.

ǂ Suppressed due to insufficient data (n < 11)

Source: *Behavioral Risk Factor Surveillance System*, 2012, 2014, Massachusetts Department of Public Health

* 70 percent of females with disabilities had a pap smear in the previous 3 years.
* 81 percent of Hispanic females with disabilities had a pap smear in the previous 3 years, compared to 68 percent of White/non- Hispanic females with disabilities, and 67 percent of Black/non- Hispanic females with disabilities.

**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 with disabilities 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%).

ǂ Suppressed due to insufficient data (n < 11)

Source: *Behavioral Risk Factor Surveillance System*, 2011-2014, Massachusetts Department of Public Health

* 51 percent of adults with disabilities ages 18-64 were ever tested for HIV.
* 70 percent of Hispanic adults with disabilities ages 18-64 were ever tested for HIV, compared to 64 percent of Black/non- Hispanic adults with disabilities ages 18-64, and 47 percent of White/non- Hispanic adults with disabilities ages 18-64.

ǂ Suppressed due to insufficient data (n < 11)

Source: *Behavioral Risk Factor Surveillance System*, 2011-2014, Massachusetts Department of Public Health

* 14 percent of adults with disabilities ages 18-64 were tested for HIV in the previous year.
* 31 percent of Hispanic adults with disabilities ages 18-64 were tested for HIV in the previous year, compared to 27 percent of Black/non- Hispanic adults with disabilities ages 18-64, and 10 percent of White/non- Hispanic adults with disabilities ages 18-64.

**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 with disabilities 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 ages 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%).

ǂ Suppressed due to insufficient data (n < 11)

Source: *Behavioral Risk Factor Surveillance System*, 2012, 2014, Massachusetts Department of Public Health

* 42 percent of adults with disabilities ages 45+ reported falling in the past 12 months.
* 46 percent of Hispanic adults with disabilities ages 45+ reported falling in the past 12 months, compared to 45 percent of Black/non- Hispanic adults with disabilities ages 45+, and 41 percent of White/non-L Hispanic adults with disabilities ages 45+.

ǂSuppressed due to insufficient data (n < 11)

Source: *Behavioral Risk Factor Surveillance System*, 2012, 2014, Massachusetts Department of Public Health

* 21 percent of adults with disabilities ages 45+ reported being injured in a fall in the past 12 months.
* 24 percent of Black/non- Hispanic people with disabilities ages 45+ reported being injured in a fall in the past 12 months, compared to 21 percent of White/non- Hispanic adults with disabilities ages 45+, and 20 percent of Hispanic adults with disabilities ages 45+.

**4. Community Forum at the Multi-Cultural Independent Living Center of Boston**

The Multi-Cultural Independent Living Center of Boston, Inc. (MILCB) is a non-profit community-based, consumer-controlled organization serving adults with disabilities and their families in unserved/underserved populations and cultures who reside in Boston’s inner city. MILCB’s mission includes creating opportunities for adults with disabilities to achieve self-determination at their maximum level of independent functioning within their family and community environment, and improving each consumer's quality of life by providing comprehensive services to enhance the range of available options. Core services include advocacy, information and referral, peer support, skills training, and deinstitutionalization (http://www.milcb.org/).

MILCB hosted a community forum, conducted by the Health and Disability Program of the Massachusetts Department of Public Health. The forum’s aim was to collect data regarding the needs, experiences and challenges of members of underserved communities who have disabilities. This forum was intended to serve as a preliminary assessment of the needs of people of color with disabilities in Massachusetts, in order to ensure representation of communities of color within state level disability-related needs assessments.

*Data Collection*

Approximately thirty-five people attended the forum at MILCB. At the beginning of the forum, attendees were asked to complete a survey. The survey gathered basic demographic data, and asked about participants’ perceptions of the importance of each of a series of health issues for adults with disabilities in their communities. For each health issue, participants were asked to identify whether the health issue was a “Small Problem,” “Big Problem,” or “Not a Problem.” They could also reply “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 their communities. Included in the survey was a set of questions on “reactions to race” which are aimed at assessing perceptions of differential treatment in health care and work settings, and reports of emotional and physical symptoms as a result of race-based treatment. Survey results are described below, and the full survey is included as Appendix 1.

[Ethn Dis.](https://www-ncbi-nlm-nih-gov.resources.library.brandeis.edu/pubmed/?term=Perceived+reactions+to+race+and+health+status+in+the+Massachusetts+Behavioral+Risk+Factor+Surveillance+System+Survey.) 2012 Autumn;22(4):492-6. Perceived reactions to race and health status in the Massachusetts Behavioral Risk Factor Surveillance System Survey. [Zuckerman RB](https://www-ncbi-nlm-nih-gov.resources.library.brandeis.edu/pubmed/?term=Zuckerman%2520RB%255BAuthor%255D&cauthor=true&cauthor_uid=23140082)1, [Tinsley LJ](https://www-ncbi-nlm-nih-gov.resources.library.brandeis.edu/pubmed/?term=Tinsley%2520LJ%255BAuthor%255D&cauthor=true&cauthor_uid=23140082), [Hawk H](https://www-ncbi-nlm-nih-gov.resources.library.brandeis.edu/pubmed/?term=Hawk%2520H%255BAuthor%255D&cauthor=true&cauthor_uid=23140082), [Cohen B](https://www-ncbi-nlm-nih-gov.resources.library.brandeis.edu/pubmed/?term=Cohen%2520B%255BAuthor%255D&cauthor=true&cauthor_uid=23140082).

**Survey Results**

*Socioeconomic Characteristics*

Participants at the forum included a majority of adults with disabilities (70.4%), as well as family members and caregivers of children (14.8%) and adults (7.4%) with disabilities, community leaders (11.1%) and staff members at governmental (14.8%) and other agencies or organizations that work with adults with disabilities (29.6%), and other concerned individuals (7.4%). Participants personally experienced or supported people with a range of disabilities, including physical, cognitive, mental health, and sensory disabilities, and other conditions that caused the person to need support with activities of daily living. Participants who were employed by agencies and organizations reported that their agencies serve people with a variety of disabilities, including physical disabilities (76.9%), intellectual or developmental disabilities (69.2%), mental illness (69.2%), and/or who are blind (69.2%), or deaf or hard of hearing (69.2%). These agencies served children and youth with disabilities (61.5%), as well as older adults (69.2%) and specialized populations such as refugees, college students and other groups (30.8%).

Of the forum participants, 51.8% identified as male and 48.2% as female and 85% identified as heterosexual or straight. Participants ranged in age from 25 to over 65, with the majority of participants being between 35-44 (25.9%) or 45-54 (40.7%) years old. Most participants (77.8%) stated that they prefer to discuss and receive information about their health care in English, with Haitian Creole as the second most preferred language. All participants lived in Massachusetts.

 A majority of participants (55.6%) described themselves as Black or African-American and 14.8% described themselves as Latino. Of the cohort, 18.5% of participants described themselves as White, and 7.4% described themselves as Asian. An additional 7.4% of participants preferred not to answer the questions about their race/ethnicity. In response to the questions on “reactions to race,” the majority of forum participants responded that they thought about their race either constantly (33.3%) or at least daily (18.5%). Only 14.8% of participants said that they never thought about their race, an answer that often represents few lived experiences of racism. Some participants stated that they felt they had been treated the same (14.8%) or better than people of other races (11.1%) at work. 11.5% reported feeling they were treated worse than other races at work and 11.5% also reported being treated worse than some races but better than others. 50% either responded they did not work in the past 12 months, “don’t know/not sure,” or left it blank. In health care settings, 29.6% reported being treated the same, and 11.1% reported being treated better than people of other races. None reported feeling they had been treated worse than other races. 58% either only encountered people of the same race, did not know/were not sure, or left it blank. Finally, 11.1% of participants also said that they had experienced physical symptoms such as an upset stomach or a racing heart related to how they were treated based on their race within the previous 30 days. An additional 37% of participants said that they had felt upset, angry, sad and/or frustrated within the past 30 days as a result of how they were treated based on their race.

Public Health Needs

*Levels of Need: Top “Big Problems”*

Each participant answered a series of questions aimed at assessing the level of need for specific health indicators. The questions began, “In your opinion, is it a problem for adults 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 most reported categories for all participants who reported that indicator as a “Big Problem” for adults with disabilities in Massachusetts.

Most reported categories for all participants who reported that indicator as a “Big Problem” for adults with disabilities in Massachusetts.

As shown in Figure 1, access to affordable housing was seen as a “Big Problem” for adults with disabilities in Massachusetts by 82% of forum participants, and access to employment opportunities was seen as a “Big Problem” by 70% of forum participants. In addition, 52% of forum participants believed that finding doctors that use communication supports, like American Sign Language, large print, Braille, or Communication Access Realtime Translation (CART) reporters, was a “Big Problem.” Other issues that were commonly perceived as big problems for adults with disabilities in Massachusetts included finding a dentist and managing chronic conditions, like diabetes, asthma, or high blood pressure, which were each named as “Big Problems” by 48% of forum participants. Of forum participants, 41% felt that it was a “Big Problem” for adults with disabilities in Massachusetts to find a doctor’s office that is accessible and has, for example, wheelchair ramps, exam tables that raise and lower, and other accommodations. Getting durable medical equipment, such as wheelchairs, scooters and hospital beds was also viewed as a “Big Problem” for adults with disabilities in Massachusetts by 41% of forum participants.

Other issues that forum participants considered to be “Big Problems” for adults with disabilities in Massachusetts included adequate mental health services (by 37% of forum participants); finding a doctor who accepts public insurance/MassHealth (33%), finding a doctor who is sensitive to disability issues (33%), and paying for prescription medications (33%). Of forum participants, 30% felt that the following issues were big problems for adults with disabilities in Massachusetts: finding a mental health provider; getting routine medical tests such as annual physicals, mammograms or colonoscopies; transportation to doctor’s appointments, and accessible supports and programs if they are experiencing violence or abuse. In addition, 25% of forum participants felt that getting health insurance was a “Big Problem” for adults with disabilities in Massachusetts, and 15% of participants considered finding a grocery store that sells healthy food, like fruits and vegetables a “Big Problem.”

There were some gaps in community knowledge of whether certain issues were problems for adults with disabilities in Massachusetts or not. Most notably, 41% of forum participants stated that they didn't know whether finding accessible supports and programs for people experiencing violence or abuse was a problem. Of forum participants, 30% didn’t know if there were problems with finding doctors who accept private insurance or getting routine medical tests like an annual physical, mammogram or colonoscopy. In addition, 22% of forum participants said that they did not know whether problems existed for adults with disabilities in the following areas: finding a doctor that uses communication supports, finding accessible doctor’s offices, receiving adequate mental health services, finding a doctor who accepts public insurance, finding a doctor who is sensitive to disability issues, paying for prescription medicines, finding a mental health provider, and accessing transportation to medical appointments.

**Forum Conversation**

This section includes information from the community forum hosted by the Multi-Cultural Independent Living Center of Boston, Inc. The forum was facilitated by Dr. Linda Long-Bellil, and was audio-recorded with the permission of all participants. The audio recording was then transcribed. The primary questions posed to the group were related to identifying the most relevant concerns related to the health and health care of adults with disabilities from underserved communities, including the barriers to and facilitators of health and health care, unmet needs, and strategies going forward. It is important to note that the forum participants were asked to focus on the health issues of adults 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 participants 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 forum participants. They include:

1. Navigating the health care system and “pulling the pieces together”
2. Accessible care environments and practices
3. Attitudinal barriers and differential treatment
4. The double challenges encountered by people of color with disabilities

The first theme, “pulling the pieces together,” outlines participants’ experiences and challenges navigating the health care system and attempting to meet their individual care needs. The second theme, “accessible care environments and practices” focuses on challenges with using health care services and receiving equitable care. The third theme, “attitudinal barriers and differential treatment,” explores perceptions by participants of being treated differently or encountering problematic attitudes related to their disability. Finally, the last theme, “double challenges encountered by people of color with disabilities,” focuses on the intersections of racial, ethnic, language or cultural minority status and having a disability, and interacting with the health care system as a member of an underserved community who also has a disability.

***Pulling the Pieces Together***

An important theme for many participants was the complexity of the health care system, particularly for people with disabilities, and the resultant need to navigate the system. Participants described their efforts to coordinate care across multiple agencies and institutions in order to get their needs met. For example, several participants with physical disabilities described the difficulties they encountered with meeting personal care needs while hospitalized:

*Folks who are on the PCA [personal care attendant] program, say you have an extended stay in the hospital and you are not able to brush your teeth or do your own grooming, the nursing staff will not do that for you.*

As another participant explained, this important gap in care is related to parallel systems that may lack coordination or communication between them:

*[T]hey will often suggest to people if they are on the personal care attendant program “why don’t you have your PCAs come in and do that?” But unfortunately if you have your PCAs come in and provide services to you while you are in the hospital, MassHealth considers that fraud because they are already paying for the hospital stay. So often times people with significant… disabilities are often while they are in a hospital getting lesser care, because of the hands on care needs that they have, are not going to be met by hospital staff.*

Participants also perceived disconnects between acute care systems, like hospitals, and longer-term, community-based services. Several participants, including both service providers and individuals with disabilities described challenges securing needed follow up care services after being discharged from a hospital. Some participants also described feeling that, in the absence of needed follow-up, perhaps they had been discharged too soon, or denied opportunities for optimizing their health. As one participant stated:

*Because I was at the hospital and I had [major surgery on a limb], but now upon discharge they said I am not going to rehab. Why am I not going to rehab?....How am I going to recover with my [limb]?*

One provider felt that such disconnects were preventable, given the wealth of resources and services available within Massachusetts. However, this participant felt that important resources were not being accessed effectively by people in underserved communities, often due to lack of knowledge and outreach specifically to their communities:

*So you know when people are talking about some of the medication stuff there is chronic disease self-management classes like [community-based agency] right down the street runs one, but when people are newly diagnosed with something how often are they told about the chronic disease self-management program that they can enroll in to help manages their diabetes, or whatever else… There is not a good job many times of letting folks know that. I think centers can play some role in that, but again by getting the information out to the discharge planners, the folks that are actually having the [inaudible], and meeting with the folks pre-discharge, and are discharging folks without VNA, without a referral to an independent living center, or a PCA for personal care attendant services, things like that. I mean whatever the mechanisms people are using to acquire information, whether it be different language radio stations, bulletin boards, IOC, clinics, health centers, where do people go and where can they… but you can put it there and sometimes folks don’t look for it.*

Another participant seconded this perception with a statement that, though needed resources exist and are available, they are not accessible to their community if the community is not adequately informed about them:

*I think, it sounds like a lot of this all is stemming from the fact that there is a lack of community knowledge, so because the providers, it seems like they are lacking when it comes to getting information out there in these communities, minority communities. So these communities that are unserved or underserved we remain unserved and underserved because they’re not getting the proper knowledge, so it is not empowering for them, it’s no way informative for them as well. So because they don’t know, they don’t know who to go to, who to talk to, what to ask for, what type of services that they should be getting based upon their medical coverage, what types of services are supposed to be offered inside the medical centers, and hospitals, accessibility, accommodations, it’s just simply because they do not know. And in a lot of cases with medical providers are people who are governed to assist they are not forthcoming with this information, so the minorities are at a disadvantage. When you go into other communities that doesn’t… it’s an issue but not at the level as in the minority community*.

This theme was echoed by another participant who also recognized the wealth of health care resources in Massachusetts, but felt that these resources were not as available in their community:

*I just don’t understand why there is such a major disconnect between the medical community and aftercare for everybody that lives in the state, regardless though more so in the inner city.*

Another instance of perceived need for navigating among systems was described by a provider who felt that disconnects between care systems often exist for individuals with multiple disabilities, who therefore receive services from multiple types of providers and agencies, such as a client in need of substance abuse treatment, mental health care and physical health care. This provider expressed frustration, echoed by the group, that the various systems of care required by the individual were not in contact with each other, leading to additional challenges for individuals whose needs span multiple care systems.

*One thing I ran into is an individual had comorbid diagnoses, in another word he had two diagnoses, two issues, suffering from substance abuse, and because of his mental issues was kept in an open area with a gurney, sitting in a wheelchair for days and hours. Hours and hours, and he stood there and suffered that because he wanted to get sober, and yet it took all of that time because of his mental disability they were afraid to provide him with the care that he really needed.*

In an important example of resiliency and community strengths, many participants viewed themselves and their communities as important resources for filling the gaps they perceived between systems. Several participants described themselves as “squeaky wheels” who made noise and thus prevented loved ones from falling through perceived cracks in the system. For example, when their loved ones were hospitalized, this individual with a disability used their prior knowledge of the hospital-based care system to ensure that their relatives’ needs were met.

*[H]e had [terminal illness] and they didn’t change his bed, I used to be there every morning make sure his bed got changed, washed him up because the nurses wasn’t doing it, you know and the same thing when my father went to the hospital. He had a stroke, they put the food in front of him, he couldn’t use his hand, they’d come back and get his food you know there was no one there, so we had to be there to make sure my father ate, we had to feed him because no nurses, or no one was feeding him.*

Several participants voiced the feeling that advocating for themselves, their loved ones and their communities were of the utmost importance. For example, one participant described how her continued advocacy efforts on behalf of her mother, who was caught between two parallel systems, led to her opportunity to receive rehabilitation services:

*Because I experienced that as well with my mother, where as she had fallen and she went to the hospital. They were trying to figure out what was wrong with her and I sat there from 7 o’clock first shift, to after 9 o’clock and she laid in that bed for three days unable to move and the only time that she had had any assistance was when they brought her originally to the emergency room….But my mother is in a bed over here that can’t move, the sink and everything is over here, she can’t get out of the bed plus she had a catheter, there was no towels, no wash, like she was given nothing, but the minute I sat there and voiced my opinion they shipped her off to rehab.*

***Accessible health care environments and practices***

When participants successfully advocated and navigated their way to needed care, they sometimes encountered barriers related to the accessibility of health care environments and practices. Many participants voiced their concerns with the physical accessibility of health care settings and services. As described by several participants, physical access to hospital facilities was often ironically lacking:

*When I was in my manual chair I was unable to get inside of the hospital bathroom doors because they don’t have the push activating door.*

*And many other (health facilities), they do not have the push activated door. Even [a specific hospital], this is a hospital that is supposed to be working with people with disabilities, and the toilet is too low, and I have to use something else, another chair on top of that, and I can’t even get in the bathroom, and it’s the same when it comes time for my eye examinations and all of that.*

Issues with physical access at health care facilities also extended to the accessibility of basic care services, such as weight monitoring and receiving needed exams. As described by some participants, there was a perception that care quality might be compromised by a lack of accessible equipment.

*[H]ospital access is a really critical issue, often time adults with disabilities don’t have access to getting weighed, so they take an estimate because they don’t want to transfer people from a wheelchair, exam tables not being accessible, women with significant disabilities not getting breast exams things like that. But the ironic thing is hospitals don’t really seem to be made for people with disabilities*.

Another participant described this phenomenon as being at play in their dental health care, in that they needed assistance to transfer themselves from their wheelchair to the dental exam chair, which was not provided, thus denying them access to needed dental treatment:

*I think we need to know that we don’t have to sit on the [dental] chair to be attended; you have to transfer to the dentist chair and sometimes you can’t do that yourself. No one can do that to you. We cannot treat you. Being able to use dental equipment is very important for all of us.*

In addition to physical access to health care, several participants spoke about issues with cognitive access to health care. In other words, as they described it, the health care system was not structured to allow providers to meet their accessibility needs, such as allowing for additional time to speak with a person with a speech or communication disability:

*[T]he doctors are under that pressure, they are only allowed 10 or 15 minutes. You cannot get a full evaluation from somebody, especially if they have a speaking disability in ten minutes, because you overbooked 25 patients.*

***Attitudinal barriers and differential treatment***

Many participants at the forum discussed difficulties they encountered related to what they perceived as differential treatment and problematic attitudes in health care and community settings. For some participants, these barriers appeared to stem from lack of awareness about adults with disabilities and their needs.

*One of the biggest problems I run into in the community…is attitudinal, I mean really serious issues, disability issues are way below their radar. Very subtle things, the way they speak to you, and basically they don’t think anything if you need an interpreter, they don’t think that that is a big deal. No this is not a problem, I will just work around it. But you can’t, there are some things you just can’t work around, there are so many issues they can’t work around and they don’t even seem to understand that there’s a problem.*

A few participants felt that a general lack of awareness of disability issues by health care providers sometimes resulted in an inappropriate focus on the person’s disability, rather than their presenting health issue. For example, one participant described their experiences with physicians as follows:

*Very often I have found that if you go [to the doctor’s] even if you have a cold…you are there to see the doctor about your cold; they are more interested in your, in the fact that you have a disability than prescribing cough syrup. It’s important that you teach them, or step back and say ‘look, Doctor, okay, let’s make this a teachable moment. Be nice and everything even if you’re aggravate[d], but we can educate them, too.*

The participant above viewed this gap as a “teachable moment” in which to educate the physician to reduce stigma or differential treatment. While this perspective is important, it is also important to note that other participants viewed their experiences not as potential teaching moments, but as receiving a lower quality of care. For example, a participant describes not receiving needed anesthetic for a dental procedure, which they felt was due to the providers’ view of their disability:

*And a lot of dentists they won’t do like, knock you out if you have a disability.*

Providers also felt that medical professionals did not always provide equitable care for reasons related to their perceptions of disability:

*I have seen experiences where seasoned medical professionals have done such idiotic decision making around certain types of patients, particularly around not providing the right anesthetic for a procedure, kind of assuming that the client or the patient didn’t need the full amount that everybody else had because they couldn’t articulate it, so I know I have seen just a couple of experiences where I was just blown away by the decision making of the seasoned specialist.*

For several participants, perceived disability-related stigma against them made their interactions with the health care system uncomfortable. For example, one participant described their perception of being treated as different or contagious based on their HIV status, and the impact this perceived treatment had on their health care seeking behaviors.

*[T]he nurses, doctors they do need training on how to treat people with HIV and AIDS when we come in the hospital. Don’t sit us over there. I can sit with her. You don’t know. You don’t have no look, can’t say I got it if I don’t tell you. And the way they have it set up now you don’t want to say nothing [about your HIV status]. Your barriers, that’s a barrier, stigma, the whole thing just sits there. So we don’t go to the hospital for our exams, no we don’t.*

As described by this participant, their perception of being subjected to stigma led to less utilization of (presumably necessary) health care services. While it is beyond the scope of this forum to explore specific impacts of such treatment and the resultant lower care utilization on health, perceived stigma or attitudinal barriers appear to be negatively affecting participants.

For other participants, negative attitudes or presumptions of incompetence in health care settings have had more immediate impacts, such as a participant who described her experience of nursing staff assuming she would not be able to parent effectively due to her disability after she delivered her infant. As she describes, she was not asked about her needs, strengths or skills before she was reported as higher risk for perpetrating abuse or neglect of her child:

*I had an experience not with race, but with lack of sensitivity to disability. One of the biggest hospitals, instead of them asking me questions like how to help me and stuff like that they just assumed I couldn’t do it…[T]hey wanted to take my baby away because I am [a person with a disability; disability type omitted]. ..they never asked me like ‘how could you do it [parenting]. No, she never asked me ‘how could you do it?’ Do you have a skill? Did you take a training? Or do you have somebody involved to help you, any community involved to help you? She just assumed because I am [disabled] that I couldn’t take care of my [child], and she’s calling 51-A on me to take my baby away, because she was not going to give me a chance and listen to what I have to say, that I could do [it], and here’s my strategies, here’s how I could do it. She just presumed that I actually couldn’t do it.*

For this participant, the assumption of inability made by the health care provider was incorrect; as the participant described, she is an excellent mother. However, assumptions were made about her parenting due to her disability status, and the participant felt unseen by the system, a sentiment that was echoed by many participants.

***The double challenges encountered by people of color with disabilities***

Throughout the forum, participants spoke about their experiences navigating and interacting with the health care system as people with disabilities, people of color and people from underserved communities. Participants agreed that societal perceptions of these various identities impacted how they were treated within the health care and social service systems. For example, as voiced by one participant, people who are racial, ethnic and linguistic minorities sometimes receive different treatment:

*I think we need to add to that, if you are, depending on your color, the treatment you get, if you are black, or Hispanic, or Mexican, different from the white person, and sometimes even the accent, you know if you speak a different language, just because you have a different language, you get treated differently. And most importantly if you have a disability because it double jeopardy itself that kind of perception is very complex. It gives you a different kind of attitude.*

This statement was seconded by another participant, who focused on the “double jeopardy,” as voiced by the participant above, of having a disability and not being a native English speaker:

*I just kind of wanted to add to what you were saying, touch lightly on the cultural competency. I feel as though if you don’t speak the native tongue, you are just going to fall into that stigma where they are just going to write you off or put you wherever they feel like they think is necessary, is going to be best for you.*

Other participants shared examples of feeling that they were treated differently because of their race or skin color.

*I was mistreated at the major hospitals, two of them, and one rehab center because of my color.*

Another important theme regarding challenges facing people of color with disabilities related to a perception that the system was built for other people, and did not always take the needs of non-white adults with disabilities into account sufficiently. One participant provided a powerful example related to MassHealth policies for personal care attendant (PCA) time management that overlooked the additional grooming needs of individuals with different hair types:

*I think that sometimes some of the agencies, I will use MassHealth for example, they have what is called a Time for Task list, so they go by a general guideline for how long it is going to take you to do certain things based on your disability, and one of the things you run into, particularly with people of color is grooming because they give you a set amount of time for your hair, and we have a lot of different kinds of hair. You know, so 15 minutes isn’t going to cut it for me, I have locks, it’s going to take me an hour to dry mine. Right, but so often times we actually have to have the nurse explain that. Why the excessive time for the grooming of your hair. So they say the person has locks, or they have this type of hair….* *They kind of operate from a paradigm that doesn’t really account for different types of people. Not everybody’s hair takes 15 minutes to wash, dry and style if you are having a PCA do it….but you have to flesh out and explain my hair is going to take longer for grooming…So it is just a word to the wise if you have PCA services make sure that they are able to deal with you, and your hands-on needs, and not the template. Because the template doesn’t really account for everybody.*

This individual was quick to clarify that they were able to successfully advocate for additional PCA time to meet their hair care needs, and that in their experience, MassHealth was willing to accommodate their individual and culturally-based needs. However, this example illustrates that while individual, racial, ethnic, cultural and language needs can be accommodated, the “template” (as described by the participant) for determining needs and services may not be as inherently inclusive as possible.

When asked about the impact of such perceived differential treatment, participants identified negative experiences as stressful. As one participant replied:

*This is discrimination. Those things make the person very…get stressed, get stressed.*

In addition to the immediate impacts on well-being, participants voiced concern that differential treatment of both individuals and communities equated to disparities in care quality over the long-term. For example, as noted earlier inthe section about navigating the system, many participants felt that further efforts were needed to notify people in underserved communities of the resources that are available to them. Participants said that efforts to bring services to minority communities, and make them welcoming and culturally accessible, would be appreciated to combat feelings of exclusion:

*We need more of these information forums, we need more of these types of situations. ‘Cause when people come together there is strength in numbers. And you can teach somebody what you have learned from someone else and it goes on, you’re like walking, talking billboards for the services that are offered and being provided. So if more of these forums could be accessible to the community, specifically our community, the people that reside in the communities then I think people will come out.*

**5. Stavros Center for Independent Living Community Forum**

The Stavros Center for Independent Living serves adults with disabilities and Deaf people throughout the Pioneer Valley, with offices in Amherst, Springfield and Greenfield, Massachusetts. The mission of Stavros is to help persons with disabilities and Deaf people develop the tools and skills they need to take charge of their own lives. This is accomplished through programs and services designed to meet the needs of persons of any age or disability as they work to achieve the life goals that are important to them. Stavros believes that real independence also means a community free of barriers, and so they work as advocates throughout the Pioneer Valley, across the state, and nationally to bring an end to discrimination--whether it's rooted in a set of stairs, prejudice about employment, limited access to health care, or anywhere else.

*Data collection*

Similar to the community forum at the Multicultural Living Center of Boston, participants at the Stavros Center for Independent Living forum completed a survey that gathered basic demographic data and asked about participants’ perceptions of the importance of 20 selected health issues for adults with disabilities in their communities. Survey results are described below, and the full survey instrument is included as Appendix A.

**Survey Results**

*Demographic Characteristics*

Forum participants included adults with disabilities (33%), family members and caregivers of adults with disabilities (8%), staff members at governmental agencies that work with adults with disabilities (8%), and 67% of people who identified as “other.” It should be noted that 42% of participants left this question blank. All participants stated that they lived in Massachusetts.

Participants reported for either themselves or those with whom they worked regarding difficulty with dressing or bathing (75%), difficulty walking or climbing stairs (92%), difficulty concentrating, remembering or making decisions (42%), blindness or severe difficulty seeing even with glasses (33%), Deafness or serious difficulty hearing (17%). Those who worked with or provided care for adults with disabilities provided support to people with a wide range of disabilities including people with physical disabilities (38%), intellectual and developmental disabilities (13%), mental illness (38%), deafness (13%), and visual disabilities (13%). Caregivers and their agencies served children and youth with disabilities (13%), and older adults with disabilities (50%).

Among forum attendees, 25% identified as male and 58% identified as female. Regarding sexual orientation, 58% identified as heterosexual or straight, with several choosing not to answer. Attendees ranged in age from 45 to over 65, with the majority of participants being between 55-64 (42%) or 65 and over (42%). Most participants (83%) reported that they preferred to discuss and receive information about their health care in Spanish. Only 8% of participants stated they preferred to discuss health care in a language that was not listed on our survey, and 8% of participants left this question blank. No participants selected English as their preferred language for discussing health care.

 A majority of participants (56%) described themselves as White Latino or Latino (50%), and an additional 33.3% of participants described themselves as Black Latino or Latino. 8% of participants described themselves as Latino/other, and 8% declined to answer this question. A majority of participants described their ethnicity as Puerto Rican, with a few other Central American and Caribbean nationalities represented. Of the cohort, 83% of participants stated that they felt that other people in this country usually classified them as Latino, with 8% of participants saying that others classified them as White and an additional 8% saying that they were usually classified as Black or African-American by others.

In response to the questions related to “Reactions to Race,” the vast majority of participants also responded that they thought about their race either constantly (58%) or at least once a week (17%). Only 8% of participants said that they never thought about their race, an answer that often represents few lived experiences of racism. A significant proportion of forum participants stated that they felt they had been treated the same (67%) as people of other races in health care settings, while 33% of participants also said that they had experienced physical symptoms such as an upset stomach or racing heart related to how they were treated based on their race within the previous 30 days. An additional 8% of participants said that they had felt upset, angry, sad and/or frustrated within the previous 30 days as a result of how they were treated based on their race. Related to work settings, 17% of participants said that they had been treated the same as people of other races, but it should be noted that 67% of participants stated that they did not work outside the home in the past 12 months, a finding that makes sense given the advanced aged of many participants.

**Public Health Needs**

*Levels of Need: Top “Big Problems”*

Each participant answered a series of questions aimed at assessing the level of need for specific health indicators. The questions began “In your opinion, is it a problem for adults 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 categories for all participants who reported that indicator as a “Big Problem” for adults with disabilities in Massachusetts. At this community forum, seven indicator areas were identified as “Big Problems” by more than 15% of forum participants, as shown below in F*igure 4.*

As shown, paying for prescription medications was perceived as a “Big Problem” for adults with disabilities by 42% of all forum participants. Finding affordable housing was seen as a “Big Problem” for adults with disabilities by 33% of forum participants. One-fourth of forum participants described each of the following three issues as “Big Problems” for people with disabilities: managing chronic conditions like diabetes, asthma or high blood pressure; finding doctors who use communication supports like American Sign Language, large print, Braille or Communication Access Realtime Translation (CART) reporters; and finding employment opportunities. Finally, 17% of forum participants described both finding a doctor who is sensitive to disability issues and finding a grocery store that sells healthy food, such as fruit and vegetables, as “Big Problems” for adults with disabilities in Massachusetts.

The following issues were described as “Big Problems” for adults with disabilities in Massachusetts by a small number (below 15%) of forum participants: finding a dentist; finding a mental health provider; getting adequate mental health services; getting routine medical tests such as annual physicals, mammograms or colonoscopies; getting vaccines like the flu or pneumonia vaccine; finding a doctor’s office that is accessible (e.g. has wheelchair ramps, exam tables that raise and lower, etc.); finding transportation to doctors’ appointments; getting durable medical equipment such as wheelchairs, scooters or hospital beds; and finding accessible supports and programs if they are experiencing violence or abuse.

A third of participants reported that they didn’t know whether the following issues were problems or not for adults with disabilities in Massachusetts: finding doctors who use communication supports like American Sign Language, large print, Braille or CART reporters; finding employment opportunities; finding a doctor who is sensitive to disability issues; and finding a mental health provider. In addition, 25% of forum participants reported that they did not know if finding a dentist or getting adequate mental health services were problems for adults with disabilities in Massachusetts.

**Forum Conversation**

After completing the surveys, participants engaged in a forum-style focus group, facilitated in Spanish by Ms. Christine Roa of the Disability, Health and Employment Unit at the University of Massachusetts Medical School. The forum was audio-recorded and remotely CART-reported via telephone, with the permission of all participants. The forum was later translated into English by a professional translation service. The primary questions posed to the group were related to identifying the most relevant concerns related to the health and health care of adults with disabilities from underserved communities, including the barriers to and facilitators of health and health care, unmet needs and strategies going forward. Forum participants were asked to focus on the health issues of adults with disabilities in Massachusetts and to speak from their experience. It should be noted that all comments and opinions recorded in this report are the opinions of the forum participants and do not necessarily represent the opinions of their respective employers or organizations.

We analyzed the information that participants shared and identified four themes. They included:

1. Barriers and disconnects in the system
2. Language barriers and information quality
3. Lack of relationships and connection with the health care system
4. “Fighting for our rights wherever we go”

The first theme, “barriers and disconnects in the system,” describes the various issues that participants encountered as they attempted to meet their care needs in the context of a complex health care system. Note that language barriers are not discussed within this theme; rather, they are described as part of theme two, “language barriers and information quality.” This theme also details issues with interpreters, including family members who serve as ad-hoc interpreters, and participants’ perceptions of the information quality they receive. Theme three, “lack of relationships and connection with the health care system,” describes a feeling of disconnection and discontinuity expressed by many participants in response to questions about their relationships with health care systems and providers. Finally, theme four, which is named for a participant’s words, “fighting for our rights wherever we go,” explores participants’ perceptions of sometimes adversarial or challenging relationships with health care providers and systems.

***Barriers and Disconnects in the System***

Forum participants described significant challenges and frustrations with their access to health care, including problems knowing where to get care, difficulties with transportation, challenges navigating the system and weaving together various services to meet their unique needs, and long wait times, sometimes compounded by lack of information about how the system works. It should be noted that language barriers and issues with interpreters also contributed to challenges experienced by participants, but these ideas will be discussed in the next section, related to theme two.

Throughout the forum, participants described the challenges associated with the process of receiving needed health care. For many participants, their ability to access health care was limited by unreliable transportation and unpredictable work schedules, their own or those of family members who assisted them with attending medical appointments. The following situation, leading to missed medical appointments, was common:

*I had this situation where I would go with my husband to his appointments and then, recently, my husband was working and he works in the farms and he left at 7:00 at night…I have to wait for someone to take me to the appointment.*

Several participants reported issues with public transportation, including unreliable bus schedules and a lack of knowledge of the transportation system:

*I don’t know how to go on the transportation bus here. I don’t know. I get on there and it takes me who knows where?*

For others, even when transportation was provided, there were additional logistical barriers. Many participants relied on family members to interpret for them at medical appointments, but the transportation service was not able to transport the patient, their spouse and the family interpreter together, creating multiple access barriers.

*The day that I used it [the transportation service provided] my daughter was going to be an interpreter with the doctor. [The driver] would not let us go. And they even sent an inadequate vehicle, sent a man in a car. And did not let all three of us ride.*

For many participants, these barriers were very significant. As described by one participant, the bottom line for many people was that without logistical supports and transportation, health care is simply inaccessible:

*[If we] do not have the transportation, do not have the interpreters, we do not have, well, we would miss the service.*

For some participants, these time and transportation barriers were compounded by administrative difficulties and a lack of understanding of the processes and culture of health care. For example, many participants encountered difficulties with scheduling appointments, and with accessing urgent care services.

*[W]hen you need an appointment urgently, they can’t give you one for up to three weeks. They do not see you on the same day. You have to wait two or three weeks to be seen.*

Another participant described waiting months to get an appointment, traveling to the doctor’s office and then being informed that her public health insurance was not accepted at this office.

*[It is] negligence also after going months and months for the moment they don’t accept the card. So the administrative delay that things can be better, so they don’t waste their time going. In any case, let us know by phone or letter. Do not wait until the appointment to let us know that you don’t take the plan.*

Participants also expressed that they did not always understand the rules and systems of health care facilities, such as the policy related to fees for missed appointments, and time frame for canceling an appointment in order to avoid the fee.

*[T]he recording said he had an appointment and he missed it so that you know that you are not going to come. And my husband did it the day before and they called him if he wanted to change the appointment and he said yes and he got a bill without missing the appointment and you have to pay it because if not it affects your credit.*

This experience was seconded by other participants, including this participant who also expressed their frustration:

*I was also in that situation, my husband was also coming late [from work, leading to a missed appointment] and I went to pay the $50 and because you have to pay $50 after having cancelled the day before…And you do it because then you have to pay $50 and they said that they are the rules. I said but what is it, I told them after that we cancelled it and they told me no, because the lady said same thing to me that there are other people that really need to go to the appointment and they miss out, but we had already cancelled it. They could have put another person. We had to do what they said, you have to pay because it is already posted. I had to pay $50 for having done nothing.*

These barriers were experienced by many participants as very frustrating, which some participants experienced as disenfranchising, leading to negative perceptions of health care systems and missed opportunities for care. For example, one participant described her long wait for an appointment, which caused her to leave the health care facility without notifying the staff, so she was later billed for the appointment.

*I went at 11:00 in the morning and was there until 7:00 at night and I told my daughter ‘let’s go’ as I was already dying of hunger and thirst and had to use the bathroom. I don’t like the bathrooms there. [I said] Let’s go because I can’t stand it anymore. And we left. And the other day they called my house that I had not waited for the doctor. [T]hey were going to send me a bill for the appointment. They sent me bill to my house. With all that the doctor did not see me and they sent me a bill for one hundred and forty one dollars and twenty-five cents.*

This participant did not receive needed care, and felt that she had been unfairly charged. Other participants described added stress as an impact of interacting with the health care system:

*[A]nother thing is that you go to the clinics and leave with your blood pressure in the clouds and you leave with stress, with headache due to all the waiting that you have to do.*

Another participant described this knowledge gap in response to a question about what supports and services participants were accessing:

*I do not know any program because nobody tells me anything.*

This lack of knowledge about the parts of the health care system and supportive programs may limit participants’ ability to navigate the health care system and meet their needs. Knowledge of available resources and coordinated care led to improved health behaviors for one participant, who appeared to be an outlier, and who was the only one to mention coordinated care and its impacts:

*For example, we, my husband has his doctor, his diabetes nurse, me too because I am diabetic, and she has taught us a lot like how to eat but we already knew some things and administering food at home yes, we eat healthy.*

***Language Barriers and Information Quality***

Closely related to the barriers and challenges described above are issues of language, interpreters and understanding. Participants agreed that navigating the health care system in English presents a set of challenges, and impacted the quality of information that they received from health care providers, and, in turn, their knowledge of and comfort with the system. For example, one participant was unaware that free transportation to medical appointments was provided by MassHealth, due to language-related communication gaps.

*I had a year calling taxis because I did not know that there was transportation. What my doctor’s office had notified me that perhaps many do not know.*

This participant talked about finding out that they were eligible for social security benefits, and wondering if perhaps other people in their community were also eligible, but not accessing these benefits because of information gaps and lack of knowledge about their availability:

*I went to a Social Security counselor and [in] my experience there are many [potential] beneficiaries who live in the projects and there are programs that exists, but they are unknown. People don’t know due to a lack of communication.*

Another participant described waiting to register for social security benefits until they learned that they could enroll over the phone, when a relative was available to interpret:

*[S]ocial security, they can do it by phone, since I do not know English and my [relative]…was in the house. I got him to answer the call.*

Without the presence of an English speaking relative to interpret, this participant would not have been able to access an important resource, social security, despite qualifying for assistance, which illustrates a lack of access to available community resources due to language barriers. In fact, many participants relied on family members, and in particular children, to serve as interpreters.

*I have to take my grandson and he is 14 years old.*

Participants had mixed feelings about family members serving as interpreters, particularly minors, as described below:

*Then sometimes you go to speak things that are true that you can’t and well, there are minors that don’t understand and a lot of times I see older people, myself included, with minors to interpret.*

Despite some of the privacy issues inherent to children or grandchildren serving as interpreters as described above, participants sometimes felt that they would not be served without the presence of a family member to interpret. The experiences described below by two different participants were common:

*You have to wait a lot for a [professional] interpreter. I go to a center, I don’t know if I can say the name. I take my husband because there is no interpreter. If you don’t take someone [to interpret], you aren’t going to consult [with the provider].*

*If you do not bring your own interpreter, they do not take care of you and that is not fair.*

There were also some privacy concerns with professional interpreters, such as the female participant who expressed discomfort with male interpreters being involved in some of her health care:

*If I go to a gynecologist I don’t want to speak with a male interpreter.*

In addition to privacy concerns, many participants expressed concerns about the quality of professional interpreters, especially those participants who had some degree of English proficiency.

*When you get an interpreter and say one thing and [the interpreter] assumes that you do not understand [English]. I do not know to speak [English] but I understand it. But they [interpreters] are saying something different.*

Another participant seconded this feeling, and further stated their feeling that the interpreters are “associated” with the doctor, not the patient.

*[M]y son works and my grandson is in school. I have to go alone, so [I] need the services of an interpreter but there are very few that interpret what you say to the doctor and also return the message to you, because most do not know what you are telling them that well. Also they are associated with most doctors that care for you.*

Further, several participants felt that interpreters increased their wait time, as they had to wait for both the doctor and the interpreter to be ready to see them, only to have the time needed for interpretation further curtail the amount of time spent in conversation with their clinician. As described by several participants, the lack of sufficient time for communication had impacts on their perceived care quality:

*We arrive at 10:00 and the interpreters are sent at 10:15 and I have 15 minutes and I come to leave even though we haven’t finished. Then they leave me. They don’t have time to be there for the entire appointment.*

In addition to issues with the perceived quality and availability of professional interpreters, several participants stated that they had felt mistreated as a result of their language preferences and needs. Some participants described instances in which they felt that they were given a lower quality of care due to not speaking English fluently. For example, one participant described taking their son to an emergency room with a broken bone and experiencing what they perceived as differential treatment due to the fact that they spoke some English but still required an interpreter to communicate effectively and fully:

*I took my son who had broken his arm to the emergency room and I was told that I did not know English. [A]nd she got a bad attitude when I asked a question [in English] but the boy was in pain and I said I don’t know English and she said ‘you know English-why didn’t you answer me?’ and I said to tell them he has pain. And the interpreter said ‘we are not here for that and not being willing to answer is illegal.’*

In other words, participants who had some command of English felt that they could be denied needed interpreter services if they attempted to make their needs known in English. Other participants described their perception that some employees of the health care system who they believed spoke Spanish refusing to speak with them in Spanish. In a response that echoed participants’ statements about navigating language barriers, another participant suggested that, perhaps…

*Many times there are companies that do not allow any Spanish-speaking employees to speak Spanish, they say they cannot speak Spanish. That’s why they do not want to speak Spanish to a Spanish-speaking person.*

While this may or may not be policy at a given health care facility, this perception speaks to the feelings of alienation and disconnection that many participants experienced as a result of the language barrier discussed below.

***Lack of Relationships and Connection with the Health Care System***

In light of the many barriers discussed above, it is perhaps unsurprising that many participants reported feeling disconnected from the health care system. For many participants, this perceived lack of connection related to frequent changes in insurance mandates and facility policies, long wait times, administrative challenges and inconvenient scheduling, and, for some, a generalized mistrust of clinicians or the health care system.

Several participants discussed the difficulty of developing a relationship with their primary care provider due to frequent changes in their insurance coverage, MassHealth rules and/or clinic policies. As described by several participants, it is frustrating to get to know a primary care provider only to have their “card” [Masshealth coverage] change, preventing them from continuing this relationship:

*There is sometimes that you spend so much time with the doctor…That happened to me and they told me that they don’t take my card. Out of nowhere they just don’t take the card anymore. Because they do not accept you if the doctor does not accept the card that you have. And it makes you have to look for another doctor and resources.*

The frustration associated with this experience was articulated by another participant:

*And help from MassHealth is something that comes and goes. It changes all the time. And when your life changes, you change as well. When you go to the doctor, they don’t accept it. Call MassHealth. And while more change their cards the doctors also change and your life also changes.*

Another participant described the team-based structure of their primary care practice as contributing to their sense of disconnection from their primary care provider:

*Sometimes you have a primary doctor and when you go to the appointment it’s another [doctor]. Then your doctor does not appear. They put a student, a practitioner to attend to the people. And I have the name of the doctor and asked for information on other doctors to see, I do not know what it is because we deal with so many who do not know who really is the primary care doctor. Sometimes American, but Latino, none.*

Another participant agreed with this assessment, further stating:

*It causes confusion, different faces and not knowing who your primary care doctor is.*

In other words, though these participants might have had an official primary care provider listed on paper, they did not report feeling as though they had a primary provider who knew them and cared about their wellbeing.

For other participants, their sense of lacking relationships with a clinician related to feeling ignored. For example, one participant described being prescribed medication without being examined or interviewed, a situation they did not appreciate:

*There was a particular clinic that I was in for a lot of my illnesses, that prepared on many occasions to meet the patient but many times in my case when my gynecologist came he got my prescriptions changed and had not interviewed me. If you do not know me, how can you change the medicine? He didn’t even interview me. That happened to me.*

This sense of not being accommodated or cared for was reinforced by administrative difficulties and long wait times for many participants. In a representative story, one participant described their attempt to overcome transportation and language barriers in order to make it to an appointment, where they were not served, due to their tardy arrival:

*One day it happened to me that I asked for a taxi and it arrived, but it was already time for the appointment and I had not gotten in the taxi with my husband because he has not arrived and I called the clinic office and I told the secretary, if they could hold it [my appointment] for 15 minutes, that I believe he was on his way. And they told me no, that I had to change the appointment but what I want to add is that because you arrive at your appointment up to an hour beforehand and [spend] two hours waiting for them to tend to you, and then you wait patiently and everything and they never say anything. And they can’t wait 15 minutes.*

For many participants, these long wait times were perceived as more than simply an inconvenience. Instead, they spoke to a feeling of being ignored, and increasing feelings of isolation and disconnection. In other words, while waiting to receive care, some participants perceived that their needs were being neglected.

*I find that when you go to the emergency room, you wait the whole day. You’re there very sick, very, very sick and if you go at 7:00 [am] you are there until 8:00 at night and if not, [until] the next day in the waiting room, waiting and waiting. I think that’s negligence.*

Some participants even felt that this wait time was due to clinicians not “doing their jobs”, rather than more mundane administrative or scheduling issues:

*Well, one is willing to wait, but often what happens is not because of emergency patients, but the doctor is in there doing nothing.*

This feeling, expressed by participants, that they were alienated from the system and not being served effectively leads to the fourth and final system we discuss here, “fighting for our rights wherever we go.”

***“Fighting for our rights wherever we go”***

For many participants, interactions with the health care system were often contentious, and many participants spoke about their feelings of mistrust of clinicians and health care facilities. Several comments by participants that illustrate mistrust and negative interactions are below:

*[T]hey [clinicians] are passing the time talking and not taking care of the patients who are inside and giving evaluations. But I say this from my own experience and how it was in the emergency [room]. It’s not fair.*

*Imagine waiting for so long and leaving with chest pain. That is not why you go to the doctor.*

In addition to negative interactions with clinicians and the urgent care system, some participants also reported experiences with other aspects of the health care system that they perceived as less than compassionate. For example, a participant described their experience of slipping and falling as they exited an insurance-provided medical transportation service:

*I fell down [when] the driver dropped me off at the sidewalk, okay, without being able to stop. I did not have my cane. I was lying on the floor for 15 minutes.*

As summarized by one participant who reported several negative interactions with the health care system:

*I think they should treat us like humans, not animals.*

Perhaps related to these negative perceptions and experiences, participants stated that in order to receive needed care, it was important to advocate for oneself and one’s family and community. As expressed by one participant in response to a question about accessing health care:

*We have to fight for our rights wherever we go. And we are silent and they step on us.*

Another participant agreed, stating:

*We have to look out and complain.*

Many participants described their strategies for navigating the health care system, showing sophisticated knowledge and advocacy skills:

*For the emergency room, I ask to speak to the person who is in charge of the emergency room. And if there is a written complaint, often times it is not read.*

*They always taught me that when we have a problem with the doctor I should go to his supervisor. And from that report he goes and he speaks and if he doesn’t do anything the next step is to speak with an attorney. That’s what they taught me. Speak with the person’s supervisor and give them a report and they give you a copy. If they don’t do anything, the second step is to an attorney.*

*Yes, go to the interpreter’s office and you can put a complaint. Their office is on the first floor. I had problems with one of them because he started being a little rude and I went and spoke.*

*What I do is most of the time when they get [chart] sheets in the emergency room, they take the information down wrong and I communicate with the invoice and they ask me for all the information and the problem gets resolved.*

Several participants also described the importance of advocating for themselves persistently, such as this participant who described the advice they gave their mother related to health care bills she was receiving:

*For any little thing they send you a [bill]. And my mom was sent one and she has her insurance, but they sent it to her that time. And she tried to call over there and sometimes they put her on hold and put music on and leave her there. I told her she has to get angry to resolve the problem.*

Though many of the participants quoted above demonstrated strong personal advocacy skills, there was general agreement among forum participants that access to health care and treatment within health care settings is a community-wide issue best addressed together. As explained by this participant:

*Sometimes it is, it is stronger to do things in a group than it is to do it alone.*

This was seconded by another participant, who commented:

*When the community comes together and protests due to things that are bad and come together in small groups to protest, complain about the things that are happening that we are not benefiting from as a community this way we can help things to improve.*

Hinting at potential directions forward, one participant described areas in which community mobilization was used effectively to address problems, and suggested that the same strategies be applied to health care access and quality:

*And now when there is something bad, we’re going to put the place we live, and we do not want this to happen when problems like shootings happen or problems where you live happen, the neighbors come together and start to sign and send letters and they take the problem out of the place because they complained and if it doesn’t get fixed and the neighbors get signatures to get a solution to the problem. And [if] we do it with Medicare or the doctors with hospitals, we also have the right to protest for things to get better, correct?*

As agreed upon by participants, an engaged community is a strength that could be further capitalized upon to support health. At the end of the forum, participants agreed that meeting together at the Stavros Center for Independent Living had been helpful for them personally, as well as providing important data for this project. As stated by a participant:

*And what I want to add is, everything changes. And every time that a system changes when we meet we can talk about how it is. If there is not a meeting, we will not find out about what is happening with us or others. At least every three months there should be a meeting here. We’re all talking, conversing and we know the problem that we need to help answer.*

1. **Summary**

Although the needs assessment conducted in 2013 provides a useful overall picture of the needs of adults with disabilities in Massachusetts, adults with disabilities come from diverse backgrounds and therefore do not always experience the same interactions with health care. Therefore, it is important to examine the needs and experiences of subpopulations of people with disabilities, especially those who might not be well-represented in traditional data collection efforts. People who are members of racial, ethnic and linguistic minority groups are often under-represented in data collection efforts, and may face additional health disparities and barriers to receiving health care services. Therefore, we conducted this supplemental needs assessment, which included analysis of Behavioral Risk Factor Surveillance System (BRFSS) data about racial, ethnic and linguistic minorities with disabilities, as well as two community forums. These community forums were conducted in an urban, underserved community of color in the Boston area and a Spanish-speaking Latino community in Western Massachusetts.

MA BRFSS data from adults with disabilities reveal that Latino adults with disabilities were more likely to report poor physical and mental health. Black people were less likely to report having health insurance and were more likely to have lost six or more teeth due to decay, an indicator of a lack of access to preventive oral health care. White people were more likely to report being former smokers, while Black people were more likely to report being a current smoker. Black and Latino adults were more likely to be overweight and obese. Black people were more likely to report diabetes and Latino people were more likely to report asthma. This analysis does not compare people with and without disabilities; that information is presented in the 2013 needs assessment report.

Community forums were conducted at the Multi-Cultural Independent Living Center of Boston (MILCB) and the Stavros Independent Living Center’s Springfield location. Findings from the surveys conducted at the community forums dovetailed with BRFSS data. Forum participants completed surveys asking whether they considered various issues and health indicators to be problematic for adults with disabilities in Massachusetts. Issues of importance were identified by how many participants rated the issue as a “Big Problem” for people with disabilities. At the MILCB forum, the top identified issue was finding affordable housing (82% said this was a “Big Problem”). The second issue was employment (70%), followed by finding a doctor who uses communications supports (52%), managing chronic conditions (48%), and then accessing dental care services (48%). At the Stavros forum, the top identified problems were paying for prescription medications (reported as a “Big Problem” by 42% of respondents); finding affordable housing (33%); managing chronic conditions like diabetes, asthma or high blood pressure; finding doctors who use communication supports like American Sign Language, large print, Braille or CART reporters; and finding employment opportunities (each rated by 25% of forum participants as a “Big Problem”).

There were important similarities in our qualitative findings from both forums. Participants at both forums reported difficulty navigating the health care and social service systems, with particular challenges reported in coordinating needed supports across systems. Examples provided by participants included challenges navigating conflicting policies, such as a clinician who encourages patients to bring a family member to interpret but medical transportation services are unable to transport an additional person, or insurance policies that prohibit personal care attendants from providing assistance with grooming or bathing to a hospitalized patient, though hospital policies also prohibit nursing staff from providing such assistance.

Participants at both forums also voiced their perception that services were available, but knowledge of such services was lacking within minority communities, and they were therefore not accessed as frequently as they could be. As stated by a participant at the MILCB forum, “[It] *seems like they are lacking when it comes to getting information out there in these communities, minority communities. So these communities that are unserved or underserved we remain unserved and underserved because they’re not getting the proper knowledge.”* Participants at the Stavros forum also felt that lack of knowledge about available services complicated their access. One participant provided the following example, which they attributed to language barriers: “*I had a year calling taxis because I did not know that there was transportation. What my doctor’s office had notified me that perhaps many do not know.”* These knowledge gaps and issues navigating the health care system sometimes led to missed opportunities for care, and perceived lower care quality.

Participants at the MILCB forum also discussed gaps in accessibility they experienced in medical settings. For example, many participants noted that clinical offices sometimes lacked needed equipment, such as scales or exam tables that accommodate people in wheelchairs, or were physically inaccessible due to problems like narrow doorways or inaccessible restrooms. As one participant stated “*hospitals don’t really seem to be made for people with disabilities*.” At the Stavros forum, discussion centered around language barriers and gaps in interpreter service availability and quality, which participants perceived as creating gaps in accessible care. Participants at both forums also experienced transportation and other logistical barriers that impacted access. As expressed by one participant at the Stavros forum: “*[If we] do not have the transportation, do not have the interpreters, we do not have, well, we would miss the service.”*

When care was linguistically inaccessible, some participants were left feeling that the quality of care they received was less than optimal, and that they were not given sufficient time to communicate. “*We arrive at 10:00 and the interpreters are sent at 10:15 and I have 15 minutes and I come to leave even though we haven’t finished. Then they leave me.”* Some participants expressed that language barriers complicated their access to care. As expressed by one participant: “*If you do not bring your own interpreter, they do not take care of you and that is not fair.”* Many participants relied on family members, especially children, teenagers and young adults, to interpret at medical appointments. However, participants reported issues with privacy and discomfort, especially when minors were interpreting. Even when professional interpreters were available, participants had concerns about the quality of translation they received, and some participants felt that, even with interpreters, they were treated differently due to negative perceptions of linguistic minorities.

Participants at both forums reported perceived attitudinal barriers and differential treatment. For many, this was felt to be disability-related, and due to a lack of knowledge on the part of health care providers. As voiced by a participant at the MILCB forum: “*One of the biggest problems I run into in the community…is attitudinal, I mean really serious issues, disability issues are way below their radar.”* While some participants viewed these gaps as “teachable moments,” other participants expressed concern that they were not getting needed care, or being treated differently in ways they perceived as less than fair. For example, a participant at the MILCB forum talked about difficulties getting “past the disability” in accessing primary care. “*Very often I have found that if you go [to the doctor’s] even if you have a cold…you are there to see the doctor about your cold; they are more interested in your in the fact that you have a disability than prescribing cough syrup.”* This perception was also expressed at the Stavros forum, who perceived health care as a difficult situation where, “[*w]e have to fight for our rights wherever we go. And we are silent and they step on us.”*

Many participants at both forums felt that their treatment and opportunities within the health care system were impacted by both their disability status and their status as racial, ethnic or linguistic minorities. Participants at the MILCB forum reported experiences of feeling they were treated differently due to their race and their disability. As voiced by one participant: “*I think we need to add to that, if you are, depending on your color, the treatment you get, if you are black, or Latino, or Mexican, different from the white person, and sometimes even the accent, you know if you speak a different language, just because you have a different language, you get treated differently. And most importantly if you have a disability because it double jeopardy itself that kind of perception is very complex. It gives you a different kind of attitude.”* Participants described negative experiences in health care settings, including long waits and perceived lack of treatment. As voiced by one participant at the Stavros forum: *[T]hey [clinicians] are passing the time talking and not taking care of the patients who are inside and giving evaluations. But I say this from my own experience and how it was in the emergency [room]. It’s not fair.”*

Participants at both forums also described several instances of what they perceived as overt discrimination. For example, as stated plainly by a participant at the MILCB forum: “*I was mistreated at the major hospitals, two of them, and one rehab center because of my color.”* Other participants at the MILCB forum talked about “not fitting the template”, or experiences where they felt services were not delivered in a way that matched their unique needs as people of color. For example, one participant described how the standard amount of time allocated for personal care attendants to provide assistance with grooming was insufficient, as they wore their hair in an Afro-centric style that required more time to care for properly. As this participant advised others: “*So it is just a word to the wise if you have PCA services make sure that they are able to deal with you, and your hands-on needs, and not the template. Because the template doesn’t really account for everybody.”*

Participants at the Stavros forum, in particular, also reported a sense of isolation from the health care system, and reported that they lacked relationships with clinicians and other system representatives. As described by one participant: “*It causes confusion, different faces and not knowing who your primary care doctor is.”* For many participants, changes in public insurance policy often lead to frequent changes in primary care clinician and other aspects of service delivery. One participant described the impact of a change in coverage on their relationship with their health care provider: “*There is sometimes that you spend so much time with the doctor…That happened to me and they told me that they don’t take my card. Out of nowhere they just don’t take the card anymore.”* Other participants expressed their perceptions that this lack of longstanding relationships led to diminished care quality: “*[M]y gynecologist came he got my prescriptions changed and had not interviewed me. If you do not know me, how can you change the medicine? He didn’t even interview me. That happened to me.”*

Participants at both forums viewed health care access and quality as an important community issue. Several participants at each forum voiced their desire for increased community mobilization around these issues. As stated by a participant at the Stavros forum: “*And now when there is something bad, we’re going to put the place we live, and we do not want this to happen when problems like shootings happen or problems where you live happen, the neighbors come together and start to sign and send letters and they take the problem out of the place because they complained and if it doesn’t get fixed and the neighbors get signatures to get a solution to the problem. And [if] we do it with Medicare or the doctors with hospitals, we also have the right to protest for things to get better, correct?”* This thought was also expressed by a participant at the MILCB forum, who said: “*when people come together there is strength in numbers.”* Participants at both forums appeared oriented towards action, and desired to work with others to create positive change.

Many participants expressed appreciation for the opportunity to participate in forums, and requested more frequent opportunities to become involved in such community-based public health efforts. As a participant at the Stavros forum stated “*everything changes. And every time that a system changes when we meet we can talk about how it is. If there is not a meeting, we will not find out about what is happening with us or others. At least every three months there should be a meeting here. We’re all talking, conversing and we know the problem that we need to help answer.”* The same sentiment was expressed by a participant at the MILCB forum, who stated: “*We need more of these information forums, we need more of these types of situations. ‘Cause when people come together there is strength in numbers. And you can teach somebody what you have learned from someone else and it goes on, you’re like walking, talking billboards for the services that are offered and being provided. So if more of these forums could be accessible to the community, specifically our community, the people that reside in the communities then I think people will come out.”*

1. **Strengths and Limitations**

This report contains some important limitations. First, the surveys conducted at our forum had a relatively small sample size, and therefore cannot be considered representative of sub-populations of adults with disabilities in Massachusetts. In addition, both the survey and qualitative findings of the forum are based on people who were connected enough to community agencies to attend a forum, and may have had fewer transportation and knowledge barriers than other people who were not able to attend. This phenomenon is known as selection bias, and suggests that there may be needs and challenges of which we are unaware, which should be explored further in future needs assessments.

Second, adults with disabilities are heterogeneous and communities of color are quite diverse. Our sample of Spanish language speakers and members of an underserved Black and Latino neighborhood in Boston is not inclusive of all the diversity that is present among adults with disabilities in Massachusetts. Future assessment of the needs of adults with disabilities in diverse communities and groups in Massachusetts is necessary, and could include additional linguistic minorities, people who are incarcerated, religious communities, and many of the immigrant and cultural groups in the Commonwealth. However, our work represents a model that could be used to conduct these future needs assessments.

Despite these limitations, our work explores important issues among racial, ethnic and linguistic minorities with disabilities, an underserved disparity population. We successfully identify issues and concerns that warrant further investigation, and provide documentation of important gaps in services and supports. Our method provides a template for future engagement and assessment of marginalized populations and suggests a way forward for community-engaged public health.

**8. Acknowledgements**

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**9. Appendices**

**1. Survey Instruments**

**Health Needs Assessment for People with Disabilities, Massachusetts 2014**

The Health and Disability Program in the Office of Health Equity, Massachusetts Department of Public Health is conducting a survey to understand and prioritize the health needs of people with disabilities living in Massachusetts.

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!

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.

**Background**

1. **Please describe yourself (check all that apply):**
* Person with a disability **[Go to 2]**
* Family/guardian/caregiver of an adult with disabilities **[Go to 2]**
* Family/guardian/caregiver of a child or youth with disabilities **[Go to 2]**
* Staff at organization (agency/provider/advocate) that works with people with disabilities
* Staff at government agency
* Community leader
* Other \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**1a. 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\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
1. **Do you live in Massachusetts?**
* Yes
* No

1. **What city or town do you live in?** \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
2. **Do you work in Massachusetts?**
* Yes
* No

**Activities of daily living**

**If you are not a person with a disability or caregiver, GO TO 10.**

1. **Do you, or a person you care for, have difficulty dressing or bathing?**
* Yes
* No
1. **Do you, or a person you care for, have serious difficulty walking or climbing stairs?**
* Yes
* No
1. **Because of a physical, mental, or emotional condition, do you, or a person you care for, have serious difficulty concentrating, remembering, or making decisions?**
* Yes
* No
1. **Are you, or a person you care for, blind or have serious difficulty seeing even when wearing glasses?**
* Yes
* No
1. **Are you, or a person you care for, deaf or have serious difficulty hearing?**

* Yes
* No

**Health Issues**

1. **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

1. **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
1. **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

1. **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
1. **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

1. **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
1. **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

1. **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

1. **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

1. **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

1. **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
1. **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

1. **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

1. **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

1. **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
1. **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

1. **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

1. **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
1. **In your opinion, is it a problem for people with disabilities in Massachusetts to find employment opportunities?**
* Not a problem
* Small problem
* Big problem
* Don't know
1. **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
* Accessible doctor's offices
* Accessible gyms or place to get physical exercise
* Access to healthy food such as fruits or vegetables
* Accessible public transportation
* Access to health insurance
* Affordable prescription drugs
* Cancer
* Dental care
* Diabetes
* Drug and alcohol abuse
* Durable medical equipment (wheelchair, hospital bed, etc.)
* Employment
* Heart disease (stroke, hypertension, etc.)
* Infectious/contagious disease (tuberculosis, pneumonia, flu, etc.)
* Quality public education
* Safe neighborhoods
* Sexually transmitted infections (HIV/AIDS, chlamydia, etc,)
* Smoking
* Teen pregnancy
* Vaccinations
* Violence (gangs, street or domestic violence)
* Overweight or obesity
* Aging problems (Alzheimer's, arthritis, dementia, etc.)
* Asthma
* Mental health issues(anxiety, depression, etc.)
* Other (please specify) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
1. **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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**Reactions to Race**

1. **How do other people usually classify you in this country?** (We want to know how OTHER people usually classify you in this country, which might be different from how you classify yourself.)
* White
* Black or African American
* Hispanic or Latino
* Asian
* Native Hawaiian or Other Pacific Islander
* American Indian or Alaska Native
* Some other group (please specify) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Don’t know / Not sure
1. **How often do you think about your race?**
* Never
* At least once a year
* At least once a month
* At least once a week
* At least once a day
* At least once an hour
* Constantly
* Don’t know / Not sure
1. **Within the past 12 months at work, do you feel you were treated worse than other races, the same as other races, better than other races, or worse than some races but better than others?**
* Did not work in the past 12 months
* Worse than other races
* The same as other races
* Better than other races
* Worse than some races, better than others
* Only encountered people of the same race
* Don’t know / Not sure
1. **Within the past 12 months, when seeking health care, do you feel your experiences were worse than other races, the same as other races, better than other races, or worse than some races but better than others?**
* No health care in past 12 months
* Worse than other races
* The same as other races
* Better than other races
* Worse than some races, better than others
* Only encountered people of the same race
* Don’t know / Not sure
1. **Within the past 30 days, have you experienced any physical symptoms, for example a headache, an upset stomach, tensing of your muscles, or a pounding heart, as a result of how you were treated based on your race?**
* Yes
* No
* Don’t know / Not sure
1. **Within the past 30 days, have you felt emotionally upset, for example angry, sad, or frustrated, as a result of how you were treated based on your race?**
* Yes
* No
* Don’t know / Not sure

**Background**

1. **Do you consider yourself to be one or more of the following (check all that apply):**
* Male
* Female
* Transgender
* Something else (please indicate) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Prefer not to respond
1. **Do you consider yourself to be one or more of the following (check all that apply):**
* Heterosexual/straight
* Gay or lesbian
* Bisexual
* Something else (please indicate) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Prefer not to respond
1. **What is your age?**
* 18-24 years
* 25-34 years
* 35-44 years
* 45-54 years
* 55-64 years
* 65 years and older

1. **What is your ethnicity? (check all that apply)**

* African (specify) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* African American
* American
* Asian Indian
* Brazilian
* Cambodian
* Cape Verdean
* Caribbean Islander (specify) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Chinese
* Colombian
* Cuban
* Dominican
* European
* Filipino
* Guatemalan
* Haitian
* Honduran
* Japanese
* Korean
* Laotion
* Mexican, Mexican American, Chicano
* Middle Eastern (specify) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Portuguese
* Puerto Rican
* Russian
* Salvadoran
* Vietnamese
* Unknown/not specified
* Other (specify) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
1. **What is your race? (check all that apply)**
* American Indian/Alaska Native (specify tribal nation) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Asian
* Black
* Hispanic/Latino/Black
* Hispanic/Latino/White
* Hispanic/Latino/Other
* Native Hawaiian or other Pacific Islander (specify) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* White
* Unknown/not specified
* Other (specify) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
1. **In what language do you prefer to discuss your health care?**

* Albanian
* Arabic
* ASL
* Cape Verdean Creole
* Chinese (specify dialect) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* English
* Haitian Creole
* Khmer
* Portuguese
* Russian
* Somali
* Spanish
* Vietnamese
* Other (specify) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

1. **In 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:**

Monika Mitra, Ph.D.

Assistant Professor of Family Medicine and Community Health

University of Massachusetts Medical School

508-856-8548

Monika.Mitra@umassmed.edu

Or

Georgia Simpson May

Director, Office of Health Equity

Massachusetts Department of Public Health

617-624-5590

Georgia.Simpson.May@state.ma.us

2. **Evaluación de las necesidades de salud de las personas con discapacidades, Massachusetts 2014**

El Programa de Salud y Discapacidad de la Oficina de Equidad en la Salud del Departamento de Salud Pública de Massachusetts está realizando una encuesta para comprender y priorizar las necesidades de salud de las personas con discapacidades que viven en Massachusetts.

La participación en la encuesta es voluntaria. Todas las respuestas son completamente anónimas. Las respuestas individuales no se darán a conocer y nosotros no podremos identificar los nombres de los participantes individuales. No hay respuestas correctas ni incorrectas; su opinión es lo que importa.

Sus comentarios son importantes y se usarán para contribuir a que el Programa de Salud y Discapacidad establezca prioridades para tomar medidas que mejoren la salud de las personas con discapacidades de Massachusetts. Muchas gracias por participar.

Si tiene preguntas acerca de esta encuesta, comuníquese con Monika Mitra a través de Monika.Mitra@umassmed.edu o con Georgia Simpson May a través de Georgia.Simpson.May@state.ma.us.

**Antecedentes**

1. **Descríbase (marque todas las respuestas que correspondan):**
* Persona con una discapacidad **[Vaya** a **la pregunta 2]**
* Familiar/tutor/cuidador de un adulto con discapacidades **[Vaya a la pregunta 2]**
* Familiar/tutor/cuidador de un niño o joven con discapacidades **[Vaya a la pregunta 2]**
* Personal de una organización (agencia/proveedor/organización de defensa) que trabaja con personas con discapacidades
* Personal de una dependencia gubernamental
* Líder comunitario
* Otro \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**1a. ¿Su organización brinda servicios a…? (Seleccione todas las opciones que correspondan).**

* Personas con discapacidades físicas
* Personas con discapacidades intelectuales o del desarrollo
* Personas con enfermedades mentales
* Personas sordas o con problemas de audición
* Personas ciegas
* Niños con discapacidades
* Jóvenes con discapacidades
* Adultos mayores con discapacidades
* Otro \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
1. **¿Usted vive en Massachusetts?**
* Sí
* No

1. **¿En qué ciudad o pueblo vive?** \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
2. **¿Usted trabaja en Massachusetts?**
* Sí
* No

**Actividades cotidianas**

**Si usted no es una persona con discapacidad ni un cuidador, VAYA A LA PREGUNTA 10.**

1. **¿Usted, o una persona a la que cuida, tiene dificultad para vestirse o bañarse?**
* Sí
* No
1. **¿Usted, o una persona a la que cuida, tiene dificultad para caminar o subir escaleras?**
* Sí
* No
1. **Debido a una condición física, mental o emocional, ¿usted, o una persona a la que cuida, tiene una dificultad grave para concentrarse, recordar o tomar decisiones?**
* Sí
* No
1. **¿Usted, o una persona a la que cuida, es ciego o tiene una dificultad grave para ver, aunque use anteojos?**
* Sí
* No
1. **¿Usted, o una persona a la que cuida, es sordo o tiene una dificultad grave para oír?**

* Sí
* No

**Problemas de salud**

1. **En su opinión, ¿es un problema para las personas con discapacidades de Massachusetts conseguir un seguro médico?**
* No es un problema
* Un problema pequeño
* Es un gran problema
* No sé

1. **En su opinión, ¿es un problema para las personas con discapacidades de Massachusetts encontrar un médico que acepte un seguro médico público (p. ej., Medicaid/MassHealth, Medicare)?**
* No es un problema
* Un problema pequeño
* Es un gran problema
* No sé
1. **En su opinión, ¿es un problema para las personas con discapacidades de Massachusetts encontrar un médico que acepte un seguro médico privado (p. ej., Blue Cross Blue Shield)?**
* No es un problema
* Un problema pequeño
* Es un gran problema
* No sé
1. **En su opinión, ¿es un problema para las personas con discapacidades de Massachusetts encontrar un médico que sea sensible a la problemática de la discapacidad?**
* No es un problema
* Un problema pequeño
* Es un gran problema
* No sé
1. **En su opinión, ¿es un problema para las personas con discapacidades de Massachusetts conseguir un dentista?**
* No es un problema
* Un problema pequeño
* Es un gran problema
* No sé

1. **En su opinión, ¿es un problema para las personas con discapacidades de Massachusetts conseguir un proveedor de servicios de salud mental?**
* No es un problema
* Un problema pequeño
* Es un gran problema
* No sé

1. **En su opinión, ¿es un problema para las personas con discapacidades de Massachusetts conseguir servicios adecuados de salud mental?**
* No es un problema
* Un problema pequeño
* Es un gran problema
* No sé

1. **En su opinión, ¿es un problema para las personas con discapacidades de Massachusetts pagar por sus medicamentos recetados?**
* No es un problema
* Un problema pequeño
* Es un gran problema
* No sé

1. **En su opinión, ¿es un problema para las personas con discapacidades de Massachusetts controlar afecciones crónicas como la diabetes, el asma o la hipertensión arterial?**
* No es un problema
* Un problema pequeño
* Es un gran problema
* No sé

1. **En su opinión, ¿es un problema para las personas con discapacidades de Massachusetts hacerse pruebas médicas de rutina como un examen físico anual, una mamografía o una colonoscopía?**
* No es un problema
* Un problema pequeño
* Es un gran problema
* No sé

1. **En su opinión, ¿es un problema para las personas con discapacidades de Massachusetts recibir vacunas como la de la gripe o la de la neumonía?**
* No es un problema
* Un problema pequeño
* Es un gran problema
* No sé
1. **En su opinión, ¿es un problema para las personas con discapacidades de Massachusetts encontrar un consultorio médico que sea accesible, p. ej., que tenga rampas para sillas de ruedas, camillas de altura ajustable, etc.?**
* No es un problema
* Un problema pequeño
* Es un gran problema
* No sé

1. **En su opinión, ¿es un problema para las personas con discapacidades de Massachusetts encontrar un médico que use soportes de comunicación como el lenguaje de señas estadounidense, letras grandes, Braille o servicios de transcripción de audio a texto en tiempo real?**
* No es un problema
* Un problema pequeño
* Es un gran problema
* No sé

1. **En su opinión, ¿es un problema para las personas con discapacidades de Massachusetts conseguir transporte para ir a las consultas con el médico?**
* No es un problema
* Un problema pequeño
* Es un gran problema
* No sé

1. **En su opinión, ¿es un problema para las personas con discapacidades de Massachusetts conseguir equipo médico duradero como sillas de ruedas, scooters para discapacitados y camas de hospital?**
* No es un problema
* Un problema pequeño
* Es un gran problema
* No sé

1. **En su opinión, ¿es un problema para las personas con discapacidades de Massachusetts encontrar apoyo y programas accesibles si sufren violencia o abuso?**
* No es un problema
* Un problema pequeño
* Es un gran problema
* No sé

1. **En su opinión, ¿es un problema para las personas con discapacidades de Massachusetts conseguir una vivienda asequible?**
* No es un problema
* Un problema pequeño
* Es un gran problema
* No sé

1. **En su opinión, ¿es un problema para las personas con discapacidades de Massachusetts encontrar una tienda de comestibles que venda alimentos saludables, como frutas y verduras?**
* No es un problema
* Un problema pequeño
* Es un gran problema
* No sé
1. **En su opinión, ¿es un problema para las personas con discapacidades de Massachusetts conseguir oportunidades de empleo?**
* No es un problema
* Un problema pequeño
* Es un gran problema
* No sé
1. **En su opinión, ¿cuáles son los cinco (5) problemas más importantes relacionados con la salud que afectan a las personas con discapacidades de Massachusetts? Seleccione los 5 más importantes.**
* Vivienda accesible y asequible
* Consultorios médicos accesibles
* Gimnasios o lugares accesibles para hacer ejercicio físico
* Acceso a alimentos saludables como frutas y verduras
* Acceso al transporte público
* Acceso a un seguro médico
* Medicamentos recetados asequibles
* Cáncer
* Atención dental
* Diabetes
* Abuso de drogas o alcohol
* Equipo médico duradero (silla de ruedas, cama de hospital, etc.)
* Empleo
* Enfermedades cardíacas (accidente cerebrovascular, hipertensión, etc.)
* Enfermedades infectocontagiosas (tuberculosis, neumonía, gripe, etc.)
* Educación pública de calidad
* Vecindarios seguros
* Infecciones de transmisión sexual (VIH/SIDA, clamidia. etc.)
* Fumar
* Embarazo en la adolescencia
* Vacunaciones
* Violencia (pandillas, violencia callejera o doméstica)
* Sobrepeso u obesidad
* Problemas de la vejez (mal de Alzheimer, artritis, demencia, etc.)
* Asma
* Problemas de salud mental (ansiedad, depresión, etc.)
* Otro (especifique) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**¿Hay algo más que quisiera agregar respecto a las necesidades de salud de las personas que viven con discapacidades en Massachusetts?**

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

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**Reacciones a la raza**

1. **¿Cómo los suelen clasificar las demás personas a usted en este país?** (Queremos saber cómo lo suelen calificar OTRAS personas en este país, lo que puede ser distinto a cómo se clasifica usted).
* Blanco
* Negro o afroamericano
* Hispano o latino
* Asiático
* Nativo de Hawái u otra isla del Pacífico
* Indígena estadounidense o nativo de Alaska
* Algún otro grupo (especifique) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* No sé/ No estoy seguro
1. **¿Con qué frecuencia piensa en su raza?**
* Nunca
* Al menos una vez al año
* Al menos una vez al mes
* Al menos una vez a la semana
* Al menos una vez al día
* Al menos una vez por hora
* Constantemente
* No sé/ No estoy seguro
1. **Durante los últimos 12 meses en el trabajo, ¿siente que lo trataron peor que a las personas de otras razas, igual, mejor o peor que a las personas de algunas razas, pero mejor que a las de otras?**
* No trabajé en los últimos 12 meses
* Peor que a las personas de otras razas
* Igual que a las personas de otras razas
* Mejor que a las personas de otras razas
* Mejor que a las personas de algunas razas, pero peor que a las de otras
* Solo me he encontrado con personas de mi misma raza
* No sé/ No estoy seguro
1. **Durante los últimos 12 meses, al buscar atención médica, ¿siente que sus experiencias fueron peores que las de personas de otras razas, iguales, mejores o peores que las de personas de algunas razas, pero mejores que las de otras?**
* No busqué atención médica en los últimos 12 meses
* Peores que las de personas de otras razas
* Iguales que las de personas de otras razas
* Mejores que las de personas de otras razas
* Mejores que las de personas de algunas razas, pero peores que las de otras
* Solo me he encontrado con personas de mi misma raza
* No sé/ No estoy seguro
1. **En los últimos 30 días, ¿ha tenido síntomas físicos, por ejemplo, dolor de cabeza, malestar estomacal, tensión muscular o palpitaciones, como resultado de cómo fue tratado debido a su raza?**
* Sí
* No
* No sé/ No estoy seguro
1. **En los últimos 30 días, ¿se ha sentido afectado emocionalmente, por ejemplo, ha sentido enojo, tristeza o frustración, por cómo fue tratado debido a su raza?**
* Sí
* No
* No sé/ No estoy seguro

**Antecedentes**

1. **¿Considera que pertenece a una o más de las siguientes categorías? (Marque todas las opciones que correspondan).**
* Hombre
* Mujer
* Transgénero
* Otra opción (especifique) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Prefiero no contestar
1. **¿Considera que pertenece a una o más de las siguientes categorías? (Marque todas las opciones que correspondan).**
* Heterosexual
* Gay o lesbiana
* Bisexual
* Otra opción (especifique) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Prefiero no contestar
1. **¿Cuántos años tiene?**
* 18-24 años
* 25-34 años
* 35-44 años
* 45-54 años
* 55-64 años
* 65 años o más

1. **¿Cuál es su origen étnico? (Marque todas las opciones que correspondan).**

* Africano (especifique) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Afroamericano
* Estadounidense
* Indio de Asia
* Brasileño
* Camboyano
* Caboverdiano
* Isleño del Caribe (especifique) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Chino
* Colombiano
* Cubano
* Dominicano
* Europeo
* Filipino
* Guatemalteco
* Haitiano
* Hondureño
* Japonés
* Coreano
* Laosiano
* Mexicano, estadounidense-mexicano, chicano
* De Oriente Medio (especifique) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Portugués
* Puertorriqueño
* Ruso
* Salvadoreño
* Vietnamita
* Desconocido/no especificado
* Otro (especifique) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
1. **¿Cuál es su raza? (Marque todas las opciones que correspondan).**
* Indígena de América del Norte o nativa de Alaska (especifique la nación tribal) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Asiática
* Negra
* Hispana/latina/negra
* Hispana/latina/blanca
* Hispana/latina/otra
* Nativa de Hawái o de alguna otra isla del Pacífico (especifique) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Blanca
* Desconocida/no especificada
* Otra (especifique) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
1. **¿En qué idioma prefiere hablar sobre su atención médica?**

* Albanés
* Árabe
* Lenguaje de señas estadounidense
* Criollo caboverdiano
* Chino (especifique el dialecto) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Inglés
* Criollo haitiano
* Jemer
* Portugués
* Ruso
* Somalí
* Español
* Vietnamita
* Otro (especifique) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

1. **¿En qué idioma prefiere leer material relacionado con la salud?**

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**¡Muchas gracias!**

Gracias por completar la encuesta. Su aporte es importante para nosotros. Los datos recopilados se combinarán y, junto con otros datos recabados, serán usados por el Departamento de Salud Pública de Massachusetts para establecer prioridades a fin de mejorar la salud de las personas con discapacidades.

**Si tiene alguna pregunta, comuníquese con:**

Monika Mitra, Ph.D.

Profesora adjunta de Medicina Familiar y Salud Comunitaria

Escuela de Medicina de la Universidad de Massachusetts

508-856-8548

Monika.Mitra@umassmed.edu

o

Georgia Simpson May

Directora de la Oficina de Equidad en la Salud

Departamento de Salud Pública de Massachusetts

617-624-5590

Georgia.Simpson.May@state.ma.us

1. **Moderator Guide**

People with Disabilities in Communities of Color Health Needs Assessment

1. What do you see as the most important health issues facing adults with disabilities in your community?

Prompts: Is it access to primary care, specialty care, emergency room care, mental health or substance abuse, dental, etc? Is it lack of accessibility to care? Lack of help at home?

2. Do you have trouble finding health care providers to meet your needs?

3. Do you have trouble getting health insurance to meet your needs?

4. Are there any issues with transportation to get health care?

5. Overall, what do you think are the top 3 issues?

6. Of all the health needs for people with disabilities in Boston, 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?

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

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

Prompts: How can they be addressed?

8, Why do you think the barriers exist?

9. Do you think people in this community are treated unfairly by the health care system?

9. How do you think the state or city can best remove these barriers to health?

Prompts: Age? Disability type?

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

Prompts: What are they?

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

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

C. Flyers



If you are Deaf or hard of hearing, or are a person with a disability who requires accommodation, please contact Tricia Ariole at 617.942.8060 (phone),
617.942.8630 (fax), tariol@milcb.org or 617.942.8060 (TTY) by Oct. 6, 2014.

October 8th, 2014

1-4pm

Multi-Cultural Independent Living Center of Boston

329 Centre Street, Jamaica Plain

**Health and Disability Issues in Communities of Color**

***We need your voice!***

**People with disabilities and caregivers are invited to join us for a community forum**

A ***community forum*** is a chance for people to get together and share their views on an important issue. The goal of this event is to give people with disabilities from racially and ethnically diverse communities a chance to discuss their needs and priorities related to their health and disability. Information from this session will be used by the MA Department of Public Health to develop a Health Needs Assessment Report.



**\*The first 25 people to register will receive a gift card\***

**\*Refreshments will be provided\***

****

Si usted es sordo o tiene problemas de audición, o es una persona con una discapacidad que requiere instalaciones especiales, por favor contacte a

Jessica Santana antes de 9 de octubre, 2015 al 413.781.5555 (teléfono/V/TTY),
413.733.5473 (fax), jsantana@stavros.org

**\*** **Las primeras 25 personas que se registren recibirán una tarjeta de regalo \***

**\*** **Se proveerán refrigerios \***

**Asuntos de salud y discapacidad entre los latinos**

**(Este foro se llevará a cabo solamente en español)**

14 de octubre, 2015

11am-2pm

Stavros Center for Independent Living

227 Berkshire Avenue, Springfield

***¡Necesitamos tu voz!***

**Invitamos a personas con discapacidades a unirse a nosotros para un foro comunitario**

**Por favor regístrese antes de 9 de octubre, 2015**

Contacte a Jessica Santana al: **413.781.5555**  | jsantana@stavros.org

Incluya: **su nombre** | **datos de contacto** | **alguna petición de alojamiento/ dietéticas**

Un **foro comunitario** es una oportunidad para que las personas se reúnan y compartan sus puntos de vista sobre un tema importante. El objetivo de este evento es dar a los latinos con discapacidades la oportunidad de abordar sus necesidades y prioridades relacionadas con su salud y la discapacidad. Información de este foro será utilizada por el Departamento de Salud Pública de Massachusetts para desarrollar un Informe de Evaluación sobre las Necesidades de la Salud.